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# **On the Spectrum and in the Room: The Role of Identity and Empowerment in Autistic Women's Recovery from Psychological Trauma**

*A thesis submitted in partial fulfilment of the requirements for the degree of Doctor of  
Counselling and Psychotherapy*

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Doctor of Counselling and Psychotherapy  
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2022

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# Abstract

Autistic women are at an increased risk of experiencing trauma and mental health issues compared with the general population. This is further compounded by significant barriers to diagnosis and to accessing appropriate support for this group. By employing a feminist approach, this study recognises the effects of socio-historical inequality on this group, including identity dysfunction and disempowerment, which further exacerbate the effects of trauma. This paper argues that restoring identity and supporting empowerment are paramount to Autistic women's recovery from trauma.

Previous research focusing specifically on Autistic women who have suffered trauma is scarce. This research seeks to contribute to filling the gap in the knowledge of how counsellors can best support this group. This research elevates the voices of Autistic women, by working with a board consisting of Autistic women, and through conducting semi-structured interviews with six Autistic women ranging in age and in their prior experience of counselling. The researcher, with two Autistic board members, thematically coded responses, revealing that both social and psychological empowerment were key to Autistic women's recovery from psychological trauma. Recommendations are provided as to how therapists can help facilitate empowerment for this population, including through the restoration of autonomy and decision-making capacity within the therapy process, taking a flexible and transparent approach, and by encouraging connection with the wider autism community within which individuals can thrive and grow.

# Lay Summary

Research suggests that Autistic individuals are more vulnerable to experiencing a range of mental health problems compared with the general population, including an increased risk of experiencing traumatic events and subsequent difficulties. This thesis suggests that Autistic women are susceptible to experiencing various types of trauma due to their intersecting marginalised identities (being both Autistic and female). These difficulties are often compounded by challenges in obtaining an autism diagnosis and significant barriers to accessing appropriate support.

Despite the concerns highlighted above, little is known about the impact of traumatic events on Autistic women, and the guidance available to counsellors and psychotherapists working with this unique population is scarce. This study sought to fill a gap in existing knowledge by interviewing Autistic women with self-reported trauma histories about their experiences of receiving counselling support for these issues, the aim of which was to better understand how therapists can better support this unique population.

This study utilised participatory action research, employing an advisory board formed of Autistic women who assisted in determining how the research would be conducted and in drawing conclusions from the research data. This is significant as Autistic women's voices are currently underrepresented in autism research, with previous research being conducted predominantly with male participants.

Participants' experiences were explored through semi-structured interviews which were then analysed by the primary researcher and Autistic board members. The results from this analysis indicated that the empowerment process and the restoration of coherent identity were significant aspects of Autistic women's recovery from psychological trauma.

Recommendations are provided as to how therapists can support the empowerment process

for clients, including by attending to the power differentials within the therapeutic relationship and facilitating the client's autonomy within the therapeutic process.

This study included a relatively small sample size, interviewing six participants in total. However, the findings derived from this research can still provide valuable insight to practitioners endeavouring to work with traumatised Autistic women, by enhancing their awareness of the experiences of this group, and increasing their understanding of the ways to support the empowerment process and, ultimately, the recovery from psychological trauma.

There is a demonstratable need for future research that builds on the learning from this study and there is scope to further illuminate this study's findings with the experiences of therapists already working with this population. Further, it would be beneficial to determine whether the findings derived from this study hold true when studying a larger sample size.

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# Chapter One: Introduction

## 1.1 My Journey

Working with Autistic children and adults has been a significant aspect of my life since I was a young child. Growing up, my mother was a support worker for Autistic children at my elementary school, and I frequently spent the afternoons after school in her classroom doing various craft activities and playing games with her students. It was within that classroom that my intense interest in autism was born.

After graduating high school, I had the opportunity to volunteer with an agency that provides support to young Autistic adults who are endeavouring to enter the workforce. One of the key responsibilities in my role as a mentor within this agency was to assist these young adults in developing the communication skills necessary to obtain employment. This experience only further intensified my passion, as I recognised many of these individuals' intense desire to interact and connect with others, and their frustration related to their difficulty doing so. Many shared stories of having been bullied and ostracised at school, feeling misunderstood by those around them, struggling to make and maintain friendships, and the crippling anxiety that results from living in an unpredictable world that, ultimately, is not compatible with their needs.

This interest in autism and neurodiversity as a whole followed me into my counselling and psychotherapy training and I began to ponder if and how traditional psychotherapy might be altered to better assist Autistic individuals, particularly those who have suffered varying types of traumas and abuse. I became increasingly interested in how we as psychotherapists can better work with individuals whose autism is less pronounced, but who nonetheless experience issues that dramatically impact their quality of life; such individuals are less likely to receive formal support, as their struggles are missed by medical and support professionals,

however, that does not necessarily mean that these struggles are any less challenging or important.

## **1.2 Positioning Myself**

As the primary researcher involved with this project, it is important to state my own position in regard to the topic being explored. I myself am an Autistic woman, having only recently within the past few years recognised and accepted my own neurodivergence. Many of my differences and relational/communicative difficulties came to light during my training as a psychotherapist but, in retrospect, have been prevalent throughout my entire life. I believe a part of me has always known I was Autistic, and this can be evidenced by my intense interest in autism since a very young age; I now feel that this interest was, in part, an attempt to better understand myself and make sense of my own experiences.

I feel I must also acknowledge my own position of privilege within this area, both as a cis-gendered, heterosexual, White woman and as someone who received quite a lot of support throughout my early childhood. The majority of my difficulties surfaced in adulthood, as is often the case with Autistic women, when I started experiencing severe bouts of depression, suicidal ideation, overwhelming anxiety and developed anorexia after many years of disordered eating habits, at the age of 23.

These experiences, while difficult, opened my eyes to the challenges of being an Autistic female, leading to a deepened curiosity surrounding these types of experiences and a deep desire to connect with and learn from other Autistic women who have endured similar struggles. This desire to connect and better understand others' experiences led me to decide to interview other Autistic women for this project to better understand how counsellors can best support Autistic women who have suffered trauma and adversity.

In retrospect, the process of interviewing and analysing participants' accounts for this project had a profound effect on my own personal and professional development; the stories of each of these courageous people brought me closer and closer to finding myself. At the time of originally beginning this project, about a year into my counselling qualification course, I was, retrospectively, so fragmented and confused, hardly able to recognise myself from one day to the next. Even still, my core-self prevailed, urging me to pursue my interests in autism and mental health and, correspondingly, nudging me along the path towards my own recovery and towards finding a home within myself. Losing myself to this process meant finding, or as one participant put it, **remembering** myself, guiding me closer towards inner-peace and happiness.

My own journey in many ways reflects one of empowerment, as I have, throughout this process, come to recognise and accept my own neurodivergence, identifying my own unique strengths and uniting with other Autistic women, providing a sense of connection and belonging. The act of writing this thesis is an important step in this process as it has provided me with a platform to speak about an issue that is of great importance to me.

Now that I have explored briefly my own positionality in relation to the topic being explored, as well as the events that have led me to pursue this project, I will provide the reader with an overview exploring the history of autism, the mental health implications of autism, and the particular challenges faced by Autistic women, including the barriers to receiving an autism diagnosis and subsequent support. I will also briefly offer an initial definition of trauma as it pertains to this research. The aim of this introduction is to illuminate the historic and the current plight of Autistic women, thereby demonstrating the critical need for a better understanding of this group – both generally within society, and particularly within the counselling community.

### **1.3 The History of Autism and the Autism Spectrum**

The history of autism is not linear; on the contrary, its journey from first being described in the early 1900's to today's concept of autism is rather non-direct and fraught with diversions. Originally identified in 1911 by German psychiatrist Eugen Bleuler, autism was believed at the time to be a severe presentation of schizophrenia (a concept also initiated by Bleuler), characterised by fantasies and hallucinations (Evans, 2013). Bleuler hypothesised that at the core of autism is a desire to avoid unsatisfying realities and replace them with fantasies and hallucinations, and that the Autistic individual's symbolic inner life is not readily accessible to others around them (Evans, 2013; Bleuler 1911). This is expressed within the word "autism" itself, having derived from the Greek word, "autós" which translates as "self" and "ism" to represent a state of being.

Bleuler's theory of autism was largely undisputed until 1943 when Austrian-American psychiatrist Leo Kanner identified a specific pattern of "abnormal" behaviours which was then referred to as "early infantile autism" or "Kanner's Syndrome" after having observed, at length, eleven children at his clinic at Johns Hopkins University School of Medicine in Baltimore whom he described as lacking the social instinct to orient towards other people, being mostly focused or even obsessed with objects, and as having a "need for sameness" or a "resistance to unanticipated change" (Baron-Cohen, 2015).

Coincidentally, a year later in 1944 (although his conclusions would not come to fruition until 1993), Hans Asperger published an account of children with many similarities to Kanner autism but who possessed abilities, including grammatical language, in the average or superior range. This pattern of symptoms or "syndrome" later became known as Asperger's Syndrome (National Autistic Society, 2019). There are still ongoing debates about the exact relationship between the two conditions, but it is largely agreed that both share the

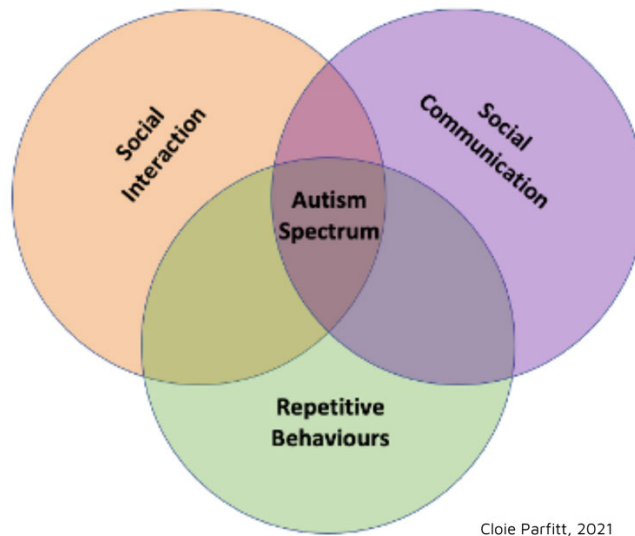
“triad of impairments” first identified by child psychiatrists Lorna Wing and Judith Gould in 1979 who examined the prevalence of autism as defined by Leo Kanner.

Wing and Gould’s findings ultimately led to the identification of a larger subset of children who did not meet the full diagnostic criteria for Kanner’s Autism, but who had difficulties with social interaction, communication and imagination as well as demonstrating a repetitive pattern of activities. Wing and Gould later went on to describe such children as belonging to the wider “autism spectrum” and possessing the triad of impairments (as well as repetitive, stereotyped behaviours) which is still used to identify and diagnose autism today. They are as follows:

- 1) the absence or impairment of two-way social interaction;
- 2) the absence or impairment of comprehension and use of language, non-verbal as well as verbal (social communication);
- 3) the absence or impairment of true, flexible imaginative activities, with the substitution of a narrow range of repetitive, stereotyped pursuits (Centers for Disease Control [CDC], 2022).

It is important to note here that what distinguishes Asperger’s Syndrome from Kanner’s Autism are less pronounced symptoms and the absence of language delays, though individuals may still struggle with social communication (National Autistic Society, 2019).

The Triad of Impairments



### 1.3.1 Autism, Asperger's Syndrome and the DSM-5

The release of the updated Diagnostic and Statistical Manual of Mental Disorders (DSM-5) in 2013, sparked even more controversy, as the formerly separate, although closely associated, diagnoses of Autistic Disorder and Asperger's Disorder were joined together under the umbrella term "Autism Spectrum Disorder" (ASD). Autism Disorder had originally been used to classify individuals with the traditional triad of impairments in addition to a delay in the development of language, while Asperger's Disorder had been reserved for those who did not show delay in language development but who also possessed the traditional triad of symptoms.

Although the term Asperger's Syndrome has predominantly been removed from the current medical discourse, many individuals still feel that Asperger's Syndrome is a fundamental aspect of their identity, and Asperger's Syndrome remains a useful profile for many diagnosticians and health professionals. Since the publication of the DSM-5, the term Asperger's Syndrome has been widely replaced by the term "high functioning autism", although many Autistic individuals find this term to be ableist and demeaning, as functioning

labels are felt to categorise Autistic people according to their ability to “function” adequately within society. A diagnosis of ASD is now separated into three categories or “levels” of severity – with level one requiring minimal support, level 2 requiring “substantial support” and level three requiring “very substantial support” (Weitlauf et al., 2014).

It is clear to see from the criteria above that autism is often framed in terms of deficits, painting a picture of a person who is largely uninterested in those around them, happily pursuing their own restricted and stereotyped pursuits. Steward (2017, 659) states, “Autism is often talked about just in terms of deficits and/or savant abilities. But this does not give a well-rounded picture of the humans being described. The autism community has expressed discomfort around discussing autism in this way.” Indeed, for many years a lack of empathy was believed to be a characteristic of autism, a belief that is only just beginning to shift thanks to the work of Autistic advocates, activists, and academics who have challenged this view (Milton, 2012; Crompton et al., 2020).

Historically, we can see a shift in the ways in which autism has been conceptualised and described, with common misconceptions about autism being challenged and extinguished throughout the years. A major determinant of this shift is the inclusion of Autistic individuals in research concerning autism, with Autistic individuals taking ownership over what it means to be Autistic, challenging the medical portrayal of autism and identifying strengths associated with neurodiversity (Jaarsma and Welin, 2012; Kapp, 2020; Kras, 2009). This shift in the medical discourse surrounding autism has everything to do with the hard-won liberation of the autism community who, after decades of activism and advocacy, have begun the transformation from a state of disempowerment imposed by the medical establishment to one of empowerment, whereby Autistic individuals have increasing power and control over what it means to be Autistic and how society can best support this community.

### **1.3.2 Language, Labels, and the Movement Towards the Neurodiversity Paradigm**

In recent years, due to the autism rights movement, many Autistic individuals have expressed their desire to use “identity first language” (i.e. “Autistic person” vs “person with autism”) to better represent the autism community, as autism is increasingly being viewed as an inherent part of an individual’s identity rather than a disease one is afflicted with (Brown, 2022). For this reason, I will be using identity-first language throughout this thesis. You’ll also notice the capitalisation of the word “Autistic” throughout this paper; this is, again, in keeping with identity-first language which acknowledges autism as an adjective, therefore being used to describe a person’s identity, rather than a condition or “disorder” one is affected by. Other examples of this are the capitalisation of the words “Deaf”, “Blind” and “Black” when used to represent each of these corresponding communities.

Furthermore, the concept of mental “disorders” as a whole has fallen under scrutiny over the past few decades, as clinicians and researchers are beginning to recognise that with perceived mental and emotional challenges also come unique strengths (Armstrong, 2015). Armstrong (2015, 348) states “...there appears to be substantial uncertainty concerning when a neurologically based human behaviour crosses the critical threshold from normal human variation to pathology,” indicating that having or not having a mental “disorder” or “disease” has more to do with the severity of certain traits vs. the total possession or deprivation of those traits. Similarly, acknowledging the strengths that come with neurodivergence has opened a path to a more compassionate approach to treating mental “disorders,” replacing “disability” and “illness” with “diversity,” and giving way to the neurodiversity paradigm (Armstrong, 2015; Resnick, 2021).

The concept of the neurodiversity paradigm was first articulated by social-scientist and autism rights activist Judy Singer in 1998. In her original thesis, Singer articulates the needs of many Autistic people, who do not wish to be defined by a “disability” but as

“neurologically different” (Singer, 1998). In a continuation of this theme, in recent years, the term “neurodivergent” has become the largely preferred term for those whose brains are thought to develop or work differently, whereas the term “neurotypical” has been adopted to represent those who do not possess any form of neurodivergence (Cleveland Clinic, 2022). With roots in the Autistic activist community, the neurodiversity paradigm has now expanded beyond autism to include many other conditions, for example, attention deficit hyperactivity disorder (ADHD), dyslexia, dyscalculia, bipolarity, and obsessive-compulsive disorders. Again, this shift from “deficits” to differences and strengths represents an increasingly empowered community.

#### **1.4 The Mental Health Implications of Autism**

While being neurodivergent doesn't necessitate disability, it *has* been suggested that Autistic individuals are more likely than the general population to experience mental health problems (Lai et al., 2019), partly perhaps due to the ways in which society has traditionally responded to Autistic individuals, as is discussed above. Among these difficulties include an increased prevalence of depression, anxiety, obsessive compulsive disorders and eating disorders in the Autistic population (Hudson et al., 2019; Hollocks et al., 2019; Lugo-Marin et al., 2019; Nickel et al., 2019; Vasa et al., 2016). Moreover, a study produced by the University of Cambridge's department of psychiatry (Cassidy et al., 2014) lent support to reports of increased rates of suicidal ideation in adults with Asperger's Syndrome, with depression being an important risk factor for suicidality in Autistic adults. Because Autistic individuals may be subjected to social isolation or exclusion and unemployment, researchers emphasise the need for appropriate service planning and support to reduce the risk of suicide for this population group (Hedley et al., 2017).

Interestingly, a report generated by the All Party Parliamentary Group on Autism (APPGA) states that 46% of Autistic adults report requiring more social support to live independently, and estimate that there are approximately 327,000 Autistic adults living with unmet needs in England alone. Similarly, without access to appropriate support, including vital mental health support, Autistic adults are more likely to be admitted to mental health hospital in crisis (All Party Parliamentary Group on Autism, 2019). Seeing as Autistic individuals are already prone to mental health difficulties, the lack of appropriate social support available to Autistic individuals creates a very worrying picture. Maddox and Gaus (2019, 15) comment,

Despite their high prevalence and associated impairment, psychiatric conditions often are untreated in autistic adults. Untreated psychiatric conditions in autistic adults are associated with a host of negative outcomes, including adaptive functioning impairments, difficulties with employment and independent living, and poor quality of life.

Recent statistics released by the Office for National Statistics further corroborates this, revealing that only approximately 29% of Autistic individuals are employed – among the lowest employment rates for various types of disability (Office for National Statistics, 2022).

Lack of employment and social support could potentially only further compound feelings of isolation and hopelessness expressed by Autistic adults, leading to worsening mental health difficulties. This is particularly significant as lack of employment has been linked with feelings of disempowerment which can worsen symptoms of depression and other affective disorders in the general population (Johanson and Bejerholm, 2017).

Moreover, social support may be a protective factor against depression and suicidal ideation in Autistic individuals, and has been shown to increase resilience to trauma and associated stress (Ozbay et al., 2007; Warrier and Baren-Cohen, 2019).

Taken as a whole, this research presents a worrying picture for the wellbeing of Autistic individuals, characterised by a myriad of interwoven exacerbating factors. As discussed later, the high incidence of trauma within this population further contributes to a discouraging status quo.

## **1.5 Autistic Women**

Being female comes with its own sets of challenges in relation to trauma and mental health as I will discuss in the literature review. For Autistic women, however, these challenges are often compounded by difficulties surrounding social interactions, sensory sensitivities, trouble regulating emotions, barriers to receiving an autism diagnosis and, consequently, to accessing appropriate support. Moreover, Autistic women face a double discrimination: being both Autistic in a predominantly neurotypical world and female in a historically patriarchal society. The intersection of these two marginalised identities increases the risk for a range of psychological traumas, including domestic violence and sexual assault (Parfitt, 2021).

Coined originally by Kimberlé Crenshaw in 1989, intersectionality was first used as a way to understand the unique oppression experienced by African-American women (Crenshaw, 1989). It has since become the key analytic framework through which feminist scholars talk about the structural identities of race, class, gender and sexuality (Cooper, 2015). Intersectionality is the notion that humans have multiple overlapping and intersecting identities, the interaction of which creates unique experiences of privilege or oppression. Intersectionality recognises that engrained socio-political systems impact an individual's life chances, including their mental health and well-being. Having multiple marginalised identities can create issues more complex and harmful than being from just one marginalised group (Schwarz, 2017). It is a useful framework because it encourages us to focus on

complex relationships and interactions rather than giving higher status to any one social category's inequality or experience of discrimination (Scottish Government, 2022).

Intersectionality is an important concept for therapists as it encourages us to recognise how the larger societal influences and environmental contexts contribute to many of the issues women experience, recognising the power dynamics within society and the impact of sexism on said issues (Ballou et al., 2008). The intersection of the identities with which this research is concerned – Autistic and female – creates unique experiences of oppression, including experiencing barriers to receiving an autism diagnosis and receiving subsequent support – a concept that will be explored further below.

### **1.5.1 The Underdiagnosis of Autistic Females**

It is estimated that there are approximately 700,000 individuals with an autism diagnosis living in the United Kingdom today. The vast majority of these individuals are male, with approximately three Autistic males to every one Autistic female diagnosed with the condition (National Autistic Society, n.d.). However, recent research suggests that many Autistic females remain undiagnosed, and therefore the number of Autistic females is likely to be underreported. One theory to explain this is the existence of a 'female autism phenotype', suggesting that females possess characteristics that don't fit the typical diagnostic criteria historically based on male participants (Gould and Ashton-Smith, 2011; National Autistic Society, n.d.). Another explanation for this imbalance is the theory that females are better at camouflaging or masking their Autistic characteristics and using compensatory characteristics to mitigate their social challenges (Dean, Harwood and Kasari, 2017; Gould and Ashton-Smith, 2011). This is believed to make it significantly harder for medical professionals to recognise and diagnose autism in women and girls. I propose that neither factor is fully responsible for the underdiagnosis of autistic females, but that it is a

complex interplay between the two as well as the western world's expectations of women and what it means to be feminine (gentle, social, quiet, nurturing, etc.), amplifying the obligation for Autistic women to mask to fit in and be deemed "acceptable" within society.

While the terms masking and camouflaging are often used interchangeably, camouflaging can be described as the intentional use of strategies by Autistic people to minimise the visibility of their autism in social situations and includes masking behaviours (Cook et al., 2022). Masking refers specifically to the intentional concealing of autism characteristics and may even include developing personas to use within social situations as Laura Hull and colleagues (2017) elaborate in their study examining social camouflaging in Autistic adults:

Masking encompasses the aspects of camouflaging that focus on hiding one's ASC characteristics and developing different personas or characters to use during social situations. Both of these emphasise a distinction between the respondent's 'true' or 'automatic' behaviours, and what they present to the rest of the world.

They continue,

Masking enabled respondents to present a different identity to the outside world, one that covered up those parts of themselves they were not happy with. The combination of controlled behaviour and appropriate conversation produced through camouflaging was often described as essential during social interactions, even though this meant concealing one's actual personality.

As is indicated by the above quotations, the effects of masking and camouflaging on identity and personal power are significant, as at the very core of these practices is the covering up of various aspects of one's identity, most commonly those associated with autism such as differences in social communication, atypical behaviours and unique (often intense) interests. Autistic women and girls often engage in this behaviour from a very young age, sometimes

relatively unaware that they are doing it. This, I believe, may make it difficult for Autistic females to truly know themselves, as they are often intentionally hiding or adapting aspects of themselves that they fear might result in social ostracism and ridicule. Kajsa Igelström, professor of neuroscience at Linköping University in Sweden, states in an interview with Spectrum News “For many women, it is not until they get properly diagnosed, recognized, and accepted that they can fully map out who they are” (Russo, 2018, 2). Autism diagnosis then, in many ways, can be seen as an invitation to reclaim previously lost or abandoned aspects of one’s identity.

The failure to identify autism in girls can lead to feelings of chronic invalidation and emotional distress, with many women reporting having felt emotionally isolated prior to their autism diagnosis (Bargiela, Steward and Mandy, 2016). An autism diagnosis therefore opens the door to suitable resources as well as a network of support (Bargiela, Steward and Mandy, 2016). The Organization for Autism Research [OAR] (2018, para. 8) state:

Diagnosing autism is critical because it allows the individual to access resources to help them cope with this diagnosis; it shows that individual that even though they are different, it is okay because there is a giant network of people with autism.

After receiving a diagnosis, many Autistic women report that they are able to reduce masking efforts and begin to accept their autism diagnosis, each of which result in an overall increase in self-confidence (OAR, 2018).

### **1.5.2 Barriers to Support**

Autistic women who require additional mental health support, such as those who have experienced trauma, often feel as if they have nowhere to turn following their diagnosis, with many mental health services failing to provide specialist support to Autistic individuals or denying Autistic individuals support altogether (Hallet and Crompton, 2018). Camm-Crosbie

and colleagues (2018, 1431) identify three significant barriers to Autistic individuals accessing mental health support:

- 1) A gap in services available to Autistic individuals **without** cooccurring intellectual disability
- 2) “High-functioning” Autistics may be perceived as coping when, in fact, they are struggling
- 3) Long wait lists and a lack of funding for support or treatment (Camm-Crosbie et al., 2018)

Studies have also suggested that Autistic individuals may require a significantly longer course of therapy to achieve results and that session caps imposed by services might be detrimental to Autistic individuals for this reason (Anderberg et al., 2017). This can be attributed to differences in cognitive and emotional processing, which will be explored further in the presentation and discussion of findings section of this thesis. When Autistic individuals are offered treatments for mental health challenges that are not compatible with their needs, therapists run the risk of further invalidating their experiences and exacerbating self-blame and feelings of defectiveness; this in turn increases feelings of hopelessness and further disempowers Autistic individuals.

Seeing as many autism-specific services fail to offer appropriate mental health support (and vice versa) it is likely that Autistic women suffering with trauma might seek support from a therapist, either privately or within a larger mental health charity or organisation. Within my own private practice, I have received many referrals from individuals after having been discharged from mental health services following their autism disclosure or diagnosis. Again, experiences such as these can further compound mental health difficulties and feelings of hopelessness as they can feel both stigmatising and invalidating. Such experiences have been the driving force for this research as I have sought clarity on the

ways in which professionals can better work with this unique population in a way that is both consistent with their needs and empowering – seeking to dissolve the debilitating effects of trauma and chronic invalidation from the medical establishment and society at large.

## 1.6 Defining Trauma

On top of the difficulties already faced by Autistic women, this group are also at greater risk of suffering trauma than the general population, and in turn, of suffering from associated poor mental and physical health, including suicidal behaviour (Warrier and Baron-Cohen, 2019). Given that trauma is a central theme of this work, it is important to first define trauma at a basic level, though the review of literature will expand on the limitations of this definition when considering trauma experienced by Autistic individuals.

The Cambridge English Dictionary define trauma as: “severe and lasting emotional shock and pain caused by an extremely upsetting experience” (Cambridge Dictionary, n.d.). This definition creates space for multiple subjective experiences, as what is deemed to have been *traumatic* will be different for each individual. These experiences might include sustained rejection and societal marginalisation resulting from autism stigma (“invalidation trauma”), prolonged childhood trauma (complex trauma), trauma resulting from a single, terrorising event (“simple” or big “T” Traumas) which are most associated with post-traumatic stress disorder (PTSD), or other little “t” traumas such as a bereavement or divorce.

In the next chapter I will proffer that there is an unfortunate interplay between trauma and autism, made even more severe for women, whose repeated experiences of invalidation and victimisation result in a traumatic response not dissimilar to complex PTSD. This, in turn, leads to further difficulties with emotion regulation and one’s sense of identity, characteristic of complex PTSD. There is a significant gap in the research around this intersection, particularly in relation to the implications of this for the therapeutic process and,

therefore, guidance for therapists endeavouring to work with this population. Any trauma-informed counselling approach that seeks to address the concerns faced by Autistic women must be willing to acknowledge the historical disadvantages faced by Autistic women and the subsequent impact on this population's sense of agency and autonomy within the mental health system and the ways in which these dynamics impact their recovery – issues that will be further explored within the literature review chapter of this dissertation.

### **1.7 Purpose of the Current Study**

Based on the social, personal and interpersonal context of autism explored above, this study seeks to examine the experiential accounts of Autistic women with self-reported histories of trauma. Particularly, this study examines their experience of receiving counselling support, with the goal of exploring how therapists might seek to better work with traumatic stress in Autistic women, as this is an area that has not been previously researched. This study takes a critical feminist approach by criticising the misogynistic view of women that characterises society (Clark, 2007). It acknowledges the ways in which the current medical discourse surrounding autism has contributed to the systemic disempowerment of Autistic women, through failing to recognise, diagnose and adequately support Autistic women in Western society, particularly those without accompanying intellectual disability who don't meet the threshold for various types of support. Moreover, this study examines trauma through an intersectional lens (Crenshaw, 2018), taking the view that the intersection of two marginalised identities, in this case female and neurodivergent, increases the risk for various types of trauma and adverse experiences.

Given the ongoing disputes surrounding recognising and, subsequently, diagnosing autism in females, this research includes accounts of both participants who have received a formal autism diagnosis and those who have self-diagnosed or are awaiting clinical diagnosis.

In many cases, engaging in the self-reflection and personal processing involved with therapy is a major precursor to identifying one's own neurodivergence, as was my experience and the experience of most participants in this study. Additionally, the current wait time for an autism assessment is over three years in some areas of the UK and self-diagnosis can be seen to improve self-understanding and provide support in the interim. Interviewing only Autistic women with a formal diagnosis would risk ignoring a significant portion of this population for the reasons stated above.

## **1.8 Current Literature**

As will be explored in the literature review, current literature surrounding therapeutic work with Autistic individuals with histories of trauma is scarce and, while we know that depression, anxiety and obsessive-compulsive disorder are more prevalent amongst Autistic individuals, the incidence of post-traumatic stress disorder and the psychological effects of trauma have largely been overlooked (Gravitz, 2018) providing motivation for me to study Autistic women who have endured trauma. Similarly, there are no existing studies to date examining trauma and traumatic stress in Autistic females, highlighting the importance of the current study. Existing studies in this area primarily address the shared mechanisms between post-traumatic stress disorder and autism and the ways in which trauma may exacerbate existing mental health difficulties and Autistic traits. While these studies help to paint a picture of the ways in which trauma may differ in Autistic individuals and the potential repercussions of such trauma, there exists a significant gap in the knowledge surrounding the implications of such findings on therapeutic practice. Crucially, there are no existing studies exploring trauma therapy from the Autistic client's perspective.

## 1.9 Summary

In this introductory chapter I have discussed the history of autism, the difficulties faced by Autistic women, and the current gap in research pertaining to the implications for therapeutic practice when working with traumatised Autistic women, which my literature review will now explore in depth.

The review of literature aims to situate my research within the existing body of literature on trauma, autism and counselling, drawing on feminist theory throughout to support my understanding of the dynamics and mechanisms at play that may affect the experience of trauma and trauma recovery in Autistic women. The literature review examines previous work that can shine a light on the intersectionality that is being female, Autistic and suffering with trauma – the interplay of which produces an extremely difficult and complex challenge. Given both the severity and the prevalence of this challenge, it is surprising that there is a paucity of research around the topic, resulting in a lack of best practice guidance for counsellors working with this population, thus establishing the rationale for my research questions, which are outlined at the end of the review of literature.

# Chapter Two: Review of Literature

## 2.1 Introduction

The aim of this review of literature is to contextualise the present study by locating its position within the existing body of research and by showing how the existing research has informed my research questions and methodology.

To begin, I will provide a review of literature conceptualising trauma and traumatic stress, before analysing what constitutes trauma for Autistic individuals, including specific difficulties around bullying, victimisation and invalidation. I will then continue to narrow my focus to look at Autistic individuals' predisposition to trauma and traumatic stress, and the interplay between trauma and autism – both how Autism exacerbates trauma features, and how trauma exacerbates Autism features. I then explore the literature of complex trauma and the ways in which it differs from the “simple traumas” largely associated with PTSD. This is intended to provide the reader with a clear picture of the ways in which Autistic women are predisposed to various types of traumas as well as more discrete, novel traumas unique to this population.

Next, the connection between trauma and identity will be explored, highlighting the ways in which Autistic women's predisposition to childhood trauma increases the risk for identity dysfunction. Then, the literature surrounding counselling marginalised groups, and counselling trauma sufferers will be reviewed, before focusing on counselling for Autistic individuals and finally Autistic individuals who have suffered trauma. This will lead to an understanding that we can draw upon to develop best practice for therapists working with Autistic individuals who have suffered trauma, and to identify the gaps in current knowledge surrounding therapeutic practice with this unique group.

Finally, the literature surrounding power and empowerment will be explored, particularly as they pertain to therapeutic practice with marginalised individuals. This is intended to give the reader a sense of the ways in which the unique disadvantages experienced by Autistic women contribute to the disempowerment of this group and the ways in which therapists can seek to assist in the empowerment of clients through the restoration of autonomy and control over their lives.

## **2.2 Conceptualising Trauma and Traumatic Stress**

Trauma may be defined as: “severe and lasting emotional shock and pain caused by an extremely upsetting experience” (Cambridge Dictionary, n.d.). This definition creates space for multiple subjective experiences, as what is deemed to have been *traumatic* will be different for each individual. However, the DSM-5 has removed the subjective component to the definition of trauma (Pai et al., 2017). The definition of trauma within DSM-5 requires “actual or threatened death, serious injury, or sexual violence” (American Psychiatric Association, 2013, 271). Therefore, stressful events not involving an immediate threat to life or physical injury are not considered trauma in this definition (Pai, et al., 2017).

Trauma results from severe psychological distress following an event that is perceived as harmful or life-threatening and has a lasting effect on the individual’s functioning as well as their emotional, mental, physical, social and spiritual wellbeing (Substance Abuse and Mental Health Services Administration [SAMHSA], 2014). Crucially, the types of events and circumstances experienced as traumatic can vary widely from individual to individual which holds particularly true for Autistic women who may be exposed to novel sources of trauma such as sensory sensitivities, peer rejection and chronic invalidation.

The DSM-5 (American Psychiatric Association, 2013) sets out specific criteria for the diagnosis of PTSD following exposure to traumatic events. Although this project seeks to

look beyond the medicalised views of trauma and distress, the criteria for PTSD as set out in the DSM are useful for understanding the core characteristics of shock trauma shared by most affected individuals. Defining DSM-5 criteria initially to build an understanding of the traditional medical model will help me to identify the areas where it falls short in respect to the experiences of Autistic women interviewed for this project.

The criteria include *intrusive symptoms* (e.g. involuntary memories, flashbacks or distressing dreams pertaining to the traumatic event), *symptoms of avoidance* (e.g. the avoidance of internal or external reminders of the traumatic event), symptoms relating to *arousal and reactivity* (e.g. hypervigilance, irritability and impulsivity), and negative alterations to thoughts and mood, including dissociative amnesia (an inability to remember important details pertaining to the traumatic event) increased self-blame and a chronic inability to experience positive emotions such as happiness or affection. The duration of these disturbances must be greater than one month, cause significant distress and impairment in multiple areas of functioning and not be a result of substance use or another medical condition to meet the diagnostic criteria for PTSD.

Acknowledging the limitations of trauma as described in the DSM, Bessel van der Kolk in his paper, “Posttraumatic Stress Disorder and the Nature of Trauma,” (2000) lists depression, increased aggression towards oneself or others, depersonalisation, dissociation, compulsive behavioural repetition of traumatic scenarios, and declines in family or occupational functioning as possible reactions without the full criteria for PTSD being met.

Importantly, an individual’s experience of the events or circumstances is key to determining whether a particular event or circumstance is experienced as traumatic, and how the event is experienced could be linked to a range of factors, such as the individual’s developmental age, cultural beliefs, past experiences, level of distress tolerance, values, morals and the support available to the individual at the time of the event (Barbash, 2017;

SAMHSA, 2014). Moreover, the ways in which a person labels, assigns meaning to, and is disrupted both physically and psychologically by an event will contribute to whether or not it is experienced as traumatic (SAMHSA, 2014). In short, what constitutes a traumatic experience is subjective to the affected individual and might differ considerably from one individual to the next. This points to a weakness of the DSM-5, namely that the manual provides a narrow definition of trauma that does not allow for idiosyncratic variation.

Mental health clinicians have come to differentiate events resulting in the development of PTSD symptoms, namely those that pose an immediate threat to an individual's life or bodily integrity, from those that exceed our ability to cope and cause disruption in emotional functioning but do not result in the development of PTSD symptoms – the first differentiated with a capital “T” (large ‘T’ traumas) and the latter a lowercase “t” (small ‘t’ traumas) (Barbash, 2017). Examples of large ‘T’ traumas include natural disasters, war combat, aeroplane accidents, acts of terror, serious injury and physical or sexual assault. Examples of little ‘t’ traumas might include divorce or the loss of a relationship, bereavement, interpersonal conflict, the death of a pet and bullying/harassment (Barbash, 2017).

The accumulation of multiple little ‘t’ traumas, especially over a short period of time, can have a profound impact on an individual's emotional functioning. This holds particular importance for Autistic women who are not only more likely to be exposed to various types of traumas such as bullying and abuse but may also have to contend with repeated experiences of rejection, marginalisation and invalidation. Moreover, inherent to many Traumatic and *traumatic* experiences is the evocation of feelings of powerlessness, often resulting in feelings of shame, humiliation, guilt and betrayal (SAMHSA, 2014). I will therefore discuss the importance of empowerment within the context of counselling Autistic women in due course.

## **2.3 Trauma and Autism**

### **2.3.1 What Constitutes Trauma for Autistic Individuals?**

Studies indicate that the types of events experienced as traumatic may differ in Autistic individuals. A recent study conducted by Rumball and colleagues (2020) indicates that up to 35% of Autistic individuals surveyed experienced events that they perceived as traumatic despite not fitting the description of trauma as indicated in the DSM. Within this study, both DSM and non-DSM traumas were catalysts for PTSD symptoms. The most commonly reported non-DSM traumas amongst this population included bullying, “non-traumatic” bereavement, anorexia and mental breakdowns; the most common traumas fitting the description of trauma as indicated in the DSM included sexual and physical abuse (Rumball et al., 2020).

Moreover, the unique characteristics of sensation, perception, social awareness, cognition, and global understanding in autism may alter what events and stimuli are experienced as traumatic and subsequently the nature and severity of posttraumatic symptoms (Kerns et al., 2015). Haruvi-Lamdan and colleagues (2018) write:

It may be assumed that individuals with ASD experience unique sources of stress that are potentially traumatic, compared with the general population. Unusual fears, difficulties with sensory overstimulation, changes in routine, and social demands (e.g. public speaking or communicating needs to others) are typical sources of stress for individuals with ASD. In addition, it was found that individuals with ASD are painfully aware of their differences from others and are hypersensitive to environmental stimuli.

A logical proposition, then, is that Autistic individuals’ heightened susceptibility to various types of traumas combined with these novel traumatic experiences could create a unique vulnerability towards traumatic stress for this population. I will now outline two ways that

Autistic people experience trauma in ways not described by the DSM-5 - through bullying and victimisation, and through invalidation.

### **2.3.1.1 Bullying and Victimisation**

Bullying and peer victimisation are common experiences for Autistic individuals. Storch and colleagues (2012) reported that between 44 and 77% of Autistic children had been bullied within a one month period as opposed to 2-17% of the general population. In a study conducted by Cappadocia and colleagues (2012) 67% of parents to children with “high functioning” autism (including Asperger’s Syndrome) reported that their child had experienced physical, social, verbal and/or cyber bullying in the preceding month, with 46% experiencing peer victimisation at least once a week (Haruvi-Lamdan et al., 2018). Peer victimisation amongst this group has been associated with a higher prevalence of somatic complaints, indicating that Autistic individuals may manifest symptoms associated with PTSD in a distinct manner (Bitsika and Sharpley, 2014; Haruvi-Lamdan et al., 2018). Such complaints are thought to be due to difficulties verbalising and processing trauma (Mitchell, Clegg, and Furniss, 2006). Similar studies indicate that bullying and peer victimisation are also associated with increased anxiety, hypersensitivity, fearfulness, self-injury, stereotyped behaviours and hyperactivity in Autistic children (Cappadocia et al., 2012; Sreckovic, Brunsting, and Able, 2014; Zablotsky et al., 2013; Zeedyk et al., 2014).

Tony Attwood (2004a) speaks to Autistic individuals’ increased susceptibility to bullying, particularly those without intellectual impairment such as those who would have previously received a diagnosis of Asperger’s Syndrome. He states, “Children with Asperger Syndrome are also more likely to be targets as they are perceived by other children as naive, gullible, eccentric, low status and 'poor' in the currency of social status and friendship.” Attwood goes on to explain how Autistic individuals may be less likely to report bullying

behaviours due to differences in theory of mind, that is difficulty determining the thoughts and intentions of others in comparison to their peers (Attwood, 2004b; Baron-Cohen, 1995). This creates a worrying picture as the consequences of being bullied can be severe and long-lasting, negatively affecting an individual's mental health, self-esteem, and educational success (Green et al., 2010; Bond et al., 2001; Turner et al., 2006).

### **2.3.1.2. Invalidation Trauma**

Autistic researcher and crisis therapist Gordon Gates (2019, 13) speaks to a phenomenon he has termed “invalidation trauma” arising from chronic invalidation and autism stigma within society. He writes,

Although trauma is often framed in terms of a terrorizing event, it is the perceived physical and/or psychological threat to our personhood and residual self-protection that underlies much of the suffering involved. Having our humanity threatened, undermined, and devalued is fundamentally traumatic.

In subsequent chapters, Gates (2019) goes on to compare invalidation trauma with what John Bowlby described as the disorganisation of emotional attachment. He notes that threats to the safety and security of developing children due to a lack of consistently supportive caregiver attention have been shown to predict extreme symptoms of emotional dysregulation and mental health difficulties in adults. Gates argues that chronic invalidation can be as harmful as other forms of abuse, and makes a case for the importance of respect, non-judgement and nurturing contact in the development of healthy and emotionally resilient adults - all of which are likely to be lacking in Autistic adults who are subjected to chronic invalidation, autism stigma, ridicule and social exclusion - not necessarily from parents or caregivers, but from society at large. The internalisation of these repeated experiences is bound to illicit psychological symptoms and subsequently increase the risk for other types of traumas and

abuse. I posit that this unique source of trauma hold particular relevance for Autistic women who are not only subjected to autism stigma but are more likely to be invalidated by the medical establishment through the failure to diagnose Autistic females and subsequently meet their unique needs.

Through the examples of bullying, victimisation and invalidation, we can see how trauma for Autistic individuals does not fit neatly with the DSM criteria for trauma. I will now examine the relationship between autism and trauma in greater depth below.

### **2.3.2 Autistic Individuals' Predisposition to Trauma and Traumatic Stress**

Interestingly, a correlation between Autistic traits and PTSD symptoms has been identified, with higher Autistic traits indicating higher posttraumatic stress symptoms (Haruvi-Lamdan et al., 2020). Likewise, the presence of Autistic traits is correlated with increased vulnerability to abuse and social stressors, each of which can be experienced as traumatic. In a recent study conducted by Haruvi-Lamdan and colleagues (2020) researchers determined that Autistic individuals were eight times more likely to report a probable PTSD diagnosis than the typically developing group and were more likely to report posttraumatic symptoms. Similarly, Hirvikoski and Blomqvist (2015) found that Autistic adults reported significantly higher rates of subjective stress and a poorer ability to cope with stress within everyday life than neurotypical adults. Further, Autistic individuals are known to exhibit more difficulties surrounding sensory hypersensitivity, a factor that has been associated with vulnerability to PTSD (Horder et al., 2014; Engel-Yeger et al., 2013).

The increased prevalence of traumatic encounters and subsequent challenges amongst Autistic individuals is thought to be due to several factors, including structural differences in the brains of Autistic individuals, social and communicative difficulties experienced by this population, emotional processing differences and limited psychological resources (Kerns et

al., 2015). Additionally, problems associated with emotion regulation are associated with both conditions with each being characterised by difficulties regulating negative affect (Haruvi-Lamdan et al., 2018). The combination of these factors may predispose Autistic individuals to trauma and impact their ability to recover from traumatic stress. An example of this is the susceptibility towards anxiety disorders and emotional processing difficulties (meltdowns, shutdowns, outbursts, etc.) amongst this group which might impact Autistic individuals' ability to both process and cope with difficult life events (Kerns et al., 2015).

### **2.3.3 The Interplay between Trauma and Autism**

There are many factors which underlie the development of traumatic stress symptoms and an individual's ability to adapt or mitigate challenging life events, many of which impact Autistic individuals. For example, individuals with pre-existing psychiatric disorders, lower IQ, limited social support and who have suffered recurrent, chronic trauma are thought to be more susceptible to traumatic stress and exhibit poorer outcomes than their peers (Kerns et al., 2015). This is significant as Autistic individuals are more likely to suffer from psychiatric illness, may also be impacted by intellectual impairment and are more likely to suffer from social isolation than their typically developing peers (Kerns et al., 2015).

The social isolation experienced by many Autistic individuals may place this population at greater risk of traumatic stress and associated symptoms (Kerns, et al., 2015) as social support has been identified as an integral aspect of recovery from psychological trauma (Ozbay et al., 2007). Similarly, the co-occurrence of autism and PTSD has been associated with decreased social skills and an overall decrease in social functioning, indicating an increased risk for this population. Studies also indicate that the social sphere can be particularly traumatic for this population, particularly Autistic females which might further decrease motivation for accessing social support (Haruvi-Lamdan et al., 2020).

Autistic individuals are also more likely to suffer from alexithymia, the inability to identify and describe one's emotions, as well as a tendency towards intellectualising over the experiencing and processing emotions (Mazefsky and White, 2014; Rieffe et al., 2007). This has important implications for individuals' recovery from trauma and traumatic stress, as emotion recognition is known to play a key role in the processing of traumatic events; such differences are therefore thought to prevent Autistic individuals from recognising, communicating and effectively coping with traumatic experiences (Kerns et al., 2015). Crucially, this difficulty surrounding identifying emotions and the communication deficits associated with autism may get in the way of reporting traumatic experiences and the seeking of treatment or support (Haruvi-Lamdan et al., 2019). Unfortunately, even following help-seeking, traumatised Autistic individuals may also find engaging with traditional trauma-focused therapies difficult as they typically involve the verbal retelling of traumatic narratives and emotional expression, each of which might be challenging for this population (Haruvi-Lamdan et al., 2018). I will explore the implications of these challenges when discussing the literature surrounding therapeutic practice for this group.

Furthermore, it is believed that certain ASD-related stressors such as social confusion, prevention or punishment of preferred behaviours (e.g. restricted, repetitive interests), peer rejection, and sensory sensitivities (e.g. lights and sounds) may engender a "traumatic conditioning process" in Autistic youths that leads to clinically significant anxiety (Wood and Gadow, 2010). Likewise, Autistic individuals' risk for experiencing a greater number of potentially traumatic events may increase this population's risk for multiple, repeated traumas hence rendering them more susceptible to traumatic stress symptoms (i.e. increased hypervigilance and anxiety) and associated challenges (Kerns, et al., 2015). This may also indicate that Autistic individuals are more susceptible to the emotional and personality challenges associated with complex trauma resulting from repeated traumatic experiences.

Similarly, not everyone will meet the full diagnostic criteria for PTSD and this might be particularly true for Autistic individuals whose response to trauma may be atypical and harder to recognise (Kerns et al., 2015). Studies in the area also indicate that Autistic individuals experience significantly higher rates of symptoms related to hyperarousal and marginally higher levels of symptoms associated with negative alteration in cognition and mood than their typically developing peers (Haruvi-Lamdan et al., 2020). In fact, Haruvi-Lamdan (2019) and colleagues suggest the potential for a symptomatic profile for PTSD specific to ASD characterised by enhanced hyperarousal. This may indicate that symptoms associated with PTSD pertaining to hyperarousal (i.e. irritability, trouble with concentration, and insomnia) are more prevalent for Autistic women than the general population.

#### **2.3.4 PTSD and Autism: Shared Mechanisms**

PTSD and autism share many underlying mechanisms, including neurological “abnormalities”, as well as cognitive-behavioural mechanisms such as increased rumination, cognitive rigidity, and avoidance of potentially upsetting stimuli (Haruvi-Lamdan et al., 2018). Interestingly, there are several pathological features of autism that overlap with those found in individuals with PTSD. For example, alterations in the functional connectivity of the amygdala and prefrontal cortex, areas central to the regulation of emotion, are found in both Autistic individuals and those suffering from traumatic stress or who have experienced chronic childhood adversity (Mazefsky et al., 2013; Grant et al., 2011; Williams et al., 2006). Autism has also been linked with dysregulated circadian changes in limbic-hypothalamic-pituitary-Adrenal axis activity as well as day-to-day rhythms; these changes are known to be characteristic of chronic stress (Corbett et al., 2008, 2009). Lastly, hippocampal abnormalities have been identified in both conditions (Ben Shalom, 2003; Lindauer et al., 2004; Wignall et al., 2004). Disruption to these mechanisms could indicate a vulnerability to future trauma or

that trauma has already occurred, setting the stage for subsequent biological and behavioural dysregulation (Kerns et al., 2015).

### **2.3.5 PTSD and the Exacerbation of Autism Features**

Interestingly, PTSD is thought to exacerbate autism features (Haruvi-Lamdan et al., 2018; National Autistic Society, 2021) which holds particular relevance to this study as participants' diagnosis and therapeutic journeys were closely intertwined, indicating that the experiencing of traumatic experiences may be the catalyst for the autism diagnostic process due to the exacerbation of traits. Wood and Gadow (2010) indicate that Autistic youth may turn to maladaptive coping strategies such as repetitive behaviours and social avoidance to avoid or limit negative affect and that such patterns may also be employed when experiencing trauma-related emotions, ultimately causing an even more severe autism profile (Haruvi-Lamdan et al., 2018). There are several socio-cognitive features of autism which may diminish the use of cognitive coping skills and other adaptive strategies to regulate emotion, leading to an exaggerated trauma response; these features include mental rigidity, information processing differences, differences in perception, impaired emotional insight, and reduced goal-directedness (Kerns et al., 2015). Autistic individuals may also struggle to disengage from thoughts or memories associated with traumatic events due to their ruminative tendencies and difficulties shifting attention (Kerns et al., 2015). Likewise, they may struggle to adapt flexibly to adversity, trauma or unexpected events due to rigid "black and white" thinking and rule-governed behaviour (Pugliese and White, 2014; Hill, 2004). Such difficulties may impact Autistic individuals' ability to both process and cope with traumatic or difficult life events.

## **2.4 Prolonged Trauma and the Development of Complex PTSD**

### **2.4.1 Trauma and Feminist Theory**

The diagnosis of PTSD falls short of capturing the developmental effects of chronic and interpersonal developmental traumas originating in childhood and clinicians have long posited that the diagnosis is not entirely appropriate for individuals whose exposure to traumatic stress is recurrent, such as with chronic childhood neglect, sexual abuse, or psychological abuse (Cook et al., 2005; Herman, 1992a). This may be particularly relevant for Autistic women who may be exposed to chronic invalidation or invalidation trauma as discussed above and who might not meet the standard diagnostic criteria for PTSD. Similarly, the social naivety and social and communicative difficulties that characterise autism may make Autistic individuals more prone to childhood trauma and adversity (Kerns et al., 2015).

Interestingly, feminist therapists were among the first to challenge the original criterion for trauma as described in the DSM, having previously created names for the traumas commonly endured by women, including sexual assault (termed “rape trauma syndrome”) and domestic abuse (termed “battered woman syndrome”) (Brown, 2004). Indeed, the identification of and subsequent diagnosis of psychological trauma as it exists today, including the explicit inclusion of interpersonal violence, has its roots in feminist practice and is largely due to the work of feminist theorists, therapists and researchers such as Judith Herman and Maria Root (Brown, 2004; Herman, 1992b; Root, 1992). Harmonious with the methodological underpinnings of this research, a feminist approach to trauma therapy acknowledges trauma as resulting from vulnerabilities resulting from bias and unfair hierarchies in culture, for example, the harassment of people of colour or the raping of women by men (Brown, 2004).

Feminist psychologist Maria Root (1992) first proposed the concept of “insidious traumatisation”, an idea that is at the forefront of feminist constructs of trauma. Having

examined the experiences of persons from targeted and marginalised groups, she argued that the lives of many belonging to these groups (i.e. women, disabled individuals, and people of colour) are impacted by the daily experience of subthreshold traumatic stressors creating a unique vulnerability for these groups (Brown, 2004). Root (1992) argues that the vulnerabilities produced by this insidious process can lead to apparently small events being experienced as traumatic and leading to known symptoms of trauma such as flashbacks, nightmares, numbing and avoidance. Again, this theory holds particular relevance to this study as the intersection of these two marginalised identities – Autistic and female – potentially increases the risk for the traumatic conditioning response proposed by Root.

#### **2.4.2 Conceptualising CPTSD**

The term “complex trauma” (also sometimes referred to as “enduring personality change after catastrophic experience” [EPCACE] or “disorders of extreme distress not otherwise specified” [DESNOS] has subsequently been used to describe the experience of multiple, prolonged and developmentally adverse traumas (most commonly interpersonal in nature) while the term “simple trauma” has been used to describe one discrete traumatic event, such as those most commonly associated with a diagnosis of PTSD (Herman, 1992a). Examples of complex traumas include sustained sexual or physical abuse, physical and emotional neglect, ongoing community violence, and war (van der Kolk, 2005). Traumas related to abuse and neglect often begin in early childhood and commonly occur within the child’s caregiving system, meaning the perpetrator is frequently someone the child depends on to meet their physical or emotional needs. Such traumas interfere with an individual’s neurobiological development and impact their ability to deal with subsequent stressors effectively, increasing the utilisation of social and mental health services in adulthood (Cook et al., 2005). Interestingly, studies have shown that Autistic individuals are more prone to

childhood trauma and that childhood trauma and associated sequelae are connected with poor mental and physical health in later life, including increased suicidal behaviour (Kerns et al., 2015; Warrier and Baron-Cohen, 2019).

While the symptoms of Complex PTSD (also known as CPTSD) include those of PTSD, there are additional symptoms that may be present. Such symptoms include relational difficulties, feelings of guilt and shame, difficulty regulating emotions, destructive or risk-taking behaviour (including self-harm and alcohol or drug misuse), isolating oneself from one's family, and suicidal thoughts and ideation (NHS, 2021). The mental health charity, Mind (2021) also cites feeling angry and distrustful towards the world, feelings of emptiness and hopelessness, feeling permanently damaged or worthless, and feeling completely different from others as potential indicators of CPTSD. CPTSD is thought to be more severe if the events happened early in life, were caused by a parent or carer, the trauma was sustained over a long period of time, the individual was alone at the time of the trauma, or if there is ongoing contact with the perpetrator (NHS, 2021). The complications of such trauma are widespread, and include difficulties in a variety of realms, including somatic, cognitive, affective, behavioural and relational (Herman, 2009).

In addition to the symptoms listed above, somatic symptoms refer to physical symptoms associated with CPTSD; examples include tension headaches, gastrointestinal complaints, and abdominal, back and pelvic pain (Herman, 2009). Affective changes associated with CPTSD include protracted or prolonged depression characterised by feelings of hopelessness about one's life, future, and the world at large. Judith Herman (2009, 382) speaks to the ways in which depressive symptoms combine with those of PTSD, further compounding difficulties:

The dissociative symptoms of PTSD merge with the concentration difficulties of depression. The paralysis of initiative of chronic trauma combines with the apathy

and helplessness of depression. The disruptions in attachments of chronic trauma reinforce the isolation and withdrawal of depression. The debased self-image of chronic trauma fuels the guilty ruminations of depression. And the loss of faith suffered in chronic trauma merges with the hopelessness of depression.

From the above quotation we can begin to understand the ways in which depression further complicates many of the processes underlying CPTSD, leaving those afflicted feeling hopeless, helpless, and isolated.

Relational complications of CPTSD refer to the oscillation of attachment in survivors of childhood abuse and can result in the formation of intense and unstable relationships in adulthood, alternating between a fear of abandonment and a fear of domination by others. This in turn puts those afflicted at risk of further relational trauma, as our earliest attachments lay the foundation for all future relationships. Indeed, survivors of childhood abuse are at a greater risk of a range of adverse experiences in adulthood, and women who were abused in childhood are more likely to choose abusive mates (Herman, 2009).

Less explored perhaps is the impact of chronic invalidation and peer victimisation on the wellbeing of victims and the lasting effects this has on a person's residual self-protection. While we know that Autistic individuals are more likely to suffer peer victimisation and bullying than their neurotypical peers (Bitsika and Sharpley, 2014; Cappadocia and Weiss, 2012; Humphrey and Hebron, 2014), such experiences are seldom considered when conceptualising trauma, specifically complex trauma resulting from repeated traumatic experiences. I posit that repeated experiences of invalidation and victimisation such as these may result in a traumatic response in Autistic individuals not dissimilar to complex PTSD resulting in further difficulties with emotion regulation and one's sense of identity characteristic of complex PTSD. The phenomenon of masking autism traits serves to further exacerbate issues related to identity as will be explored in the presentation and discussion of

findings section of this dissertation. To my knowledge, there are no existing studies examining best practice when supporting Autistic individuals with complex trauma who may exhibit standard PTSD symptoms in addition to the changes in one's emotion regulation, perception of self and others, and sense of identity that characterise complex PTSD (Haruvi-Lamdan et al., 2018).

### **2.4.3 Trauma and Identity Distress: Reviving the 'Lost Selves'**

*"In varying degrees, psychological trauma "rattles" the organism and disturbs the equilibrium of the self" (Wilson, 2006, 9).*

Herman (2009) describes pathological changes in identity as characteristic of CPTSD, and it is this alteration that is perhaps most relevant to this study. As with PTSD, dissociative symptoms associated with CPTSD refer to the disconnection of one's feelings, thoughts, memory, and sense of identity. A key difference between dissociation exhibited following simple trauma and that of CPTSD is the fragmentation of the mind characteristic of survivors of childhood abuse. This psychological splitting, known as structural dissociation, is believed to occur due to conflict between the defence system and the attachment system – when the perpetrator of abuse is also the subject of a child's attachment. This in turn causes the disintegration of different parts of the self, leading to inconsistencies in feelings, behaviour and even personality in affected individuals. An extreme example of this is dissociative identity disorder, which occurs when multiple parts of the self fail to integrate, resulting in multiple distinct personalities. Herman (1992a, 386) writes,

Survivors of childhood abuse develop even more complex deformations of identity. A malignant sense of the self as contaminated, guilty, and evil is widely observed.

Fragmentation in the sense of self is also common, reaching its most dramatic extreme in multiple personality disorder.

Moreover, many researchers have studied the correlation between trauma and identity distress, with the potential for trauma to alter the trajectory of identity development and destabilise existing identity commitments (Berman et al., 2020). Waterman (2020) describes in detail the ways in which identity can be impacted by psychological trauma in adolescents. Individuals who recover relatively quickly from adverse, traumatic experiences with their budding identities intact are said to possess identity resilience. Waterman (2020, 61) writes,

Applying the concept of resilience in the face of trauma to identity functioning, identity resilience would be evidenced by the capacity to maintain the expression of personally meaningful identity commitments despite the traumatic event and its aftermath. The adolescent's/emerging adult's roles, goals, values, beliefs, and behaviors are minimally altered by what has occurred. Identity resilience would also be indicated in instances in which an adolescent/emerging adult is able to maintain active identity-related exploration following a traumatic event.

For others, however, the impact on the individual's developing identity can be altered, ranging from delays in the development of one's identity to the formation of an identity that is fully characterised by the traumatic event, sometimes referred to as a trauma-induced identity, in which surviving the traumatic event becomes the single most important component in their self-definition to the abandonment of all other aspects of their identity. Indeed, trauma and adversity have the power to alter identity functioning for better or for worse, with some individuals emerging stronger, more dedicated, and more effective in the expression of who they are, sometimes referred to as posttraumatic growth (Waterman, 2020). Waterman (2020, 59) continues,

... the relationship between trauma and identity functioning is reciprocal. Not only does trauma impact identity functioning but identity functioning can affect the ways in which traumatic events are experienced helping to determine whether the eventual outcome is identity disruption or posttraumatic growth.

This particular point is of high importance: identity functioning at the time of a traumatic event can impact the trajectory of one's identity functioning following the traumatic event. This indicates that those with a diffused or unstable identity, as is likely the case for those who have experienced invalidation trauma or are prone to masking authentic traits and fawning, are at increased risk of identity disruption following subsequent traumatic events; this in turn can make it difficult to ascertain one's authentic emotions, beliefs, values, and preferences. This can be even further complicated by the fawning response to trauma, seemingly common for Autistic females, in which one's needs and desires are sacrificed for the appeasement of others. Moreover, this may also indicate that those who have endured prolonged childhood abuse and sustain a fragmented identity are at increased risk for identity dysfunction following subsequent traumas which holds particular relevance for Autistic women given their increased vulnerability to various traumas.

#### **2.4.4 Trauma, Meaning Making, and Identity Coherence**

Successful attempts at meaning making (i.e. the process of interpreting and understanding life events, relationships and the self) appear to be paramount for overcoming psychological trauma and promoting identity coherence. Marin and Shkreli (2019) conducted a study in which they examined 32 trauma narratives written by a sample of young adults concluding that those who constructed their narratives in ruminative ways, characterised by self-criticism and self-doubt, exhibited unsuccessful meaning-making efforts. This is of particular importance as Autistic individuals are thought to be prone to ruminative thought

processes (Arwert and Sizoo, 2020; Patel et al., 2017). On the other hand, those who constructed their narratives in self-reflective, adaptive ways were able to successfully extrapolate meaning from their traumatic experiences, reflecting an integrated sense of self. Those who lacked identity commitment showed marked difficulty in making sense of their traumatic experiences in adaptive ways. Marin and Shkreli (2019) make a convincing argument for the importance of storytelling interventions to provide support during self-reflection for traumatised individuals to help them successfully make meaning from experiences and promote psychological growth. This is an important insight for therapists, who can support the exploration of traumatic events within the context of an individual's life, their values, beliefs, and relationships, thereby assisting clients in extrapolating meaning from life experiences.

## **2.5 Therapeutic Approaches**

Due to the limited research related to counselling for traumatised Autistic women, I will now outline existing research pertaining to counselling marginalised groups in general, as well as counselling for individuals who have suffered trauma, including interpersonal trauma and gender-based violence, as we have seen that Autistic women are more likely to have had these experiences. I will then outline the modifications that can be made to therapeutic practice when counselling Autistic individuals in general. By learning from the research and recommendations for working with each of these subsets, we can begin to build an understanding of how to effectively work with the specific group of interest to this study who sit at the intersection of those subsets – Autistic women who have experienced trauma – despite the lack of research specific to this group. I will then detail existing therapeutic approaches for Autistic individuals who have suffered trauma, bringing us to the edge of

existing literature, and presenting the gap in knowledge which I will explore through the five core research questions of this study, outlined at the end of this chapter.

### **2.5.1 Therapy for Marginalised Groups**

As is discussed above, Autistic women are at a greater risk of marginalisation. Crucially, socially marginalised groups are at a greater risk for a range of mental health difficulties than the general population and can be difficult to engage in mental health care (Priebe et al., 2012). Priebe and colleagues explored the experiences and views of experts in fourteen European countries regarding mental health care for marginalised groups. Through conducting semi-structured interviews with research participants, researchers were able to identify four components that can improve the accessibility of services when working with marginalised groups including: “a) establishing outreach programmes to identify and engage with individuals with mental disorders; b) facilitating access to services that provide mental health care; c) strengthening collaboration and coordination between different services; and d) disseminating information on services to both marginalised groups and practitioners in the area” (Priebe et al., 2012, 8). These findings hold particular relevance for Autistic women as this client group face significant barriers to accessing mental health support, as is explored in the introductory chapter of this dissertation.

Moreover, Johanna Cormack (2009) using qualitative analysis explored young homeless people’s views on counselling with a view to understanding how counselling might better suit their needs. Cormack (2009) ultimately concluded that a significant barrier to the therapeutic relationship was the marginalised client’s trust of the therapist and that the therapeutic alliance must be allowed to develop slowly allowing trust to develop over time. This is likely due to the propensity for marginalised groups to feel “let down” by various systems and professionals, thus making them wary of accepting help.

Cormack (2009) recommends therapists spend time in the client's environment, becoming a trusted and visible presence, before allowing the therapeutic work to begin. She also recommends therapists take time to educate potential clients about counselling, dispelling unhelpful myths generated by the media. This is in keeping with the literature that recommends therapists endeavouring to work with Autistic clients remain transparent about the therapeutic process from the outset, an idea that will be explored further below. While it would typically not be possible for counsellors to spend time in their client's environment, the larger point that it is important to develop an understanding of a client's life holds true.

The importance of having an awareness and understanding of the factors that affect a client's life outside the counselling room is supported in another interesting study – 'Gender, race and poverty: bringing the sociopolitical into psychotherapy' by Krawitz and Watson (1997). The researchers' aim was to explore how psychotherapy should be modified to provide a more relevant service for non-dominant groups in society, including women (who made up 84% of their sample). They believe that psychotherapy fails to adequately address the condition of marginalised groups due to the field's emphasis on the "intrapsychic" as opposed to having a broader understanding of the societal forces at play that may affect the individual. They state that because of the lack of power marginalised groups experience in their daily lives, lessening the power imbalance within the counselling room is of utmost importance to prevent retraumatising the client. The paper supports what is a major theme throughout this literature review – and a key rationale for my study – namely that managing to effectively modify traditional therapeutic approaches is a meaningful and worthwhile endeavour given the painful experiences of those who face the double disadvantage of adverse intrapsychic and sociopolitical factors (Krawitz and Watson, 1997).

An understanding of the experience of marginalised groups is particularly relevant and important for today – in 2022 – given the impacts of the coronavirus pandemic since

2020. Meyer and Young (2021, 309) write in their US study presenting best practice recommendations for U.S.-based psychologists working with marginalised populations, “The impacts of this pandemic have not been felt equally. The current pandemic has aggravated pre-existing prejudices and shed light on long-standing social, economic, and health inequities that have been and continue to be perpetuated by systems of oppression.” They conclude that practitioners should reflect on their own identity, knowledge and attitudes toward sociohistorical inequalities, develop knowledge of the experience of others, including identifying impacts of systemic injustice that may be compounded by COVID-19, and collaborate with clients, identifying the mental health impacts of oppressive systems and encouraging virtual community engagement.

As we can see, groups on the edge of society face multiple disadvantages which manifest in their ability to access support and benefit from the typical support on offer, thereby perpetuating their struggle. Lastly, while COVID-19 has raised awareness of the need for effective mental health provision, it also compounds inequalities that existed before the pandemic. I will explore the role of power inequality within the context of counselling in depth toward the end of this literature review.

### **2.5.2 Trauma-Informed Therapy**

Supporting Meyer and Young above, Sanderson (2010) in her book “Introduction to Counselling Survivors of Interpersonal Trauma” describes the need for counsellors to understand the background of their clients. In her writing on how to counsel people who have survived trauma, she describes key information counsellors should know and understand. For example, she says that victims of trauma have ubiquitously suffered from coercion and being controlled, and do not have equal power in their relationships and over their future. Therefore therapists should take steps to reduce the power imbalance present in the counselling room,

for example by promoting a collaborative therapeutic encounter in which both parties share their unique expertise (Sanderson, 2010).

She also explains how it can be hard for individuals to know this type of trauma is happening, meaning it is hard for them to name the experience. Therefore, she writes that therapists should help clients name their experience, thereby helping them to legitimise and validate their experience, which also restores a sense of control (Sanderson, 2010).

Other considerations include performing a comprehensive assessment before sessions begin, creating a setting that is a “calm oasis”, being aware of seating arrangements so clients can see the escape route, explicit contracting process including firm boundaries, managing session length and pace sensitively, dealing with long silences, and being ready to work with practical topics that arise, such as changes in living situations and dealing with court orders. This is very relevant for counselling Autistic individuals, given they also experience a range of practical challenges, such as how to access different types of support.

Sanderson (2010) also notes that, “To survive abuse, victims often adopt strategies which aid survival” and “rather than judging these, the therapist needs to honour and develop them alongside the introduction of a broader behavioural repertoire from which the survivor can choose” (2010, 36). To illuminate with an example - isolation is one strategy that traumatised people often employ. However we know social interaction supports mental health and recovery from trauma (Ozbay et al., 2007), therefore, therapists should acknowledge the ways that isolation has served them, but also help clients to identify other coping strategies in a collaborative process.

The text referenced above focuses on interpersonal trauma specifically, and there is a paucity of research on trauma informed counselling for other types of trauma. However, another of Sanderson’s texts is focused on counselling sufferers of trauma through gender based violence, which is also relevant for the population I am interested in, given the

prevalence of Autistic women experiencing various types of abuse. In this she again prioritises therapists increasing their knowledge of the specific components of trauma and how their clients might experience trauma, the need for thorough assessments to increase safety, as well as the creation of a safe therapeutic space, and the capacity to utilise a diverse range of techniques (Sanderson, 2008). In this text she also prioritised the need for therapists to have grounding skills, to help support client's regulation to minimise disassociation and self-harm. This supports Herman's (1992b) work outlining the three stages of recovery from severe trauma where she says the key is establishing a solid foundation of understanding, safety, stability and self-regulation skills.

Importantly, Sanderson (2008) also points to the need for therapists to be aware of power imbalances, as that characterises both the counselling relationship and causes of and experiences of trauma. Sanderson (2008) also says that clear boundaries are important so as not to become enmeshed. So, on the one hand, it is important to develop trust and be emotionally available, holding a space where damaged self-structures can be explored and restored, but on the other hand, it is crucial therapists avoid being too overbearing or intrusive.

Additionally, a recurring theme found within the existing literature advising on best practice in relation to counselling people who have suffered trauma is the need for self-care on behalf of the counsellor (Merriman and Joseph, 2016 ). This is said to support practitioner wellbeing and empathic stamina, which can be hard to maintain when counselling people reporting traumatic events that undoubtedly effect the practitioner. Etherington (2009) points to the benefit of supervision and Ling, Hunter and Maple (2013) support this, concluding the importance of support structures. They also describe the need for diversity and variability in a counsellor's practice. Iqbal (2015), in a theoretical paper examining ethical considerations for counsellors working with trauma, wrote that an ethical and professional framework was

particularly important in enabling therapists to work competently and deal with the demands of hearing the experiences of trauma. Corroborating Meyer and Young's advice for working with marginalised groups, Iqbal states: therapists should be "honest with themselves, clients and colleagues and take responsibility for their wellbeing through the use of self-care" (2015, 50).

So, we have seen that there is a common set of priorities in the advice for therapists working with traumatised individuals, namely the importance of self-care, the need for knowledge about trauma, the awareness of power dynamics and the cultivation of a safe and collaborative relationship in the room. Next, I will explore therapeutic practice for Autistic individuals generally, before exploring the literature surrounding therapeutic practice for Autistic individuals who suffered trauma.

### **2.5.3 Adapting Therapy for Autistic Individuals**

The current literature has a dearth of information regarding best practice when counselling Autistic lives with most studies concentrating on applied behavioural interventions for autism symptoms rather than addressing co-occurring mental health difficulties. This is in spite of evidence suggesting that counselling, for many Autistic individuals, may be difficult or, in some circumstances, even traumatising (Rumball et al., 2020), highlighting an obvious need for good practice guidance. However, the National Autistic Society, in collaboration with Autistic individuals and practitioners, do provide a comprehensive guide to adapting talking therapies for Autistic children and adults. In this guide they stipulate several key points to guide practitioners endeavouring to work with this client group.

First and foremost, the National Autistic Society recommend assisting clients in identifying why they have arrived at therapy and what they can realistically aim to achieve,

speaking to the need for direction and clear communication. This is corroborated by a study conducted by Hallett and Kerr (2020) in which respondents emphasised the need for certainty around how the counselling would work and what can (and cannot) be expected from the process. Paxton and Estay (2007, 77) in their book *Counselling People on the Autism Spectrum* also speak to the need for practitioners to define the rules of the therapeutic relationship, specify what information the counsellor needs to know and for counsellors to be explicit regarding the boundaries of the therapeutic relationship. This could in part be due to the high levels of anxiety that often accompanies autism, necessitating the need for both structure and predictability.

Secondly, the National Autistic Society speak to the need to make adjustments to the therapy to better meet the client's unique needs. This may be in relation to the actual physical space or the types of tools and assessments the practitioner chooses to utilise. Physical adaptations may include dimming lights where possible, minimising clutter and background noise, avoiding the use of strong scents or perfumes, and paying special attention to the types of textures used within the counselling space to minimise sensory sensitivity distress. Hallett and Kerr (2020) also highlight the need for some Autistic clients to use fidget toys during the course of sessions to reduce anxiety. Within my own psychotherapy practice, I provide fidget toys at the beginning of each session; clients also have the option of utilising soft toys and weighted blankets to provide comfort and minimise anxiety.

With regard to the use of assessment tools, it is important that practitioners hold in mind that the types of assessments commonly employed within therapy have been developed for use with non-autistic populations. This may necessitate permitting more time for the completion of assessments and breaking questions down to make them less abstract. Paxton and Estay (2007) suggest the use of visual assessments for emotional evaluation, including emotion thermometers and bar graphs indicating the degree of emotion. Adaptations such as

these may help to make the abstract concept of degree, quality or quantity of emotion concrete and tangible to facilitate the identifying of the amount of what the assessment tool is aiming to measure (Paxton and Estay, 2007).

The National Autistic Society also suggest counsellors adapt their communication style to best suit the Autistic individual, which includes being flexible about the way in which therapy is delivered. This may mean utilising other forms of communication such as drawing or painting or even allowing clients to walk or pace within sessions. Therapists should also ensure they keep their language direct to avoid misinterpretation or confusion. Examples include keeping questions short and to the point, asking more specific and direct questions (rather than open-ended questions) and offering options and choices, where possible.

Around half of all Autistic people experience alexithymia, that is difficulties understanding and describing their own emotions (Good Practice Guide, n.d.). As is discussed earlier, the fact that Autistic individuals may find it difficult to identify emotions and verbally recall certain narratives may necessitate we find other ways to engage them in the room (Haruvi-Lamdan et al., 2018). To mitigate these challenges the National Autistic Society recommend supporting Autistic people with labelling feelings and emotions. One useful approach is the use of a feeling wheel through which a client can view a range of emotions and more easily identify which resonate most. The use of other mediums such as paint or pen may also be useful for clients who struggle to put their feelings into words. Within my own psychotherapy practice I commonly ask clients to “check in” by choosing an image that resonates for them from a database of photographs. From there, we can explore what about the image resonates with them and what emotions might be present for them judging by the image they’ve chosen. The use of such tools can assist Autistic clients in recognising and naming their emotions by providing visual support and make such concepts easier to understand (Good Practice Guide, n.d.)

It may also be useful to utilise visual supports within therapy to assist clients in processing information. Fullerton and Coyne (1999) suggest the use of visual outlines, time planners and specific notes when adapting cognitive behavioural therapy for Autistic individuals, all of which may be useful in aiding the processing of information regardless of the therapy modality. The National Autistic Society also suggest noting down what has been covered in each session to further assist in the processing of information and prevent information “overload” commonly experienced by Autistic individuals.

Crucially, the National Autistic Society suggest checking in with clients upon commencing therapy to ascertain what might work best for them and checking in regularly to assure it is still appropriate and whether it needs adapting. Such practices can be viewed as empowering as they facilitate the client’s autonomy and emphasise their agency in making decisions in the therapy room and the wider sphere.

Next, the National Autistic Society suggest structuring sessions to better support the client’s ability to process information and manage any uncertainty about what is expected of them. Setting an agenda can also facilitate the setting of boundaries and make it clear when a session is coming to an end. They recommend sending the structure of each session to clients beforehand and including approximate timings. Critically, they recommend working collaboratively with clients to set future agendas following the initial session, again honouring the client’s sense of autonomy and agency.

Finally, the National Autistic Society suggest incorporating the client’s interests into sessions in meaningful and respectful ways. A core feature of autism, intense interests (also referred to as “special interests”) are associated with a number of positive outcomes for Autistic adults, including emotional wellbeing (Grove et al., 2018). Incorporating special interests into sessions can assist in the development of the therapeutic relationship and promote the Autistic person’s engagement in therapy.

#### **2.5.4 Trauma-Specific Therapeutic Approaches for Autistic Individuals**

Despite the concerns highlighted above, research into the prevalence of and effects of psychological trauma on Autistic lives is still in its infancy and little is known regarding ways to best support this population. Moreover, little is known about the impact of trauma on Autistic females, despite studies indicating that Autistic females are at a significantly higher risk of exposure to potentially traumatic events and for the manifestation of PTSD (Haruvi-Lamdan et al., 2020). Haruvi-Lamdan and colleagues (2020, 893) write:

Our findings indicate that females with ASD face an increased risk of experiencing potentially traumatic events compared with typical females. One explanation for this finding may be that the ASD diagnosis for females usually occurs later in life, compared with males. This may expose females to a longer period of being misunderstood and potentially mistreated not only by their peers but also by authority figures such as teachers or employers, with little appropriate support.

Attempts have been made to describe the ways in which traditional therapies may be modified when working therapeutically with this client group, many of which are specific to behavioural-based therapies. An example of this are the guidelines stipulated by Stack and Lucyshyn (2018) whereby they propose a modified trauma-focused cognitive behavioural therapy model (TF-CBT) for the treatment of trauma in Autistic children based on components of TF-CBT for typically developing children and modified CBT to teach emotion regulation and treat anxiety symptoms in Autistic individuals. They suggest beginning with a functional behaviour assessment aimed at determining the function of problem behaviours and informing the development of a behaviour support plan. Such assessments can help to identify triggers for trauma-related problem behaviours and the function of these behaviours. Other important aspects of these guidelines include the teaching of both emotion identification and regulation and graduated exposure, whereby the child is

taught to tolerate stimuli that remind them of their original trauma. Psychoeducation, the process of learning about and understanding mental health and wellbeing (Anna Freud Centre, 2022) is also key to this approach as is the development of a safety plan.

Regarding other behavioural-based approaches, Harvey (2012) suggests a recovery, strengths-based approach emphasising empowerment, safety, and connection within the behavioural plan. While safety is described as having supportive and understanding staff, it also entails the identification of a “safe person” who the client can turn to when they feel overwhelmed. Empowerment on the other hand refers to assisting the individual in making choices, and genuinely listening to the client’s experiences, preferences, and desires. Finally, connection entails the fostering of both peer and staff relationships.

Harvey (2012) also recommends addressing identity development, pleasure, achievement and finding meaning within one’s life within the therapeutic process. Crucially, a positive identity should be established initially so that trauma can be addressed from a position of strength (Faccini and Allely, 2021).

Charlton and Tallant (2003) also describe the ways in which trauma therapy should be adapted for individuals with developmental disability, emphasising four phases: acknowledgement, safety and competency, processing the trauma and transitioning beyond the trauma. In the acknowledgement stage, respect for the afflicted individual is paramount. This stage involves the practitioner educating the client and those within the client’s support system of the nature of the trauma and trauma symptoms. This ensures the trauma symptoms are not attributed to autism features or co-occurring mental health issues. Within this stage there is also an emphasis on the client’s reaction to the trauma being normal given the threatening nature of what they have experienced.

The safety and competency stage involves the client’s support system ensuring that the client’s environment is safe and ensuring that the individual re-engages in a normal

routine and self-care regimen. Within this stage, there is an emphasis on clients feeling in control of their environment and the promotion of assertiveness and self-advocacy.

Processing the trauma should be approached from the perspective of empowerment, safety and competence and may incorporate play therapy, art therapy, and social stories to process thoughts and feelings associated with the trauma (Charlton and Tallant, 2003; Faccini and Allely, 2021).

Finally, transitioning beyond the trauma involves the individual's use of their new understanding about what occurred as well as their newfound competence, self-protection and advocacy skills to aid them in handling potentially triggering situations in the future (Charlton and Tallant, 2003; Faccini and Allely, 2021).

Moreover, while cognitive behavioural-based approaches remain the most studied treatment for Autistic individuals and the preferred psychological treatment for anxiety “disorders”, there is research to suggest that many Autistic individuals do not respond well to CBT or remain symptomatic after treatment (Robinson, 2018; Weston et al., 2016). Senior lecturer at University of Strathclyde Glasgow, Anna Robinson, proposes an alternative approach to working therapeutically with traumatised Autistic individuals than the behavioural-based approaches highlighted above. In her emotion-focused approach, problematic emotion schemes are transformed through a sequence of emotion processing steps within a group setting. Guided by humanistic principles, the primary change processes inherent to this approach include improving access to and symbolizing one's own and others' painful emotional experiences. This is facilitated by video playback of social-emotional interpersonal reciprocity difficulty task markers to help clients activate, deepen and transform emotions by accessing core pain and related unmet needs. This process is thought to aid the development of adaptive emotions such as compassion for oneself and for others (Robinson and Elliot., 2017).

The first step of Robinson's approach involves the differentiating of core painful emotions, similar to Stack and Lucyshyn's modified TF-CBT of which there is a focus on emotion identification and taught emotion regulation. This step is likely to be crucial to any approach addressing trauma in Autistic women as emotion recognition and regulation may be inhibited in Autistic individuals as is described above. The second step to Robinson's emotion-focused therapy for autism involves the autobiographical memory recall of distanced trauma. This process is aided by a technique known as interpersonal process recall, in which recorded group sessions are replayed, which is then used to facilitate client awareness and arousal, and support areas of difficulty related to affective empathy and cognitive empathy for oneself and others. This technique also aids autobiographical memory recall, a process that is believed to be impaired in Autistic individuals. Such deficits can result in a "fragile sense of self", thus the strengthening of autobiographical memory recall is key to restoring one's sense of self, the reprocessing of autobiographical memory, and facilitating one's self-agency within interpersonal relationships (Robinson, 2018). Such processes are thought to be key to therapeutic change (Robinson, 2018).

The penultimate step to Robinson's approach involves the articulation of unmet needs contained within core painful feelings followed by the expression of an emotional response to those feelings and needs, most often protective anger, self-soothing and compassion responses offered interpersonally by other group members.

While Robinson's emotion focused approach offers an alternative to the CBT-based approaches detailed above, studies indicate Autistic people may experience social difficulties associated with groups indicating a gap in knowledge regarding how we best work with this unique population (Paxton and Estay, 2007).

## **2.6 Power, Empowerment, and Implications for the Therapeutic Process**

Given the literature surrounding marginalised groups and the problems stemming from their relative lack of power within society, I knew that empowerment would likely be an important factor within this project. Hence, I felt it necessary to understand more about past research pertaining to empowerment, which I outline below. However, I had not anticipated just how central empowerment would prove to be within the data collected from participant interviews, as will be detailed later in this thesis.

Inherent to trauma is the perceived lack of power, during which one entity has power and control over the afflicted individual. Similarly, a lack of power can be seen to evoke psychological distress and many of the psychiatric ailments relative to the time we live in can be seen as resulting from a relative lack of power for afflicted individuals (Mack, 1994; Meyer and Young, 2021; Krawitz and Watson, 1997). Autistic women face a unique risk for disempowerment given the unique sources of trauma and adversity they face combined with the historical disadvantages this population has faced as explored previously. This is further amplified by the historical and continued disempowerment of women through psychiatry, a system that, due to higher incidence for mental health comorbidities, this population is likely to have interaction with. Furthermore, there are important implications then for the distribution of power within the therapeutic relationship, in which the therapist's power must be acknowledged.

The feminist angle and approach of this thesis are informed by the fact that feminists have largely been at the forefront of communicating how power imbalances between men and women help sustain and justify violence and other sources of trauma affecting women, so their ideas are grounded in their own experiences of oppression. The empowerment process can be seen as the antidote to the power struggle experienced by many traumatised Autistic

women and therapy provides a unique opportunity for the unfolding of this process, as therapists can work with clients to restore power and decision-making capacity.

For these reasons, within this next section I will be exploring power and its role in psychological distress as well as the ways in which the current psychiatric system continues to disempower Autistic women, the aim of which is to give the reader a clear picture of the relative lack of power experienced by Autistic women and how this contributes to recovery from trauma and psychological distress. Then, I will explore power within the therapeutic relationship, drawing attention to the various types of power therapists hold in relation to clients, providing rationale for a therapeutic model that seeks to restore power to clients. Next, theories surrounding empowerment will be explored as will the concepts of social and psychological empowerment as these are the types of empowerment that are most relevant for this project, because of the need for Autistic women who have suffered trauma to strengthen social bonds and their sense of competence over their life. Finally, the role of empowerment within the therapeutic alliance and the practices that promote the empowerment of clients in therapy will be investigated as this holds significant relevance for Autistic women's recovery from trauma.

### **2.6.1 Definitions of Power**

Within the psychological sciences, power can be defined as one's capacity to alter another person's condition or state of mind by providing or withholding resources—such as food, money, knowledge, and affection—or administering punishments, such as physical harm, job termination, or social ostracism (Keltner, 2007). In this sense, the current medical establishment can be seen as withholding power from Autistic women, as many are denied diagnosis (knowledge) and subsequent access to relevant supports and resources.

Additionally, Autistic women are often marginalised within society which can be experienced

as disempowering, particularly for those who are not affiliated with the wider autism community, an idea that will be explored below when discussing social empowerment.

*Social power* can be described as the ability of an individual to create conformity even when the people being influenced may attempt to resist those changes (Stangor et al., 2014; Fiske, 1993; Keltner, Gruenfeld, and Anderson, 2003). This is evidenced by the need for Autistic women to mask or camouflage Autistic traits in an effort to conform with what has been deemed “normal” and “acceptable” behaviour by society.

Feminist psychologist and psychotherapist Gillian Proctor (2002) relates power to the ways in which society is structured, with those differing from the “norm” (i.e., women, Black and minority ethnic people, lesbians, and gay men) being labelled as “other” and having less access to power. Such groups are also subject to stereotyping and invalidation and have less access to valuable resources. Likewise, individuals belonging to minority groups are also at increased risk for various types of violence and harassment, potentially contributing to mental health issues.

Finally, power has been used to describe “the current configuration of structural privilege and structural oppression, in which some groups experience unearned advantages – because various systems have been designed by people like them and work for people like them – and other groups experience systematic disadvantages – because those same systems were not designed by them or with people like them in mind” (D’Ignazio and Klein, 2020, 24). This is in keeping with a feminist view of gender oppression in which women’s situation is seen as a direct consequence of the power relationship between men and women in which men have fundamental interests in controlling and oppressing women (Musingafi, 2021). This position is particularly relevant to this research, as it acknowledges the structural disempowerment of marginalised groups, in this case Autistic females, whom the current system(s) neglect as they were not developed by them or with them in mind. This

undoubtedly has implications for the counselling process as Autistic females will be bringing these power narratives into the therapeutic relationship, whether conscious or unconscious.

### **2.6.2 The Role of Power in Psychological Distress**

The concept of power is both politically and psychologically situated. Becker (2005, 137) speaks to the connection between the personal phenomena in our lives and the political contexts in which these phenomena are situated. She writes, “Psychology has always been political in the sense that it often reduces social and political problems to the personal and pathological. Whereas the women’s movement explained women’s problems as arising from their oppression, psychology transforms them into mental phenomena.” This is also compatible with a trauma-informed approach to therapy, which emphasises the correlations between “mental health issues” and human trauma, distress, and oppression rather than pathologizing what could be considered a normal response to such trauma (Taylor, 2022).

Indeed, many of the concerns and ailments that mental health professionals encounter might be understood as resulting from inequalities or abuse of power in relationships and an associated sense of powerlessness and helplessness, in some circumstances evoked by trauma and adversity (Mack, 1994). For example, depression can be conceptualised as a response to powerlessness linked with learned helplessness and has even been linked with a lack of financial and psychological power in marriages including depressed women (Byrne and Carr, 2000). Similarly, anxiety can be viewed as one feeling fearful about a perceived lack of control over their environment and psychosis with a perceived lack of control over one’s identity (Proctor, 2002). Proctor (2002, 4) speaks to this, writing “There is much evidence to associate the likelihood of suffering from psychological distress with the individual’s position in society with respect to structural power. The higher rates of diagnosis for women compared with men of many disorders, such as depression, anxiety and eating disorders,

reflects women's position in society with respect to power." This holds particular relevance for Autistic women who, due to the socio-cultural factors explored throughout this thesis, may have less access to power than those belonging to the general population. Moreover, Autistic women, due to the higher prevalence of psychiatric ailments in this population (Lai et al., 2019) are likely to have had involvement with the psychiatric system, a system that, in many ways, serves to further disempower service users as will be explored in further detail below.

### **2.6.3 Psychiatry's Disempowerment of Women**

Despite evidence indicating the negative impact of powerlessness on mental health, there are many aspects of the current psychiatric system that are still experienced as disempowering by service users. Indeed, psychology and psychiatry have a long history of harmful and oppressive treatment of those struggling with mental illness and distress, particularly women. This holds relevance for therapists working with Autistic women who, due to higher incidence of psychiatric ailment (Lai et al., 2019), are likely to have had interaction with the psychiatric system and are therefore likely to bring these power narratives, whether conscious or unconscious, into the therapeutic relationship.

Pioneering feminist psychologist Naomi Weisstein (1993 [1968]) was among the first to reveal the systemic biases and stereotypes about women that dominated the disciplines of psychology and psychiatry, ultimately classifying women as "inconsistent", "emotionally unstable" and "lacking in a strong conscience" (Wigginton and Lafrance, 2019). Feminist scholars exposed how such sexist conclusions were derived from psychology's deep androcentric bias, demonstrated by the practice of deriving psychological theory from research conducted by men with male participants – most often young, educated, middle-

class, heterosexual, able-bodied White men (Wigginton and Lafrance, 2019; Fine and Gordon, 1989; Tavis, 1993).

Moreover, Thomas Scheff (1974) originally argued that people who are diagnosed as mentally ill are victims of the status quo, guilty of often unnamed violations of social norms; thus, the label “mental illness” can be used as an instrument of social control (Taylor, 2022). Interestingly, women are nearly twice as likely to be affected by anxiety than men and are more likely to be diagnosed with depression (Mayo Foundation for Medical Education and Research, 2019; Mental Health Foundation, n.d.). Furthermore, women are also much more likely to experience posttraumatic stress disorder than men – with up to 5.1% of women being affected compared with 3.7% of men (National Institute for Health and Care Excellence [NICE], 2020). While biological factors such as hormonal changes might be partially responsible, it is important that we don’t underestimate the effect that limited social power might have on women’s mental health. Moreover, the overdiagnosis of various psychiatric “disorders” in women may reflect the historical social control over women whose natural reactions to emotional distress may be deemed “abnormal” (Wigginton and Lafrance, 2019; Weisstein, (1993 [1968])). This may be further amplified due to the over-representation of men in psychological research (Wigginton and Lafrance, 2019, 2; Fine and Gordon, 1989; Tavis, 1993).

Psychiatry’s legacy of harmful and oppressive treatments and assumptions still have a significant influence on modern day thinking about mental health (Taylor 2022). A perfect example of this is the misdiagnosis of Autistic women and girls with personality “disorders”, most commonly borderline personality disorder (BPD), one of the most stigmatised diagnoses in psychiatry and mental health. Cameron Hancock (2017, para. 1) states:

Borderline Personality Disorder (BPD) remains one of the field’s most misunderstood, misdiagnosed, and stigmatized conditions. Studies show that even

some mental health professionals have more stigmatizing views about BPD than any other mental health condition: As some choose to limit the amount of BPD patients they're "willing" to see or refuse to treat people with BPD altogether.

According to the DSM-5, 75% of all diagnoses of BPD are female. Moreover, Autistic individuals without cooccurring intellectual disability, the population this research project concerns, are at an increased risk of being misdiagnosed with a personality disorder in adulthood prior to receiving their autism diagnosis (Iversen and Kildahl, 2022). Emily Katy (2021, para. 2) Autistic individual, mental health nurse, mental health activist and autism advocate writes of her own experiences of having received a diagnosis of BPD and the common experience of Autistic individuals being given a label of BPD prior to their autism diagnosis:

Many autistic people who don't have a diagnosis of autism are at first misdiagnosed with BPD or EUPD (yes, these are the same thing) before discovering that they are in fact autistic. Additionally, many autistic people who already have their autism diagnosis are then also diagnosed with BPD or EUPD, without the impact of their autism on their BPD-like symptoms being understood.

Furthermore, Jessica Taylor (2022, 82) links BPD to male violence stating:

By far, one of the most common diagnoses a woman or girl will receive after being subjected to male violence is of borderline or emotionally unstable personality disorder. Anyone working with women and girls in refuges, rape centres, women's services, domestic abuse support services or sexual exploitation services will know that the majority of their caseload will be women or girls with this diagnosis.

Taylor (2022, 13) also makes a convincing argument for implementing a trauma-informed approach when addressing mental health issues:

The trauma-informed approach to mental health, illness and distress argues that there are undeniable and consistent strong correlations between all so-called ‘mental health issues’ and human trauma, distress and oppression. Therefore, it is argued that ‘disorders,’ ‘illnesses’ and ‘diseases’ are very likely to be natural physical and psychological manifestations of human trauma and distress, in response to events and experiences in our lives – not brain abnormalities or mental illnesses.

The trauma-informed approach to mental health represents an important step in the empowerment process as it acknowledges human distress as resulting from trauma and adversity (the perceived lack of power) rather than as resulting from flaws located within the individual. This holds important similarities with the neurodiversity paradigm which acknowledges the inherent strengths of neurodiversity rather than focusing purely on deficits.

#### **2.6.4 Power within the Therapeutic Relationship**

Proctor (2002) differentiates between differing types of power within the therapeutic relationship; first, she names *role power* as resulting from the authority given to the therapist to define the client’s problem and the power the therapist has in the organisation and institutions of their work; second, she identifies *societal power* as arising from the structural positions in society of the therapist and client with respect to gender, age, ethnicity, class, etc.; finally, Proctor identifies *historical power* resulting from the personal histories of the therapist and clients and their own experiences of power and powerlessness (Proctor, 2002). These power dynamics are omnipresent within the therapeutic relationship, and, if left unchecked, may actually exacerbate feelings of powerlessness and helplessness in clients. Thus, the answer, it seems, is a therapeutic model that acknowledges the therapist’s inherent power within the therapeutic relationship and that seeks to restore power and decision-

making capacity for clients, supporting them in taking control over their lives – a process also known as empowerment.

## **2.6.5 Empowerment**

### **2.6.5.1 Defining Empowerment**

Empowerment is a concept that is always situated in context, meaning the definition of empowerment will differ depending on the context in which it is occurring (Rolvjord, 2006). At a fundamental level, empowerment refers to the process of claiming or reclaiming power. A topic that has retained a lot of attention throughout the years, empowerment has been discussed in a variety of disciplines - including psychology, social work, and community work - and many differing definitions of empowerment exist across these fields.

Broadly speaking, empowerment links individual strengths with helping systems (networks of support) and proactive behaviours to promote change (Perkins and Zimmerman, 1995). From a mental health perspective, empowerment links mental health with mutual help and compels us to think in terms of wellness versus illness, competence versus deficits and strengths versus weaknesses (Perkins and Zimmerman, 1995).

Psychologist and Professor of Public Health Marc Zimmerman is credited with having done extensive research on empowerment, specifically as it pertains to community psychology. In short, Zimmerman describes empowerment as a social process that helps people gain control over their own lives (Zimmerman, 1995). Similarly, Whitemore (1988, 51) describes empowerment as “...an interactive process through which people experience personal and social change, enabling them to take action to achieve influence over the organisations and institutions which affect their lives and the communities in which they live.” These definitions stress the importance of both personal and social change, as well as taking action to achieve meaningful change.

Empowerment has been described as a *perspective*, founded on the belief that each individual is competent and has equal value, a *process*, whereby through participatory activities and collaboration empowerment can be achieved, as well as a *performance*, referring to the skills and knowledge developed through enabling opportunities and relational experiences (Rolvsjord, 2006). Similarly, empowerment can occur at multiple levels – including at an individual level, an organisational level and a community level (Rolvsjord, 2006).

There are also varying types of empowerment, including social empowerment, educational empowerment, economic empowerment, political empowerment and, finally, psychological empowerment (Mandal, 2013). While these varying types of empowerment inevitably interact and influence the other, I will be focusing on psychological and social empowerment within this literature review as these are most relevant to this study.

While each of these conceptualisations of empowerment differ slightly, they all stress the importance of gaining knowledge in relation to oneself, taking control over one's life, and producing change; these are the aspects of empowerment which are most pertinent to this study and which, as will be explored in the presentation and discussion of findings chapter of this thesis, are most significant in recovering from the psychological effects of trauma and adversity as an Autistic woman.

#### **2.6.5.2 Empowerment Theory**

The *theory* of empowerment was first articulated in Brazil by Paulo Freire. Freire believes education plays an important role in empowering community members, liberating them from oppression. He adds that empowerment through education will enhance the individual's ability to identify their capabilities regarding knowledge and skills (Habib Sultan and Yahaya, 2018). Likewise, Habib Sultan and Yahaya (2018) cite access to information

(enabling individuals to take advantage of opportunities, access services and exercise their rights) and the participation in decision making as integral aspects of empowerment. Each of these conceptualisations of empowerment resonate with the core argument of this thesis – that individuals can gain empowerment through knowledge (autism diagnosis or self-diagnosis) and the identification of unique strengths and capabilities, including exercising power where possible. Through identifying with the autism community, individuals have the potential to gain access to information about themselves that may assist them in achieving meaningful change – discovering new ways of mediating associated challenges, gaining access to appropriate support, identifying and utilising unique strengths and, ultimately, recovering from the debilitating effects of trauma – all achieved through the process of social and psychological empowerment.

### **2.6.5.3 Social Empowerment**

Many would agree that relationships are an integral aspect of therapy – not only the therapeutic relationship, but also the client’s relationships with loved ones and their wider community. As a relational therapist, I would argue that one of the key aspects of my role is assisting clients in identifying sources of support and strengthening social relationships. This is where the concept of social empowerment becomes relevant within the therapeutic process. Put simply, social empowerment refers to the strengthening of social relationships. Quite often this entails establishing a sense of community in which the individual can thrive and grow (Mandal, 2013).

Moreover, the social empowerment of women requires that women are able to make contributions at all levels of society and that those contributions are recognised and valued (Mandal, 2013). Mandal (2013, 19) writes:

Social empowerment addresses the social discriminations existing in the

society based on disability, race, ethnicity, religion, or gender... Empowerment of women is a multi-dimensional process, which should enable the individuals or a group of individuals to realize their full identity and powers in all spheres of life.

Empowerment of women means enjoyment of equal rights, equal status, and freedom of self-development with men.

When referring specifically to *women's empowerment*, social empowerment pertains to women finding purpose outside of the home, fostering a sense of belonging, and having the opportunity to explore themselves and their identity through relationships with others and the wider community (Mandal, 2013). Within my own psychotherapy practice, many Autistic women speak to the self-knowledge and sense of belonging that can result from finding and engaging with others within an autism community. These communities also often serve as platforms for raising and acting upon social causes of importance to individuals, and can provide a sense of purpose and direction. When autism is viewed as an integral part of a person's identity, we can begin to understand how recognising one's neurodiversity and connecting with other Autistic individuals could be empowering, promoting a sense of belonging and fostering identity development.

Williams et. al (2003) studied the association between social action and identity and culture. The researchers undertook a 3-year participatory action research project in New Zealand and Canada examining the effects of social storytelling on both personal and group empowerment of marginalised groups, identifying storytelling as an important aspect of challenging predominant social discourses. They claim that storytelling incorporates elements of both personal and group empowerment and that it has the power to do the following:

- 1) Strengthen connection to identities, cultures, and values
- 2) Build self-esteem and confidence
- 3) Build common narratives from shared experiences

- 4) Build a sense of group and belonging
- 5) Draw out issues for advocacy and speaking out

They write:

There is much empowering scope in the use of storytelling with communities at the economic and social margins... Overall, results from the research project demonstrate that while marginalized communities may be relatively powerless in relation to social and economic structures, they have considerable scope for exercising power and agency. Storytelling is an important tool in this process, which enables the conscious reconnection to and reconstitution of people's identities. Newly found subject positions that are more enabling of agency and building community are conducive to the exercise of individual and group power that can challenge institutional power and dominant social discourses and structures (Williams et. al, 2003).

Within the social media groups I have been involved in, including the one from which participants for this study were recruited from, many individuals share stories of their experiences of autism – with issues for activism often at the forefront. I myself have benefitted from the feeling of solidarity that arises when I have shared aspects of my own experience only to find that I am not alone in experiencing these things.

Moreover, evidence indicates that social and psychological empowerment are closely linked, with an individual's psychological sense of community - defined as a feeling that members have belonging and matter to one another and to the group - being shown to be strongly associated with psychological empowerment (Ramos-Vidal et. al, 2019). Self-help groups have also been reported to improve social empowerment (Brody et al., 2015), highlighting the importance of psychological empowerment (i.e. perceived competence, mastery over one's own life, and the ability to exert control over one's situation) in the development of social empowerment.

#### **2.6.5.4 Psychological Empowerment**

Closely associated with social empowerment, psychological empowerment (PE) pertains to changes in an individual's behaviours, cognitions and emotions and involves the strengthening of one's perceived competence and control over one's life (Rolvjord, 2006; Zimmerman, 2000). Psychological empowerment is said to be comprised of intrapersonal aspects, interactional aspects, and behavioural aspects. Intrapersonal aspects of psychological empowerment pertain to an individual's self-esteem (an individual's evaluation of their own worth), self-efficiency (an individual's belief in their capacity to produce specific attainments), and their locus of control or how much control an individual feels they have over events in their lives (Ackerman, 2022; Bandura, 1997; Rolvsjord, 2006).

On the other hand, interactional aspects of psychological empowerment describe the use of analytical skills to influence one's environment (Rolvjord, 2006). Zimmerman (1995, 589) offers a further explanation of interactional components of psychological empowerment stating, "The interactional component of PE refers to the understanding people have about their community and related socio-political issues. This aspect of PE suggests that people are aware of behavioral options or choices to act as they believe appropriate to achieve goals they set for themselves." He goes on to describe how an individual's self-perception provides them with the initiative, confidence, and motivation to engage in behaviours aimed at achieving desired outcomes.

Finally, the behavioural aspects of psychological empowerment refer to an individual's ability to take control of their lives by participating in their community; this may also involve possessing an understanding of the social and capital resources that are needed to achieve one's goals (Rolvjord, 2006; Eisman et. al, 2016). Again, the emphasis is placed on the individual's capacity to gain knowledge, obtain control and achieve meaningful change.

### **2.6.5.5 Empowerment within the Therapeutic Alliance**

In a mental health context, empowerment refers to the “level of choice, influence and control that users of mental health services can exercise over events in their lives” (Baumann, 2010). At an individual level, empowerment is an important aspect of human development, and has been articulated as the process of taking control and responsibility for actions that have the intent and potential to lead to fulfilment of capacity. Baumann (2010) lists four crucial dimensions of this process, including self-reliance, participation in decisions, dignity and respect and belonging and contributing to a wider community.

Similarly, empowerment within counselling has been described as the process of helping clients discover personal strengths and capacities so that they are able to take control of their lives and is formed on the belief that clients are capable and have a right to manage their own lives (Shebib, 2014). Therapists are therefore challenged to relinquish the role of “expert”, demystifying the counselling process and encouraging clients to make independent decisions. At the heart of this approach is collaboration between the therapist and the client and shared decision-making within the confines of the therapeutic relationship.

Shebib (2014) describes the counselling process as inherently empowering; giving clients the opportunity to explore their current situation and feelings and bring forgotten or misunderstood feelings to the forefront presents new ways of handling problems that previously felt insurmountable. Shebib (2014) also makes the case that the empowerment process necessitates clients gain some degree of critical awareness of systemic power imbalances and cites connecting clients with information on groups and organisations whose efforts are directed towards changing problematic elements of the system as one way to facilitate this process. Perkins and Zimmerman (1995, 571) further corroborate this, stating: “Empowerment suggests that participation with others to achieve goals, efforts to gain access to resources, and some critical understandings of the socio-political environment are basic

components of the construct.” They go on to describe the process of enabling individuals through collaboration with others to achieve their primary personal goals as a central component of empowerment. Therapists are therefore in a prime position to enable meaningful change through enabling the empowerment process for clients by helping clients identify and achieve personal goals, identify socio-political imbalances and gain access to critical resources.

## **2.7 Summary of the Review of Literature**

In this second chapter, I started by building an understanding of broad conceptualisations of trauma, before honing in on what has been written about trauma for Autistic individuals particularly. Next, I explored the interplay between autism and trauma, especially for Autistic women who represent a marginalised group without power and who suffer from multiple layers of disadvantage.

Given Autistic women’s increased vulnerability to various traumas, I decided to examine the unique sources and manifestations of trauma that differ from those that meet the criteria for post-traumatic stress disorder as described in the DSM but that are nonetheless impactful, including the disruption of identity functioning.

Due to the lack of research on traumatised Autistic women specifically, I then studied literature focusing on recommendations for therapists working with marginalised groups, as well as for trauma sufferers generally (not Autistic individuals). I then narrowed in on how to adapt therapy for Autistic people, before outlining what trauma-specific therapeutic approaches for Autistic individuals exist. Throughout, I drew on feminist theory to understand better how women are subject to multiple disadvantages, before focusing my attention specifically on the role of power and empowerment within counselling.

When building an understanding of the plight of Autistic women who suffered trauma through these different, overlapping lenses, and especially when considering the difficulty post-pandemic with access to health care, an extremely worrying picture emerges of the mental health of traumatised Autistic women and their role in society, with therapists in a position to support, yet with very limited guidance on how to do so effectively.

The research on counselling this specific group is limited, despite there being literature pertaining to best practice guidelines for counsellors working with Autistic individuals generally, survivors of trauma generally, and individuals from marginalised groups generally. This thereby presents a gap in the knowledge specifically pertaining to counselling Autistic women who have suffered trauma. I believe I can contribute to the literature significantly through five research questions that focus specifically on this under-researched and hugely important intersection.

Two principal and four secondary research questions will guide this research. The core questions that will be explored throughout this thesis are:

- 1. How do Autistic women experience counselling for trauma?**
- 2. How can counsellors and psychotherapists best support traumatised Autistic women?**

The four second-tier questions being explored are:

- What difficulties are Autistic women likely to experience following psychological trauma prior to commencing therapy?
- What are the perceived benefits of therapy articulated by this group?
- What practices are likely to aid the therapeutic process for this group?
- What are the potential barriers to this group accessing mental health support?

Importantly, given the primacy of empowerment, I also believe that my methodology itself (of grounded theory and participatory action research) enables an important

contribution to be made, as I found no studies that bring the voices of Autistic women who have suffered trauma to the fore in relation to designing counselling best practice. This is despite the specific need of this group to be heard and empowered, and to be collaborators in their therapy, as is shown above.

In chapter three, I will explain my methodology, which is in keeping with the idea of prioritising empowerment and being sensitive to power imbalances. Particularly, I aim to achieve this through the use of grounded theory, where I do not know or come with the answers, but trust that answers will emerge through the perspectives and voices of the Autistic women themselves.

# Chapter Three: Methodology

## 3.1 Introduction

In order to determine my research methodology, I went to great lengths to consider the purpose of the study and how best to answer the research questions posed. Within the following chapter, I will explain how I have approached my research and shine a light on the methodological approaches used to investigate central research questions.

This study employed a qualitative approach by utilising participatory action research and elements of grounded theory. This chapter provides explanation regarding the selection of research methodology and the process of recruiting participants, collecting data and analysing data. I will explore the necessary ethical principles relevant to involving Autistic individuals in the research process, as well as my own positionality in relation to this research as the primary researcher involved with this project.

## 3.2 Research Aim and Questions:

The core questions that have guided this research are:

1. **How do Autistic women experience counselling for trauma?**
2. **How can counsellors and psychotherapists best support traumatised Autistic women?**

There were also four additional second-tier questions that helped guide this research and which influenced questions posed during interviews, including:

- What difficulties are Autistic women likely to experience prior to commencing trauma therapy?
- What are the perceived benefits of therapy articulated by Autistic women?
- What practices are likely to aid the therapeutic process for Autistic women?

And...

- What are the potential barriers to Autistic women accessing mental health support?

The overall aim of this research was to examine the experiential accounts of receiving counselling support in Autistic women with self-reported histories of trauma, the goal of which is to explore how therapists might seek to better work with traumatic stress in Autistic women.

### **3.3 My Positionality as Primary Researcher**

My motivation for undertaking this study derives from several influences – both personally and professionally. As discussed in the introductory chapter of this dissertation, autism has been a prevalent feature of my life for many years. My mother’s work as a special education teacher meant that I was often privy to the lives of her students and the challenges they faced. As a young adult, I then found myself working as a development mentor for Autistic teens, a vocation that served to further my passion for working with neurodivergent individuals to build confidence and, ultimately, improve their lives. In recent years, my work as a psychotherapist working with Autistic individuals has further alerted me to the adversities they face, particularly Autistic women and girls - many of whom go numerous years without an answer to their struggles. My own experiences as a neurodivergent woman will also influence this research and my own experiences of invalidation are closely mirrored by participants in this study.

Moreover, my social background, class, gender, ethnicity, and sexuality will undoubtedly influence my own perception of this research and the conclusions drawn, as will the time period in which this research is situated. While I am no stranger to feelings of “otherness”, there are aspects of my identity and previous experiences that place me at an

advantage when compared to other Autistic women, such as those belonging to minority groups. While I possess lived experience of being Autistic, I do not know what it is like to be an Autistic woman belonging to an ethnic minority group or the LGBTQ+ community and, therefore, cannot assume to know and understand their experiences.

The reflexive process is a valuable tool that helps to substantiate qualitative research. By engaging in reflexivity, researchers attempt to distinguish how subjective and intersubjective elements influence both data collection and analysis (Finlay, 1998). Effective reflexivity involves recognising one's own position – one's social background, preferences and predilections, political affiliations, class, gender, ethnicity and other defining factors – the result of which is often referred to as one's *positionality* (Maher and Tetreault, 1993). Maher and Tetreault (1993, 118) write

By positionality we mean... that gender, race, class, and other aspects of our identities are markers of relational positions rather than essential qualities. Knowledge is valid when it includes an acknowledgment of the knower's specific position in any context, because changing contextual and relational factors are crucial for defining identities and our knowledge in any given situation.

In short, positionality refers to our own awareness of the ways in which our life experiences and personal circumstances impact how we see, understand, and interact with the world around us, and requires a healthy amount of reflexivity and an understanding that we are continuously embedded within systems of power.

My own views, values and beliefs will have, undoubtably, influenced this research and the conclusions drawn from research data. A natural feminist, I have borne witness to the many injustices that face not only women, but other minorities throughout my life. In recent years, I have observed first-hand the effects of pervasive misogyny on policy and practice in my home country of the United States. A timely example of this is the recent revocation of

“Roe v. Wade”, which protected women’s rights to choose to have an abortion. This revocation means that abortion will become criminalised in many states, regardless of the circumstances. I come to this project with the belief that women are equally capable, and that they should have equal rights to those of men. In this I include the right to make decisions on their own behalf and the right to access services designed with them in mind and which acknowledge the innate complexities of being female. Services and treatments derived from research conducted with men by men, in my opinion, serves as an injustice to women, girls and non-binary people around the world.

As is discussed in previous chapters of this dissertation, the world of autism research and practice reflects this injustice, with Autistic women’s voices currently underrepresented in research concerning them. The result of this negligence is the underdiagnosis or misdiagnosis of thousands of Autistic women and girls in the United Kingdom and abroad, delaying access to support and oftentimes resulting in feelings of defectiveness and isolation. A manifestation of this is my own diagnosis journey, whereby I spent many years searching for a reason underlying my own mental health struggles before recognising my own neurodivergence in my mid 20s. It seems obvious now, but it was not until I began my psychotherapy training, and my own social and communicative differences came to light that I came to realise that *I, myself, am Autistic*. In some ways, this realisation caught me by surprise, however, hearing the accounts of the participants involved with this study and reading the memoirs of other Autistic women seemed to validate my entire existence and resonated with me very deeply. It was a relief to learn that I was not alone in feeling these things, but this realisation also saddened me for the pain and suffering of other Autistic women who have not had the opportunities that I have. This resonance with others’ accounts and the deepening self-understanding that has resulted can be viewed as both socially and psychologically empowering and has been a vital aspect of my own recovery journey,

supporting this dissertation's argument that empowerment is a vital component of Autistic women's recovery from trauma and adversity.

In addition to mental health struggles, I have also struggled with many physical ailments throughout my life. Since the age of 17, I have been plagued by severe joint pain, extreme muscle tension, and debilitating fatigue. For years, I have searched for an answer to my suffering, often feeling invalidated by doctors who seemed intent that my physical symptoms were purely psychological and that there was no physiological cause for my misery. After repeated experiences such as these, I began to question my own sanity. Through the years, I have transformed from a healthy, active, and fun-loving individual to a depressed and exhausted shell of the person I once was. I have witnessed my health deteriorate, year after year, without knowing what was causing my demise and feeling powerless to stop it. I continued to search for an answer to my problem – a cure to fix my ailments. As my pain and fatigue worsened, I must admit that, at times, I did not believe I would even finish this thesis, though I felt the weight of the autism community on my shoulders and of the participants who so bravely shared their stories with me. Then it finally happened: on an unseasonably warm spring day, I saw a rheumatologist who did something no one before him had done. He listened. He validated my pain. He sought additional information and did not make assumptions about my experiences. Someone had finally *seen me*, and it was on that day that I received a diagnosis of Hypermobile Ehlers-Danlos Syndrome (hEDS), a hereditary connective tissue disorder affecting the skin, joints, muscles, and blood vessels that shares links with autism and neurodivergence (Casanova et al., 2020). For some, this diagnosis might prove devastating but, to me, I was immensely relieved to have an answer to my suffering.

There is no cure for Ehlers-Danlos Syndrome, and it is possible my symptoms will worsen with age. The increased stress on my joints may indicate I am likely to suffer from

arthritis at an early age, and I now take opiates four times a day just to keep the pain at a manageable level. With any strenuous activity, I risk the chance of dislocating a joint and seriously injuring myself. One of my ambitions from a young age has been to run a marathon; I now realise that I will likely never achieve this, and that running itself poses a huge risk to my health. While these realisations have been fraught with difficult emotions and have prompted a mourning for the life I once had, it has given me a unique perspective into the experiences of my Autistic clients – many of whom also suffer physical ailments and have felt invalidated and ignored by medical professionals.

Shockingly, many physical ailments that affect Autistic individuals (and which must be noted disproportionately affect women) such as chronic fatigue syndrome, Ehlers-Danlos and fibromyalgia have historically been under-researched and treatments to aid sufferers are scarce, further substantiating the injustice faced by thousands of Autistic women regarding medical and mental health treatment (Casanova et al., 2020; Grant et al., 2022).

To inquire into Autistic experiences is to encounter disability – be it a learning disability, epilepsy, dyslexia, chronic fatigue, or Ehlers-Danlos – and this aspect of Autistic experiences cannot be ignored. Social and communicative difficulties are oftentimes accompanied by physical challenges, adding further complexity to barriers faced. My own experiences have given me some insight into the challenges faced by “disabled” individuals and have challenged my assumptions as to what it means to be disabled – emphasising disability as the outcome of the interaction between the individual and their environment – known as the adaptability approach to disability; this approach situates disability as resulting from disharmony between an individual and their surroundings, rather than as an abnormality situated within the person (Söder, 1989). This is significant as it shifts responsibility onto society for not meeting the needs of disabled individuals. Helping clients evaluate systemic

power imbalances that contribute to experiences of disability can be an important aspect of the empowerment process (Shebib, 2014).

Furthermore, for the reasons stated above, it would be unreasonable to presume that I, myself, do not have a personal stake in this project. My own experiences of feeling misunderstood, ignored, and invalidated by the medical and mental health professions closely mirror the experiences of many Autistic women, including those involved with this research. However, there are key differences between my own experiences and the experiences of many Autistic women which must be acknowledged. When viewed through the lens of intersectionality, there are aspects of my own experiences that inevitably place me at greater advantage than many Autistic women. First and foremost, I am a White, heterosexual, cis-gendered woman from the United States, one of the wealthiest countries in the world. My racial identity, sexuality, and gender place me at a considerable advantage compared to other Autistic individuals who belong to minority ethnic groups, originate from less-advantaged countries, or belong to the LGBTQ+ community. Moreover, I come from a supportive family, in which my differences and sensitivities were both accepted and valued. Such cannot be said for some Autistic individuals, for whom the most severe perpetrators of abuse and ridicule originate within the family (Sohn, 2020). Similarly, my experiences of public schooling were mostly positive; my “gifts” or talents were identified considerably early, and I was placed in a separate classroom with other “gifted” individuals, many of whom were also neurodivergent. Looking back, I recognise how incredibly fortunate I am that this was the case, as this classroom also attended to different sensory needs, allowing me to learn in a comfortable environment in which I was not overwhelmed by the bright lights and noise characteristic of many mainstream classrooms. Having worked therapeutically with many Autistic girls, I am acutely aware of the challenges associated with public schooling faced by this client group and the mental health struggles that can result.

While primary school was a predominantly positive experience for me, the same cannot be said for my high school years during which I entered mainstream classes where I was under-stimulated intellectually and overstimulated from a sensory perspective; this ultimately led to severe anxiety and boredom, causing me to frequently skip school altogether and use cannabis to cope emotionally. I have since kicked this habit, but I remain aware of the temptations to use drugs to cope with a world that is often too bright, too harsh, and too loud.

Admittedly, my own views about autism and what it means to be Autistic have been highly stigmatised and riddled with inaccuracies in the past. Like many, I grew up equating autism with the way it is frequently represented in the media – accompanied by either severe learning disability or extraordinary, savant-like abilities – completely overlooking the spectrum of variation between these extremes. Likewise, the majority of my mentoring experience (prior to beginning my psychotherapy training) was spent working with White, Autistic males, virtually unaware of the ways in which autism might present in female or gender non-conforming individuals and the unique difficulties they may face. It is largely for this reason that I was unable to recognise my own neurodivergence until reaching the point of burnout and mental health crisis. This research, as well as my own therapeutic work in this area, has illuminated the ways in which Autistic women also struggle, particularly those without accompanying intellectual disability whose hardships are often overlooked.

Within my own private psychotherapy practice, I work primarily with Autistic women and girls and I am speaking from experience when I say that, sadly, for this population, trauma seems to be commonplace – be it from chronic invalidation and autism stigma or various types of abuse. I am, therefore, commencing this project with the pre-existing belief that trauma is common amongst Autistic women and that it is only through listening to Autistic voices that we can better understand and support these individuals. I feel

it is important to use my own voice to address issues and concerns relevant to those who remain voiceless, both as a therapist and an Autistic individual.

Locating my own positionality in relation to this research also necessitates that special consideration be given to the environment to which I belong. Undeniably, the culture in which we are raised has a profound effect on how we interpret and experience the world, and autism is no exception. While autism has been identified worldwide, whether certain traits are seen as “maladaptive” or “disordered” varies across cultures. For example, a lack of eye contact may be seen as unusual in Western cultures whereas, in Eastern cultures, it may be viewed as a sign of respect (Freeth et al., 2014). Likewise, whether diagnosis results in subsequent support also varies across cultures, as articulated by Freeth et al. (2014):

For parents from certain cultures the immediate implication may be that as a result of formal diagnosis their child will be eligible for additional support and will have an easier access to services; whereas for parents from other cultures the implication may be that their child will have less access to services, in certain circumstances their child may no longer be eligible to attend the parent’s chosen school, and the parent may also feel ostracized from their extended family or community due to the perceived stigma of having a child with developmental disorder.

While autism stigma is prevalent in the Western World, diagnosis generally improves access to services such as educational support and social care; however, difficulties arise when the individual is deemed “high-functioning” or has a diagnosis of Asperger Syndrome, in which case they are unlikely to be eligible for disability services or mental health-specific services (Social Care Institute for Excellence [SCIE], 2017).

Similarly, special consideration must be given to the era in which we currently live. Indeed, a diagnosis of autism a mere 30 years ago would have differed considerably to the ways in which we conceptualise autism now – and significantly fewer women and girls

would have been diagnosed Autistic in the first place. The birth of the neurodiversity paradigm has significantly impacted the way many people view autism and, although autism stigma is still widely prevalent, there is a growing acceptance of various types of neurodiversities. Equally, more and more people are coming to recognise autism as a “difference” and less a “disorder”.

In conclusion, engaging reflexively with this research has served as an invaluable tool, one that has allowed me to embrace the wider social and political issues that may influence this study. My hope is that this research project provides a platform for the voices of Autistic women affected by trauma who have been systemically disempowered by not having their voices and experiences heard, however, it must also be noted that this is my understanding of those voices and experiences. Throughout this thesis, I do not hide my own voice, but rather use my own thoughts and experiences as an Autistic woman and psychotherapist to further substantiate conclusions drawn.

Now that I have explained how I arrived at this research project and the ways in which my own positionality influences this research, I will provide an account of my ontological position which has influenced my research methodology and methods.

### **3.4 Ontology, Epistemology and Theoretical Perspectives**

Ontology is a discipline of philosophy dating back to the time of Aristotle. Crotty (1998) described ontology as “the study of being” and spoke to the questions raised by ontology about the very nature of reality. Popular ontologies among researchers include the critical realist ontological perspective, the belief that reality exists independent of the human mind, and the relativist ontological perspective, which takes the stance that reality is not distinguishable from the subjective experience of it (Levers, 2013). Opposing in nature, these two very distinct views ultimately call into question whether reality exists independently of

human consciousness and experience, or whether it exists purely inside our consciousness and through experience (Levers, 2013).

I align myself with the ontological presumption of relativism, taking the view that truth does not exist without meaning and that reality is context bound (Given, 2008). It is my belief that there is no absolute truth, and that truth is created by our experiences and the meanings we attach to them. However, to say that I am aligned with relativism does not mean that I am opposed to realism, and I understand that both social and physical realities are equally existent. For example, a boulder exists in the physical realm with or without humans imposing meaning on it – even when it is stripped of its social connotations. What I am suggesting, however, is that when inquiring into humankind’s experience of a particular phenomenon, reality is shaped via subjective experience. For example, within this project, participants may hold different perspectives depending on a variety of factors; participants’ age, race, socio-economic status, sexuality, and level of social support will invariably lead to different perspectives or “realities”. Indeed, one participant’s conceptualisation and experience of trauma may be in stark contrast to another’s. It is my view that there are no “absolutes” when inquiring into trauma amongst Autistic women, but that by inquiring into their experiences, comparisons can be drawn, leading to a deepening understanding of the phenomenon and the ways in which Autistic women can best be supported.

Closely related to ontology, epistemology, the study of knowledge, can be described as a way of understanding how one knows what one knows and how one makes sense of the world (Levers, 2013). Crotty (1998) highlights the significance of epistemology and theoretical perspective in determining one’s methodology and methods and promoting intellectual rigour by ensuring consistency between the multiple facets of a research project. He defined theoretical framework as “the philosophical stance informing the methodology and thus providing a context for the process and grounding its logic and criteria” highlighting

the importance of theoretical framework in every stage of the research process, as each component informs the other (Crotty, 1998, 3).

Broadly speaking, many researchers locate themselves within one of three epistemological stances: subjectivism, objectivism, or constructivism. While objectivism posits that truth and meaning exist independently of any consciousness, subjectivism takes the polarised view that truth and meaning reside only within one's mind (Crotty, 1998). Constructivism, however, seeks to bridge the gap between these two opposing epistemological stances, focusing instead on the interaction between the subjective and the objective. In the constructivist stance, meaning is not discovered but constructed (Crotty, 1998) and this is the epistemology I situate this study within. It is my view that, while objects within our world are full of potential meanings, it is only once they are engaged with human consciousness that meaning can truly emerge. In alignment with my ontological perspective, Crotty (1998) states that constructivism is simultaneously relativist and realist. He writes, "To say that meaningful reality is socially constructed is not to say that it is not real" (1998. 63).

Furthermore, one's theoretical perspective can be defined as a set of assumptions about reality that informs both the questions we ask as researchers and the answers we arrive at after having asked those questions; it has been described as a lens through which what we see is either focused or distorted (Crossman, 2020). Locating my own theoretical perspective regarding this research was, admittedly, not an easy nor linear process. Undeniably, I struggled initially with the juxtaposition between my predominantly positivist nursing background and the interpretivist nature of my psychotherapy training. The temptation to provide a solid, evidenced-based solution to the problem identified was significant, however, the more I engaged with the academic and grey literature in relation to my topic, the more I began to realise the innate complexities involved. It soon became clear to me that the solution was not as simple as I had hoped, and that my own search for meaning and subjective reality

would inevitably be influenced by the culture and environment in which I live, my own experiences, and the historical processes at play. I quickly found that it is impossible to separate autism from the historical events that led to its creation. This is because the concept of autism itself is a social construct – meaning its very existence is based not in objective reality, but as a result of human interaction. In short, autism exists because humans agree that it exists.

Indeed, the defining features of autism have changed significantly since its conception, as described in the introductory chapter of this thesis. Likewise, the concepts of autism and neurodiversity as a whole are largely influenced by the power dynamics prevalent within society, as those with the most power (male, middle-upper class, Western, White) have disproportionately represented the Autistic population and research surrounding autism, an issue that is only just beginning to be addressed. I felt it was imperative that this research addressed the power imbalances that have influenced how we conceptualise autism and the ways these processes have influenced the recognition of autism in women and girls and their recovery from psychological trauma.

During each stage of the research process, therefore, attempts have been made to break down the power imbalance between researcher and participant that is characteristic of many types of research, the result of which could serve to further disempower Autistic women by positioning the researcher as “expert” over their experiences and lives. In that sense, there are many parallels between this study’s design and the components that aided Autistic women’s recovery from trauma, with the facilitation of the client’s autonomy, social, and psychological empowerment at the forefront.

Likewise, through engaging with other Autistic women, it became apparent that a large proportion of this population have felt let down by the current mental health system, and that there is an enormous need for inciting meaningful change within the system itself.

Having recognised the need to elevate Autistic voices, ignoring my own experiences and the knowledge I have acquired, both as an Autistic woman and a psychotherapist working with Autistic women and girls, felt as if I would be ignoring a significant source of knowledge, thus I knew my chosen methodology must acknowledge the perspective of the researcher while also confronting the existing, often unjust, social systems influencing the realm of autism and mental health. Ultimately, I was able to locate myself within the critical theory research paradigm, a perspective that recognises the role of power in the acquisition of knowledge, including through the perspective of the researcher. Israel et al. (1998, 176) write of critical theory:

From the critical theory et al perspective, a reality exists that is influenced by social, political, economic, cultural, ethnic, and gender factors that crystallise over time; the researcher and the participant are interactively linked; findings are mediated by values; and the transactional nature of research necessitates a dialogue between the investigator and participants in the inquiry.

More specifically, this project takes a critical feminist theoretical approach, combining elements of critical inquiry and feminism and acknowledging the ways in which reality is shaped by historical processes, in this case, the longstanding history of the oppression of women through psychiatry and the unmet needs of Autistic women suffering with ill mental health (Russell, 1987; Camm-Crosbie et al., 2018; McCarty, 2022).

While critical inquiry seeks to challenge social structures, confront unjust social systems and incite meaningful change, feminism acknowledges women as an oppressed class and recognises the unique knowledge that can be obtained from emotion and personal experiences of oppression unique to being female (Gray, 2014). A critical feminist approach to research is concerned with looking beyond the standard male viewpoint, seeking out women's knowledge and experience, and acknowledging that participants are experts in their

own experiences; likewise, a feminist approach to research involves the constant awareness of our own power as researchers and requires constant reflective practice, challenging our own cultural assumptions and biases to better understand how these impact our research (VCU Libraries, 2019). This perspective is congruous with my chosen methodology of participatory action research which I will expand upon further below.

### **3.5 Methodological Approach**

#### **3.5.1 The Case for Incorporating Elements of Constructivist Grounded Theory with Participatory Action Research**

Originally developed by Glaser and Strauss during their study ‘Awareness of Dying’, grounded theory is a research method concerned with generating theory that is “grounded” in data that has been systematically collected and analysed (Noble and Mitchell, 2016). A contemporary version of Glaser and Strauss’s (1967) original statement, *constructivist grounded theory* locates the research process and product in historical, social and situational conditions (Charmaz, 2017). It differs from its predecessors by 1) assuming a relativist epistemology, 2) acknowledging both the researcher and the research participants’ multiple standpoints, roles and realities, and 3) adopting a reflexive stance toward your background, values, actions, situations, relationships with research participants, and representations of them (Charmaz, 2017).

On the other hand, participatory action research aims to construct knowledge and action that is useful to the community it seeks to serve (Reason, 1994). It is a process through which researchers and participants develop goals and methods, participate in the gathering and analysis of data, and implement the results in a way that will promote change in the lives of those involved (Reason, 1994). Participatory action research pays careful attention to power relationships advocating for power to be deliberately shared between the researcher

and the researched. It seeks to enable action via collective, self-reflective inquiry that researchers and participants undertake, so they can understand and improve upon the practices in which they participate (Baum, MacDougall, and Smith, 2006).

Incorporating grounded theory approaches into participatory action research is still a relatively new concept. At face value, these two distinct approaches appear somewhat different, however, a deeper exploration reveals important similarities. An example of this is the iterative nature of both approaches; in each of these approaches theory building occurs at the same time as data collection (Azulai, 2021; Dick, 2007). Similarly, each approach is emergent in that understanding of the phenomenon being explored emerges as the study proceeds, and the research process can be modified to capitalise on that understanding; in this sense, both the theory development and the research process themselves are emergent in both grounded theory and participatory action research (Dick, 2007).

Participatory action research is often criticised for having “weak methodological foundations” and failing to adequately demonstrate approaches to data collection and analysis (Canlas and Karpudewan, 2020). Thus, applying a grounded theory approach to data analysis was appealing to me as a new researcher as it provided a clear structure for the process and promoted intellectual rigour. Constructivist grounded theory was particularly attractive as it moves away from the positivist nature of traditional grounded theory, situating itself instead within the constructivist paradigm and acknowledging reality as multiple, processual, and constructed (Charmaz, 2014). The combination of these approaches offered the best of both worlds, maximising participation of members of the autism community and providing a strong framework for data analysis through constant comparative analysis.

I was inspired initially by a study completed by Teram, Schachter, and Stalker (2005) in which they utilised both participatory action research and grounded theory to explore experiences of female survivors of childhood sexual abuse with the aim of informing physical

therapy professionals about how survivors experience physical therapy and what they consider best practice. The researchers argued that the integration of grounded theory and participatory action research can empower clients to inform professional practice. Similar to the aims of this research, their integration of these approaches was guided by the need to produce knowledge that was both relevant and acceptable to the professional community while also considering the power differentials between survivors and practitioners. Moreover, grounded theory's emphasis on the emergence of theory from data allowed for the exploration of survivors' experiences of physical therapy without the confines of a predetermined framework. This was of particular importance for my project as Autistic individuals' experiences of trauma therapy is relatively unexplored. Even less explored are the experiences of Autistic *women* who, as this thesis argues, are more susceptible to traumatic events given their multiple marginalised identities.

Redman-MacLaren and Mills (2015) also make a convincing case for the integration of grounded theory and participatory action research, terming their approach 'Transformational Grounded Theory'. Within this approach they emphasise participatory methods and decolonising methodologies, making the case for the enhancement of intellectual synthesis through the identification of power within the research process. They posit that grounded theory's systematic approach to data generation and analysis can enhance action research. Similarly, they speak to the knowledge that grounded theorists can derive from sharing knowledge with research participants, stating, "If validity in grounded theory is regulated by socially constructed reality... then greater participation of those who have experience of the phenomenon has the potential to increase the rigor of research results" (Redman-MacLaren and Mills, 2015, 5).

Furthermore, data generated and analysed by coresearchers (in this instance Autistic members of my research advisory board) is less likely to be forced into a theoretical position

by the primary researcher (Redman-MacLaren and Mills, 2015) something that was of particular importance to me given my own proximity to the topic being explored. It was imperative to me that this research was applicable to the community it seeks to serve and not simply a reflection of my own experiences and assumptions, making meaningful participation from the autism community of paramount importance. Indeed, the founder of the constructivist approach to grounded theory, Kathy Charmaz (2014), has spoken to the importance of constructing knowledge with research participants to ensure socially just outcomes. This was a motivation for the inclusion of Autistic women's voices in this research.

In short, utilising grounded theory methods of data analysis within participatory action research provides solutions to each of the concerns stated above, ensuring intellectual rigour while incorporating meaningful participation from the community, producing knowledge that is relevant to the professional community (psychotherapists working with Autistic women), equalising the power imbalance inherent to the research process, and promoting deeper knowledge of the phenomenon being explored by the inclusion of those who have relevant experience in the research process (Teram, et al., 2005). Furthermore, the iterative nature of both of these approaches makes them compatible, as each allows for the emergence of both theory and the research process throughout the research journey. The combination of these approaches allows for meaningful participation from the autism community while providing structure for the analysis of data.

In subsequent sections I will provide an overview of the research process at which point my own utilisation of grounded theory within the data analysis process will be explored in further detail.

### **3.5.2 Participatory Action Research: Overview and Rationale**

It was crucial to find a methodology that effectively acknowledged the power dynamics prevalent within society and the historical processes underpinning the issue at hand. This meant finding a methodology that had the capacity to pay attention to the power dynamics inherent to the research process and that could mitigate associated inequities within this process. Likewise, it felt imperative that this research be both applicable and accessible to the wider community so that the findings could be used to inform current practice and incite meaningful change. Participatory action research was a good choice of methodology for the project as it meets each of these criteria, enabling meaningful participation of the community with which it is concerned and seeking to elicit meaningful change. Indeed, a defining principle of participatory research is that it seeks to undermine the traditional power imbalance between participant and researcher and that both parties work together to achieve shared goals (Fletcher-Watson et al., 2018). This allows for a more equal distribution of power, contrary to more traditional research designs in which research is conducted “on” participants rather than “with” participants. Moreover, drawing on participatory values fits within my stated paradigm of critical theory, as it enables emancipation and acts as a call for community action.

Participatory action research is a practice that has received a lot of traction in the field of public health throughout the past decade, namely due to the growth of the mental health survivor movement, highlighting the importance of self-determination for people with psychiatric diagnoses, and the disability rights movement, which has historically emphasised the importance of the inclusion of disabled voices in research surrounding disability (Schneider, 2012). Most people are familiar with the popular slogan that originated out of the disability rights movement, “Nothing about us without us” which speaks directly to this need for greater participation of the populations about which the research is concerned. Moreover,

greater recognition of health inequalities associated with powerlessness and poverty has led to calls for a renewed focus on research approaches that recognise the social, economic, and political systems that shape behaviour and access to resources necessary to maintaining health (Israel, et al., 1998).

The principal aim of participatory action research is to elicit meaningful change for the parties with which the research is concerned and it seeks to achieve this by incorporating meaningful participation of these parties in every stage of the research process.

Unfortunately, many have described a disconnect between researchers and the autism community, a disconnect likely fuelled by the researchers' lack of involvement in the autism community, the rare dissemination of research findings to the autism community, and the use of demeaning language regarding Autistic individuals (Keating, 2021). Seeing as Autistic voices have routinely been underrepresented in research surrounding autism and mental health, it is understandable that the utilisation of participatory action research in autism research has increased dramatically over the last few years (Pellicano et al., 2013; Vincent et al., 2016; Ostmeier and Scarpa, 2012; Lam et al., 2020). Given the historical oppression of the population this research seeks to serve, encouraging meaningful participation of Autistic women in this research project was of the highest priority.

There are few studies to date that have inquired into Autistic women's experiences, underlining the importance of Autistic women's participation in research concerning them. It is my own perspective that the best way to meaningfully influence this imbalance, it would seem, is to include Autistic women's voices in research regarding them, of which participatory action research is primarily concerned. This is particularly important in the realm of autism, as the current understanding of autism is based on research conducted with predominantly male participants, increasing the need for the meaningful inclusion of women in autism research. Saxe (2017, 153) elaborates:

Autistic women represent an important segment of the population of individuals with [disabilities]. Despite this fact, little research has been conducted with them in consideration and interventions used to support them are based on that male-centric research.

Moreover, Sue Fletcher-Watson (2018, 1) makes a clear case for participatory research in the field of autism and gives evidence of poor implementation of autism research and dissatisfaction within the autism community:

Participatory research enables meaningful input from autistic people in autism research. It is one important way to overcome barriers to effective translation and to ensure that research yields relevant benefits. By participatory research, we mean incorporating the views of autistic people and their allies about what research gets done, how it is done and how it is implemented.

Overcoming barriers to translation and ensuring research results are relevant to the autism community are obvious benefits of participatory action research. Equally, this approach to research affords the opportunity for the empowerment of stakeholders, as it seeks to elevate Autistic voices and divides responsibilities and powers amongst those involved in the project, facilitating a sense of control and agency. Israel et al. (1998, 179) further substantiate this, speaking to the empowerment that can result from community-based participatory research:

Community-based research is a co-learning and empowering process that facilitates the reciprocal transfer of knowledge, skills, capacity, and power. For example, researchers learn from the knowledge and “local theories” of community members, and community members acquire further skills in how to conduct research.

In this sense, the chosen methodology for this research project is synonymous with its core aims, emphasising the importance of psychological empowerment in Autistic women’s

recovery from trauma and adversity, a process that can be aided by participating in research and taking action on issues that are of importance to the individual.

Additionally, participatory action research has the benefit of enhancing the relevance and usefulness of knowledge constructed from research, improving the quality of research by engaging local knowledge and acknowledging the knowledge and experiences of non-academics, promoting the wellbeing of community members by addressing identified needs, examining the impacts of marginalisation, and helping to overcome the distrust of the research community held by communities who have historically been “subjects” of research (Israel, et al., 1998). Each of these factors contributed to my own decision to utilise participatory methods within this research project, implementing an advisory board comprised of members of the population this research seeks to serve: Autistic women.

### **3.5.3 Facilitating Community Participation within Autism Research: The Research Journey**

Characteristic of participatory research, this project implemented an advisory board comprised of both Autistic and non-autistic individuals (Newman et al., 2011). This was to ensure that the views of Autistic women were both heard and incorporated into this research, and that the results of this research were both accessible and applicable to the autism community. While Autistic board members were involved directly with coding and data interpretation, non-autistic board members assisted with other matters such as participant recruitment and advising on mental health policy and practice.

Non-autistic board members included one former member of parliament, health minister and current vice-president to the National Autistic Society as well as a well-respected psychotherapist working with Autistic individuals. Autistic board members

included one Autistic psychotherapist with extensive experience in trauma therapy and an Autistic woman with her own extensive trauma history.

While vital to the research process, employing an advisory board was not without its associated difficulties, particularly given the time restraints of this particular project; these challenges will be explored throughout this section as will the ways in which these challenges were mitigated or overcome.

Advisory boards represent an important element of participatory action research, the role of which is to inform the development of the research agenda and to provide guidance and input regarding the needs of the community which the research serves (Newman et al., 2011). Advisory boards provide an infrastructure for members of a given community to voice concerns, raise priorities that might otherwise not reach the researcher's agenda, and advise about suitable research processes that are respectful of and acceptable to the community (Newman et al., 2011).

Non-autistic board members were approached at the commencement of this project as they each had vast knowledge and experience working with Autistic individuals and were well-placed to advise on ways to increase participation of the autism community throughout this project. They were initially asked to advise on ways to recruit Autistic board members to participate in this project. From those conversations, it was decided that the best way to recruit Autistic board members was to utilise the Facebook community, in which there are varying groups dedicated to Autistic women; in these groups, Autistic women can share experiences, gain support, and offer advice and support to others. It is also a useful platform for raising issues of concern to the community, which offered hope that there might be some uptake of an opportunity to be involved in research pertaining to Autistic women's mental health, an issue I, myself, have often seen broached within these forums.

A call for participants was placed within two separate groups dedicated to Autistic women. I received a total of eight responses. Of those eight responses, two individuals agreed to take part in the project. Unfortunately, these initial two advisory members each dropped out due to personal circumstances pertaining to the Covid-19 pandemic, speaking to the effects of the pandemic on Autistic individual's mental health and emotional capacity. Indeed, after having contracted Covid myself, it became necessary for me to take a break from this research project to allow for my own recuperation and mental vitality. Despite this setback, each of these advisory board members offered valuable input regarding the ways in which interviews would be conducted. Interestingly, they each preferred to communicate by written text, expressing immense anxiety in relation to audio and video calls. This insight alerted me to the potential for similar concerns when interviewing participants, leading me to offer interviews by audio, video or via the chat function within Zoom.

A second call for advisory board members was then placed within the same groups with the addition of another group dedicated to Autistic counsellors and psychotherapists that I had become aware of since my initial post. That post elicited a further two responses, one from an Autistic psychotherapist with substantial experience in trauma therapy and an Autistic woman with her own extensive trauma history. These advisory board members were involved for the remaining duration of this project, helping to determine interview questions (see Appendix III), and offering key input during data analysis. Information regarding board member inclusion criteria and responsibilities provided to prospective board members can be found in Appendix IV; the advisory board agreements signed by board members prior to commencing the project can be found in Appendix V.

During the initial board meeting, an overview of the project was given, and the essential research questions and aims were shared. Traditionally within participatory action research, co-researchers are involved from start to finish, helping to determine the direction

of research and essential research questions (Whyte et al., 1991). However, there were associated difficulties with conducting participatory action research within the confines of an academic institution. For example, student researchers are more often than not required to develop research competencies, identify a research query, design a proposal, and obtain ethics approval prior to actually engaging in a partnership with the community of interest; however, in taking control of the research process, researchers risk jeopardising the defining principle of participatory action research (Burgess, 2006). I faced similar challenges within this project and endeavoured to facilitate meaningful participation while satisfying the requirements of my institution for the fulfilment of my doctoral degree.

An example of this is evidenced within my experience of gaining ethics approval. Upon submitting my ethics application for review, there were concerns raised about the nature of this project and whether it would truly reflect my own work if done in partnership with other parties. I realised I would have to be flexible with my approach, facilitating community participation in the project while ensuring that it satisfied the requirements for the obtainment of said degree. And, while I invited board members into the decision-making process, I was continually conscious of how their views resonated with my own knowledge of the topic. I was also extremely cognisant of the potential consequences of any decisions made and of ensuring that there was onto-epistemological and methodological coherence throughout the research. Additionally, the general direction of this research would need to be established to obtain ethical clearance prior to commencing this project, leading me to develop the core research questions associated with this project prior to community collaboration. These questions were left intentionally broad to allow scope for collaboration when determining what elements of Autistic women's experiences should be explored. This collaboration led to the development of four, second-tier questions used to guide this research.

Similarly, I was the primary researcher involved in the analysis of research data; this was, again, to ensure that this project reflected my own work and to accommodate the limited timeframe permitted for this project. However, efforts were made to increase collaboration between myself and board members throughout this process, where possible. I soon realised that I had grossly overestimated the time community members would have to devote to this project, and this became apparent as early as the first board meeting. For example, it became evident that I would need to devise a way to enable meaningful participation in data analysis without necessitating board members complete the labour-intensive and time-consuming task of coding data line-by-line (a process known as open coding). The coding process will be discussed in more depth below.

There was collective agreement in the group that interviews would serve as the best method for exploring participants' experiences and that a semi-structured approach to interviewing would be employed. Based on my knowledge of the advantages and disadvantages of a range of possible methods, I shared their view, and was therefore content that this was an appropriate way forward. Semi-structured interviews allowed for the exploration of associated feelings and attitudes and afforded the opportunity to "probe" for more detailed responses or clarifications where necessary. The project's specific research questions and aims were discussed at length, leading to the identification of several broad topics for exploration within interviews. These topics included conceptualisations of trauma (i.e. how participants define trauma), the types of experiences that were experienced as traumatic by participants, the impact of traumatic stress on functioning, barriers to participants accessing support, participants' experiences of the counselling relationship, and the therapist's own knowledge of autism and the impact of this knowledge on the participant's experience of therapy.

From these topics, questions were developed that were felt by myself and the Board to best support the exploration of these topics while allowing for flexibility within the interview process. The decision was made to provide participants with the interview questions a minimum of one week prior to the scheduled interview to allow ample time to formulate responses and provide a sense of predictability. This decision was informed by our own professional and personal experiences and the wealth of literature that exists in relation to reduced processing speed in autism and Autistic individuals' preference for predictability (Haigh et al., 2018; Goris et al., 2019). Our hope was that by providing interview questions ahead of interviews it would help alleviate associated anxiety and ensure that participants had sufficient opportunity to represent their experiences and views within interviews. Given that Autistic women's voices are underrepresented in research concerning them, we were keen to facilitate this process as best as possible and help mediate these associated challenges.

During this initial meeting, it was also decided how participants would be recruited for this project. Drawing again on the power of social media to elicit civic engagement, it was decided that calls for participants would be posted within autism-specific Facebook groups. Essential criteria for taking part in this project included:

- 1) being 18 or more years of age
- 2) identifying as a cis or transgender woman
- 3) residing in the United Kingdom
- 4) having experienced some sort of trauma (I left it to participants to define trauma)
- 5) having had a minimum of six psychotherapy sessions in the past five years.

Crucially, we encouraged participation of both formally and self-diagnosed Autistic women given the current underdiagnosis of Autistic women and the substantially long wait times for formal diagnosis. Similarly, we left it up to participants to define trauma as we did not want to exclude various adversities that might not fit the definition of trauma as defined in the

DSM but still have profound impacts on participants' functioning and quality of life.

Likewise, what constitutes trauma for Autistic individuals might differ from the neurotypical population.

Six participants were recruited in total, all of whom agreed to be interviewed via Zoom. Of these six participants, three were recruited by Facebook and the rest from within a non-autistic advisory board member's personal network. The difficulty recruiting participants for this project might represent Autistic individuals' reluctance to engage in research efforts, as Autistic individuals have previously reported dissatisfaction with the research community (Fletcher-Watson, 2018).

The age of participants varied, with the youngest participant aged twenty-seven at the time of interviews and the oldest aged fifty-five. Similarly, participants' nationalities varied; while the majority of participants resided in Scotland, the remaining two resided in England, with one participant having recently immigrated to England from South Africa. While most participants sought private therapy, some sought therapy through charitable organisations or the NHS. Most participants were unable to comment on the type of therapy they were offered and whether they felt this influenced their experience of therapy. I have deliberately chosen not to disclose additional demographic information in an effort to protect participants' confidentiality, something that is of the utmost importance to me – particularly given board members had direct involvement in participant recruitment.

After interviews were conducted and transcribed, they were shared with Autistic board members who were asked to provide written reflections on transcripts. This presented additional challenges as board members found it difficult to offer reflections in the desired timeframe. In the end, it became necessary to alter my approach, obtaining verbal reflections on transcripts during board meetings rather than relying solely on written reflections. These reflections were then coded as additional data and used to inform conclusions drawn.

One of the rationales for board members and myself conducting the coding process rather than the participants coding their own transcripts was because they and I would have more distance from the subject matter than the participants themselves. I did, however, strive to facilitate participation of board members throughout the coding process. For example, board members were trained in the coding process by myself in an effort to increase confidence and competence in the data analysis process. During board meetings, transcripts were discussed in detail and the emergent themes were explored, with board members giving input on the relationships between themes. Their involvement was predominantly utilised in the axial stage of the analytic process, in which categories are formed from data derived from open coding, and during the selective coding stage, in which these categories are compared for similarities and organised under an overarching theme. Their participation in this process was aided by the use of a chart clearly representing common themes originating out of the open and focused coding stages of data analysis (see figure one, within the presentation and discussion of findings). This chart enabled board members to easily view all categories and subcategories and make connections between them. Through axial and selective coding, we then arrived at a final model representing participant answers (see figure two, within the presentation and discussion of findings).

This tactic enabled meaningful participation without necessitating board members undertake the arduous tasks inherent to open coding, during which transcripts were coded line-by-line. Requiring board members to participate in this task would have likely exceeded the timeframe of this project and required a substantial amount of knowledge regarding the data analysis process by board members. Contrarily, involving board members in the axial and selective coding stages enabled them to assist in making connections between formerly identified categories, further condensing these categories, and ultimately identifying empowerment as the core concept linking each of these categories together. It is this core

concept of empowerment that forms the basis of the findings for this research and which, as I argue in subsequent chapters, is central to Autistic women’s recovery from trauma. A chart detailing each step in the analytic process is provided below (Figure 1). A diagram demonstrating the evolution of interview data throughout the analytic process is subsequently provided (Figure 2).

<b>CODING STAGE:</b>	<b>DESCRIPTION:</b>	<b>RESEARCHERS INVOLVED:</b>
OPEN CODING	Both transcribed interviews and Autistic board members’ reflections are descriptively coded	Primary researcher alone
FOCUSED CODING	The most frequent codes are sorted and synthesised into defining categories	Primary researcher alone
AXIAL CODING	Relationships between categories derived from focused coding are examined for similarities and grouped accordingly into concepts	Primary researcher + Autistic board members
SELECTIVE CODING	Concepts derived from the axial coding stage are connected under the core category of empowerment	Primary researcher + Autistic board members

Figure 1 (above).

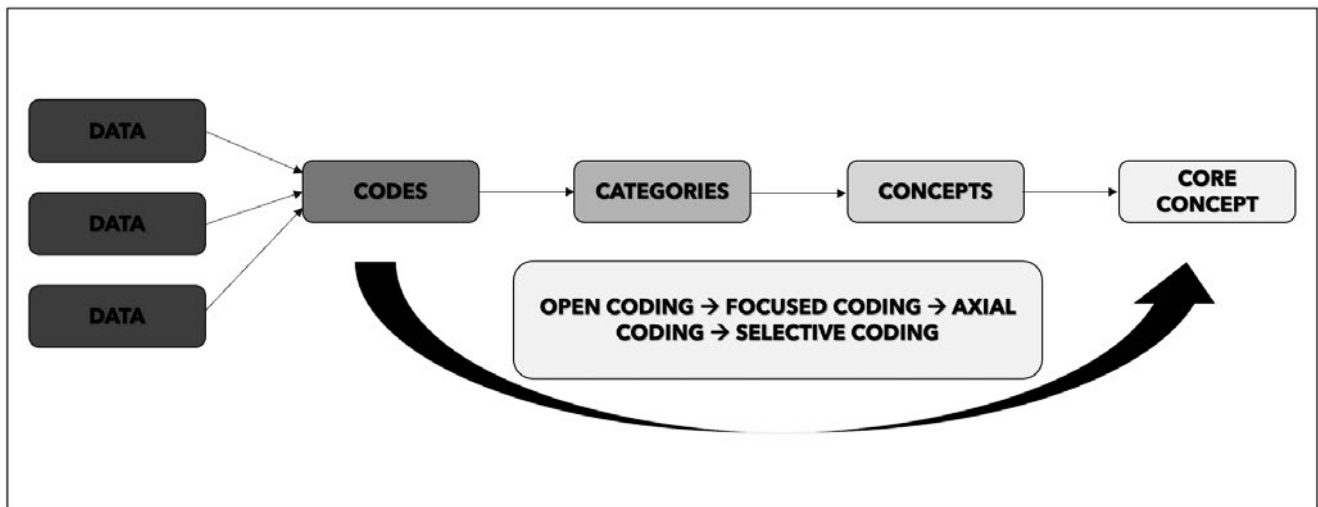


Figure 2 (above).

After the data analysis process was complete, the presentation and discussion of findings chapter was drafted and shared with board members to ensure that the language used best represented the autism community.

Furthermore, the work begun with this research project will not end with the submission of the thesis. Rather, it is the first step in a larger process. My aim is for the results of this study to be used to inform practitioners working with this client group – the “action” component of participatory action research. At the time of writing, this component is very much in the planning stage, with board members and myself brainstorming the ways in which findings derived from this research can be made best accessible to practitioners in the field. The current proposal is that a set of guidelines be produced to guide counsellors, psychotherapists and other practitioners working with Autistic women who have suffered trauma and adversity, with the facilitation of the client’s autonomy and empowerment at the forefront. Board member Sir Norman Lamb, a former member of parliament, health minister and current vice-president of the National Autistic Society, is well situated to assist in

disseminating findings and advise on ways these findings can be used to inform relevant policies and procedures.

### **3.6 Methods**

Above, I detailed how the Board decided upon semi-structured interviews for the collection of data. Here I will discuss how the semi-structured interviews I conducted fit with the broader literature on this method. Interviews were determined to be the best method to achieve this research project's goal of exploring Autistic women's experiences of trauma and receiving trauma-specific support. This is in part due to the exploratory nature of interviews, during which participants' feelings and attitudes regarding a given topic can be explored in a depth and breadth that is not possible when using methods commonly applied in quantitative studies, such as questionnaires. At the heart of interviewing is the intent to understand the lived experiences of others and the meanings they derive from those experiences (Quinney, Dwyer and Chapman, 2016) making this method a natural fit for this project.

If I had adhered strictly to the grounded theory approach to research, unstructured interviews would likely have proved most useful, as they refrain from imposing any preconceived theories or ideas and allow for in-depth exploration into a given experience (Foley et al., 2021). However, given the population this research pertains to, semi-structured interviews were collectively agreed upon as offering the "best of both worlds", combining the structure of a list of issues to be covered with the freedom to follow up points if needed (Thomas, 2013). Providing a structure for interviews and sending this structure to participants well in advance was intended to reduce uncertainty and aid the processing of information, a process that can be impaired in Autistic individuals. This is in line with guidelines produced by the National Autistic Society in partnership with the mental health charity, Mind, which recommend therapists provide the structure of psychotherapy sessions in advance when

working with Autistic clients. Indeed, asking individuals to recount difficult or challenging experiences, such as within therapy sessions or within interviews conducted for this project, has the potential to evoke strong emotion; thus, providing an agenda for the structure of interviews attempts to help reconcile any associated anxiety.

Essential to conducting effective interviews that elicit rich, expressive responses is the establishment of rapport between interviewer and interviewee putting interviewees at ease and facilitating open, authentic responses to questions posed (Thomas, 2013). For this reason, I chose to disclose my own autism to participants prior to conducting interviews, emphasising myself as an equal rather than as a neutral, detached observer. Doing so also implies that I, too, have experienced common difficulties associated with neurodivergence and helps to further equalise the power imbalances inherent to the research process. Throughout interviews, I used this shared experience to facilitate connection with interviewees, where appropriate. Given my own close proximity to the phenomenon being explored within interviews, I was careful to check my assumptions throughout the interviewing process to ensure I captured the essence of participants' experiences without imposing my own understandings of the subject of discussion. Interview transcripts were also explored at length with Autistic board members, again keeping my own assumptions in check and ensuring participants' views and experiences were represented as authentically as possible.

Due to the Covid-19 pandemic, all interviews were conducted online via Zoom. While this presented limitations in discerning body language and non-verbal communication, it also enabled the participation of individuals with additional support needs who might otherwise struggle to attend in-person interviews, an issue that is particularly relevant given the population this research pertains to.

Interviewees were also permitted to participate by video, audio only, or via the chat function in Zoom. This was intended to enable meaningful participation by helping to

mediate anxiety associated with autism. Of the six individuals who participated in this study, four agreed to meet via video and the remaining two by audio only. Given differences in communication style and information processing in Autistic individuals, the time devoted to interviews was flexible with the longest interview totalling one hour and thirty minutes. Throughout interviews, I was careful to “check out” whether participants were happy to continue, emphasising their comfort within the process. Such adaptations speak to the need for flexibility within the therapeutic process when counselling Autistic clients, a point I will expand upon within the presentation and discussion of findings section of this thesis.

### **3.7 Data Analysis**

#### **3.7.1 Constructivist Grounded Theory: An Overview**

My approach to the coding process was influenced heavily by the grounded theory approach to data analysis. Seeing as research quality is often scrutinised within participatory action research due to weak methodological underpinnings and a failure to adequately demonstrate the data collection and analysis (Canlas and Karpudewan, 2020) the combination of these approaches offered a methodological basis for this research that encouraged participation of the autism community. This also provided a clear structure for the analysis of data, something that was also appealing to me as a first-time researcher. An inductive approach to research, grounded theory was developed in the 1960’s by sociologists Barney G. Glaser and Anselm L. Strauss from their successful collaboration studying death and dying in hospitals (Charmaz, 2014). The results of this collaboration lead Glaser and Strauss to propose that systemic qualitative analysis could generate theory, a bold claim considering quantitative methods had gained dominance at that time just as qualitative research within sociology was losing ground (Charmaz, 2014). In this approach to research, theories are generated from data rather than using research data to prove or disprove a predetermined

hypothesis (Gray 2014). The use of grounded theory is particularly useful when there is no existing theory to explain a given phenomenon, as it offers a higher-level understanding of a certain phenomenon that is “grounded” in data, allowing for the full expression of multiple dimensions of a studied experience.

Representing a diversion from the original approach to grounded theory described by Glaser and Strauss in 1967, the constructivist approach to grounded theory acknowledges resulting theory as having been constructed rather than emerging from the data (Charmaz, 2014). In the constructivist approach, the flexibility of the method is highlighted, rejecting the mechanical application of grounded theory and moving away from the positivism in both Glaser’s and Strauss and Corbin’s earlier versions (Corbin and Strauss, 1990; Corbin and Strauss, 1998; Charmaz, 2014). First articulated at the turn of the 21<sup>st</sup> century by Kathy Charmaz, constructivist grounded theory argues that the researcher is not simply a neutral observer but rather a co-participant in the study. She writes,

Researchers can use grounded theory strategies without endorsing mid-century assumptions of an object external reality, a passive, neutral observer, or a detached, narrow empiricism. If instead, we start with the assumption that social reality is multiple, processual, and constructed, then we must take the researcher’s position, privileges, perspective, and interactions into account as an inherent part of the research reality. It, too, is a construction (Charmaz, 2014, 13).

Moreover, the role of the researcher in both “classic” and constructivist grounded theories reflects their epistemological differences. The classic approach to grounded theory has often been accused of being founded upon positivist and objectivist assumptions while the constructivist approach lends itself to interpretivist and subjectivist assumptions (O’Connor, Netting and Thomas, 2008). Indeed, many authors have described the classic

approach to grounded theory as adopting an objectivist stance in which an objective reality can be studied and understood by following the methodological approaches outlined in the approach (Charmaz, 2014). Alternatively, Charmaz (2014) has argued that reality is fluid, that the subject changes based on the participant's construction of it, and that all knowledge is, therefore, constructed; likewise, she has accused classic grounded theory as being "outdated" in that it supports an objective, external reality in which the researcher is a passive, neutral observer equating it with a detached, narrow empiricism (Charmaz, 2014). Constructivist grounded theory, therefore, not only acknowledges but encourages the researcher to serve as an active agent in the construction of theory and that, as such, his or her positionality and perspectives are acknowledged as impacting the research process and conclusions drawn. Charmaz (2014, 13) writes,

Thus, relativism characterises the research endeavour rather than objective, unproblematic prescriptions and procedures. Research acts are not given; they are constructed. Viewing the research as constructed rather than discovered fosters researchers' reflexivity about their actions and decisions.

My own personal experiences in relation to this subject necessitate that my own privileges and perspectives are acknowledged and that I take a reflexive stance, acknowledging the ways in which these factors may influence the research product. Likewise, given my own onto-epistemological position, embracing both relativism and constructivism, constructivist grounded theory was a natural fit for this project. From a theoretical perspective, constructivist grounded theory is harmonious with a critical feminist stance as it locates the research process and product within historical, social and situational conditions (Charmaz, 2017). Given the historic lack of research in this area, a grounded theory approach is also

harmonious in that it affords the opportunity to derive theory from data and does not rely on the validating of existing theories.

### **3.7.2 The Analytic Process**

Throughout the analytic process, the accustomed steps to constructivist grounded theory were followed; interviews were transcribed and coded line by line initially before moving onto focused coding, during which the most frequent codes were sorted and synthesised. The board members and I then engaged in axial coding, during which connections were drawn between codes and these codes were grouped into categories. Finally, these categories were organised under the single, overarching theme of empowerment through a process known as selective coding.

Crucial to the grounded theory approach to data analysis, these steps were conducted in an iterative manner, meaning further rounds of coding were completed based on codes and categories derived from each step in the analytic process. This reflexive, iterative process is thought to provide a deeper understanding of research data and increase the reliability of research (Mills, Durepos, and Wiebe, 2010). Similarly, interviews were analysed prior to subsequent interviews, allowing for the further exploration of themes identified in succeeding interviews.

### **3.8 Ethical Considerations**

Gray (2014) suggests four areas of ethical principles that researchers should adhere to when conducting research, including avoiding harm to participants, ensuring informed consent, respecting the privacy of research participants, and avoiding the use of deception. These principles are particularly important when conducting participatory research, in which the researcher's contact with participants or co-researchers is extended and they are granted

access to sensitive research data. This study was designed to cause no harm to participants, carefully attending to the principles outlined above. For example, participant information sheets and interview consent forms were written at an S4 reading level or lower to ensure that prospective participants could make an informed decision as to whether they wished to participate in the project (see Appendices I and II). This also ensured that participants with additional learning support needs could easily comprehend information regarding the project. It was also made clear within both the participant information sheet and consent forms that any questions or concerns could be raised with myself in an effort to provide ample opportunity for participants to raise associated questions or concerns. Consent was gained prior to interviews and participants understood that their responses would be anonymised and that they could withdraw from the research at any time, including after interviews had been conducted. Participants were also given access to their transcribed interview and allowed to change or omit statements within these transcripts, ensuring that their views and experiences were represented fairly.

Perhaps the most notable ethical consideration is the emotional wellbeing of research participants, as sharing accounts of trauma and chronic invalidation holds the potential of being significantly upsetting. To mediate this risk, participants were required to have received mental health support prior to interviews (6 sessions at minimum) within the last five years. This was also crucial to engaging in this research as it was the subjective accounts of receiving this support that this research project sought to explore. Participants were also given the opportunity to “debrief” with myself, a qualified mental health professional, following interviews. Participants were made aware prior to participating that interviews would last approximately one hour but that interviews may exceed this should they wish to expand on themes generated within interviews.

Having recently completed a postgraduate diploma in online counselling, I was well equipped to mitigate the challenges of conducting online interviews. For example, I was mindful of the ways in which interviews were concluded in an effort to ease participants' transition from speaking about sensitive and potentially upsetting material back into their daily lives. This is particularly important when conducting online therapy as clients are not afforded the transition period provided by one's journey to and from the therapy space. Remaining mindful of the ways in which discussing sensitive material might impact participants, I was careful not to end interviews abruptly, instead speaking of other, unrelated themes such as what participants planned to do following the interview, emphasising the need to attend to their own wellbeing. Following interviews, participants were thanked for their time and contributions.

Another ethical consideration is the confidentiality and anonymity of research participants. Seeing as the female autism community is relatively small in the UK, it was possible that research board members might identify participants when involved in the analysis of their transcripts. For this reason, extra diligence was taken by myself to remove or anonymize details from transcripts that could be used to identify participants, such as names, locations, aspects of participants' experiences or any other details shared in the interviews that could potentially lead to participants being identified prior to their transcripts being shared with Autistic board members for analysis. Crucially, all transcripts, consent forms and other records were securely stored and board members were given access to interview transcripts via a password secured university OneDrive, eliminating the need to download transcripts onto board members' individual computers and thus limiting the chances of transcripts falling into the wrong hands.

Finally, Gray (2014) posits researchers should aim to bring positive benefit to participants, including demonstrating meaningful results. This project aims to achieve this by

informing the ways in which practitioners best support Autistic women following trauma and adversity, an area that has previously been unexplored. Seeing as, to my knowledge, no other research of its kind has been conducted to date, participants have the benefit of knowing they have contributed meaningfully to the field and that their contributions will be used to inform best practice. The planned work with the National Autistic Society and other organisations as a result of this study is a further benefit to participants.

# Chapter Four: Presentation and Discussion of Findings

## 4.1 Introduction

In this chapter I will present the findings derived from participant interviews as well as provide a detailed analysis of each finding and a discussion surrounding the ways these findings relate to existing research and literature in the field. Figure one shows the diagram provided to board members after the open and focused coding stages; this diagram was provided in an effort to assist co-researchers in drawing connections between themes in the axial coding stage. Figure two shows the result of the axial and selective coding done in collaboration with board members. It displays the results of my coding process, showing the themes and subthemes emerging from the data analysis; you will find the findings divided into four categories: presenting difficulties experienced by participants at the time of commencing therapy, barriers to accessing appropriate support, the participants' perceived benefits of therapy, and qualities that aided the therapeutic process. Each of these themes were seen as either promoting empowerment – by strengthening social relationships, encouraging the exploration of identity, and strengthening participants' sense of control and autonomy over their lives – or disempowerment – by depleting one's confidence and sense of control over their lives, depriving participants of power, authority or influence and evoking feelings of helplessness, hopelessness, and defectiveness. The concepts and themes listed in figure two form the structure of the following chapter and will each be explained fully within the context of power and empowerment below.



Figure 1 (above).

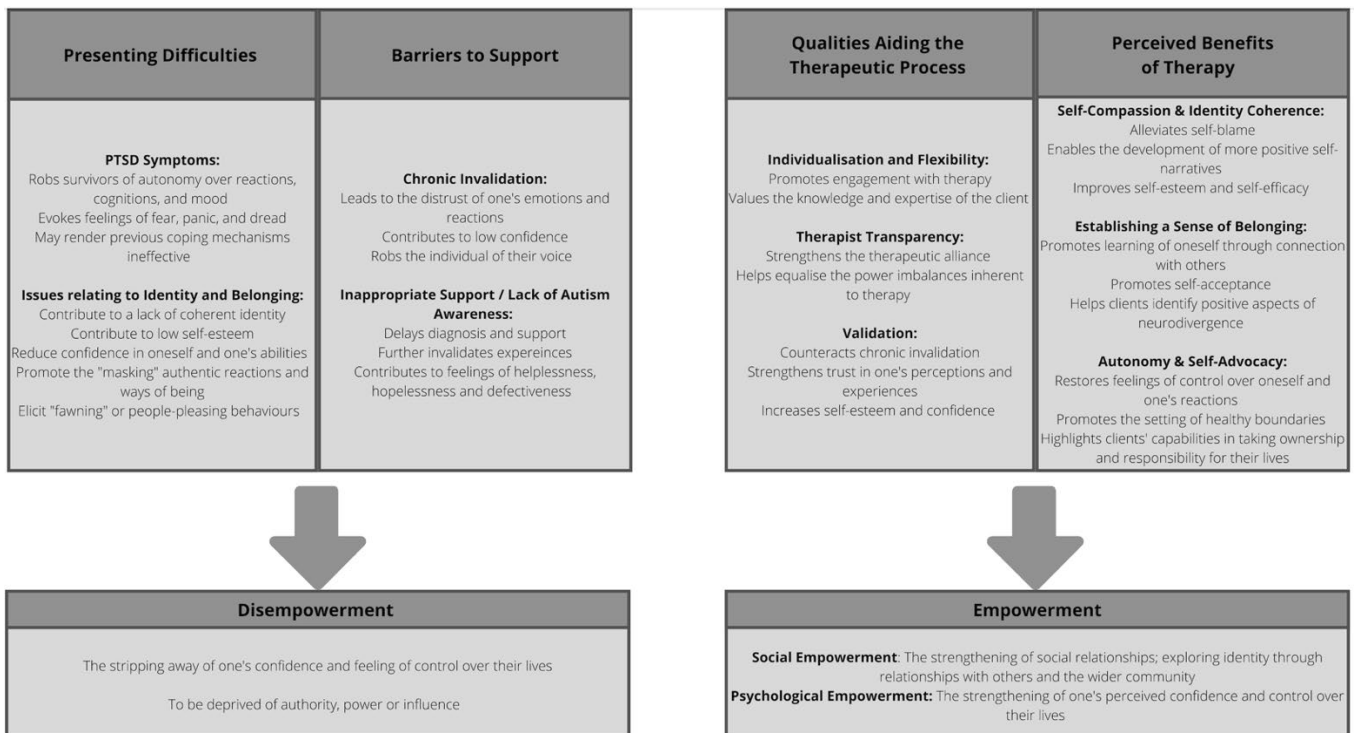


Figure 2 (above).

## **4.2 Presenting Difficulties Experienced by Participants**

In this section, I will outline the difficulties expressed by participants through their interviews. Throughout the inductive coding process, I could see clearly how some of the data collected related to the categories of symptoms described within the DSM-5. However, there were elements of participants' experiences that did not fit neatly into these categories, namely issues related to identity and belonging. These findings highlight a shortcoming of the DSM-5 in describing psychological distress following trauma for Autistic women. I will, therefore, first focus on making connections between participant responses and the classic symptoms of PTSD as described in the DSM to illustrate how some of the emergent data aligned with traditional notions of trauma. Then I will look at the responses that related to identity and belonging, which are *not* considered classic PTSD symptoms. This will enable me to demonstrate the shortcomings of the medical model in respect to Autistic women's experiences of trauma.

### **4.2.1 Classic PTSD Symptoms**

Interestingly, each participant involved in this study experienced what can be considered "classic" PTSD symptoms alongside additional emotional complaints. Whether these symptoms can be viewed as having arisen explicitly out of traumatic experiences or as having resulted from an exacerbation of autism symptoms secondary to trauma is irrelevant to this study, however, the differentiation of these symptoms remains an important area for future research. While the aim of this study is not to define the ways in which classic or core symptoms of PTSD differ in Autistic individuals, I will explore each symptom briefly below highlighting the ways in which they contribute to the felt experience of powerlessness in Autistic individuals suffering from psychological trauma. This sense of powerlessness results in the felt experience of disempowerment for afflicted individuals, as symptoms can be seen

to rob survivors of autonomy over their reactions, cognitions, and mood, and evoke feelings of fear, panic, and dread.

Post-traumatic Stress Disorder (PTSD) is experienced by approximately 5-10% of the total population, and women are twice as likely to experience PTSD as men (Yehuda, 2006). Moreover, researchers have speculated that autism may serve as a vulnerability factor for PTSD, increasing the risk of exposure to traumatic events due to a higher propensity for bullying and other types of abuse (Haruvi-Lamdan et al., 2018). The intersection of two or more marginalised identities, in this case Autistic and female, therefore, places such individuals at a considerable risk for the development of the disorder, and studies have indicated that Autistic females are more likely to suffer trauma and subsequent post-traumatic stress symptoms than their male peers (Haruvi-Lamdan et al., 2020). Moreover, research into autism and PTSD is still in its infancy with regard to the prevalence of PTSD in the Autistic population and its effect on Autistic lives. Information derived from studies conducted with neurotypical individuals (such as that found within the DSM), therefore, remains the primary source of knowledge in this area, as the specific ways in which PTSD differs in Autistic individuals is, as of yet, largely undetermined.

The DSM-5 categorises symptoms as belonging to one of four categories: A) symptoms of intrusion, B) symptoms of avoidance, C) symptoms associated with negative alternations of cognition and mood, and D) symptoms related to alterations in arousal and reactivity. Although this project seeks to look beyond the standard, medicalised views of mental distress, the construct of PTSD as described in the DSM is useful for understanding the core characteristics of shock trauma shared by most affected individuals, in part to reveal both its utility and its weaknesses, per the views of critical feminist theorists like Herman who see the need for a more suitable way of understanding the experiences of women.

#### 4.2.1.1 Symptoms of Intrusion

Each participant articulated having experienced intrusive symptoms, whether they were intrusive thoughts or memories, flashbacks, dissociative episodes, or psychological distress following exposure to reminders of the traumatic event(s). Flashbacks can be defined as an involuntary reliving of the traumatic event(s), whereas dissociative episodes can be seen as a defence mechanism whereby threatening feelings or ideas are separated from the rest of the psyche (a type of extreme compartmentalisation); a person experiencing a dissociative episode might feel disconnected from their body and the world around them and experience a disconnection between their thoughts, identity, consciousness and memory (American Psychological Association, 2022; Mind, 2019; National Alliance on Mental Illness [NAMI], n.d.).

Participant E speaks to her own experiencing of intrusive symptoms following reminders of traumatic events:

*When I was having to sit through that training, all of a sudden, that seemed to trigger all these really classical PTSD symptoms, like, I think I've always had... I've always had trauma responses, but hadn't identified them as that, whereas, that training, as soon as I left, I broke down, like totally... Like, I'd held it all in, all of the suffering, and broke down and then, I just, that was when the kind of, flashbacks and stuff kind of started.*

For some participants, such as those who suffered prolonged developmental trauma rather than shock trauma resulting from a single event, intrusive symptoms were less overt but nonetheless impactful. While the DSM does not recognise trauma resulting from prolonged issues during development, the difficulties described within participant interviews were as equally disempowering as those described within the DSM. For example, Participant D

describes her reaction to having her parents visit, the perpetrators of the emotional neglect and psychological abuse she suffered as a child:

*I had a bad experience lately where they visited for my birthday, and... so, we slotted back into that dynamic and that's why I find aging really difficult. I regress really quickly into this, sort of, mute, tearful and frustrated person.*

The above quotation highlights her own feelings of powerlessness, shifting or “regressing” involuntarily back into the mindset she exhibited at the time of the trauma, falling “mute” and therefore powerless to speak out against her aggressors.

The very nature of intrusive symptoms implies that the recollection of these emotions or memories are involuntary, eliciting a feeling of a loss of control in the afflicted individual; this is distressing in and of itself, however, the re-experiencing of the traumatic memory can also be incredibly painful. Participant C speaks to this phenomenon when asked of their own relationship with trauma, stating:

*It's always there in the back of your mind it's, kind of, this lingering waiting to kind of pounce when you're feeling slightly more emotionally connected...And it never really goes away unless you fully find a way to deal with it, I suppose.*

This statement highlights the powerlessness that is characteristic of psychological trauma, particularly intrusive symptoms; the use of the words “linger”, and “pounce” are incredibly poignant, further emphasising this – giving the illusion of an unsuspecting doe being struck down by the mighty panther lurking inconspicuously in the darkness.

Interestingly, Autistic individuals are also believed to have deficits in autobiographical memory which might further impact trauma-specific memories and self-concept:

Autobiographical memory (AM) is closely linked to the self-concept, and fulfils directive, identity, social and adaptive functions. Individuals with autism spectrum

disorder (ASD) are known to have atypical AM, which may be closely associated with social and communication difficulties. This may result in qualitatively different autobiographical narratives, notably regarding social identity... AM enables the construction and maintenance of a sense of identity and continuity over time (Wantzen et al., 2021, 1).

It is reasonable to postulate then that the intrusive symptoms characteristic of trauma might further impede this autobiographical process, leading to a fragmented sense of self in those afflicted. This is significant as many participants in this study – as will be seen – also articulated issues relating to identity and sense of self prior to beginning therapy. Similarly, seeing as Autistic individuals are prone to intrusive thoughts and ruminative thought processes (Patel et al., 2017; Brenner et al., 2017), it is perhaps unsurprising that the participants in this study articulated experiencing intrusive symptoms. While it is beyond the scope of this study to postulate whether these ruminative tendencies increase the likelihood for intrusive symptoms amongst Autistic individuals, and whether these symptoms further impair autobiographical memory, these could be important areas for future research.

#### **4.2.1.2 Symptoms of Avoidance**

Trying to avoid reminders of the trauma is another core feature of PTSD, and many try to mitigate challenges by withdrawing from certain people or places that remind them of the trauma, distracting themselves with work/hobbies or “emotionally numbing” (i.e. attempting to repress all emotions, even the more positive ones). The U.S. Department of Veteran Affairs (2007) differentiates between emotional avoidance – avoiding thoughts and feelings of a traumatic event – and behavioural avoidance – avoiding reminders of the trauma such as places, people, sounds or smells. This withdrawal from activities and loved ones can result in afflicted individuals feeling isolated and low (NHS, 2021). The social and

communicative difficulties associated with autism might further isolate Autistic individuals following trauma, and having adequate social support is believed to serve as a protective factor for the development of PTSD, something that could possibly be lacking for Autistic individuals even prior to the traumatic events(s) (Maheux and Price, 2016; Moschopoulou et al., 2018).

Perhaps unsurprisingly, intrusive symptoms were closely linked with symptoms of avoidance, which can be seen as an effort to mitigate flashbacks and intrusive thoughts and memories. This can be observed in Participant E's transcribed interview when she describes the phenomenon she refers to as her "Pandora's Box Moment". She states,

*And then I got a job as a part time support worker in an autism support and had to do an on-boarding and, like, training and stuff, ...the child protection training seemed to just like be this pandora's box moment of, like... I think it was just having to sit through a training... like, because... they were describing and chatting about different experiences and using the tag of abuse and things like that... I think my coping strategy, my brain's coping strategy for a lot of things up till then had been total avoidance.*

From the above quotation we can deduce that hearing of instances of abuse and maltreatment in a child protection training context not only brought the participant's traumatic memories to the forefront of her mind, but also enabled her to identify her own adverse experiences as trauma and abuse. Her previous coping strategy, avoidance, was rendered ineffective against the reminders of the abuse and trauma she suffered, leading to a flood of intrusive symptoms. Another characteristic example of avoidance, Participant A describes the repression of memories and her own self-isolation following traumatic events:

*I had extreme memory issues, obviously, I repressed so many memories that I had a type of amnesia, now, and I'd forgotten, not only the memories I was attempting to*

*repress, but so much of the other memories too, you know, just people, events family members, friends...*

She continues:

*...there was a period of about 18 months that I was so... terrified of leaving the house that, I just, I didn't... I didn't step out of my front door for 18 months.*

Perhaps an extreme example of avoidance, Participant A's inability to leave her home could have potentially left her feeling isolated and powerless.

Similarly, Participant C speaks to their need to avoid the location at which their trauma took place and their dilemma in doing so:

*And I find like that's where everything happens so that's where I find a very kind of dramatic place to be, okay, but... I also don't want to not see my gran at the same time, because it's she's... she's really quite old and frail and I don't want to, kind of, miss out on that, but at the same time, pulling myself away from it seems to help... or helps me mentally, anyway.*

From the above quotation we can see that efforts to avoid reminders of traumatic events can result in isolation from loved ones, in this case their elderly grandmother. Comparably, Participant B speaks to her need to evade reminders of her trauma by avoiding returning to the home she shared with her deceased husband:

*... my family banned me from going back to the RAF base where we had lived... because they... they said, "You can't do it. Every time you go back there it's really affecting you and we can tell by your voice and your movements... and all that sort of thing that it is not good for you, so please don't go back there, send us instead."*

While the temptation to avoid reminders of traumatic events is high, doing so often actually hinders recovery from trauma; hence, confronting avoidance behaviours has historically been

a key aspect of exposure therapy in the treatment of PTSD (American Psychological Association, 2017; Rothbaum and Schwartz, 2002).

Self-medicating with drugs and alcohol can also be viewed as symptoms of avoidance, as afflicted individuals may drink, use drugs, or over-eat to avoid feelings and thoughts associated with the trauma; this hypothesis is particularly pertinent to women who have endured various types of abuse (Simons, et. al, 2003). Studies also indicate that women who have endured multiple types of abuse rather than one single type are at an increased risk for addiction behaviours (Simons, et. al, 2003). This would appear to be the case for participant E, who endured physical, sexual, and emotional abuse in childhood and reportedly has suffered with drug and alcohol misuse:

*I had addiction issues, well, a few addiction issues, like, substances and, I guess, actions and things... suicidal ideation and all that stuff... there was a bit of an issue around alcohol, not like full-blown alcoholism but it was not within my control, umm... that was having a negative impact and was definitely drinking way, way, way too much at all the wrong times...*

Similarly, Participant F describes her attempt to avoid sexual encounters following sexual abuse in childhood by over-eating and gaining excess weight:

*I put on a lot of weight and almost did that consciously, umm...and there was a period of time, where I was quite promiscuous, and I was sleeping with different people and having one-night stands and drinking and that kind of stuff.... and I wanted it to stop, and I wanted to be sure that I wasn't going to go down that road anymore, and I wanted only friendships with men and so I almost, on purpose put weight on and put more weight on because, when you're fat, people don't see you as a sexual object, but they will be friends with you, kind of thing, so I was almost taking sex off the table.*

She continues:

*And that was quite a negative thing for me to do, almost like self-harm because I still carry that weight now. That's a lasting effect from when that happened.*

These are each examples of how avoidance symptoms can manifest as substance abuse or “disordered” eating habits in an effort to avoid reminders of the trauma. In situations such as these, the effects of the trauma are likely to be long-lasting, as is evidenced by Participant F’s statement above.

While avoidance symptoms may minimise the possibility for intrusive symptoms, the social isolation that results can hinder trauma recovery, as prolonged social isolation has been identified as detrimental to both physical and mental health (Novotney, 2019). Studies suggest that Autistic women are more likely than their male peers to experience trauma in relation to social encounters (Haruvi-Lamdan et al., 2020) and Autistic individuals (both male and female alike) are more likely than their neurotypical peers to experience social isolation related to social and communicative difficulties (Peterson, 2019). Each of these factors heighten the risk for the increased social isolation of Autistic women following traumatic events and hold implications for their recovery from trauma, as resourcing with people can be an important factor in trauma recovery (Graham, 2020).

I posit that the experiencing of avoidance symptoms is inherently disempowering for Autistic women who have endured trauma, one reason being that the supports and resources available to them, such as social connection with trusted others, are rendered inaccessible. Similarly, some traumatised Autistic women may feel powerless against the influence of drug, alcohol and food addictions, as is evidenced by the statements by participants above.

#### 4.2.1.3 Symptoms Relating to Negative Alterations of Cognition and Mood

The DSM-5 cites feelings of isolation, difficulty experiencing positive emotions, negative affect, negative assumptions about oneself and the world, a lack of interest in activities once enjoyed, and exaggerated blame of oneself for having caused the trauma as evidence of negative alterations in cognition or mood. Each participant involved in this study expressed negative alterations in cognition and mood, be that depression, suicidal ideation, feelings of isolation or chronic low self-esteem.

For many participants who had sustained multiple traumas, particularly in childhood, these negative alterations were present for many years, having become internalised and incorporated into their own beliefs about themselves and their own abilities. A prime example of this is Participant F's articulation of chronic low self-esteem and the ways in which this impacted her studies and career. She states,

*But actually, the impact of the trauma that I experienced as a kid actually led to me having a lack of self-esteem... and... and that has... I mean, I dropped out of university; I didn't even get to go where I wanted to go... and I can look back on it now and see where a lack of confidence, if somebody told me I couldn't do something, I quite often took that as, "Well, I must be rubbish at this. I can't do this." I had some really horrible experiences at university because I was different from them. As a result, dropped out of uni and didn't end up doing what I wanted to do, had to take on a job and I feel like, all my life, up until fairly recently, I've been doing like lower-level jobs than what I probably could.... I didn't have the confidence to sell myself at interviews and things like that, so, ended up in in a care home job which wasn't what I wanted to do. It was low-pay, and it was only part time... I think, probably the biggest impact on me from trauma, is just a lack of self-esteem that goes through everything.*

We can see from the above quotation that both Participant F's childhood trauma and her experience of "otherness" greatly impacted her self-esteem and by extension her experiences at university and within the workforce. Participant E reports similar experiences, and credits her experience of counselling as having helped her overcome these negative responses: "...counselling addressed and worked on so, so many, like, different issues, a wide variety of issues, you know, a lot of different negative responses and things, totally wide-ranging from confidence and self-esteem..."

For other participants, negative alterations in cognition and mood were articulated as depression and suicidal ideation, as is evidenced by Participant A's statement: "*Mentally, I had recurring severe depression and suicidal thoughts which I was... I was diagnosed with depression...chronic depression and put on a series of antidepressants.*"

Interestingly, adequate self-esteem has been shown to prevent depressive symptoms following adverse life events amongst the general population (David et al., 2008), indicating that other participants who reported depressive symptoms may also suffer from low self-esteem, possibly associated with their neurodivergence. David et al. (2008, 735) writes:

Other investigations in student samples have revealed that low self-esteem and a negative attribution style predicted an increase in depressive symptoms in participants who experienced negative life events. For others, the impact of traumatic events manifested as depression and suicidal ideation.

While the study quoted above was not conducted exclusively with Autistic individuals, its findings could have important implications for Autistic women, as Autistic individuals have been shown to display lower self-esteem and higher rates of depression (Cooper et al., 2017). Attribution styles, also called explanatory styles, indicate how an individual explains why they experience a particular event; a negative attribution style indicates that the individual

attributes an event as having happened due to an internal factor, for example, their own perceived shortcomings (Leighton and Terrel, 2020).

Studies have also indicated that individuals with Asperger Syndrome or Level One ASD (AKA “high functioning autism”) may be especially prone to low self-esteem as they are more aware of their own social and communicative differences; this is believed to increase the risk of depressive symptoms (Sterling et. al, 2007). This is significant as Autistic women’s perceived differences and difficulties may influence the ways in which they perceive themselves, as indicated by the quotations above. To this researcher, it seems possible that Autistic women might be more susceptible to negative attribution styles given their own experiences of difference and stigma, increasing the risk of depression and low self-esteem following adverse life events and trauma. To my knowledge, however, there are no studies substantiating this theory to date.

Both low self-esteem and depressive symptoms involve an inherent lack of power and control in the afflicted individual. Hopelessness, for example, can be described as the belief that one will not experience positive emotions or that one’s situation will not improve, and has been linked with depression (Assari and Lankarani, 2016). Bejerholm and Johanson (2017) cite empowerment as being a significant factor in the reduction of depressive symptoms in unemployed individuals with affective disorders, and programmes incorporating opportunities for empowerment have been shown to reduce depressive symptoms in college youths (Hart Abney et al., 2018).

Participant D articulates addressing these negative patterns of thinking as being a significant aspect of her therapy journey, stating: “...*that's what those hourly sessions, bit by bit, are trying to achieve... the counteraction of hours of negative patterns, you know? Where you have a very negative, critical, guilty voice and it's full of shame, and that's very sad.*”

Her expression of shame is also significant as shame is thought to be a risk factor for

depression. Similarly, toxic shame resulting from rejection, blame and abuse (all commonplace for many Autistic individuals) is traumatic in and of itself and can result in a hyper-aroused state of defensiveness or withdrawal and self-isolation (Gates, 2019; Bradshaw, 1988).

#### **4.2.1.4 Symptoms Relating to Alterations in Arousal and Reactivity**

The DSM-5 cites irritability and aggression, risky or destructive behaviour, hypervigilance, a heightened startle reaction, difficulty concentrating and difficulty sleeping as possible symptoms related to arousal and reactivity. This presents a unique challenge in differentiating PTSD symptoms resulting from hyperarousal from symptoms associated with autism, as many of these symptoms are also present in Autistic individuals. For example, irritability and aggression, hypervigilance and a heightened startle reaction can all be attributed to higher rates of anxiety in the Autistic population and sleep disorders such as insomnia are also known to be prevalent (Gara et al., 2020; Robb, 2010; Hohn et al., 2019). Many symptoms associated with other PTSD criteria could also be classified under arousal and reactivity, such as a survivor's propensity to engage in alcohol and drug misuse, an activity that could be viewed as engaging in risk-taking behaviour. Participant B, however, specifically describes this increased reactivity, linking it with amplified mood swings – namely anger and irritability – and disrupted sleep patterns: *“I couldn't... I couldn't sleep properly, and I was dissociating a lot. I was very reactive to things, like, if I wasn't shouting at something, I was crying at something, and if I wasn't doing that, I was just sort of sitting very, very still, staring straight ahead.”* Participant B's shouting, crying and difficulty sleeping can be seen as alterations in arousal and reactivity, while the act of “sitting very still and staring straight ahead” may indicate a dissociative response. Likewise, Participant C

describes the increased hypervigilance and anxiety experienced in response to certain auditory triggers, specifically the sound of a car approaching their home:

*...the therapist that I'm currently seeing had said that they believe I may even have, they said they can't confirm it because they've not got enough experience or they don't want to officially diagnose, but they said I could have some PTSD from it... in the sense that I hear a car door slamming outside my house or a car pulling up and I panic, because I think someone's coming to get me, someone's coming to reprimand me again, even though it's... the time has passed.*

This constant hyperarousal can leave trauma survivors feeling irritable, angry, paranoid and easily startled. For some survivors, it may make gaining restorative rest difficult and result in an inability to concentrate. I, myself, have heard clients equate this hypervigilance with a lack of control over their reactions or mood – evoking a feeling of powerlessness. Thus, learning to regulate the nervous system, characteristic of many trauma-focused somatic therapies, may help to restore survivors' sense of empowerment and control over their bodies and reactions.

#### **4.2.2 Issues Related to Identity and Belonging**

Inherent aspects of psychological and social empowerment include the realisation of one's identity and powers and experiencing a sense of belonging to a wider community (Mandal, 2013, 19; Rolvsjord, 2006). Intriguingly, participants spoke to the phenomenon of feeling as if they did not belong in a variety of contexts as well as identity confusion associated with being Autistic in a predominantly neurotypical world, both of which indicate the felt experience of disempowerment as having been relevant to participants in this study prior to commencing therapy.

Relevant themes articulated by interviewees include masking autism traits, low self-esteem, and people-pleasing or “fawning” behaviours, all of which can be experienced as

disempowering for participants as they deny the affected individual the empowerment of coherent identity and belief in oneself and one's abilities. On the other hand, establishing a sense of belonging with the autism community can be experienced as both psychologically and socially empowering as it gives individuals the opportunity to learn of themselves through connecting with others, build narratives of common experiences, strengthen self-esteem, and, as was evidenced by the participants in this study, identify strengths associated with neurodiversity.

Masking has been described as adopting neurotypical behaviours and hiding autism traits in an effort to avoid stigma and judgement and has been linked with feeling disconnected from one's true identity, feelings of exhaustion, low self-esteem, meltdowns and anxiety (Tabb, 2018; Miller et. al, 2021). Many participants spoke to these sorts of behaviours and their effect on their identity and self-esteem. For example, Participant E speaks to the trauma of not being able to live authentically, and the loss of identity and "voice". This participant actually draws on the term "masking" to give meaning to these symptoms:

*...what is actually Autistic neurology and what is trauma from an Autistic experience of society, which I believe have trauma responses... So, like, all your, sort of, common, societal negative experiences like not being able to be your authentic self... all the stuff that basically leads to masking and things and... like, not fully, authentically sharing or fully, authentically speaking. Things like the negative experiences when you do overtalk or interrupt someone, you know? All of them that build up over a lifetime that lead to people sometimes going the opposite way.*

She continues,

*Like, I'd say I'm one of the Autistic people that used to be hyper... very energetic, very sharing, very, you know, chatty and stuff at times and then also very insular-focused... but then, I would say over time I've lost that, kind of... voice, you know?*

It is logical to imagine how this shift from authentic, energetic sharing to voicelessness has implications for one's sense of identity and personal empowerment. Seeing as psychological empowerment is comprised of positive self-perception, which determines one's perceived ability to take control of one's life and achieve desired outcomes, it is unlikely that individuals who are unable to exercise their voice or live authentically are going to feel psychologically empowered.

The implications of not masking, however, can also be severe. For many, the act of masking is simply an act of survival, and a failure to mask can also have significant consequences. For example, participant A articulates the consequences of not masking and the temptation to hide her authentic self:

*...there were times when I hadn't fully learned how to mask when I was in school, yet, and there were times that I did things that were not socially acceptable... and the consequences were always so severe that I quickly learned to just hide... everything... I would just copy my peers and do what they were doing, say what they were saying, wear what they were wearing, and yeah... just, survival.*

While the failure to mask as a child might have consequences, it would seem the penalties can be just as severe as an adult. Participant F speaks to the consequences of “dropping” her mask and the impact on her relationships:

*So, always being a little bit different... always ended up not getting along with my bosses at work and upsetting important people. I always have been a controversial person despite not wanting to be, despite just wanting to melt into the background a little bit, there always ends up being a controversy, because I do or say something that I now understand to be, like, the mask dropping, kind of thing... and looking back, I can see, I can begin to understand that yeah, okay, people were picking up*

*some kind of difference and I also now can see that I was a lot more vulnerable than I thought I was at the time.*

From the above quotation we can get a sense of the powerlessness experienced by many Autistic women when their natural way of being and relating to others is not well-received (in this case leading to the destruction of relationships) leading to the temptation to mask one's authentic way of being. For many Autistic women, efforts to reduce masking and regain a positive sense of identity begins with an autism diagnosis and identifying with the autism community, a point that will be further explored in subsequent sections of this thesis.

While many Autistic individuals, particularly women, speak to identity confusion prior to their autism diagnosis or self-diagnosis, alienation from oneself can also be a result of having sustained psychological trauma, particularly relational trauma in childhood, as Janina Fisher (2017, 19) explains:

In the face of abuse and neglect, especially at the hands of those they love, children need enough psychological distance from what is happening to avoid being overwhelmed and survive psychologically intact. Preserving some modicum of self-esteem, attachment to family, and hope for the future requires victims disconnect from what has happened, doubt or disremember their experience, and disown the “bad [victim] child” to whom it happened to as “not me.”

This compartmentalisation or fragmentation of the self can be seen as a defence mechanism employed when survivors have suffered childhood abuse.

While some participants might have experienced fragmentation of their selves in the face of childhood trauma and abuse, the identity confusion expressed by participants in this study was specific to their neurodivergence, with autism diagnosis or self-diagnosis being crucial to its resolution. For example, Participant B speaks to the clarity experienced when receiving her autism diagnosis:

**Participant B:** *It was like being given a gift... it was... it's like, and I don't know if you wear glasses?*

**Cloie Parfitt:** *I do.*

**Participant B:** *You know that first pair of glasses you get, and you put them on and think, "Oh my God, I've missed all these details... I've been walking around totally unaware of these little bits and those little bits..."?*

**Cloie Parfitt:** *Yeah!*

**Participant B:** *And that's what it was like when she said, "Yeah, yeah, you are Autistic," and suddenly, I thought, it all makes sense... Everything about me that I never understood, suddenly, has come into focus.*

**Cloie Parfitt:** *Wow, that's a brilliant analogy [participant's name] I do, I know that feeling well of suddenly seeing individual leaves on trees.*

**Participant B:** *Yeah! Yeah, it really was like that, like someone had given me a pair of glasses for myself almost...and yeah, everything just came into focus and became a lot easier to discern.*

The analogy of being given a pair of glasses for oneself is a poignant one, and I imagine many Autistic women would resonate with this.

In her award-winning book, *Aspergirls*, Rudy Simone (2010, 63) speaks to the identity confusion that is all too common for Autistic girls and women:

It's not just gender identity that we may struggle with – it's identity in general. It does seem to be a trend, for some of us, to have a changeable personality either based on our current role model, or changing interests... Are we just impressionable or are we true chameleons?

Interestingly, Participant A speaks to this "chameleon effect," highlighting her propensity towards taking on the interests and preferences of those around her:

*...also completely forgot myself, I had no sense of identity. At the time, I was very much a chameleon and I think that it's only now it's become clear, after the PTSD has been resolved, that this is not just a result of PTSD and having a lack of identity, it also ties in with the whole being Autistic and wanting to fit in... in that I was a chameleon....I would find out subconsciously what a person wanted from me, and I would then take on that role. And if you'd asked me at the time what my favourite food, flowers, music, anything was, I wouldn't have been able to tell you... it was, whatever the person I was trying to make like me wanted if they liked something, I did... so on and so forth...*

Extreme people-pleasing behaviours such as this have often been described as “fawning”, the fourth response to perceived threats (the remaining three being the classic “fight”, “flight” and “freeze”). Articulated first by psychotherapist and well-known author Pete Walker, the fawn response arises out of a need to avoid conflict and results in the individual appeasing others and resorting to extreme “people pleasing” behaviours (Schwartz, 2021; Walker, 2003). Trauma expert Arielle Schwartz (2021) describes this fawning response as the abandoning of the self to attend to the needs of others, disconnecting from one’s own emotions, and needs. She cites growing up with parents or guardians who are controlling, withholding or abusive and being denied a healthy emotional environment as likely causes for the development of this response.

Tony Attwood, a British psychologist best known for his work surrounding Asperger Syndrome, speaks to this phenomenon in a private conversation I held with him earlier this year, suggesting another motivation for these people pleasing behaviours in Autistic women. He states:

So, for that individual, they don't want to create something that could break the relationship. They want to do everything to be good, happy, and wanting to connect.

And they'll be very flexible and accommodating. But can I suggest another dimension that needs to be explored? And that is the extraordinary sensitivity, especially for Autistic women of negative mood in other people.

He continues:

So, there can be a determination to make people happy because of the negativity there, but there isn't a barrier to it... there's a sensitivity, an oversensitivity. There's no skin for protection of negative emotion in others. And so when other people have that negative mood, it's really quite aversive for the autistic person. So they do whatever they can and it can be appeasing and pleasing other people to make them happy again (T. Attwood, personal communication, February 17, 2022).

So, while these fawning behaviours may well result from sustained emotional abuse in childhood, these behaviours may also be employed in an effort to connect and be accepted by others – a need that is likely fuelled by the sustained rejection and invalidation experienced by Autistic women. Likewise, Autistic women's increased sensitivity to the emotions of others may serve as a further motivation for this response as Attwood suggests above.

Having experienced sustained emotional neglect from her own parents, Participant D expresses her own tendency to adapt to other's needs while suppressing her own, a classic example of people-pleasing or fawning behaviours:

*I think I don't understand everything about trauma, but one of the biggest things about it, which for me is very real, is how much I adapt to other people before knowing what I want. I feel like very... fluid it in that sense, like I'm accommodating, and I also pick up on so many cues... I'm very vigilant about, like, intonation and body language and... and not wanting to provoke people... I just feel like I adjust myself to others – people-pleasing, masking... behaviour where I shrink.*

She continues:

*You know, like, you call someone and say, “I’ve got something on my mind” and then ends up being what they’ve got on their mind, you know, that kind of thing... you’re like, I can put myself to the bottom of the pile... That comes from low self-esteem, constantly being made to feel like a failure or inadequate, or things like that. It comes from, like, unrealistic expectations and, I think, denying who I actually was, versus who they wanted.*

These “unrealistic expectations” imposed on her by others and the denial of her true self can each be viewed as adverse consequences to identity characteristic of being Autistic in a neurotypical world. The answer to these difficulties, it would seem, is the self-discovery inherent to the counselling process, identifying with the autism community and achieving a sense of belonging, and regaining a sense of autonomy and control over one’s life – all of which were articulated within participants’ perceived benefits of therapy.

The concerns surrounding identity and belonging described above substantiate the relevance of social and psychological empowerment in Autistic women’s recovery from trauma. While the issues related to identity and belonging articulated above as well as the symptoms associated with PTSD are significantly disempowering for survivors, the self-discovery inherent to the therapy process is likely to promote both social and psychological empowerment in Autistic women, as will be explained further when exploring participants’ perceived benefits of therapy. Unfortunately, the disempowerment of Autistic women is not exclusive to their traumatic experiences; indeed, many Autistic women appear to face further disempowerment when attempting to access trauma-specific support, a point that will be explored further below.

### **4.3 Identified Barriers to Accessing Appropriate Support**

There were three key barriers to accessing appropriate mental health support following traumatic experiences articulated by participants including invalidation by medical and mental health professionals, a lack of autism awareness, including autism stigma and other misconceptions, and participants being offered inappropriate or inadequate support, most often by the NHS. Each of these factors contributed in various ways to the disempowerment of traumatised Autistic women by further invalidating their concerns, dismissing associated pain and suffering, and failing to provide appropriate support, heightening feelings of inadequacy and helplessness. Likewise, each contributed to the delay in accessing appropriate support and will be explained fully below within the context of empowerment below.

#### **4.3.1 Disbelief and Invalidation by Professionals and Others**

Many participants articulated having been invalidated by medical and mental health professionals throughout their lives both prior to and following their autism diagnosis. For some participants, the source of this invalidation was deeply personal, and the perpetrators were those closest to the individual. For many, however, this chronic invalidation was less overt, and was experienced at a visceral level by society at large. A striking example of having one's experiences discounted and dismissed, Participant A describes how a medical doctor dismissed her mental distress, indicating she was seeking attention. She states,

*...my GP and my husband decided I was just looking for attention.... I wanted to sue that GP so badly because I went to him repeatedly asking for help, and I was saying that... I was having difficulties and it wasn't just depression, I was... really struggling. And he just... basically, decided, I was... a hypochondriac and he wasn't going to treat me.*

Interestingly, many Autistic women share experiences of being labelled as a hypochondriac and being denied adequate medical treatment. Autistic author and comedian Sara Gibbs (2021, 10) speaks to this, writing:

Worse, imagine that while you're struggling with extreme sensory sensitivities, muscle weakness, exhaustion, food aversions and a whole other laundry list of physical difficulties, you're being told that you're putting it all on for attention and are often scolded about how you really should be able to do these basic things.

A moving quotation, Gibb's words speak to the pain that is inherent to having one's experiences and suffering dismissed and invalidated, as well as the physical suffering that often accompanies autism - the pain of which I myself know too well. The question must be asked, if medical professionals are so quick to dismiss physical ailments in Autistic women, how likely are they to elevate mental health difficulties? Moreover, what if the source of such invalidation is the mental health professionals themselves? Unfortunately, this was the case for Participant A who, upon finally receiving mental health support was further invalidated by the very individual who was meant to provide support. She states,

*She... she'd had enough. She didn't want to do much more of that, but also because she herself had very limited time in which to do the therapy. This is a big problem I have with the NHS. They give you a limited period of time in which to get therapy, which is putting a time limit on something that should not have a time limit. It takes as long as it takes for you to be treated, and she was obviously feeling the pressures of that time limit, because she never came out and said, "You need to not stop because I don't have enough time to treat you," but she was very... You know the little gestures people make when they're impatient... little facial expressions, little tics? Like lifting the hand subconsciously to say, "stop." You know, it was like that.*

Upon being asked how this made her feel, Participant A continues,

*I immediately want to curl up into a little ball inside. I just... curl up inside myself defensively, I suppose, because... I'm being told that I'm wasting her time... that I'm taking up too much of her time... And it certainly didn't make me feel good... it didn't make me trust her. And... and it did make me stop. I had so much more to say, you know, but...yeah, I stopped.*

The above quotations are powerful examples of the sheer power of invalidation, and its ability to rob individuals of their voice. Likewise, it is easy to see how invalidation within therapy is extremely detrimental to the therapeutic relationship, and the importance of validating one's experiences and emotions within the therapeutic space, particularly for those who have been chronically invalidated by their environment.

For one participant, the source of such invalidation were her own parents who blatantly ignored her pain and suffering for many years. Interestingly, this invalidation appeared to have been internalised, resulting in the dismissal of her own pain and her reluctance to access mental health support. The chronic invalidation experienced from society is likely to have only solidified these feelings. When speaking to her decision to commence therapy, Participant D states:

*I felt very ashamed to be needing.... yeah, like I said, "there's more serious things," like, I don't know. That's how I saw it for so long...*

She continues,

*I guess it comes from, like, people seeing me really upset and distraught and not being affected by it... like, you cry yourself to sleep as a child, you know? Things not really being acknowledged is how you end up... you just don't acknowledge it later... if it wasn't prioritised, if it didn't make the cut for people who apparently love you most... if they aren't concerned then why should you give yourself that concern?*

Instances of invalidation such as those articulated above are likely to be experienced as significantly disempowering as they are likely to result in the distrust of one's own perceptions and experiences (Ferguson, 2022), leading to a lack of confidence in oneself and one's abilities. Being consistently ignored and invalidated is also likely to result in the distrust of one's authentic emotions and reactions, which could lead to the heightened compulsion to mask such reactions. As was articulated previously, such masking has negative implications on one's sense of identity and belonging. Furthermore, as is evidenced from this study, the combination of autism diagnosis or self-diagnosis and effective therapy, within which the client feels validated and valued, is the antidote to such sustained invalidation.

Unfortunately, many Autistic women experience further invalidation when disclosing their autism diagnosis, and this is likely to result from misconceptions of autism and autism stigma, a topic which will be further explored in subsequent paragraphs. Participant D speaks to her own experience of disclosing her autism diagnosis and the further invalidation that resulted:

*I was told I was being, like, a bit of a diva when I disclosed.... I think I just was like, I might have... I might have told my flat that that's what my therapist said in the first session and then people sort of alluded to me, like, gathering problems and that being my next one after Brexit [laughing]... and it just felt really... it was negative, it was toxic, like, people being like, "You can't be that, you're this and that..."*

I proffer that the invalidation that often results from one's autism disclosure being dismissed or disbelieved is likely to result from incorrect perceptions of autism, those derived from male-centric presentations, and autism stigma. Such representations of autism are likely to contribute to the underdiagnosis of autism in women and girls and may lead to the dismissal of genuine complaints by Autistic women. Similarly, autism stigma itself can be viewed as a form of invalidation as individuals may be discredited and dismissed due to a distinguishing

characteristic or quality (Mayo Foundation for Medical Education and Research, 2017), in this instance the social and communicative differences associated with autism.

As we can see from the examples outlined above, invalidation by medical and mental health professionals considerably impacts an individual's ability to both access and engage with support. Likewise, repeated experiences of having one's emotions ignored or dismissed can lead to a lack of trust in one's authentic reactions and a failure to identify a need for said support. In this regard, chronic invalidation by both professionals and trusted others serves as a significant barrier to recovery from psychological trauma.

#### **4.3.2 Inappropriate Support and Lack of Autism Awareness**

Many participants also articulated having been offered support that was incompatible with their needs or being denied support entirely, most often by the NHS. For several participants, this resulted in their seeking of private therapists to meet these needs. For others, a lack of autism awareness by medical and mental health professionals and other stigmatised misconceptions of autism further delayed the process of diagnosis and subsequent support. A striking example of this is Participant A's journey, during which she experienced multiple misdiagnoses before recognising her own neurodiversity and receiving suitable trauma-specific support. Through consistently advocating for her own needs, she was able to gain this support after many years of persevering. She states,

*It was essentially 15 years' worth of saying, "Help me!" and people ignoring me... And then, when I specifically asked, I essentially had to diagnose myself first and then specifically ask for the help I needed... and even then, I wasn't given the support I had asked for. I had asked specifically for someone who had experience in trauma, and I wasn't given that... I had to go through that first and it would have been so easy to give up at that point.*

She continues:

*I feel like more than a decade of my life has been taken away from me because of people just not caring enough to ask the right questions.*

Participant A's experience is not an isolated incident. Indeed, many Autistic individuals articulate similar experiences of being denied appropriate support and studies have confirmed this occurrence (Camm-Crosbie et. al, 2018; Hallet and Crompton, 2018). Moreover, studies have cited a lack of autism awareness by health professionals, problems with accessibility of services, and a lack of appropriate support as potential barriers to accessing support, and these themes were further corroborated by the stories of participants involved with this study (Camm-Crosbie et. al, 2018; Hallet and Crompton, 2018). Experiences such as these can be experienced as disempowering by Autistic individuals who have experienced trauma, as it may serve to further invalidate their experiences and intensify feelings of helplessness. These feelings of hopelessness and helplessness have the potential to amplify feelings of inadequacy and defectiveness commonly reported by Autistic individuals.

Participant C articulates a similar experience, having been offered support that was inconsistent with their needs following a mental health crisis. They state,

*When I started becoming suicidal, I went to the... I went through the NHS system... and... that was...looking back, it's.. it's, it's horrifying but also laughable, umm... Because I went in crisis, to the crisis team, and they basically discharged me the same day, and said that I seemed fine, even though I was displaying suicidal tendencies... And yeah, basically got given a group course of CBT... to do which... sitting there and looking around, the majority of the people there didn't need CBT, they needed an intervention.*

Participant B goes on to describe how they eventually came to receive support from a local charity, but acknowledges the misfortune of those who do not go on to gain appropriate

support and the risks associated with this. Further still, many Autistic individuals report problems utilising cognitive behavioural therapy (CBT) despite various studies showing a reduction in symptoms of anxiety and obsessive-compulsive disorder (OCD) in Autistic individuals (Kose et al, 2017; Lake et al, 2020; Danial and Wood, 2013). Regrettably, CBT is commonly utilised by the NHS and its duration is generally limited to six to twelve sessions. It is possible that any type of therapy with such a time restraint would prove ineffective for Autistic individuals due to differences in emotional processing necessitating the need for a longer stint of therapy than those belonging to the general population (Anderberg et al., 2017). Participant E speaks to this issue, stating:

*...long term processing and work in counselling has improved my life enormously. I went private because what helped me simply isn't available on the NHS, and that is shocking because it's a huge need but also the NHS could save itself so much money by investing in that rather than firefighting people in mental health crisis or physical health issues resulting from poor mental health.*

Longer term processing work, in which one has adequate time to process events in their lives and make meaning from difficult experiences, may better lend itself to the development of one's self-esteem and self-efficacy, affording Autistic women the opportunity to feel empowered and motivated to produce change in other areas of their lives. While CBT may address unhelpful patterns of thinking and behaving, it is not likely to address the root of such issues, in this case the sustained invalidation associated with being neurodivergent in a predominantly neurotypical world, or the long-lasting effects of complex trauma.

Another key factor articulated by previous studies is the occurrence of Autistic people being denied mental health support due to their autism diagnosis or mental health complaints not being taken seriously by health professionals. The question must be asked whether clinicians might have trouble recognising distress in Autistic women as the presentation of

such distress might differ considerably from neurotypical individuals. Indeed, many of the symptoms associated with autism can be mistaken for acute emotional distress, resulting in the wrongful sectioning of Autistic individuals (National Autistic Society, 2022). On the contrary, some Autistic women may have trouble recognising and communicating their distress, which might result in their struggles being discounted or underestimated by professionals, leaving them without adequate support. This was certainly the case for some participants in this study as was articulated by Participant F:

*My experience of having low self-esteem...and... and looking for help, thinking I was really anxious, thinking I was really depressed and looking for help and not really being able to get it, never quite hitting, you know, like... I don't know, never quite hitting the threshold for mental health support through the NHS but still knowing that I needed some kind of support...*

She continues:

*You know, and that's quite a hard thing to come to terms with was, like, there was so much pain, there was so much acting out, there was so much, you know, emotional stuff going on, and nobody... nobody cared and maybe if somebody had, I could have had the diagnosis and understood what was going on before I was bloody 46 like I am now.*

The experience of consistently being denied support despite one's struggles is likely to have further implications on one's mental health and emotional resilience. Certainly, it is perhaps easy to see how this denial of mental health support may further contribute to low self-esteem, with self-esteem being an essential component of psychological empowerment. When Autistic women are denied appropriate support, this may serve to ignite feelings of unworthiness and undermine survivors' sense of competence and control over the events in

their lives. Additionally, the experience of being sectioned against one's will has a similar effect, robbing individuals of their autonomy and freedom.

Closely related to invalidation, stigma refers to unfavourable attributes that discredit individuals, leading them to be viewed as less valuable to society (Turnock et. al, 2022). Individuals who are discredited within society, such as those subjected to stigma, are more likely to experience the invalidation of having one's thoughts and emotions dismissed or ignored. Autism stigma was identified by some participants as having been a barrier to their own diagnosis and acquisition of support, with one participant speaking directly to the ways in which stigma impacted her own experience of therapy and her relationship with the therapist. For other participants, their own stigmatised view of autism may have contributed to the unrecognition of their neurodivergence and their reluctance to identify with the autism community, as was described by Participant A when she states:

*I'm quite ashamed to admit it, but I would look at people who were stereotypically Autistic and think, I do not want to be identified with that...don't want people to look at that and associate me with it.*

Such stigmatised views are likely to impact one's experience of diagnosis, as it emphasises associated "deficits" and undermines strengths. Interestingly, Participant A articulates a shift in her own perceptions of autism upon joining an autism community, emphasising the empowerment that can result from Autistic women taking control over the narratives associated with autism and neurodivergence. She says,

*And I've been able to now get over myself, essentially, and acknowledge that I do have difficulties and disabilities, but I also have strengths and...just because somebody looks stereotypically Autistic doesn't mean they don't have any strengths and that I should respect them just for who they are.*

Therapists therefore should remain curious about the Autistic client's experience of autism and neurodivergence rather than relying solely on the medical establishment's depiction of autism or the representations present within the media.

Intriguingly, Participant E speaks to the presence of stigma and stereotyped associations of autism within the therapeutic space and its ability to negatively impact the therapeutic relationship, stating:

*I do think my main core feeling is that the most... most harmful thing that I've... harmful, or thing I didn't like, has just been other people thinking that they knew, you know, as soon as they hear the fact that you're Autistic... there's just all these assumptions that goes along with it... One example, particularly, comes to mind of that whole empathy thing and... and also the social connection, like, I've spent a lot of time in fully Autistic spaces and the social connections Autistic people make between one another, sometimes, are incredibly intense and way more authentic and sharing than most non-autistic spaces I've been in... Like, some counsellor I knew thought that that was a trait of autism, that people were those type of... you know, they have that Spock idea of things in their head... I just think get any preconceived ideas of what autism is and what Autistic people are out of your head and just learn from the Autistic person themselves.*

The belief that Autistic individuals lack empathy or a desire to connect with others is a common misconception, as Participant E speaks to above. Therapists entering a therapeutic relationship with stigmatised views of autism run the risk of further invalidating Autistic clients and miss the totality of their experience. The solution, as described by Participant E, is to learn from the Autistic individual themselves, checking one's assumptions at the door. Such approaches are likely to be experienced as empowering for Autistic clients as it encourages the client to look beyond the medicalised view of autism and form their own

unique narrative, one that recognises associated strengths and unique capacities, strengthening one's self-esteem and their perceived competence over circumstances in their lives.

In summary, each of the barriers to accessing support articulated by research participants can be seen to exacerbate the disempowerment experienced by traumatised Autistic women. Certainly, being further invalidated by medical and mental health professionals, having one's pain and suffering dismissed, and professionals' own misguided views about autism and neurodiversity can heighten feelings of powerlessness and helplessness and further delay recovery. Interestingly, upon receiving adequate support, participants involved in this study articulate many perceived benefits of therapy as well as qualities that aided the therapeutic process, all of which can be seen to promote empowerment, further corroborating the role of empowerment in Autistic women's recovery from psychological trauma. Each of these expressed qualities will be expanded upon below.

#### **4.4 Perceived Benefits of Therapy**

The benefits of therapy articulated by participants also reflect the significance of empowerment and identity coherence in Autistic women's recovery from trauma and are closely related to the issues identified prior to commencing therapy. Each identified theme is concerned with the self-discovery, achieved sense of belonging, and autonomy inherent to psychological and social empowerment.

A core component of many participants' therapy journey was the recognition of their own neurodiversity, a process which resulted in further self-compassion and identity coherence, and which provided an opportunity for participants to achieve a sense of belonging through identifying with the autism community. For those who received an autism diagnosis or self-diagnosis during the course of therapy, identifying with the autism

community was a crucial element of recovery, strengthening self-acceptance and helping to resolve feelings of isolation.

For most participants in this study, their diagnosis and therapy journeys were closely intertwined, highlighting the significant role therapists are likely to play in Autistic women's route to diagnosis. Speaking personally, the self-reflection and emotional processing inherent to my own counselling training and personal therapy were the precursors to acknowledging my own neurodivergence; similarly, I have worked therapeutically with many women who have gone on to receive an autism diagnosis through the course of therapy. While psychotherapists do not diagnose autism, they are often an integral component to the recognition of one's neurodivergence, particularly for Autistic women who are likely to arrive at therapy searching for a reason behind repeated experiences of feeling dejected and misunderstood.

#### **4.4.1 Self-Compassion and Identity Coherence**

Developing a coherent sense of identity, one characterised by greater understanding of oneself and self-compassion, was a prominent feature of participants' therapy journeys. One participant spoke to the phenomenon of not only creating an identity for herself, but the process of actually "remembering herself," suggesting there were aspects of her identity that had been lost or forgotten. This is relevant from a complex trauma perspective, in which one's identity is "lost" or fragmented but may also speak to the loss of identity subsequent to the masking of one's authentic reactions and fawning reactions articulated by participants at the time of commencing therapy. It seems possible that the social pressures for Autistic women and girls to mask their autism traits from an early age and adopt fawning behaviours may contribute to this phenomenon of an identity lost.

For some participants, both the process of therapy and receiving their autism diagnosis resulted in greater self-understanding and subsequent self-compassion. For example, Participant C speaks to the clarity resulting from recognising their neurodiversity and the ways in which this has resulted in greater understanding of themselves and their differences:

*It certainly helps to be able to look at things and go, “Okay, that's why I do that” or “That's why I think like that,” and not... and not perpetually beat myself up for thinking or feeling certain ways because it's not the norm or what's expected.*

This propensity towards “beating oneself up” for deviating from the norm or failing to meet other’s expectations is likely to have resulted from accumulated experiences of invalidation; similar experiences were articulated by other participants in this study, and I have heard comparable stories from clients within my own psychotherapy practice.

For other participants, the reframing of past adversities was also a significant aspect of the counselling process, resulting in greater self-acceptance and compassion. Participant F states,

*I'm in the process of almost reframing experiences, like, understanding them in a different way... thinking about those experiences and how vulnerable I was as well and as a kid I didn't realize it... I now understand where the neurodiversity kind of came into that as well, being that slightly square peg in a round hole.*

For many, recognising their neurodivergence was an integral factor in resolving the self-blame that is characteristic of trauma, particularly complex trauma and invalidation trauma, both of which can be considered interpersonal in nature (Unthank, 2019). Recognising one’s neurodivergence and reframing experiences with this knowledge allows the individual to realise the ways in which they were vulnerable, alleviating some of the responsibility for adversities, as is evidenced in the above quotations. This process of recognising one’s vulnerability is likely to be an important factor in developing self-

compassion, as it eliminates self-blame and reframes difficult experiences within the context of neurodivergence.

Participant A also speaks to this reframing of experiences and the clarity and relief resulting from identifying her own Autistic traits:

*But then I found a thread on Aspien women and it's like, oh my God, this is me, you know? Tick for tick, every single thing, this is just... me. And it felt like I finally had a reason for all the things that have gone wrong in my life that had been so difficult for me that I always felt like other people have got the memo and, somehow, they forgot to send it to me.*

The accumulated experiences of things being difficult for oneself compared with others is bound to influence one's self-perception, leading to feelings of inadequacy or defectiveness, feelings characteristic to toxic shame. Theologian and counsellor John Bradshaw explored shame thoroughly, differentiating "innate" shame related to healthy humility and "toxic" shame resulting from repeated experiences of rejection, blame and abuse; these experiences oppress us into believing our true selves are defective and flawed (Bradshaw, 1988; Gates, 2019). For Autistic women who are at greater risk of rejection and abuse, toxic shame is likely a common experience. Similarly, repeated experiences of deviating from the norm or failing to meet other's expectations is likely to contribute to feelings of defectiveness characteristic of toxic shame.

Gaining an autism diagnosis or self-diagnosis appears to help alleviate these feelings, encouraging survivors to challenge negative beliefs about oneself and one's abilities, as is evidenced in Participant D's statement:

*I just did everything to hide everything from people because of shame and guilt... it's hard being like, not being sure why you can't reach things when other people can... So, it's been nice not feeling like a total failure as a person, like with therapy and a*

*diagnosis, official or unofficial, is part of chipping away at those narratives that you've built up for so long... and...takes me a really long time to reset some of those thought patterns that have just been looping around for so long.*

The act of reframing experiences and challenging negative beliefs about oneself allows for the development of newer, positive narratives, a process that can be extremely empowering for trauma survivors as it allows for improved self-esteem and an enriched belief in one's ability to take control over one's life, each of which are key components of psychological empowerment. Participant B speaks to this phenomenon of "building herself up" into a more resilient, self-compassionate person following her autism diagnosis and therapy journey, speaking to her newfound confidence in navigating future adversities:

*And going forward, now that I know that about myself, and I feel in a better position, knowing that, to be able to react to it or mitigate for it... if a similar thing happened again, I do feel I'd be in a much better place to be able to deal with it because I understand myself a lot better now... the end of the therapy was the start of my, sort of, personal journey of building myself back up into, maybe a more resilient person, but also a more empathetic, understanding person of myself... it's very empowering, so, I did feel like I'd been beat down to nothing, and I had, because of the therapy, I had a solid foundation to build back up from.*

Participant B's words further highlight the significance of autism diagnosis in the journey towards better understanding oneself and the development of self-compassion. Moreover, her words speak to the empowerment resulting from this self-understanding and her confidence in navigating future hardships – taking control of her life and her own narrative.

#### 4.4.2 Building a Support Network and Achieving a Sense of Belonging

Similarly, participants who reached their autism diagnosis or self-diagnosis throughout the course of therapy or shortly thereafter expressed having attained a sense of belonging after having had the opportunity to connect with other Autistic individuals. This sense of belonging as well as having the opportunity to learn about oneself through connection with others are fundamental aspects of both psychological and social empowerment.

One participant voices,

*...getting to understand myself, having an identity...knowing that I'm Autistic, understanding there's a reason for me being how I am and finding a community... it made a massive difference, it made me despise myself less... it gave me a sense of community... a sense of belonging, something I've never had in my life.*

These feelings of affinity with the autism community are closely related to the identity development spoken to earlier, as it appears to have played a vital role in helping participants accept certain aspects of their experiences and identities that might have previously been a source of shame. For example, participant B speaks to her own experience of learning that other Autistic individuals suffered similar abuse to herself:

*And I did feel for a long time that I was literally the only person in the world it was happening to, but then having joined all the Autistic forums and things on Facebook and Reddit, it seems par for the course, sadly. Just hearing that a lot of other people's experiences are very, very similar.*

Furthermore, inherent to trauma, particularly the complex trauma experienced by many participants in this study, is the development of critical inner voices and negative beliefs about oneself (Mind, 2021; Walker, n.d.). For Autistic women this is likely to be further complicated by the effects of chronic invalidation or invalidation trauma. Participant D

speaks to the power of identifying with other Autistic voices in mitigating these personal attacks on herself having originated out of the adversities she experienced as a child:

*I'm more comfortable applying things that I read on Reddit, that has been a huge source of support... the every-day manifestations of ASD or whatever, neuro-divergence, and that's been really... just all of us bumbling through it, has been nice to read and be part of. It makes me kinder to myself hearing people be kind to themselves; it's just going to take a really long time to balance out all these attacks... whether they're from me or externally.*

These “attacks” on oneself are likely to arise from one’s perceived differences and inadequacies as well as from more overt attacks to one’s personhood from others. Seeing as the medical establishment often frames autism in terms of deficits, connecting with other Autistic individuals is likely to be key in identifying more positive aspects of neurodivergence.

One participant spoke to their sense of relief and liberation resulting from being helped to identify her own strengths by another Autistic woman. This appeared to play a vital role in overcoming a very negative narrative, one originating from childhood, in which the participant viewed their own intellectual abilities in a significantly negative light.

Unfortunately, Autistic women’s intellectual strengths may be hidden by their difficulties, which can leave them feeling insecure about their abilities, despite possessing significant, albeit often atypical, intellectual strengths (Dawson et al., 2007). Participant A states:

*... when [name of professional] assessed me and said that, you know, she believes I'm on the spectrum, she started asking me some questions about some of the things I do, more positive things, I think, that I just assumed everybody else does and... through that, I realized that I have an eidetic memory, which explained quite a few things to me... It also was why I finally decided to take the Mensa (IQ) test and, this is going to*

*sound like humble bragging, but I didn't do the Mensa test because I thought I would pass, I did it because I've had so many people tell me that I was... I'm going to use a horrible word here, but this is because they were using it in relation to me... told me, I was retarded, or stupid, or whatever the case is - variations on the theme... so I grew up believing that I was subpar intellectually and it didn't help that I kept marrying men who reinforced that idea for their own manipulative purposes... So, essentially, I wanted to finally put the question of my IQ to rest. I wanted to at least know that I was average...*

Participant A goes on to express how learning of her unique capacities enabled her to feel more confident within her own abilities, a characteristic that is key to self-esteem and, subsequently, psychological empowerment:

*It's made me feel a lot more self-confident knowing myself, knowing that I have strengths and don't only have weaknesses. I've discovered that I have some superpowers and I have no shame in saying that they are superpowers, because they are.*

This transformation of perceived deficits to “superpowers” is a poignant concept and in many ways represents the shifting from the medicalised view of autism to that of the neurodiversity paradigm, in which “disorders” are increasingly viewed instead as “differences”. Participant A goes on to describe how the empowerment resulting from identifying with the autism community and recognising associated strengths made her more confident in identifying her needs and advocating for these needs to others, a point that leads us nicely into the next identified benefit of therapy, *developing autonomy and self-advocacy*.

#### 4.4.3 Developing Autonomy and Self-Advocacy

Having achieved a sense of autonomy and learning to advocate for one's needs throughout the course of therapy appeared to be a major factor for several participants. This is hardly surprising seeing as this particular population is likely to have had repeated experiences of marginalisation and having their needs consistently ignored by medical and mental health professionals. Moreover, the sense of powerlessness associated with trauma can leave individuals feeling as if they have little control over themselves or their present situation. Participant B speaks to this experience, stating:

*I just didn't feel like any.... I've forgot what the word is, like... autonomy, I felt like I didn't have autonomy over myself and my reactions, let alone, like, the bigger world... Just sort of felt like... yeah, like dust buffeted about in the wind.*

Feeling “like dust buffeted about in the wind” is a powerful metaphor and speaks strongly to the powerlessness and lack of autonomy characteristic of psychological trauma. Participant B goes on to describe the ways in which therapy allowed her to regain a sense of autonomy over herself and her reactions, and also identifies her autism diagnosis as being significant in her taking ownership over and communicating her needs:

*...but then also being diagnosed with autism, though, that was even more solid, you know?... It allowed me to understand myself in a depth and breadth that perhaps I hadn't before, so, I'm a lot more comfortable being me and doing the things I need to do.*

Participant B goes on to identify the setting of personal boundaries as being a significant aspect of this process, stating:

*Yes, setting boundaries or things like...my brother, I'm very close to my brother, and he would say “Look, why are you lining yourself up for this? I can tell looking at you that you're not going to cope with that, so why are you doing it?” And, it was,*

*“Because you have to, because that's what you're supposed to do.” And now I'll just think, actually, “That will cost me more than other people will benefit from it, so I'm not going to do it, and I'm not going to feel bad about not doing it either.”*

This setting of boundaries is likely to be a significant aspect of recovering from trauma, particularly trauma of an interpersonal nature, such as emotional or psychological abuse where personal boundaries are likely to have been lacking (Firestone, 1993; Rose-Junius, 2007). Similarly, setting boundaries and managing expectations of oneself can be an important aspect in managing the sensory sensitivities and exhaustion experienced by many Autistic women. A significant aspect of my own journey has been learning to cater to my own sensitivities and manage the expectations I have of myself, avoiding the temptation to compare myself to and strive to be like others – a process which Participant B also speaks to above when weighing her own expectations of herself with the associated “costs” to her own physical and emotional wellbeing.

Moreover, some participants spoke to the mutuality of the therapeutic relationship and its importance in helping them feel a sense of autonomy within the therapy. This mutuality is particularly empowering as it encourages the participant to become the “expert” in their own experience and highlights their capabilities in taking ownership and responsibility for their lives. Participant D articulates this mutuality and the counsellor’s ability to adapt to her changing needs:

*.... the hard work and stuff together, like, that has such an impact and was so productive and stuff was because it was like a kind of, mutual learning, if that makes sense? So, like a lot of trial and error on both our parts... the way that we did counselling, changed over time...as I've changed and developed my needs or focus or whatever has changed and developed.*

Participant E goes on to describe the autonomy she felt within the therapeutic relationship, incorporating a variety of practices into her therapy journey, each of which helped her to process her own emotions and communicate these emotions to her therapist. She articulates many practices as being essential to her therapy journey, including psychoeducation, writing, drawing, music, and reading – all of which also speak to the importance of individualisation and flexibility when counselling Autistic women, a point that will be further explored in subsequent sections. Furthermore, the therapist’s ability to adapt to the client’s needs is likely to play an important role in the client’s sense of autonomy and self-advocacy as it encourages the client to voice their needs and acknowledges the client as an individual with their own preferences and strengths. This point will be further explored in subsequent sections of this paper, but its importance cannot be understated, particularly with clients whose trauma robbed them of their own autonomy, such as in instances of emotional or psychological abuse.

Two participants articulated previous negative experiences of therapy, both in childhood, in which the clients’ autonomy was not at the forefront of the therapy, further highlighting its importance within the therapeutic alliance. In each of these circumstances, participants were made to attend therapy by authority figures for reasons undetermined by participants. One example is Participant D’s expression of having been made to attend counselling as a teen for issues surrounding school attendance. She states:

*... my first ever experience with counselling as a young person was when I was 16 and they put me in mandatory counselling because I missed a few lessons... They said it was about my identity because my parents were [nationality].. It always just felt really scripted, the whole thing, like, they’d inserted a reason and they were going to solve it and... do you know what I mean? Like, all this strange attention, but never*

*really genuine or addressing you personally, almost, it's all very like performative support and it really put me off...*

The idea of “mandatory counselling” in which the aim of therapy and therapy goals are predetermined by someone other than the client is likely to be experienced as significantly disempowering. Such scenarios deny the client the opportunity to gain confidence through the setting and achieving of therapy goals and acquire self-assurance in their abilities and unique strengths. Equally, an integral aspect of psychological empowerment is one’s locus of control, or how much control an individual feels they have over events in their life (Bandura, 1997; Rolvsjord, 2006). When clients are not involved in decisions concerning them, it is likely to enforce an external locus of control in which the client feels their successes and failures have resulted from external factors beyond their control (Rotter, 1966). Intriguingly, Participant A describes her efforts to exert control when made to attend therapy by her father as a teen:

*Like if, when I wasn't willing to go to therapy, and I was being forced to do it by other people, by my parents or whatever... I didn't want to be there, so I just took the opportunity to run circles around the people who were there to help me... and it started a bit of a trend with me playing games with therapists... because it was just easy to do. To be honest, it was almost fun, and it made me feel in control...*

Participant A’s propensity towards “playing games” with therapists can be seen as an effort to enact control over a situation in which she experienced very little power or autonomy. As is evidenced in the above statement, the client’s autonomy within therapy is a crucial component in, not only promoting a sense of empowerment, but also in establishing the therapeutic alliance. Contrarily, Participant A also articulated an occasion during which her therapist supported her in exercising her autonomy when negotiating treatment with her psychiatrist. She states,

*So, it was great having someone support me like that, you know? They couldn't have forced me, obviously, to take medication, but they could have, again, manipulated or told me that it's really for my own good and infantilized me but they didn't, and it had a lot to do with her having my back.*

This example emphasises the importance of self-advocacy of clients, and the potential need for therapists to support this process when collaborating with medical professionals, particularly when working with marginalised groups.

In conclusion, there were three key benefits of therapy voiced by participants, each of which promote the empowerment of Autistic women. For many Autistic women, their therapy journeys and diagnosis journeys are closely intertwined, the result of which often leads to the development of a more coherent identity characterised by greater self-compassion and self-acceptance. Both diagnosis and the therapeutic process appeared to alleviate self-blame and help dissolve the effects of toxic shame inherent to many Autistic women's experiences. Furthermore, building a support network and developing a sense of belonging with the autism community appeared to have a similar effect, encouraging participants to view their neurodivergence in a different light, emphasising strengths over deficits and providing a feeling of solidarity. Moreover, therapeutic relationships that emphasise clients' autonomy also promote the empowerment of Autistic women, inciting feelings of control over one's life and promoting self-esteem and self-efficacy. Identified qualities that aided the therapeutic process, all of which will be explored below, were equally empowering, again emphasising autonomy and control and encouraging clients' participation within the therapeutic process.

## **4.5 Qualities that Aided the Therapeutic Process**

Participants articulated several qualities that were essential to the forming of a therapeutic bond with their therapist. These were: individualisation and flexibility, transparency, and validation. With the therapeutic alliance having long been established as the key factor in determining the success of therapy regardless of the therapist's theoretical orientation (Lynch, 2012; Ardito and Rabellino, 2011; Arnd-Caddigan, 2012) these factors each hold important implications for the overall success of therapy when counselling Autistic clients. Each of these factors encourage psychological empowerment as they recognise the client as an equal participant in the therapeutic process, acknowledge the client's own knowledge and expertise regarding their own lives, and validate emotions and experiences, all of which have the benefit of promoting self-esteem and self-efficacy, the essential components of psychological empowerment. Such practices serve to restore the client's confidence in themselves and their abilities and resolve feelings of helplessness and powerlessness inherent to psychological trauma.

### **4.5.1 Individualisation and Flexibility**

Perhaps the most significant quality articulated by participants was the therapist's ability to be flexible within the therapeutic process and to tailor the therapy to best meet the client's needs. This is likely to be of particular importance when working with a population for whom social communication and emotional processing might differ from the general population, such as with Autistic women. For example, Participant E speaks to the flexibility of her therapist, who allowed her to write emails between sessions as this was the way in which the participant was best able to engage with therapy. She states,

*We ended up getting a system in place where before each session I would send her an email... a summary of what went on since the last time I saw her... and what I'd want*

*to chat about... she didn't judge me on length or anything like that which was very much appreciated, because I do... I can struggle with condensing stuff, and then, basically, she printed that and would bring it along to each session and then just started the chat from there, which was an enormous, enormous support, like, I don't think I would have made the same progress in counselling without that.*

As evidenced from the above quotation, a simple adjustment such as allowing the client to email between sessions can make a tremendous impact on the client's ability to engage with therapy. Seeing as many Autistic individuals show deficits in processing speed and social communication (Haigh et. al, 2018), it is not unreasonable to postulate that writing might serve as an invaluable method for mitigating these challenges as such practices allow the client to both process and communicate at their own speed. Participant E goes on to describe the ways in which writing after sessions allowed her to express herself more clearly, adding insight into the ways she was feeling within sessions, at which time she was unable to communicate to her therapist.

Interestingly, writing for emotional expression has been shown to improve both physical and mental health and has even been shown to aid in the processing of traumatic events (Smyth, 1998; Foa and Kozak, 1986; Herman, 1992b; van der Hart, Steele, Boon, and Brown, 1993). This may indicate that allowing clients to write in between sessions not only affords the Autistic client another means of expression, but that doing so might actually aid the processing of traumatic memories.

Similarly, many Autistic clients may benefit from using other means of expression in therapy, such as drawing or painting; this is corroborated by the guidelines produced by the National Autistic Society which emphasise allowing Autistic clients to "do something" (i.e., writing, drawing, painting, or pacing) within therapy to increase clients' comfort within sessions. Allowing clients to communicate feelings and emotions in other ways is also an

effective way to mitigate for Autistic clients' difficulties with receptive communication (the ability to understand verbal language and facial expression) and expressive communication (the ability to communicate one's feelings and emotions).

Comparably, Participant F describes the regularity of sessions as being an important adjustment in allowing emotional processing to take place. She states:

*And so, we have our sessions not too close together because I find that they're quite intense and I feel I need a good few weeks after a session to almost process everything and think it through and think where we're going next.*

Allowing for biweekly or even monthly sessions is a simple solution to these associated challenges and gives clients ample time to process thoughts and emotions brought to the surface during sessions. Similarly, Participant E also speaks to the significance of the length of sessions, stating:

*At one-hour sessions by the time I've settled in I'm already clock watching, and then often stop bringing things of big value as we got closer to end in an effort to wind down. It's really limiting...*

The above quotation indicates that flexibility surrounding the length of sessions may also be significant when counselling Autistic clients. Due to differences in emotion regulation and processing speed, it is not unreasonable to presume that some Autistic women may require additional time to ease into the session and explore topics of importance; equally, Autistic women may benefit from having additional time to regulate challenging emotions at the end of sessions.

The National Autistic Society also speak to this issue within their good practice guidelines, highlighting its impact on both the therapeutic relationship and therapy outcomes. They write:

Similarly, having the same therapist, for longer sessions and meeting with them over a longer period, were mentioned as some of the best adaptations a service can make...

Some people need longer sessions to help process all the information, while for some a full session of communicating in a new situation could be overwhelming; it is all down to the individual (Good Practice Guide, n.d.).

The National Autistic Society go on to cite increased engagement with therapy and improved therapy outcomes as potential benefits to remaining flexible regarding session length and duration.

Participant E goes on to describe her therapist's flexibility and adaptability as being one of the most helpful aspects of their therapeutic alliance, highlighting the long-term benefits of making adjustments to session length and duration. They state:

*Yeah, it's that that checking, not having assumptions, just focused on the individual, learning together what's best for that person - all of that stuff. Yeah, and I think the main core things that were helpful from her, I would say... a willingness to adapt, to try different things, to listen when I suggested things, but then also suggesting things herself...*

The therapist's ability to suggest and try different things within the therapy was articulated by several participants as being an important quality of the therapist, as was having the freedom to make suggestions themselves. Interestingly, Participant C speaks to the individualisation characteristic of their own therapy sessions, which is in stark contrast to the support they received from the NHS:

*I think that was... that was the really important thing that I found at [name of organisation] was that it felt like everyone, there saw you as a person. Umm... and not just a, kind of, additional commodity to deal with... it can feel like that a lot of the*

*time, and it certainly felt like that with the NHS, for example, where you're just another box to tick, kind of thing. You're not... they just want to, kind of, get you in, get you out and say, "Okay, that's you. You're done now."*

They continue:

*...that was the main thing, I think, was that they gave plenty of structure and individuality... and treating me as an individual, not as a "one size fits all...here's how we deal with suicide or depression," it was very much, "Okay well, how can we help you specifically and what do you need specifically?"*

Instances such as these can be experienced as significantly disempowering for clients, particularly for those whose needs differ from the general population. Receiving support that is incompatible with one's needs may only amplify feelings of defectiveness and minimise clients' hope for their recovery. On the contrary, the therapist's willingness to adapt to clients' suggestions and needs can be experienced as empowering for clients, as it values the knowledge and expertise clients hold regarding their own lives. Likewise, as stated earlier, allowing clients to communicate in alternative ways might help to bridge the gap between Autistic women's difficulties identifying and describing their internal landscapes (termed "alexithymia") and communicating these internal workings to therapists.

#### **4.5.2 Therapist Transparency**

The therapist's willingness to be transparent regarding the therapeutic process was another important quality articulated by participants; this includes being upfront regarding the stages of therapy, approaches used and, at times, the therapist's own internal workings and experiences. Failing to be transparent about the therapeutic process can be experienced as disempowering to clients as it may amplify feelings of helplessness and a lack of control over one's mental health and recovery from trauma; likewise, a lack of transparency on the part of

the therapist might result in a lack of trust between parties. On the other hand, clear communication and transparency may actually serve to strengthen the therapeutic alliance, as it acknowledges the client as an equal participant and affords them the opportunity to articulate their needs, expectations and challenges. As a prime example of these potential implications, Participant A speaks to the lack of transparency exhibited by former therapists, causing her to feel both manipulated and controlled:

*...I didn't trust her, and she had obviously been trying to manipulate me into that point... You know a lot of therapists they... they have this idea that they have to get you to think something that they believe. And they will prompt you and guide you and prod you in that direction and, for me, it's just extremely obvious.*

This lack of transparency and communication about the therapeutic process is likely to the detriment of the therapeutic relationship as it amplifies the power imbalances often present within the therapeutic relationship in which the therapist is revered as an “expert” tasked with identifying the client’s problem and determining a solution. Such practices may actually serve to exacerbate feelings of powerlessness already inherent to psychological trauma.

Within person-centred therapy, congruence, the therapist’s commitment to being both genuine and authentic within the therapeutic relationship, is considered a necessary condition for enabling therapeutic change. It is this core condition of congruence that enables the development of a trusting relationship between therapist and client – a relationship in which the client feels both valued and accepted (Rogers, 1957). There are two facets of congruence, each of which are imperative for enabling the client’s growth. The first refers to the therapist’s mindful genuineness, personal awareness, and authenticity; the second facet refers to the therapist’s ability to communicate his or her experience to the client (Norcross et al., 2011). Interestingly, congruence within client-therapist relationships has been linked with reduced symptoms in clients, further strengthening Rogers’s hypothesis that congruence is a

vital and necessary condition for promoting therapeutic change (Zilcha-Mano, Snyder, and Silberschatz, 2017). The need for therapist congruence is likely to be amplified for clients, such as Autistic women, who may find it difficult to read nuances within conversation and interpret body language. In such instances, therapists may need to be more overt in communicating these internal workings to clients.

On a similar note, Participant C speaks to the importance of clear communication within the therapeutic alliance, stating:

*... communication was key within that. I never felt left in the dark at any point. It always felt like I was... I was kept in the loop, it wasn't a separation, it didn't feel like a separation thing. It wasn't a me and them, it was an us...*

From the above quotation we can presume that the therapist's clear communication with the client enabled the client to feel not only respected and valued but also better connected with the therapist, as evidenced by the words, "It wasn't a me and them, it was an us..."

Similarly, Participant E speaks to the trust that developed between herself and her therapist through the therapist's honesty and authenticity:

*I think she managed to hit that balance with things as well... managed to build up a bit of trust, as well, like that aspect of trust in that I can trust her to be honest and stuff rather than being like, "Oh, this is some person that I pay just to say whatever the hell they think I want them to say that makes me feel good"... And I think that helps me, therefore, be more authentic as well...*

Each of these examples speak to the power of genuine attunement and authenticity between the therapist and client and the implications of this on the therapeutic alliance. Likewise, the therapist's authenticity gives clients the permission to be authentic as well, as was articulated in the statement above. When Autistic women are enabled to be their authentic selves and are

subsequently accepted for being themselves, it has the added benefit of increasing self-esteem, contributing to psychological empowerment.

The therapist's willingness to be straightforward regarding the therapeutic process was also significant, providing a sense of control and predictability. This is in correspondence with research conducted by the Autistic Mutual Aid Society of Edinburgh (AMASE) cited earlier in this thesis which recommends therapists provide written information about the therapy process to clients, including how therapy works, how therapists can assist clients in achieving change, and what clients could expect from the therapy process. They write:

Anxiety and uncertainty are big parts of the autistic experience. Respondents emphasised the need for certainty around how the counselling would work, what is and isn't okay, what is and isn't expected. Part of knowing the rules is also about the client knowing what they want from counselling. Some respondents also stated that they just didn't know what to say in the sessions, or how to use them. A number of responses talked about the value of the counsellor explaining how counselling worked, what sort of help the counsellor could give and what clients could expect. It was also suggested that it would be helpful to provide this information in written form to clients (Hallett and Kerr, 2020).

The National Autistic Society also speak to this issue, recommending therapists provide written information about the therapy process before the therapy commences; the National Autistic Society also recommend therapists communicate the structure of each session and the process as a whole to help Autistic clients manage uncertainty about the process (Good Practice Guide, n.d.). Participant F speaks to this, identifying the ways in which communicating the structure of the therapy process might help to alleviate associated anxiety:

*... maybe at the start, we could have been a wee bit more structured... I think I would have benefitted from knowing the structure of how we're going to move forward... because it's a fear of things being unknown, especially when you're, kind of, laying yourself bare. It can add a bit to the anxiety of the whole thing.*

Communicating the structure of sessions and the therapeutic process as a whole may help to alleviate anxiety in Autistic women, as Autistic individuals have been shown to have a strong preference for predictability and routine (Goris et. al, 2019). Similarly, given the associated difficulties with social communication, it is understandable that Autistic individuals would show a preference for clear communication and transparency, as it may help to mitigate these challenges.

#### **4.5.3 Validation from the Therapist**

Feeling heard and validated was another common theme identified by participants as being integral to the therapeutic relationship. This is perhaps less than surprising as many participants articulated having been repeatedly invalidated, whether it be by medical professionals, mental health professionals, caregivers, or society at large. Alarming, emotional invalidation has been linked with various psychological concerns, including Borderline Personality Disorder (Linehan, 1993), disordered eating (Haslam, Mountford, Meyer, and Waller, 2008), relationship problems (Selby, Braithwaite, Joiner, and Fincham, 2008), and depressed mood (Krause, Mendelson, and Lynch, 2003; Wright, Crawford, and Del Castillo, 2009) – all of which Autistic individuals are at an increased risk for, thereby strengthening the hypothesis of this thesis that chronic invalidation serves as a pervasive source of trauma for this group.

Contrasting, the validation of one's feelings and experiences can help one to feel understood and valued, experiences that are likely to be lacking in Autistic women who have

suffered trauma, particularly chronic invalidation. Validation can also be experienced as empowering as it can help strengthen an individual's trust in their own perceptions and experiences, increasing self-esteem and confidence in one's abilities, also known as self-efficacy. Participant A speaks to this, highlighting the significance of validation over one's perception of themselves and their belief in their ability to handle adversities:

*And she was also very validating... When I needed her to validate my experiences, my thoughts, she did that, without hesitation... Also, when I told her that I felt weak and pathetic for needing help, she said I'm not weak. Life threw its worst at me time and again but I'm still here, still fighting. That makes me a survivor. That was very important to me - so many times when I felt I couldn't go on or get through whatever was happening, I'd remember her saying that and I would feel that I can survive anything. It gave me faith in myself.*

The above quotation is a powerful one, signifying the influence of validation over one's personal sense of power and resilience. Similarly, Participant D speaks to the importance of therapist validation in helping clients determine the significance of key experiences in their lives, experiences that might have previously been ignored and the feelings associated with these experiences stifled. She voices,

*That understanding is always there. She's like, "no wonder," or "of course," or she'll be visibly upset by something that was out of order and that's been important. It's almost like I'm learning that a little bit, where I'm like, "You're right, it might not feel like a big deal to someone else, but it was everything to me."*

Acknowledging the significance of experiences within one's life is an important step in the processing of emotions associated with these experiences and, ultimately, in recovering from psychological trauma. Moreover, when therapists validate the experiences of clients, clients in turn learn to validate such experiences for themselves.

Interestingly, the therapist's use of validation within sessions has also been linked to an increase in positive affect and improved treatment outcomes in dialectical behaviour therapy (Carson-Wong, Hughes, and Rizvi, 2018). This may indicate that the therapist's use of validation strategies not only combats chronic invalidation but may also serve to improve treatment efficiency. Moreover, the therapist's use of validation has also been linked with increased emotion regulation and the promotion of therapeutic change, an issue that is particularly relevant for Autistic women given their challenges surrounding emotional dysregulation (Carson-Wong, Hughes, and Rizvi, 2018). Studies also indicate that individuals who encounter difficulties regulating emotion are more likely to experience reactive aggression following emotional invalidation than the general population; however, therapist validation has been shown to dramatically reduce reactive aggression for this population, demonstrating the influence of emotional validation over one's emotional affect (Herr et al., 2015).

Intriguingly, many participants also spoke to the therapist's validation of experiences and emotions associated with neurodiversity, and such validation was an important aspect of their therapy journeys. A prime example of this is the clarity experienced by Participant B after voicing her suspicions of autism to her therapist. Upon having these suspicions validated by the therapist, Participant B describes feeling as if previous experiences suddenly made sense, adding validation to these experiences and the emotions associated with them. Similarly, Participant C speaks to the validation they experienced after voicing their speculations to their therapist:

*I suppose that's where going and seeing a therapist specifically about the autism really helped was because it was having someone kind of affirm that and be able to explore that topic...that was certainly validating to have someone go, "Yes, that makes sense and you don't have to feel bad."*

As is evidenced from the above quotation, having autism-centric experiences validated can help clients resolve feelings of defectiveness and inadequacy resulting from experiencing the world differently. Therapists are therefore in a prime position to validate such experiences, helping clients regain confidence in themselves and their abilities, behaviours that are likely to be experienced as psychologically empowering.

#### **4.6 Conclusion**

In this chapter, I have spoken to various themes that originated from the data derived from interviews conducted with research participants. These themes include the difficulties participants arrived at therapy with, barriers experienced by participants to accessing appropriate support, participants' perceived benefits of therapy, and qualities that served to aid the therapeutic process. Each of these themes have been explained within the context of empowerment and its role in participants' recovery from psychological trauma. In summary, each participant articulated some combination of "classic" PTSD symptoms, those pertaining to symptoms of intrusion, avoidance, negative alterations of cognition and mood, and symptoms related to alterations in arousal and reactivity.

However, the responses of participants showed how trauma experienced by Autistic women is not wholly captured by the traditional DSM criteria. This study found that the key aspects of trauma ignored by the traditional medical model relate to empowerment, identity and belonging, which are inherently social and influenced by a range of historical, cultural, and societal factors. This speaks to my recurring criticism of the medical model, in line with other feminist thinkers, that the experiences of Autistic women are not adequately heard, and their needs not adequately met, due to their position as a marginalised group in society that experience the compounding disadvantages of intersectionality.

When trauma is viewed as the absence of power, in which one entity has control over the victim, it follows that empowerment is an important feature of recovery. However, the very symptoms of experiencing trauma are themselves disempowering in nature, further exacerbating the difficulties faced. For example, individuals who have suffered trauma often engage in exaggerated self-blame leading to low self-esteem, and symptoms such as flashbacks and dissociative episodes can rob individuals of their autonomy and control over their reactions.

Similarly, participants articulated difficulties related to identity and belonging prior to commencing therapy, the effects of which can be experienced as disempowering as they rob afflicted individuals of the benefit of cohesive identity and belief in oneself and one's abilities. The barriers to accessing appropriate support were equally disempowering, including chronic invalidation by professionals, autism stigma and other misconceptions prevalent within the mental health professions, and having been offered inappropriate or inadequate support. These barriers run the risk of robbing women of their voice, further delaying autism diagnosis and subsequent support, and further contributing to feelings of helplessness and shame characteristic of trauma. The antidote to the issues articulated by participants is a therapeutic alliance in which one feels empowered, both socially and psychologically.

Participants' perceived benefits of therapy further corroborate this theory with self-compassion, identity coherence, autonomy and self-advocacy, and locating a sense of belonging articulated as being integral to the therapeutic process, all of which serve to promote both psychological and social empowerment through the strengthening of social relationships, building of self-confidence and self-esteem, and reinforcing feelings of competence and control over one's life.

Finally, the qualities that were articulated by participants having aided the therapeutic process, namely individualisation and flexibility, therapist transparency, and validation - also serve to foster empowerment as the combination of these qualities acknowledge clients as equal participants in the therapeutic process, recognise clients' unique knowledge and expertise, provide structure and predictability, foster self-esteem, and counteract the effects of chronic invalidation so common for Autistic women. These findings have important implications for therapists working with Autistic women for whom trauma, including chronic invalidation, is commonplace. Such client groups are likely to benefit from therapeutic practices that foster social and psychological empowerment, such as the practices dictated above.

# Chapter Five: Conclusions

## 5.1 Implications for Practitioners

Therapists working with traumatised Autistic women are afforded a unique opportunity to facilitate the empowerment process for this population through a variety of practices, the results of which may aid Autistic women in their recovery from the effects of psychological trauma. First and foremost, it is of vital importance that therapists working with this population remain cognisant of the high incidence of trauma amongst this population and the effects of recurrent trauma and chronic invalidation on one's sense of autonomy and control over one's life. Therapists working with this population should, therefore, remain transparent about the therapy process and enable the client's decision-making within this process as much as possible. Such practices provide the client with a sense of autonomy and sets the stage for decision making in other areas of life, promoting self-efficacy and confidence. Additionally, facilitating clients' decision-making within the therapy process both acknowledges and values the client's own knowledge and expertise regarding their own health and wellbeing.

Moreover, therapists working with this population should be willing to remain flexible with their approach as much as possible, making allowances for differences in emotional processing and social communication. A fantastic example of this is Participant E's experience of therapy within which her therapist allowed her to write emails between sessions, allowing her additional time to process her emotions and communicate her thoughts and feelings. Similarly, therapists may need to be flexible regarding the regularity of sessions and session length to best promote emotional processing and therapeutic change. Crucially, therapists should work together with clients to determine what works best, facilitating an open dialogue at every stage of the therapy process.

A key theme identified within this research project was that therapists working with traumatised Autistic women should remain cognisant of the potential for difficulties surrounding identity and belonging. While trauma holds the potential to destabilise existing identity, this process is likely further complicated for Autistic women due to the temptation to mask one's authentic way of being, potentially disrupting identity development and leading to issues related to identity and belonging. The fawning response to trauma may further inhibit this process, leading to extreme people pleasing behaviours and the suppression of one's own needs and desires. Further still, the often delayed diagnosis of Autistic women and girls prevents individuals from recognising what could be considered significant aspects of one's identity and robbing them of the opportunity to connect with individuals who share this way of experiencing the world.

Therapists are in prime position to facilitate the exploration of strengths and unique abilities associated with neurodivergence, allowing for the development of an identity that is not characterised exclusively by deficits. Likewise, helping clients identify strengths and capacities to take control over their lives can be considered psychologically empowering, and it is this sense of control that is often lacking following traumatic events. Encouraging participation in the autism community may further assist the recovery process as social connection has been identified as a key resource for overcoming trauma and associated sequelae (Maheux and Price, 2016; Moschopoulou et al., 2018). This connection with others can be considered to promote social empowerment and provide a community within which an individual can thrive and grow (Mandal, 2013, 19).

There are many organisations offering both virtual and in-person meet-ups as well as informational talks and courses addressing key issues for this population. Examples include the National Autistic Society, the Scottish Women's Autism Network (SWAN), Autism Anglia and the Autistic Girls' Network. Online forums and communities, such as the

Facebook groups from which participants for this study were recruited, also remain a valuable resource for connection and promoting issues for advocacy and speaking out.

Moreover, for many participants in this study, their diagnosis and therapy journeys were closely intertwined, possibly indicating that the onset of trauma-related symptoms was the catalyst for the recognition of their Autistic traits and the diagnostic process. Therapists should therefore remain open to exploring neurodivergence within the counselling room and familiarise themselves with autism traits in females, an area that is still very much under exploration. This illustrates why materials produced by Autistic females remain a vital source of knowledge regarding autism traits in females. An example of this is Autistic author Samantha Craft's 'Autistic Traits Checklist' detailing both strengths and limitations associated with being an Autistic female (Craft, 2016). Ultimately, however, therapists should remain curious about the client's own experience of autism and neurodivergence, not allowing themselves to be limited by any preconceived notions or ideas. This is particularly important when working with Autistic women, as many individuals' conceptualisations of autism are likely to be largely influenced by the male-centric representations of autism that have largely dominated both existing research and the media.

Further still, therapists working with this population should remain cognisant of the potential for the experiencing of chronic invalidation, be it from the medical community or society at large. This experience can be traumatic in and of itself, and it is of vital importance that therapists do not subject clients to further invalidation by undermining clients' experiences. This is of particular importance as the types of events experienced as traumatic by Autistic individuals may differ considerably from the general population, with bullying, bereavement, and even, in some cases, experiences of psychotherapy, being experienced as traumatic by this population (Rumball et al., 2020). Therapists working with this population should not underestimate the power of validating a person's experiences and the effect this

can have on that person's trust in their own perceptions and experiences, ultimately helping to increase self-esteem and confidence and laying the foundation for psychological empowerment.

## **5.2 Strengths and Limitations**

The first study to examine Autistic women's experiential accounts of trauma therapy, this thesis contributes to the limited knowledge regarding how Autistic women experience trauma and trauma therapy and provides recommendations for best practice for counsellors and psychotherapists working with this client group. It reveals the ways in which empowerment and disempowerment impact Autistic women's recovery from psychological trauma and their experience of the counselling process. This study explores the perceptions and accounts of Autistic women through semi-structured interviewing which allows the researcher to seek further explanation or clarify the answers by probing or prompting questions (Thomas, 2013).

It brought together co-researchers who had experiences relevant to the study, and the capacity and willingness to share their thoughts and stories. The interviews also provided opportunities for Autistic women to share their stories, to feel valued, and to make their experiences meaningful to themselves and others with similar experiences.

Moreover, this study's findings contribute to existing literature in the field, corroborating the guidelines produced by the National Autistic Society (n.d.) cited earlier in this thesis which emphasise the need for clear communication and transparency, flexibility of approach, and collaboration with the Autistic client. Similarly, the emphasis of this thesis on the therapist's validation of the Autistic client's experiences closely mirrors conclusions drawn from Hallet and Kerr's (2020) earlier study emphasising the importance of therapist validation when working therapeutically with Autistic clients. Finally, this study corroborates Camm-Crosbie and colleagues' (2018) study emphasising the role of both invalidation and a

lack of autism awareness and knowledge amongst practitioners as a significant barrier to Autistic individuals accessing appropriate support.

While this study's findings share many similarities with earlier studies, its emphasis on the role of identity distress in Autistic women's recovery from psychological trauma is unique to this thesis. Similarly, this study contributes to knowledge discourse by acknowledging Autistic women as a marginalised group who experience unique experiences of oppression, shining a light on the power differentials within therapeutic relationships and how therapists and the wider system can contribute to the empowerment or disempowerment of Autistic women, challenging psychiatry's perception of autism and associated "deficits", and acknowledging invalidation as a unique source of trauma amongst this population. This study also illuminates the ways in which socio-historical inequality impacts recovery from psychological trauma, holding implications for other marginalised groups.

There are several limitations to this study which must be considered when interpreting the findings, however. One limitation relates to large parts of the research process being conducted by the primary researcher alone, leaving the findings vulnerable to my own subjective views and interpretations. However, the decision to exclude advisory members from conducting interviews, transcribing interviews, and completing open and focused coding was made due to significant time restrictions for this project's completion and the limited availability of advisory board members. Moreover, the ethical approval process inherent to conducting research within academic institutions necessitated that some elements of research design be decided prior to community collaboration. Future research would benefit from having more researchers involved at all stages of the research process from start to completion.

Given the nature of the phenomenon this research sought to explore, this study included a relatively small sample size, interviewing six participants in total. This was to

allow space for a deeper exploration into the lived experiences of participants, favouring depth over breadth. While research findings likely hold implications for the population this research concerns, broader claims about the applicability of the study findings should, therefore, be held tentatively. Furthermore, while participants were asked specifically about the therapist's theoretical orientation, most were unable to comment on the type of therapy they received. Likewise, participants in this study were not asked how they engaged in counselling; therefore, we are unable to identify whether the medium (face-to-face, via webcam, or telephone) impacted the participants' experiences of therapy.

At the time of writing, findings derived from this research have yet to be disseminated and promoted amongst the wider community to promote social change – the all-important “action” component of participatory action research. However, plans are under way to distribute these findings, and it has been suggested by board members that guidelines be produced to guide practitioners working with this unique population. It has also been suggested that our findings be included within relevant journals and promoted at conferences, and we have approached several national bodies, including the National Autistic Society and the British Association for Counselling and Psychotherapy (BACP), regarding our research and its wider relevance to members. In the coming months, I will be presenting this study's findings to both the London and South Maudsley Trust and members of the Autistic Girls' Network. Plans are also underway to develop a course aimed at therapists working with traumatised Autistic women with an emphasis on empowerment practices and tailoring the therapy process to best promote client engagement in the therapeutic process and, ultimately, recovery from trauma and traumatic stress.

Finally, this study was specific to Great Britain, with participants residing in both England and Scotland. As conceptualisations of autism are similar throughout the Western World along with current therapeutic approaches to addressing trauma and traumatic stress,

this study holds relevance to other geographic areas, such as the United States, Canada, Australia, New Zealand, and parts of Europe. However, this study is likely to be less relevant in areas with different conceptualisations of autism or for whom current therapeutic practices for trauma and traumatic stress differ, requiring a much broader study to derive conclusions applicable at a global level.

### **5.3 Research Significance and Recommendations for Future Research**

To date there have been a surprising lack of enquiries into Autistic individuals' subjective experiences of trauma, with the current research literature focusing primarily on the shared underlying mechanisms between autism and PTSD, the ways in which the features of autism may predispose Autistic individuals to both traumatic events and traumatic sequelae, and the ways in which core features of autism may inhibit the processing of trauma.

The research presented here represents an important development in the field, having explored for the first time the subjective experiences of trauma and trauma therapy amongst Autistic women. The overall aim of this research was to gain insight into Autistic women's experiences of trauma and trauma therapy to better inform practitioners regarding best practice when working with this population. While there is existing guidance on the ways to best support Autistic individuals, this guidance is primarily behaviour-based with an extraordinary lack of guidance available to practitioners working from other traditions, such as those originating from the humanistic school of thought. To date there is no guidance available to practitioners working with traumatised Autistic women specifically, a population who, as current research suggests, are at an increased risk for traumatic experiences compared with their male counterparts. The findings presented within this thesis provide a "jumping off point" for practitioners endeavouring to work with traumatised Autistic women, with the facilitation of the empowerment process at the forefront.

There is a demonstrable need for future research that builds on the learning from this study. For example, there is scope to further illuminate the findings of this thesis with the experiences of therapists working with this population already, to understand the extent to which they apply the recommendations highlighted in this thesis and whether those recommendations have proven to be effective or not. Further, it would be beneficial to ascertain if the theory that has developed through this thesis, namely that identity and empowerment are central to Autistic women's recovery from trauma, holds true when studying a larger sample of Autistic women who have suffered trauma, or whether such a study will identify points of difference to explore further.

I am extremely grateful to participants and board members, who through their participation have shown that it is possible for the experiences, needs and voices of Autistic women to be front and centre in research about this group, supporting their empowerment and recovery from trauma. My hope is that this research sets a precedent in terms of both content, i.e. the focus on experiences of Autistic women who have suffered trauma, and in terms of methodology, i.e. trusting Autistic women themselves to provide insights into their experiences of trauma and counselling, and their view of what they need from counselling and psychotherapy. As seen through this research, a multitude of complex barriers exist for this group to experience mental wellbeing and empowerment, however, there are clear steps therapists can take to meaningfully support these individuals in breaking through those barriers and facilitating their recovery from psychological trauma.

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# Appendix I

## Participant Information Sheet

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### ***“On the Spectrum and in the Room: Exploring Experiences of Trauma-Related Mental Health Support Among Autistic Women”***

This is a participatory action research project that will explore autistic women’s experiences of receiving mental health support for issues related to trauma/traumatic stress.

#### **About the Researcher:**

My name is Cloie Parfitt and I am a Counselling student at the University of Edinburgh. I have lots of personal and professional experience around mental health and neurodiversity and this is something I am very passionate about. I am completing this research project as part of my doctorate degree, and I hope to develop this research further in the future.

I will be working closely with an advisory board formed of Autistic women and professionals with experience in autism throughout this project.

#### **Why have I been invited?**

You have been invited to take part in this research project because you are a member of the “Autistic Women Support Group”, “Neurodiversity Affirmative Therapists”, “Women with Autism Authentically” and/or the “Counsellors Working with Neurodivergence” Facebook community groups.

#### **What will happen if I take part?**

If you decide to take part in this research, you will be asked to an interview with myself, Cloie Parfitt, by Zoom (video or audio) or by chat, if you prefer this. The interview will last about 1 hour. You will be asked questions related to your experiences of receiving mental health support for mental health issues related to trauma and traumatic stress.

You will also be invited to attend a group interview by Zoom (by video or audio only, depending on what you’re comfortable with) where you can explore this topic with other participants. However, this is **not required** and you do not have to participate in the group interview to be involved in this project. You can, however, choose to *only* participate in the group interview if you would find this easier.

You will receive a copy of 1:1 interview and/or group interview topics one week before your interview so you know what to expect. You may also add any topics/questions you feel are relevant that haven’t been addressed and return this to me prior to your 1:1 interview. It will not be possible to add topics prior to the group interview due to other participants being involved and accompanying time restraints. You are free to skip any interview questions or end the interview early without explanation. You may also choose to pause the interview and

take a break at any point. *Additionally, you will have the opportunity to debrief after interviews or group interviews with myself, a trained mental health professional.*

**What are the benefits of taking part?**

By taking part in this research project, you will be contributing to the knowledge about trauma and trauma treatment in Autistic females, an area that is currently under-researched and not well understood.

**Are there any risks associated with taking part?**

There are no significant risks associated with taking part in this research project.

**Data Protection and Confidentiality:**

Your information will be stored and processed within the United Kingdom in accordance with Data Protection Law; all information collected about you will be kept strictly confidential. Your consent form will be kept separately from your interview responses in order to minimise risk. Your name and any other information you share that could be used to identify you will not be shared with anyone. Your recorded interview will be deleted within two weeks, after a written copy of your interview has been created. Information such as your gender, age, and ethnicity, as well as your answers to interview questions, will be kept in a password-protected file on a fully secured university one-drive. Your name will not be saved with this information and extra diligence will be taken by myself to change all potentially identifying details, including names, locations, aspects of your experiences or any other details shared in the interviews that could possibly lead to you being identified before interview transcripts are shared with Autistic research board members involved in this project.

**What if I decide to withdraw from this research project?**

The decision to participate in this research project is completely yours. You are not obligated to remain involved after agreeing to participate, and you may withdraw your consent at any point prior to your interview.

If you do decide to take part and agree to be interviewed, you will receive a written copy of your 1:1 interview/group interview that you can make changes to within a month of receiving it to ensure you do not feel you have been misrepresented in any way. You may also withdraw your 1:1 interview entirely from the project within four weeks of receiving your written interview. Interviews cannot be withdrawn after this time as data from interviews will have already been included in my doctoral thesis. If you choose to participate in the group interview, you are unable to fully withdraw your involvement in this interview, as it will be impossible to remove one person's contribution from the group discussion.

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

Once the project has finished, it will be written up as part of a PhD thesis and held at The University of Edinburgh. It will then be uploaded onto the University's Open Access library where it can be read by university students and other professionals. I will use parts of this research in the future within publications, reports and presentations to inform the way mental health practitioners work with autistic women experiencing mental health difficulties from trauma. Again, due diligence will be taken by myself to anonymise any potentially identifying information and maintain confidentiality in all future publications.

You will be provided with a copy of my completed PhD thesis if you decide to take part in this research project.

**What if there is a problem?**

If at any time you are unhappy with something, please get in touch with me, Cloie Parfitt. Also, if you have any questions about the information on this form and would like speak with me before registering your interest, please get in touch with me by email:

Cloie Parfitt

Email:

If I am unable to help with your concern, you can make a complaint to the University of Edinburgh's School of Health in Social Science:

Professor Matthias Schwannauer

01316513954

**Further information and contact details:**

If you would like to participate in this study, please contact me to register your interest by **Friday, 2<sup>nd</sup> April, 2021.**

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**Thank you**

# Appendix II

## Interview Consent Form

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Research project title: *“On the Spectrum and in the Room: Exploring Experiences of Trauma-Related Mental Health Support Among Autistic Women”*

Researcher: Cloie Parfitt

Research Participant’s name:

Thank you for agreeing to be interviewed as part of the research project, *“On the Spectrum and in the Room: Exploring Experiences of Trauma-Related Mental Health Support Among Autistic Women.”*

Within UK universities, it’s required that people being interviewed for research projects openly agree to being interviewed and to the ways their interviews will be used. This consent form is necessary to ensure that you understand the purpose of your participation in this research project and that you agree to how your information will be used for this research.

After reading the information sheet given to you, please sign this form **only if you fully** agree to the following:

- Your interview will be recorded by audio, video or chat, and a written copy of your interview will be created.
- Your name will be removed from the written copy of the interview, and I will change all potentially identifying details, including names, locations, aspects of your experiences or any other details shared in the interviews that could possibly lead to you being identified.
- This written interview will be analysed by Cloie Parfitt (the researcher) and Autistic members of the research advisory board; access to your written interview will be limited to Cloie Parfitt and Autistic members of the research advisory board.
- You will receive a written copy of your interview that you can make changes to within a month of receiving it to ensure you do not feel you have been misrepresented in any way. You may also withdraw your interview entirely from the project within four weeks of receiving your written interview. Interviews cannot be withdrawn after this time as data from interviews will have already been included in my doctoral thesis.
- Your recorded interview will be deleted within two weeks after a written copy of your interview has been created.
- Once completed, this research will be used within a PhD thesis, which will be uploaded onto The University of Edinburgh’s open access library where it can be read by academics and other professionals.

- Anonymised data from this research will likely be used in future publications, reports or presentations. I understand that due diligence will be taken to anonymise any potentially identifying information, such as my name, geographic location or specific services I have accessed in all future publications and that my anonymised interview responses may be quoted within these publications.

By signing this form I agree that;

1. I volunteer to take part in this project. I understand that I don't have to take part, and I can stop the interview at any time;
2. My interview (or parts of it) may be used as described above;
3. I have read the information sheet;
4. I know I won't receive any benefit or payment for taking part in this project;
5. I will be given a copy of my interview and I can make changes to this within a month of receiving this copy.
6. I have been able to ask any questions I might have, and I understand that I am free to contact Cloie with any questions I may have in the future.

Your Name:

Your Signature:

Date:

Researcher's Signature:

Date:

**Contact Information:**

This research has been reviewed and approved by the Edinburgh University Research Ethics Board. If you have any further questions or concerns about this study, please contact:

Cloie Parfitt  
Email:

*If you have any questions or concerns about the information on this form please contact Cloie Parfitt to discuss this before giving your consent.*

If you are concerned about how this research is being conducted and would like to file a complaint, you can contact the head of the University of Edinburgh's head of the School of Health in Social Science:

Professor Matthias Schwannauer  
01316513954

# Appendix III

## Semi-Structured Interview Questions:

1. What does the word *trauma* mean for you?
2. Could you tell me about the experience(s) that led you to seek counselling?
3. What sort of impact were these experiences having on your life before you sought support?
4. How easy/difficult was it for you to access support?
5. Could you tell me about your experience of counselling (relationship with therapist, what was helpful/unhelpful, therapy modality)?
6. What knowledge did the therapist have about autism?
7. Is there anything you wished the therapist had done differently to better support you?
8. Is there anything else you'd like to add?

# Appendix IV

## Research Board Member Position Criteria:

### Board member criteria:

To participate as a board member you must have...

- A lived experience of being autistic- this can include formal diagnosis or self-diagnosis
- Be [or identify as] female
- *Ideally*: have an experience of the United Kingdom mental health system
- Reside in the United Kingdom
- Be 18+ years of age

### Expectations:

As a research board member, you will be expected to...

- Use your own lived experience of autism and mental health to steer the direction of this research. This will be done by:
  - Working collaboratively with other board members to decide how to best recruit research participants.
  - Working collaboratively with other board members to decide the type of methods most appropriate for this research project.
  - Being directly involved in the interpretation of research data depending on the type of methods used (interview responses, focus group themes, etc.)
- Attend quarterly board meetings online via Zoom (approx. 1 hour in length with, 4 meetings in total)
- Provide feedback on written work periodically to ensure that the language used best represents the autistic community and the initiatives this research aims to achieve.
- Project duration: This project will conclude in August of 2022, when Cloie's PhD programme has finished and the board report has been generated. However, there will likely be opportunities to take this research further for those who are interested.

***\*\*\* PLEASE NOTE: If you feel you are unable to commit to being a board member at this time and would like to participate as a research participant, please let me know and I will be in touch again when we begin the recruitment process\*\*\****

# Appendix V

## Research Advisory Board Member Agreement:

### Expectations:

As a research board member, you will be expected to...

- Use your own experience of autism and mental health to steer the direction of this research. This will be done by:
  - Working collaboratively with other board members to decide how to best recruit research participants.
  - Working collaboratively with other board members to decide the type of methods most appropriate for this research project.
  - Being involved in the interpretation of research data (Autistic board members only) depending on the type of methods used (interview responses, focus group themes, etc.)
- Provide feedback on written work periodically to ensure that the language used best represents the autistic community and the initiatives this research aims to achieve.
- Project duration: This project will conclude in August of 2022, when Cloie's PhD programme has finished and the board report has been generated.

### By signing this form I agree that:

7. I have read the above information and agree to take part in this project per the conditions stated above;
8. I understand that if I do not have to participate in this project and I can withdraw my participation at any time;
9. I understand that I won't receive any benefit or payment for taking part in this project;
10. I understand that Cloie Parfitt is the sole owner of raw data associated with this project;
11. I understand that Cloie Parfitt is the sole author of the PhD thesis associated with this project and all future publications related to this project;
12. I have been able to ask any questions I might have, and I understand that I am free to contact Cloie with any questions I may have in the future.

Your Name:

Your Signature:

Date:

Researcher's Signatu

Date: