# An Interpretative Phenomenological Analysis of the Lived Experiences of Women with Autism Spectrum Disorder

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BA, Hons BA, MA, MA

Thesis submitted in partial fulfilment for the award of

Doctor of Psychotherapy

School of Nursing, Psychotherapy and Community Health

Dublin City University

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June 2021

# Declaration

I hereby certify that this material, which I now submit for assessment on the program of study leading to the award of Doctor of Psychotherapy is entirely my own work and that I have exercised reasonable care to ensure that the work is original and does not to the best to my knowledge breach any law of copyright and has not been taken from the work of others save and to the extent that such work has been cited and acknowledged within the text of my work.

Signed: Liezl Wienand (Candidate)

ID Number: 14211259

Date: 28 June 2021

## Acknowledgements

“Autism is one word trying to describe millions of stories…” Anon

My heartfelt gratitude and appreciation go to the participants in this study whose honesty and courage brought autism to life.

Sincere thanks to my supervisors Dr Gemma Kiernan and Dr Aisling McMahon for their endless patience, support and encouragement throughout this process.

To my beautiful children and my family: My daughter Alex, my son Leo; my parents George and Elaine; my siblings Albert and Lee-Handre; my inspirational Nana Ouma Suzie Cilliers: Words cannot convey my appreciation for all the years of love, support and encouragement on my journey of discovering myself.

To Lourenza Fourie: soul-friend, mentor, Mensch.

To Nico for his friendship, patience, advise, support and encouragement at every twist and turn of the thesis journey.

To Dr James O’Connor for his unconditional positive regard and support, and for sharing his personal experience of supporting an autistic women

To my friends, in alphabetical order since that feels fair! Amy, Colette, Cynthia, Tannie Engela, Hilary, Paula, and Ronald: thank you for your love, encouragement, and support. For patient listening, for much laughter along the way.

This research was ultimately inspired by Alex: my wide-eyed warrior-child whose unlimited curiosity and resilience never ceases to amaze. May the world continue to receive your wonderment with grace and ease.

# Abstract

## Liezl Wienand

## An Interpretative Phenomenological Analysis of the Lived Experiences of Women with Autism Spectrum Disorder

In a recent report by the Centre for Disease Control (CDC, March 20), the Autism and Developmental Disabilities Network (ADDN) reported in increased prevalence in Autism Spectrum Disorders (ASD) diagnoses. USA surveillance figures for 2016 suggested a prevalence of 18.5 per 1,000 (one in 54) for children aged 8 years. ASD was 4.3 times more prevalent in boys than in girls. Norther Ireland school census figures for 2016/2017 showed 2.5 % of school aged children had autism compared to 1.3% in 2006/2007. The male to female ratio in these figures was 3.5% : 1% . Similar statistics are not available for the Republic of Ireland.

There is a relative paucity of qualitative research exploring the needs and experiences of autistic adults, in particular autistic women. Employing an Interpretative Phenomenological Analysis methodology, the purpose of this study was to give voice to the lived experiences of seven autistic women.

Semi-structured interviews were used to generate rich descriptions of the phenomenon. Data analysis identified four superordinate themes*: (1) Experience of being (2) Being alongside others (3) Coping and resilience, and (4) Receiving and giving support.*

Participants highlighted their struggles in understanding and accepting themselves as well as in being understood and accepted by others. Social and communication challenges, particularly in interaction with non-autistic others, caused significant distress for all participants. Participants shared frustration with typical "talk" psychotherapies, which they felt were poorly suited to their needs. They expressed hope for greater understanding of the support needs of autistic women as well as a need for enhanced expertise of psychologists and psychotherapists who seek to support them. Resultant implication and recommendations for psychotherapy training, practice, supervision, and for autistic women themselves are presented

# CHAPTER 1: INTRODUCTION

## 1.1 Introduction

Autism, as a complex neurological condition, has been observed, debated, researched and diagnosed since the Swiss psychiatrist Eugen Bleuler first used the term “autistic” in 1911 (Bluestone, 2004). Leo Kanner’s studies of early childhood development is widely credited with using the term “autism” to describe so-called atypical emotional contact with the external world, leading to a perception that autistic people live in a world of their own, which excludes all others (Bluestone, 2004). When I embarked on my study in 2014, the central narrative on autism, propounded by non-autistic “experts” (predominantly paediatricians and psychiatrists), subscribed to assumptions that autism was a constellation of unusual, “disordered” social behaviours, interests and characteristics typically identified in infancy or early childhood. The process of knowledge generation, research, has thus largely been driven by assumptions that, whatever the underlying neurological underpinnings may be, autistic traits represent an undesirable departure from the neurotypical norm (Ebben, 2018). There is, furthermore, is a growing realisation amongst researchers that so-called autism symptomatology derives from studies whose participants were predominantly young males, and that the presentation of autistic girls and women is different (Kreiser & White, 2014; Leedham et al., 2020; Pearse, 2020; Pellicano et al., 2014; Trubanova et al., 2014). This has led to autism in girls and women persistently being under-diagnosed or misdiagnosed (Ferrie, et al. 2018; Hull et al. 2020). For example, autistic girls and women appear to be more willing and able than autistic males to mask, camouflage and compensate for the challenges they experience in daily living, due to a greater desire for social connectedness (Bargiela, 2016;

Dean et al., 2014, 2017; Lai et al., 2011, 2017). Consequently, the difficulties and challenges autistic females face in coping with a non-autistic world has gone largely unrecognised by researchers and clinicians alike (Attwood, 2015; Bargiela et al., 2016; Gould & Ashton-Smith, 2011; Gould, 2017; Hearst, 2014; Krahn & Fenton, 2012; Leedham, 2020; Pearse, 2020). Autistic autism advocates, including researchers, invite us to reflect on autistic as being simply “different”, and neurodiversity advocates encourage us to see autism as valuable human diversity (Bagatell, 2010; Brownlow & O’Dell, 2013; Den Houting, 2019; Kapp et al., 2012; Ortega, 2013; Pearse, 2020). Despite all this, it is still currently the case that autism is formally defined in terms of its “deficits” and “impairments” which find expression in its classification as a “disorder” (DSM 5, APA, 2013).

While quantitative research on autism across the lifespan is plentiful, there is a relative paucity of qualitative research based on the experiences of autistic adults in general, and autistic girls and women with no associated learning difficulties. This study aims to contribute to a slowly emerging body of research on autism in women. This chapter will introduce the background and rationale to the research I have undertaken and presented here. It will include a description of the medicalized view of autism as per the DSM 5 “autism spectrum disorder criteria” (APA, 2013), a synopsis of my aim and objectives and a summary of the methodology that informed the research process. I will also outline the structure of the thesis and offer a reflection on my motivations for conducting this study.

## 1.2. Autism prevalence

Autism Spectrum Disorders (ASD) is being diagnosed at an increasing rate, as evidenced in the most recent statistics by the Centres for Disease Control and Prevention (2020). Surveillance figures for 2016 suggested 1 in 54 children in the USA had autism, with a prevalence of 18.5 per 1000. Autism was 4:3 times more prevalent in boys than in girls in these figures. The ratio is estimated at 2:1 where autism is accompanied by significant intellectual disability, and rises to circa 10:1 amongst individuals with an average or superior intellectual ability (Dworzynski et al., 2012). These ratios have come under scrutiny considering recent findings from epidemiological studies with active case ascertainment revealing significantly smaller male to female ratios within general population groups. Loomes et al. (2017) concluded that the ratio as estimated by methodologically rigorous studies is likely to be 3:1, with little anticipated variation across the spectrum or intellectual ability range. School census figures in Northern Ireland for 2016/2017 showed 2.5 % of school aged children had autism compared to 1.3% in 2006/2007. The male to female ratio in these figures was 3.5%:1%. Similar statistics are not available for the Republic of Ireland. Underdiagnoses of autism in females is believed to result from the male-centric diagnostic criteria of the DMS 5, the higher propensity of autistic females to mask their autistic behaviour, as well as a general lack of professional and public awareness of how autism presents in individuals with no associated learning difficulties (Hull, 2020). In the public health system in Ireland ASD diagnostic assessments are only accessible through disability teams, which require evidence of associated developmental delay and/or learning disability to access services. Therefore, girls who may be autistic but who present with good communication skills and no evidence of intellectual disabilities will not qualify to be assessed through the public system in Ireland. Private diagnostic assessments are typically expensive, which renders them inaccessible to many people.

### 1.3 Defining autism.

The fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM 5) lists two primary diagnostic criteria for autism: (a) ongoing deficits in social communication and interaction that persist across multiple life contexts, and (b) patterns of restricted and repetitive behaviour and interests (American Psychiatric Association [APA], 2013). The previous version of this manual, the DSM-IV-TR, contained differentiated diagnoses for autism, Asperger's Syndrome and Pervasive Developmental Disorder, not otherwise specified (PDD-NOS), but these varied diagnoses have in the DSM 5 been collapsed into one diagnostic label of ASD. Asperger's Syndrome was previously considered to be a "milder" form of autism, with relatively typical language development and intelligence. The diagnosis of PDD-NOS was applied to individuals who exhibited many symptoms of autism and were significantly affected by these symptoms, but who did not meet the full criteria for an autism diagnosis (Young & Rodi, 2014).

High functioning autism (HFA) is not an official diagnosis from the DSM 5 or DSM-IV-TR, but is a term that persists colloquially, and in research literature, to refer to persons with autism (and sometimes Asperger's Syndrome) who have IQs in the average or above-average range (Böckler et al., 2014). The DSM 5 does not include "high functioning" as a specifier for ASD, and provides ASD severity levels, which are required additional specifiers (i.e., with or without accompanying intellectual impairment; APA, 2013). For the purposes of the present study, HFA is autism without any associated intellectual disability. The specifier "intellectual disability" is typically applied when a person's IQ is below 70 (Böckler et al., 2014). Thus, ASD as per the DSM 5 now includes those previously diagnosed with Asperger's Syndrome, autism, or PDD-NOS and research including individuals with these diagnoses remains relevant to the present study. The research reviewed in the literature search often included comparison or control participants who did not experience autism; these participants will henceforth be referred to as "*neurotypical*" or "*non-autistic*".

### 1.3.1 Restricted and repetitive behaviour and interests

Restricted and repetitive behaviour (RRB) and interests reflect one of the primary criteria for the diagnosis of autism in the DSM 5. These include stereotyped behaviours (completed in the same way each time), repetitive thoughts, actions or vocalizations, insistence on sameness and preoccupations with subjects, objects or activities that require the investment of excessive time or energy (APA, 2013). For example, autistic individuals may engage in repetitive behaviour such as repeating certain words or phrases, lining up objects and engaging in body movements (i.e., rocking, hand flapping) (García-Villamisar & Rojahn, 2015).

Research indicates that restricted and repetitive behaviours may serve self-regulatory functions for autistic persons. In a study of 43 autistic adults with intellectual disability, García-Villamisar and Rojahn (2015) found that the frequency of stereotyped and repetitive behaviours correlated with autism symptom severity and was also influenced by stress and psychopathology. These findings suggested that repetitive behaviours might help autistic individuals manage feelings of distress and other aversive psychological and emotional states. Cognitive inflexibility also correlated with restricted and repetitive behaviours, as indicated by a study (Miller et al., 2015) showing a greater need for sameness in 60 non-verbal intellectually disabled autistic adults than in 55 non-verbal intellectually disabled non-autistic adults. Insistence on sameness in interests and behaviour may provide comfort to individuals who are challenged and stressed by a constantly changing world (Miller et al., 2015).

**<u>Sensory differences:</u>** Differences in sensory experiences are included under the repetitive and restricted behaviour and interest diagnostic category of autism, as autistic people may express sensory differences either as preoccupations with or persistent avoidance of certain stimuli (APA, 2013). Autistic persons may experience hyper- and/or hypo-reactivity in any or all their sensory modalities. Findings from a quantitative sensory testing battery of 13 autistic adults and 13 matched controls (Vaughan et al, 2020) indicated that autistic people experienced under-sensitivity to touch or pain as well as a greater range of extreme scores (outside of the 95% range) compared to non-autistic participants. This study also reported paradoxical heat sensation and allodynia (where pain is experienced from stimuli which do not typically cause pain, e.g., light touch). Jussila et al. (2020) used the Autism Spectrum Screening Questionnaire (ASSQ) and a parental questionnaire to study the association between quantitative autism traits (QAT) and so called “sensory abnormalities” (SA) in a population 8-year-old children (n= 4397). They reported that auditory and tactile hypersensitivity predicted autism and concluding that QAT and SA were associated. An integrated systemic review of 22 quantitative, qualitative, and mixed methods studies were conducted by Williams et al. (2021) to ascertain the associations among anxiety, RRB and sensory hyper-responsiveness. They noted the impact of environmental factors, social context and behavioural and cognitive coping strategies and urged further research into how autistic people experience these phenomena. In a study on autistic women’s experiences of menopause (Moseley et al., 2020), participants identified sensory sensitivities, anxiety and depression as the main triggers for autistic meltdown over their lifespan. Meltdown and shutdown reactions to sensory overwhelm appear to be the manifestations of fight or freeze reactions to perceived threat. Shutdown, the “freeze” reaction, is labelled as “*catatonic-like motor behaviour*” in the DSM 5 (2013: 55).

### 1.3.2 Social and communication challenges

The DSM 5 specifies social and communication deficits as primary criteria in an autism diagnosis (APA, 2013). This may include lack of social reciprocity and poor understanding of relationships, along with difficulty interpreting nonverbal communication (APA, 2013). Shared attention (also referred to as joint attention) is often impaired in autistic people. The development of appropriate social skills is adversely impacted by atypical joint attention, since shared focus between young people and parents and mentors is an important mechanism for learning about social expectations and emulating socially appropriate behaviour (Gillespie-Lynch et al., 2012). While autistic individuals with associated intellectual disabilities may exhibit severe communication challenges, including impoverished vocabulary or an inability to use verbal language, communication difficulties for non-intellectually disabled autistic people primarily involve challenges with discourse (Howlin et al., 2014). Adaptive skills related to social and interpersonal interactions may improve with age but commonly remain an area of below average performance for autistic adults (Matthews et al., 2015). The continued deficits in adaptive social skills have been found to differentiate an autism diagnosis from other neurodevelopmental disorders (Mouga et al., 2015).

There is a relative dearth of information on how autistic people without intellectual disabilities should be supported to best encourage social and cognitive growth (Hofvander et al., 2009). Although gender-based studies focusing on the experiences of autistic women have seen growth in recent years, this population still remains relatively under-represented in autism research (Schneider et al., 2013). Howard et al. (2019) identified two studies with autistic women (Cridland et al., 2014; Tierney et al., 2016) that used IPA as a methodology at the time of their brief report on using IPA in autism research. Existing research suggests that autistic girls and women with no intellectual disabilities present differently from autistic boys and men (Bargiela et al., 2016; Milner et al., 2019; Pearse, 2020) and consequently experience different challenges related to friendships and sexuality (Byers et al., 2013; Dean et al., 2014). The need for more qualitative research about autistic women's experiences in general and their experiences of interpersonal relationships and sexuality specifically thus remains.

### 1.3.3 Psychological and emotional experiences

Samson et al. (2012) found that autistic adults reported experiencing more negative emotions than non-autistic adults, although their experiences of positive emotions were comparable to that of their neurotypical peers. Although core diagnostic criteria for autism do not specifically include other psychological or emotional symptoms, autistic people often present with comorbid psychiatric diagnoses, of which depression and anxiety disorders have been the most reported (Kirkovski et al., 2013). Accordingly, in a sample of college students, Liew et al. (2015) found that autism traits were correlated with higher social anxiety and deficits in social competence were common. These findings suggested that a lack of social skills increased the likelihood that autistic people would develop anxiety disorders (Liew et al., 2015). Autistic males generally experience greater impairment causally related to autism characteristics (Pisula et al., 2013) than autistic women, who were more likely than autistic men to report symptoms of mood and anxiety disorders (Kreiser & White, 2015). In a study comparing 27 non-intellectually disabled autistic adults (16 females, 11 males) with non-autistic peers (matched for age and gender), the autistic participants exhibited higher rates of alexithymia (difficulty in identifying and labelling one’s own emotions) (Samson, et al. 2012). Inability to identify distressing emotions, or delayed recognition of distress, can lead to ineffective coping and exacerbation of psychological distress in autistic persons (Samson et al., 2012). Coping with anxiety and other mental health issues presents another dimension of difficulty for autistic persons (Liew et al., 2015). As previously noted, García-Villamisar and Rojahn’s (2015) findings suggest that autistic people’s repetitive behaviours often have a self-regulatory function. Being prevented from engaging in such self-regulatory (“stimming”) behaviour was associated with increased worry and obsessive-compulsive behaviours (Liew et al., 2015). According to Khor et al. (2014) ineffective coping strategies such as disengagement adversely impact psychological functioning for non-intellectually disabled autistic adolescents. This impact was associated with higher levels of emotional and behavioural problems (Khor et al., 2014). Autistic adults with no intellectual disabilities were more likely to use suppression as an emotional regulation strategy than non-autistic adults (Samson et al., 2012). Although the researchers identified disengagement and suppression as common ineffective coping strategies, the participants’ reasons for choosing these coping methods were not explored or explained, nor did these studies differentiate the experiences based on gender, thus revealing gaps in the research literature (Khor et al., 2014; Samson et al., 2012).

### 1.3.4 Summary

The DSM 5 (APA, 2013) characterizes autism as a disorder with social-communication difficulties, repetitive behaviour, and sensory deficits, all which impact individuals in a variety of ways, and at varying levels of severity (APA, 2013; Young & Rodi, 2014).

Challenges include hypo- and hyper-sensitivity in some or all sensory modalities (e.g., Jussila et al., 2020; Vaughan, 2020). Insistence on sameness, and/or discomfort with change, is typical in autism, frequently manifesting in repetitive behaviour, focusing on specific topics or interests, and insistence on rigid routines (Miller et al., 2015). Although repetitive behaviours are symptomatic of autism, they may have self-regulatory functions in reducing anxiety and other aversive psychological states (Garcia-Villamisar & Rojahn, 2015). However, when combined with social and communication challenges, repetitive behaviour can create substantial barriers to autistic individuals' socialization (Matthews et al., 2013; Smith & Sharp, 2013). Significant quantitative research has been dedicated towards studying the characteristics of autism as per DSM 5 criteria. Whilst research has demonstrated the link between autism and mental health challenges the impact of autism characteristics on the daily lives of autistic people, particularly autistic females has received less attention. The lived experiences of phenomena related to being autistic women have furthermore been largely neglected.

### 1.4 Aim and objectives of the study

This study aims to "give voice" to the lived experiences of autistic women who have no concomitant diagnoses of intellectual disabilities. These women are referred to as autistic women henceforth.

With this overall aim in mind the objectives of the study are:

- to explore the experiences of being autistic women
- to examine the experiences of how autism affects the social functioning of women.
- to identify women's perspectives on how being autistic impacts their intimate relationships.

- to explore women’s experiences of the relationship between autism and their mental well-being
- to highlight the types of formal and informal supports autistic women find helpful and may feel they need.
- to consider how the knowledge gained from this study can inform psychotherapeutic practice.

## 1.5 Methodology

The chosen methodology for this study is Interpretive Phenomenological Analysis (IPA) (Smith et al., 2009). Semi-structured, in-depth interviews regarding the lived experiences of being an autistic woman were carried out individually with seven autistic women. One interview was conducted face-to-face and the remaining six were conducted online as per the preferences of participants. Utilizing IPA as a research approach throughout the entire process yielded richly descriptive interviews of the experience of being an autistic woman. Systematic and rigorous analyses of interviews generated the findings of this study.

## 1.6 Thesis outline

Following the present, introductory, chapter, chapter two provides a literature review of autism. Chapter two examines relevant research on autism and Asperger’s Syndrome predating the DSM 5 (2013) as well as relevant research on autism that emerged since its introduction. The information in chapter two is presented in alignment with the study objectives noted above.  To afford a glimpse into the experience of being autistic chapter two outlines the clinical presentation of autism and the gender differences in autism experience. It examines research on how autism manifests in the interpersonal and intimate relationships of autistic people, paying attention to how autistic differences impact socialization and communication. The chapter discusses the relationship between autism and mental health challenges and concludes with a discussion of different types of supports and therapies that may benefit autistic women in their social- and occupational functioning an in addressing their mental health challenges.

Chapter three reiterates the aim and objectives of the study and provides a justification for using IPA as the obvious methodology to examine the research aim and objectives. It highlights the three philosophical underpinnings of IPA: phenomenology, hermeneutics and idiography. The chapter also outlines the research design and discusses the processes of sampling, recruitment, data collection and data analysis. The ethical considerations that informed the study are presented, and the validity of the project is examined.

Chapter four presents the findings of the study. In this chapter, participants' experiences of being autistic are given voice using direct quotes, supported by the researcher's interpretations of the data. The superordinate and subordinate themes that emerged from data analyses are introduced in a master table. Each superordinate theme is introduced with its subordinate themes. In-depth exploration of the themes highlights emerging patterns of convergence and divergence.

Chapter Five presents the discussion of the research findings considering the study objectives and positions the findings in relation to existing literature. Novel findings are included and recommendations and implications for psychotherapists, relevant stakeholders and autistic women are presented.

A reflexive account of the researcher's thoughts, insights and learnings is provided at the end of each chapter.

## 1.7 Conclusion

Autism is a complex neurological condition and is currently still defined in terms of its deficits and as a disorder in the DSM 5 (APA, 2013). The criteria for autism, as contained in the DSM 5, evolved from research conducted with mostly male participants. As such it does not account for the way in which autism manifests in females. The consequence of this is that autistic females of all ages are vastly underdiagnosed, which leaves their support needs unmet. Autism is characterised by differences in social-communication behaviour, RRB and sensory differences. The characteristics of autism impact autistic individuals across all areas of their lives and co-occurring mental health challenges are thus a common feature of autism. This chapter sought to define autism as per DSM 5 diagnostic criteria and noted available prevalence statistics. The chapter provided the aim and objectives of this study and briefly outlined the methodology used in this study, IPA. It concluded with an outline of thesis chapters.

### *Reflexive notes*

*I am an autistic woman. I am also a mother of an autistic daughter and a clinical psychologist. Over the 18 years that I have worked with autistic clients across their lifespans, I have been repeatedly struck by how poorly understood autism is in general, but particularly in girls and women. I have worked with countless undiagnosed autistic females referred for anxiety, depression, inability to cope in school, being overwhelmed as mothers, as employees, only to discover upon meeting them that autism was at the core of the experiences that led them to my door. My awareness of likely being autistic dates to my training as a psychologist many moons ago. NFL, normal for Liezl, was a term of endearment used by friends and family over the years.*

*The subject matter of this study was never in question, it was simply a matter of choosing a methodology. And in many ways that too became a given as soon as I reflected on what the aim of a study with autistic women should be for me personally: Experience. What it is like to be an autistic woman in a world not designed for us.*

# CHAPTER 2: LITERATURE REVIEW

## 2.1 Overview

This chapter is a review of existing relevant research literature on autism spectrum disorder (autism) with no accompanying intellectual disabilities (also termed Asperger's Syndrome in earlier versions of the Diagnostic and Statistical Manual of Mental Disorders (DSM)). In line with the preferences expressed by autistic people (e.g., Kenny, et al, 2015; Pearse, 2020), the words "autistic" and "autism" will be used in the remainder of this chapter and thesis instead of the autism spectrum disorder label used in the fifth edition of the DSM.

This chapter will reflect on current research related to Asperger's Syndrome and autism more broadly, including a brief discussion on related "symptomatology". The information in this chapter will be presented in alignment with the study objectives. Quoted research findings will be presented from an autistic perspective with medicalised and pathologizing terminology presented in quotation marks. Recent research by autistic autism researchers and advocates will also be included. A large section of this chapter will focus on the clinical presentation of autism and autism and social relationships, with attention to how autistic differences impact socialization and communication. This will be followed by a discussion of the different supports and therapies that may benefit autistic persons in addressing mental health challenges and social- and occupational-functioning. The rationale for the present study is presented followed by concluding comments.

## 2.2 Search strategy

To evaluate the existing literature in the field under study, I conducted an extensive search of multiple databases, giving priority to research articles published in peer-reviewed sources. I searched databases including PsycINFO, ERIC, HealthSource: Nursing/Academic Edition, Psychology and Behavioral Sciences Collection, Academic Search Premier, and Google Scholar using terms such as Asperger’s, autism, autism spectrum disorders, high functioning autism, females, sex differences, gender differences, social relationships, social functioning, activities of daily living, wellbeing, psychological functioning, psychological health, psychosocial functioning, supports, therapies, assistance, adaptation, adaptive skills, psychotherapy, psychological treatment, mental health treatment and psychosocial treatment in appropriate combinations. I also reviewed reference lists to source additional relevant articles. Theoretical, autobiographical, and clinical resources also contributed to this literature review.

## 2.3 Experiencing Autism

Autistic communication, which differs from non-autistic communication, often lead to interpersonal experiences in which autistic people experience lack of empathy and feel poorly understood by non-autistic others (Milton, 2012; 2018; Pearse, 2020; Yergeau, 2013;). Research highlighting the 'double empathy problem (Milton, 2012, 2018), misconceptions and stigmatizing stereotypes about autism (Bargiela, et al., 2016; Milner, et al., 2019; Pearse, 2020; Pellicano, et al., 2014), suggested that the lived experience of being autistic, of having a neurological predisposition which differs from a non-autistic/neurotypical predisposition, can likely only be fully appreciated and understood by autistic people For non-autistic/neurotypical people to be afforded a glimpse into what it is like to be autistic the characteristics of autism as per existing criteria (DSM 5, APA, 2013) needs to be examined.

### 2.3.1 Autism's clinical presentation

This section will focus on autism research more generally. At the onset of this study the likely existence of the female autism phenotype was not yet under investigation and thus studies where no attempts were made to investigate gender differences are also included in this section.  Studies dedicated to the experiences of autistic females are also included.

Autistic "*Dasein*" (Heidegger, 1996), or being in the world, has found itself imperfectly summarized by the pathologizing, medicalized language of the DSM 5 (APA, 2013). As was the case with the DSM IV, autism is still classified as a disorder (DSM 5 299.00, APA, 2013) with social-communication difficulties, repetitive behaviour, and sensory deficits. The DSM 5 Neurodevelopmental Disorder Workgroup , charged with revising DSM IV autism criteria, admitted early on in their work that the DSM IV *"worked best for five-to-eight-year old white boys"* (Kapp, 2020, p.169). While this group aimed to improve identification of females, racial and ethnic minorities, they were largely unsuccessful in doing so and Kapp (2020) noted: *"..psychiatrty must acknowledge the autistic community (and other similar communities) as an equal, not as a junior partner."* (p189*).* As noted, Loomes et al. (2017) suggested that the ratio of male/female, as estimated by methodologically rigorous studies, is likely to be 3:1, with little anticipated variation across the spectrum or intellectual ability range.

Belek's (2019) ethnographic research led him to conclude that autistic adults seemed inclined to discuss their autism through its physical and sensorial manifestations as is also evident in the autobiographic writings of, amongst others, Temple Grandin (2006) and Donna Williams

RIP (2006). Since the introduction of the DSM 5, the sensory differences, and the challenges these pose have been included as a core feature of autism, with significant research conducted into how sensory dysregulation contributes to social-communication challenges and restricted repetitive behaviour. A recent study by Jussila et al. (2020) (p.6) found that the relationship between SA and QAT persists across the lifespan and that autistic people who present with fewer overt or obvious sensory "abnormalities" are less noticeable and therefore less likely to be diagnosed. These findings are at odds with the lived experiences reported by several renowned autistic women (e.g., Grandin, 1995; Williams, 1992, 1994; Willey, 1999).

In their qualitative interviews with five autistic people, Robledo et al. (2012) explored the sensory and motor differences experienced by their participants and previous researchers' limited understanding of the potential impact of these differences on autistic people's behavioural, communication and social functioning. As noted, numerous autiobiographical accounts by autistic women who pioneered research into autism (e.g., Grandin, 1995; Williams, 1992, 1994) referenced perceptual differences, such as differences in hearing, vision, smell, taste, proprioception, and synaesthesia and the ways in which these differences could often be experienced as confusing and disorientating. These authors also described challenges in their ability to control, execute and combine movements and actions, such as when trying to smile or otherwise execute an action deemed appropriate (in a non-autistic sense). Robledo (2012) quoted a moving account of this.

> "*… when I should be smiling, sometimes I know that I am not smiling but may be even frowning. This causes me a great deal of pain and makes me look as though I am not comprehending when, in fact, I am trying to respond in an appropriate manner.*" (p. 32).

Several first-hand accounts also highlight that sensory motor differences impact on emotion regulation, capturing the sense of helplessness and paralysis (Ballou, 2021; Barron & Barron, 2012; Joliffe et al., 1992; Williams, 1992, 1994). Theresa Joliffe described it thus:

> *"[stress] occurs at any time, but always when I know I have to go somewhere stressful. Sometimes the pain is so bad that my whole body becomes stiff and then I am unable to move.* " (p.14.).

Belek (2019) noted that the body and sensory systems play a crucial role in the "*enactment of autistic subjectivities"* (p. 1). and quoted Yergeau (2013): *"Autism is embodied; my embodiment is autism."* (essay has no page numbers)

Garcia-Villamisar and Rojahn (2015) investigated the relationship between comorbid mental health difficulties, stress in autism and restricted repetitive behaviour (RRB). They gathered data from 42 autistic adults with intellectual disabilities using a battery of questionnaires. They concluded that RRB increased in line with participants' experiences of stress and/or distress, which suggests that RRB was how their participants attempted to cope with unpleasant experiences and, possibly, support emotional processing. RRB can, inter alia, manifest as the repetition of physical actions, verbal rituals, self-injurious rituals and -behaviour (SIB) and/or stimming (self-stimulating, repetitive behaviours). Kapp et al's (2019) research on autistic participants' perceptions and experiences of stimming (20 male, 10 female and 1 non-binary) used focus groups and interviews. Their thematic analysis revealed that stimming provided sensory stimulation, reinforcement and/or regulation, and decreased sensory overload for autistic people. Their participants concurred with autistic researchers and autism activists (eg Zamzow, 2019) in the neurodiversity community that stimming is a useful coping mechanism that also aids in processing of intense emotions.

Survey research by Moseley et al. (2020) (n=103) on the links between self-injurious behaviour (SIB) and suicidality found that SIB was used for emotional regulation, sensory stimulation, as deterrence from suicide or as a form of self-punishment. However, these researchers also found higher levels of SIB related to higher levels of suicide ideation and attempts. Paquette-Smith et al. (2014) surveyed 50 adults with Asperger's in their study on suicide attempts and reported that 35% had attempted suicide at some point, significantly higher than the 4.6% lifetime prevalence of suicide attempts in the general population (Paquette-Smith et al., 2014).

Attwood (2015) noted that it was common for children and adults with Asperger's syndrome to experience sensory overload, noting hypersensitivities to a variety of sensory stimuli. The autistic autism researcher and advocate Sainsbury (2000: p.101) described it thus:

> *"For anyone with the sensory hyper-sensitivities and processing problems typical of an autistic spectrum condition, the result is that we often spend most of our day perilously close to sensory overload."*

Ryan (2010) conducted a study with parents of autistic children and used thematic analysis to identify themes. Parents in her study linked their children's so-called embarrassing or disruptive behaviours (such as "melting down", screaming, head-banging, going to ground, "hissy fit", "running off, "having a paddy") to sensory overload; overwhelming sensory experiences of lights, unusual noises, darkness, and smells, as well as the difficulties autistic children have in managing different settings with unfamiliar places and people, crowds and queues. Ryan concluded that autistic children went into "meltdown" "*not as wilful displays of bad behaviour but as intense responses to overwhelming situations*" (p. 871). Belek (2019), who investigated bodily experiences of autism, also studied autistic overload, shutdown, and meltdown alongside the bodily experiences of distress in his autistic adult participants. Contributors to Belek's study experienced the effect of sensory-related meltdown as a greater impediment than their social and communication challenges. One of Belek's female participants described visceral experiences of sensory overload and consequent meltdown as akin to being forced to watch a horrible scene until "*my brain literally eats itself*" (p. 6). Research is increasingly focussing on the significant role played by sensory differences and challenges in the overall experiences of being autistic. More studies are focussing on the experiences of autistic adults with no associated learning impairments, which is heartening as it recognises that autistic adults with no learning impairments are a distinct, often overlooked group. However, as has traditionally been the case in autism research, limited research attention has thus far been dedicated specifically to the impact of sensory differences on the functioning and experiences of autistic girls and women.

### 2.3.2 Gender differences in autism

Only a relatively limited amount of research relates to sex differences, or the female experience of living with autism. Hull et al. (2017) included 13 studies to conduct a meta-analysis of gender differences in the cognitive abilities (IQ) and core autistic traits identified in the DSM 5 (2013) and found these were comparable to non-autistic samples. However, a different pattern of gender differences in autistic people was visible on qualitative measures such as internalizing and externalizing behaviours, executive functioning and play behaviour as well as in empathising and systemising traits (Hull et al., 2017). It has been reported that males generally experience greater impairment deriving from autism characteristics (Pisula et al., 2013) than females, who were more likely to report symptoms of mood and anxiety disorders (Kreiser & White, 2015). Furthermore, autistic females are at greater risk of experiencing co-occurring internalising disorders; in other words, the inward expression of emotional difficulties such as anxiety, eating disorders, depression and self-harm. By contrast, autistic males are more inclined towards the outward expression of experienced difficulties (called externalising problems), which manifests in behavioural problems such as inattention and aggression and the consequent challenges in interpersonal relationships (Lai et al., 2011, 2015; Hull et al., 2017). Notably, autistic girls were found to exhibit higher levels of social anxiety than autistic boys, but had lower levels of hyperactivity (May et al., 2014). These findings align with research by Tierney et al. (2016), whose 10 female adolescent participants reported experiences of despair, were rejected in social situations and, subsequently, felt stress and anxiety.

Bargiela et al. (2016) noted that there are uncertainties about the medicalized hypothesis of a female autism "phenotype" due to two key methodological challenges: firstly most studies focused on autistic women referred through autism clinics, in so doing excluding the cohort of undiagnosed autistic females missed by clinical services because their presentation differs from autistic males; secondly: autistic males and females were typically compared on so-called "gold-standard", well-established measures of autism symptoms. These measures (e.g., Autism Diagnostic Interview- revised, Lord, et al., 1994) were developed and validated largely with autistic males, and therefore lack sensitivity to the so-called female autism "phenotype".

In their qualitative study of 18 autistic women Milner et al. (2019) note that 4-5:1 was regarded as the traditionally reported ratio of autistic males to autistic females. However, these ratios have been challenged by a meta-analysis study by Loomes et al. (2017) that concludes "*the ratio as estimated by methodologically rigorous studies, is likely to be 3:1,* *and may not change very much across the spectrum or intellectual ability range*". Given nonverbal and gestural communication might create the impression of more sophisticated social abilities in non-intellectually disabled autistic girls, Rynkiewicz et al. (2016) hypothesized that this cohort tends to be inaccurately diagnosed with mild autism. In other cases, such communicative behaviour camouflaged the disorders altogether, resulting in lower diagnosis rates overall (Rynkiewicz et al., 2016). This view is supported by Milner et al.'s (2019) findings that the desire to find peers is one of the driving forces behind autistic girls and women's adoption of camouflaging behaviour.

Research into how gender differences relate to autistic people's emotional or psychological experiences has emerged in recent years. However, Rubenstein et al. (2015) urge caution about individual studies of sex differences in the psychological functioning of autistic people because widely contrasting findings have been reported. Jacquemont et al. (2014) investigated molecular characteristics associated with the increased male-to-female ratio in autism, attention deficit hyperactivity disorder, and intellectual disabilities. Considering the possibility of a female autism "phenotype", they suggested that the male brain requires milder alterations to exhibit autism than the female brain. Ferri et al. (2018) hypothesized that a combination of physiological factors and how these factors interact with the environment might explain the higher male to female ratio in autism. These include the greater genetic burden in females, sex-specific gene mutations, sex chromosome and sex hormone involvement, and/or epigenetic changes that might confer protection to females or risk to males. Hull et al. (2020) further investigated the so-called female autism "phenotype" through narrative review and hypothesized that existing research into epigenetics suggested that females required greater genetic and or environmental risk to manifest with similar autistic characteristics to males, and that females therefore seemed to be protected *"from autistic characteristics relative to males with a comparable level of risk factors"* (p. 307). They acknowledged that no protective genetic or other risk factors had been identified to date. There is an increasing awareness that autism is often missed or misdiagnosed in autistic girls and women not only because of the different ways in which autism clinically presents in autistic females but also the greater propensity of autistic females to hide, mask or camouflage their difficulties. The value of comparative research cannot be understated. However, considering the large body of research that has already been dedicated to how autism presents in males, as well as how best to support autistic males of all ages with varying levels of cognitive abilities across the spectrum, the amount of research dedicated to investigating, understanding and supporting autistic females of all ages is lagging. A greater understanding of autism in females will contribute to the development of more accurate diagnostic criteria and improved, gender-sensitive diagnostic instruments and ultimately increase the likelihood that autistic girls will receive timely recognition and benefit from early intervention supports (Lai & Szatmari, 2020)

### 2.4 Autism and social/interpersonal functioning

Social cognition refers to how the perception, interpretation, and application of social information guides interactions with others. It includes recognition of nonverbal indicators of another person's emotional state, which then allows one to engage with the other person appropriately (Eack et al., 2013). Autistic people have documented differences in social cognition, which typically detract from their ability to simulate neurotypical, non-autistic social behaviour (Yoshimura et al., 2013). Although intellectually disabled autistic persons may exhibit greater departures from normative social cognition features, Eack et al. (2013)

found that social cognitive differences were also present in autistic adults with average to above-average cognitive functioning. These include difficulties in emotion facilitation, emotion understanding, emotion management, and facial emotion recognition. First-hand accounts of differences in cognition are also provided by autistic authors who pioneered research into the lived experiences of autistic women such as Jolliffe et al. (1992), Williams (1994) and Grandin (1995). Grandin described how she translated written and spoken words into pictures in her head, a technique she called "visual thinking": *"full-[color] movies, complete with sound, which run like a VCR tape"* (p.19). These social cognition differences were recently examined in a study by Pagni et al (2020) with 95 autistic participants (67 males/28 females) and a control group of 82 non-autistic participants (48 males/34 females). They administered the Reading the Mind in the Eyes (RME) task and found that autistic adults performed poorer than non-autistic adults. No gender or age interactions of significance were noted. RME assesses the emotion recognition as expressed by human eyes. Yoshimura et al. (2015) also found that autistic participants had greater difficulty than non-autistic participants responding "neuro-typically" to the dynamic facial expressions of others. A qualitative analysis of interviews with and autobiographical writings of autistic adults indicated that sensory differences might interfere with "normative" perceptions of facial expressions and other forms of physical communication (Chamak et al., 2008). Difficulty interpreting the facial expressions of others detracts from the ability to respond in an emotionally congruent manner (characteristic of non-autistic others) (Yoshimura et al., 2015). This poses significant challenges for autistic persons' social acceptance, as their behaviours may be perceived as non-reciprocal or inappropriate (Yoshimura et al., 2015).

First-hand accounts of communication difficulties (Barron & Barron, 1992; Jolliffe et al., 1992; Williams, 1992, 1994; Grandin, 1995) include descriptions of how these autistic women found it challenging to interpret non autistic social communication. These accounts alongside recent research (e.g., Pagni et al 2020) provide some support for the so called Theory of Mind deficits as a possible underlying cause of this population's social cognitive problems. Extensive research has been conducted on perspective taking/taking the abstract attitude or Theory of Mind (TOM), most of which has caused outrage in the neurodiversity movement for its assertion that autistic people are deficient in " reading" others, otherwise known as perspective taking (e.g., Milton 2012, 2017; Chown, 2016; Chown & Leatherland, 2018). Autistic autism researchers assert that the difficulties of non-autistic people in reading the minds of autistic people are comparable to the difficulties autistic people experience in "reading" non-autistic people (e.g., Milton, 2012; Gernsbacher & Yergeau, 2019). TOM research will nonetheless be briefly outlined here for context. TOM speaks of several types of "errors" in autistic social cognition. TOM has also been referred to as social intelligence, cognitive empathy, or mentalizing (Mathersul et al., 2013). It refers to a non-autistic capacity to understand another person's mental state, and to use this understanding to infer that person's intentions, thoughts, emotions, beliefs or potential reactions (Mathersul et al., 2013). Some researchers have questioned the role social error monitoring "deficits" play in the social cognitive "difficulties" that autistic persons experience (McMahan & Henderson, 2015). TOM "deficits" adversely impact autistic people's ability to read social cues (emitted by non-autistic others), and they may thus find it difficult to appreciate the perspectives of non-autistic others (Channon et al., 2014; Yang & Baillargeon, 2013). In a study by Channon et al. (2014), 21 adults with Asperger's Syndrome and 21 non-autistic participants read vignettes in which non autistic mentalizing was required to correctly answer a single question about the vignettes. Non-autistic mentalizing was central to assessing a non-autistic subject's mental state. Autistic participants had difficulty inferring sarcasm and intentions. Channon et al.'s (2014) study seem to directly contradict Scheeren et al. (2013), who found that autistic participants performed at the same level as non-autistic participants on TOM tests. Several other studies produced findings in line with Channon et al. (2014). Bodner et al. (2015) found autistic participants had greater difficulty than non-autistic participants in making inferences about the unstated causes of non-autistic people's behaviour. Similar findings were reported by Buon et al. (2013), who showed participants non-autistic cartoon characters engaging in either accidental or deliberate harmful actions toward each other. In this study, autistic participants had more difficulty assessing intentionality related to harmful actions depicted in image sequences than non-autistic participants.

TOM asserts that autistic people often describe having difficulty with perspective taking, which detracts from their ability to "read" the non-verbal cues that non-autistic people take for granted. Difficulty interpreting others' perspectives, emotions, and intentions may affect the social functioning of all people and this was the key message in the phenomenon coined the "Double Empathy Problem" (Milton, 2012). DEP can be defined as "disjuncture in reciprocity between two differently disposed social actors", who have differing perspectives on and expectations of one another (Milton, 2017, p.45). The DEP theory was developed by the autistic scholar Damian Milton who, prior to his son's autism diagnosis and, thereafter, his own, referred to DEP as "*conditioned relativism*" and "*dispositional diversity*" (Milton 2014). Milton first presented the concept of DEP at a conference in 2010 and then published it in 2012 (Milton, 2012). He stated:

*"For many philosophers, the way we talk about something is "more than just words" but frames the way we think about ourselves and one another. By viewing the "autistic person" as the "disordered other", it can reduce an individual's sense of self-worth and self-esteem."* (Milton, 2017: p. 5).

Autism research has predominantly focused on the way autistic people perceive and interact with non-autistic people, with little emphasis on the perspectives of their interactional partners. Autistic individuals such as Milton (2012, 2017) have asserted that non-autistic others have an equal part to play in the two-way breakdown in communication, which originates from differences in people in general rather than deficits in any one individual. This is commonly the case when autistic and non-autistic individuals interact as, according to Milton (2012):

*"Where communication partners have differing dispositional outlooks and personal conceptual understandings frequent misunderstandings and a breakdown in communication is to be expected. It is not a problem that exists in one person, typically the autistic person; rather, it is a double problem, experienced by both people."* (p.884)

Whilst it is known that autistic people often struggle with "typical" social communication due to a variety of factors, Gernsbacher and Yergeau (2019) criticized the widely held belief that TOM deficits are unique to autistic people, and critically examined the empirical basis of this assertion. Their research followed that of Milton (2012) and other autistic researchers who originally critically examined TOM research. DEP resituated empathy and perspective-taking as an interactional process, a two-way street. Their review showed that TOM research failed to support claims that autistic people are uniquely impaired, much less that all autistic people are universally impaired. Gernsbacher and Yergeau (2019) meticulously documented multiple instances in which the various TOM tasks failed to converge or to predict autism, social interaction and empathy. They concluded that data generated by researchers working outside the TOM rubric failed to support assertions made by researchers working within the rubric. They asserted that the claim that autistic people lack a theory of mind is empirically questionable and societally harmful. Yergeau's (2013) "*autie-ethnographic"* essay expressed outrage at the implications of theories such as TOM:

> "*My argument here is that theories about ToM impact the autistic bodymind in material and violent ways. My argument here is that denying autistic selfhood and denying autistic corporeality and denying autistic rhetoricity reifies systemic abuse and ableism. My argument here is that autistic people have come to represent a tidily bounded limit case that signifies what it means to be inhuman—all in the name of empiricism, all in the name of ToM".* (No page numbers in essay).

Belek (2019) concurred with Yergeau, noting that TOM's insistence that autistic people lack the ability to understand that other people have their own mental states, persistently *"and violently"* denied the agency of autistic people. Alkhaldi et al. (2019) investigated the link between the difficulties non-autistic people have with reading autistic people's minds and the negative perceptions they have of these individuals. In their study, videos of autistic and non-autistic people were shown to non-autistic adults who viewed non-autistic people more favourably. Participants were unaware of which videos showed autistic people. Sasson et al. (2017) reported on three studies that found that first impressions of autistic people made by non-autistic observers from thin slices of real-world social behaviour were not only far less favourable compared to controls but also associated with reduced intentions to pursue social interaction. These researchers noted that these impressions were robust, occurred within seconds, and did not change with increased exposure. Furthermore, they persisted across child and adult age groups.

Alongside these growing arguments against TOM stands the alexithymia hypothesis (Bird & Cook, 2013), which proposes that emotional "problems" observed in autism are likely due to co-occurring alexithymia, rather than autism per se. *Alexithymia* is a Greek term used in Freudian analysis that loosely translates to "no words for emotions" and describes challenges in feeling emotions (Cherney, 2020). Alexithymia was found to be a distinctive condition that occurred in at least 50% of autistic people (it occurs in 10% of the general population) (Hill, 2004; Hill et al., 2004). A study by Shah et al. (2016) reported that difficulties with empathy, emotional recognition, and attention to the eyes, as reported by Bird et al. (2010), and Cook et al. (2013), were not, after controlling for alexithymia, associated with autism.

Bolis et al. (2021) used self-report questionnaires to investigate the "dialectical misattunement hypothesis" and social interactions among autistic individuals. Their results demonstrated that the more similar two people were in autistic traits, the higher the perceived quality of their friendship, irrespective of friendship duration, age and gender. Higher interpersonal similarity regarding autistic traits was associated with greater experiences of closeness, acceptance, and help. Carré et al. (2015) examined social motivation in relation to an actual diagnosis of autism. They defined social motivation as "the underlying drive to socialize with others" and noted that social differences in autistic people may relate to differences in social motivation. In their comparison of 20 adults with autism and 20 neurotypical participants, they found that autism diagnosis was significantly correlated with social anhedonia, which refers to a lack of pleasure associated with socialization (Carré et al., 2015). However, these findings were contradicted by those of a qualitative study of 18 autistic adults that used individual interviews as its source (Müller et al., 2008). Almost all these participants expressed a desire for close social relationships but reported “disability-related” obstacles (i.e., difficulties interpreting social cues) to their attainment. While Müller et al. (2008) did not make any gender-based distinctions between participants, in a study on the qualitative differences between male and female autistic people’s experiences, Milner et al. (2019) noted that autistic women had a desire to interact with others and a greater awareness of the need for social interaction. Challenges to socialization and relationship development had substantial adverse effects on the lives of most study participants (Milner, et al, 2019). Autistic people are more likely to be socially isolated (Orsmond et al., 2013), and this combination of isolation and social anxiety appeared to create a feedback loop for some individuals, ultimately exacerbating social anxiety and possibly decreasing social motivation (Swain et al., 2015).

Differences in eye contact and use of physical space have been noted as indicators of social skill “deficits” in autistic persons (Asada et al., 2016; Doherty-Sneddon, 2012), and feature as diagnostic criteria in the DSM 5 (2013). Paying attention to eye gaze cues are a part of social cognition that helps people keep up with nonverbal communication in groups (Böckler et al., 2014, Moriuchi et al., 2015). Missing or misunderstanding such non-autistic communication typically puts autistic people at a disadvantage when interacting with non-autistic people (Böckler et al., 2014) and non-autistic people usually interpret this as a lack of interest in socialization or poor social skills (Doherty-Sneddon et al., 2012). Asada et al.’s (2016) observational study found that autistic people maintain smaller personal space than non-autistic people. This may lead autistic persons to stand closer to others, which non-autistic others may find uncomfortable, adversely affecting their social acceptance of autistic people.

However, an encouraging finding of Asada et al's study (2016) was that autistic participants were able to gage another’s social intentions based on the presence or absence of eye contact and adjusted their personal space in relation to that person based on expectations of social communication.

Although little research focuses specifically on autistic females’ experiences of social relationships, some researchers did find evidence that autistic adolescent girls experienced gender-specific challenges when socializing with typically developing girls (Cridland et al., 2014; Kirkovski et al., 2013). Cridland et al. (2014) conducted a qualitative study exploring the social relationships of autistic girls using three mother-daughter dyads as their source of data. As social relationships among girls became more complex and competitive in adolescence, autistic girls increasingly experienced exclusion that sometimes involved being mocked or ignored because of their “disabilities”. Kirkovski et al. (2013) suggested that adolescent girls’ relationships involve much higher expectations of social reciprocity and communication than that of boys’, which could create additional social hardships. A comparison of primary school-aged autistic boys and girls indicated that both groups experienced challenges related to social acceptance; however, while boys were often overtly rejected, girls were more likely to be simply ignored or overlooked (Dean et al., 2014). Goodall and MacKenzie (2019) presented the educational experiences of two teenage girls with Asperger’s Syndrome with respect to the school environment, teachers, the curriculum, and peers in a mainstream setting in the UK. The findings from semi-structured interviews and several participatory methods revealed that these autistic girls experienced exclusion, isolation and anxiety. Findings from Cridland et al. (2014) and Kirkovski et al. (2013) research suggest that a pattern of being overlooked in earlier years frequently escalates to being actively mocked and ridiculed in adolescence.. Sedgewick et al. (2016) report similar findings in their study on gender differences in autism, noting that autistic girls and women show higher social motivation and a greater capacity for traditional friendships than autistic males, despite the significant social communication challenges generally reported by both groups. Participants in Milner et al’s (2019) study described additional pressure to conform to peer norms, noting that their female peers were much less forgiving towards them than towards autistic males. It is thus unsurprising that autistic females have been more inclined to mask or camouflage their difficulties than autistic males.

The link between camouflaging in autistic women and a desire to fit in has been explored in several recent studies (Milner et al, 2019). Bargiela et al. (2016) explored the lived experiences of autistic women who were diagnosed 'late' (ie: in late adulthood/beyond the optimal early years period of under 5 years of age) and described how their participants felt they had to work hard to “camouflage or mask” their autistic characteristics. Hull et al. (2017) used thematic analysis to identify key elements of camouflaging in their autistic female participants. They developed a three-stage model of the camouflaging process. Firstly, they noted that camouflaging was used to fit in and connect with others. Secondly, they found that camouflaging is a combination of masking and compensation techniques. Thirdly, they identified the adverse short- and long-term consequences of camouflaging, which include exhaustion, threats to self-perception and lack of challenges to autism stereotypes. Cage and Whitman (2019) additionally found that autistic women tend to mask to “fit in” and avoid bullying and stigmatization. Cassidy et al. (2018) reported a stronger, more direct link between camouflaging and suicidality than between suicidality and a delayed diagnosis.

Cage and Troxell-Whitman (2019) assert that the greater propensity for autistic females to camouflage/mask could be explained through an intersectional approach to this phenomenon. Intersectionality refers to the interconnectedness of social constructs/categories such as gender, race, class, sexual orientation which creates interdependent and overlapping systems of disadvantage and/or discrimination (Crenshaw, 1989). Through the lens of intersectionality autistic women face specific barriers due to the male-centric autism narratives (Saxe 2017) and have multiple minority statuses (Cage and Troxell-Whitman 2019).. Bargiela et al. (2016) reported the struggles of autistic women to fit in with gender role expectation (eg being a mother, a partner). An intersectionality  interpretation is further supported by Botha and Frost (2018), who found that autistic people experience minority stress similar to that of other marginalized groups (Altman 2001; Smart 2006), whereby poor mental wellbeing results from *"everyday discrimination and internalised stigma"* (Botha and Frost 2018).

### 2.5 Intimate partner and sexual relationships

Previously discussed challenges to socialization were also relevant to examinations of autistic adults' intimate partner and sexual relationships. Anxiety and lack of social experience adversely impacted the development of intimate partner or sexual relationships for participants with autism, who reported great difficulties understanding communication associated with flirting or courting (Barnett & Maticka-Tyndale, 2015). Once relationships were established, autistic symptoms such as sensory differences leading to under- as well as over-arousal, continued to be challenging (Barnett & Maticka-Tyndale, 2015; Byers et al., 2013). Autistic adults who experienced satisfying intimate partner relationships attributed this success to open and explicit communication with partners about their needs, preferences, and aversions (Barnett & Maticka-Tyndale, 2015; Byers & Nichols, 2014). Notably, however, Barnett and Maticka-Tyndale (2015) did not report gender-based differentiation, thereby leaving a gap in the research.

Difficulties with courting were reflected in a higher likelihood that autistic people would engage in socially “inappropriate” behaviour (Barnett & Maticka-Tyndale, 2015; Dewinter et al., 2013). For example, in a narrative review of 55 studies on autism and sexuality and sexual behaviour, Dewinter et al. (2013) found that autistic participants were more likely to engage in inappropriate courting behaviours, such as touching another person without consent. Autistic adults were also less likely to engage in typical courting behaviour such as asking a person out on a date (Dewinter et al., 2013). Difficulties engaging in socially appropriate/neurotypical courting behaviour may reflect challenges related to reading social cues, cognitive empathy challenges (i.e., reduced emotion recognition), and a lack of disability-relevant education (Barnett & Maticka-Tyndale, 2015). For example, an autistic person who has difficulty understanding nonverbally communicated disinterest might be more inclined to continually pursue the person of their interest (Dewinter et al., 2013). This continued pursuit might reasonably be experienced as intrusive or inappropriate (Dewinter et al., 2013). Reluctance to pursue dating and relationships may prevent autistic individuals from obtaining experience that might lessen their anxiety (Lamport & Turner, 2014). The significance of social functioning “symptoms” of autism such as social cognition and communication was illustrated by Byers and Nichols (2014), who found that individuals who exhibited more significant impairments to social functioning reported lower levels of satisfaction in intimate relationships. Byers et al.’s (2013) online survey of 130 single, non-intellectually disabled autistic adults included some pertinent examination of gender differences. In comparison with single autistic men, single autistic women reported greater levels of difficulty with sexuality, including greater sexual anxiety, lower arousal levels and fewer positive sexual thoughts. Despite these differences autistic women were as likely as autistic men to have engaged in dyadic sexual activity and had similar levels of sexual knowledge. Mothers of adolescent girls with autism also reported concerns about their daughters experiencing greater sexual vulnerability (Cridland et al., 2014). The conjunction of a lack of social cognitive skills and a desire for social acceptance was the root of this sexual vulnerability. Bargiela et al. (2016) reported on autistic women's relationship experiences, including bullying, victimization and sexual abuse. The authors hypothesized that uncertainty about social rules, not knowing how to navigate nuances in social interactions and masking all might play a role in the high incidence of abuse experienced by autistic women. As observed previously, experiences of exclusion and ridicule in adolescence may directly manifest as higher social anxiety among autistic girls (Lai et al., 2011; Lai et al., 2015; May et al., 2014; Milner et al., 2019); however, as also noted, women's own perspectives on their higher likelihood of experiencing mood disorders and sexual anxiety were not explored (Byers et al., 2013; Kreiser & White, 2015). A positive finding was that autistic woman with no intellectual disabilities and who were in intimate partner relationships, reported sexual satisfaction that equalled that of their male counterparts, and an even higher level of overall relationship satisfaction (Byers & Nichols, 2014).

There is a general paucity of interview-based research compared to survey research with autistic women. A noteworthy gap in the literature pertains to explorations of how autistic women achieve positive relationship outcomes, and what supports they might find helpful in this. A greater appreciation and understanding of the support needs of autistic women can only be fully realized through examining the lived experiences of social challenges and associated mental wellbeing difficulties.

## 2.6 Mental health challenges and supports for autistic people

Various studies mentioned above highlight the association between autism and mental health challenges such as depression, anxiety and suicidality (Cassidy et al., 2018). Autistic women have been found to be at greater risk of internalizing difficulties such as depression, anxiety and eating disorders than autistic men who are more inclined to present with externalizing difficulties such as ADHD and challenging behaviour (Hull et al., 2017; Kreiser & White, 2015).

CBT has the largest research base in autism and its efficacy has been well documented (Ung et al., 2015). Preparatory Education and Scripting approaches also benefit autistic people (Gantman, 2012; Kandalft et al., 2013; Morgan et al., 2014). Both approaches are discussed below. Inference generation instruction and Psychodynamic approaches are also presented.

### 2.6.1 Cognitive behaviour therapy

Cognitive behaviour therapy (CBT) is a commonly used psychological treatment that supports individuals to change maladaptive patterns of thinking and behaving (Russell et al., 2013). As CBT is often effective in treating anxiety disorders, and autistic individuals experience anxiety disorders at a higher rate than non-autistic people, CBT has been tested in multiple studies involving participants with autism (Russell et al., 2013; Ung et al., 2015). Russell et al. (2013) described a CBT program that was tailored for use with autistic people. It addressed issues of emotion identification, making connections between emotions, thoughts, and behaviour, and made use of visual tools to clarify psychological concepts

(Russell et al., 2013). Another CBT program that was specifically adapted for autistic participants included social skills education and training, communication training and coaching to develop effective coping skills (Storch et al., 2015).

CBT programs that were specifically adapted to the needs of autistic people all demonstrated positive results. In a sample of 46 autistic adolescents and adults, who were randomized to either CBT or a control anxiety management treatment, both treatments were found to be effective at reducing obsessive-compulsive symptoms in individuals with comorbid OCD (Russell et al., 2013). Non-intellectually disabled autistic adolescents with significant comorbid anxiety who received CBT showed better symptom reduction than those who received their usual treatment of pharmacological or psychosocial treatment (whether already in use or newly initiated during the 16-week study) (Storch et al., 2015). In affirmation of the findings of these two individual studies, Ung et al.'s meta-analysis supported the efficacy of CBT for the treatment of anxiety in autistic adolescents (2015).

### 2.6.2 Preparatory education and scripting

As differences with social cognition and communication tend to affect all areas of autistic people's functioning, treatment approaches are targeted at building these capacities through explicit teaching of social behaviour. Ryan (2001) investigated the therapeutic value of improving narrative competence in non-intellectually disabled people with autism. She posited that since people with autism struggle to absorb and use cultural narratives in communications with others, therapists could aim to support clients in developing coherent self-narratives that could enhance their communication skills.

Several approaches described in the literature addressed "deficits" in social knowledge through social scripting and rehearsal strategies (Bishop-Fitzpatrick et al., 2014; Karayazi et al., 2014; Koegel et al., 2013). For example, the PEERS for Adolescents Program provided education and modelling related to various areas of socialization, including rehearsal of appropriate social behaviour and is associated with significant improvements in social skills, cognitive empathy, social responsiveness, and frequency of attending social events (Gantman et al., 2012).

Virtual reality was another modality used to build social and occupational skills in autistic participants. This uses a realistic representation of another person or persons via computer, which can be controlled by the clinician to speak and behave in specific ways. This instructional modality allows the clinician to present the participant with a safe arena for practicing appropriate social interaction (Kandalaft et al., 2013; Smith et al., 2015). Kandalaft et al. (2013) evaluated a virtual reality intervention that included eight non-intellectually disabled autistic adults who participated in sessions that presented them with a variety of social scenarios. Participants completed a series of measures both before and after the 10-session intervention, and results indicated significant improvements in several areas following the intervention. Specifically, they found that participants improved in areas of emotion recognition, recognizing another person's perspectives and conversational skills. Because job interviews are a fundamentally social process, undeveloped social skills may adversely impact autistic adults seeking employment and preparatory treatments have been developed to help with this. Morgan et al. (2014) evaluated a 12-week program that provided group-based education, modelling, and practice related to social-pragmatic skills that are specifically relevant to job interviews. This included guidance on how to present oneself in terms of attitude and character, how to make small talk and interpret nonverbal communication and how to respond to interview questions. Participants who completed the intervention performed noticeably better on social-pragmatic communication in mock job interviews than control participants, indicating positive treatment effect (Morgan et al., 2014). These findings were reassuring, as they indicated that skills gained in preparatory treatments are transferable to the actual social and employment worlds (Smith et al., 2015).

Although CBT dominates literature as the go-to therapy of choice for autistic people other supportive approaches have also received some attention.

### 2.6.3 Inference generation instruction

I only identified a single study examining the effects of inference generation instruction on autistic participants. Inference generation instruction is defined as an instructional intervention explicitly designed to improve the skill of inference-making (Hall, 2016) Since autistic individuals commonly find inferring unstated information in both social and written forums challenging, explicit instruction on strategies to increase inference generation has therefore been found to be helpful (Murza et al., 2014). These researchers evaluated the effects of an inference generation instructional program that used reading-based strategies. 26 non-intellectually disabled adults with autism were randomly assigned to either treatment or control conditions, and completed pre- and post-tests measures. The intervention provided participants with explicit strategies for developing questions and analysing written text to infer unstated meanings. At the end of the six-week program, the researchers found abilities in making inferences from written material improved, but this ability did not generalize to social inferences. This finding underscored the importance of developing structured interventions that specifically address necessary competencies, as difficulty with generalization is a well-documented challenge for autistic people.

### 2.6.4 Psychodynamic approaches

Vecchiato et al. (2016) provided qualitative research of a single-case Lacanian intervention with an autistic adolescent male. The researchers reported improvement in life skills and socialization over a 12-month period. They also cautioned that research into adequate autism treatments recommended that structured interventions should be regarded as best practice. The psychoanalytic work of Anne Alvarez (1992; Alvarez & Reid, 1999) with autistic children and adults also deserves acknowledgement. Attempts to support autistic children and their parents using psychoanalytic countertransference have added to the understanding of the lifeworld of autistic children and adults. However, Alverez's work operated from the assumption that autism is a pathology, a disordered condition, and interventions were thus treatments for autism. Current understanding of autism as a neurodiversity rather than a pathology, challenges psychotherapists to examine their internalized ableism, and therefore Alvarez's work will not be detailed further here. Considering the needs of autistic individuals for structure and predictability, the unstructured nature of psychodynamic approaches in general seems ill-suited to this population.

### 2.6.5 Psychosocial supports

Psychosocial supports specifically tailored for the diagnosis of autism have been traditionally overlooked, possibly because of the perception of the diagnosis as a profound neurodevelopmental disorder with severe and persistent symptoms (Tebartz van Elst et al., 2013). Researchers who examined both the psychotherapeutic and occupational therapy domains posited that such lack of attention to the therapeutic needs of autistic people impoverishes the skills and knowledge of treatment professionals and deprives autistic individuals of effective autism specific interventions (Ashburner et al., 2014; Tebartz van Elst et al., 2013). Occupational therapists have noted the lack of guidance on appropriate therapies for autistic persons in the research literature (Ashburner et al., 2014).

### 2.6.6 Experiences of supports

Alongside the research on existing therapies and support approaches which may benefit autistic people there is a growing body of research which highlights the dissatisfaction of autistic people with mental health service provision and other supports for autistic people. Vogan et al. (2017) investigated the barriers experienced by 40 non intellectually disabled autistic adults who dot have intellectual disabilities in accessing medical, health and mental health services appropriate to their needs. Their findings highlighted the dissatisfaction and significant challenges experienced by their study-participants who rated the quality of services they were able to access as poor.

There are several strong voices within autistic and neurodiversity communities who have discussed the unsuitability of traditional psychotherapy interventions for autistic clients. Wilson’s (2017) qualitative study on the counselling experience of people with Asperger’s Syndrome (AS) (9 females; 4 males) noted traditional counselling did not “work” for them. Participants expressed their wishes for therapists to have a better understanding of autism, autistic ways of communicating, sensory differences in autism, and emotional challenges inherent to being autistic. Participants furthermore wanted practical strategies and interventions from therapy, and expected respect within the therapeutic relationship. Crane et al (2019) called for a change in mental health supports for autistic people after their online survey of 130 young autistic adults (51.4 % female) (109 online survey; 21 interview) found that participants were stigmatised for being autistic and, in line with other studies, reported significant difficulty in accessing mental health supports. Zener's (2019) investigation into the barriers confronting females in getting a timely autism diagnosis also commented on the overlap between mental health difficulties and autism and urged mental health professionals to consider autism in females who present for intervention. Mandy (2019) asserted that research on camouflaging suggests that autism supports, and interventions should aspire to improve the fit between the autistic person and their environments, using context-based, more ecological approaches instead of focusing on interventions that place the onus on autistic individuals to change how they think and behave.

Milton (2018) similarly cautioned against interventions aimed at equipping autistic people to behave as if they are not autistic asserting that attempts to reduce the so called 'symptomatology' of autism may not improve wellbeing, whilst experiences of stigmatization due to lack of understand felt by autistic people could adversely impact their mental health, ability to access education, employment and support services and encounters with the criminal justice system (Milton, 2018).

### 2.6.7 Training and expertise of mental health clinicians

The previous section noted several studies in which autistic people reported dissatisfaction with support services, and felt poorly understood by clinicians. Courses for clinical psychologists and psychotherapists in Ireland currently include disability placements as potentially the only setting in which trainees may encounter autistic service users. Pearse's (2020) research on deconstructing narrative about autism noted that there are currently no requirements to include neurodiversity and autism in counselling psychology training. She stated: *".. it has been hard to avoid the conclusion that the counselling psychology profession has been inadvertently complicit in the 'hermeneutical marginalisation' of autistic women* *(and autistic individuals in general), and therefore in the wider implications of that for individual lives."* (Pearse, 2020: 97).

Research on existing training and expertise of mental health clinicians who support autistic people suggests that specialist training benefitted professionals in supporting autistic clients. Cooper et al (2018) surveyed 50 CBT therapists in the United Kingdom (UK) to ascertain their confidence in working with autistic clients. Participants reported finding it challenging to work with autistic individuals and that their confidence in providing support was positively associated with level of therapy training received and not with years of practice or adaptations made to CBT programmes. Finding by Cooper et al. (2018) seem to suggest that therapist might have experienced greater challenges in working with autistic clients had they not received specialist training and appeared to find the challenges of working with autistic clients detrimental to confidence in their support provision. Crane et al (2019) reported similar findings to Cooper et al (2018) in their online self-report survey of 172 psychiatrists in the UK. Participants were satisfied with the training they received in autism and linked higher self-efficacy and greater knowledge to this specialist training and to experience of working with autistic clients. Psychiatrists who had personal connections to autism (eg. being autistic themselves, having autistic family members) reported having greater knowledge of autism.

This section has presented a discussion of research related to treatments and therapies for persons with autism, which, overall, seem to point to a need for autism-tailored therapies and competency-specific education and training for persons with this diagnosis (Chown, 2016; Chown & Leatherland, 2018; Milton, 2018; Morgan et al., 2014; Murza et al., 2014; Pearse, 2020; Ung et al., 2015). Researchers have described adjustments to CBT approaches that accommodate the specific needs of persons with autism.

Another common form of treatment or therapy for people with autism was preparatory education and scripting, which addressed social and occupational deficits through combinations of explicit instruction, modelling, and rehearsal by participants (Bishop-Fitzpatrick et al., 2014; Karayazi et al., 2014). These interventions reported improvement in areas such as emotion recognition, perspective-taking, and communication skills (Gantman et al., 2012; Kandalaft et al., 2013). Competency-specific training research presented an optimistic outlook for persons with autism seeking to improve social and occupational outcomes through therapy and training (Murza et. al., 2014) Despite literature highlighting therapies and supports which could potentially benefit autistic people, research into autistic people's experiences of supports found dissatisfaction among autistic people with mental health service provision with some therapies regarded as poorly suited to autistic people's needs (eg.: Milton, 2018; Vogan, 2017; Wilson, 2017): this seems to suggest that existing training programmes for mental health clinicians may not adequately equip them to support autistic clients. To build on the therapeutic and instructional modalities that have been found to be effective for adults with autism the perspectives of non-intellectually disabled autistic women on their desired treatment and support should be solicited. This might contribute to therapists’ awareness of this population’s psychotherapeutic needs.

## 2.7 Rationale for current study

Autistic people with varying levels of cognitive abilities experience significant social and communication challenges that impact their relationships (Barnett & Maticka-Tyndale, 2015), employment (Baldwin et al., 2014), education (Van Hees et al., 2015), and overall quality of life (Orsmond et al., 2013). Non-intellectually disabled adolescent girls with autism appear to experience heightened social difficulties, anxiety and challenges in establishing friendships with typically developing girls than autistic boys do with their peers (Cridland et al., 2014; Kirkovski et al., 2013). They often use coping skills such as masking or camouflaging, which has its own detrimental effect on mental health (Bargiela et al., 2016; Cage & Whitman, 2019; Milner et al., 2019). Several therapies have been found effective in treating anxiety and building social skills in autistic persons (Gantman et al., 2012; Ung et al., 2013); however, little specific attention has been given to the experiences of non-intellectually disabled autistic women nor to supports or therapies that may be experienced as beneficial by this group.

Other gaps in the literature were also identified, including a limited focus on the coping skills of autistic people and the reasons that many utilize ineffective or maladaptive coping strategies (Khor et al., 2014; Samson et al., 2012). Milton and Bracher (2013) and Milton (2018) criticize both the exclusion of autistic voices from research and problematic narratives about autism, noting that scientific discourse has failed to meaningfully explore or engage with the lived experiences of autistic people. Although the specific perspectives of autistic women have received somewhat more qualitative research attention in recent years, (e.g., Bargiela et al, 2016; Leedham et al, 2020; Milner et al, 2019; Tierney et al, 2016) more needs to be done to highlight their experiences and the unique challenges inherent to being an autistic woman.

### 2.8 Conclusion

This chapter has examined existing literature on autism. It presented research on the clinical manifestations of autism referencing and critiquing associated literature on gender differences, interpersonal challenges, intimate relationships, and co-occurring mental health manifestations. As noted in chapter one, the vast majority of autism research has historically used quantitative methodologies, with mostly male participants and  little attention was paid to autism in females, therefore leading to underdiagnoses of the latter population (Pearse, 2020). Relevant studies from this large body of research were included alongside studies from a growing body of qualitative research and research dedicated to autistic women. Considering the significant mental health support needs of autistic individuals, attention was necessarily brought to existing mental health supports, referencing CBT, preparatory education and scripting, inference generation instruction, psychodynamic approaches and psychosocial supports. Following review of the literature a relative dearth of qualitative research about autistic females has been identified. By focussing on richly individual stories and experiences, this study aims to add to the knowledge base on non-intellectually disabled autistic women, through seeking to address existing gaps in research, particularly those relating to the social and relationship experiences of these women. Chapter 3 will provide an explanation of the methods used to address this aim.

### ***Reflexive notes***

*I realized from the outset of my literature review that there was a vast amount of literature dedicated to autistic males, particularly those with associated intellectual disabilities. Conversely, as I commenced this study in 2014, literature on females, especially those with no intellectual disability, was sparse. Qualitative research in autism was also limited, and followed the trend of quantitative research, with a lack of attention paid to autistic girls and women with no intellectual disabilities. I was, furthermore, challenged and frustrated by the deficit-based, medicalized language used in autism studies. Acknowledgement of the strengths and skills inherent to being autistic were difficult to find in literature studies during the early part of my research journey. In recent years research by autistic autism researchers has increased exponentially and was a joy to discover and include in this review. Autism, as it presents in girls and women, received little attention in research to date, which naturally explains why it is so often overlooked in females and there are fewer diagnoses. I felt it was vital to present research that describes autism in general, even if that meant including studies that did not include the presentation of autistic girls and women, as autism is a poorly understood and often stigmatized phenomenon. Although the relative lack of autism research focused on girls and women provided a clear rationale for my study, using literature that mostly examined autism in males felt uncomfortable.*

# CHAPTER 3: METHODOLOGY AND METHODS

## 3.1 Outline

This chapter presents my chosen research design and methodology and my rationale for selecting interpretive phenomenological analysis (IPA) as the most suitable means to address my aims and objectives. I will also outline the philosophical stances underpinning IPA, and their influence on my position. I will describe specific methods, including participant recruitment, data collection and analysis and give an overview of how ethical considerations were safeguarded and rigour was ensured throughout the study. The chapter concludes with a discussion of data collection and reflexive notes.

## 3.2 Aims and objectives.

The primary aim of this qualitative enquiry was to “give voice” to the lived experiences of autistic women who have no concomitant diagnoses of intellectual disabilities. These women are referred to henceforth as autistic women.

The objectives of the study were to:

- to explore the experiences of being autistic women
- to examine the experiences of how autism affects the social functioning of women.
- to identify women's perspectives on how being autistic impacts their intimate relationships.
- to explore women's experiences of the relationship between autism and their mental well-being
- to highlight the types of formal and informal supports autistic women find helpful and may feel they need.
- to consider how the knowledge gained from this study can inform psychotherapeutic practice.

### 3.3 Research design

Quantitative methodologies are, in short, concerned with measurement and numerical data, and are designed to test theories (Creswell, 2007). Lyons and Coyle (2007) assert that the interrelated positivist-empiricist domains are usually the epistemological core of quantitative methodological research. Conversely, qualitative methodologies strive to generate knowledge through the application of inductive reasoning. This study used a qualitative methodology: interpretative phenomenological analysis (IPA). There are a variety of qualitative research methodologies from which to choose while planning a research project. The selection of methodology depends primarily upon the question posed by the researcher. Thus, the research question, as well as the researcher's aims and objectives, aid in selecting an appropriate methodology. During a researcher's analytic engagement with data gathered from participants, themes emerge that lead to pattern identification and ultimately to theorising which may illuminate the phenomena under investigation (Durr, 2008).

The interpretivist paradigm honours the subjective experience of participants and in doing so acknowledges the ontological assumption that social reality can only be understood from within (Nieuwenhuis, 2007) and is therefore socially constructed (Mertens, 2014). While positivists begin their research endeavours with a theory firmly identified in advance, interpretivists do not. Instead, interpretivists research to *"generate or inductively develop a theory or pattern of meanings"* (Creswell, 2007, p.9). Within the field of interpretive research, the role of the researcher is as an active participant in data generation and interpretation (Maree, 2007).

When qualitative research uses a phenomenological lens, the aim is to illuminate "something" specific, to identify how phenomena are perceived by the actors in a situation. Phenomenology is thus interested in studying the subjective experiences of individuals as they appear to those individuals through their uniquely individual perspectives. Phenomenology posits the value of understanding lived experience and meaning making, which Van Manen (2016) viewed as inextricably linked with existence and Heidegger's notion of *Dasein* (being in the world). This view slices through the clutter of taken-for-granted assumptions and conventional wisdom.

> *"Phenomenological method is driven by pathos: being swept up in a spell of wonder about phenomena as they appear, show, present, or give themselves to us. Phenomenology is more a method of questioning rather than answering, realising that insights come to us in the mode of musing, reflective questioning, and being obsessed with sources and meaning of lived meaning."* (Van Manen, 2016: Preface)

Phenomenology stands in stark contrast to positivist research paradigms that seek objective, universal, generalizable "truths" in pursuit of "theory-testing". Two phenomenological approaches are often used to pursue qualitative research: Descriptive or "pure" phenomenology, as per Husserl (2001, 2012) and Giorgi (1997, 2010), and interpretivist phenomenology, championed by Heidegger (Heidegger et al. 1996). Smith et al.'s (1996) Interpretative Phenomenological Analysis fits within this latter paradigm.

### 3.4 Why IPA?

Since the principal aim of this qualitative enquiry was to "give voice" to the lived experiences of autistic women, IPA recommended itself as the most suitable methodological approach. IPA, which is concerned with meaning making rather than describing essential experiences (*a la* Husserl) guided me, the researcher, to interpret the participants' own interpretations of their experiences.

My concern in this study was with participants' experiences of being autistic and how these experiences could improve psychotherapeutic support for autistic women more generally. IPA is informed by a variety of different schools of thought, in particular phenomenology, hermeneutics and ideography. Each of these underlying philosophies forms an important part of the IPA approach, which seeks to understanding the nature of human experience within a specific context, and which I elaborate upon below. At its core, IPA is concerned with lived experiences and how these are interpreted and with immediate claims about the group under study (Smith et al., 2009).

**Phenomenology:** As its name suggests, IPA is a methodology that draws heavily from phenomenology. A phenomenological tradition was utilized for this study, which allowed me to encounter *"[the] phenomenon with a fresh perspective, as if viewing it for the first time,* *through the eyes of participants who have direct, immediate experience with it"* (Hays & Singh, 2011, p. 50). Phenomenology is a philosophical paradigm that intensively studies the human experience. It focuses upon the daily lives of individuals and pays attention to the ways in which things "matter" to them. As it is impossible to view the world from a truly objective standpoint, phenomenology does not attempt to present its findings in an objective light. Simply put, phenomenology concerns itself with the sense people make of their unique personal worlds. Van Manen (2011) posits that phenomenology concerns itself with lived experience rather than categorizing, conceptualizing, or theorizing.

Edmund Husserl (1858-1938) developed phenomenology, and his student Martin Heidegger (1889-1976) expanded on his mentor's project. Husserl's "transcendental phenomenology" (2001) urges a focus on the essential structures of objects, through "bracketing off/out" that which we take for granted about an object in the "natural attitude", which is characteristic of both our everyday life and ordinary science. Husserl posited that the resulting perspective on the realm of intentional consciousness would enable the phenomenologist to develop a radically unprejudiced justification of his or her basic views on the world and his or herself and thereby explore their rational interconnections. He considers intentionality – how the world is "given to consciousness" – to be phenomenology's primary principle. To access intentional consciousness, the reflective technique of "bracketing off/out" or "epoche", a setting aside of our preconceptions of the world, is used.

Husserl wanted to arrive at the structure of the pure essence of experience. By contrast, Heidegger's *Dasein* (Heidegger, et al. 1996), a philosophy of thrownness, an already-being-in-the world, a being-with, challenges Husserl's ideal of core essences by emphasizing inter-subjectivity: a making sense of the other.

The philosopher Merleau-Ponty (Russon, 1994) posited that our living body, our embodiment, is in a dynamic process of establishing contact with the world. It is in, through and as this process of being-bodily-in-the world, that what the world is, and who we are, comes into being (Smith, et al 2009). Sartre (1905-1980) contended in “Being and Nothingness” (2001) that there is not a mere “being” but a “becoming”. The conscious being, by realizing what it is not, thereby discovers what it is: a becoming being with absolute freedom to choose its own being, and, in doing so, taking responsibility for the being-ness chosen. Heidegger’s “embedded”, Merleau-Ponty’s “embodied” and Sartre’s “becoming” each moved away from Husserl’s transcendental focus towards a Heideggerian interpersonal interpretative focus: the field of hermeneutics, which is the second paradigm underpinning IPA (Smith et al., 2009).

**Hermeneutics:** Hermeneutics as a paradigm is older than the philosophy of phenomenology. It originated from interpretation of Biblical texts. The aim of this interpretation was to get as close to the author’s original intention as possible: to uncover an original meaning. Hermeneutics is thus meaning making via interpretation. While discourse must be accessed to be interpreted, for Heidegger, *Dasein*, as an existential, transcends discourse. What he proposed was not discourse but “in-sight: ‘a seeing into’ the hidden structures of people’s *being,* and the hidden structures of *being*, per se. The phenomenology of *Dasein* is hermeneutic in the primordial signification of this word, where it designates this business of interpreting (Heidegger, et al.1996). For Heidegger truth of *being* is primordial. It begs to be uncovered or revealed. Heidegger uses the Greek word *aletheia*: an unconcealment, to refer to this process of uncovering. Heidegger’s methodology attempts to broaden out, or re-situate, notions of “understanding” and “interpretation” as being more than mere tools of critical reflection. For Heidegger, understanding and interpretation are instead modes of *being* (Mills, 1997). *Dasein*, as a pre-reflective and universal means by which individuals find themselves in the world, is inevitably hermeneutic in nature (Heidegger, et al. 1996). The world is familiar to people through basic and intuitive ways of doing things, whereby intuitive and tacit approaches, coupled with pragmatic ideals of know-how, predominate. Initially, Heidegger argues that people do not start understanding their world by just acquiring the objective facts, representational knowledge, or algorithms from which they can derive or establish universal laws, propositions or judgments that to some extent correspond to the world. People understand the world first and foremost by simply being in it. The hermeneutic circle of interpretation, as presented by Heidegger, thus encompasses the interplay that exists between an individual's self-understanding and their understanding of the world (Schalow & Denker, 2010).

In this study the researcher engages in second order sense making of the first order sense that the participants make of their own experiences. Through this so-called double hermeneutic process (Smith et al., 2009), *"The researcher starts with a pre-understanding and 'moves on to being opened to discovering something'"* (Finlay, 2011, p. 53). This openness to re-interpreting an initial understanding, revising this understanding, and then challenging the new interpretation, allows one to arrive at a deeper understanding of a phenomenon. This iterative process, a to-and-fro between the researcher's preconceptions and stimuli provided by the data, is a central feature of IPA analysis in which interpretation is seen as *"a dialogue between what we bring to the text and what the text brings to us"* (Smith et al., 2009, p.26).

**Idiography:** Idiography is the third major influence on IPA, and, unlike the nomothetic of psychology, concerns itself with the particular, the detail, and thus the depth of analysis

(Smith et al., 2009). However, it is understood that the particular never finds itself in isolation. It also gives rise to the general. This means that researchers are just as interested in how various themes and trends can be generalised across certain cases and sets of data (Rizq & Target, 2008). Thus, the *"idiographic study can form part of, and work towards a general law, but the way of doing this will be different from methods beginning with nomothetic assumptions*" (Smith, et. al., 1995). In IPA, the analytic procedure and general statements are derived from single case analysis (Smith et. al., 2009) and broadened to create trends and themes across participant experiences.

### 3.5 Critique of IPA

Willig (2001) has been vocal in her criticism of IPA, noting, for example, that she could not ascertain the difference between it and grounded theory. In response, Smith (Smith & Osborne, 2008) contended that the critique raised "*questions*" rather than "*limitations*". Larkin et al (2011) responded to Willig's "*questions*" in a systematic fashion, as outlined below.

**Language and loquacity:** IPA requires the selected participants to enunciate their views effortlessly using language. Willig (2001) argued that reality is constructed through language and that a variety of different words can be employed to describe a single event or experience. She was furthermore of the opinion that what is captured by a transcript is not the experience of the participant but rather the participant's felicity or absence of it. Elaborating, she stated that the ability to capture the minutiae and nuances of experiences is an unwieldy task and the ability of participants to do just that is questionable.

Larkin et al (2011) noted that IPA makes no claims about its ability to access the personal experiences of another, but rather tasks itself with reaching the person's personally described account of their experiences. Larkin et al (2011) supported by Smith & Osborn (2008) also emphasized that, in analyses of transcripts, IPA does not advocate for the interpretation, in isolation, of the meaning of the words used by participants to describe their experiences. Instead, it seeks a keen awareness of the meaning offered up by the context the in which participant finds him or herself.

I contend that Willig's argument that the language of IPA is incapable of capturing subtleties and subtexts of experiences in the natural world is moot. This argument can be made of language in its most general sense. As Wittgenstein (1953) noted in Proposition 7 of his *Tractatus Logico-Philosophicus*: "*Wovon man nicht sprechen kann, daruber muss man schweigen*" ("whereof one cannot speak, thereof one must remain silent.") (White, 2006). Language per se is limiting and limited. Wittgenstein's frustration with this reality was evident in his assertion that our worlds are limited by the ability of our language to capture it.

**Describing vs explaining:** Willig (2001) further argued that IPA is merely descriptive in its engagement with the lived experiences of participants, it does not sufficiently explain how these experiences came to be. She felt that the origin of a phenomenon is thus disregarded, thereby limiting any understanding of it. Willig (2001) noted that the rich descriptions of how participants perceive the world that IPA provides do not tend to further our understanding of why such experiences take place (Durr, 2008). Larkin conceded that IPA is *not* explanatory by design but stated that this is true of all qualitative psychology and, as such, he did not view this as a limitation of IPA (Durr, 2008).

Giorgi (2010) provided an extensive critique of IPA in which he contended that, due to its methodological flexibility, IPA was not good science; he maintained that a so-called lack of rules governing the researcher's cognitive processes in terms of data analysis renders resultant studies difficult to replicate, and that the lack of a critical view of raw data leaves researchers open to be selective with the raw data. Smith (2010) responded to Giorgi's criticisms by stating that Giorgi used selective sources in his critique of IPA and that IPA has a clear theoretical grounding in phenomenology and hermeneutics, as detailed by Smith, et al (2009). Smith noted that IPA does not have a prescriptive methodology akin to quantitative approaches, yet offers the researcher built-in constraints in the form of their own professional and personal skills and the quality control criteria advocated by Yardley (2007). Smith furthermore disregards Giorgi's replicability criticism, noting that it was not "... *an appropriate referent for judging most qualitative approaches to psychology"* (p.189). Fitzgerald (2012) described IPA as a new approach, not as highly developed as other qualitative methodologies and suggested that the use of phenomenological philosophy and theory in research is both varied and contested. Shaw (2010) described IPA as the new kid on the block and felt that a lively debate, including critiques from a variety of researchers is, in fact, healthy.

I was intrigued by Willig and Giorgi's critique of IPA particularly Giorgi's contention that IPA lacked sufficient rules and guidance about how to conduct research. I wondered how the richness of a phenomenon could be explored in qualitative research if a less flexible, more constraining, rule-bound approached was to be used (my reading of Giorgi's criticism).

### 3.6. Reflexivity: the researcher's position

In qualitative research such as IPA there is an acknowledgement that the researcher's subjective involvement with the data collected added richness to both the data itself and the findings generated.

The experiences of participants are not directly available to the researcher. The IPA researcher has an active role (Smith & Eatough, 2007) and the use of the double hermeneutic makes IPA a dynamic process (Shaw, 2010). Chapman and Smith (2002: p.126) thus contented that:

> *… the researcher's own conceptions are required in order to make sense of the personal world being studied through the process of interpretative activity.*

Many researchers advocate for a turning back on oneself by way of reflection on practice, to track the research process and capture one's presuppositions, expectations, hunches and evolving ideas. Moustakas (1990) introduced the "self" as a tool in psychological research and, since the qualitative approach acknowledges that the research and the researcher's "self" are invariably intertwined, it is important to conduct disciplined reflection on this phenomenon. A reflexive researcher is aware that the personal, social, and cultural contexts in which we live - and work - inevitably influence how we interpret at each stage of the research (Etherington, 2004).

Howard et al (2019) argue that the double hermeneutic nature of IPA, in which the researcher strives to makes sense of the participants' experiences just as the participants themselves are attempting to make sense of their own experiences, can bridge the gap of the "double empathy" problem (Milton, 2012), making it a valuable method for data analysis with autistic participants (see p. 21).

One of the challenging aspects of being an "insider researcher" has been to notice how my acculturation into the context of working as a psychologist in autism services motivated me to conduct this research. My own association with other autistic researchers, clinicians and professionals may also have influenced how I embarked on this study. Reflexivity thus demanded that I consider how my own *Dasein*/selfhood and presumptions influenced my relationship with the data. It was thus important to me to explicitly dwell and reflect on my own lived experience as an autistic woman, my personal background, and my professional training. I did so by questioning any emerging assumptions, particularly during the data collection and transcript analysis stages of the process. My engagement with my supervisors, who are experts in IPA, further aided my reflections on the data and the emerging themes.

## 3.7. Methods

### 3.7.1 Sample size

In keeping with IPA's small participant-number design, seven women were interviewed in semi-structured interviews, as recommended by Smith et al. (2009) and Pietkiewicz and Smith (2014).

> *"… six to eight participants is appropriate for an IPA study as this size sample gives an opportunity to examine similarities and differences between individuals. At the same time, the amount of qualitative data gathered is not overwhelming. In general, IPA researchers should concentrate more on the depth, rather than breadth, of the study."* (p.9)

### 3.7.2 Recruitment

Purposeful sampling was used to identify potential participants. A Facebook site for autistic women living in Ireland was used as a forum to invite potential participants. This closed and private Facebook group is solely dedicated to autistic women. Groups such as this are generally closed and private to protect the identities of members, as well as their posts and comments. I thus first had to request to be added as a member, clearly declaring my intent to join as a researcher. Study participants were aware from the onset that I am autistic. Two participants on this fact by indicating that they find it easier to speak to autistic people than to people who are not autistic. Once accepted, I wrote a brief post inviting group members to participate in this study, asking any interested women to send me a private message if they wished to receive further information on the study (See Appendix A). Interested parties were sent a more comprehensive outline of the study along with inclusion and exclusion criteria. (Appendix E). After one week I posted a reminder. Unfortunately, too few women had responded by that point, so I moved on to using “snowballing”: participants who had already put themselves forward were asked to inform other autistic women of my study. Four of the seven participants were recruited through snowballing.  At the end of this process, I had contacted enough interested women to conduct the study. After any potential participant contacted me, I checked if they met the inclusion criteria. I then emailed them details of the study, including a Plain Language Statement (See Appendix C) and Consent Form (See Appendix D). I asked that potential participants indicate if they still wanted to participate in the study after reading the provided material. Participants who indicated their interest were offered the option of a face-to-face interview at DCU, or an online interview via FaceTime or Skype. Early in the recruitment process, I submitted an ethics amendment application to allow me to offer the choice of remote interviews as some potential participants cited anxiety and trepidation at the thought of meeting a stranger in an unfamiliar setting. Six of the women opted for an online interview, the seventh was willing to attend in person.

I have listed the relevant inclusion criteria below (also outlined in Appendix E):

- Be female.
- Have a diagnosis of autism spectrum disorder (ASD): self-report.

- Have no diagnosed intellectual disability: self-report.
- Be over the age of 18 to give informed consent.
- Resident in the island of Ireland

Once participants met these inclusion criteria no further or additional exclusion criteria were applied.

### 3.7.3 Participants

To capture participants’ demographic information concisely I set about generating a table with the relevant participant details (Appendix G). I realised that the participants would easily be able to identify themselves in this representation of their personal demographics, and, furthermore, given the relatively small but active nature of the online community of autistic women, were also highly likely to be able to identify other participants. This concerned me as I was obliged to fulfil my ethical commitments to participants regarding anonymity and confidentiality. In lieu of representing demographic details in this chapter, I captured pertinent demographic data in a descriptive summary below.

#### 3.7.3.1 Summary of participant demographics

**Age ranges:** Three of the women were in the 20-35 age range, two were in the 35-50 age range and two were in the 50-65 age range.

**Relationship status:** Five of the women were single. One was married and one had relationships which she described as "casual". Three participants were mothers. Two were single parents and one shared parenting duties with her husband.

**Living arrangements:** One participant lived alone. Three lived with a parent or parents. Two lived with their children and one lived with her husband and children.

**Age at diagnosis:** One participant was diagnosed in primary school. Two were diagnosed in late adolescence. Four received their diagnoses as adults.

**Employment:** Two participants were unemployed or seeking employment. One was a full-time student. Two participants were self-employed. Two participants were in full-time employment.

### 3.7.4 Data collection

Semi-structured interviews were used to gather rich accounts of the seven women's experiences of being autistic. As previously stated, one woman was interviewed in person, while the rest opted for online interviews via FaceTime and Skype. As noted by Deaking and Wakefield (2013), rapport-building can be a challenge in online interviews due to the lack of physical presence. However, the two researchers also highlight the benefits of online interviews, arguing online interviewing can be a useful supplement to or replacement for face-to-face interviews. Considering that the participants claimed to be less anxious in having the interview via Skype or FaceTime, I felt that the data collected online were likely to be richer than would have been the case if participants were constrained by the anxiety of in-person interviews. Participants also communicated feeling at ease with the interview process. During the interview sessions (averaging 1 h 31 minutes) I remained vigilant to any potential emotional strain participants might be experiencing. I offered breaks if participants seemed like they needed to pause. Given the pervasive anxiety that is often reported by autistic people in general (Kent & Simonoff, 2017), the likelihood of participants experiencing emotional strain was at the forefront of my mind during the interviews. One participant opted for a brief pause; others were offered opportunities to pause but declined them. A protocol was put in place if any participant became distressed during the interview (Appendix F).

The single face-to-face interview was held at the DCU campus to ensure the safety of both the participant and the researcher. A comfortable and confidential atmosphere was provided for the duration of the interview. The six online interviews afforded the participants the safety and comfort of their own familiar surroundings (see also Beneficence in section 3.8 on Ethical Considerations). The participants were asked to complete the written consent form (Appendix D) before the interview and invited to ask any further questions they might have via email. Participants were assured that the information they shared would be managed with due concern for their privacy and anonymity. The use of semi-structured interviews addressed the main study aim, which was to gain rich, full experiential narratives of the life-world of autistic women (Durr, 2008). I developed an interview schedule (Appendix B) before commencing the interviews. This schedule was designed to help facilitate natural conversation whilst also serving as a gentle guide to keep myself and particpants on track throughout the process. The questions were expansive and open in order to encourage thoughtful and detailed responses. The interview schedule also included various potential prompts designed to help participants answer questions that they might find abstract or confusing. These prompts were included with due consideration to the nature of autistic understanding and use of language, which tends to lean towards the concrete. The use of prompts and follow-up questions proved useful in facilitating deeper exploration of some the experiences offered, whilst also providing a scaffolding type structure to support the participants in sharing their narratives. Given the sensitive nature of some of the interview questions, as well as the thought-provoking prompts, I needed to remain alert to the emotional state of each participant, as previously noted. This allowed me to offer pauses or breaks to participants who became emotional.

### 3.7.5 Data analysis

The enquiry process that typifies qualitative research features a recursivity and fluidity between the gathering of data and data analysis. To remain on track, I utilized the systematic approach proposed by Smith, et al (2009).

Step 1: This step constituted my initial encounter with the text. In this phase, I first listened to the recordings of each interview, and then read, and re-read the verbatim transcript. I noted what I perceived as interesting and significant elements of the participant narratives in the right column of the transcribed interview. These were categorised in three types of comments: descriptive, linguistic (e.g. striking phrases, unusual/interesting use of language etc.) or conceptual (e.g. what is the participant saying here, what is her concern?). I also included my own thoughts and observations here.

Step 2: In this step I moved towards identifying themes by reading the text more sytematically, using provisional labels in notes recorded in the left column of the transcript.

The titles used for emerging themes aimed to capture something of the intrinsic quality of the participants' accounts.

Step 3: Here I explored emerging themes and remained vigilant to potential experiential connections between themes (Dallos & Vetere, 2005; Willig, 2012). Connecting themes were clustered together, thereby introducing structure into the analysis. I compiled a themes table for each participant in which I captured emerging themes and related quotes. Some emerging themes that had been identified were eliminated at this point as they were not substantiated in the narratives during the iterative phase of moving between theme development and data.

Step 4: In this step I repeated the process of steps one through three for each participant.

Step 5: I compared individual theme tables, seeking converging patterns that might exist across participant tables, whilst respecting divergence and the individuality of each participant's experience .

Step 6: In this step results were collated in table format to highlight four superordinate themes with their respective subordinate themes. The themes aimed to capture some semblance of the phenomenon itself (Willig, 2013). (See samples of analysis in Appendices I & J).

The next stage was the development of narrative accounts using illustrative quotes. This is included in the next chapter.

Reflexive research journal: In addition to regular engagement with my supervisors, making use of reflexive journaling and attending peer consultations at IPA workshops helped me maintain objectivity in the interviews and during the analysis phase. I wanted participants' voices to be the focus, and understood that my role as researcher was to be faithful in my reflections on and descriptions of their experiences. The iterative analysis process allowed me to review my interpretations against the data so that new insights were not overlooked. In addition, this helped me to be aware of areas in which I identified with participants' experiences (in relation to sensory sensitivities, for example, or the so-called "double empathy gap"), as well as when my own lived experiences of autism differed from those of the participants (for example in my Dasein/thrownness, relationships or employment).

### 3.7.6 Data management

All the interviews were audio recorded and then transcribed. Participants were assigned pseudonyms to protect their identities. The recorded interviews were downloaded onto the researcher's computer and protected by a password. A unique serial number was allocated to each recording. Thereafter, the recordings were copied to a USB device. The USB device served as back-up of the data, which was later transferred back to the researcher's computer for further analysis. During this stage of my research, General Data Protection Regulation (GDPR) (EU: 2016/679) guidelines regarding the management of personal data came into being in Irish law. It now forms the basis of new Irish Data Protection laws (Data Protection Acts 1988-2018). In accordance with GDPR directives I moved the data from a USB storage device and onto DCU's secure Google Drive. The verbatim transcriptions were saved on my secured computer for the research period, where they could be studied further in the data analysis stages.

## 3.8 Ethical considerations

Before the study commenced, approval was applied for and granted by the DCU Ethics Committee (Appendix H). Once approved, the recruitment and selection of participants began.

I was guided by the following primary ethical principles in this study (Beauchamp & Childress, 2001).

- **Autonomy:** Respecting the autonomy of participants includes ethical considerations of consent and anonymity. The privacy of participants and their informed consent, anonymity and confidentiality were therefore critical considerations during the study design. The limits to confidentiality were outlined in the Plain Language Statement (see Appendix C) and Consent Form (see Appendix D). As noted, the participants signed consent forms prior to the commencement of interviews, indicating that they understood the interview process, the limits to confidentiality, and how the information garnered from interviews would be managed. I safeguarded confidentiality and anonymity throughout the study by:
    - Separating the transcripts from participant demographic information
    - Considering how participant demographics were presented, considering that participants were recruited primarily through a Facebook group for autistic women in Ireland. This is a small group and thus participant information was at high risk of being identifiable. All potentially identifying details were removed from the transcripts. Quotes also had to be used carefully. As noted previously, a summary of the participant demographics was given instead of a narrative description of each participant's demographic information to further protect the participants' personal data.
    - Participants were made aware that all participant data were encrypted and kept on a password-secured computer and USB device. After GDPR came into being, data were stored on DCU secure Google Drive and the USB storage was

no longer used. All transcripts were anonymized. After data has been used for further publications, it will be destroyed, not only through deletion of files from the computer, but also by applying a confidential scrubbing program to devices.

Autonomy also refers to the right of individuals to make their own choice with regard participating in studies or not. Participants and potential participants thus have the right to choose to participate in any project of their own volition and, similarly, to withdraw from participation if they so wish. The voluntary nature of participation in the study was emphasised to the participants, and it was explained that they could withdraw at any time until the moment that the data analysis had commenced, without having to explain or justify such a decision, and with no negative consequences. Participants self-selected to participate, which means they were not coerced into participating in this study. Participants made the initial contact with me themselves and it was important for me to clarify early in the process that their participation was voluntary. In terms of respecting autonomy, one participant requested to speak at length until she was finished and a two-hour interview was facilitated.

- **Beneficence:** Any researcher should always act in such a way that the best interests of the research participants remain paramount. This was a major ethical consideration that had to be kept in mind in this study due to the vulnerability of the population being researched. Additional efforts therefore had to be made to ensure the emotional and physical safety of participants. Providing participants with the option of an online interview allowed them to participate from the comfort, safety, and familiarity of their own home environments, thereby reducing their anxiety and freeing them to speak without concern that their interviews might be overheard or they might be recognised en route to a face-to-face interview, all of which were concerns that many of the women had voiced. I took care during interviews to monitor participants for signs that could indicate they were experiencing distress. In some cases, accounts of sexual abuse were named, although these were not described in detail by participants. One participant's experience was reported to the gardai by her parents when it occurred as she was under the age of consent at the time. These particular experiences were not examined in this study as my instinct of "first do no harm" dictated that I do not probe participants beyond what they spontaneously divulged.

Known communication difficulties inherent to autism also had to be considered. All written material used plain, concrete language; the option of augmenting plain language statements with visual representation was considered, but since all the participants had completed formal education to at least leaving certificate level, this was not required. As per the inclusion criteria, none of the women had an associated intellectual disability which might have affected their ability to make informed decisions regarding participation in the study.

I also exercised respect and due care towards participant vulnerability in my approach to the narrative write-ups of participant accounts ensuring no identifying information was included.

- **Non-maleficence**: Non-maleficence refers to the act of doing no harm to research participants in order to reach a beneficial outcome. In other words: research participants cannot, under any circumstances, be subjected to physical or psychological harm in order to achieve a specific study goal. In the event of participants requiring more than a debriefing after the interview process, I had to ensure that a list of relevant, easily accessible support services to which I could refer participants, was ready to hand. I provided the list of support services to participants (Appendix F) after their interviews. However, none of the participants presented with distress indicative of needing onward referral following their interviews.

- **Justice**: The concept of justice demands the fair and equal treatment of all research participants. The right of the participants to have their study contributions considered as equal by the researcher also falls under the concept of justice. I attended to this concept by striving for the fair inclusion of participant experiences in the iterative process of the narrative accounts and checking that I stayed true to the participants' experiences and by reflexively engaging in the analysis process and avoiding veering too far from participants' own voicing of their experiences.

### 3.9 Validity and rigour

In any research study, quality and rigour are essential considerations. Rigour in qualitative research can be enhanced using standards such as responsiveness, reflexivity, purposive sampling, rich description and transparency (Cook et al., 2016).

The validity and trustworthiness of any study should be demonstrated through a transparent audit trail (Smith, 2010; Smith et al., 2009). I aimed to demonstrate this by striving for credibility, confirmability, and dependability and by using transferable interview and analysis methods. To increase the credibility and "truthfulness" of the study, I reviewed themes as per Smith's (2009) guidance that "*each theme presented has been supported with sufficient extracts from participants to illustrate both convergence and divergence in how the theme is manifest*" (p.190).

Credibility was increased through data saturation and reflexivity. Data saturation demanded that I engage in an iterative process of repeated, close reading of the data and emerging themes until no new information surfaced. A firm commitment to self-enquiry aided me in minimizing personal bias, which also increases the confirmability of any study. This reflexivity required me to engage in constant self-inquiry throughout the data collection and analysis procedures. The suspension of personal judgement was a key aim of mine as I am an autistic woman, however, my own lived experience of being autistic afforded me a greater sensitivity to some of the emerging issues.

Proper documentation of data was a necessity, as this increases dependability and consistency, aids transferability, and, furthermore, allows future researchers to replicate the study. It also enabled me to cross-check the data with accurate quotes.

Smith (2010; Smith et al., 2009) recommends the use of Yardley's model (2007) to demonstrate the credibility in an IPA study. This model highlights the following four criteria:

**Sensitivity to context:** The researcher demonstrates a sensitive awareness of the socio-cultural context of the study: *"language, social interaction and culture are understood by most qualitative researchers to the meaning and function of all phenomena"* (Yardley, 2000, p.220). Mindfulness of context asked me to pay attention not only to existing literature and research regarding autism, but also to my interpretation of such information in order to allow diverse perspectives to inform my own analysis.

**Commitment and rigor:** Commitment denotes an in-depth immersion with the topic, and the research question; in other words, the researcher should do what they set out to do. I also had to develop skills and competencies in IPA as my chosen methodological approach (e.g. sampling and data-collection and -analysis). Demonstrating rigour involved my producing completed accounts of analysed data. My data analysis thus had to be sufficiently sophisticated; not only in its focus on deep, insightful accounts of individual participant narratives, but also, in the final analysis, by highlighting convergences and divergences.

**Coherence and transparency:** A coherent study has a clear rationale and demonstrates a good fit between the research question, approach and methods and the interpretation and persuasive dissemination of the data collected. A transparent study makes it clear to the reader how the study was conducted in a step-by-step basis, explicitly disclosing all aspects of the research process (through, for example, the use of tables, a clear paper trail and details of the reflexive processes, see Appendices I and J for examples of this).

**Impact and importance***:* It is a necessity that any study makes a clear and identifiable impact in one or more of the following areas:

- **Practical implications:** Informing clinical psychologists, psychotherapists, other health care practitioners, policy makers, the general community, and the autism community of study outcomes by disseminating this research in relevant journals and publications, presenting at conferences , providing training opportunities to relevant stakeholders.
- **Theoretical implications:** Sharing knowledge garnered from the study with colleagues via for example conference presentations could enhance understanding of a phenomenon, in this case autism in women, which, in turn could potentially lead to changes in the real-world approach to identifying, diagnosing and appropriately supporting autistic women.
- **Socio-cultural implications**: Changing views or perspectives and treatment of a group because of findings generated by research. A desired outcome of this

study was to raise awareness of autism in women, and to emphasize the support needs of autistic women regarding diagnoses and interventions (see section 5.6 in the following chapter for more on the implications of the study).

### 3.10 Conclusion

IPA was deemed the most appropriate methodology to address the research aims and objectives "*What is it like to be an autistic woman?*" Since the "*experience*" of being autistic is the main subject of this research, IPA offered flexibility in answering psychological rather than sociological questions (Howard et al 2019; Willig, 2013) The study was grounded in constructivist as opposed to positivist paradigms, and in the belief that all experiences are "*soaked through with language*" (van Manen, 1990, p. 38). As researcher I therefore immersed myself in analysis and interpretation of the data contained in the participants' stories. Through reflexivity and critical self-questioning, I engaged with each step of the process, as well as with my expanding thought-processes at every twist and turn of the study. IPA invited me, the researcher, to bring myself to this study as the methodology assumes that the researcher's analysis, awareness, and interpretations are valuable and intrinsic to the process of interpretation.

#### ***Reflexive notes***

*Considering that autistic women are a vulnerable population I had to mindfully consider and anticipate that ethical, methodological, and perhaps also philosophical considerations might arise, which would require additional attention and flexibility in my approach. As a novice IPA researcher, I felt nervous about "getting it right": doing justice to my participants and honouring their narratives by staying close to their own accounts of their lived experiences in* *my analysis. I was excited and concerned at the same time. I felt that IPA gave me a semi-structured map; a systematic method and guidance about how to position myself as researcher that would equip me to manage challenges and issues that might arise in my study.*

# CHAPTER 4: FINDINGS

This chapter will present and discuss the four superordinate themes and respective subordinate themes that emerged from my analysis of the seven interviews.

The discussion of each superordinate theme and its corresponding subordinate themes is provided alongside excerpts from the interviews in order to illuminate the lived experiences of the participants and provide a narrative account for each theme.

I conclude the chapter with a summary of the key points.

Four superordinate themes were identified from each of the seven interviews:

1. **Experience of being**
2. **Being alongside others**
3. **Coping and resilience**
4. **Receiving and giving support**

| **Superordinate Themes** | **Subordinate Themes** | **Nr of participants referencing theme** |
|---|---|---|
| **1. Experience of being** | 1.1 Believing there is something wrong with me | 6 |
| | 1.2 Being at the mercy of heightened senses | 7 |
| | 1.3 Melting down, shutting down: you cannot outrun the tidal wave | 7 |

| | | |
|---|---|---|
| **2. Being alongside others** | 2.1 Struggling to understand and to be understood; wondering why people don't just say what they mean | 7 |
| | 2.2 It is easier to interact with people who know what it's like to be me | 7 |
| | 2.3 Being on the outside, looking in: missing intimate connectedness | 7 |
| **3. Coping and resilience** | 3.1 Masking: Driven to morph into others | 6 |
| | 3.2 Finding the voice that I never had | 6 |
| | 3.3 Valuing strengths and discovering resilience | 5 |
| **4. Receiving and giving support** | 4.1 Experiencing traditional psychotherapy as a waste of everyone's time | 7 |
| | 4.2 Needing suitable support: a different approach is needed | 7 |

| | | |
|---|---|---|
| | | |
| | 4.3. Sharing our experiences and stories can change perceptions about autism | 6 |

***Table 4.1: Superordinate themes, subordinate themes, number of participants referencing theme.***

### 4.1 Experience of being.

This theme was derived from the participants' recurring expressions of their sense and view of themselves before, during and after receiving their autism diagnoses. Participants reflected on the intrapersonal challenges that resulted from their autism, such as heightened senses and feelings of being overwhelmed, which translated into meltdown and/or shutdown for all of the women.

All the participants mentioned experiencing distinct feelings of disconnection from non-autistic people, and of being flawed, "*different*" or "*alien*".

Once diagnoses were made or confirmed, six of the participants developed greater insight into the reasons for their different perspectives on the world, their challenges, and their strengths. Five of the participants started experiencing enhanced wellbeing, particularly if they pursued connections with other autistic people. All of the women, however, appeared to have continued to be excessively self-critical.

Following my analysis, three subordinate themes were developed.

***Table 4.2 Experience of being: subordinate themes***

**EXPERIENCE OF BEING**

- **Believing there is something wrong with me**
- **Being at the mercy of heightened senses**
- **Melting/shutting down: you cannot outrun the tidal wave**

### 4.1.1 Believing there is something wrong with me

This theme emerged from participants' perceptions of themselves prior to, during and after their autism diagnoses. These were stippled with phraseology suggesting harsh self-criticism and a lack of self-regard. This was particularly evident prior to participants receiving their autism diagnoses. Six of the seven participants used self-descriptions such as "*rubbish*", "*crazy*", "*stupid*", "*drama-queen*", "*hard to be with*", "*bold*", "*terrible*", "*naïve*", "*mad*", particularly when reflecting on their pre-diagnostic experiences of themselves. Some of the women continued to see themselves negatively after receiving a diagnosis

Six participants viewed receiving an autism diagnosis as an enormous relief, a validation and a pivotal point in their lives. This new knowledge helped some of them experience enhanced self-compassion, which translated into feeling more justified and empowered in their self-care practices. Most of the women also moved towards accepting the unique, individual challenges of their autism.

Cathy noted that, although receiving a diagnosis, "*a formal validation*", enabled her to be kinder to herself and less self-critical, her overriding experience of herself as somehow flawed, unintelligent, or mentally unwell, persisted:

> *"I really did feel really stupid or crazy, both intersecting all of my life, from a really young age…"* (p.2)

Cathy was very aware of her propensity for harsh self-criticism and negative self-talk, especially when she found herself becoming overwhelmed in social contexts:

> *"... and my thoughts would be very negative and saying, "you are so stupid" I think I typically go into a lot of negative talking... the names I would call myself were way worse than anyone else would have called me."* (pp.17-18).

Throughout their interviews the other six women, who received their diagnoses later, in late adolescence or adulthood, used the word *"different"* frequently, especially in the context of how they viewed themselves in relation to non-autistic others.

The experience of being different and not fitting in with the status quo left burning negative imprints on participants' developing self-esteem. Being different was a *"struggle", "hard"*, "*difficult"* and painful for many. The women reported how being different gave rise (low) to negative self-appraisal, poor self-esteem and -regard. It also compounded difficulties in interpersonal interactions, which included agonizing experiences of being bullied, discriminated against and denounced for certain behaviours.

The word *"suppose"* occurred with high frequency (40 times) in Illana's narrative account. The hesitancy communicated therein captures her sense of uncertainty about her identity, her experiences of self, the accuracy of her own judgements, and the validity of her perceptions of the world, which was evident throughout her interview. It explained why she deferred to others, notably her mother and peers, allowing them to narrate her identity. She was often labelled a *"drama queen"* by peers, and assimilated this tag into her self-referential language, as the word featured prominently throughout her narrative.

> *"I would have started to believe people that I was a drama queen..."* (p.9).

Illana described how her understanding of herself and her life experiences changed radically after her diagnosis. She experienced an overwhelming sense of affirmation, relief and elation; being diagnosed was the best thing that ever happened to her.

> *"... I finally understood myself and who I was. And all the questions that I could never answer about myself or explain, they were all answered by just one word. Autism."* (p.2)

Indigo gave detailed accounts of the struggle and confusion she experienced due to being different from others. In her early school years, she often engaged in significant self-injurious behaviour. She believed that she needed to be fixed, and that this was what medical professionals did. And so, as she craved for "*everything to be ok" and* to find resolution, she repeatedly attempted suicide, which led to inpatient admission to hospitals and psychiatric facilities. She was desperately seeking answers and clarity on her experience of brokenness.

> *"I got it into my head, that there was something wrong with me and there was something broken about me, so if I took an overdose, I would end up in hospital and hospitals are meant to fix you. The only way to end up in hospital is to be sick, so you had to be sick to end up in hospital. So I kept up with my overdoses to get into hospital, so they could fix me, so they could tell me what was wrong with me, so everything would be okay".* (p.22)

Notably, Sarah, who was diagnosed in childhood, used no negative labels to describe herself. She also had a clear sense of self and of her likes, dislikes and behaviours that might be viewed as inappropriate by others.

> *"... I am very black and white with people, even with my friends, people say you can't say that, but that's just me. I'm very straight, black and white... I'm a very blunt person, even when I was working I was like that…"* (p.2).

Although Sarah was aware that her "*straight"* way of communicating was sometimes inappropriate, she spoke about this matter-of-factly, and seemed unburdened by the concern that others might judge her or have negative perceptions of her. There was no suggestion in Sarah's narrative that she engaged in any self-criticism or experienced poor self-regard.

### 4.1.2 Being at the mercy of heightened senses

All the participants experienced significant discomfort related to their sensory experiences. For most of them this posed a daily challenge to their wellbeing and in most areas of their life. Several also reported viscerally uncomfortable reactions to sensory triggers.

Sarah repeatedly used the words *"disgust"* and "*disgusting"* in her accounts of her sensory experiences. This speaks of the repugnance and revulsion she experienced in relation to certain tactile, visual, and olfactory stimuli:

> *"... smells or the thought of it, [touching something] or if put my hand in you are going to touch something wet and then I hurl, and it is just disgusting and it makes my skin crawl thinking about it."* (pp. 17-18)
>
> *"I would never touch jewellery it is making me sweat just thinking about it now, horrible…It just makes me feel ill... it's so disgusting, really horrible.*" (pp. 20-21)

Sarah described how she was unable to go into certain shops due to feeling overwhelmed by patterns on floors, the smell of food sections, visual presentation of food and products, *"chaotic"* displays, lighting and noises. Consequently, basic food and clothing shopping remained an ordeal for her, and at times she completely avoided shopping for necessities.

Sarah’s sensory sensitivities also, frustratingly, posed the biggest challenge to her ability to remain employed in a position where she had to work directly with customers.

> *“... people breathing down my neck… people standing all over me, pulling out at me, touching me elbows, touching my shoulder… sends me off my rocker and I had to leave so many times”*. (p.5)

Illana noted how sensory difficulties presented challenges on occasions when food and social interactions were combined. These experiences caused her to feel *“bad”* throughout her life. “*Bad”* by way of physical unpleasantness, but also “*bad”* in terms of how others perceived her. She consequently experienced the futility, and despair, of not being able to live up to expectations.

Since meals with others or in public evoked anxiety and feelings of awkwardness and embarrassment, Illana found she was unable to eat. She tried to manage these feelings by forgoing food, or by choosing the same predictable meals.

> *“I have taste aversion issues and sensory issues and smell issues… I actually got to the stage where I would pretend not to be hungry to avoid an awkward situation… It is a textural thing sometimes… and it makes me gag and throw up with the texture of it, so it is issues like that which are really complicated, so I tend to stick with the same meals, so I don’t have situations… that can embarrass myself in public.”* (pp.23 - 24)

Aine had learnt how to manage unpleasant sensory experiences. She eloquently detailed her sensory dislikes thus:

> *“Light particularly, strong daylight is really tough… I can be very sensitive to noise and particularly a lot of conflicting sources of noise at the same time... would be very difficult… I am very sensitive to the type of clothes I wear. I will always wear soft*

> *fabrics and I would have struggled early on in my career having to wear "supressionible" type of clothing"*. (pp.8 - 9).

Aine coined the word "*supressionible",* to describe body-hugging type clothing often worn to provide proprioceptive feedback. She found the sensations of tight fitting clothing irritating, suggesting that her proprioceptive sense was hyper-sensitive.

Aine's knowledge and understanding of how her body reacts to sensory inputs also empowered her to deliberately utilise and manipulate sensory stimuli for her own benefit. She described how she effectively employed sensory likes in self-care activities. She regulated and self-soothed through sensory "stimming" by moving her tongue in patterns behind her teeth, stroking fabric, rolling paper and rubber bands and fiddling with objects in her pockets. She also unwound by indulging sensory pleasures.

> *"… I would go for a really hot long shower, again the sensory thing, the stream of water as strong as I can bear it, as hot as I can bear it works and that is a real recharge. Sometimes, and occasionally if I am incredibly stressed, I will do that in pitch darkness."* (pp.12 -13).

For Cynthia being autistic was "*a sensory way"* of being, it wholly dominated her experience of herself and the world. Like Aine, Cynthia also mentioned the benefits and drawbacks of having heightened senses. On one hand she almost felt at the mercy of her heightened senses.

> *"… I also get overloaded sensorially very easily…"* (p.2).

She had an acute awareness of her sensory sensitivities, and the pervasive potential to become engulfed by sensory triggers at any moment. She gave a vivid account of how terrifying it was for her to negotiate travel by train, which she regularly had to do. The experience was, without fail, anxiety provoking and exhausting, and it taxed her coping abilities to their limits.

> *"... when I have gone through… station and I have gone through the smell of diesel, I have gone through the chequered floor, or I have gone through the noise in train, the smells, the people poking me on the train, the crisps packages... the screech of the brakes… I just manage to escape…"* (p.3).

Cynthia noted how she always had to have time and space to recalibrate after a commute. Since Cynthia's experience of being was primarily sensory, she also knew how to use her sensitivities to enhance her own wellbeing as well as her experiences of situations and the world around her. As she exclaimed *"... the sensory can be good!"* Cynthia had become an expert in manipulating her environment and getting it *"right",* by adding desirable sensory elements to it:

> *"... have the light right, the sound right and bring my own smells, lavender and all that kind of stuff... sensory experience, I think probably also heightens them a lot.*" (p.13)

### 4.1.3 Melting/shutting down: you cannot outrun the tidal wave

All the participants shared experiences of losing control in the context of *"overload",* which led to autistic meltdowns and/or shutdowns. They all had strong urges to *"escape",* flee, or retreat from others prior to, during or after losing control. Shutdown could be distinguished from meltdown in the women's narratives: the former represented internal states or feelings, while the latter represented observable involuntary actions or behaviours. Meltdown was the more dominant of their reactions to overload, with some women experiencing shutdown following episodes of meltdown.

Most of the participants noted that they tried to delay or avert meltdowns and shutdowns by fleeing, if they noticed in a timely fashion that they were becoming overwhelmed. The general experience was that they had a small window of opportunity to flee before losing control. Further demands, expectations, or triggers, however insignificant to others, decreased tolerance, shrunk the window of opportunity and manifested as involuntary articulation of loss of control for all the participants in this study.

Hilary described putting in "*an awful lot of effort"* to avoid overwhelm and the inevitable need to *"flee"* or "*withdraw"*. Sarah emphasised having to *"leave"* to avoid melting down. Most of the women described impending irrationality, internal and external disarray, and trepidation at what might happen in terms of their overt behaviour if they were unable to escape in time. Participants described the experience of meltdown variously as internal and external eruptions, violent outbursts and loss of verbal and/or emotional control. After-effects of depletion, exhaustion, and shutdown, which endured for hours, days, or, in Aine's case, up to a week, were mentioned by all the women.

Cathy gave an extensive account of her experiences of a meltdown cycle, and her reflections on her meltdowns. Prior to her diagnosis of autism, her lack of knowledge and understanding of her own related vulnerabilities generated fear that she might be *"crazy"* or going crazy. Cathy used the phrase *"losing my mind"* in her meltdown narrative on numerous occasions. Her physical experiences included feeling *"sick"* with migraines, dizziness and blurring of vision. Her mental experience was of fearing for her own sanity, whilst being gripped by anxiety, as well as the concern that she might be unable to negotiate her way through each episode. During the build-up to and experience of meltdown, Cathy typically spoke out loud to herself: "*I just thought I am losing my mind, I cannot cope, so that is a phrase I would repeat out loud..." (p.16)*

Cathy compared a meltdown to *"drowning",* the ensuing panic and fear resembling the experience of being overcome by the sea:

> *"I am in the meltdown before I know it or I am in the build-up, or if it started to build up I cannot really stop it, it is like to push against a tidal wave."* (p.24)

Since her diagnosis Cathy had implemented protective measures to reduce the possibility of melting down. Cathy viewed melting down as the inherent price of socializing, given her known sensory sensitivities.

> *"... I end up getting sick… it is burnout, or I will have a meltdown, so the cost to me to go out to a pub on a Friday or Saturday, I will probably have a huge meltdown within the next few days and that is a cost I am not prepared to give…*" (p.15).

For Aine, experiences of overload typically followed a pattern of shutting down, melting down and then shutting down again. For her, overload was often signalled by struggling *"to get words together"* and express herself verbally. At these times Aine needed to regain self-control by being *"silent"* and disengaging (with) from others. Aine's need to *"be silent, be quiet"* lasted anywhere from a number of hours to several days, depending on how long it took her to realise her need. At these times, while Aine sought to regain equilibrium and manage her overload, she found herself unable to tolerate any demands others might have made of her, as this had the potential to trigger a full meltdown/shutdown.

*"… if I haven't caught it early enough it can last for days, and if somebody makes demands on me when I am in that state, I can just erupt… and then I will shut down and I may not speak for a week…"* (p.11).

Cynthia also likened melting down to the unstoppable force of a tidal wave. The experience was like being overcome by a power greater than herself, outside of any internal or external control, and to which surrender was inevitable:

> *"... So it arises from powerlessness, you cannot stop the tide… you cannot stop it, and then the tears might come or you might want to run away, and you might run away. Yes, powerlessness is a big part of it, powerlessness over the outside, but then when you get to meltdown stage, powerlessness over you yourself."* (pp.4-5)

Cynthia perpetually struggled to keep from crying. This spurred an urgency to "*escape"* to privacy at times of vulnerability. She voiced a fearfulness about how others might judge or perceive her, admitting that there were only a few people she could "*trust"* to see her in a state of "*powerlessness".* In the safety, security and privacy of her own *"space"* she found freedom to be out of control, or let go.

> *"... I have only had major meltdowns at home… in my space… and then I might cry in my room for a day."* (p.3).

## 4.2 Being alongside others

It was evident throughout the interviews that all seven participants were acutely aware of the barriers they experienced when interacting with others. Furthermore, their parents and family-members often struggled to support them due to misconceptions about the reasons for their behaviour and the needs communicated thereby.

Illana's parents concluded she was *"bold"*, while Cathy felt excluded, like the *"black sheep"* of the family. She felt humiliated by frequently being negatively compared to her sister.

All the participants spoke of being "*gullible and naïve*", which left them vulnerable to being targeted by others. Six of the women shared experiences of prejudice, isolation, and bullying in school, college or work. Four reported manipulation and exploitation in intimate partner relationships. Three of the women spoke of experiencing emotional, psychological, and sexual abuse at the hands of an intimate partner. Cathy captured the latter end of this scale of experiences thus:

> *"... verbal, physical and sexual abuse seems to be scarily common in the autistic community."* (p.33)

These particular experiences were not explored in this study due to their sensitive nature and the potential distress participants might have experienced had I probed further.

Lamentably, most of the participants had trouble in forming and maintaining friendships from a young age. Some shared experiences of being stigmatized due to their autism, or of being bullied and perceived by others as *"weird."* Participants reflected on their, primarily negative, social experiences; however, some noted they had containing friendships that sustained them over time.

Three subordinate themes emerged in relation to interpersonal and relationship experiences.

***Table 4.3 Being alongside others: subordinate themes***

**BEING ALONGSIDE OTHERS**

- **Struggling to understand and to be understood: wondering why people don't just say what they mean**
- **It is easier to interact with people who know what it's like to be me**
- **Being on the outside, looking in: missing intimate connectedness**

### 4.2.1 Struggling to understand and to be understood: wondering why people don't just say what they mean

All seven women reported on their experiences of the challenges of social communication. Illana pithily captured their experiences by saying:

> *"... being misunderstood and lack of understanding, words that resonate for me when I look back..."* (p.23)

Illana's experiences echoed the frustration and sadness, tinged with hopeless resignation, detailed by the other women, who all, to a greater or lesser extent, feared being misunderstood might be their pervasive, lifelong experience of interacting and communicating with others.

Participants noted their considerable difficulties in understanding non-autistic people's ways of communicating. They commented frequently on their frustration when non-autistic people did not speak *"straight"*. This frequently gave rise to confusion and perplexity in equal measure due to the participants' general tendency to take things "*quite literally"*. Cynthia captured the hope expressed by some of the participants that communication between autistic and non-autistic people could be improved if both sides had a better understanding of the other's ways of communicating and if non-autistic people realised and accepted that mutual misunderstanding was likely and remained mindful of this likelihood when they communicated with autistic people. Cynthia also captured participants' feelings of annoyance and desperation by saying:

> *"... they [non-autistic others] should be able to speak with us very clearly, so that we don't have misunderstandings... but it is the whole double empathy gap... it therefore*

> *means that the person has to engage in their communication very carefully with us as we do of them…"* (pp. 21-22)

Both Cathy and Aine gave detailed descriptions of struggling with confusion, which was an experience shared by all the participants. Cathy exclaimed that since she often did not know "*what is going on"* she sought clarification and understanding by asking many questions. This strategy rarely proved successful, as Cathy was typically left confused, and feeling growing frustration, and despair. She also felt *"stupid"*.

> *"... if I asked a question, somebody might repeat their answer, but they were repeating the exact same words in a louder voice and that does not help me understand, I need you to rephrase it… people tend to just repeat the same sentence, with emphasis, but that just makes me feel stupid…"* (p.5)

Aine viewed herself as an intellectual person. Her narrative was characterised by the frequent use of *"recognise(d)/not recognise(d)"* (used 25 times) and *"realise(d)/ not realise(d)"*(used 11 times) in the context of understanding herself and others. Accomplishing this was *"difficult"* for her; a perpetual *"struggle"*. Aine spoke of being aware of her inability to instinctively grasp the meaning communicated by others. She expressed a deep sense of frustration and annoyance with herself for not always realising/recognising spoken or implied meaning in the verbal and non-verbal communication of non-autistic others.

> *"... being aware of living in a perpetual state of confusion, not really understanding. I was incredibly intelligent, but no real idea what was going on with other people, you know."* (p.28)

Aine repeatedly emphasised her need to "*realise"* and "*recognise"*. Her frustration with the fact that she had superior intelligence and that, although she had the cognitive capacity to understand, realise, and recognise, she often did not, hinted at her internal *"struggle"* with self-acceptance and regard. For Aine, understanding, albeit on a cognitive level, was central in mental and emotional processing.

> *"... very much a cognitive one, wanting to understand, yeah. Yeah, very much so, wanting to understand it cognitively…* (p.17).

Aine vividly recalled her invigorating *"epiphany"* when she realised that other people have different perspectives to her own. However, this excitement gave way to embarrassment at the lateness of *"realising"* that others had different points of view. This was soon followed by denigrating, berating self-admonition for lacking this instinctive understanding:

> *"... suddenly the realisation coming to me...: what is going on inside of her is somewhat different to what is going on inside of me… how could I "this intelligent one" have been so stupid to not realise that up until now."* (p.29).

Hilary experienced communication as a frustrating and anxiety-provoking process of trying to figure out how to give voice to her thoughts in such a way that her meaning was clear and not offensive to others. Hilary described this process as a perpetual struggle. Sometimes she tried to say what she meant, but it was not received well, which further inhibited her efforts to communicate:

> *"… I'll seem to say them in the wrong way or people take it the wrong way, which also stops me dead as well, 'cause I will say something and I will think it is fairly clear but then someone will say "what do you mean by that" and gets offended and I have to stop and figure out what did I actually say, what did they think I said?"* (p.3).

Hilary was terrified of failing, of saying the wrongs thing, and of her own distress and confusion when others reacted with disapproval:

> *"... you see the expression on the person's face and I think I got that wrong and you are baffled and you don't know why, you don't know what you said, but they are really annoyed or disappointed… it is the most horrible thing you could have done and it is very confusing…"* (p.41)

Indigo spoke of frustration and sadness at repeatedly trying to express what was in her head and failing, encountering an impassable *"brick wall"*. She experienced a *"divide"* between how others interpreted what she said, and the meaning she was attempting to impart. She felt as if she had been:

> *"... born with a dictionary of words that are subtly different, not hugely different, but subtly different to all the other words that the normal people were given."* (p.5)

Indigo valued being understood, however, her foremost concern was with translating her own thoughts into words that captured her meaning. This was challenging for her, and she felt intense frustration with herself when she was not able to verbalise her thoughts as adequately or eloquently as she wanted. She therefore repeated herself frequently; continuously rephrasing and rewording her statements, desperate to capture her intended meaning:

> *"... 'cause it is me that is communicating what I am trying to say and that is a big problem. I will repeat myself in communicating with people a lot 'cause I haven't gotten it out right… I think most people say I can understand you, but in my head, I am like, I know you think you can but… but I know they don't…"* (p.11)

### 4.2.2 It's easier to interact with people who know what it's like to be me

Due to challenges that are inherent to autism, such as communication differences and social anxiety, the participants generally had trouble with friendships, especially establishing and maintaining these relationships. However, some participants did have positive experiences of containing and supportive friendships.

Sarah shared that she was comfortable with her current group of friends, but that she found meeting friends of her friends *"awkward."* Sarah feared that these strangers might talk to her friends behind her back, and she anxiously noted that she would worry about what they were talking about. Sarah also found it *"difficult"* to establish new friendships. With her own friends she could communicate freely, and she was not concerned that they would be offended at her direct way of communicating, saying they "*will give me a bit of slack"* (p.10). However, she was aware that she tended to say things that others might find inappropriate, and this inhibited her desire to make new friends as she *"could not be as straight"* with new people as she was with her long-time friends.

Illana and Cynthia shared experiences of friends who knew them before their diagnoses, and who remained understanding and involved thereafter. For Illana, who made her *"first real friend"* at age 11, the experience of having friendships at university had been affirming and validating. She expressed gratitude for these caring friends, who also provided containing support after her diagnosis.

> *"I have some amazing friends; they have been so supportive to me and they all care so much about me. I have been really blessed with the friends I have been given and it is not always easy for me to get to the level of friendship and there are times as well, like when I got my diagnosis they were all so supportive and understanding and loving…"* (p.16).

These friendships stood in stark contrast to Illana's negative and harmful peer experiences at secondary school. Illana used the word *"difficult"* 25 times during her interview, thus emphasising just how challenging it was for her to be autistic amongst others in the world. She struggled to manage her anxiety, the behavioural manifestations of which left her vulnerable, and she was bullied in school on a regular basis. A group of peers went as far as to record one of Illana's meltdowns and post it on social media.

After this incident Ilana was left fearful and paranoid, and she "*kept hearing the whispers"* (p.7). To cope, she avoided her peers, opting to spend time with her younger sister instead. It was anguishing for Illana that teachers did not understand why she avoided her own peers, and thus regularly separated Illana and her sister.

Cynthia essentially gave up on making friends until well into adulthood:

> *"I would definitely understand now that I think it is easier for me to be around other like-minded people and it turns out that a lot of them, I think, are now autistic."* (p.13)

Cynthia expressed gratitude for the caring support of a long-time friend who has stood by her through challenging times, even when she had to abandon arrangements due to stress and being overwhelmed. She gave an example of a planned meal out to celebrate her birthday. Arrangements went awry as the restaurant was closing earlier than expected, while Cynthia's friend was also delayed. Cynthia became extremely distressed and tearful at the unforeseen unfolding of events. She left to seek the solace of her own company.

> *"… I got so upset, I had to walk out and my friend then rang me and said "are you okay, come and talk to me, let me give you your present" and at least I was able to text, so I said leave me alone… so, that was a friend who really understood and they are still a good friend…"* (p.6)

### 4.2.3 Being on the outside, looking in: Missing intimate connectedness

The participants disclosed that they frequently experienced isolation and loneliness. For some these experiences happened periodically, whilst for others, the sense of alienation was more pervasive and enduring. Some described having friendships that met their need for social connectedness and belonging, while others expressed dissatisfaction with their social connections and their quality.

Six of the women had experiences of romantic relationships, however, they generally gave few details about these experiences. Four of these six participants disclosed that they had been manipulated and exploited in intimate relationships, including suffering sexual abuse. Some of the women identified the need for companionship as a major motivation for seeking and being in romantic relationships.

Sarah perceived her first romantic forays as akin to a typical teenage relationship. On one hand she seemed annoyed when she described being frequently cheated and having "*the wool pulled over my eyes"*(pp.13-14), but she immediately went on to shrug it off with the comment:

> *"I think it is the same for all girls… someone seeing your body, you know, that kind of way, but at the time I thought I could trust him."* (p.15).

Once Sarah's relationship dissolved, she did not experience sorrow for the person she lost, but rather for the companionship she no longer had. She longed for the comfort and predictability of always having someone to do things with.

> *"... it was someone always there, something always to do, in fact, I don't miss him, but I miss the things we did together."* (pp.16 -17).

The friends she had were unable to compensate for the security of her familiar and routinized partnered relationship.

Cathy thought of herself as the *"black sheep"* in her family, who habitually compared her negatively with her sister, thereby withering away Cathy's fragile self-regard. Cathy endured similar exile at school, as she was ill-equipped to settle in amongst her peers. She described the anguish of wanting to join in, but not knowing how to do so, or how to conduct herself. She felt lost, confused, and terrified of unwittingly making social mistakes.

Cynthia longed to be "in" amongst her peers, but often experienced the humiliation of being laughed at.

> *"I would have been anxious to join in, in case I made a mistake, because when I did make a mistake, it seemed to be pointed out a lot or I was laughed at, but I did not know why they were laughing at me."* (p.3)

Cathy spoke fondly of her late husband, who loved and understood her. His unconditional love and acceptance brought much joy and laughter to her life.

> *"... he accepted me for who I was and he was the first person to ever do that and to truly do it. He never ever tried to change me.."*. (p.31)

Cathy commented on the effortless innocence of their courting, and how kindly he treated her. Years after his passing Cathy tried online dating. However, she was rendered vulnerable to further manipulation and exploitation similar to what she experienced in school, due to her fragile self-regard and her need to belong and be liked.

These humiliating experiences devastated Cathy's self-confidence and left her "*beyond petrified*" at the thought of venturing down the path of intimate relationships again, saying:

> *"... I don't actually trust myself to do it."* (p.27)

Cynthia tirelessly dedicated herself to social justice causes for many years. She derived satisfaction from this passion, but she also experienced isolation and loneliness outside of these endeavours: "*But I am actually quite lonely in life..." (p.7).* She wryly stated that she probably knew half of the country and was often approached by others who just wanted to say *"hello".* Although she appreciated the recognition she received for her work, the acquaintanceships she made in the process could not fill the void of intimate social connection.

> *"People don't realise that if something goes wrong in my life, I have nobody to call on."* (p.8).

Cynthia speculated that people who put a high value on being accepted by others might be satisfied with superficial relationships, but that she longed for *"warm, clear, no bullshit connections" (p.8)* in which she could be completely relaxed, free, unbridled in her "*extreme autistic honesty" (p.8).* Cynthia valued the warmth and intimacy of being heartily connected to others and seemed intensely aware of the chilly absence of any such close bond in which she could comfortably be her authentic self.

## 4.3 Coping and resilience

All the participants shared their experiences of having received negative reactions to their behaviours throughout their lives. All the women sought to avoid such experiences and used various strategies to hide their authentic selves. Each of the participants carefully planned how they communicated with others. Particularly motivating factors were the fear of offending others or of being misunderstood. Most of the participants worked hard to avoid melting down in front of other people for fear of the adverse reactions and negative perceptions they might encounter. Some women directed their energy towards learning to suppress their instinctive behaviour whilst others were encouraged by carers, teachers, or support persons to behave more like their non-autistic peers in order to avoid causing offense or being targeted.

Many of the women were silenced by the reactions of others, and consequently lost the motivation or the courage to speak freely.

Diagnoses freed many of the women to rediscover their voices. For some this involved simply deciding to say what they thought, for others it became a process of first accepting themselves before they could speak their truth. One of the women continued to monitor what she said and how she said it, as the horror of others' reactions was more painful to her than not speaking freely.

Some of the participants highlighted the strengths and qualities inherent to being autistic and many spoke of their resolve in managing social and communication challenges and the coping and self-care strategies they used. Others commented on valuing qualities such as empathy, honesty, and loyalty. An emerging resilience and the capacity to cope typified post-diagnostic living for several of the women.

***Table 4.4  Coping and resilience: subordinate themes***

| **COPING AND RESILIENCE** |
|---|
| • **Masking: Driven to morph into others**<br>• **Finding the voice that I never had**<br>• **Resilience: Valuing strengths and discovering tenacity** |

### 4.3.1 Masking: Driven to morph into others

Participants generally commented that they had to work hard in order to learn strategies that would help them fit in with their peer group. Due to agonizing social failures, bullying and other harmful, negative experiences, all of the participant adapted by showing less or none of their true selves. Most masked or camouflaged their autistic behaviour to protect themselves and fit in. None of the women expressed satisfaction with having to hide their authentic selves and many reported that masking negatively impacted their self-regard. Some women continue to use masking despite the significant distress it causes them. Of the others, some refuse to mask, while others noted that their need to do so decreased after they received their diagnosis.

Sarah, who refused to use masking as her default strategy in social engagement, nonetheless emphasised the struggle and frustration of not being able to say what she wanted to others:

> *"... I couldn't say stuff to people, and I had to just be nice… I find it very hard."* (p.3).

Hilary felt compelled to people-please, due to her fear of potentially offending others when speaking her truth. She was frustrated with herself for using this avoidance-avoidance coping strategy:

> *"... I am aware that I will tend to try and please other people; and quite a bit. I was unhappy about this because I would be thinking am I two-faced or is this a weakness or compare myself as a chameleon…"* (p.20).

Regardless of the negative impact masking had on her self-regard, Hilary's deep need to be inoffensive trumped her need to be authentic.

Cathy described a similar masking struggle. The need to be likeable and the exhaustion of trying to be acceptable to others were threads that ran through Cathy's narrative. Needing to fit in, she began copying the dress sense, personality, and body language of her sister and, later, her peers. Cathy's lack of self-esteem and -regard was evident in her description of her efforts to hide her true self. She felt driven to "morph" into others. She changed her physical appearance and copied behaviour of people she liked, down to their hand-writing.

> "*… I couldn't act naturally because it wasn't me and it was just exhausting, even talking about it seems exhausting."* (p.8)

Cathy despairingly voiced how masking has adversely impacted her fragile self-regard:

> *"... it has absolutely destroyed my own self-esteem and I did not trust my own judgement, my own way of being did not seem… people did not seem to like it..."* (p.7).

As Cathy became more accepting of herself, and accessed counselling support, she learnt to set boundaries, and allowed herself to be true to her own needs.

Indigo's disdain for university social skills training programmes in which masking and camouflaging of the authentic autistic self were promoted, was evident in her exclamation that:

> *"I think masking is dangerous, it should be seen as maladaptive behaviour."* (p.62).

Indigo vocalised alarm that young, impressionable autistic students were being encouraged to learn neuro-typical, non-autistic social skills, "*… to be the right person"*. Social skills programmes seemingly confronted Indigo with her own fear of being "*sick"*, and her perception that she needed to be fixed. This time, however, she also feared that other autistic students would similarly start viewing themselves as somehow not "*right"*. She voiced her objection/projection thus:

> *"... it is kind of like telling an autistic person "for the rest of their life, they have to be in an interview". They have to do all things. If you told a neurotypical person they*

> *don't just have to do this, it is not just in the interview that they have to do this, they have to do this for rest of their lives, and they have to hide who they are forever, I think you would have a lot of angry neurotypical people…"* (pp. 61- 62).

After she received her autism diagnosis, Indigo deliberately stopped using masking behaviour.

### 4.3.2 Finding the voice that I never had

Many of the participants experienced being silenced through the reactions of non-autistic others who disapproved of their communication styles. Others lost motivation or confidence in expressing their wants and needs. Some, like Aine, lost their voices during episodes of shutting down. Aine has only recently begun to guardedly discuss her experience of being autistic. She was reluctant to reveal her diagnosis for fear of *"barriers"* arising in her career. She cautiously started to discuss her diagnosis, yet still felt that she needed to protect her reputation by being selective about when she revealed her autism.

> *"... and starting to talk about the fact that I recognised all those traits from myself and that I also see the world through an autistic lens. I have not as yet come out to any of my colleagues and said straight out and said I am autistic..."* (p.21)

Cathy, who sought understanding by asking questions, stopped doing so, as the disapproval and misconceptions of others robbed her of the desire to speak. Cathy felt unable to speak her truth; she thought her voice was inconsequential, and had no effect on changing people's minds about who she was. Cathy referred to an experience of seeking help for anxiety and low mood. She queried the possibility that she might be autistic and was dismissively told by her GP to "*park that*". She was mortified by the GP's reaction:

> *"Yes it was just the change in the facial expression of the GP… I just felt shame…"* (p.35)

Cathy's journey after her diagnoses included the quest to reclaim "*the voice that I never had"* *(*p.13*)*. In recent years she has reached a stage in which she felt able to share her story and also more able to *"[tell] the difficult, vulnerable parts of it"* (p.39). Cathy has since learnt to talk freely, less inhibited by fears of how others might react. She emphasised that it took time to learn and believe that her own voice was as important and valuable as anyone else's. The development of self-regard, and self-belief also took time.

Indigo felt heard and received by other autistic people, she emphasised that conversing with non-autistic others was tiring, frustrating and impacted adversely on her mood.

> *"But is kind of interesting when you meet autistic people, I don't get exhausted, but with neurotypical I get exhausted and I feel really down afterwards cause they did not understand me, and I find it really frustrating."* (p.13).

Depletion and futility characterised Indigo experiences in searching for, but never quite finding, the right words to voice her thoughts and feelings. Indigo expressed frustration and irritation when she described suffering the ignorance of others.

> *"... they are just disgusted or offended or just some sort of negative disapprovement going on or even judgemental... you are a source of comedy for them.."* (p.14).

Indigo implied that the reactions of others are, for her, of less concern than her need to speak freely about things that matter to her.

> *"I can now talk… and you are not going to tell me to be quiet. That is another reason to do an interview like this."* (p.1)

### 4.3.3 Valuing strengths and discovering resilience

The participants commented on their varying degrees of agency and resilience. Some described long-standing benefits of autism, such as focus and concentration, which empowered them in different areas of their lives. Others reflected on how resilience and strength developed after being diagnosed. Receiving diagnoses enhanced the self-acceptance and self-esteem of some of the women, bringing associated improvements in self-care. Others experienced emancipation by devising strategies to manage their challenges.

Hilary saw herself as a self-contained person; she felt content in her own company, and she reported rarely feeling alone. She seemed proud of her ability to either get "*lost"* in her own thoughts, or, conversely, to initiate and intensely focus on a task and *"keep going"*. Her satisfaction was palpable in her description of her autistic strengths:

> *"... I can really focus on something that catches my attention. I can analyse things as well… I have a quirky sense of humour… I suppose, I am sure there is more. I am quite good in a crisis…"* (p.28).

Hilary's description of how her competence in crises situations was stippled with irony. She said that ruminating on "*worse case*" scenarios and "*... expecting the worse, being on the edge of this adrenalin rush all the time...*" *(p.28)* had enabled her to effectively deal with challenging situations when they arose. She could get "*on with it*" and the preparative work had been done, as she already rehearsed it repetitively in her mind.

Illana described how she succumbed to the narration of others regarding her own identity. Following their views, she was a "*drama queen*" who subsequently suppressed her feelings, as she started believing they "*were irrelevant*" *(p.9).* After her diagnosis Illana had become more at ease in her "*own skin*", and no longer drove herself "*insane*" with self-flagellating thoughts:

> *"I am not constantly driving myself insane, wondering why did you say this, why did you do that? And life has become so much easier now."* (p 30)

Aine became increasingly aware and able to "*recognise*" when demands exceeded her coping capacity and ability to take timely self-care actions. Aine previously felt "*obliged*" to surrender to social demands, at her own peril. She repeated the phrase "*give/ing myself permission*" in her description of her developing self-care, suggesting that she had also become kinder to herself and more accepting of the necessity to "*take the space that I need to meet my own needs…*" *(p.3)*. Aine also developed other skills and strategies to mediate challenges inherent to autism. She referenced how she would "*deliberately*" focus her attention on one person when she was in a crowd and "*consciously remind*" herself of how that other person had a full, real and different inner and outer life. Aine's ability to see another person's point of view improved through her use of this strategy, and it, furthermore, enhanced her sense of connectedness to others and the world.

> *"… it helps me to stay grounded in terms of other people and connection to the world in general. It is one of the strategies I developed and somehow it seemed to help."* (p.31)

## 4.4 Receiving and giving support

Most of the women in this study acknowledged that psychotherapeutic support might benefit them. Their main concern was the difficulty of finding and accessing suitable support. The women additionally shared how their needs were overlooked, misunderstood, or dismissed when they did find and access psychotherapeutic supports.

Participants agreed that autistic women would benefit from the support of appropriately experienced and qualified healthcare practitioners in a variety of disciplines. They expressed hope that ongoing autism awareness drives and education about how autism presents in girls and women would eventually bring this support into being.

When asked their reasons for participating in this study, several participants stated that they wanted to speak of their experiences of being autistic in order to help educate people about the condition. Participants believed acceptance could only be achieved through enhanced education of the general public about the nature of autism and the experiences of autistic people. They saw their own voices as crucial for raising awareness, understanding and acceptance.

***Table 4.5 Receiving and giving support: subordinate themes***

**RECEIVING AND GIVING SUPPORT**

- **Experiences of traditional psychotherapy: A waste of time**
- **Needing suitable support: a different approach is needed**
- **Sharing our experiences and stories can change perceptions about autism**

### 4.4.1 Experiences of traditional psychotherapy: A waste of time

The participants’ narratives were dominated by criticism of traditional therapies, which were viewed by most of the women as being a poor fit for their needs.

Several participants commented that they felt that understanding and acceptance of autism was sorely lacking among professionals. Six of the participants took exception with the medicalised view of autism and the deficit-based language associated with it. They felt this type of language did nothing to aid in diagnosing autistic women who do not have associated learning disabilities, and, equally, did not equip therapists to understand their support needs. In her search for an autism diagnosis, Hilary encountered psychotherapy through a GP referral. She was disillusioned and frustrated by her experience. Unfortunately, this permanently discouraged Hilary from looking for a more suitable therapeutic fit. She described it as:

> *"... very frustrating and quite pointless. It was a waste of everyone's time really."* (p.31)

Hilary despondently noted that, once autistic people are over the age of 18, they receive no support. Although this was upsetting to her, she seemed resigned to this reality:

> *"But for the majority of us… There is pretty much no support."* (p.34)

Aine, who desperately searched for clear, unambiguous therapeutic support, rousingly voiced her frustration with traditional psychotherapies in which therapists attempted to guide her towards finding her own *"solutions"*.

> *"Traditional psychotherapy, traditional counselling! ... Asking me, trying to get me to come to solutions by myself, by asking me what I thought about things. Sure, I did not have a clue about what I thought about things! [raised voice] What do you think is going on in that conflict in a relationship, I have no idea! Can you give me an idea of what might be going on? You are the person who is neurotypical"!* (pp.26 -27).

Aine noted that she had spoken with *"countless"* mental health professionals during her lifetime. She sought support each time a *"crisis"* arose, attended for a while, and then stopped attending until another *"crisis"* arose. Aine was irritated by professionals and therapies that lacked an understanding of autistic women, noting it was "*a complete waste of time*" *(p.26).*

Sarah attended a children and youth mental health service, but she was discouraged by her experience and stopped attending. She derived no benefit from the service, and, furthermore, left with the impression her needs were overlooked by therapists who showed indifference to her presentation as a young autistic woman with associated mental health challenges:

> *"I didn't like going… I felt they were only there because they were being paid…"* (p.30)

Illana's experience of talking to "*someone who was paid to listen*" *(p.26)* contrasted with that of Sarah. Illana felt more empowered to speak freely and benefitted from a structured, directive psychotherapeutic approach. She said that "*...CBT was useful*", however, she added that it took time and several failed attempts to discover a therapy that worked for her. She spoke of her own experience when she noted:

> *"… there are so many mental health issues for women with autism and it is not being dealt with and they are not being supported…"* (p.29)

Cynthia's general perception of autism support services was that they simply did not exist.

> *"I don't think it exists… I have not got any professional support. But I think you are starting at ground zero in terms of professionals understanding autism in Ireland at the moment unfortunately…"* (p.15).

Cynthia witnessed clinicians providing frustratingly unhelpful input to her autistic brother through the years. She was therefore extremely wary of seeking psychotherapeutic or counselling support for herself. Her disappointing experiences led her to query the usefulness of support provided by non-autistic clinicians and therapists, as she believed that they did not inherently understand the needs of autistic people.

> *"Can people support autistic people when they are not autistic? I think they need to have a very high degree of empathy and a very high understanding of autistic people."* (p.15).

Cynthia reluctantly accessed psychological assessment in pursuit of her own autism diagnosis, as her desire to clarify her own lived experiences was greater than her mistrust of mental health clinicians.

> *"I got diagnosed by [name of psychologist]and it was kind of a one-line diagnosis and I did not go back again..."* (p.15).

### 4.4.2 Needing suitable support: A different approach is needed

The lack of experienced, qualified clinicians who could diagnose autism in early childhood caused anger and frustration for participants, who lamented that early diagnoses, which are typically regarded as essential in supporting autistic girls and boys, eluded them. Many of the women took a dim view of traditional talk therapies, which provide no structure to support them engage meaningfully in the process. They expressed strong preferences for structured, directive therapeutic support.

Indigo's self-esteem and mood deteriorated during the social skills sessions she attended. When she voiced this, she was dismissively told the programme was designed for imaginative thinkers:

> *"... I told them I felt worse and they told me it was obviously not designed for me because it was for people who are able to think outside the box. Which made me feel worse again..."* (p.54).

Indigo strongly emphasised the need for autism-friendly, accessible approaches that take neurodiversity and all its associated sequelae into consideration. She viewed the mental health challenges of autistic women as similar to those of non-autistic people, even though autism is founded in a different neurological predisposition.

> *"Yes, we present with the same things, but the internal workings, the reason why we present with those things is very different than normal people… We just need to take a different approach… when they don't consider the different working of the autistic mind and the different ways we think, then it can cause harm."* (p.54).

Although Cathy's need for her autism to be acknowledged was dismissed by a GP, she expressed gratitude for the support she received from a psychotherapist who accurately perceived her needs and adjusted the therapeutic support accordingly. Cathy described her therapist as "*a blessing, a gift*". Her self-discovery was kick-started by her therapeutic process, in which she could express herself freely, and, as per her wishes, have her words echoed back to her verbatim. Hearing her own words repeated back to her helped Cathy process her thoughts and feelings, and discern between helpful and unhelpful self-reflections:

> *"I need to hear the words out loud in order to process my feelings."* (p.18)

Illana, who suffered with generalised anxiety throughout her life, also referred to the need for skilled professionals who understood autism to support autistic women with comorbid anxiety, obsessive-compulsive disorder and other conditions which typically co-occur with autism. Illana felt that women often access support for comorbid conditions but she believed that unless their underlying autism was identified first, these supports would not be sufficient.

> *“... there is a need for psychotherapeutic support especially with the issues of anxiety and OCD and all kinds of things, so many times women become co-morbidly diagnosed with the separate mental health issue, but they are not getting the autism diagnosis, so without the two, you know if you have one, you are not fully getting to the root of the autism…”* (pp. 29-30)

### 4.4.3 Sharing our experiences and stories can change perceptions about autism

Most participants voiced their hopes for not only a greater understanding of autism but, primarily, for greater acceptance.

Participants felt that knowledge and understanding of the presentation of autistic women and girls was virtually non-existent. Being compared to “*stereotypes*” relevant to autistic boys and men caused further frustrated and angered many participants. They felt they needed to move out of their own comfort zones by voicing about their lived experiences in support of other autistic people and in the hope of drawing attention to the presentation of autistic women. Cathy voiced this frustration and despair eloquently.

> *“... I have had someone saying... “I would have never thought, I did not know who you were, but you don’t look autistic”.... [annoyed tone] Well of course I don’t resemble a five-year-old boy, cause I am a 48-year-old woman! ... so it is the misconceptions...”* (p.36)

Cathy found it anxiety-provoking and challenging to speak in front of large gatherings but she believed that it was essential to share her own experiences of being an autistic woman in order to help other autistic people to embrace their own autism.

> *"... getting up on stage in front of 350 people at a conference and telling my story like my only hope is that and I know it is connected with people, 'cause people immediately came up to me afterwards, that the is only reason I do it... I am doing it to free someone else to be themselves..."* (p.39)

Aine felt alarmed that limited understanding, *"awareness really, awareness",* of how autistic women present, had exacerbated their difficulties, resulting in many women falling through the net, and not getting the "*medical*" and "*psychology services*" to which they were entitled. Since Aine had benefited from attending autism events, she felt compelled to get involved in advocacy: "*I am starting to do some writing and starting to get involved in advocacy in different places and I am really enjoying that.*" *(p.21).* Aine was particularly motivated to raise awareness of autism amongst medical professionals as she experienced that many undiagnosed professionals "*have either given up or have changed careers"* due to challenges related to being autistic and undiagnosed. She planned to speak at medical conferences about this matter and felt that:

> *"... with a bit of specific knowledge in terms of how to handle our challenges, life can be so much easier."* (pp.22 & 23)

Cynthia's belief that autism services are "*non-existent*" in Ireland was one of the reasons she felt compelled to share her experience of living with autism in order to raise awareness of the presentation and needs of autistic people. Cynthia was of the opinion that a lack of awareness about how autism presents was partially due to stigmatization, which silenced many autistic people. Fear of discrimination and negative perceptions left many autistic people mute, reluctant to identify themselves as autistic and unmotivated to express their needs.

> *"There is an absolute lack of people to diagnose and to identify it, and then, full understanding of autism and support needs. It is so stigmatised that people are not talking about it."* (p.17)

## 4.5 Conclusion

This study focused on collecting detailed accounts of the lived experiences of seven autistic women. Following an iterative data analysis process, the researcher identified superordinate themes that depicted the experiences of the participants. These were presented in four sections: (1) Experiences of being (2) Being alongside others (3) Coping and resilience (4) Receiving and giving support

Six women, who were diagnosed in late adolescence and adulthood, voiced how earlier diagnoses might have benefitted their developing sense of self, as they struggled to make sense of their own experiences and challenges, whilst encountering the negative reactions of the outside world to their behaviour and atypical ways of communicating.

Sensory sensitivities were perceived by all of the women as a pervasive challenge. Unpleasant sensory experiences compelled many women to avoid certain situations and environments, detracting from their ability to work and socialise, and limiting their capacity for typical activities of daily living, such as shopping, domestic tasks and parenting. Overwhelm, meltdown and shutdown were described by all the participants, who spoke of frantic attempts to avoid reaching the point at which such experiences were imminent. Fleeing the sources of overwhelm was a go-to strategy for most of the women. Eloquent descriptions of being in the throes of meltdown/shutdown were given and included such language as "*powerlessness*", "*tidal wave*" *and* "*loss of control*".

Considering the high value placed on fitting in with peers throughout adolescence and early adulthood, the age of identity development and self-esteem, it is hardly surprising that participants variously viewed themselves as "*different*", "*broken*" or "*crazy*", which adversely impacted their developing sense of self, self-regard and self-worth.

The participants' experiences of engaging with non-autistic others were largely negative. Attempts at communicating meaning often failed, leaving participants frustrated at being misunderstood, and discouraged from speaking freely. Similarly, they found it extremely challenging to decipher meaning and intention in their communication with non-autistic others. All of the women expressed frustration and annoyance with the lack of clarity that typifies neurotypical communication.

The participants were united in their agreement that it was easier to be amongst autistic peers than non-autistic others. They had to worry less about communication barriers, felt more at ease, and, most importantly, largely accepted for their true selves. The few women who had longstanding friendships with non-autistic peers had similar experiences of acceptance and understanding in those relationships.

Experiences of loneliness and not belonging were described by most of the participants as pervasive. Some participants were able to connect with other autistic people online or in their local communities after being diagnosed and noted that this benefitted them.

Participants described using a variety of coping strategies to mediate their challenges. Masking, hiding and camouflaging were used by all of the women to a lesser or greater extent in order to fit in amongst non-autistic others. Some participants were encouraged through comments from parents or educators to mask themselves in order to pass as neurotypical. Others adopted this strategy in reaction to negative social experiences.

Many of the participants also referred to adaptive coping strategies, most of which came about after they received diagnoses of autism. Greater understanding and acceptance of their own needs and challenges spurred some of the participants towards developing better self-care practices, including putting healthy boundaries in place, and recognising when expectations of them to engage exceeded their capacity. Greater resilience characterised six of the seven women's experiences after diagnoses. Some of the participants also shared the aspects they valued in their autism, including self-reliance, attention to detail and empathic understanding of others.

The participants all expressed strong views about psychotherapeutic support as it relates to autism. They were critical of the lack of available clinicians who understand autism as it presents in women, and also had doubts as to the capacity of non-autistic clinicians to adequately support clients who are autistic. Traditional psychotherapy was deemed by all the women as a poor fit for their needs.

Some women had experience of structured therapies such as CBT, which they found beneficial. The general consensus was that it was essential for any therapist wishing to support autistic women to use structured therapeutic approaches and have extensive expertise in working with autistic individuals in order to adequately address the therapeutic needs of autistic women.

The participants believed that greater understanding of autism was necessary in order to educate the public and particularly professionals. Some individuals could help by coordinating or participating in autism support groups, others through research and advocating at conferences, and others simply by feeling freer to share their experiences of autism with the hope of gaining greater acceptance.

Findings and implications will be discussed in more detail in the next chapter, and considered in light of the existing literature.

### 4.6 Reflexive Comment

*In the days before I started with the analysis of the data I experienced paralyzing fear and trepidation. I did not know how to jump start the process. A colleague who had experience of IPA suggested that I just started writing any observations that came to mind as this would break open my resistance and fear of getting it wrong. When IPA was discussed in the methodology block of the course work part of this doctorate I had to look up the word "iterative" and took some comfort from the definition: a systematic, repetitive process of analysis. This, I thought, would suit my autistic dasein, however, once confronted with having to do exactly that, I felt stuck. As I took tentative steps I realised I had to guard against perseveration, repetition and reiteration as I became hooked by my own neurological predisposition towards it. Alongside the support of my supervisors I received invaluable support from IPA masterclasses and IPA tutoring and my confidence in my ability to work with this methodology slowly grew. I had to continuously challenge myself to venture away from participant accounts and risk some interpretation of their richly descriptive narratives as I felt deeply responsible for remaining as proximal as possible to their own meaning and experiences. Considering how often autistic people experience being misunderstood I felt duty bound to not project my own experiences of being autistic on their lived experiences. At times my own autistic inclination to box things off aided me in this: If I didn't have an experience relayed by a participant in common with them it was easy for me to say "theirs, not mine".*

*This sense of responsibility to participants as well as the passion I feel about increasing the knowledgebase of autism in women helped me to negotiate uncertainty, doubt, and periods of extreme physical and mental exhaustion and overwhelm throughout this process. I reached a point where I had to give myself permission to stop and say: "It is enough, I did my best"*

# CHAPTER 5: DISCUSSION

## 5.1 Introduction

The aim and objectives of this study were to use the qualitative methodology, IPA, to examine the lived experiences of autistic women. To achieve this I conducted semi-structured interviews with seven Irish women. As there is a limited, yet growing body of research on autistic women, particularly those without associated intellectual or learning disabilities, the present study, by focusing on this neglected population, makes a significant contribution to existing literature. Key writers and researchers in the autism field have highlighted how the marginalisation of autistic voices and the subjective experiences of autistic people has distorted "knowledge" about autism (Milton & Bracher, 2013; Milton, 2014; 2017; O'Dell et al., 2016; Pellicano et al., 2014; Woods et al., 2018; Yergeau et al., 2013). The current study thus provides a valuable focus on the largely overlooked area of autistic women's subjective experiences. Bargiela et al (2016) investigated the so-called female autism "phenotype" through her focus on the experiences of late-diagnosed autistic women. Leedham et al (2020) similarly focussed on the lived experiences of autistic women who received diagnoses in middle to late adulthood. Pearse's (2020) study examined how autism discourses were deployed, and/or resisted in the autobiographical stories of autistic women. The current study is the first IPA study in Ireland which examined the experiences of autistic women. Through its broad focus on these women's experiences of being autistic the study yielded unique findings as to what it is like to be an autistic women without an associated learning disability in Ireland. Participants described experiencing a general lack of understanding amongst medical and mental health clinicians alike of how autism presents in women. They, furthermore, shared their largely negative experiences of traditional psychotherapies emphasising that these approaches were ill equipped to support their needs. Participants' experiences of their sensory differences were at odds with the DSM 5 levels of impairment (APA, 2013), which suggest that autistic people with no associated learning disability are less impacted by their sensory differences. All the participants eloquently described the adverse impact of their sensitivities on their capacity to be alongside others and in the world in general. Novel findings also arose regarding the strengths, coping skills and resilience of autistic women, which could inform psychotherapeutic practise and other mental health supports for autistic women.

I will discuss this study's findings through the lens of its original objectives: Participants' experiences of being autistic women; experiences of how autism affects social/interpersonal functioning of these women; participants' perspectives on how being autistic impacts their intimate relationships; participants' experiences of the relationship between autism and their mental well-being; participants' experiences of support services and supports required.

The novel findings about autism in women will be examined alongside existing knowledge and autism literature. This will be followed by reflections on the implications of the findings for psychotherapy training, practice, supervision and for autism mental health support services. I will also consider the implications for autistic women. Finally, I will examine the strengths and limitations of the study, make suggestions for future research, offer some reflections and provide concluding remarks.

## 5.2 Being autistic

The superordinate themes "Experience of being" and "Coping and resilience spoke most eloquently to the women's experiences of being autistic.

### 5.2.1 Experience of being

The subordinate themes that arose from the superordinate theme "Experience of being" were: 1. Believing that there is something wrong with me; 2. Being at the mercy of heightened senses; 3. Melting down, shutting down: you cannot outrun the tidal wave.

Polkinghorne (1988) viewed narrative as a way through which *"human beings give meaning to their experience of temporality and personal actions"* (p.11). In addition, narrative inquiry assumes that all humans instinctively seek to understand and make sense of their lives (Polkinghorne, 1988). It was clear from the participants' narratives that they found it challenging not to have meaningful frameworks for understanding what they perceived as being *"different"* from the non-autistic/neurotypical norm. Participants spoke eloquently about their unique experiences of being autistic, using terms such as *"different", "broken"* and *"alien"* as they reflected on the intrapersonal challenges they faced related to their autism, including the sense of being disconnected from non-autistic people, and feeling as if something was wrong with them. Participants' views of themselves were adversely affected by their experiences of the largely negative views of their significant others, including parents, teachers and peers. These misconceptions adversely impacted the participants' identity formation and external pathologizing narratives became the internalised self-talk of many of the women, with words such as *"crazy", "bold", "sick" "drama-queen"* and *"stupid"* gaining a foothold in their narratives about themselves, especially before they were diagnosed.

Timely autism diagnoses eluded these women, as the ways in which females manifest autistic traits fits imperfectly with the male-based conceptualisation of autism (APA, 2013). Pellicano et al. (2014) reflected on this by noting that exaggerating the male preponderance in autism results in autistic females going undiagnosed, with consequent negative effects on their mental health and well-being. This aligns with the experience of six of the seven women interviewed in this study, all of whom were diagnosed beyond their childhood years; their late diagnoses left their presenting behaviour and needs misinterpreted and misunderstood by others and themselves. Participants noted that, following their diagnoses, their views of themselves improved as they finally understood the reasons for their pre-diagnosis experiences of being *“different”*. Diagnosis aided greatly in fostering a positive sense of self and a changing identity that reduced self-criticism and enabled the women to become more self-acceptant and -understanding. This is in line with a recent IPA study conducted by Leedham et al. (2020), who found that receiving a diagnosis facilitated her participants’ (autistic women over the age of 40) transition from self-critical to self-compassionate and provided an improved sense of agency. Pearse (2020) reported similar findings in her study with autistic women. Emotional, social, behavioural and occupational difficulties often associated with autism (Howlin & Moss, 2012) may, furthermore, be mitigated by early identification and diagnosis of autism, as the participants in this study noted.

Sensory differences were central to participants’ experiences of being in the world. All seven participants experienced significant discomfort related to their sensory experiences. For most of them this posed a daily challenge to their wellbeing and across most areas of their lives. Since the introduction of the DSM 5 (APA, 2013), sensory challenges are now considered a core difficulty in autism, and autistic people’s sensory differences are understood to adversely affect their ability to manage day-to-day living. A recent study by Jussila et al. (2020) on the relationship between sensory abnormalities (SA) and quantitative (number of traits) autism traits (QAT) in children supported DSM 5 (2013) in noting that SA is usually positively associated with an increase in autistic traits, and that, as per the DSM 5 (APA, 2013), at ‘Level 1’ of impairment (previously known as Asperger’s Syndrome, DSM IV, APA) sensory challenges are not typically anticipated to pose a major barrier to daily functioning. Jussila et al. (2020) noted that the relationship between SA and QAT persists across a person’s lifespan. The experiences of the women in this study, all of whom had completed education to at least the Leaving Certificate level, and had no known intellectual impairments, and who would thus be considered ‘Level 1’, contradicted these findings. All of the participants experienced significant sensory difficulties, which adversely affected all areas of their functioning. One participant elaborated on this, stating that if she ignored the reality of her sensory difficulties, for example on a night out, she knew with certainty that there would be a “*price to pay”*; she would become overwhelmed, exhausted, or have a meltdown. Some women in this study explained how they ameliorated the effects of sensory sensitivities – to lighting, sounds and smells for example – after realising their sensory experiences were in fact commonly associated with autism. One woman noted *“...I tend to stick with the same meals, so I don’t have situations… that can embarrass…”.* These findings are in line with those reported by Robledo et al. (2012) in which autistic participants described the significant impact sensorimotor challenges had on their ability to successfully negotiate social interactions and communication therein.

The adverse impact of sensorimotor challenges on day-to-day functioning was similarly described by Belek (2019), who explored the bodily experiences of autistic adults from a sensory perspective, particularly in the context of feeling overwhelmed and while experiencing meltdowns. She noted how participants benefited from engaging with autism-related social groups, and learning to identify their sensory triggers and give voice to their bodily experiences of overload, shutdown and meltdown.

While most of the women spoke about the adverse effects of sensory sensitivities, two participants additionally spoke of how they engaged in sensorially pleasing activities and/or added sensorially pleasing elements to their environments to relax, unwind and process emotions. One woman exclaimed: *“the sensory can be good!”* and another explained *“... I would go for a really hot long shower... if I am incredible stressed,”.* This resonates with findings by Garcia-Villamisar and Rojahn (2015), who used a battery of questionnaires to investigate the relationship between comorbid mental health difficulties and stress in autism and repetitive behaviour in autistic adults. Kapp et al. (2019) conducted focus group research into 31 autistic adults’ (20 male, 10 female 1 non-binary) perceptions and experiences of “stimming” (self-stimulating, repetitive behaviours). Their thematic analysis revealed that stimming provides sensory stimulation, reinforcement, and/or regulation, and decreases sensory overload for autistic people. The study’s participants concurred with autistic researchers and autism activists in the neurodiversity community that stimming is a useful coping mechanism that also aids the processing of intense emotions. The sensory coping strategies vividly illuminated by the women in the present study, should therefore be understood as an important, adaptive mechanism in communicating and processing intense emotions and thoughts, that, furthermore, also provide an essential self-soothing outlet.

The present study’s participants struggled to put words to their experiences of losing control in the context of *“overload”,* which frequently culminated in what they experienced as autistic meltdowns and/or shutdowns. Participants’ experiences of overload were more typically associated with meltdown rather than shutdown, with shutdown reported by some women as typical consequences of melting down. Reflecting Scarry's (1987) description of the inexpressibility of physical pain, the participants found the experience of voicing sensory pain in the context of meltdowns arduous, and felt that non-autistic others could not therefore relate to their bodily experiences of meltdown. They highlighted their strong urges to *"escape",* flee, or retreat from others prior to, during, or after losing control and their feeling that only a small window of opportunity existed to flee/escape prior to losing control. Lights, noises, crowds, queues, smells and unfamiliar places and people were all perceived to be bewildering and overwhelming. Meltdowns were variously experienced by participants as internal and external eruptions, violent *"outbursts"* or verbal and/or emotional loss of control. The after-effects of depletion, exhaustion, and shutdown could endure for hours, days, or, in one case, up to a week.

As noted by Ryan (2010), autistic "meltdown" has been well documented in research with autistic children. The participants in this study linked their experiences of being overwhelmed to sensory challenges and autistic difficulties they faced in transitioning from one environment or situation to another and in managing new or strange situations and environments. This strongly suggests that, as demonstrated in Ryan's (2010) study, these meltdown experiences are not wilful displays of challenging behaviour, but rather intense, uncontrollable responses to overwhelming situations.

Belek (2019) used an ethnographic fieldwork methodological approach to investigate autistic overload, shutdown and meltdown as well as bodily experiences of distress in autistic adults in the UK. Contributors to his study experienced sensory related meltdown as significantly impeding their social and communication challenges. He concluded that autistic adults tended to discuss autism in relation to its physical and sensory manifestations. One of Belek's female participants described the visceral experiences of sensory overload and consequent meltdown as akin to being forced to watch a horrible scene until "*my brain literally eats itself*" (p. 6). This striking quote captures the commonality of autistic people's experiences of meltdown across contexts and cultures and resonates with experiences described by women in the present study, such as *"...I hurl.. makes my skin crawl.."*. The women vividly described the experience of being powerlessness in the face of a meltdown and at the mercy of their own bodily reactions to overload. This was often accompanied by an intense urge to flee situations.

### 5.2.2 Coping and resilience

The subordinate themes that arose from this superordinate theme were: 1. Masking: Driven to morph into others; 2. Finding the voice that I never had; 3. Resilience: Valuing strengths and discovering tenacity.

All the women shared experiences of receiving negative reactions to some of their behaviours. These drove them to use various strategies to hide, camouflage or "mask" their authentic selves to avoid such experiences. Participants' keen awareness that they remained on the periphery despite their efforts caused them intense distress. Strongly motivated by the need for friendship, the women in this study were willing to endure what felt like the harsh normative social expectations of non-autistic others. This is consistent with existing studies (Bargiela et al., 2016; Hull et al., 2017), whose participants had to strive to "camouflage/mask" their autistic characteristics. In addition, Cage and Whitman (2019) found that autistic women tend to mask to "fit in" and avoid bullying and stigmatization. In the current study, this need for acceptance and to fit into the social "in-group" was very evident and was felt particularly keenly pre-diagnosis. The participants described how they observed others and copied or mimicked their behaviours. They spoke of the careful, effortful planning they employed when acting and communicating, motivated by anxiety about offending others or being misunderstood. Most feared adverse reactions and negative perceptions to their meltdowns, and worked hard to avoid this happening around others, typically by fleeing when meltdowns were pending. Some participants were encouraged by their carers, parents or teachers to behave like their non-autistic peers in order to avoid causing offense or being targeted. Others dedicated their energy towards suppressing instinctive behaviours such as stimming or speaking without editing their thoughts. They all commented on the internal discomfort of behaving incongruently with their true selves, which also exacerbated existing mental health difficulties. Hilary noted: "*…I will tend to try and please…I was unhappy about this…thinking that I am two faced…a chameleon…"* (p.20). These experiences are consistent with existing literature by Cage, et al (2017) who surveyed 111 autistic adults. They found that external and personal autism acceptance significantly predicted stress and depression among their participants, and that "camouflaging" was associated with higher rates of depression. Cage and Troxell-Whitman (2019) noted the high prevalence of camouflaging in autistic women, despite its detrimental effect on mental health. A study of 58 autistic women by Beck et al. (2020) found a similarly strong positive link between masking/camouflaging and poor mental health. Their findings also suggested that it is the degree of camouflaging not the severity of the traits being camouflaged that determines the adverse effects on mental health. A study by Cassidy et al. (2018) on the risk markers for suicidality in 164 autistic adults (99 females/65 males) concluded that self-reported suicidality (SBQR) was not associated with the participants' Autism Quotient scores (how many autistic traits participants displayed), but rather with the extent of their camouflaging efforts of participants.

Six of the seven participants in the current study described experimenting with reducing their masking or camouflaging behaviour after receiving their diagnoses. However, some of the participants experienced inner conflicts, with one in particular wanting to show her true self, but fearing the reactions of others. Participants shared their experiences of frustrating, stereotyped assumptions that being autistic was a less desirable way of being than being non-autistic. As noted, one of the participants described how her need for others' approval took priority over her need to express her authentic self. Her fear of disappointing and experiencing adverse reactions from others drove her to continue engaging in people-pleasing behaviour. Hull et al. (2020) noted in their research into the female autism phenotype that camouflaging is a common strategy in autistic women with no intellectual disability, concluding that it could be adaptive as well as maladaptive. Hull et al.'s findings are at odds with the experiences of the current study's participants, who uniformly viewed their masking and camouflaging as undesirable and maladaptive.

Loss of voice was another manifestation of camouflaging. The negative reactions of others silenced most of the participants, many of whom consequently lost the motivation or courage to speak freely. Participants additionally spoke of battling to understand themselves, feeling self-doubt and having difficulty in trusting their own judgements, all of which suggests that these factors detracted from their willingness to speak about their experiences and voice their opinions. These experiences align with a recent study by Harmens et al. (2021), whose thematic analysis of autistic women's blogs revealed that a lack of acceptance by others significantly impacted autistic women's abilities to voice their lived experiences. One participant in that study noted that *"Being an undiagnosed autistic can feel like the whole world is gaslighting you… you're being told every day that your lived experience isn't real" (p.10).*

Some participants in the current study initially sought self-understanding by questioning others, but halted their efforts in the face of disapproval. One woman noted that she started thinking her voice was inconsequential and had no effect on changing people's minds about who she was. She was dismissed by her GP when she wanted to explore the possibility of an autism diagnosis and vividly recalled her GP's facial expression, saying "*... I just felt shame…".* This experience also arose as a theme in Harmens et al.'s (2021) study. Participants in the current study spoke of their pre-diagnostic struggles to have their autism recognised and validated and their needs understood, which left them exhausted and lacking the energy to speak their most basic truths. Autistic women's experiences of exhaustion are also referenced in studies by Leedham et al. (2020) and Harmens et al. (2021). Considering the growing body of research suggesting that autistic women experience significantly poorer mental health than the general population and that depression and anxiety impact autistic females more significantly than autistic males (Bargiela et al., 2016; Harmens et al., 2021; Pearse, 2020; Tint & Weiss, 2017; South et al., 2019), participants' experiences of loss of voice are even more concerning. Although not voicing autistic perceptions and realities amongst non-autistic others felt safer for the participants, this sadly contributed to their autism remaining invisible as they were overlooked for assessments and their support needs went unmet.

Some of the participants were cautious about disclosing their autism diagnosis due to receiving mixed reactions from others. One participant found her diagnosis was validating, but she remained silent about it for fear that she would experience similarly invalidating reactions to those she had experienced pre-diagnosis. Another participant noted that she felt an ongoing reluctance to voice her diagnosis at work due to fear that it might have an adverse effect on her professional reputation. She did, however, feel free to disclose it amongst autistic others. This feeling of freedom grew as time passed.

Post-diagnosis, many of the women reported rediscovering their voices, which is an encouraging finding. Some participants simply decided to say what they thought, while for others a process of arriving at self-acceptance and a clearer understanding of their own internalized autistic stereotypes had to precede the development of a growing ability to speak their truths. One of the women described her joy and delight at having an opportunity to speak as long as she wanted during her research interview. However, another participant continued to monitor her way of speaking; her need to voice her feelings was trumped by her *"horror"* at the reactions of others.

Alongside the significant challenges of being autistic, the participants also highlighted qualities inherent to autism, such as self-reliance, focus and concentration. These strengths empowered them in different areas of their lives. Many of the women spoke of their diverse strengths and skills, including their intelligence, creativity, resilience, physical skills and their resolve in managing social and communication challenges, including through coping and self-care strategies.

Notably, these skills encompass areas often perceived as autistic weaknesses, such as hyper-focus and attention to details rather than the whole. Warren et al. (2020) used thematic analysis to analyse parent questionnaires and reported similar strengths, many of which are viewed as autistic weaknesses by parents of autistic adolescents (aged 12-19, 88% male).

The capacity to cope, emerging resilience and experiences of emancipation typified post-diagnostic living for several of the current study's participants. A study using thematic analysis (Russell et al., 2019) with 24 autistic people (17 male: 7 female) found that autistic strengths could be experienced *either* as advantageous *or* disadvantageous dependent on moderating influences such as the social context, ability to control behaviour and extent to which a trait was expressed. They reported that autistic adults value traits such as creativity, hyper focus, attention to detail and memory prowess. They concluded that it would be a "false dichotomy" to separate autistic traits into strengths and weaknesses or advantageous vs problematic for the purposes of intervening with so called problematic traits.

One of the women in the current study was proud of her ability to either *"get lost"* in her own thoughts or, conversely, to initiate and intensely focus on tasks, to *"keep going".* Her satisfaction was palpable in her description of her autistic strengths, which included analytic skills and *"a quirky sense of humour".* There has been no study with autistic women to date which reported on their own experiences of autistic strengths, and this thus represents a novel finding.

An emerging resilience and increased capacity to cope typified post-diagnostic living for several of the women. Those who felt "*obliged"* to surrender to social demands pre-diagnosis spoke of a growing self-compassion that allowed them to develop their self-care capacity, learn to say "no" and take time out to meet their own needs. Another participant, who referenced her high intelligence frequently throughout her narrative, spoke of how she developed skills and strategies to mediate autistic challenges that directly affect social proficiency. She described how she would "*deliberately"* focus her attention on one person when she was in a crowd and *"consciously remind"* herself of how that other person had a full, real and different inner and outer life. This participant's ability to see another person's point of view improved through her use of this strategy, and, furthermore, enhanced her sense of connectedness to others and the world. This participant's experience of having to consciously focus in order to see the world from another person's point of view speaks to the social cognition challenges experienced by autistic individuals. The perspective-enhancing strategy she employed suggests that so-called autistic deficits in cognitive empathy are not fixed or insurmountable barriers to gaining an understanding of others' lives.

### 5.3 Autism and social/interpersonal functioning

The theme "Being alongside others" arose from the participants' experiences of their social/interpersonal challenges. The subordinate themes that arose from this superordinate theme were: 1. Struggling to understand and to be understood; wondering why people don't just say what they mean; 2. It is easier to interact with people who know what it's like to be me; 3. Being on the outside, looking in: missing intimate connectedness.

The participants experienced the inherent differences between autistic and non-autistic people's approaches to communication and social interaction as *"difficult"* and challenging. They all reflected on the challenges and frustrations that derived from understanding non-autistic people's ways of communicating, and often wished people could be more *"straight"*, i.e. communicate clearly and unambiguously. Equally, the women experienced despair at being misunderstood by (mostly non-autistic) others, who frequently took offense at their direct way of expressing themselves. The participants expressed feelings of sadness, frustration, despair and fear that being misunderstood by others might be their enduring experience across their lifespan. One participant described having an awareness of "*… a perpetual state of confusion,… but no real idea what was going on...*"

These experiences align with what Milton (2012; 2017) described as the "double empathy problem". Central to this view is the notion that empathy is a two-way street. Milton, like many autistic autism researchers, took exception to the large body of Theory of Mind (TOM) research (Baron-Cohen, 1995; Bodner et al., 2015; Buon et al., 2013; Channon et al., 2014; Mathersul et al., 2013) that suggests it is due to defects in empathy that autistic people do not understand non-autistic ways of communicating.

In a similar vein Fletcher-Watson and Happé (2019) note that non-autistic people automatically and unconsciously track others' mental states, but autistic people can only do so through conscious calculation. Conversely, Milton discovered that non-autistic people have significant difficulty "tracking" the mental states of autistic people, and in their understanding of autistic ways of communicating (Milton, 2012; 2017). Additionally, non-autistic people were found to be negatively biased against autistic communication, believing that the burden to communicate clearly lay with autistic people (Milton, 2012; 2017). The writer Jim Sinclair (1992) eloquently captured this in a reflection on his own experiences of being autistic: "*Not all the gaps are caused by my failure to share other people's unthinking assumptions. Other people's failure to question their assumptions creates at least as many barriers to understanding."* (1992: p. 4). Research by, inter alia, Alkhaldi et al. (2019) and Sasson et al. (2017) suggests that non-autistic people have accurate perceptions and inferences about non-autistic behaviour, but significant difficulty reading autistic behaviour. Non-autistic participants not only misread autistic participants, but also rated them less favourably than non-autistic participants. These studies explain the experiences of the women in the current study, who perceived their non-autistic peers lacked the capacity to empathise with them, and it is therefore unsurprising that a lack of motivation to continue reaching out to non-autistic people eventually took hold of many of the women.

Despite the challenges with interpersonal relationships, including friendships, the participants reported a desire for social connectedness. Some described having both positive and significantly more negative experiences of friendships with non-autistic others. The experiences of desiring social connection, whilesimultaneously finding the establishment of such connections challenging, has also been reported by Bargiela et al. (2016). Their study referenced research by Sedgewick et al. (2016) on gender differences in autistic people, which provided empirical evidence supporting their own findings that autistic girls and women show higher social motivation and a greater capacity for traditional friendships than do autistic males, despite the significant social communication challenges reported.

Participants in this study spoke about feeling anxious, and *"awkward",* particularly when attempting to establish new relationships or maintain an existing one. All the women noted that they found it significantly easier to be amongst people who understood and accepted their way of being in the world, typically other autistic people.

Bolis et al. (2021) report that people who share many autistic traits (i.e. have significantly similar autistic profiles) perceive the quality of their friendships as higher, regardless of their duration, and irrespective of age and gender. The reports of the women in this study concur with these findings on interpersonal similarity as they also described a greater sense of acceptance and closeness with autistic peers who were like themselves.

Difficulties in establishing and maintaining relationships resulted in feelings of loneliness and isolation for six of the women in this study. For some these were periodic feelings, whilst others felt a more pervasive and enduring sense of alienation. Baumeister and Leary's (1995) research on the belongingness hypothesis posited that belonging is an intrinsic human need, a view echoed by the participants in this study. Their experiences align with existing research suggesting that autistic people are more likely to be socially isolated than their non-autistic peers (Orsmond et al., 2013). The combination of isolation and social anxiety appears to create a feedback loop for some individuals, ultimately exacerbating social anxiety and possibly decreasing social motivation (Swain et al., 2015).

While the majority of the women experienced validation through positive interactions with autistic others in online communities and in real life situations, they found “offline” friendships difficult. A few described having friendships that met some of their needs for social connectedness and belonging;  others expressed dissatisfaction with their social connections or the quality of these connections. One woman reported feeling lonely and isolated, with few people she trusted and little hope that this could ever change.

Bagiela et al. (2016) found that autistic female experiences of disconnection from non-autistic female peers gave rise to or exacerbated pre-existing depression and anxiety, as well as suicidal ideation in their participants. Paquette-Smith et al. (2014) surveyed 50 adults with Asperger’s and reported that 35% had attempted suicide at some point. Many of the women in the current study reported anxiety and depression, and one referred to suicidal ideation and attempts on her own life. These experiences align with research by Tierney, Burns and Kilbey (2016) whose 10 adolescent female participants all, despite their best efforts, frequently experienced rejection in social situations, consequently leading to stress and anxiety.

Participants in this study shared valuable experience of loneliness and isolation, all of which builds on the existing literature. One participant in the current study commented on her general loneliness in life. Despite having many acquaintances, she felt unable to meet her need to have intimate connections in which she could unabashedly be herself, speak freely, and have deep, meaningful *“no bullshit”* conversations. Other participants shared prevailing feelings of isolation and a sense of separation from non-autistic others, who they believed did not appreciate or understand their perspectives and life experiences. One participant however commented that she was satisfied with her own company, saw herself as a self-contained person and rarely felt lonely. Interestingly, the same woman reflected on her inability to let go of masking behaviour due to her overwhelming fear of the negative, disapproving responses of others. It is perhaps thus unsurprising that she valued her own company, and was happier not to expose herself to the anxiety-provoking experiences of interacting with mostly non-autistic others.

## 5.4 Experiences of supports

Participants experiences of support services and of providing support to other autistic women gave rise to the theme "Receiving and giving support"

The subordinate themes that arose from this superordinate theme were: 1. Experiences of traditional psychotherapy: A waste of time; 2. Needing suitable support: A different approach is required; 3. Sharing our experiences and stories can change perceptions about autism

All the participants agreed that autistic women would benefit from support from qualified healthcare practitioners who had knowledge, understanding and experience working with autistic women with complex mental health needs. Several commented that they felt professionals were sorely lacking in understanding and acceptance of autism. They all believed that psychotherapeutic support might have benefitted them. The availability of suitable supports was of significant concern to the participants, who shared their frustration at their needs being overlooked, misunderstood or dismissed, even if they found and accessed psychotherapies. This left their psychotherapeutic support needs largely unmet, further compounding their distress. Participant narratives were dominated by criticism of traditional talk psychotherapies, which most of the women viewed as *“frustrating”* and *“pointless”,* or a generally poor fit to their needs. One woman noted that, in her view, suitably qualified therapists with an understanding of autism in woman simply do not exist in Ireland. Another participant study noted the mental health support needs of autistic women are not radically different from those of non-autistic women, yet the approach required to support those in need of help seems to require a radical review. Milton (2018) made a relevant and complementary observation in reference to the Double Empathy Problem (DEP) noting that it not only takes differing cognition and interests into account, but also the social context in which interactions occur. DEP thus has the potential of radically shifting the way in which autistic people are perceived and supported. Mandy (2019) similarly reported on the necessity of environmental adaptations in autism interventions, cautioning against placing the onus on the autistic individual to change and adapt to their environments.

Participants expressed strong preferences for structured and directive therapeutic support. Two participants noted their frustration at unstructured therapeutic approaches after *“countless”* poor experiences in this regard. These participants eventually found benefit in structured psychoeducational therapeutic approaches. Bargiela et al. (2016) noted findings in line with experiences of the women in this study. They reported that their 14 autistic female participants had similar experiences of their autism not being recognised by mental health professionals, with five participants also noting their GPs dismissed their concerns and failed to offer further assessments. Participants in Wilson’s (2017) qualitative study on the counselling experience of people with Asperger’s Syndrome similarly noted that traditional counselling did not “work” for them. Findings by Vogan et al. (2017), who tracked barriers in service provision and satisfaction in a sample of 40 autistic adults, also highlighted the significant challenges autistic adults without intellectual disability experienced in accessing appropriate and high-quality medical and mental health services. Six of their 40 participants took exception to the deficit-based language associated with the medicalised view of autism. Participants in this study found the language of the DSM 5 (APA, 2013) provided little aid in terms of diagnosing autistic women, particularly those without associated learning disabilities, and felt that this also left therapists ill-equipped to understand their support needs. These experiences are in line with those reported by Leedham et al. (2020), whose participants reported facing ongoing battles to have their needs recognised by mental health service providers and a generally poor understanding of autism among mental health professionals.

Most participants voiced their hopes for not only a greater understanding of autism, but, primarily, for greater acceptance. They expressed hope that ongoing autism awareness drives and education about how autism presents in girls and women would eventually bring these supports into being. Participants felt that knowledge and understanding of the presentation of autistic girls and women were virtually non-existent. Being compared to *“stereotypes*” based on autistic boys and men caused further frustration and angered several participants. Participants shared a strong desire to change the narrative of autism as a disorder and a deficient way of being in the world to one in which autism is viewed as a “*difference”* in neurological predisposition, with autistic individuals accepted as being equal, not less, than non-autistic others. Dr Luke Beardon had a similar reflection, as referenced by Jackson-Perry (2017): he refuted the medical reading of autism and strongly asserted that, while autistic people may be *"inherently impaired in non-autistic social skills",* if the premise of "different not less" is applied earnestly, it has to be accepted that non-autistic people are equally impaired in autistic social skills (p. 21).

Participants expressed strong desires to support other autistic women. To this end they felt that they needed to move out of their own comfort zones and voice their lived experiences in support of other autistic people with the objectives of drawing attention to the presentation of autistic women and improving life for all autistic people. Participants believed acceptance could only be achieved through enhanced education about the nature of autism and the experiences of autistic people. They saw their own voices as crucial to the struggle to raise awareness, build understanding and gain acceptance. Many of the women in the study did indeed find themselves freed up to start sharing their stories, experiences and perspectives on social media groups dedicated to supporting autistic people. They expressed gratitude at learning more about autism from other autistic women, and, in turn, being able to support others who might be new to the journey of discovering their autistic identities. Their need to raise their voices and challenge prevailing narratives about autism echoed Walker's (2016) view that the pathologising of autism is a social construction rooted in social power inequalities and cultural norms rather than in scientific reality.

Both Bagatell (2010) and Brownlow and O'Dell (2013) found that social media can provide important opportunities for autistic women to share their experiences and acquire the skills and confidence to tell their stories outside of social media forums. This was noted as an important goal by some of the participants in this study.

## 5.5 Implications of this study

There is emerging recognition that the longstanding marginalization and "invisibility" of autistic girls and women has led to the exclusion of autistic females from the processes of the production of "knowledge" about autism. As Lai and Baron-Cohen (2015) assert "*These late-diagnosed individuals tend to suffer from concurrent mental health challenges potentially related to long-term stress in adaptation to daily life in the society"*. The experiences of participants in this study highlight the need for mental health support practitioners to have a keen understanding of autism as it presents in girls and women.

### 5.5.1 Implications for trainees, psychotherapists, supervisors and other mental health service providers

> *"Grant me the dignity of meeting me on my own terms… Recognise that we are equally alien to each other, that my ways of being are not merely damaged versions of yours. Question your assumptions. Define your terms. Work with me to build bridges between us."* (Jim Sinclair in Milton 2017, p. 118)

Participant's' narratives in this study echoed findings of other studies (eg.: Bargiele, et al., 2016; Milner et al., 2019; Pearse, 2020) that the male-centric, pathologizing view of autism (as per the medicalised DSM 5 (APA, 2013) has served them poorly. Therefore, clinicians are invited to take a critical view of existing diagnostic criteria for autism as per the DSM 5 (2013) by engaging with literature by autistic women (eg,: Grandin, 1995, 2006; Halliday-Willey, 2015; Hendrickx, 2014, 2015; Williams, and Yergeau (2013) and by prioritising work by autistic researchers (eg,: Chown, 2016; Chown and Leatherland, 2018; Milton, 2012, 2018; Wilson, 2017),. Psychotherapists and other mental health clinicians need to be aware that this study and existing research evidence suggest that most autistic people do not subscribe to the conceptualism of autism as a disorder. The reference Autism Spectrum Condition (ASC) is preferred to Autistic Spectrum Disorder and autistic people prefer being called “autistic” rather than being referred to as “women/men with autism."

The women in the current study experienced lack of understanding of their presentation and their needs in their encounters with mental health services: These findings are in line with findings from existing literature on the late and misdiagnosis of autistic girls and women (eg.: Bargiela, et al., 2016; Milner et al., 2019). It therefore raises questions about the training and experience trainee mental health professionals are currently receiving in autism, and seems to suggest that the learning disability placements of these training programmes do not adequately equip clinicians to recognise autism in girls and women who do not have intellectual disabilities. The work of autistic female advocates and autism advocacy groups are valuable resources for improving knowledge of autism as it presents in females and will enhance understanding of the subjectivities of autistic females.

Findings from this study and existing research point to the significant mental health challenges faced by autistic girls and women. Autistic females are more likely than autistic boys and men to have the so-called “internalizing” problems, such as anxiety and depression, which brings clients to therapy. Hollocks et al. (2019) reported that estimations of current and lifetime prevalence of depression for autistic people are 23% and 37% respectively. When broadening out to consider all anxiety disorders the respective prevalence is 27% and 42%. Autism can therefore no longer be considered a niche or specialist area: There is a clear need for mental health practitioners of all persuasions, training orientations and settings to develop core competencies in recognising autism and in working with autistic clients.

Multicultural competency training should be viewed as an opportunity to identify and reflect on potential internal bias and ableist views about autism. The concept of intersectionality could provide a framework for clinicians to monitoring their internal monologues about autism and autistic people. Supervision aids reflective practise and provides invaluable opportunities to increase awareness of knowledge and competency deficits related to autism. Autistic mental health clinicians or psychotherapists/psychologists/supervisors who have extensive experience in working with autistic females should be sought out if they are not available through training programmes.

The participants in this study reported challenges in communicating with non-autistic others, including therapists. Therefore, clinicians need to develop an awareness and understanding of the “Double Empathy Problem” (Milton, 2012, 2018), which could provide clinicians with a departure point towards improving clinical prowess and empathic engagement with autistic clients/service users Milton noted that the burden of communication is a shared responsibility between the autistic person and the non-autistic person, wherein both parties must ensure that the other is supported as much as possible to communicate their diverse experiences and views to the satisfaction of the other. In psychotherapy the autistic client is not responsible for educating their therapist in how to work and communicate with them. The responsibility of ensuring flow and effective communication within the therapeutic relationship is solely that of the clinician/therapist.

It is imperative for clinicians at any level of training/experience to be aware of research into camouflaging and suicidality in autistic women (Cassidy et al., 2018). Research suggest that masking/camouflaging adversely impact the mental wellbeing of autistic women (eg,; Bargiela et al., 2016; Mandy, 2019; Milner et al., 2019; Pearse, 2020).

Clients may approach clinicians for support in maintaining or enhancing masking or camouflaging with the goal of achieving greater social acceptance and integration. In such cases it is vital to identify which aspects of their camouflaging behaviour may help clients connect with others and thus be helpful, and which aspects are harmful. In the cases of clients who are loathe to let go of masking strategies clinicians should, furthermore, consider wrap-around services such as social clubs or groups for autistic women where they are encouraged to express their authentic selves to mediate the identified adverse effect of masking or camouflaging on psychological wellbeing.

Clinicians should be aware that autistic women likely experienced challenges in obtaining their autism diagnosis. Mental health professionals might therefore need to support autistic women in their journey of identity formation, and a balance might need to be struck between potential and acceptance in managing autistic challenges. The notion of striving for equilibrium, or searching for psychological balance, can mediate the inflexibilities that typify autistic thinking and often lead to clients either “getting stuck” or fleeing therapy when confronted with their so-called impairments.

Sensory hyper- and hypo-arousal has a significant impact on the lived experiences of autist women. Clinicians should consider how the sensory elements of the physical space in which therapy occurs can be adapted to the comfort of each individual autistic client.

Participants in this study spoke out against traditional psychotherapies and noted a preference for structure in therapy. Existing research on effective and ineffective psychotherapeutic interventions for autistic clients furthermore indicate that structured psychotherapeutic approaches such as CBT are more beneficial to autistic people than traditional talk therapies.

This study highlighted that clinicians who endeavour to work in a client-centred manner will benefit from asking autistic women what they expect from therapy (eg: what  might "work” and what might not “work” for them), onset/contracting stage. As with any client group autistic women will benefit from periodic review of whether therapy is being experienced as beneficial in meeting their needs.

### 5.5.2 Implications for autistic women attending psychotherapy

While research into autistic women is a rapidly expanding field, the experiences of the women in this study suggest that mental health professionals in Ireland are still falling short in their awareness and understanding of how autism presents in women. Existing research into women’s’ experiences of support services align with the experiences of the women in this study. Women who are diagnosed autistic and seeking therapeutic support find themselves at an advantage over those who are querying whether they are autistic. Women in this position do not have to cross the hurdle of convincing others of their autism and can thus focus on exploring their support needs and how to communicate these to psychotherapists.

Autism support groups on social media sites such as Facebook could be a useful resource for word-of-mouth referrals from other autistic women who have benefitted from therapy. Psychotherapy bodies and the Psychological Society of Ireland (PSI) website offer “find a therapist” options where therapists usually state the therapeutic modalities they work within. Many therapists who use holistic or eclectic approaches will likely be willing to offer structured cognitive therapies. The findings in this study supports existing research that suggest that highly structured therapeutic approaches such as cognitive therapies benefit autistic people more than traditional “talk-therapies”.

The Double Empathy Problem should be considered: women will assume that they are going to encounter barriers to communicating with non-autistic therapists. It may be worth exploring whether autistic therapists are available, which may reduce the risk of communication barriers. If autistic therapists are not readily available, offering a brief synopsis of Milton’s (2012; 2017) DEP findings and putting forward the likelihood of a communication dissonance might be a good the starting point for any therapeutic engagement. A therapist who is willing to start at this juncture should also invite the client to suggest what type of approaches and supports might benefit them. Autistic women who experience significant challenges from sensory sensitivities may wish to note these at the earliest opportunity, thereby giving the therapist the opportunity to change aspects of to the therapeutic environment that may be bothersome to the client.

Women who self-identify as autistic and who may be seeking a formal diagnosis might identify with the barriers some participants in this study encountered in their attempts to receive an autism diagnosis. However, they may be heartened by the knowledge that research in autism in women is rapidly expanding and, with that, an awareness of how autism presents in women is increasing among mental health professionals.

## 5.6 Limitations and strengths of the present study

While the results of this study offer descriptive and nuanced insight into the lived experiences of autistic women, the small sample size, which is intrinsic to IPA, precludes wider conclusions about autistic woman. IPA holds an idiographic focus which requires intensive analysis of individual transcripts and does not propose to lend itself to generalizability or transferability of findings generated in studies which employs this methodology. Findings of this study therefore relate to the study population and not to autistic women in general. However, small sample size does not preclude logical and conceptual inferences to be drawn from and about cases (ie: idiographic generalization) and it is thus still possible to generate understanding which could potentially advance knowledge about autistic women. IPA, furthermore, allows for rich descriptions of participants' experiences to emerge and was the obvious methodology to allow the voices of this marginalised population to be heard. Semi-structured interviews provided scaffolding for autistic women, who emphasised the high value they place on structured approaches, while being flexible enough to explore participants' narrative through additional prompting.

Snowballing was used as an additional recruitment strategy, which was effective at identifying participants who met the inclusion criteria; however, it also generated a group of participants who had connections on social media sites and who were all caucasian and of middle-class backgrounds.

I am an autistic researcher. Being an insider has its strengths and limitation in terms of both lived understanding and potential bias. Researcher bias is an acknowledged limitation of qualitative studies: the judgment of the researcher influences the way the data obtained from interviews is organized and analysed. I was the sole researcher in this study. I conducted and transcribed all the interviews. With support from my supervisors, I determined the thematic content of the transcribed interviews. It is thus possible that my personal bias has influenced the content and conduct of the interviews, as well as the identification of themes.

Precautions, including the use of a semi-structured interview schedule to guide the interview process, were taken to mitigate the effects of possible bias. After the completion of data collection and analysis of the transcripts, I reviewed the themes with my supervisors to ensure accuracy and that I was not excluding relevant topics. Throughout this process I carefully considered my thoughts and feelings about my own experiences as an autistic woman; my supervisors' prompts aided in this.

Participants were aware that I am autistic from the outset, and I believe this likely aided them in speaking freely about their experiences of being autistic as there were relatively few occasions where I had to ask for further clarification of participants' meanings. Participants generally seemed unburdened by the concern that I would not understand their lifeworld.

## 5.7 Recommendations for future research

This study offers the reader an in-depth analysis of the lived experiences of autistic women in a world not set up for autistic people.

Research on the lived experiences of autistic women is in its infancy and more work in this area will continue to serve this population well. Six of the seven participants were diagnosed late in life. More qualitative research on the way in which autism presents in girls and women is thus vital to expand the knowledge base with a view to addressing the male-centric diagnostic criteria of the DSM 5. I found IPA a helpful methodology to explore experiences of autistic women, and would recommend its use in future research. However, qualitative research methodologies such as IPA are typically characterized by small sample sizes. Studies using quantitative methodologies and mixed methods studies have transferability and generalizability of findings as objectives. Research using these designs will greatly contribute to the knowledge base in this area.

Masking or camouflaging behaviour was described by all the participants in this study. Research about how best to support autistic girls and women in developing an identity true to their authentic selves is sorely needed.

Some participants referred harmful experiences in intimate relationships such as sexual abuse, which was in line with findings by Bargiela et al., (2016) and Milner et al (2019). I did not probe any further on these matters due to the fragility of the relevant participants observed in this study. I felt ethically bound by my duty of care in terms of non-maleficence and my integrity as a researcher. However, anecdotal and research evidence suggest that these experiences are by no means uncommon for autistic women and further research focussing on these experiences may be of benefit to autistic women.

CBT has been the go-to psychotherapeutic approach when working with autistic clients. Research into how other therapies can be enhanced to better support autistic people will greatly benefit this population.

### 5.8 Summary

This chapter discussed the findings of the study considering existing research. If one overarching theme had to be identified, it would be the general experience of participants that being an autistic woman is "*difficult*". Participants spoke eloquently about their experiences of feeling *"different"* prior to being diagnosed autistic, and having poor self-esteem and self-regard as they struggled to develop an authentic identity without an understanding of why they felt *"alien"*. Some of the study findings were in line with existing literature (e.g., social communication challenges, feelings of 'difference', masking and its association with poor mental health). Others expanded on existing knowledge (e.g., the need for different approaches in supporting mental health), whilst other findings stood in contrast to diagnostic information contained in the DSM 5 (e.g., the significant adverse impact of sensory differences on overall functioning and well-being). Novel findings about the strengths, coping skills and resilience of autistic women emerged, which could inform psychotherapeutic support of autistic women. Implications of this study for mental health service providers, including psychologists and psychotherapists were discussed followed by study implications for autistic women. Finally, study limitations and suggestions for future research were presented.

### 5.9 Conclusion

This study aimed to contribute to the knowledge base of autism in females through using a qualitative methodology, namely IPA. The study highlighted how current diagnostic criteria for autism, as contained in the DSM 5 (APA, 2013), has served autistic women poorly by leaving most autistic women without associated intellectual disability undiagnosed. There is an increased awareness of the under- and misdiagnoses of autism in women in recent research (e.g., Bargiela et al. 2016; Leedham et al. 2020; Pearse, 2020), and the consequent adverse impact of this phenomenon on the mental wellbeing of this neglected population. The paucity in research with autistic females has left the traditional view of autism unchallenged and has contributed to the invisibility of this cohort. Pellicano et al. (2014) stressed the need to understand why women with autism 'slip through the net'. The findings in this study suggests that a lack of knowledge and understanding of how autism presents in women may indeed be a contributing factor as suggested by Bargiela et al (2016). The latter study suggested that research into the so-called female autism ‘phenotype’ should include measures of camouflaging and its effects on diagnosis and wellbeing. Lack of awareness, understanding and acceptance of their autism furthermore significantly impacted participants’ capacity to develop their core identity and to reach their full potential. Participants found the disregard of their autism amongst health care professionals and mental health clinicians distressing and infuriating, and experienced dismissal of their concerns by incognizant professionals as harmful to their mental wellbeing. The women in this study described the adverse impact of camouflaging and masking on their mental health and noted it exhausted their coping resources. Masking/camouflaging is known to adversely impact the mental wellbeing of autistic individuals (e.g., Cassidy et al, 2018; Lai et al. 2017; Milner et al. 2019) and participants in this study concurred that it harmed them. Participants’ experiences of the adverse impact of sensory differences on their day-to-day functioning were not in line with DSM 5 criteria: DSM 5 severity levels suggest that autistic people who do not have intellectual impairments are less impacted by their sensory differences and therefore require less support.

A novel finding in this study was the subjective experiences of autistic women of their own strengths, ability to cope and resilience.

Participants were critical of traditional psychotherapies and shared poor experiences of psychotherapeutic interventions, which were in line with existing research (e.g., Bargiela et al, 2016; White et al, 2017). However, some persisted in looking for support and those few derived benefits from structured approaches such as CBT. Most of the participants in this study felt passionate about increasing awareness and understanding of autism in women, and some actively advocated for this goal. Regardless of their negative experiences with medical and mental health services some participants remained hopeful that increasing awareness and understanding of autistic women might lead to better experiences for other autistic females of all ages.

## Reflexive Notes

*For autistic researchers, it is important to consider issues of internalised ableism and the effect these may have on one's work and interpretations. This research process energised, challenged and excited me in equal measures. I felt delighted and privileged to give voice to the experiences of autistic women, which have thus far been so neglected in autism research. The struggles the participants experienced in their day-to-day living and which might have been lessened had they received a timely diagnosis, spurred me on with the hope that this study will increase psychology and psychotherapy professionals' awareness and understanding of autistic women's presentation, associated mental health manifestations and support needs. The prospect of contributing to the knowledge base on autism left me feeling hopeful that future generations of autistic women might have more positive stories to tell about their encounters with healthcare professionals. I was shocked but not surprised by the extent to which autistic women experience exploitation, particularly in intimate relationships. I could not but wonder whether a timely diagnosis would have equipped participants with a better understanding of their own potential vulnerabilities and coping and protective strategies for being with others.*

*I am aware of the need to reflect on how to incorporate these findings into my own psychotherapy practice and to disseminate them as widely as possible. As an autistic researcher, psychologist, psychotherapist and a parent to an autistic daughter, the non-autistic narrative and media representation of autism fills me with despair and trepidation. My own encounters with mental health professionals have left me equally distressed by the prevailing misunderstandings of the nature of autism in women, and it is usually with some trepidation that I approach media representations of autistic people. I have personally experienced Milton's now renowned double empathy problem in my encounters with other mental health professionals, at which I feel it is expected of me to make myself as clearly understood as would be expected of a neurotypical person. Outside of my family and my close circle of friends, the people I have resonated with most, both professionally and personally, have invariably all been autistic. I was thus unsurprised by the experiences of anger, despair, and hopelessness noted by the participants in relation to their experiences of being alongside non autistic others, and their distress at the lack of understanding of their clinical presentations and autism related needs. Nonetheless, I was impressed by participants' resilience, and their self-identified strengths.*

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# APPENDICES

## Appendix A

### Pre-Recruitment Notice/Post to females on Facebook Groups for Women with Autism

Dear potential participant,

My name is Liezl Wienand. I am a women with autism/Autism Spectrum Disorder (ASD). I am also a Psychotherapy student, at Dublin City University conducting research into women with ASD/Autistic women and how living with ASD/Autism affects their life experiences.

To participate you must be a women with ASD/an Autistic women, over the age of 18.

You must also live on the island of Ireland to eligible to participate.

Should you be interested in potentially participating please PM me. I will then send you a formal invitation to participate which you can reflect on before deciding if you wish to participate.

Kind regards

## Appendix B

### INTERVIEW SCHEDULE

Thank you very much for agreeing to take part. I would like to ask you about the experience you have living as a woman with autism.

---

**Question 1: Could you tell me briefly what convinced you to be willing to participate in research on the lived experiences of women with autism?**

**Question 2: What it is like to live with autism?**

**Question 3: Could you tell me about your social experiences?**

Potential prompts: Do you find social interactions challenging? Do you enjoy social interactions? Can you tell me about times that you've noticed your ASD impacting on your social experiences, interests motivations etc?)

**Question 4: Could you tell me about your experiences of intimate relationships?**

Potential prompts: Can you tell me about your experiences of friendship? Please also tell me about your experiences of intimate sexual relationships? Can you give me examples of how you think ASD has impacted on your experiences of friendship and intimate relationships?)

**Question 5: What is most challenging about living with autism?**

Potential prompts: what are your perceived difficulties living with autism? What are the potential benefits of living with autism?)

**Question 6: What kind of support do you find most helpful in living with autism?**

**Question 7: What kinds of supports do you experience as lacking for women who have autism?**

**Question 8: What are the things about living with autism as a woman the general public should be educated about?**

**Question 9: Is there anything we didn’t touch upon that you feel you would like to add?**

**Thank you so much for engaging with me.  I really appreciate it.**

## Appendix C

## Plain language statement to participants

### Introduction

My name is Liezl Wienand. I am a 4th year student in the Doctorate of Psychology programme at DCU, School of Nursing and Human sciences. The proposed title of the study is:

An exploration of the lived experiences of women with Autism Spectrum Disorder (ASD)

### What is the research about, and why is it being conducted?

The research study is about women with diagnoses of Autism Spectrum Disorder and how living with ASD affects their life experiences, particularly their relationships, their social interactions, their mental wellbeing, the effect they feel ASD may or may not have on their lives and the supports they may feel they need.

The research is being conducted with women who have ASD diagnoses and no associated learning disabilities because very little is known about this population. A lot of research has been done on boys and men with ASD. By contrast, limited research has been done to date of girls, but especially women with ASD. It is known that women and men experience their ASD differently, and in order to be better able to diagnose and support women with ASD, more research needs to be conducted with women who have ASD.

### Study participation

Should you decide to participate in this study, you will be offered a choice between attending in Dublin for an interview with myself, or being interviewed via SKYPE/telephone. You will need to sign a consent form before the interview can start.

The interview will last 60 – 90 minutes approximately. The interview will be audio-recorded and later transcribed to be analysed.

Your participation in the study is completely voluntary. You can withdraw from the study at any time up until data analysis commences without any negative consequences to yourself.

Your participation is also anonymous and audio-recordings and transcripts of the recording will be assigned a unique code and stored **separately** in order to protect your identity.

The data will be stored in a secured filing cabinet and on an encrypted USB device on separate premises. The audio-recording will be destroyed after the dissertation is successfully completed

Your participation is also confidential. The only limits to confidentiality would be if you threaten harm to yourself, towards another identifiable person, or if there is any disclosure of sexual abuse, which carries a mandatory reporting requirement.

I will use the raw data from the transcripts of your interview in analysis of themes, and I will write a dissertation afterwards in which the themes that arose will be discussed. I want to again emphasise that this will be done without revealing your identity or any identifiable materials. However, since a small number of participants will be interviewed this may have implications for privacy/anonymity

## Risk and/or benefits to participating

As with any research study there is always a small risk that some of the information you provide may identify you even though it may not seem to be identifiable information. In other words, your anonymity cannot ever be guaranteed 100%, but every effort will be made towards it.

There are no direct benefits to you from participating in this study, however, there may be indirect benefits, such as you feeling a sense of satisfaction in contributing to knowledge of ASD. You may also experience the interview as cathartic.

### Data destruction

The audio-recording of your interview will be destroyed after the research dissertation as been successfully completed. The transcript of the interview will be kept for 5 years after completion of the study to allow me time to potentially publish articles using the research data.

### Outcome of study

If you wish to receive a hard copy of the results of the study I will post it to you.

### Contact details

Should you have any further questions about this study, you can contact me at liezl.wienand@mail.dcu.ie.

If you have concerns about this study and wish to contact an independent person, please contact:

***The Secretary, Dublin City University Research Ethics Committee, c/o Research and Innovation Support, Dublin City University, Dublin 9. Tel 01-7008000, e-mail rec@dcu.ie***

## Appendix D

## Informed Consent Form

### I. Research Study Title

My name is Liezl Wienand. I am a 4th year student in the Doctorate of Psychology programme at DCU, School of Health and Human sciences. The proposed title of the study is: An exploration of the lived experiences of women with Autism Spectrum Disorder (ASD)

### II. Clarification of the purpose of the research

I have read and understood the reason and purpose of the study as contained in the plain language statement sent to me.

### III. Confirmation of particular requirements as highlighted in the Plain Language Statement

I understand and consent to attending an interview in Dublin, which will last approximately 60 – 90 minutes

**Please complete the following (Circle Yes or No for each question)**

| | |
|---|---|
| *I have read the Plain Language Statement (or had it read to me)* | *Yes/No* |
| *I understand the information provided* | *Yes/No* |
| *I have had an opportunity to ask questions and discuss this study* | *Yes/No* |
| *I have received satisfactory answers to all my questions* | *Yes/No* |
| *I am aware that my interview will be audiotaped* | *Yes/No* |

### IV. Confirmation that involvement in the Research Study is voluntary

I may withdraw from the Research Study at any point up to and until data analysis starts. If I decide to withdraw from the study there will be no negative consequences to me.

## V. Advice as to arrangements to be made to protect confidentiality of data, including that confidentiality of information provided is subject to legal limitations

I have read and understood the plain language statement as to how the information gathered from my interview will be managed and destroyed to protect my anonimity

## VI. Signature:

I have read and understood the information in this form. My questions and concerns have been answered by the researchers, and I have a copy of this consent form. Therefore, I consent to take part in this research project

**Participants Signature:** ________________________________

**Name in Block Capitals:** ________________________________

**Witness:** ________________________________

**Date:** ________________________________

## Appendix E

## Inclusion and exclusion Criteria

**In order to participate in this study you must meet the inclusion criteria**

Inclusion criteria are as follows:

- Be women
- Have a diagnosis of Autism Spectrum Disorder (ASD)
- Have no diagnosed intellectual disability
- Be over the age of 18 in order to give informed consent
- Resident in the island of Ireland

Exclusion criteria are as follows:

- Men
- No diagnosis of ASD
- Intellectual disability diagnosis
- Under the age of 18
- Not resident in Ireland

## Appendix F

## List of Support Services

Should you feel you need support after your study participation please consider contacting the following services:

1. **SAMARITANS**

www.**samaritans**.org

(01) 872 7700

2. **PIETA House**

**www.pieta.ie**

**Pieta House have services in various contacts, details on their website**

## Appendix G Participant Demographics

| **Name *** | **Age Range** | **Autism diagnosis** | **Relationships situation** | **Living situation** | **Employment status** |
|---|---|---|---|---|---|
| Sarah | 20-35 | Childhood | Single | With parent/s | Currently unemployed |
| Illana | 20-35 | Adolescence | Single | With parent/s | Post grad job seeker |
| Cathy | 35-50 | Adulthood | Single parent | With child/ren | Full-time employment |
| Aine | 50-65 | Adulthood | Casual relationships, parent | With child/ren | Employed professional |
| Hilary | 35-50 | Adulthood | Married, parent | With partner & child/ren | Full-time employment |
| Cynthia | 50-65 | Adulthood | Single | On own | Self-employed professional |
| Indigo | 20-35 | Adolescence | Single | With parent/s | Student |

**Pseudonyms are used to protect identity and privacy of participants*

## Appendix H

Ollscoil Chathair Bhaile Átha Cliath
Dublin City University

DCU

Ms Liezl Wienand
School of Nursing and Human Sciences

5 January 2017

| | |
|---|---|
| **REC Reference:** | **DCUREC/2016/192** |
| **Proposal Title:** | **An exploration of the lived experiences of women with Autism Spectrum Disorder (ASD)** |
| **Applicant(s):** | **Liezl Wienand, Dr Gemma Kiernan, Dr Aisling McMahon** |

Dear Liezl and colleagues,

Further to a full committee review, the DCU Research Ethics Committee approves this research proposal.

Materials used to recruit participants should note that ethical approval for this project has been obtained from the Dublin City University Research Ethics Committee.

Should substantial modifications to the research protocol be required at a later stage, a further amendment submission should be made to the REC.

Yours sincerely,

Donal O Gorman

**Dr Dónal O'Gorman**
Chairperson
DCU Research Ethics Committee

DCU
Research & Innovation

**Taighde & Nuálaíocht Tacaíocht**
Ollscoil Chathair Bhaile Átha Cliath,
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Dublin 9, Ireland

T +353 1 700 8000
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E research@dcu.ie
www.dcu.ie

## Appendix I

## Participant Sarah: Sample Analysis and Narrative Summary

| | | |
|---|---|---|
| | I So, what you are describing there is basically the sensory aspect of people touching and pushing against you and even being in your space too much and you said you felt overwhelmed. Did you feel anxious? | |
| **SOCIAL DISLIKES/DIFFICULTIES:**<br>People would unfold pj's ive folded, I got really upset and angry<br>**NEEDING TO FLEE:** I would have to leave | S Yeah. Very sweaty and me hands would get all clammy and I would have to leave, go upstairs. I use to fold pyjamas and then they would unfold them and I'd feel like throwing the pyjamas at them, like I'm folding these, why are you unfolding them. It | Visceral description of experience<br>Anxiety, feels like throwing things at people<br>Struggles to cope with sensory and things not being 'just so'/perfect/her way???<br>*Emphasis: frustration?difficulty in holding it together? really really really* |

**x I**

| | | |
|---|---|---|
| **COPING:** I would get sweaty and clammy and leave, go upstairs | would really make me feel really upset or really angry, leaving there all the time. | Meltdowns when things are not"right"? |
| | I It did not turn out to be a place that you felt you could continue working at. | |
| **SOCIAL/SENSORY OVERLOAD:**<br>Christmas time is hard, overwhelming, I hated going in | S Well it was only Christmas that was overwhelming yeah from September to Christmas and it was very hard for me to go in and I hated it. | Christmas period: Overwhelming<br>*"hated it"* strong feelings. Clear about what she likes/doesn't like?? Also is she saying how difficult her world is? |

| | | |
|---|---|---|
| **IDENTITY:** I can be straight with my normal friends<br>**MASKING:** I cant say what I want with work friends, I had to make a good impression<br>**IDENTITY:** my normal friends know me, know what im like | I O.K. What you are saying to me is a lot to do with social experiences, so what is it like socially for you?<br>S I think in the work sense, you see I made friends at work, I found it alright to make friends, it wasn’t too bad but again I could not be as straight with them as I was with my normal group of friends, I had to not be saying certain things while with my normal group of friends, like some of the girls have known me for 12 years and some have known me since secondary school, so they all know me and what I am like but when I was | When playing field is even and everyone is a stranger its “not too bad” “*..I could not be as straight with them as I was with my normal group of friends, I had to not be saying certain things..”*<br>I can say what I want with friends, I have to mask with others I cant be myself?<br>Talks about what is expected: had to make good impression. Couldn’t be herself. Had to mask<br>*“..when I was in work and made new friends you had to make a good impression..”* |

| | | |
|---|---|---|
| | in work and made new friends you had to make a good impression. | |
| | I So, you were making new social relationships. | Awkward as a child, better as she got older: <u>Dev coping skills?</u> |
| **<u>IDENTITY; YOUNGER SELF v NOW:</u>** I hated meeting new people, I(t) was awkward, I've gotten better at making new friends as I got older | | *Hated; strong dislike*<br>Better at making friends now older |
| | S But I used to be when I was younger very very awkward, I hated making new friends but as I have got older I am better at making new friends. I do like meeting new people. | Easier as she got older, <u>Dev coping skills?</u> |
| | I So, it has become easier. | Awkward initially with others |

| | | |
|---|---|---|
| **<u>IDENTITY & SOCIAL:</u>** Its easier as I get older, but I'm awkward with the friends of my friends. Its hard | S It has become easier as I have gotten older but then again if I was to go out to maybe my friends' group of friends I would be very awkward at the start, but if I was to go into work and make new friends that would not be as hard as being with my friend's group of friends. | <u>Easier with new friends than with friends of old friends. Why??? Concerned about people talking behind her back?</u><br>*Really: emphasis* |
| **<u>SOCIAL/FRIENDSHIPS:</u>** Its not awkward with my normal friends | I So even now with the group of friends you have known for a very long time is it sometimes still awkward.<br>S No no never really. | |

| | | |
|---|---|---|
| | I Yes, cause the main thing you seem to be saying is that they know you for a long time. | |
| **IDENTITY:** I’m alright with my friends | S Yeah | |
| | I So, you don’t have to hold it in. | |
| | S No so I am alright with that. | People don’t know officially but she feels accepted by old friends |
| | I I know you don’t want people knowing you have autism, so these friends that you have had for a very long time, you have | Her long time friends know<br>*“..they would know”* |

|  |  |  |
|---|---|---|
| **IDENTITY/FRIENDSHIP:** I'm known by my long time friends | mentioned friends you have had for a long time, for years. |  |
|  | S Yeah me friends on the road and literally one that lives next door there and then another lives beside her and another lives four doors down and I have known them for 12 years and they are my long long friends and they would know. | Not big deal with old friends<br>*Maybe told in passing? "not a big deal"*<br>Feels accepted by friends. Does she accept herself? Is it a big deal for her? |
| **IDENTITY/ACCEPTANCE:** my friends accept me its not a big deal | I And would they know because you told them, or did your mum tell their mums or how did it work, did you tell them? |  |

| | | |
|---|---|---|
| **IDENTITY/ACCEPTANCE:** My old friends know why im blunt, straight, black and what | S I think I have told them before but it's just in passing conversations, it's not a big thing and there is not a big deal made about it.<br>I I would like to ask you about the friends that know that you just mentioned and the friends that don't know, is there any difference between how they are with you or are the all the same. Are the friends that know closer to you because they know and because they understand why certain things are what they are for you socially? | People who don't know thinks she's blunt, those who know she is autistic knows its becauise of that<br>Blunt: clear about self<br>inflexible thinking??<br>Friends accept her for her<br>Straight; used repeteadly. What does straight mean to her? Not straight is what? Crooked? Wrong? Deceitful? |

| | | |
|---|---|---|
| | S Yeah, I think the friends that don’t know think that I am a very blunt, black and white straight forward person but my friends that I have known for many years know why I am like that. I won’t do certain things and they know it’s because of that | Easier with old friends they understand<br>*“..they would understand*.. <u>feels accepted and understood by friends?</u><br>Accepted by those who know her<br><u>Doesn’t care/ does care?</u> |
| **<u>BEING UNDERSTOOD/ACCEPTED:</u>**<br>My old friends understand and accept me, I don’t care what others think. My real friends give me slack | I So actually, although it is very hard for you to think about telling people, you just told me that the ones that know, it is actually easier with them than the ones that don’t know, so maybe it is something that you should think about in the future, you know, | |

| | | |
|---|---|---|
| **IDENTITY: KNOWING SELF:** I Like being outside, alone or with friends, I hate being in house. | for friends who know seems to make your life easier.<br>S Yeah it’s not even that it makes it easier, they would understand why I am like that, you see if my other friends don’t know why I am like that, I don’t care what they think, or why they think it or what they are like cause that doesn’t bother me they can think what they like, but my real friends, those who have been there for a long time they obviously know and will give me a bit of slack. | *Hate; strong word*<br>Likes being outside in nature, with familiar others<br>Hard with friends of others<br>What bothers her so much about friends of friends? Past bad experience/s?<br>*Awkard “its not too bad”; used “awkward often* |

| | | |
|---|---|---|
| **<u>SOCIAL/FRIENDSHIPS:</u>** Its hard with the friends of my friends its awkward<br>**<u>COPING:</u>** I tell myself its not too bad when making new friends | I O.k. you know it is great to know you have that group of friends because as you might know some people with autism have very few friends and it sounds like you have a good group of friends. Are they male and female friends?<br>S Yeah, I have both because I one think I hate is being in the house so I always try to get myself out on walks or even if it is being on my own or with my friends, I just like being out talking to people and stuff like that. I just find it hard with my other people's friends, I mean my friends talking to other people and I don't know what they are talking | <u>Does she feel awkward bout herself? Does she think she is awkward?</u> |

|  |  |  |
|---|---|---|
|  | about and it does be a bit awkward, but when I am making friends I say to myself "it's not too bad". | Easier to make friends when no one knows each other<u>. Can start a fresh, make fresh impression?</u><br>*"all in one boat"* <u>so it was ok?</u> |
| **<u>SOCIAL/FRIENDSHIPS:</u>** Its easier to make new friends when we are all in the same boat. With friends of friends I don't know what theyre like, what impression they have of me because they've been talking<br>**<u>IDENTITY/NARRATED BY OTHERS:</u>** they already have an impression of me, they've been talking | I O.K. so when it is a completely separate group of friends, you don't have contact with your current group of friends that is easier for you because you are not worried about what people are talking behind your back. | *Impressions; what others may think* <u>Age appropriate concern about opinion of others</u> |

| | | |
|---|---|---|
| **<u>IDENTITY: KNOWING SELF:</u>** I'm an outdoors person, I think i can only get out if im with people | S Not even that say going into work and I was making new friends, no one knew each other, we were all new, my induction day, it was all fresh, it was easier to make friends, cause we were all in the one boat, but say it was my friend for instance that brought me out, it would like "well I don't know your friends, I don't know what they are like" and they already have an impression of me cause they have been talking.<br>I I see what you mean, so it's meeting people who may have heard things about you and you are wondering what have they heard, | Says only goes out with others |

| | | |
|---|---|---|
| **IDENTITY: KNOWING SELF:** I’ll go anywhere sometimes I prefer going on my own, earphones in doing it by myself | what do they think, yeah that would stress me out as well to be honest. So you said to me you actually like going out, like meeting people, so what is that motivates you to go out to meet these people, do you enjoy being with others?<br>S I just put it down to being a very outdoors person, I won’t sit in the house all day at all and I think the only way I can get out of the house is if I am with people.<br>I So not going out on your own is this something that you would not be comfortable with? | *Prefer on my own>contradiction to only go out with others??*<br>Likes being alone outside, walking alone<br><u>Alone but not lonely?</u> |

| | | |
|---|---|---|
| **INTIMATE RELATIONSHIP:** My boyfriend constantly cheated on me, I broke it off | S No I have got the train on my own to Howth before, I’ll go anywhere, sometime I prefer going out on my own and putting my earphones in and there plenty of times when my mam said “I will drop you there” but I say “no I’ll walk and stick my earphones in,” because I prefer to do stuff.<br>I O.k. by yourself.<br>S Yeah<br>I So you feel more independent. | Boyfriend. 3 years, cheated on her constantly<br>being betrayed and rejected? |

| | | |
|---|---|---|
| **<u>COPING:</u>** I obviously ended it | S Yeah<br>I We talked about friendships now, socially, people at work and I am wondering if you have had intimate relationships, you know have you had a boyfriend, boyfriends and how has that been for you?<br>S I had a boyfriend a year ago, and I broke up with a year ago, but we had been together for three years and that was I constantly got cheated on.<br>I I'm sorry he cheated on you. | Ended it. <u>Acted in own best interested, coping skill</u> |

| | | |
|---|---|---|
| **IDENTITY/YOUNGER SELF:** I met him through friends, I was young, naïve and wool was pulled over my eyes<br>He showed interest in me and I believed him, I was naive | S Yeah but then I obviously ended it.<br>I O.k. so that is a healthy response as he was constantly betraying your trust.<br>S Yeah<br>I Can you tell how you met and was it difficult to get going with the relationship or how was it for you?<br>S My friend was with his best friend and we ended up just going out and we went out for a couple of months and it just went on | first intimate relationship. Then cheated on her.<br>*"wool was pulled over my eyes.."* I was blinded/deceived; does she feel foolish??<br>1st boyfriend, naive |

| | | |
|---|---|---|
| **<u>RELATIONSHIP:</u>** we broke up 5 times ( typical of that age, break-up and make-up; i am the same as others) | from there. But I think back then I was just a bit younger and a bit naive and the wool was pulled over my eyes and I believed what was being told to me. (shows annoyance here)He was my first boyfriend, the first person to show interest in me and I was very naive. | Many breakups <u>reconciliations-breakups: typical for age: on again/off-again relationships</u> |
| **<u>IDENTITY/YOUNGER SELF:</u>** I was only a child, 15, still growing up, I trusted, believed him | I Is that what you put down to you staying with him, were you aware that he was cheating on you?<br>S Yeah, we broke up five times during the relationship. | Was young, teenager, <u>typical experiences</u> *"I was still only* a baby, *you are still only a kid when you are 15"* |

| | | |
|---|---|---|
| **INTIMACY/TRUST:** It was difficult at first but after 2 years it was grand | I And then got back together again, because he told you he loved you or what.<br>S Yeah, he would say it's not true, he would say he was sorry and I would just say ok and at the time I was 15, 16, 17 and I was only growing up. I was still only a baby you are still only a kid when you are 15.<br>I And was it ever physically intimate, did you have sex?<br>S Yeah | Intimacy difficult at first then It was grand "Yeah at first it was difficult… two years it was grand" <u>Typical for her age?</u><br>Experience of sex |

| | | |
|---|---|---|
| **IDENTITY/SENSE OF SELF:** I am the same as other girls with someone seeing my body, and I trusted him | I And how was that for you as you said sometimes being with people can be awkward, was it difficult or easy.<br>S Yeah at first it was difficult but then obviously, a year and a half, two years it was grand. | No significant difficulties with sexual exp.<br>The same as for every girl. I am the same as others<br>*"I thought I could trust him"* I was wrong? |
| | I And what was the difficulty in the beginning about being physical ? | |
| **INTIMACY/TRUST:** I knew and trusted him | S I think it is for all girls someone seeing your body, you know that kind of way but at the time I thought I could trust him. | She trusted him<br>Betrayed by someone she knew?<br>"*a trust thing"* |

| | | |
|---|---|---|
| **INTIMACY/TRUST:** I trusted and was comfortable, now I find it hard to trust | I And you said to me earlier when you were working in Penny's, people touching off you and pushing you, you know coming into your space was very tough for you, so it wasn't tough for you in your relationship. | Now she finds it hard to trust |
| Now i wont go out of my way to talk to a fella | S No because it was someone I knew and I trusted him and it was more, I don't know like, it was more like a trust thing that I knew. | She wouldn't make an effort, go out of her way, to talk to a male |
| | I And was it comfortable for you? | |
| | S Yeah after a while it was, yeah, but now I find it hard to trust a fella. | Her mom was an amazing support to her |

| | | |
|---|---|---|
| | I O.k. | *"My mam was amazing during it"; "my mam was there for me yeah"* |
| **BEING SUPPORTED:** MY mom was there for me, I should have listened to her | S Like I wouldn't go out of my way to talk to a fella do you know that kind of way. | Felt minded and supported by her mom?<br>Importance of mom as attachment figure: identity formation? |
| | I So, it is difficult for you to think about him cheating on you and the fact that you believed him. And did you have support when you were breaking up? | |
| **BEING SUPPORTED:** my mom was brilliant **IDENTITY FORMATION:**: | S Yeah, my mam was amazing during it, she told me a lot of the time it isn't a healthy relationship cause we use to always argue and | Brilliant to be supported by her mom<br>*"..my mam DID support me she was brilliant"*Solid, stable attachment base? Key in identity formation? Is this why she knows herself so well? Was mom a good mirror? |

|  |  |  |
|---|---|---|
| importance of stable attachment figure. My mom supported me she was brilliant | now I look back on it and say why didn't I just listen to her. My mam was there for me, yeah.<br>I I don't think we listen to our mum as a rule. I think when we only learn the hard way, I think that is everyone.<br>S No, my mam did support me she was brilliant. |  |
| **<u>INTIMATE RELATIONSHIPS:</u>** I'm not in a rush, if its meant to be it will be |  | Not in a rush for relationship, if its meant to be it will be *"whatever is meant to be will be"*<u>wise attitude is this her mom's words???</u> |

|  |  |  |
|---|---|---|
| **INTIMATE RELATIONSHIPS:** we had a great times, someone always there, a companion. I miss that | I Looking to the future with intimate relationships do you think it is something you might want when you have kind of …..<br>S I am not in a rush<br>I You are not in a rush.<br>S Yeah if it is meant to be it will be, but I am not going out of my way.<br>I Were there positives about being with a boy? | Boyfriend. Had great times , he was always there Misses the things they did together rather than him<br>Companionship. Importance of |

| | | |
|---|---|---|
| **INTIMATE RELATIONSHIPS& COPING:** if its meant to be it will be | S Yeah, we had great times, there was always someone there and he only lived across the green which is a bit of a pain now but it was someone always there, something always to do, in fact I don’t miss him, but I miss the things we did together. | *Repeating “whatever is meant to be will be”* is it a self soothing coping strategy? |
| | I Companionship. | |
| | S Yeah but other than that no. | Describes what is difficult about being autistic |
| **ASD PROS & CONS:** Cons: Its thelittle quirks, aversion to certain sensory experiences: I wont go near a dishwaher, wasn’t able to go to Dunnes | I So, it is going to be a long time for you by the sounds of it. | Sensory sensitivities *“little quirks*”<br>“*like I wish I could give,”* wish to be rid of it? A wish to struggle less? A wish to be different? Identity? |
| | S Yeah whatever is meant to be will be. | |

| | | |
|---|---|---|
| | I Thank you because I know that is a tough question, so thank you for being so honest about that. | |
| | I What is the hardest thing for you living with autism, most challenging thing do think from your experiences in the world. | Experience of dishwasher *"hurl"* |
| **SENSORY SENSITIVITIES:** It's the smell of the dishwasher, touching something wet, makes me want to hurl, my skin crawl | S I think it is the little quirks I have, things I won't do, like I wish I could give, from small things like I won't go near a dishwasher, ever, ever, ever go near a dishwasher. I used to not be able to go to Dunnes (store). | *"its just disgusting and it makes my skin crawl"*<br>Difficult to cope? Difficult not to meltdown? |

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| **SENSORY SENSITIVITIES:** I wouldn't set foot in Dunnes when younger, I still don't like going | I Is it because of the noise of the dishwasher or why the dishwasher?<br>S It smells or the thought of it, or if put your hand in you are going to touch something wet and then I hurl and it is just disgusting and it makes my skin crawl thinking about it.<br>I So again, it is the sensory stuff, touch and smell and then going into Dunnes you said. | She still avoids Dunnes for neg sensory experiences<br>Same sensory sensitivities in a particular Dunnes<br>*"..I wouldn't step foot inside Dunnes"* why? For fear of how sensory my trigger meltdown? |

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| | S I don’t know what it was when I was younger, now I have been into Dunnes now but I still don’t like going into Dunnes now, I will go into Dunnes, but when I was younger I wouldn’t go near Dunnes, I wouldn’t step foot inside Dunnes. | |

| **MAIN THEMES WITH EMERGING THEMES** | **QUOTES** |
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| Sensory aversions<br>• Tactile: Unpleasantness of being touched<br>• Smells: evoking strong physical experiences | • *“..people breathing down my neck and a lot of people standing all over me, pulling out of me, touching me elbows, touching me shoulder and I had to leave it would send me off my rocker and I had to leave so many times.” (p.5)*<br>• *“..I won’t go near a dishwasher, ever, ever, ever go near a dishwasher…* |

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| - Visual: the “look” of things evoking unpleasantness | *It smells or the thought of it, or if put our hand in you are going to touch something wet and then I hurl and it is just disgusting and it makes my skin crawl thinking about it” (p. 17& 18)*<br>- *“.. I won’t touch jewellery, I have a really bad phobia of jewellery..” (p.19)*<br>- “I would never touch jewellery it is making me sweat just thinking about it now, horrible.” (p20)<br>- *“It just makes me feel ill.” (sight of beehive)…its so disgusting, really horrible.” (p. 21)* |
| Identity<br>- Sense of self, who I am<br>- Knowing self, what I like/dislike | - *“.. I am very black and white with people, even with my friends, people say you can’t say that, but that’s just me. I’m very straight, black and white, there is no… I’m a very blunt person, even when I was working I was like that as well… (p.2)* |

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| • Insight into what is difficult for her | • *"..when I was younger ( I was) very very awkward, ….. but as I have got older I am better at making new friends." (p.8)*<br>• *"I am a very blunt, black and white straight forward person.." (p.10)*<br>• *"..I hate is being in the house so I always try to get myself out on walks or even if it is being on my own or with my friends, I just like being out talking to people and stuff like that…" (p. 11)*<br>• *"… I wish I was more outgoing,…. I wish I could have not felt awkward and done more stuff and be more outgoing. " (p.29)* |

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| School and work challenges<br>- Experiences of hopelessness/resignation around academic challenges<br>- Feeling her talents are not good enough to make a living from | - *"yeah exams were very hard but.. they are done now.."* (p. 26)<br>- "*I could have written so much more but I could sit there" (p.24)*<br>- "*… I loved it and I was told to go into Art College by a load of people but I just think there is no jobs out there for people to do art so… there is no point in doing it if you can't get a job out of it..(p.23).* |
| Social challenges<br>- Not understanding the ways of others<br>- Not knowing how to react, respond<br>- Struggling with social expectations | - *"..if people would ask me a stupid question I would look at them …, I'm like well why would you not know that yourself." (p.2)*<br>- *"Even with managers …I thought she was saying all the wrong things and I was just giving it loads back and that is my manager and I shouldn't be doing it." (p.3)*<br>- *"..I never understand that why people don't speak straight,.." (p.5)* |

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| - Feeling awkward around/threatened by strangers | - *"I use to fold pyjamas and then they would unfold them … like I'm folding these, why are you unfolding them. It would really make me feel really upset or really angry, leaving there (work)all the time." (p.7)*<br>- *"..when I was younger very very awkward, I hated making new friends but as I have got older I am better at making new friends." (p.8)*<br>- *".. I just find it hard with my other people's friends. I mean my friends talking to other people and I don't know what they are talking about.." (p.11)*<br>- *"I love animals, they don't talk back." (p.27)*<br>- *"..when I was younger I was quite bullied….. I wouldn't talk to anyone in the stable only to the owner, but I wouldn't talk to anyone, just do my own thing,.." (p.27)*<br>- *"I had a group of friend (secondary school)..it wasn't too bad" (p.28)* |

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| Coping<br>• Not speaking her truth<br>• Fleeing/leaving difficult situations<br>• Masking, having to be less authentic with strangers | • *"I think it is tough being in work situations because I don't tell people(im autistic), people don't know,.." (p.2)*<br>• *"..I couldn't say stuff to people and I had to just be nice..i find it very hard" (p.3)*<br>• *"..Very sweaty and me hands would get all clammy and I would have to leave,..leaving all the time" (p.7)*<br>• *"..I could not be as straight with them as I was with my normal group of friends, I had to not be saying certain things.." (p.7)*<br>• *"..when I am making friends I say to myself "it's not too bad"…" (p.11)*<br>• *"..i constantly got cheated on…then I obviously ended it.." (p.13)* |

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| Negative experience of Supports<br>- Suspicious of intentions of support people<br>- Anxious to engage | - *" I didn't like going…I felt they were only there because they were being paid.." (p.30)*<br>- "*… I would be anxious going up at the start, but I would say I would be o.k. I hope I will. I just have to think about what I will say." (p.31)* |

**Summary of analysis of Sarah's interview on living with autism**

"Sarah" is 21 years of age and received a diagnosis of Aspergers Syndrome (DSM IV) when she was 11. Prior to her diagnosis of ASD Sarah was diagnosed with Attention Deficit Hyperactivity Disorder (ADHD). Sarah presented as restless and anxious during the interview, which she attended in person, supported by her mother.

Sarah lives with her family of origin. Sarah noted that social interactions with strangers or people who are "not my friends" are difficult for her, and she would avoid such interactions *"I find it hard.. my friends talking to other people,....and I don't be knowing what they are talking about.. its a bit awkward.."* (p.12)

She has a core group of neighbourhood friends who she's known since primary school years, who she feels at ease with and has regular positive contact with. "*me friends on the road... one literally next door.. I've known them for 12 years and they are my long long friends they would know (about diagnosis)"* (p. 8): "*my real friends will give me ..slack"* (p.12) Sarah experienced bullying in primary school: "*Well when I was younger I was quite bullied*" (p. 26) however, as with her neighbourhood friendships, she described peer relations in secondary school as typical for her age, noting that she doesn't feel she had significantly greater negative peer relationship experiences than any other girl her age. "*I went to an all girl's school…we all got on brilliantly and we were all nice to each other cause we were all growing up, ... I had a group of friends and I was friends with everyone in the Year, I wasn't just friends with one group"* (p.27). Yet, Sarah noted that she prefers the company of animals to that of people, as communication barriers are not an issue with animals. Some of her happiest, most peaceful times have been spent tending to horses and going horse-riding. The combination of interacting with the horses, whilst not having to engage with human interaction appealed greatly to Sarah. "*I love animals, they don't talk back… animals are so nice and loving and they aren't mean to you if you are nice to them they will be nice to you….I wouldn't talk to anyone in the stable only to the owner….just do my own thing, working in the stable and then going home then on Sunday morning up again and I would go back.* (p. 26)

Sarah similarly described her experience of her first intimate relationships as rather typical of what one would expect of those in adolescence: *"..we had great times..someone always there.. I don't miss him I miss the things we did together"* (p. 15 & 16);*" …. I was still only a baby you are still only a kid when you are 15".*(p.12)

*it is (difficult) for all girls, someone seeing your body, you know that kind of way but at the time I thought I could trust him.* (p. 14*)*

She remarked that she learned a lot about trust and intimacy from this relationship .. *"we had been together for three years and that was I constantly got cheated on… we broke up five times.. he would say he was sorry and I would just say ok and at the time I was 15, 16, 17.." (p.12).* Sarah noted that she received amazing support from her mother who mentored and supported her through it. *".. my mam was amazing during it, she told me a lot of the time it isn't a healthy relationship…now I look back on it and say why didn't I just listen to her. My mam was there for me, yeah.. my mam did support me she was brilliant..*(p. 15)

Sarah found experiences of holiday- and part-time jobs in retail challenging and discouraging. She felt overwhelmed by demands to engage with the public and had little tolerance for seemingly straightforward interactions with shoppers.

. "*… it is tough being in work situation …I use to work in Penny's and I wouldn't like people touching me ….people would ask me a stupid question I would look at them…. Like" well* *why would you not know that yourself???"..people say you can't say that, but that's just me. I'm very straight, black and white…. a very blunt person, even when I was working I was like that.."*(p.2). Sarah added that her inability to see the perspective of others meant that she became frustrated easily by "stupid" people who messed up displays: ."*.. me hands would get all clammy and I would have to.. go upstairs. I use to fold pyjamas and then they would unfold them and I'd feel like throwing the pyjamas at them, like "I'm folding these, why are you unfolding them???". It would really make me feel really upset.. really angry,.."* (p. 6) Sarah has a clear sense of identity, of who she is and what she is like: *"I am a very blunt, black and white straight forward person.." (p.10) "..I hate is being in the house so I always try to get myself out on walks or even if it is being on my own or with my friends, I just like being out…" (p.11).* Sarah noted that she regrets that she wasn't a more outgoing person, and that she felt very awkard when she was younger, although that has improved with age

> *… when I was younger ( I was) very very awkward, ….. but as I have got older I am better at making new friends." (p.8) "… I wish I was more outgoing,…. I wish I could have not felt awkward and done more stuff and be more outgoing. (p.29)*

Sarah's self-esteem seems to have been adversely affected by her academic difficulties. She seemed despondent when she was discussing this during the interview; she slumped forward and avoided eye contact completely during this part of the interview: Sarah finished her leaving cert, however had great difficulty managing the exams due to inability to sit still for adequate periods of time as a result of ADHD. This markedly reduced time she could dedicate to working on her test papers. "*I could have written so much more but I couldn't sit there"* (p.24). *"yeah exams were very hard but.. they are done now.."* (p. 26)

Sarah speech and body language signalled a sense of hopelessness in her future outlook and her view of her own academic ability and is of the opinion that if she sat the exams again, the outcome would be no different. "..*I got a reader as well but I couldn't sit there for more than an hour and I wouldn't sit there for more than an hour." (*p. 24).*Even during a 40-minute class I would get very restless because I can't sit around for very long. .... my learning support teacher had to take me out because I wouldn't sit there (p. 25 & 26). " I wouldn't like to have to do maths again, like repeating exams or stuff like that.*" (p. 23).

Sarah is talented at art, and was encouraged to go to art-college. However, she felt that there are no jobs in art and therefore there was not point for her to pursue this as a potential career: "*… I loved it and I was told to go into Art College by a load of people but I just think there is no jobs out there for people to do art so… there is no point in doing it if you can't get a job out of it..(p.23).*

Sarah was hoping to do Equine Management study in England, unfortunately Sarah didn't score enough points. "*.. I don't think I have a good enough Leaving Cert and I done Foundation Maths.." (p.23).* Sarah feels frustrated by not having been able to train as an equestrian behaviour specialist.

Sarah gave elaborate detail about sensory experiences, which evoked viscerally unpleasant feelings in her: *"I hurl and it is just disgusting and it makes my skin crawl thinking about it."* (p.17). She stressed that sensory "quirks" was by far the most difficult part of being autistic. "*…it is the little quirks, things I won't do,… .. small things like I won't go near a dishwasher, ever, ever, ever go near a dishwasher. I used to not be able to go to Dunnes"* (p. 16)*;* "*I wouldn't like things with circles in them……I hate that ring (points at my ring), I would never look at a bee hive, things that have a lot of circles in them...*

> *It sends chills down my back and I feel sick…I remember me mam got a beehive out the back garden and brought it in because she thought it was so interesting.. so disgusting, really horrible."* (p.20)

Sarah's sensory sensitivities furthermore impacted adversely on her tolerance for being alongside costumers. She typically coped by escaping situations when dealing with customers overwhelmed her:*"I would get very overwhelmed particularly at Christmas …a lot of people breathing down my neck … standing all over me, pulling out of me, touching me elbows, touching me shoulder … it would send me off my rocker and had to leave so many times"* (p. 5).

As noted mom has played a pivotal role in Sarah's life to date. She references this positive support from her mother frequently and seems to have internalised her mother's positive encouragements in much of her self-talk, which has served her in terms of emerging coping skills "*my mam had to tell me a load of times "don't react and don't say the things you want to be saying".* (p.2). Sarah reminded herself to supress her instinct to say what she wants and to mask at times

> *..I couldn't say stuff to people and I had to just be nice..i find it very hard" (p.3). "..I could not be as straight with them as I was with my normal group of friends, I had to not be saying certain things.. (p.7)*

Sarah's view on the psychotherapeutic supports available to her when she was younger was negative. She noted that she found it very difficult and unpleasant to attend a CAMHS team*:* *".. I didn't like going in and talking and I felt they were only there because they were being paid.." (p.30)*. During the time of this interview Sarah was on a waitlist to see a counsellor.

She had mixed feelings about this "… *I would be anxious going up at the start, but I would say I would be o.k. I hope I will. I just have to think about what I will say." (p.31)*

## Appendix J

## Participant Illana : Sample Analysis and Narrative Summary

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| | **Interviewer:** O.k. Ilana thank you so much for agreeing to participate in the study and that would be my first question that I would like to put to you, could you tell me what convinced you to participate in the study about the living experience of a woman with autism? | Setting scene |
| | **Ilana**: I thought it was a very interesting concept, because we don't hear too much about the experiences of women with autism in general, it is only recent years that the evidence is emerging that there are different experiences to women and men with | Describing motivation for participating, we don't hear about experiences of women with ASD |

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| In recent years evidence emerging that women and men experience autism differently, I am interested to expand and explore that | autism, so I thought it was very interesting to expand on that and explore that.<br>**Interviewer**: O.k. so thank you. Tell me a little bit about what is like for you living with autism.<br>**Ilana** Well I SUPPOSE it is just normal to me because I was twenty three when I got diagnosed so it has always been there and I never knew it, but living with it has been, like getting the diagnosis was one of the best things that ever happened to me, because I finally understood myself and why I was and all the questions that I could never answer about myself or explain, they | Cognitive rational reason for participation<br>Different Experiences, men vs women, women vs women? Her Taking part in study is to gain more information of herself for herself?<br>Talks about getting diagnosis. The best thing tghat ever happened to her Yes socially awkard, pushes through, ASD a gift at times: seeing the world differently is rewarding |

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| **IDENTITY:** Having autism is normal to me Getting dx was one of the best things that happened to me, I understood myself. One word, autism, answered all my questions about myself<br>**RUNNING AWAY/FLEEING:** Its not the easiest thing, my social awkwardness | were all answered by just one word, Autism. As I say in my blog all the time, it is not the easiest of things, there are times with social awkwardness that it's like "I want to run away" that when you are situations but you push through. It is not the easiest all the time, but I see autism as gift, that living with autism, it can be DIFFICULT but it is so rewarding at the same time, when I see the world in different ways to other people or how I am constantly curious or even when I'm born wise out of something simple, the fact that I can get that emotional about something, I just really think it's a gift. | "SUPPOSE, just" (words expressing uncertainty. Oxford dictionary "Think or assume that something is true or probable but lack proof or certain knowledge.")<br>"normal" - Perceived normalcy for 23 years. She instinctively knew her behaviour was not normal.<br>*"I finally understood myself"*<br>What is normal?<br>Diagnosis + relieve and answers, but not 'normal'<br>Constant uncertainties = lots of questions, less acceptance, she never understood herself,: Autism |

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| makes me want to run away, but I push through<br>**<u>AUTISM AS GIFT:</u>** It can be difficult but its also rewarding. I see the world differently, I'm constantly curious. I ca be born wise out of something simple. It's a gift that I can get that emotional | **<u>Interviewer</u>**: Tell me a little more about that feeling of wanting to run away, can you bring me to an example of a time when this happened to you and tell me a little bit about a time when you felt exactly like that.<br>**<u>Ilana</u>**: Sometimes in social situations and sometimes it is just something sensory that is driving you mad and you are screaming inside your head. A few weeks ago I was Mass and we were saying The Rosary and someone was behind me and she was completely out of time with everyone, she was whispering so her voice was at a higher pitch and she was right behind me and in my ear the whole time and I was just there screaming inside my head, but on the outside I was saying "I can't show any reaction at all", but you get those kind of moments or I remember once, I'm | <u>being not easy, DIFFICULT, yet rewarding, a gift</u><br>*Its difficult*<br><u>Different from other people (social identity)</u> She doesn't <u>know any other way of being.</u><br><u>Diagnosis brought clarity?</u><br>*".Constantly curious.." even when I'm born wise out of something simple, the fact that I can get that emotional about something, I just really think it's a gift"*<br>current view: positive <u>positive aspects of autism? It's a gift?</u><br><u>Values how it allows her to see the</u> |

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| | terrible for turning up exactly on the time when specified, but in Ireland, it is always at least an half an hour or an hour after, which is terrible, so I got to a pub once at 8.00 p.m. and no one was there and like on my own in a pub with drink, on the phone to my sister, “oh God nobody is here, what do I do, what do I do, I’m going to run away now and go to leave”, but the minute I did, someone turned up, so there are moments like that where you just say “I have to run away”, | world? Values the emotionality of it?<br>mentions benefits |
| **MELTDOWN/TRAUMA NARRATIVE**,. Something sensory driving me mad, screaming inside my head | **Interviewer**: So, you say the feeling of wanting to run away, what else is happening inside? | Tells of unpleasant social experiences Couldn’t tolerate things being out of sync<br>Want to run but does the opposite |

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| Example of attending mass<br>1. Build up: someone out of rhythm with rosery, higher pitch<br>2. **MELTING DOWN**: screaming inside my head<br>3. Run away/withdrawal ? **RUN AWAY/FLEE**<br>4. Physical fall outs | **Ilana:** Sometimes like a tightness in the chest, kind of almost tethering on the edge of panic or anxiety kind of thing and usually my head is just “run away, run away” or just screaming a little bit and it is verily a mild response, I SUPPOSE, but when I was younger, it would have been far more overwhelming that you know, when I was younger something like that would have completely triggered a melt down and I would have run off crying somewhere, or God only knows what I could have done, if I was in a full scale meltdown.<br>**Interviewer**: Tell me a little bit about a full-scale meltdown as you remember it when you were little. Can you remember one specifically that you tell me about. | Many contradictions, Why? Loss of sense of self?<br>Emotional – run away, why?, ineffective defence mechanism contrast to emerging coping skill of not melting down on outside?<br>contradiction – gift….???<br>*“I was just there screaming inside my head”*<br>Phone sister, ask and answer question…’never’ or… act on impulses? Restraint or ? sound like a trauma experience?!<br>Another unpleasant soc situation leading to meltdown |

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| 5. After shock<br>**NEEDING TO FLEE/RUN AWAY**<br>Example of turning up too early for pub meeting. Im terrible for turning up early. No one was there yet, wanted to flee, having to run away then someone showed up<br>**SOCIAL DIFFICULTIES/NEEDING TO FLEE** | **Ilana** There were many, they still happen occasionally but you know about three in the last ten years, these days it takes a very strong emotional stimulus to actually set me off, but I mean it is a case of you just completely lose control and it is kind of like you are there and it's like "what's happening, why are you doing this" but you are completely out of control and you have no control of the situation. | *"I'm terrible" negative/critical selftalk*<br>Knows, or perceives, people always late yet still turn up on time, why? Puts herself knowingly in situations like that? Obsessive thougts: overthinking? anxiety…<br>Struggles with things not being as she expects them to be<br>*"I have to run away"*<br>*"it's a flight or fight response, but you know you just push through it."*<br>Emerging resilience; push through; developed this coping strategy as an |

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| | | <u>adult vs how she melted down visibly as child and teen?</u><br>Talking about how hard being with others can be for her wants to run way<br>*“..run away, run away or screaming a little bit..”*<br><u>Fight-flight preferred coping style?</u><br><u>Visceral experience of stress,</u> |

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| **<u>MELTDOWN/TRAUMA NARRATIVE</u>**:<br>Like tightness in my chest, on edge of panic, anxiety, head saying run away or screaming, running away crying. much more overwhelming when I was younger, god knows what I'd done in a full scale meltdown<br>**<u>NEEDING TO FLEE</u>** | | <u>triggers-fight-flight. Illana chooses "flight"</u><br><u>Again contradiction between what how she would like to react to her feelings and thoughts, why?</u><br><u>Says she copes better now than when she was younger. Managing MELTDOWNS more internally? Effectively? Trauma narrative again of MELTDOWNS here compares now to when she as young child</u><br>MELTDOWNS, crying<br>Describes feeling panicked, screaming |

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| **LOSING CONTROL**<br>I completely lose control<br>**MELTING DOWN/TRAUMA NARRATIVE** | | its rare now, she says that her emotions, overwhelming trigger loss of self-control/MELTDOWNS. she couldnt make sense of her reactions MELTDOWNS: fight/flight reflex. Prefers flight again<br>*"what is happening, why are you doing this?.." questioning self; negative selftalk* |

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| These days it takes a strong emotional stimulus<br>**IDENTITY: WHO AM I/NOT UNDERSTANDING SELF PRIOR DX** im wondering whats happening and why im losing control | | I don’t understand why this is happening/I don’t understand me? Search for own identity?<br>PERSONAL IDENTITY, SENSE OF SELF. DIFFERENT IDENTITES (KUBIE, 2014)<br>Personal identity consists of six components, namely “autobiographical identity (lived narratives), body identity (physical appearance), sense of agency (control and intervention strategies), social identity (group interaction), beliefs (structure of knowledge) and conscious identity |

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| | | (internal capacity)" (Kubie, 2014, para. 2-6). |
| **IDENTITY:WHO AM I/NOT UNDERSTANDING SELF PRIOR DX** | **Interviewer:** Can you remember a specific day or a specific incident that you have a clear memory of, that you could share with me?<br>**Ilana**: Well I SUPPOSE there was one when I was 16, of course naturally as many women with Asperger's or anyone at all really who goes against the grain, you get bullied in school, in general for wanting to be yourself and I SUPPOSE years of that | Speaking about being Bullied at school. Describing it 3rd person |

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| **NO ONE CARED (BULLYING)**<br>I got bullied for wanting to be myself<br>**LOSING CONTROL:** I just snapped, launched, attacked, I was out of control, I regained control but still melting down | built up, there was just one day, when I was sitting on desk and a guy pulled the desk out from underneath me, and I just snapped and I launched and attacked him, completely out of control and suddenly you set away from the situation and you starting to reclaim some of the control but you are still in a meltdown, so you run away crying and you are shaking and you are just completely out of control in a situation like that.<br>**Interviewer**: And do you remember you were telling me about that day, do you remember anything else about what was happening for you, in launching at him, during it, after it, can you remember anything about the details about that. | Frequently talks in 3rd person “you” talks about herself where is the “I”?? identity not well formed?<br>Fight/Flight reactions under stress.<br>Low frustration tolerance following years of being bullied<br>*“I just snapped…”* Attempts to manage MELTDOWNS, to self-regulate often unsuccessful in youth: runs away?<br>Out of control/MELTDOWNS impacts her behaviour, running fighting back again sounds like a trauma narrative? |

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| **MELTDOWN NARRATIVE** when younger I was completely out of control<br>6. Build up<br>7. Meltdown: completely out of | **Ilana** It’s kind of hazy, cause sometimes when it happens afterwards, you are just so completely out of control that you forget, but I SUPPOSE it is like blinding rage and like it is essentially a meltdown, heightened butterfly response, so you are completely just operating on adrenalin and you know, I SUPPOSE showed reaction, I was just caught up in the anger of the moment I SUPPOSE. I always remember, my sweets went flying, so I don’t know if I was angry about him pulling the desk from under me or that my sweets were gone flying on me, but I SUPPOSE when you are out of that you are shaking and you are scared and you are just lashing out and then eventually suddenly you become aware and all you can do is just “Oh my God” and you are just crying until you calm down and you are shaking an awful lot. | Again describing her Physical Experience of loss of self control now forgets *(blinding rage*) and and how she reacted. followed by emotional exhaustion<br>*..just operating on adrenaline..”*<br>Terror of being out of control? No control?Trauma? |

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| control **LOSING CONTROL**<br>8. Run away/withdrawal **RUNNING/FLEEING**<br>9. Physical/emotional fall outs: I was operating on adrenalin; I was caught up in anger, lashing out<br>10. After shock; I was shaking and scared, I was crying and | **Interviewer** Did you at time what was the reactions of friends or teachers, supports that may have been there for you on that day for you.<br>**Ilana**: There wouldn’t have really been, I SUPPOSE much, the teachers were not aware and when these happened, the fact that I was a “goody two shoes” was in my favour that I didn’t get punished for it I SUPPOSE, but the things was nobody knew I was on the spectrum and I didn’t even know, so I SUPPOSE there wasn’t really support there in that sense and I SUPPOSE my friends, although I look back they weren’t necessarily my friends, I mean at first they were but then kind of they get to the stage that where you cry so often, or you lash so often that it is considered normal behaviour, so around that time I would have been depressed, because I was crying so much and because I had in the | Trying to cope, regain composure. Not sure what she was most upset about the chair being pulled out from under her or that her sweets went flying<br>“You”/I. where is Illana? Is it a dissociation? Is that a quirk of her general speech or is tis a distancing from self? Or a not knowing of self?<br>*“.. just crying until you calm down and you are shaking an awful lot”*<br>struggling to cope? Aftershock? |

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| shaking until I calmed down | past from MELTDOWNS and stuff, nobody asked, stopped to ask was I o.k, nobody noticed that there was something wrong, cause they just normalised my tearful behaviour and marked me down as a drama queen, so I SUPPOSE, they saw me as crazy, so I don't really remember much of a reaction to the situation, there may have been some shouting or unintelligible kind of cat calls about it, I SUPPOSE and somebody actually recorded the incident and I heard whispers that it was on Bebo at some point, so I don't know what the story was on that, I don't know if that ever happened or nor, but it doesn't matter. | Talks about how In school she tried to please<br>*"a goody two shoes.."*<br>Search for acceptance? |

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| **<u>MISUNDERSTOOD:</u>** Teachers were not aware, nobody knew I was on spectrum<br>**<u>IDENTITY, AS AUTHORED BY OTHERS</u>**, Teachers saw me as goody two shoes. She didn't know she was on spectrum, teachers didn't know The friends i thought she had saw me as crazy | **<u>Interviewer</u>**: How was that for you when you heard that people were actually recording this and reacting to you in a way that sounded to me like quite insensitive.<br>**<u>Ilana</u>**: It was very DIFFICULT to hear I SUPPOSE, because especially now if that had of been today, that would have been terrible for my reputation, that would have followed me to jobs and beyond. It is really terrible that for people that is their first instinct, that someone has a moment and they feel need to record it and anything like that and it is terrible that that is the first instinct, it was very insensitive but I SUPPOSE at the time it would have been marked down to "boys will be boys" or anything freakish they thought it was hilarious or something like that. I remember a few months later, when I kept hearing the whispers, I got so paranoid about it and all that, that it was really upsetting and kind of triggered not a full-scale meltdown, but more of a | Says teachers didn't know she was autistic, peers didn't know, she didn't know herself. Friends, then realised they weren't really friends.<br>How peers treated her: bullied<br><u>Impact on mental health of Lack of peer support/acceptance? What is normal? Their perceptions of her is how she self-id.</u> |

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| ; **IDENTITY:NOT KNOWING SELF PRIOR DX** I lashed out so often it was considered normal behaviour for me. | smaller one anyway that I would have run away and cried quietly I SUPPOSE about it. | She describes MELTDOWNS, depression everybody just considered this normal for her and nobody tried to help. S<br>*"..drama queen.."* Negative labelling of self/self-loathing? Not normal? No authorship shown here of own identity? Others dictate who she is?<br>*"..they saw me as crazy.."* |
| **IDENTITY, AUTHORED BY OTHERS:** I was called a drama queen, they saw me as crazy **NO ONE NOTICED/CARED no** one noticed my distress, , nobody asked if i was ok, | **Interviewer**: You were mentioning a few things there about your mood being quite depressed, feeling quite paranoid, you were mentioning about rage and tightness in your chest. Can you tell me a little bit more about the emotional side of living with autism? | Tells of what peers did: recorded an outburst and posted it to social media. She isn't sure what happened. |

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| isolation, lack of support, bullied:<br>**NO ONE CARED (BULLYING)** cat calls, shouting at me Social media bullying: they recorded my meltdown | **Ilana**: The emotional side is a quite intense, you know yourself the common misconception that we are just emotionless robots, but it is actually a case of we feel way too much, so everything just gets on top of you and you feel things much more intensely, but is funny most of the time, because I can go the cinema and I see the Disney, like I was at Beauty and The Beast with my sister there recently and I am not ashamed to say I was crying through most of it, cause the happy emotions, and nostalgia, I love musicals, the whole thing, but this can be embarrassing and awkward at times when things like that happen, but as people who know me just laugh and get on with it, “it’s just Ilana being Ilana”, but there are other times, and my mother reminded me recently there was a time I missed the bus and I had been under serious pressure and anxiety because my bus was late and I was constantly there saying “when is it going to come, when | Denial of impact of bullying. Too painful. Unbareable lack of acceptance?? *“..but it doesn’t matter”*<br>*“it was difficult”. recurring use of difficult. Emphasising this often*<br>Betrayed by peers? If this happened today in 2019 the posting to social media would very likely have caused significant negative impact. |

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| **<u>NO ONE CARED/BULLYING</u>**<br>rejection it was difficult to hear my meltdown was recorded.  If that happened today it would have been terrible for my reputation | is it going to come" and it was lashing rain and then I sprinted to the station and missed it by two minutes and ended up balling crying, having a bit of a meltdown, cause just the stress of the previous hour trying to get there got on top of me. The bus driver seemed to think that I was unbalanced or I was a drama queen or whatever, they were very nice but at the same time they didn't fully understand and they were saying "stop crying" and I was screaming "I can't actually stop crying I don't have control over this" and there are lot of moments like that, but it is DIFFICULT when sometimes when it is coming to the negative emotions cause it can be consuming and can be DIFFICULT, but sometimes you just have feel it, that you just have to sit there for a couple of hours, thinking through, cry over whatever is causing the negative emotion and then move on and just everything is fine, but when I was younger, before I would have had any understanding of this, I would have pushed an awful lot of my feelings down, I would | <u>Cyber bullying. Back then not yet as big an impact?</u><br>Describes how peers took advantage, recording her, it would have had a neg impact on her reputation if it happened now<br>*"boys will be boys"* <u>the poor stereotypical socialisation of "typical kid" caused significant damage to her? Autistic people not only ones who are poorly socialised?</u><br><u>Painful dev years. Tries to make sense/justify it in hindsight?</u><br><u>Instinctive reaction what is natural for typical teen, what is not natural?</u> |

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| **IDENTITY AUTHORED BY OTHERS** I kept hearing the whispers.<br>**EXPERIENCED BULLYING:** Experience of paranoia and betrayal, terrible that its people's first instinct, it was minimalised as boys will be boys, my experience invalidated | have started to believe people that I was a drama queen and that my emotions I SUPPOSE were irrelevant so I would have pushed a lot of things down, I would not express my anger at being bullied or anything like that, or I would have pushed down any emotions and concerns about being a teenager and all those kinds of problems, emotions in someone who was already highly emotional. So, I have noticed it since then, as soon as I found out about the Asperger's I am not as emotional in public I SUPPOSE, I am able to control it better, because I know where it is coming from, so pushing it down then did not help, cause then that just acerbated the although except in cases when you are in the cinema and it's dark and nobody can see you anyway (laughter) | These experiences very typical/age-appropriate yet she sees them as factor of her ASD?? Not sure who she is?<br>Justifies how she was treated? Why? (I deserved it???)<br>She says she felt, anxious, paranoid, like running away<br>Does/doesn't she feel she copes better now? Contradictions, I do I don' cope better??<br>*"I kept hearing whispers.."*this likely to increase anxiety/paranoia? Trauma experience? |

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| **TRAUMA FROM MELTDOWNS** and what happened afterwards, people whispering about me, led to more paranoia and anxiety, further triggering upset, smaller meltdown, **RUNNING AWAY** I ran away, cried quietly | | Talks about intense emotions, intense experiences and a sense of being out of control emotionally most of the time :vicious circle<br>*"..feeling things more intensely.."*earlier mentioned this a gift of ASD, to feel intense emotions, also has neg |

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| **ASD PRO’S & CONS**<br>Emotional side of living with autism. I have Intense emotional experiences, I feel too much | | consequences. The MELTDOWNS resulting from it<br>*“..but is funny most of the time”*<br>figure of speech its not funny at all, irony, tragedy, self-pity perhaps?<br>Musical: was DIFFICULT to attend. overwhelmed<br>Anxiety, stress leading to MELTDOWNS<br>When things go wrong she struggles<br>Inability to adjust when things are not as expected. inflexibility “*when things like that happen”* passivity: things happen to me, I have no |

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| I cry at Disney movies due to nostalgia and happy emotions; and musicals, this is embarrassing and awkward for her.<br>**<u>ACCEPTANCE FOR SELF:</u>** people who know me accepts "its just Ilana being Ilana" | | <u>control? The out of control of meltdown</u><br>, *"it's just Ilana being Ilana.."*<br><u>She accepts how others evaluate her as fact.? Why? Doesn't trust own perceptions of self? Identity struggles. Who am i? CONTRAST: sometimes others are more accepting of her than she is; sometimes others judge her harsher than she does</u><br>Talks of missing the bus, very upset, raining a lot, crying, having a meltdown, overwhelmed by stress *"The bus driver seemed to think that I was unbalanced or I was a* |

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| **MELTDOWN/TRAUMA NARRATIVE**<br>& **LOSING CONTROL**<br>I missed the bus ended up crying and having a meltdown. The stress got on top of me | | *drama queen or whatever,”* Again: identity based on what others think?<br>..*They didn’t fully understand..”*<br>they could only judge what they could see, her behaviour, therefore they didn’t understand<br>“..*they were saying “stop crying”..”*<br>She accepted external evaluations of her?<br>Tells of negative impact on identity, mental health<br>*“..pushed an awful lot of my feelings down..”* Why? Trying to cope/avoid meltdown?? |

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| **BEING MISUNDERSTOOD**<br>The bus driver didn’t understand<br>**IDENTITY; AUTHORED BY OTHERS** busdriver thought I  was unbalanced or a drama queen<br>**LOSING CONTROL** | | 3rd person  you instead of i? has she told this many times before or is this a distancing from self? From painful memories?<br>(Ref Alan Priest:pronoun use)<br>*“..started to believe people that I was a drama queen..”*<br>She doesn’t know who she is?<br>Identity again<br>Not normal? Emotions therefore don’t matter? I don’t matter I’m different?<br>*Suppose; uncertainty;* I don’t know; I don’t matter |

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| Meltdowns A lot of moments, during meltdowns, when others tell me to stop crying and I'm screaming back<br>**<u>ITS DIFFICULT/COPING STRATEGIES</u>**<br>emerging coping strategies; I just have to sit with it and feel the negative feelings VS I would have pushed feelings down |  | She says others misunderstood her experiences, feelings. So she suppressed feelings<br>Says knowledge re diagnosis brought perspective, relief, better emotional control she says she is less emotional in public since being diagnosed<br><u>Self acceptance improved when diagnosis known perhaps? Why? Again external confirmation of who I am I'm autistic ill accept this external labelling of me since I cant figure "me" out for myself? I don't know who I am? Could only understand self via perceptions of</u> |

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| **IDENTITY:NOT KNOWING SELF PRIOR DX/WHO AM I**<br>Younger self: before I understood what was happening I pushed negative feelings down, believing others that I was a dramaqueen, my emotions irrelevant<br>**IDENTITY: SINCE DX** I am less emotional |  | others? Dx was a 1st step towards defining her identity? |

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| in public, better able to control, because i knows why/where its coming from<br>**<u>CONTROL/ LOSING/FINDING</u>**<br>Since dx better I understand myself better; I have better coping skills more selfacceptance |  |  |
|  | **<u>Interviewer</u>** Well you wouldn't be alone crying in the cinema, you are in good company of many people balling their eyes out. You were saying there that one word that as you say captured and made sense of everything, you are better able to control the emotions in public. Tell me about the time leading up | Talks about being/feeling awkward <u>Neg self-eval pre dx. Also around food awkward around food, didn't understand why</u> |

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| <br>**<u>ITS DIFFICULT/COPING STRATEGIES</u>** it was difficult because I didn't know there was a problem<br>**<u>IDENTITITY:NOT KNOWING SELF PRIOR DX/WHO AM I</u>** It was difficult, I didn't know why I felt | to that diagnosis where you didn't have an answer for what was happening for you or how you were experiencing the world.<br>**<u>Ilana</u>** It was very DIFFICULT at times, because you don't know that there is a problem, you think it is just you or that you are being awkward for the sake of being awkward, like I have a lot awkwardness with food and then I feel terrible because I could never explain why tastes, smells, textures were an issue and there would be a lot of that kind of thing or everyone thought I was just being a drama queen, when I was in the lab and I was in a very high stress environment, I was working 12 hour days and there would have been long periods, where I would not have eaten much at all and loud noises would be going off constantly when machines were backfiring, I would be crying in frustration and it would be seen as I was incompetent, when in actual fact, I did not understand what was going on and because I kept having those | Describes work environ: frequent discomfort & frustration and she couldn't eat<br>*Again "drama queen".* <u>Again neg self evaluations. Continuous negative internal dialogue, I'm a drama queen I am different I am not ok, I cant cope? Not knowing, not understanding, being labelled</u><br>*"..crying in frustration.."*<br>She didn't understand why she kept having these experiences in the lab and became more anxious socially. |

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| awkward, eg around food, sensory aversions everyone thought I was a drama queen<br>**<u>IDENTITY NARRATIED BY OTHERS</u>**<br>i was seen as incompetent because I reacted to sensory experiences ; I didn't understand what was going on<br>**<u>LOSING CONTROL</u>** I was crying in frustration, | incidents and my social anxiety was getting quite bad at that point, that my parents sought fit to get me diagnosed and after that it was easier, once I had a diagnosis because before I was hungry, thirsty or did not get enough sleep I could become erratic and irrational, but after my diagnosis I learnt how to control my emotions and life became easier, by this having that one question answered and I felt more comfortable in my own skin. | She knew she didn't understand (didn't know): Again contrast between what was seen/judged on outside and her internal experience.. *"* <u>they could only judge what they could see, her behaviour, therefore they didn't understand</u><br><u>I don't understand myself/others don't understand me</u><br>*"..kept having those incidents.."*<br>Parents sought dx because of how she struggled she says. Tells of how these struggles neg impacted mental health. <u>Dx brought self-compassion, -acceptance?</u> |

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| my social anxiety was bad<br>**MELTDOWNS/TRAUMA NARRATIVE**; I became irratic, irrational when hungry, thirsty, tired<br>**IDENTITY AFTER DX** . I felt more comfortable in own skin, life became easier I | **Interviewer** And you said your parents finally sought the diagnosis, so growing up what was your relationship with your parents and your siblings around the mystery of what you were experiencing, before anyone had an answer.<br>**Ilana** It was quite DIFFICULT; my parents were at end of their tether. I was in the middle of it all, having MELTDOWNS. I don’t know the number of times I tried to run away. There was one night my mother caught me and I told her “I can’t be done with this”, I have to go, I was a destructive child, I was the one having temper tantrums, I couldn’t control myself, that I was violent throwing things, irrational and because I was bold and did not get my own way, when the whole time I was having autism MELTDOWNS due to the fact that I was getting overwhelmed and I understand now what was going on or why I would set fire to a picture, that that was bad rather than curiosity, things like that | *“..life became easier..”* when *question* of ‘why things like these keep happening,/why am I not normal/what is wrong with me’ was answer: when dx was made<br>MELTDOWNS when overwhelmed. Escape, run away.<br>Losing control, violent, irrational<br>Parents didn’t understand<br>Misunderstood by parents. Even parents don’t accept me?<br>Being misunderstood triggered fight flight?<br>Temper tantrums, couldnt control herself |

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| learnt how to control eamotions<br>**COPING SKILLS/EMERGING RESILIENCE** after dx I learnt how to control my emotions | going on. I SUPPOSE my parents did the best they could. There were a lot of time when they would not react in the best way as they wouldn't had known what was going on, that they were hard on me. There was one time my mother told me to give up losing it for lent.<br>**Interviewer** O.k. that is extreme<br>**Ilana** And there was another time my mother had a sticker system and I would get a sticker each day if I did not completely lose it and if after a month, I had a complete line I would get a toy. I think I only managed to get the toy once. These things were seen as bad behaviour, which I SUPPOSE then I was feeling bad, constantly being punished, feeling like a failure and feeling like a | She says she lost control often during childhood<br>Outbursts mismanaged by her parents, she says she set fire to a picture out of curiosity<br>Never succeeded in meeting expectations<br>Experiences of failing: impact on self-esteem?<br>parents didn't react in the best way to her actions because they didn'tunderstand |

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| **RUNNING AWAY/FLEEING:** I tried to run away<br>**IDENTITY NARRATED BY OTHERS:** I was called a destructive child, I was bold, my parents were at the end of their tether, I suppose parents did best they could<br>**LOSING CONTROL** I couldn’t control myself | naughty child, when in actual fact there was something more serious going on that none of us could understand.<br>**Interviewer** And you were saying there that you felt like a naughty child, that your parents treated you like a naughty child, was that actively the verbal message that your behaviour was an issue, how was that brought across to you.<br>**Ilana** Yeah, I was constantly being told I was being bold. I think about some of the things my mom use to tell me like that the Gardaí were coming for me because I was so bold. She actually put my pyjamas in a plastic bag and left them at the door and told me the Gardaí were coming to take me away because I couldn’t be good.<br>**Interviewer** Gosh that is quite scary. | Her parents didn’t understand either, her having meltdowns, they didn’t know what to do. She told her mom that she (ilana) had to leave she cant deal with it, she was a destructive child, having temper tantrums when not getting her own way. Couldn’t control herself, threw things, irrational. *“.. I was a destructive child, I was the one having temper tantrums, I couldn’t control myself, that I was violent throwing things, irrational and because I was bold and did not get* |

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| **MELTDOWN/TRAUMA** I was having meltdowns, having temper tantrums, violent, irrational throwing things<br>**NOT KNOWING SELF PRIOR DX/WHO AM I** i didn't understand myself<br>**IDENTITY AFTER DX:** I understand why now.<br>**UNDERSTANDING/BEING UNDERSTOOD:** I understand now what was going on, my | **Ilana** It is and I was terrified. There were other scare tactics my parents would use, like a time when we were in a hotel and I must have pressed the emergency button in the lift. My mother told me that if I pressed the button again, the maid (that really scared me) would come and take me away.<br>**Interviewer** Oh my goodness.<br>**Ilana** These kind of stories were constantly being put to me to try and get me to behave.<br>**Interviewer** Looking back on these situations what feelings are left for you from those things, how was it for you? | *my own way..”*Now understand it was meltdowns from being overwhelmed in context of being autistic loss of control, not knowing self prior dx<br>*“there was one time when my mother told me to give up losing it for lent”* |

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| parents didn’t understand.<br>**NOT KNOWING SELF PRIOR DX/WHO AM I**<br>I failed at sticker system | **Ilana** It varies how I feel about it, because I understand that my parents did not know any better, but there are times when it is DIFFICULT cause you know life could have been so much better if they had treated or handled the situation better. I mean I don’t blame them, but there were times when it is DIFFICULT to look back on those memories like dear God why did they do that or why were they so rough with me, it could have been much better or better handled. Now we just laugh about it. They keep me grounded, we don’t use Asperger’s, we embrace it, we laugh about it, I mean if I say something we make jokes, like the fact I can’t take responsibilities, I’ll make a joke like “that because you did something, it’s not my fault” and they will say “Oh Ilana that’s your Asperger’s”, it’s a constant joke. We laugh about it, it’s not a source of drama, you know you just get on with it and move forward. | Her mother used a reward chart.<br>She only once got a reward<br>Feeling “not good enough”<br>*“..feeling like a failure..”* her parents constantly punished her<br>*“..Something serious going on..*”<br>Something  is wrong with me? Im different? Out of control? Unable to cope<br>Says no one understood it |

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| **LOSING CONTROL** I would get a sticker if I didn't lose it | **Interviewer** So it sounds like the relationship with your parents has improved, that is the sense I am getting from you. What is your experience with your parents before and after your diagnosis. |  |
| **LACK OF SELF ACCEPTANCE:** I constantly felt bad, like a failure, like a naughty child<br>**IDENTITY NARRATED BY OTHERS** I felt like a failure, constantly punished, feeling like a naughty child when | **Ilana** So I SUPPOSE with my mother, it was easier. My father on the other hand is not easy. He has undiagnosed Asperger's himself and living proof of the research papers suggest Asperger's gets worse with age because last year he was getting worse and getting on our nerves and driving us all insane and I am finding it very DIFFICULT you know, I have to be responsible for what my brain says or my behaviours, but yet we all have to bend down to put up with his and that is particularly hard for me to swallow as well that would have made it very DIFFICULT for me as a child because without knowing, I was having a meltdown and he was having a meltdown back, reacting to me and not necessarily in a | Recalling painful childhood experiences. How parents disciplined & treated/threatened her. She was scared<br>Feared parental rejection/abandonment<br>*"She actually put my pyjamas in a plastic bag and left them at the door and told me the Gardaí were coming to take me away because I couldn't be good…"* |

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| something else was going on undx ASD.<br>**<u>NOT UNDERSTANDING/BEING MISUNDERSTOOD</u>**<br>None of us understood something more serious was going on | very helpful way. There have been fights between the two of us, and he is just coming back at me, thinking he is right and to be honest there are two of us in it and this doesn't help.<br>**<u>Interviewer</u>** And is that still the case you are experiencing, it is disimproving.<br>**<u>Ilana</u>** It is disimproving but that is because it is doing my head in because I know why. We have tried to tell him but he won't accept it and he is blaming me when in fact there are two of us in it. It is quite a strained relationship. I find it DIFFICULT. When I look back into my past there was one incident where he grabbed me around the waist and dragged me upstairs to my room when I | She felt threatened & scared by parental attempts to discipline her. She recalls pressing emergency button in a lift of a hotel. Mom said the maid would come and take her away if she pressed the button again<br>Again *"..take me away.."*<br><u>Feared parental rejection/abandonment, attempts to discipline through installing fear of rejection</u> |

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| **IDENTITY NARRATED BY OTHERS** I was constantly called bold, I was threatened with the gardai. | was having a meltdown, so when you think about those memories it is hard even though you understand neither of you are at fault, sometimes you have no residual, when it is DIFFICULT to move past these things. | Parents used these threats constantly to get her to behave<br>Fear of abandonment for not being good enough |
| | **Interviewer** That sounds like a vivid memory for you, what happened that day? | |
| **FEARING REJECTION** I was terrified, I was scared | **Ilana** I can’t remember, all I really remember is it being dark and he was grabbing me around the waist and dragging me upstairs to my room. I was around 6/7 years and very volatile. I think my Asperger’s was really flaring up. My memory is me being an absolute nightmare, constantly getting into trouble, constantly having what I thought were temper tantrums but I know now there were MELTDOWNS, so a lot of that was blur. I just pushed it | Memories are DIFFICULT, parents used physical disciple, she says they didnt know any better, but she says her life would have been better if her behavious was handled better<br>Unresolved anger. Developmental trauma? |

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| **MELTDOWN/TRAUMA NARRATIVE** I as told the maid would take me away<br>**FEARING** REJECTION I was threatened to get me to behave | down. I don’t remember the reason for it and I SUPPOSE it was probably a trivial thing, knowing me.<br>**Interviewer** It looks like it still hurts, even looking at you, there is a lot of emotion with all these memories.<br>Ilana Yes it is quite DIFFICULT sometimes. I SUPPOSE that the things with emotions, they can be irrational, but I don’t blame him, however, the hurt is there to some degree. (upset) | She wonders why they treated her the way they did, Says her parents could have handled it better. “ *I mean I don’t blame them, but there were times when it is DIFFICULT to look back on those memories like dear God why did they do that or why were they so rough with me, it could have been much better or better handled..”*<br>Says they laugh, joke about it now. Repeating joke, laugh, joke, laugh. Using humor to cope? Not funny/ tragic/denial???<br>*“it’s a constant joke..”* painful irony |

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| **IDENTITY;DEVELOPMENT:** I know life could have been better if my parents handled situation better<br>**TRAUMA:** the memories are difficult, why was I treated roughly?<br>**REJECTION:** how I feel about it varies, it | | Identity: understands better after dx?<br>*"Its not a source of drama vs recurrent use of dramaqueen"*<br>Tension persists in relationship with father. He is getting worse Unable to see each others' perspective |

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| could have been handled better, it was difficult<br>**COPING/EMERGING RESILIENCE:** We laugh and joke about it now, I get on with it I move forward. |  | Struggles to accept father's behaviour/unacceptable behaviour shouldn't have to accept being treated this way??<br>*Suppose-uncertainty?* Was it really easier with mom???<br>*"..hard for me to swallow"* I' swallowing this treatment of me/ I was consumed by it contradiction???<br>She and her father had MELTDOWNS in reaction to each other |

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| **LACK OF ACCEPTANCE/ANGER**<br>Its not easy with my father, its difficult, I have to take responsibility but he doesn’t. he’s driving us insane | | Trying to make sense of abusive experience. Trying to justify it.<br>Attachment trauma?<br>Relat with fathers deteriorating<br>Memories of  physical discip. It was hard. Recalls being dragged upstairs when she was having a meltdown, then says neither of them were at fault<br>Trying to justify abusive treatment? |

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| **FEARING REJECTION:** It is hard for me to swallow<br>**COPING:** I have to bend down to him, its hard to swallow<br>**MELTDOWN/TRAUMA NARRATIVE:** I was having a meltdown without knowing it<br>**MISUNDERSTANDING/BEING** | | DIFFICULT for her, what is DIFFICULT, the relationship or the memories around it?<br>Justification of the abusive treatment. Does she believe she deserved it? It was her own fault?<br>Meltdown: traumatic memories/flashbacks?<br>*”..neither of you are at fault..”*<br>DIFFICULT to let go<br>Cannot accept what happened to hard. Cannot accept herself??? |

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| **MISUNDERSTOOD:** I was melting down without knowing it.<br>**RELATIONSHIP DIFFICULTIES:** Its | | Remembers being volatile. Coped by suppression<br>Was a challenging child; temper outburst Identity-younger self?<br>Traumatic memory of it being dark, dad grabbing her by her waist and dragging her upstairs<br>*"..a lot of that was a blur"*<br>Taking responsibility for behaviour of others? Why? I was the problem? Jumps to defend her father's treatment of her, "*My* |

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| doing my head in, he is blaming me, it’s a strained relationship<br>**MELTDOWN/TRAUMA:** he dragged me upstairs when i was having a meltdown<br>**BEING REJECTED:** Its hard even though I understand neither of us is at fault | | *memory is me being an absolute nightmare, constantly getting into trouble, constantly having what I thought were temper tantrums”*<br>*Suppose: she doesn’t really think it was trivial???* Passive Aggressive-Denial stance?it was my fault-but I don’t really belief it was my fault |

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| **MELTDOWN/TRAUMA:** Its difficult to move past these things<br>**MELTDOWN/TRAUMA NARRATIVE:** I cant remember, its hard to remember, I pushed it down | | Says her emotions were irrational<br>States that she doesn't blame father, and she still hurts<br>*Suppose; contradiction" I don't blame him">but actually I do blame him*<br>*Upset, tearful at this point*<ins>does she blame herself??</ins> |

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| **IDENTITY NARRATED BY OTHERS:** I was a nightmare child, constantly in trouble, having tantrums, I was volatile, over trivial things knowing me<br>**LOSING CONTROL** I was constantly having tantrums | | |

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| **MELTDOWN/TRAUMA NARRATIVE** Its difficult the memories of hurt,<br>**LACK OF SELF-ACCEPTANCE**: My emotions are irrational, I don’t blame him. (Does she blame herself?) | | |
| | **Interviewer** Would you like to take a break, get a glass of water or something? | Break offered |

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| | **Ilana** No it's grand, honestly, | She says she is ok |
| | **Interviewer** We are talking about relationships impacting on you and I am wondering if you could tell me about some of your other relationships, your friendships or any intimate relationships and your experiences of these. | |
| **IDENTITY/YOUNGER SELF:** being different. I had my first friend at 11, I chose my own company i found it difficult to connect with others | **Ilana** Relationships, I SUPPOSE, they vary because when I look back at my life, I was about 11 years old before I had my first real friend. I kind of drifted between groups or I would choose my own company because I found it DIFFICULT to connect with the people around me, but I SUPPOSE a lot of people find this and it is really only when you go to college you make friends with people and I SUPPOSE my own individual sense it is DIFFICULT to make friends with people who were not like me. I | She was 11 when she made her first friend she moved between groups or kept to herself<br>Feelings of being different. A block to making friends |

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| **BEING DIFFERENT IS DIFFICU**s: I found it difficult **SOCIAL RELATIONSHIP DIFFICULTIES:** Its difficult to connect with people who are not like me.<br>**BEING UNDERSTOOD/ACCEPTED:** My university friends are amazing, supportive and | have some amazing friends, they have been so supportive to me and they all care so much about me. I have been really blessed with the friends I have been given and it is not always easy for me to get to the level of friendship and there are times as well, like when I got my diagnosis they were all so supportive and understanding and loving, but there is a tendency of course with some become one of my specialised interests, which can then cause rifts. I know myself, I SUPPOSE there were times with my sister, who is two years younger than me and I would try to hang around with her, when I wasn't able to connect with my own peers. I remember one particular time when the girls in her social group would hide her or block me off from her. We had system in school where 4th class and above would mind the younger children and the teachers stopped me minding my sister at this stage because they thought I was focussing too much on her. They | It was DIFFICULT to connect I am different she recalls it was DIFFICULT to make friends with others who were different to her<br>*Suppose: IDENTITY/Contradiction:* she does not have her own individual sense?<br>*"..people who were not like me.."*<br>Has friends now, its been challenging to form these relationships, these friends are supportive to her and understands |

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| understanding when i received dx | did not understand, none of us understood. This was the 90's and in Ireland Autism was barely a thing at that time. | her, risk a friend may become a specialised interest, an object of obsession "*.. there is a tendency of course with some become one of my specialised interests, which can then cause rifts…"* |
| **SOCIAL/RELATIONSHIP DIFFICULTIES:** I have a tendency to make another a specialised interest (become obsessed with another person).<br>**COPING:** I wasn't able to connect with own | **Interviewer** How was that for you being prevented from being with your siblings and in a very real way stopped from being with them.<br>**Ilana** It was very DIFFICULT at the time because again I was being made out to be bold or weird. I SUPPOSE I hadn't really thought about it too much but I was very displeased because they put me with someone I did not know and it was a boy, with a | <u>Identity: different to others?/ difficult to connect as result?</u><br>School had a buddy system where older kids minded younger kids so she socialised with younger sister instead of her peers as a result "*..and I would try to hang around with her, when I wasn't able to connect with my own peers.."*<br><u>trying to cope with loneliness by</u> |

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| peers, I overfocussed on my sister | snotty nose, so it is one thing to have a sibling like that but when it is a complete stranger it was very DIFFICULT (laughter) | overfocussing on one other person?? |
| **FEARING REJECTION** | **Interviewer** It sounds like you know, blowing his nose at you really sticks in your mind | Her sisters friends tried to stop her from having access to her sister<br>Teachers also stopped her from minding her sister |
| **NOT KNOWING/UNDERSTANDING SELF PRIOR DX/WHO AM I/NOT BEING UNDERSTOOD** | **Ilana** I can still see him there, green gunk around his nose, standing in front me, I must have been about 10 years old and I'm thinking "dear God why is this responsibility being put on my shoulders" (laughter) | Misunderstood by teachers. not fitting in with peers<br>Little known about Aspergers at the time in the 90's<br>lack of understanding harmful to her |
| Teachers didn't understand, I didn't understand, no one understood | **Interviewer** Yes it doesn't sound like a good experience to me. | |

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| **<u>IDENTITY NARRATED BY OTHERS:</u>** I was made out tobe bold and weird, I was depressed | **<u>Ilana</u>** Yes. I SUPPOSE as a teenager I had a tendency to make friends, but it can be DIFFICULT especially if they are specialist interest and sometimes you can push them away, because they think you might have feelings for them, but then you don't and they might misinterpret. I had a friendship with a guy there recently but it completely fell apart in the end because he was so paranoid about me being myself, although I SUPPOSE that 99.9% he was on the spectrum himself and that would explain a lot about the rifts, but there are times like that when the person becomes a specialised interest and you just want to spend all your time with them, you want them to be your friend and you want to talk to them all the time and you get frustrated when you can't be or when the plans get cancelled and then you act irrationally and then it can create a lot of tension. My answer to that is to try to meet in groups because that dilutes the effect a bit. | She says it was DIFFICULT for her, she was paired with a boy whom she didn't know to get her away from her sister *"..again I was being made out to be bold or weird.."* <u>to be made feel bold and weird???</u><br><u>Attempts to cope by being with sister thwarted</u><br>*Suppose:uncertainty:* <u>has she thought about it a lot?</u><br><u>Using humour to cope with recalling unpleasant memory</u><br>*"..a boy, with a snotty nose.."* |

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| **BEING MISUNDERSTOOD:** I was put with a boy I didn’t know, it was difficult | **Interviewer** And you say that it is kind of how it was for you when you started forming friendships, you would meet a boy or a guy and that person would become someone you would get very interested in and then there would be all kinds of misinterpretations around that. Can you remember a most recent experience or another time and can you tell me more about these experiences where it started coming undone for you? | She recalls how the boy looked and how she felt, she had to blow his nose. She laughs as she recalls this<br>Laughter as coping strategy??? |
| **LAUGING AS COPING (EMERGING RESILIENCE):** I can still see him there with | **Ilana** The last time, well, I SUPPOSE I was kind of blinded first and I was friends with the person around the time I got my diagnosis and with everything going on the lab I SUPPOSE some of my more intense specialist interest were formed when | She tried to make friends, her intentions misunderstood. Rel. |

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| green gunk around his nose<br>**LAUGING AS COPING (EMERGING RESILIENCE)** | something big is happening, so this person was constantly texting me and I was constantly texting back and as the time grew on my texting ratio to his grew higher, so I was reliant on the friendship more and needing the escape more and I was leaning more on this person to the point that it was obsessive. I was just being myself, but I seen halfway through that I was being obsessive and it was like I couldn't stop myself and I SUPPOSE after this it fell apart as I had gone overboard and when I noticed my behaviour I was then constantly going around trying to undo the damage, constantly going around apologising for my behaviour and trying to explain my behaviour, completely hyper analysing the situation and making things so much worse, so friendships broke down and sometimes you start getting paranoid as well, thinking the person is ignoring you when they do not respond to your texts. But there was a lot of things like that going on and friendships being quite intense, but in general since I noticed these things happening and I | failed, boy was afraid of her being herself. tendency to over attach to a person, someone becomes a specialist interest *"..it can be DIFFICULT especially if they are specialist interest and sometimes you can push them away..",*<br>Obsessional about peers,<br>*Suppose: just not sure about many things*<br>*"..the person becomes a specialised interest.."*<br>Lack of social skills >relationship failures? |

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| **SOCIAL/RELATIONSHIP DIFFICULTIES:** Its difficult to make friends. I make people my special interest and I push them<br>**BEING MISUNDERSTOOD:** They think I have feelings for them but I don’t and I’m misinterpreted | became aware of it, I try to pull back and I think for most of my friendships it is not too bad. If I have the misfortune of making someone a specialist interest then it can become complicated.<br>**Interviewer** The last relationship that broke down that was there more of a friendship feeling or was there an intimacy there. Are you or have you even an intimate relationship that you can tell me a little more about. | Trying to find ways of remedying her social issues? Trying different copings strategies>approach/avoidance?? Terrified of getting it wrong socially and loosing friendships?<br>“*..but there are times like that when the person becomes a specialised interest and you just want to spend all your time with them, you want them to be your friend and you want to talk to them all the time and you get frustrated when you can’t..”* |

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| **SOCIAL DIFFICULTIES/FEARING REJECTION** I want to be with them all the time I Get frustrated, irrational. It causes tension and rifts<br>**COPING/EMERGING RESILIENCE/ MEETING IN GROUPS** My answer is to meet in groups to dilute the effect | **Ilana** No I have the terrible habit of being friends only. I don't have intimate relationships but this was the closest I ever got to one and first you know we had the conversation and I thought I did like that and then I realised that I didn't but then when I kept trying to tell them I didn't, they seem to think I was secretly in love with them because of my behaviours and because I was being slightly obsessive. I find as well because I can't say I love you or tell people how much they mean to me; my gestures can be a little too much. I can be very generous I SUPPOSE. I make a lot of gifts, I can kind of be a little too much sometimes and that can be hard.<br>**Interviewer** What is the hard parts of that | says attempted to compensate by meeting in groups to dilute coping by meeting in groups |

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| **SOCIAL DIFFICULTIES**<br>My specialist interest in another forms when | **Ilana** Well the friendship ends and you know a lot of the time it is my fault because I drove them away a bit, for being myself (upset).<br>**Interviewer** Do you need a break<br>**Ilana** No, no I'll be grand. It is DIFFICULT because even though you couldn't help it and you know it's not your fault you still blame yourself for things falling apart and even though you know the other person, if they were a real friend they would have stopped hyper analysing but at the same time it is still DIFFICULT because you know that you are responsible for a lot of that breaking down. | She talks of how she is unable to unhook. Persev. Repetit. Soc. behav.<br>Inappropriate social approaches, she cant stop it, leads 2 relationship DIFFICULTies & breakdowns as she becomes dependent on/obsessed with another<br>*"I SUPPOSE some of my more intense specialist interest were formed when something big is happening, so this person was constantly texting me and I was constantly texting back and as the time grew on my texting ratio to his grew higher, so I was reliant on the* |

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| other big things happen.<br>I become dependent, obsessive. I realise too late | **Interviewer** It sounds like you do feel responsible for a lot of these breakdowns of relationships and you are really hard on yourself. | *friendship more and needing the escape more and I was leaning more on this person to the point that it was obsessive..”* |
| **NEEDING TO ESCAPE/FLEE:** I need to escape | **Ilana** Yes I tend to be hyper critical. I can be very hard on myself. I do know I am not responsible for most of it, but you cannot help what you feel sometimes. | Suppose: expressing great deal of uncertainty here. Uncertainty /hesitancy related to remembering or rather uncertainty about her own abilities to cope? Social attempts often unsuccessfull |
| **LOSING CONTROL:** I couldn’t stop myself, it fell apart, I tried to undo the damage, it made it worse |  | *..I was just being myself,”* but she doesn’t know herself? Identity poorly formed? so who was she?<br>*“..obsessive..”* |
|  | **Interviewer** You were telling me about difference with intimate relationships and social relationships in general, could | Feels helpless to stop obsessive-compulsive behaviour, repair |

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| **FEARING REJECION:** I constantly apologise, hyperanalyse trying to undo the damage | you tell me about not the intimate friendships but just social experiences in general.<br>**Ilana** Social experiences in general are quite positive I think, I do have a lot of friends and they are quite positive. I have friends all over the world. We socialise positively but…sorry I have lost my train of thought. | relationships? Psychological effects of being the victim of a diagnosis/condition/ dis-ease in which the individual has no choice and little control?<br>Compulsive behaviours, I'm a victim of my own lack of control |
| **IDENTITY:** I was just being myself, realsing too late I was being obsessive. | **Interviewer** When you were younger, was your social experience less positive. | Describes vicious circle of inapprop approaches, inapprop reactions<br>*“..but in general since I noticed these things happening and I became aware of it, I try to pull back..”* |
| **ASD CONS; PERSEVERATING/R** | **Ilana** It varied because kids are quite cruel and anyone that is different or who dares to be different or if you have a temper tantrum or you can lose it completely, and in one particular | ASD: pros/cons: intense: Intense interactions, stuck, perseverating, |

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| **<u>UMINATING:</u>** I get paranoid thinking im being ignored<br>**<u>COPING/EMERGING RESILIENCE:</u>** I'm becoming more aware when these things happens I pull away, I try to pull back, it becomes complicated | incident I was asked to draw and I just wouldn't do it or in my head I got a block that I couldn't do it and I pretty much crawled under the table and stayed there for a couple of hours, when you do these things kids can be cruel. I SUPPOSE now a days it is easier because kids are being taught about autism and people are being diagnosed, so kids are told "it is just something that Ilana does, but it does not mean you can't be her friend or treat her differently". Kids can be quite hard about this. I think I found first kids were good to me, liked me but the more of myself I shared and the more I showed the DIFFICULT side of things, or if I was having a meltdown, attitudes changed and they could be quite negative in how they perceived me, but in general especially since going to college I find social friendships are a more positive experience but there are the odd ones that breakdown because they become too intense. | <u>ruminating on special interest person</u><br>*"If I have the misfortune of making someone a specialist interest then it can become complicated."* |

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| | **Interviewer** So what is the most challenging thing in your opinion?<br>**Ilana** It is that you function differently. I remember I was in school and I was doing honours maths and when I look back maths would trigger MELTDOWNS particularly if I got confused or didn't understand where a sum was going, I would just go into meltdown. I remember the class teacher was explaining something to me and did not understand it. I started getting upset and she said it again and I just wasn't getting it and she said, "I don't understand why you are not getting it" and told me I was stupid for not getting it and then moved on, while I was sitting there crying. I look at it now and think I was so misunderstood. If she had understood what was going on and if she had known she | Trying to negotiate hurdles in relationships by staying in "friends" zone. *"..I have the terrible habit of being friends only."* This is how she copes/manages her inclination to overfocus/obsess about another Struggles to communicate her meaning, tries to cope by not getting intimate, fears loss of self-control/own compulsivity? "..d*idn't but then when I kept trying to tell them I didn't, they seem to think I was secretly in love with them..*"Getting the tone wrong in |

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| **SOCIAL DIFFICULTIES:** I have terrible habit of being friends only<br>**COPING BY AVOIDING INTIMACY:** i don't have intimate relationships | could have said I will talk to you after class and go through this slowly with me, the situation would have been handled sensitively and that is the same for a lot of people, they just don't understand and I know in the past I did not understand so how could they understand, so now a days the need for understanding is huge, to know why people react the way they do, what's going on or when you look at someone crying in the corner it doesn't always mean they are creating a drama, there might actually be something wrong. The might be completely overwhelmed and they just might need someone to talk to. | attempts to negotiate relationships. Complexity of social nuances hard for her<br>*"..because I can't say I love you or tell people how much they mean to me; my gestures can be a little too much."*<br>*Too much* I am too much?? Of what? Identity? |
| **GETTING IT WRONG/BEING MISUNDERSTOOD:** I was being slightly | **Interviewer** And you feel that was something that was lacking for you all through your life basically. | Difficult when Friendships end, her fault compulsive social attempts leads to failures *it is my fault* |

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| obsessive, my generous gestures too much. Its hard<br>**GETTING IT WRONG**<br>Its my fault I drove them away<br>**IDENTITY:** I drove them away for being myself | **Ilana** Yes definitely in recent years being misunderstood and lack of understanding, words that resonate for me when I look back at my whole childhood. I don’t blame people, teachers, friends etc, they just did not understand and I did not understand but it is a huge issue and going forward people need to be conscious of that sense of misunderstanding and that is why I keep trying on my blog to promote the understanding of what I am going through. Explaining what is going on, you know just explaining the whole thing, so people will understand that this is the norm for some people and that this is not weird behaviour. This is actually what is normal for this person, so we have to try and embrace that kind of sense and we need to understand difference and embrace it. | *because I drove them away a bit, for being myself*<br>Blames herself yet unable to change, takes responsibility for rel break downs, for things falling apart<br>Its hard: *“..and you know it’s not your fault you still blame yourself..”* |

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| **IDENTITY/<br>LACKING SELF ACCEPTANCE**<br>I cant help it its not my fault, I still blame myself, im responsible | | Its my fault/its not my fault/I am responsible? The control is not mine? Compulsivity controls me? Pronoun "you" are responsible" distancing?? Very difficult to accept her own behaviour causes her heartache?) |

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| **IDENTITY/LACKING SELF ACCEPTANCE:** im hard on myself, hyper critical |  | States the she’s hard on self even if she cannot control what/how she feels behaves <u>why? Is self not acceptable?</u><br>Pronoun “I” a am not responsible<br><u>Easier to deal with heartache of breakdowns if I tell myself I am not really responsible/its not in my control?</u><br>Contradiction: “..not responsible for most of it..” earlier she said she was??? |

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| **<u>NEEDING CONNECTION/FRIENDS:</u>**<br>My social online experiences are positive, I have friends all over the world | | Positive online experiences, Social network friends<br><u>How do we define friendships? Online friends are still friends? Its normal these days/typical. I</u><br>*“..i do have lot of friends..”*<br>*contradiction? earlier she said she didn’t have many?* |

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| **<u>BEING REJECTED:</u>**<br>kids were cruel to me because I’m different<br>**<u>LOSING CONTROL:</u>**<br>Younger self: kids were cruel to me. I couldn’t draw and crawled in under a table staying there for hours |  | Social experiences when younger, *“..anyone that is different or who dares to be different or if you have a temper tantrum or you can lose it completely..”* Loss of control. MELTDOWNS, Describes how she was treated by peers when she struggled with task, she hid<br><u>Bullied for Meltdowns, meltdown narrative/trauma narrative.</u><br><u>aftershock</u><br>*“..kids can be cruel..”*<br>Says Education about ASD can improve things |

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| **<u>EXPERIENCING MELTDOWN/TRAUMA</u>** I can lose it completely<br>**<u>MASKING:LACKING SELF ACCEPTANCE</u>**<br>Kids initially liked me until I shared more of myself | | <u>The fine line between social acceptance and rejection. Im different. I was/get rejected. Did this become her part-identity? mantra</u><br>Children started out being good to her but then started seeing her in a negative light when she showed herself<br><u>When she shows her true self rejection follows?</u> *"..the more I showed the DIFFICULT side of things, or if I was having a meltdown, attitudes changed and they could be quite negative in how they perceived me.."* |

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| **BEING REJECTED**: the more I showed the difficult side of things, had meltdowns, attitudes towards me changed for the negative<br>**MELTING DOWN/TRAUMATISI** | | In college more pos exp of friendships<br>Propensity for social fixations/compulsions remains a barrier.<br>States she functions differently<br>Maths: MELTDOWNS when she couldn’t understand. Maths |

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| **NG** maths triggered it, when I got confused, didnt understand something, felt that I couldn’t do it.<br>**IDENTITY: NOT KNOWING/UNDERSTANDING SELF PRIOR DX/WHO AM I:** I function differently<br>**MISUNDERSTANDING>BEING MISUNDERSTOOD** Teacher didn’t understand why I wasn’t |  | triggered meltdowns (I am different)<br>Negative experience of ignorance of her disorder *“..the class teacher was explaining something to me and did not understand it. I started getting upset and she said it again and I just wasn’t getting it and she said, “I don’t understand why you are not getting it” and told me I was stupid for not getting it and then moved on,..”*<br>Arousal increases when she cannot communicate her meaning<br>Stress leads to MELTDOWNS |

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| getting it and said I was stupid<br>**BEING MISUNDERSTOOD:** I didn’t understand so how could they understand?<br>**IDENTITY: NARRATED BY OTHERS:** I was crying | | *“..I was so misunderstood..”*<br>painful memories of lack of understanding/lack of empathy of others<br>States that everyone wants understanding, acceptance, & need to talk through things with others<br>The human condition. Everyone wants to be seen for who they really are. She doesnt know how she is. She wasn’t seen (as a result of lack of sense of self??)<br>Lack of understanding of ASD caused harm during developmental years |

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| in the corner, I wasn't creating a drama | | *"..completely overwhelmed.."*<br>Unable to cope/melting down?<br>Society's general inability to tolerate differences/variations to the norm? |
| **LACKING SELF-ACCEPTANCE:** I didn't understand myself in the past, I wasn't creating a drama, something was wrong, I was completely overwhelmed | | Speaks of lack of understanding of autism, being misunderstood<br>Desperate to understand self and to be understood<br>Nobody understood |

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| **MISUNDERSTANDING>BEING MISUNDERSTOOD:**<br>Being misunderstood and lack of understanding are words that resonate with me. I don’t blame people, teachers, friends for not understanding. I didn’t understand | | She wants people to understand, accept, again talks in 3rd person., she uses her blog to educate people to try and get others to understand autism<br>I can talk about this if I distance myself from it through blogging, I still am not sure who I am?? I have assumed this identity of an autistic women as prescribed?<br>hard to speak about lack of acceptance through the “I” the “me”? easier through the 3rd person??<br>*“..we have to try and embrace..”* |

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| **NOT KNOWING/UNDERSTANDING SELF PRIOR DX/WHO AM I:** I keep trying on my blog to promote understanding<br>**IDENTITY:AUTHORING OWN:** I keep explaining what im going through, what the norm is, my behaviour isn’t weird. | | |

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| **NEEDING/WANTING TO BE UNDERSTOOD:** we/they need to understand and embrace difference | | |
| **IDENTITY/LACKING SELF-ACCEPTANCE** | **Interviewer** I want to go back to something you mentioned and we have not really pursued it, the food thing. Can you share a bit about that with me? You were saying food is an issue, could you tell me a little bit about that experience.<br>**Ilana** I am an extremely awkward eater. I have taste aversion issues and sensory issues and smell issues. I don’t eat salad because just looking at it makes me want to throw up. All through my life I felt bad because I had a restrictive pallet and I would go to someone’s house and I wouldn’t eat the meal they had prepared | awkward eater. It causes social issues |

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| I am an awkward eater, I have sensory and smell issues.<br>I felt bad not eating at other people’s houses because of my restrictive pallet.<br>**MASKING>LACKING SELF-ACCEPTANCE**: I would pretend not to be hungry to avoid awkward situation<br>**NOT KNOWING/UNDERSTANDING SELF** | for me and I actually got to the stage where I would pretend not to be hungry to avoid an awkward situation. So there were a lot of times like that and there are still some situations like that today. I couldn’t explain this for years and people would say “oh when you are in your 20’s you will start eating properly again”, but I could never explain there was much more going on. It is a textural thing sometimes because for example I love the taste of strawberries, like in ice cream, but I cannot eat a strawberry because of the texture, it is so lumpy and it makes me gag and throw up with the texture of it, so it is issues like that which are really complicated, so I tend to stick with the same meals, so I don’t have situations like that, that can embarrass myself in public, like have you read The Curious Incident of the Dog at Night-time.<br>**Interviewer:** Yes | Central role food and eating plays in human interactions. Barrier to people with ASD?<br>Experiences of food and eating difficulties. Eats same foods to avoid social embarrassment as she might choke on some food types, and she finds it hard to explain these sensory experiences to others *“..I couldn’t explain this..”* I didn’t understand myself? |

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| **PRIOR DX/WHO AM I:** I couldn’t explain this for years<br>**COPING:** I eat the same predictable food to avoid aversive sensory experiences with food THAT CAN EMBARRASS ME | **Ilana:** There is a part in that book where the main character separates his food on the plate, so nothing is touching, I have that. I read the book 10 years ago and never put two and two together, so like my potatoes should not be touching my gravy or something that is going to change the flavour of the potatoes, so there are behaviours where people do not understand and it makes me like awkward.<br>**Interviewer** So tell me how you eat if a meal is put in front of you, tell me about a meal being put in front of you.<br>**Ilana** In like a bad experience<br>**Interviewer** Good or bad one, give me an example of both, one positive and one negative. | *“..it makes me gag..”* Sensory issues<br>eats the same types of food when out as to avoid social discomfort caused by her food issues<br>coping masking strategy: eat same food to avoid embarrassing herself in public. |

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| **IDENTITY:**<br>**LACKING SELF ACCEPTANCE**<br>i recognises myself in book Curious incident: food separated.<br>**BEING MISUNDERSTOOD:** | **Ilana** Recently enough I was out for dinner and I ordered these chicken goujons and of course they came with salad. Normally when it comes I can just pick off the salad, but unfortunately they had the goujons on top of the salad with the dressing over them, which is a big no no so that was awkward. I had to try and scrape all of the dressing off because in mind it was contaminating the chicken and I was just looking at my parents and seeing my face thinking “no no no”. Positive experience even though my diet is quite restrictive, food is such a pleasure for me, like it may be different for healthy foods, but I have a palette for sugar.<br>**Interviewer** You love sugar<br>**Ilana** I love to bake, dessert and when you get a dessert that is really nice it is like your brain is just lighting up and I’m so happy | Talks about book “Curious incident”, says she identifies I’m different I’m awkard? Ive embraced this identity of awkawardness ,as im not sure of who the “I” is? Who am i<br>“..people don’t understand..” Foods issues leads to awkward social experiences : people wont understand? I wont be understood? |

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| People not understanding makes me feel awkward. | when you have a nice cup cake or some butterscotch sauce and brown bread ice cream, just days like that, it is just the best thing ever.<br>**Interviewer** Tell me about a day of butterscotch sauce, how is that, what goes on when you have the delights in front of you.<br>**Ilana** My brain is just relaxing, just shutting off, when you are kind of eating, just really content, but sometimes I tend to stress eat as well. So I SUPPOSE there is a lot of reward pathway going on with me as well, so that is why I have the tendency to gravitate towards sugar. If something is going wrong, and you go for the chocolate, it's a temporary moment where you are completely forgetting about the fact that you have x amount of assignments to do when your brain is fried. | Dinner out: chicken presented on top of salad, she doesn't like it this way<br>*"..a big no no, so that was awkward"*<br>Food is pleasure |

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| **IDENTITY:**<br>**LACKING SELF ACCEPTANCE:**<br>I couldn’t pick off the food as I normally do, it was awkward, I was thinking “no no no” | **Interviewer** So food has been difficult, joyful, soothing, so many things it sounds like.<br>**Ilana** It is but that’s the thing with autism, it is good and bad. It’s so much, it’s everything, it’s like food there is good and there is bad. There are moments when I say I am so glad I have this or it is a gift. It is so many different things, again it has its bad side that is portrayed, but the experience of autism itself, it’s a spectrum, you get everything. | Positive experiences When things are exactly as she expects it all is well? Cognitive rigidity. Cant cope otherwise? |
| **ENJOYING FOOD:**<br>Food is a pleasure for me, I have a palette for sugar | **Interviewer** What are the things you found to date that are helpful, living with autism, what kind of supports have made a difference in a positive way?<br>**Ilana** I SUPPOSE there were not many supports at the age I was diagnosed. There was not a lot that could be done. I did CBT for a | enjoys sugary food<br>Enjoys baking, happy when she can bake what she enjoys to eat, *“..dessert and when you get a dessert that is really nice it is like your brain is just lighting up..”* |

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| **<u>ENJOYING FOOD/BAKING:</u>** I love baking desserts. My brain lights up with a nice dessert. It's the best thing ever | while and it was helpful in that it helped me to talk through when I was being diagnosed, to discuss feelings when I was processing everything and to learn about myself. While I had the answer, there were still a lot of things I didn't understand about how I worked and like "oh that thing happened because I have autism". There were a lot of things like that that I found helpful to discuss and to read and to learn and to understand why but then again, I am a scientist so I like to learn how things work, break them down into a million pieces and build them back up again. That is how I like to work.<br>**<u>Interviewer</u>** Did CBT fall into that category, did it help you in that way to break down and build them back up again. | <u>Is it best thing ever because she can control it? Is being in control the best thing ever???</u><br>Brain relaxes foods she likes is, how she can loose herself in this, get away from world "M*y brain is just relaxing, just shutting off, when you are kind of eating, just really content"* . <u>Is being in control what</u> |

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| **ENJOYING FOOD/BAKING:** My brain relaxes and shuts off. I am really content<br>**COPING:** I tend to stress eat, there is reward pathways going on for me. If something goes wrong I go for chocolate. I can forget when my brain is fired with assignments | **Ilana** Yes I thought it was very good, but it got to the point where I gave it up because I was literally going in to have a moan every few weeks, but at first it was helpful, because it gave me the space to talk about things. My mother has a tendency to rush in and try to smooth things over saying "look stop crying this and this and this", but sometimes you have to talk about what is going on. You have to talk through your emotions and while my mother's intentions are good, it can push this down and not allow me to bring them out, so CBT was useful from that kind of perspective, to have the space to separate where I could talk about it completely to someone who was paid to listen.<br>**Interviewer** You have actually answered this question, but maybe you could go through it again, what kind of supports did you find lacking for women with autism. | soothes???the familiar, the loved soothes?<br>Typical: Food and eating as self-nurturance; as escape from demands of outside world?<br>*"If something is going wrong, and you go for the chocolate it's a temporary moment where you are completely forgetting about the fact that you have x amount of assignments to do when your brain is fried."* |

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| **ASD PROS 7 CONS:** autism is good and bad, its everything, like food. It can be good and bad. Autism as a spectrum, I get everything, it's a gift and has a bad side | **Ilana** I SUPPOSE it is a hard one to answer because there is an awful lot lacking as a child because I didn't understand but definitely there is a lack of support in the fact that women are being diagnosed so much later that they are missing out so much in their formative years, so definitely there is a need to formalise specific supports and better diagnostics for wome*n*, so they can get supports the same time that boys are, so that they can better integrate and learn about themselves, because women I have talked to say that once they knew their diagnosis things got so much easier as they finally realised why they were different.<br>**Interviewer** So you are saying female specific support, early intervention and diagnosis, these are things that you feel were lacking for you. | Noting Pro's & con's of ASD<br>*"..there is good and there is bad.."contradictions?*<br>True of all human exp// human condition? Shes not so different after all?<br>*"..but the experience of autism itself, it's a spectrum, you get everything…"* |

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| **FINDING APPROPRIATE SUPPORT:** there wasn’t many supports when I was dx. CBT helped me to talk through feelings when I was learning about myself | | She found ASD supports lacking.<br>CBT helped her to talk through things<br>Suppose: uncertainty again. There wasn’t supports/I felt unsupported??<br>CBT Fitted her cognitive style<br>I like being in control. When things are my way/familiar to me? I know what workds for me? Identity sense?<br>(Strongest research base in treatment of ASD co-morbidities)<br>CBT helped her to talk to learn to understand herself |

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| **NOT UNDERSTANDING:** I didn’t understand how I worked. (CBT helped, it suited my cognitive style, it helped me to understand my experiences in context of being autistic)<br>**IDENTITY; HOW I LIKE TO WORK:** I’m a scientist, I like to learn how things work | | *“That is how I like to work.”*<br>CBT allowed her space to talk. No longer attending.<br>Mom rushed her & minimalised things |

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| **BENEFIT OF SUPPORT/CBT:** I thought the CBT was good, helpful, space to talk. I had to talk about what was going on, not push it down.<br>**IDENTITY; FINDING SELF**: I learnt about |  | *"..look stop crying.."* Mother didn't understand/didn't feel understood by mother?<br>CBT paced/supported her in expressing herself "..s*o CBT was useful from that kind of perspective, to have the space to separate where I could talk about it completely to someone who was paid to listen…"* When given the space to explore she could get in touch with aspects of her me-ness?? Authorship of self; identity formation |

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| myself when given the space and time in therapy, with someone paid to listen | | Talks generically about lack of supports. Early diagnosis and supports as for boys *Suppose; unsure; "..I didn't understand.."* late dx, lack of support for women <br> <u>3rd person accounts a distancing from the me which is not yet fully formed??? Identity?</u> |

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| **<u>IDENTITY:</u> <u>NOT KNOWING/UNDERSTANDING SELF PRIOR DX/WHO AM I</u>**<br>Support was lacking when I was a child, I didn't understand myself. People like me are missing out in our formative years<br>**<u>LACK OF SUPPORT:</u>**<br>there is a need for formal support and better | | Diagnosis brought her and others answers & relief, can learn about self *"..because women I have talked to say that once they knew their diagnosis things got so much easier as they finally realised why they were different.*"<br><u>Search for understanding self, own self, own identity? I am different I will identify with that: ASD: as I don't have my own identity. Hang on to this "identified for me" sense of self</u> |

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| diagnoses of women. With dx things get so much easier and we realise why we are different | | |
| **<u>IDENTITY</u> <u>NOT KNOWING/UNDERSTANDING SELF PRIOR DX</u>** I didn't know im autistic and I didn't understand, this was the biggest barrier in me getting to know herself. But it meant I didn't grow up disabled, | **<u>Ilana</u>** So much so, definitely, the lack of understanding was probably one of the biggest barriers in my whole life. In some ways, it was a good thing that I did not know growing up, it meant I was never disabled. My mother would never use the excuse, you can't do this or you can't do that. My mother is a teacher and she often see students whose parents think "oh he can't do that because he has Asperger's, oh he is not able to do that "but mam knows that child is very capable but his mother says no and at least I never had that experience. I was always pushed and told "Ilana of course you can do this". You know even learning to skip and constantly falling over and not being able to master it, but I | Says biggest barrier of her life was not knowing when she was growing up/ on the other hand not knowing meant she didn't grow up with a label of being disabled<u>Negative impact on identity formation of not being understood by others</u> talks of own lack of understanding self "*I did not know"*; lack of being understood |

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| I was always pushed. I was told I could do it<br>**COPING/TRYING/RESILIENCE**: My mom pushed me to keep goinguntil I got the hang of it | kept getting back up and kept going until I got the hang of it, so I SUPPOSE there can be some of that disabling features, so there is a need for that I SUPPOSE.<br>**Interviewer** Resilience is strong by the sounds of it.<br>**Ilana** It kind of needs to be.<br>**Interviewer** What are the things do you think again the general public need to be educated about around women with autism?<br>**Ilana** The need for understanding I SUPPOSE, that women are different to men with autism. They have issues people do not understand, the difference in presentation, just because a woman knows how to respond socially and can maintain some level of | Mother instrumental in encouraging perseverance<br>mother a teacher, mother pushed her<br>Adversity breeds resilience? Result of repeated traumas of meltdowns?<br>*Know; she didn't know/others didn't know* Lack of understanding? Identity?<br>*Suppose; unsure;didn't understand self*<br>*“You know even learning to skip and constantly falling over and not being able to master it, but I kept getting back up and kept going until I got the hang of it,..”* |

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| **COPING/RESILIENCE:** I had to be resilient<br>**NEEDING UNDERSTANDING/ACCEPTANCE:** People don’t understand autistic | eye contact does not mean that she is not going through the same awkwardness and the same panic that men with autism are going through. There is a real awareness needed around the issues, so that they will understand especially. One of the most fascinating things that I found out was that MRI studies of the brain of females with autism show their brains show a lot of anatomical similarities with the normal male brain and men with autism share of lot anatomical similarities with the normal female brain, so it is fascinating to learn that it is like having a male brain in a female body and my mother would say “don’t say that people will think you are weird”, but it is just very interesting to learn that there are high levels of differences between men and women. Women are being forgotten and there are so many issues pushing things down and internalising their problems, so they are not getting the service or the help they need to manage. You know there are so many | generic discussion of need for understanding women with ASD, different to men<br>need for understanding/acceptance as self? |

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| women are different to autistic men.<br>We go through the same awkwardness and panic as men<br>**BEING MISUNDERSTOOD:** real awareness and understanding around this is needed | mental health issues for women with autism and it is not being dealt with and they are not being supported.<br>**Interviewer** You touched there on an area which is of interest to me and that is psychotherapy. You see that is something that is lacking for women with autism and as well as psychotherapy supports they may need<br>**Ilana** Yes definitely, there is a need for psychotherapeutic support especially with the issues of anxiety and OCD and all kinds of things, so many times women become comorbidly diagnosed with the separate mental health issues but they are not getting the autism diagnosis, so without the two, you know if you have one, you are not fully getting to the root of the autism. So you need to | There are differences but also similarities between men and women with ASD "..just because a woman knows how to respond socially and can maintain some level of eye contact does not mean that she is not going through the same awkwardness and the same panic that men with autism are going through."<br>Identity: Being different is hard.<br>Social judgements of difference?<br>Describes how she was interested to learn that women with ASD had similar brains than typical men |

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| **IDENTITY/NARRATED BY OTHERS** my mom would say don’t say that they’ll think you’re weird | fully understand what is going on, so if you have autism and OCD you can do something about it as opposed to just targeting one. It is very important to be fully aware of the mental health implications. | *“..don’t say that people will thing you are weird”* mother doesn’t understand her, doesn’t accept her |
| **BEING MISUNDERSTOOD/FORGOTTON:** we women are being forgotten, we internalise our problems and are not getting help to manage | **Interviewer** So you were saying basically if the autism diagnosis is not there or has not been assigned and I asked you about what the general public should be educated about women with autism in your experience do professional people not get it either. Is there room for education here too? | Women are not being diagnosed<br>*“..women are being forgotten..”*<br>Failure to id underlying problem>women are not getting supports<br>Adverse effects of unrecognised disorder detrimental to mental health |

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| **LACK OF SUPPORT:**<br>We have mental health issues and are not being supported to deal with it | **Ilana** Definitely there is room because so many don't realise that there is a difference between men and women and autism. It is only emerging in recent years looking at the science and everything, so there is definitely a need for physicians to understand that. I was reading something recently which said many G.P.'s would not understand so much about autism and you need a specific psychologist I SUPPOSE to diagnose it and it can be hard to diagnose especially in women, so a professional needs to know the differences and to design new diagnostic tests because all the original research looked at men with autism, so all current diagnostic tools are based on the male prospective and a lot of women just slip through the radar not presenting in that way.<br>**Interviewer** Your experience of being diagnosed, the diagnostic process how did you experience that. | There are no therapeutic supports<br><u>Lack of understanding by professionals is harmful. Failing to diagnose leads to incorrect treatment of mental health problems</u><br>Talks of how not getting the right diagnoses stands in way of getting |

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| **LACK OF SUPPORT/NEED FOR SUPPORT:** We need psychotherapeutic support. We are not getting diagnosed and the root of our autism not gotten<br>**BEING MISUNDERSTOOD**: Understanding and awareness of what's going on is needed | **Ilana** Well I was tricked, I did not know I was being diagnosed. I was told I was going to a session for anxiety, that I was convinced to go to a counsellor for mild anxiety and I was asked all these extremely weird questions and I did not know where this was going and at the end I was asked had I ever heard of Asperger's syndrome and would I be surprised to know that I scored very high on the test for it. So the penny dropped and I was hoodwinked. It was a good thing ultimately but in that moment it was like "why did you do that to me", I felt tricked.<br>**Interviewer** And why do you think your parents went that way about it. | to the bottom of women's presenting problems in psychotherapy *"..there is a need for psychotherapeutic support especially with the issues of anxiety and OCD and all kinds of things, so many times women become comorbidly diagnosed with the separate mental health issues but they are not getting the autism diagnosis, so without the two, you know if you have one, you are not fully getting to the root of the autism..".* |

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| **<u>IDENTITY</u>**: The root of our issues are not discovered | **<u>Ilana</u>** Because they knew if they told me I would refuse to go and I would not have accepted it, so they had to be careful in how they handled the situation.<br>**<u>Interviewer</u>** Looking back on it now do you feel that the experience of that because you did not know what you were being diagnosed for, did it help in any way that you did not know.<br>**<u>Ilana</u>** I don't know, in some ways it probably did because I answered more honestly but in some ways no, because I remember being asked if I had any textural issues and I said no, and when I told my sister, she said "Ilana of course you do, look at you now, you want to stroke my fluffy jumper, don't you" and of course I did. But I was not expecting these types of questions and never put two and two together, so maybe if I had known I would have scored even higher. | <u>Identity: Desperate need for understanding/for being understood</u><br>*"need to fully understand.."*<br>important that professionals have ASD understanding<br><u>Mental health professionals *need* to be upskilled in ASD in women</u> |

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| **NEEDING UNDERSTANDING/ACCEPTANCE:** I need physicians to understand us (me)<br>Professionals need to know, new tools to diagnose us (women) are needed. | **Interviewer** Well at least you know there is a cut-off point and by the sound of it, it has made a huge difference in your life knowing, just by listening to you.<br>**Ilana** It has made a huge difference and certainly the last couple of years, I have felt more comfortable in my skin. I now finally know who I am, really learnt how to fall in love with myself in a much deeper and better way. I understand all the different things that make me who I am. There are fewer unanswered questions then there used to be. I am not constantly driving myself insane, wondering why did you say this, why did you do that and life has become so much easier now. | People don’t realise women and men with ASD are not the same<br>Ignorance/not being understood by professionals is harmful?<br>*Understanding: emphasises need for understanding* We are not understood/*suppose: uncertainty*I don’t understand me either. Identity theme here?<br>*“..so a professional needs to know the differences..”* |

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| **NOT BEING SEEN/UNDERSTOOD:** We slip through the radar. We don't present like men<br>**MISUNDERSTANDING:** My dx happened | **Interviewer** Ilana the last question, is there anything we did not touch on that you really feel you would like to add<br>**Ilana** I'm not really sure.<br>**Interviewer** I wonder can you tell me about the experience you had with the professional course you were on where actually having a diagnosis of autism counted again you, would you mind sharing that experience with me.<br>**Ilana** No that is not a problem. I was in a lab environment and things started off o.k. but then things were different. There was a dissection technique that I should have mastered and I was taking three times longer than it should take and I wasn't mastering it and I was having regular MELTDOWNS from the stress and things kept going wrong. There were also some teaching issues | Describes that her mother encouraged her to go to a counsellor and how she discovered she was actually being assessed for autism *"Well I was tricked, I did not know I was being diagnosed*."<br>She did not know she was being assessed for ASD. Not knowing?. Betrayal??<br>Impact of betrayal on forming relationships? |

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| through me being deceived/betrayed<br>**<u>IDENTITY:</u>** I was hoodwinked, I felt tricked, but ultimately it was a good thing | that I was having, too many people teaching me and missing some pieces of information but of course that was not factored into the situation. When I got my diagnosis, I was initially told they would support me, that they would change my research to better suit me, but about a month later I was called in and advised to reconsider my career in research and I was advised that I should leave because of my dexterity issues and later told off the record that if they had known I had Asperger's in the beginning that I would not have been let onto the programme. A lecturer told me "oh we had a student like that before and he caused all sorts of trouble, but you are nothing like him". I was being prejudged. I was not given sufficient time to prove them wrong and as a result of this I had to completely change my course and my career path. | *I don't know/I didn't know* <u>Not being understood/not understand self</u> *"So the penny dropped and I was hoodwinked. It was a good thing ultimately but in that moment it was like "why did you do that to me", I felt tricked."* Getting diagnosis was good, but way it was achieved was not; 'hoodwinked' <u>Does the end justify the means?</u> "*why did you do that to me", I felt tricked*<u>. (I don't understand)</u> |

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| **BEING MISLED:** I wouldn't have gone if they told me the truth | **Interviewer** How was that, hearing that, sitting there listening to people saying that to you.<br>**Ilana** It was extremely DIFFICULT, probably one of the worse times of my life. I had only found out about my Asperger's a month before this and I was still trying to process that and suddenly a nuclear bomb was dropped on top of me and I had to deal with it. It was extremely DIFFICULT because I had banked my career on research and this was my plan and suddenly they would blacklist me if I wanted to go back into any level of scientific research, so it was very DIFFICULT to know that I would have to completely change my course and my career direction and at 24 start all over again, having spent how many | Says if her parents told her it was assessment she wouldn't have gone, however with hindsight understands why they did it<br>*"Because they knew if they told me I would refuse to go.."* <u>the dilemma of every parent?? She understands they had to to it?</u><br>Not knowing she was being assessed caused confusion. Betrayal |

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| **BEING MISLED**<br>I have mixed feelings about dx process. I was confused, I didn't put two and two together | years in college and earning my degree, it was extremely DIFFICULT, especially that I would be prejudge.<br>**Interviewer** How did that day progress, tell me about the day when they called you in and told you?<br>**Ilana** I was literally just told to go to the office and suddenly my whole world changed in that second and then I chatted to my mother afterwards and we said to them, no we don't agree with this decision, that we would like to continue until we had completed the masters, but I was told that would not be an option that they would not let me finish even with just four months to go, so it wasn't easy and I suffered an autistic shut down afterwards, | by parents, impact on trusting relationships,<br>Was she annoyed at herself for not seeing through the process of ax?<br>Sounded annoyed here. "But I was not expecting these types of questions and never put two and two together, so maybe if I had known I would have scored even higher. .."<br>Identity: Not knowing not understanding not being understood? |

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| **IDENTITY; UNDERSTANDING SELF THROUGH LENS OF ASD:** My diagnosis made a huge difference. I’m more comfortable in my own skin. I know who I am, ive learnt to love myself. Im not driving myself insane with questions, second guessing myself<br>**ACCEPTING SELF AFTER DX:** I | that I remember leaving the lab, pulling on my headphones and it was like a wall went up in my brain, every time I would try to access the file and just breakdown and process what they had just done, my brain was saying “no we are not going there”. When I called my mother it actually took me a full five minutes of umh’s and ah’s before I could finally access the file and say the words of what actually happened. It was a very DIFFICULT time but I came out the other side, received a master’s in scientific communication and I had one of the best years of my life, met some fantastic people and I got to focus on autism for my thesis and aside from not being able to find a job life is so much better now.<br>**Interviewer** Thank you so much I know that last one was tough for you to share, so I really appreciate it and I would like to | diagnosis made huge difference she feels more comfortable, says she learnt to love herself<br>IDENTITY:Self understanding. Sense-of-self benefitted?? Did it reall help?. Is she really closer to knowing who she is? *Understand: does she?* Or has she assumed this ASD identity? A stereotype authored by “others?”<br>*“..I am not constantly driving myself insane..”* |

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| understand what makes me me | thank you again for your time and the great informative stories you shared with me. Thank you very much for that. | <u>Has she given up on finding an identity aside from/outside of ASD? Its just easier if I wear ASD as ‘me’ then I can cope???</u> |

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| **MELTING DOWN/TRAUMATISED**: I struggled to master a technique, I had regular meltdowns from stress and failing<br>**IDENTITY:** I was told my dx would be factored in, that id be supported but I wasnt | | Describing her experience she couldn’t master a technique .She was taught by too many different people, didn’t process some information, not considered. Had meltdowns when she struggled, main trigger for meltdowns for her *“..I was having regular MELTDOWNS from the stress and things kept going wrong.”*<br>ASD impact on her tertiary education. |

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| **<u>BEING DECEIVED/REJECTED:</u>** I was rejected for who i was, prejudged, not allowed time to prove “them” wrong<br>**<u>COPING/RESILIENCE:</u>** I had to completely |  | *“..but of course that was not factored into the situation.”*<br><u>Resentful: Struggled to cope, anger, felt betrayed?</u><br>Initially told by her college she’d be supported then asked to leave dexterity issues. Says she learned that she wouldn’t have been accepted to course if her dx was known at start<br><u>Identity: Impact of being rejected for who you are? Its ‘unfair’??</u><br>*”. I was being prejudged. I was not given sufficient time..”* |

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| change my corse, my career path<br>**BEING REJECTED:** It was extremely difficult, one of the worst times of my life | | She had to change course, career path |

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| **<u>IDENTITY POST DX:</u>** I was still processing the dx, then a nuclear bomb dropped, I was told I had to change career course<br>**<u>BEING REJECTED:</u>** I had to deal with it, I had to change my plans, I would have been blacklisted. It was very difficult. I was prejudged<br>**<u>COPING:</u>** I had to change my course in 24 |  | It was a difficult time in her life hearing people say that to her, one of worst times<br>*"..probably one of the worse times of my life.."*<br><u>Struggled to process dx ; followed by pain of rejection?</u><br>*".. it was extremely DIFFICULT,.." (3rd exact comment)* She planned to be a researcher, had to change direction completely<br><u>She had a vision of herself his had to change</u> <u>Impact on sense of self of having goals thwarted</u> |

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| hours. I had to start all over again<br>**<u>BEING REJECTED/HAVING TO COPE:</u>** I only had 4 | | Had to start over again, new direction after years already spent, degree earned "*..and at 24 start all over again, having spent how many years in college and earning my degree..*"<br><u>Not being seen for herself. Being judged. Impact on sense of self. Who am i? identity?</u><br><u>Injustice of being judged: its not fair. Its unfair</u> |

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| months left but wasn't allowed to finish<br>**MELTDOWN>SHUTDOWN:** I suffered an autistic shutdown, it wasn't easy<br>**COPING THROUGH SHUTIING DOWN**: I pulled my headphones on, a wall went up in my |  | didn't agree with this decision made on her behalf by college<br>Not accepted for who she is.<br>Having to start again<br>She was not allowed to cont, it wasn't an option<br>*Difficult:"..it wasn't easy and I suffered an autistic shut down afterwards.."* vividly recalls shut down/meltdown<br>Unfairness of being rejected for who you are |

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| brain, I wasn't going there<br>**<u>MELTDOWN/TRAUMA NARRATIVE:</u>** I suffered, just breakdown, I could access the file, I couldn't speak<br>**<u>COPING:</u>** It was a difficult time, I came out the other side<br>**<u>IDENTITY; ACCEPTING SELF AFTER DX:</u>** I received |  | <u>Repeated experiences of betrayal. Peers, parents, university: adverse impact on self-acceptance?</u><br>Difficult: emphasises how hard it was<br>made it earned masters, met good people, had new focus<br><u>its better now? What is better? Why? Because of identity given of ASD diagnosis given?she's been gifted an identity??</u> |

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| a masters, I had one of the best years of my life, life is so much better now |  | *"..life is so much better now.."*<br><u>Because ive been told who I am when I didn't know myself??</u><br><u>identity</u> |

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| **MAIN THEMES WITH EMERGING THEMES** | **QUOTES** |
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| **SENSE OF SELF AND DIAGNOSIS**<br>- Finding/accepting self after dx<br>- Not knowing self prior to dx<br>- Authored by others<br>- Lack of self-regard/esteem | - *"..like getting the diagnosis was one of the best things that ever happened to me, because I finally understood myself and why I was and all the questions that I could never answer about myself or explain, they were all answered by just one word, Autism." (p.2)*<br>- *"..the common misconception that we are just emotionless robots, but it is actually a case of we feel way too much, so everything just gets on top of you and you feel things much more intensely…" (p.8)*<br>- "*.. I would have pushed an awful lot of my feelings down, I would have started to believe people that I was a drama queen and that my emotions I suppose were irrelevant…" (p.9)*<br>- *"..everyone thought I was just being a drama queen.." (p.10)*<br>- *"… but after my diagnosis… having that one question answered and I felt more comfortable in my own skin." (p.10)* |

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| | *"I understand all the different things that make me who I am. There are fewer unanswered questions then there used to be. I am not constantly driving myself insane, wondering why did you say this, why did you do that and life has become so much easier now." (p30)* |
| **MELTDOWN**<br>- Losing control<br>- Shutdown<br>- Trauma narrative | - *"Sometimes in social situations and sometimes it is just something sensory that is* driving *you mad and you are screaming inside your head.." (p..2*-3)<br>- *"..they just normalised my tearful behaviour and marked me down as a drama queen, so I suppose, they saw me as crazy.." (p.6)*<br>- *"..having meltdowns. I don't know the number of times I tried to* run away. *(p.10)*<br>- *"I couldn't control myself, that I was violent throwing things, irrational .." (p.11)* |
| **COPING**<br>- Fleeing/running away<br>- Emerging resilience<br>- Laughing as coping | - *"oh God…, what do I do, what do I do, I'm going to run away now and go to leave", …"I have to run away"*,..(p.3) |

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| - Avoiding intimacy<br>- Masking<br>- Cooking and eating | - *“..when I was younger something like that would have completely triggered a melt down and I would have run off crying somewhere, or God only knows what I could have done, if I was in a full scale meltdown.*” (p. 3-4)<br>- *“… you just completely lose control and it is kind of like you are there and it’s like “what’s happening, why are you doing this” but you are completely out of control and you have no control of the situation,..” (p.4)*<br>- *“… after my diagnosis I learnt how to control my emotions and life became easier,…” (P.10)*<br>- *“..having meltdowns. I don’t know the number of times I tried to run away. (p.10)* |
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| **UNDERSTANDING**<br>- Being misunderstood | - *“..they didn’t fully understand..” (p.8)*<br>- *“..there was something more serious going on that none of us could understand.” (p.12)* |

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| • Misunderstanding/being misled/deceived<br>• Needing/wanting understanding<br>• Getting it wrong | • *“..when I got my diagnosis they were all so supportive and understanding and loving,..”* (p.16)<br>• *“..because they think you might have feelings for them, but then you don’t and they might misinterpret.” (p.17)*<br>• *“..it is my fault because I drove them away a bit, for being myself..” (p.20)*<br>• *“..I was so misunderstood. If she had understood what was going on…” (p22)*<br>• *“..being misunderstood and lack of understanding, words that resonate for me when I look back at my whole childhood… people need to be conscious of that sense of misunderstanding and that is why I keep trying on my blog to promote the understanding of what I am going through” (p.23)*<br>• *“..people do not understand and it makes me like awkward..” (p.24)*<br>• *“There is a real awareness needed around the issues, so that they will understand especially…” (p.29)* |

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| **SOCIAL/RELATIONSHIP DIFFICULTIES**<br>• Fearing rejection/Being rejected<br>• Being bullied<br>• Avoiding intimacy<br>• Being misled/deceived | • *"..shouting or unintelligible kind of cat calls about it, I suppose and somebody actually recorded the incident and I heard whispers that it was on Bebo at some point,.." (p.6)*<br>• *"..freakish they thought it was hilarious… I remember a few months later, when I kept hearing the whispers, I got so paranoid about it.." (p.7)*<br>• *"Well I was tricked, I did not know I was being diagnosed. I was told I was going to a session for anxiety, …and I was asked all these extremely weird questions and I did not know where this was going and at the end I was asked had I ever heard of Asperger's syndrome and would I be surprised to know that I scored very high on the test for it. So the penny dropped and I was hoodwinked. It was a good thing ultimately but in that moment it was like "why did you do that to me", I felt tricked.(p.30)* |
| **BEING AUTISTIC**<br>• Difficulties<br>• Rewards/benefits | • *"…it can be difficult but it is so rewarding at the same time, when I see the world in different ways to other people or how I am constantly curious or even when I'm born wise* |

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| | *out of something simple, the fact that I can get that emotional about something, I just really think it's a gift… (p.2)*<br>• "*.. it is good and bad. It's so much, it's everything, There are moments when I say I am so glad I have this or it is a gift. …but the experience of autism itself, it's a spectrum, you get everything." (p.26)* |
| **SUPPORTS**<br>• Benefitting from CBT<br>• Unsuitable support services<br>• Lack of knowledgeable support people | • *"..so CBT was useful…to have the space to separate where I could talk about it completely to someone who was paid to listen. (p.26)*<br>• *"..not getting the service or the help they (autistic women)need to manage. You know there are so many mental health issues for women with autism and it is not being dealt with and they are not being supported…"(p.29)*<br>• *"..there is a need for psychotherapeutic support especially with the issues of anxiety and OCD and all kinds of things, so many times women become co-morbidly diagnosed with the separate mental health issues but they are not getting the autism diagnosis, so without* |

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| | *the two, you know if you have one, you are not fully getting to the root of the autism…" (p29 & 30)*<br>• *"…many G.P.'s would not understand so much about autism… need a specific psychologist… to diagnose it and it can be hard to diagnose especially in women, so a professional needs to know the differences…" (p.30)* |

## Summary of analysis of Illana's interview on living with autism

Illana is a woman in her twenties, who was diagnosed with ASD in her late teens. She was quite an emotional participant, who welled up with tears on several occasions during her interview and though an opportunity was offered to her to take a break she declined and the interview continued. In the debriefing following the interview Illana noted dryly that she tended to get tearful about "most everything".

Illana mentioned feeling *"misunderstood*" throughout the interview. This is a major recurring theme for her. Being and feeling misunderstood during her childhood prior to her diagnosis characterised her relationships with her parents and peers.

> *… getting the diagnosis was one of the best things that ever happened to me, because I finally understood myself … all the questions …answered by just one word,* autism (p.2*)*
> *... I was.. constantly being punished, feeling like a failure and feeling like a naughty child, when in actual fact there was something more serious going on that none of us could understand.* (p.12)

It arose again for her when she experienced a traumatic ending to her initial course of study in college/university. Illana had to change her career pathway after being told she couldn't complete her studies due to *"dexterity issues"* related to her autism. She experienced this as being *"prejudged":*

> *I was initially told they would support me, …but about a month later I was called in and… advised that I should leave because of my dexterity issues and later told off the record that if they had known I had Asperger's in the beginning that I would not have*

> *been let onto the programme… I was being prejudged. I was not given sufficient time to prove them wrong and as a result of this I had to completely change my course and my career path…* (p.32)

Although Illana has a strong desire to be better understood by others, she also noted that before her ASD diagnosis her understanding of herself and her own 'Dasein' impacted her developing identity adversely. Throughout the interview she repeatedly used negative self-labelling, particularly the word *"drama-queen"* to refer to herself, a label initially used by others which then became part of her self-referencing, her perception of her behaviour during times of traumatic meltdowns or shutdowns.

> *... nobody asked, stopped to ask was I o.k, nobody noticed that there was something wrong, 'cause they just normalised my tearful behaviour and marked me down as a drama queen, ..they saw me as crazy...* (p.6)
>
> *... when I was younger, before I would have had any understanding of this… started to believe people that I was a drama queen... that my emotions... were irrelevant* (p. 9)

Illana experienced physical, emotional/psychological and social media bullying in school, which likely further contributed to her negative self-evaluation and lack of self-regard: "*you get bullied in school… for wanting to be yourself.* (p.5) "*..shouting or unintelligible kind of cat calls …and somebody actually recorded the incident and I heard whispers that it was on Bebo.."*(p. 6& 7*) "boys will be boys"… they thought it was hilarious."* (p.7)

Illana experiences being autistic as both "*difficult"* and *"rewarding"*, a mixture of *"good and bad".* She feels that her ability to experience emotions intensely, is a *"gift""…it can be difficult but it is so rewarding at the same time, when I see the world in different ways to other people or how I am constantly curious or even when I'm born wise out of something* *simple, the fact that I can get that emotional about something, I just really think it's a gift… (p.2)*

Illana emphasised hypersensitivity to sensory stimuli, which particularly impacted her eating, and has caused embarrassment in social situations. "*…I could never explain why tastes, smells, textures were an issue ..everyone thought I was just being a drama queen, ….and loud noises would be going off constantly when machines were backfiring… ",*(p. 10). "*I am an extremely awkward eater. I have taste aversion … and smell issues.."* (p.23 & 24). *".. I actually got to the stage where I would pretend not to be hungry to avoid an awkward situation.."* (p. 24).

In addition to sensory triggers, her fear of imperfection/failure presents as her main triggers towards potential meltdown/shutdown. "*..you can lose it completely, and in one particular incident I was asked to draw and I just wouldn't do it or in my head I got a block that I couldn't do it..*" *(p.21) "..when I look back maths would trigger meltdowns particularly if I got confused or didn't understand…. She (teacher)….told me I was stupid for not getting it and then moved on.."*(p.22)

She eloquently gave several detailed accounts of childhood experiences which led to meltdowns. *".. blinding rage … a meltdown, heightened butterfly response, so you are ….operating on adrenalin .. shaking and you are scared and you are just lashing out and then eventually suddenly you become aware …you are just crying until you calm down and you are shaking an awful lot.* (p. 5& 6)

> *… My memory is me being an absolute nightmare, constantly getting into trouble, constantly having what I thought were temper tantrums but I know now there were meltdowns, so a lot of that was blur. I just pushed it down.."* .(p.15)

She noted that her difficulty with social interactions/friendships primarily manifested as an over-focus on individuals, which often led to breakdown in these relationships. She referred to this as making people her *"topic of special interest",* noting that this tendency to over-focus on a particular friend created significant difficulties in these particular relationships as she was experienced as being obsessive. "*..when the person becomes a specialised interest and you just want to spend all your time with them, you want them to be your friend and you want to talk to them all the time and you get frustrated when you can't…* (p.17 & 18*) "If I have the misfortune of making someone a specialist interest then it can become complicated.". (*p. 19)

Illana feels that these attempts at making and maintaining friends have presented as barriers to progressing any friendship to the level of an intimate relationship as relationships routinely broke down as a direct result of her need for continuous contact and interactions. In an attempt to manage her own tendency towards hyper-focussing on others she developed a reactive coping skill characterised by keeping a distance, socialising in groups, and *"friend-zoning*" others. "*My answer to that is to try to meet in groups because that dilutes the effect a bit..".*(p. 18); " *I have the terrible habit of being friends only…"* (p. 19)

Illana employs other coping strategies, such as masking, to manage her presentation "... *I found first kids were good to me, liked me but the more of myself I shared ….or if I was having a meltdown, attitudes changed and they could be quite negative in how they perceived me.."*(p.21 & 22) Enjoyment of food also served as a self- soothing strategy: "… *when you get a dessert that is really nice it is like your brain is just lighting up and I'm so happy ….My brain is just relaxing, just shutting off, when you are kind of eating, just really content,..*(p.25)

Illana noted that she benefitted from CBT as it gave her the space to talk things out and to process her own experiences

> *... so CBT was useful… to have the space to separate where I could talk about it completely to someone who was paid to listen. (p.26)*

She did , however, comment on the general lack of understanding of autism amongst medical professionals and service providers, noting that it seems to her that women are often misdiagnosed or treated for conditions co-morbid to autism, without the possibility of a diagnosis of autism being explored.

> *... not getting the service or the help they (autistic women)need to manage. You know there are so many mental health issues for women with autism and it is not being dealt with and they are not being supported… there is a need for psychotherapeutic support especially with the issues of anxiety and OCD and all kinds of things, so many times women become co-morbidly diagnosed with the separate mental health issues but they are not getting the autism diagnosis, so without the two, you know if you have one, you are not fully getting to the root of the autism… (pp. 29 & 30)*

> *... need a specific psychologist… to diagnose it and it can be hard to diagnose especially in women, so a professional needs to know the differences… (p. 30)*

Illana concluded the interview by emphasising the benefit of receiving an autism diagnosis, as it helped her to understand herself better, and has also improved her life by making “things” easier*:*

> *I understand all the different things that make me who I am. There are fewer unanswered questions then there used to be. I am not constantly driving myself insane, wondering why did you say this, why did you do that and life has become so much easier now. (p. 30)*