



Why is the hidden disability of autism so visible in mental health inpatient services? The autistic view from personal stories.

Submitted for the Degree of Doctor of Professional Practice
At the University of Northampton
Year 2025

Louise Caroline Kirby

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Abstract

Autistic individuals are overrepresented on mental health wards in the UK compared to in the general population. This has implications for the provision of mental health care. It is important to understand why this minority group appear to be more inclined to reach mental health crisis and require inpatient admission. All individuals have rights to equity of access to mental health support, autistic people are no different in this regard. Uniquely this study takes a life story approach to gather personal stories of autistic people through loosely semi-structured interview to gain their perspective. Using Interpretative Phenomenological Analysis (IPA), analysis was checked with each participant to agree a shared interpretation, guarding against the double empathy problem, before looking across the five stories for any commonalities. Themes for risk of mental health hospital admission emerged as: “being different, not fitting in”; “not believed, misunderstood”; “negative sense of self” and “unhelpful support not addressing needs”. Protective themes against mental health hospital admission were “trusting relationships”, “understanding self” and “using skills for a purpose”. This study has evidenced hospital admissions for autistic people due to mental health crisis is not simply a clinical concern but a relational, rights-based issue that requires societal and systemic change to meet statutory commitments to inclusivity. In addition, the thesis demonstrates methodological implications for authentic coproduction with autistic people, providing recommendations towards best practice.

Acknowledgements

I have many people to thank who always encouraged me, my parents, Great Uncle GCB and others. In addition, my Health Trust employer, particularly my manager Simba Pasipamire for his positive support throughout. Most especially, I would like to thank Professor Andrew Pilkington and Professor John Horton, Director of Studies and Dr Katy-Louise Payne, Supervisor, for their relentless dedication in trying to make me believe in myself and reveal what I take for granted. Without exception they inspired me with enthusiasm and made every supervision enjoyable. Thank you!

Special thanks also to my family: husband, children and grandchildren, for their patience as I did my interminable “Words” and didn’t come out to play.

Grateful thanks of course to the participants, I am honoured and humbled to hear your stories. You are the purpose. I hope these efforts will go some way to influence practice to make experiences better for autistic people when attempting to access services and when taking part in coproduction opportunities.

For Chris.

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Chapter 1. Introduction

There is a high prevalence of autistic people in mental health wards (Mandell, *et al.*, 2012; Tromans, *et al.*, 2018) in the UK; given the percentage of diagnosed autistic people in the community (Brugha, *et al.*, 2011) the numbers in mental health wards is higher than expected. In the literature the autistic inpatient proportion in England ranges from 2.4% – 4.0% (Tromans, *et al.*, 2018), compared to approximately 1% of the English population diagnosed as autistic (O’Nions, *et al.*, 2023). The Transforming Care Programme (DH, 2012) that ended in March 2019 intended to reduce the numbers of autistic people and people with a learning disability in mental health hospitals and improve services so they could live successfully in the community. The number of admissions of autistic people in England continues to rise; between March 2015 and September 2020, the number of autistic adults who were in mental health hospitals went up from 440 to 720 (NHS Digital, 2021) by December 2023 the number was 1,335 (NHS Digital, 2024). The NHS Long Term Plan (2019) aimed to reduce the number of people with a learning disability and autistic people in hospital from March 2015 to March 2024 by 50%. Despite this there has been a 116% increase in autistic patients without a learning disability admitted over that time (Foster and Bunn, 2024; NHSE, 2024).

More people are being diagnosed as autistic and evidence shows that this group tend to become some of the most distressed in society. A lived experience perspective supports understanding of how hospital admission may be avoided and appropriate support in the community provided. This research has been designed to meet this gap.

1.1. Justification for focus on hospital admission

There are a diverse range of reasons that research focussing on the lived experience of autistic people admitted to mental health wards is needed and they will be discussed here. It is acknowledged that the acute psychiatric ward environment is not therapeutic for autistic people and can be traumatising (Belcher, 2022; Maloret and Scott, 2018), therefore not a helpful place to be. Along with the NHS Long Term Plan (NHS, 2019), a priority from the National Strategy for autistic children, young people and adults: 2021 to 2026 (DHC&Ed., 2021) is to reduce the number of autistic people in mental health hospitals. To achieve this, the factors that lead autistic people to hospital admission need to be understood so support can be targeted in an informed way pre-crisis to divert voluntary and statutory admission whenever possible. Despite recent policy efforts to reduce the numbers of autistic people in mental health hospitals, between 2015 and February 2024 the number of autistic people

without a learning disability detained in England increased by 109% (National Autistic Society, 2024). To ensure healthcare commissioners understand the autistic perspective, research on their lived experience is needed, supporting raised awareness of adverse outcomes and inequity of care / support (Doherty, *et al.*, 2022). What autistic people need to support their quality of life may not be what professionals advise nor what services offer (Hwang, *et al.*, 2024). Gaining autistic perceptions of factors leading to hospital admission could help with policy making and clinical practice to support autistic mental health and therefore hospital avoidance.

The National Health Service (NHS) does commission community mental health support, talking therapies, mental health hubs, etc. with other mental health support available from charitable organisations, that autistic people can be signposted to access. However, young autistic people and autistic adults experience significant challenges in obtaining support (Camm-Crosbie, *et al.*, 2019; Crane, *et al.*, 2019; Maddox, *et al.*, 2020). Reasonable adjustments are required under the Equality Act (2010) but are of limited availability despite the autistic view that they are particularly important in mental health settings (Brice, *et al.*, 2021). Please see section 2.5.5 where the concept of reasonable adjustments for communication is explored in the literature review. Jordan, *et al.*, (2020) suggest that there is not enough mental health support for autistic adults, that clinicians don't understand autism and mental health together resulting in negative experiences for the autistic person, reluctance to ask for help and reduction in self-esteem. Clinicians can interpret this as the autistic person not engaging, resulting in discharge according to policy, and no help. Parents seeking mental health support for their autistic child can also experience relationship breakdown with the practitioner if they feel their concerns are not validated and blamed for the way their child behaves (Jackson, *et al.*, 2020). This will also develop a lack of trust in support being available. Belcher (2022), from their lived autistic experience, describes the fear that the support available will do harm, this is an important consideration for autistic people when deciding to seek or accept help (Bradshaw, *et al.*, 2019). It appears that autistic people are encountering stigma (Nicolaidis, *et al.*, 2015; Tint and Weiss, 2018) and institutional bias (Catala, *et al.*, 2021) within the services who are supposed to support. Hatzenbuehler, *et al.*, (2013) describe stigma as a 'fundamental cause' of health inequalities, limiting access to support. This could be due to lack of recognition by staff of autistic communication traits, difficulty in managing uncertainty and in recognising emotion and mental states, resulting in perceived lack of credibility of the autistic person (Lim, *et al.*, 2021). If the autism is not acknowledged and there is an expectation that the autistic person

will be able to conform and respond to the support offered to non-autistic people both clinician and autistic patient will be disappointed. The impact of a breakdown of relationships and trust results in lack of access to social and health care, this leads to disparity in support for the autistic person and therefore non-compliance with the human rights model of disability. For the autistic person it leads to a deterioration in quality of life and the risk that practitioners assume the autistic person is difficult and won't accept help. The Oliver McGowan mandatory training for learning disability and autism (HEE, 2022), advised for all health and social care staff, aims to address assumptions and raise staff awareness to promote equity of care. "The Autism Act 10 Years On" (APPGA, 2019), speaks of "*deeply concerning levels of unmet need*", (APPGA, 2019, p.27) in relation to autistic people being failed by the mental health system. It cites 76% autistic adults reaching out for mental health support in the five years up to 2019, with only 14% saying there were enough mental health services in their area to meet their needs, also identifying that 71% autistic adults have unmet health and social care needs. Recommendations to the government from "The Autism Act 10 Years On" includes a review to track the journey of autistic mental health inpatients to develop understanding of how they end up in that environment (APPGA, 2019, p.53).

In summary, the reason this study focusses on hospital admission is because numbers of autistic people on mental health wards are increasing despite it not being the right environment for them (Belcher, 2022; Maloret and Scott, 2018), and despite the efforts over years to reduce numbers (Marshall-Tate, *et al.*, 2017). It is recognised that autistic people have difficulty accessing community mental health support (Camm-Crosbie, *et al.*, 2019; Crane, *et al.*, 2019) which could leave escalation of mental health needs unchecked to admission. It is a national priority to reduce numbers of autistic mental health inpatients (DHSC&Ed., 2021) and mental health is a priority area for research identified by the autistic community themselves (James Lind Alliance, 2016; Cage, *et al.*, 2024). This was also endorsed by local autistic people when approached with the suggestion of this study. It is hoped that knowledge gained from this research could inform practices and processes to avoid hospital admission and improve timely access to appropriate social and health care.

1.2. Focus of the study

This study was designed to collect and examine the life stories of a small number of autistic adults without a learning disability who have experienced crisis and hospital admission, using the premise that events are not experienced in isolation but are connected to a life lived before and after (Sloan, 2020). From these stories individual experiences and reflections on interactions between environment, services and societal views of autism will be gained. The

research questions are clearly stated in section 1.4 seeking to develop a greater understanding of the autistic perspective of how living as autistic in a non-autistic focussed world impacts on their mental health.

1.3. Theoretical Underpinning

As outlined in the positionality section (3.2) my practice has been informed by the social model of disability, but in writing this thesis I have also found the theoretical underpinning of the human rights model of disability useful. The Convention on the Rights of Persons with Disabilities (CRPD) (United Nations, 2006) codifies the principles that autistic people, although they may face barriers to inclusion in society, are equally entitled to respect for their identity and to enjoy the same dignity and rights under the law as everyone else. Degener (2016) describes the human rights model of disability as conceptualised within the CRPD. The UK adopted the CRPD in 2009 pledging to protect the freedom of disabled people from discrimination, abuse and exploitation and to enable inclusive education and independence to live in the community (Abreu, 2022). These messages underlie the research questions formulated to expose precipitating and protective factors to mental health crisis from the autistic lived experience perspective from a rights-based rather than deficit-based approach. The human rights model extends the thought that it is society that is disabling for autistic people (social model of disability) to recognise intersectionality, critiqued as being overlooked in the social model (Hwang, *et al.*, 2024). The data collected for this study included a range of demographic information about participants (e.g. age, gender, ethnicity, educational achievement), taking into account intersectionality rather than concentrating solely on the autism diagnosis (s.3.6). This holistic approach supports greater understanding of the lived experience (Cascio, *et al.*, 2021). The human rights model recognises the life course inequalities that autistic people face. Individuals may need support to live independently in the community, be involved and of worth, both from a personal and civic perspective (Degener, 2016; Lawson and Beckett, 2021). Therefore, it is of fundamental importance to focus on what autistic people say their experiences are, considering any misunderstandings that may occur between autistic and neurotypical communication (double empathy theory, Milton, 2012. s.2.5.3) and mitigating against this, to obtain a true, in depth and honest picture of what it is to be autistic in our society. That is the core of this thesis. The human rights model of disability can be described as relating to policy, a model of disability policy, whereas the social model of disability describes disability as situated outside the person and caused by society, a model of what disability is (Lawson and Beckett,

2021). For this reason, the inclusion of the human rights model extends the thinking behind this study, upholding respect and participation as the standard, ethical approach to considering autistic wellbeing. Aligning with the neurodiversity paradigm, the human rights model accepts disability as part of human diversity to be respected and equitably included. Along with the social model of disability, the human rights model requires health care systems to provide equitable access to services for autistic people to avoid their health deteriorating (Lawson and Becket, 2021) see section 1.1. Theoharis (2007) describes how leaders implement social justice in the educational setting to ensure equity, explaining the challenges faced in an institutional context but giving the possibility that this could be translated to a health context for autistic people. The importance of lived experience knowledge informing practices affecting them is emphasised in the CRPD (United Nations, 2006). Hwang, *et al.* (2024) acknowledge that what providers offer and what professionals may recommend without lived knowledge may not match the person's wants and needs for the quality of life they are seeking. For these reasons the emphasis on gaining lived experience knowledge is at the heart of this study, from the research questions, participatory nature, to promoting autistic voices. The phenomenological aspect of Interpretative Phenomenological Analysis lends itself well to the human rights approach as it aims to understand other people's relationship with the world (Smith, *et al.*, 2022), this is particularly pertinent for hearing experiences of minority groups.

1.4. Research Questions

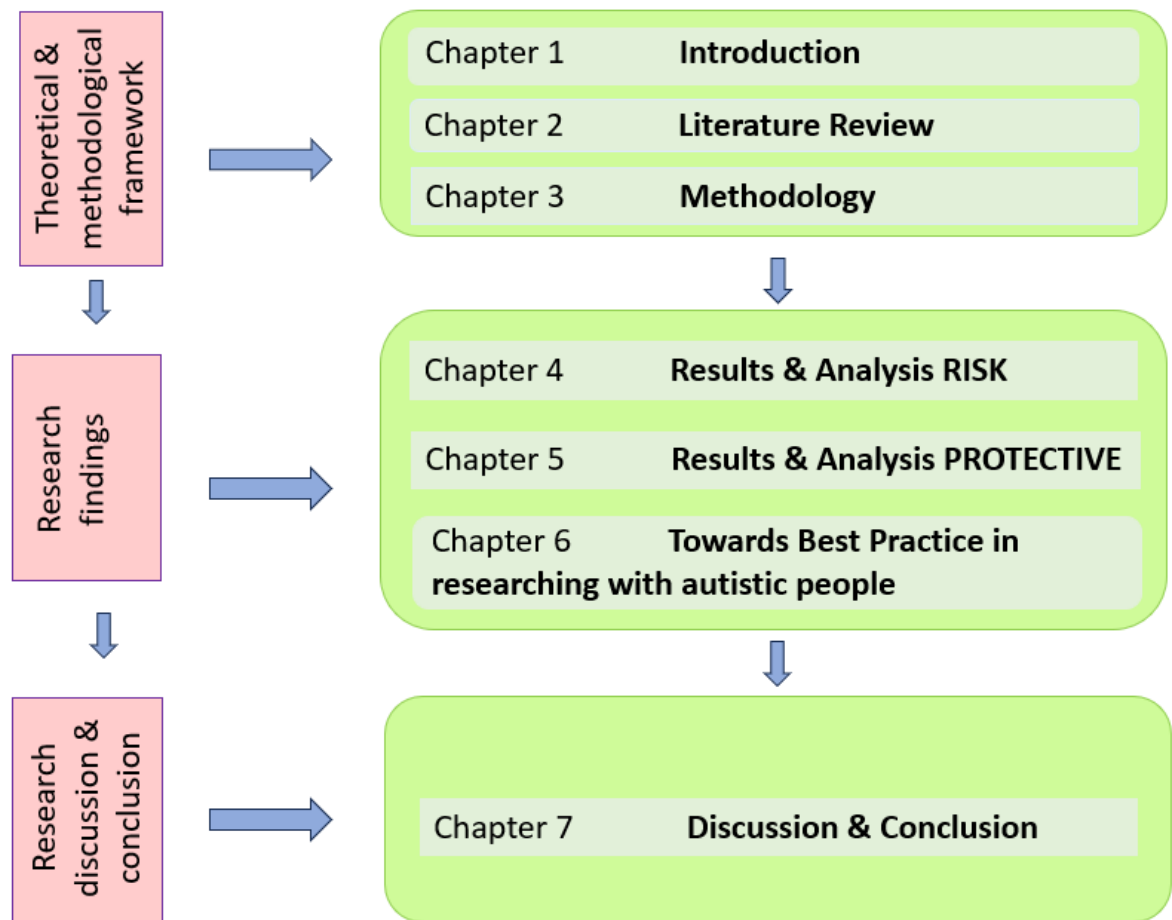
The research questions are:

1. What is the autistic lived experience perspective of the precipitating and predisposing risk factors for mental health hospital admission?
2. What is the autistic lived experience perspective of the protective factors that promote resilience to avoid mental health hospital admission?

The resulting picture of personal autistic perception of risks and protective factors related to mental health crisis could be used in practice to inform early support in the community to avoid hospital admission.

1.5. Thesis Structure

Figure 1 Thesis Map



The thesis is structured into three parts (Figure 1). The first part contains the theoretical and methodological framework of the study. After the introduction, the literature review provides a historical look at theories showing knowledge changing over time. This is important as the context of dominant theories defines how autism, and mental health, is considered at the time and affects how an autistic person is viewed and views themselves, which could impact on whether they feel positive, safe and able to cope. Chapter 2 also reviews the literature on predictors of mental ill health and inpatient admission to identify what has been done before and where this research fits in, methodology of existing studies is also considered. The following chapter moves onto methodology of this study, describing the researcher's positionality, ethical considerations, the choice of IPA and introducing the participants who are the focal point of the research. Part 2 gives the research findings which include group experiential themes (GETs) derived from the personal experiential themes (PETs) from each participant covering precipitative and protective factors regarding reaching crisis and hospital admission. The analysis was underpinned by my ethical and professional practice and

commitment to sharing the authentic autistic voice. Continuing the focus on authentic voices PETs are checked with each participant for accurate interpretation. These concepts of fairness, respect and justice can be articulated by the Human Rights approach and influenced my interpretation to identify key themes “being different, not fitting in”; “not believed, misunderstood”; “negative sense of self” and “unhelpful support not addressing needs” as being precipitative factors. Using this approach, I was able to reflect the words participants used themselves, valuing and showcasing their lived knowledge. In the same way, protective themes against mental health hospital admission were identified as “trusting relationships”, “understanding self” and “using skills for a purpose”. Results and analysis for each of the research questions are written together under Chapters 4 and 5 illustrating the hermeneutic cycle of IPA and co-development of interpretation through participant’s voices and my ethical and theoretical perspective. Through the reflexive nature of the process the research findings also were found to provide information towards best practice in research and co-production with autistic people, this is covered in Chapter 6. Part 3 covers the research discussion, conclusion and implications for practice which stresses the importance of relationships, family, societal and therapeutic for autistic wellbeing as well as how to include autistic people in research. Consistent with the human rights approach this section continues to foreground the emphasis on inclusion and co-construction of meaning with participants’ voices being central, adding to theory by contributing recommendations on how to include autistic lived experience voices in matters that concern them.

Chapter 2. Literature Review - Autism and Mental Health

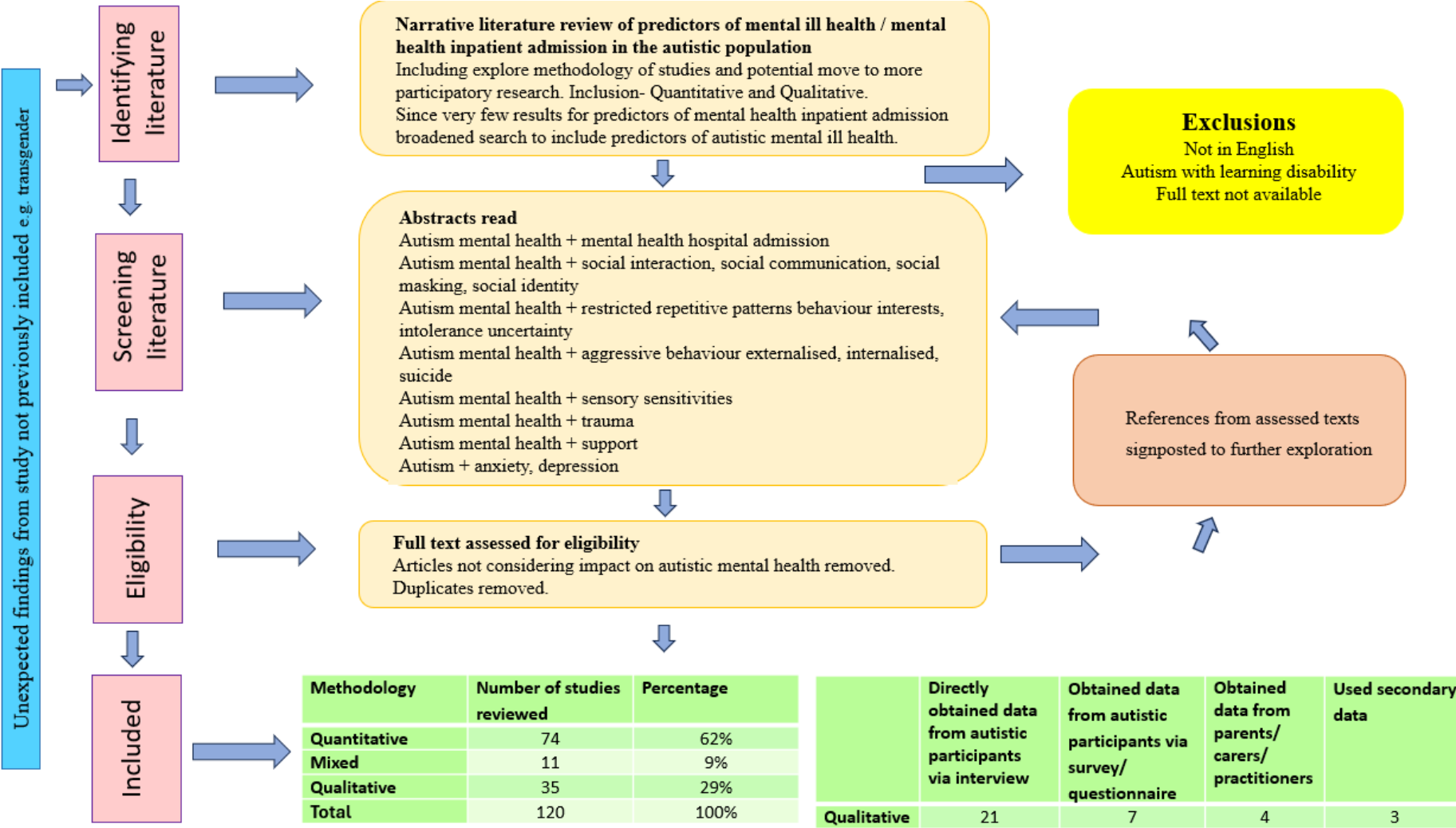
2.1. Introduction

This chapter presents a narrative literature review of the research evidence identifying possible risks to common mental health problems in the autistic population that lead to hospital admission. The structure of the chapter follows key themes from existing literature. It first establishes the context of the research by conceptualising what mental health is and what autism is, including relevant legislation and policy, before moving on to consider the relationship between mental health and autism. This section of the chapter highlights the human rights approach to address the inequity experienced by autistic people and the intersectionality between mental health and autism as both being stigmatising. The next part of the chapter discusses the literature pertaining to possible susceptibility of autistic people to mental ill health under headings loosely relating to autistic traits, namely, social interaction and social communication challenges, social masking, autistic and social identity, lack of reasonable adjustments for communication, restricted and repetitive patterns of behaviour and interests, sensory sensitivities, trauma and then ending with lack of support. Gaps in the literature are highlighted throughout. Table 1 gives a summary of the process of searching, collecting and selecting the literature for the review.

Item	Specification
Databases and other sources searched	CINAHL References from articles – NELSON Google Scholar Gov.UK Publications
Search terms	Autism or ASD or autism spectrum disorder or Asperger's or Asperger's syndrome or autistic disorder or Aspergers Mental health or mental illness or mental disorder or psychiatric illness Hospital admissions or hospitalisation
Timeframe for search	Initial search: 2016 – 2021. Update searching: 2022 - 2025
Exclusion criteria	Autism with a learning disability Articles not written in English
Inclusion criteria	Peer reviewed articles. Quantitative and Qualitative and mixed methods Grey literature: current UK Government, WHO documents. Included articles relating to autistic children as well as autistic adults as taking a lifelong approach.

Table 1 Literature Search Strategy Summary

Figure 2 Iterative nature of narrative literature review process



The initial search string (Table 1 ‘search terms’) in CINAHL gave very few results and none that specifically addressed the trajectory of autistic adults to mental health admission. The process was therefore broadened both in sources searched and to include predictors of autistic mental ill health. The process took on an iterative nature as detailed in Figure 2 (p.15).

The purpose of the review was to identify gaps in the literature that aim to develop understanding of why an autistic person could be up to ten times more likely to be admitted into mental health inpatient services (Harper, *et al.*, 2019; Mandell, *et al.*, 2012; Tromans, *et al.*, 2018) than someone from the general population. When looking specifically at qualitative studies gaining data directly from autistic interview regarding their mental health experience to hospital admission, only one considers mental health experiences of young autistic adults aged 16 to 25 (Crane, *et al.*, 2019) another, autistic adults experience of low mood and depression (Jordan, *et al.*, 2020) with Maloret and Scott (2018) looking at autistic experience of acute mental health facilities. This indicates a gap to explore autistic adult perception of precursors to mental ill health and escalation into a need to be admitted to a mental health ward, keeping the autistic voice firmly at the centre of the study following the theoretical underpinning of human rights model. The literature review chapter also acknowledges the importance of identifying existing evidence to recognise how this research can contribute to the field.

2.2. Mental Health and wellbeing

The following section discusses the interplay between mental health, well being and quality of life. It is important to reflect on these terms because we can not assume that the definitions mean the same thing for autistic people as non-autistic people. Mainstream definitions were created without autistic experience in mind and reflecting on them can identify possible assumptions that may be made that would not align with an authentic autistic self and thus not provide helpful support.

2.2.1. Definitions of mental health and wellbeing

The World Health Organisation (WHO) uphold their original description of health in their constitution:

“Health is a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity” (WHO, 1946)

From this we understand that mental health is not separate but an equal aspect for overall health. Social wellbeing is not a medical diagnosis but a condition where one feels good and

functions well (Department of Health, 2014). Wellbeing can also be described as experiencing good mental health. WHO describes mental health:

“as a state of wellbeing in which an individual realises his or her own abilities, can cope with the normal stresses of life, can work productively and is able to make a contribution to his or her community” (WHO, 2021, p.1)

Positive wellbeing is protective of good mental health and longevity in the general population (Diener and Chan, 2011). Burns *et al.* (2022) describe high wellbeing as flourishing and found it was that level of wellbeing, as well as moderate wellbeing, that strongly protected mental health outcomes across participants with age ranges of 20 to 64 randomly selected from the electoral roll in Australia. The participants in these studies were not autistic and it would be useful to understand if positive wellbeing is a protective factor across the autistic life span. Cooper *et al.* (2017) suggest this could be the case. When developing preventative public health measures to decrease the number of autistic people reaching mental health crisis and hospitalisation this should be considered. In a societal context, autistic people may find this wellbeing more challenging to maintain in the non-autistic focussed world than neurotypical (non-autistic) people (WHO, 2014). Being in the autistic minority could exacerbate normal stresses of life as experienced by the general population (Botha and Frost, 2020). As Burns *et al.* (2022), Pellicano and Heyworth (2023) use the term “*flourishing*” when considering what a good life for an autistic person may be, which likely would not follow what is conventional for non-autistic people nor be picked up in Quality-of-Life measures for neurotypical people. The eight domains of quality of life for people with intellectual disabilities are; emotional wellbeing, interpersonal relations, material wellbeing, personal development, physical wellbeing, self-determination, social inclusion and rights (Schalock, *et al.* 2002). These domains are fixed within the context of the social system in their application model as well as being from the individual’s perspective of what wellbeing is for them (Schalock, *et al.*, 2002). This could also be appropriate for autistic people (Robertson, 2010). The concepts fit well with WHO descriptions, endorsing that mental health is not simply an absence of mental ill health but dependant on personal feelings of being a worthwhile person within the context of society and their culture. “Worthwhile” in the context of WHO relates to a measure of wellbeing, “*overall, to what extent do you feel the things you do in your life are worthwhile?*” (DH, 2014) which is not designed for non-autistic people. An autistic personal feeling of worthwhile may not be due to the same things in life as neurotypical but relate to an authentic sense of autistic self (Milton, 2012; Jaswal and Akhtar, 2019; Crompton, *et al.*, 2020b; Gillespie-Lynch, *et al.*, 2017).

Galderisi *et al.* (2015) challenge the notion that WHO, in their definition, have gone far enough in clarifying that mental health is not dependent on feeling positive and doing well but includes coping with adverse life events. They offer a description of mental health which aims to be more inclusive and less culturally bound to the Western world. When describing mental health as:

“a dynamic state of internal equilibrium which enables individuals to use their abilities in harmony with universal values of society” (p.231,232)

most components explained as contributing to that state of equilibrium are precisely those that are described as challenging for autistic people, (i.e., social skills, emotional recognition and regulation, flexibility of thought, executive function and empathy). UK No Health without Mental Health strategy (DH, 2011) positions mental health at the centre of quality of life, interdependent with education, employment and society problems of homelessness, crime and drug and alcohol misuse. Many of these issues are more prevalent in the autistic population. The following examples show the broad range of contexts in which autistic people encounter challenges throughout their lives:

- Education - School non-attendance is frequent among autistic students, predominantly due to school refusal (Totsika, *et al.*, 2020), with 43% of autistic students having persistent absence, (i.e., missing 10% or more of available sessions; Totsika *et al.*, 2020). Autistic school non-attendance (43%) is higher compared to the reported 13% persistent absenteeism across all students in all maintained schools in England in term one of the 2019/20 academic year (Department for Education, 2020). School refusal is not the only reason for autistic children and young people miss education. If their behaviour does not conform to the school behaviour policy or if being in school causes serious harm to their welfare or the welfare of others they could be excluded (Department for Education, 2012). School exclusion can be four times higher for autistic pupils than other children (Ambitious About Autism, 2017).
- Employment - The Office for National Statistics reports autistic people as having the lowest employment rate of people with disabilities, their employment rate being 22% compared to 81% for ‘non-disabled people (July - September 2020; Office for National Statistics, 2020).
- Homelessness – evidence suggests that autistic people are over-represented in the UK homeless population and more at risk of homelessness (Churchard, *et al.*, 2019)
- Drug and alcohol misuse - The No Health without Mental Health strategy (DH, 2011) recognises drug misuse affects quality of life. Autistic individuals could be up to nine

times more likely than non-autistic individuals to use recreational drugs to manage their behaviour and three times more likely for managing their mental health (Weir, *et al.*, 2021).

This would suggest increased prevalence of mental health difficulties in the autistic group. Autistic people who consider quality of life should include conventional success in education and employment may feel their outlook bleak.

Mental health and wellbeing and quality of life are inextricably bound in the idea of “good health” (Diener and Chan, 2011). The factors that need to be taken into account are; interactions with others, the environment, societal values and expectations on the internal state of wellbeing. This suggests that some definitions of quality of life may not be what an autistic person may feel they can, nor want to, aspire to. This illustrates the importance of directly including autistic people in research to truly understand their lived experiences. The described complex interplay of multiple factors in maintaining mental health, and the individual nature of these, confirms autobiographical life accounts a fitting method to gain perspectives on personal trajectories to crisis in autistic people.

2.2.2. Mental health legislation/policy guidelines

In this section the changing legislation and policies, as well as societal attitudes to mental ill health, are considered. Mental health and mental illness are viewed and treated differently in different cultures and alter throughout history. Table 2 shows how understanding and care relating to mental ill health has changed in the UK. This historical context is relevant for the current study as it positions participants’ stories.

17TH CENTURY	VICTORIAN ERA	MENTAL HEALTH ACT 1959
The first “hospital for the insane” was built in London with a rather indiscriminate range of patients from those who were poor to those who were violent. (Killaspy, 2006)	Victorians reviewed treatment of “lunatics”, including “paupers and criminals”, and introduced asylums as the method for caring for them. These were self-enclosed, away from society. Legislation required someone to be certified insane, usually by the Parish GP, to be admitted. This differed from the hospitals where people could be treated voluntarily. (Killaspy, 2006)	As the political and social context changed, asylums, where people could stay for life, closed. The Mental Health Act (1959), legislated reasons why a person could be admitted to hospital, clarifying involuntary treatment against a person’s will and voluntary admissions (Killaspy, 2006). This was a first move against lifelong institutionalisation to care in the community.

Table 2 Understanding and care relating to mental ill health over time

Legislation in the UK aims to protect the vulnerable of society as well as society as a whole. The reviewed Mental Health Act (1983) describes Autism Spectrum Disorder and Asperger's syndrome as conditions that are covered under the Act's description of mental disorder. The Mental Health Act 1983, Code of Practice, (DH, 2015, 2.17) allows autistic people to be involuntarily detained without an additional mental health need. Although relevant in the eighties when the Act was passed, this does not sit well with the current neurodiversity paradigm where autism is considered as different but not broken (AM-HeLP, 2021; Robertson, 2010; Whiteley, *et al.*, 2021). The review of the Mental Health Act (DHSC, 2018) found that the Act was being used inappropriately to detain autistic people in crisis that had arisen from lack of suitable care in the community. The draft Mental Health Bill (DHSC&MoJ, 2022) proposed removing autism as a criterion for being detained unless there was a co-occurring mental health condition, at this time this has not been legislated due to concerns of a lack of community support for autistic people and the risk of other legal powers being used for detention (Foster and Bunn, 2024). Complexity and co-morbidities could make it difficult to clinically differentiate between the autism and the mental illness (Lugo-Marin, *et al.*, 2019).

2.3. Autism

2.3.1. Definitions

Autism has its origins in mental health. Challenges with social interaction, social communication and rigidity of thought were put together as traits of a cognitive disorder of childhood (Kanner, 1944; Asperger, 1944) after separate observations and case studies of children who had "*extreme aloneness*" in common. In 1943 when Kanner first identified the condition it was linked to schizophrenia, the word 'autis' had previously been used by the psychiatrist Bleuler to describe a type of schizophrenia (Crespi, 2010). It was not until 1980 that 'Infantile autism' (Kanner, 1944) first appeared in the Diagnostic Statistical Manual of mental disorders (DSM-III). Therefore, relatively recently, autism was viewed as a psychiatric condition but does technically remain a psychiatric diagnosis. Adults in the community may have been diagnosed with infantile autism, although as children they may have been given a different mental health diagnosis or labelled 'mentally retarded' (D'Astous, *et al.*, 2016). The advice would have been institutionalisation, that, and the belief that parents were to blame (Bettelheim, 1967; Eisenberg and Kanner, 1955) added to stigma and shame, hence people with the condition would not be spoken about generally and society

was largely unaware (D'Astous, *et al.*, 2016). Understanding historical knowledge of autism is important for this study with adult autistic participants because there have been vast developments within a lifetime. This will impact on an autistic individual's life experiences and perspective of themselves which can have a lasting effect.

Autism is described in both the DSM 5 and the eleventh revision of the International Classification of Diseases (ICD-11) diagnostic criteria as having traits that are present from birth and comes under the neurodevelopmental disorders section. In the WHO Comprehensive Action Plan 2013 - 2030 (WHO, 2021) developmental aspects of mental health are emphasised for children, such as having a positive identity and social relationships and managing emotions (p.1, i06). Considering autism as a developmental condition, (ICD-11), the emphasis on developmental aspects of mental health could be useful in promoting autistic mental health across the autistic life span. This is because developing a positive identity (Ratner and Berman, 2015; Tan, 2018), forming social relationships with neurotypical peers and managing emotions (Brede, *et al.*, 2020; Maddox, *et al.*, 2017), can present challenges for autistic adults as well as children. However, since autism tends not to be diagnosed until being autistic has become such a problem that it is impairing function it could be hard to redefine as being a positive (Farahar, 2022).

Autism as a diagnosis represents the medical model of disability with the impairment being owned by the person. The neurodiversity paradigm (Singer, 1999) taken up by autistic activists argues that autism is not a condition to be treated but part of the natural diversity of neurotype i.e. a neurodifference, (Singer, 1999; Kapp, 2020). This is changing the way we think about autism (Masataka, 2017; Whiteley, *et al.*, 2021), rather than the autistic person being expected to change to fit into a neurotypical world that is not suited to them, reasonable adjustments can be expected as society supports diversity and equality (Oshima, *et al.*, 2014). The neurodiversity paradigm does have critics who suggest it may not reflect experiences of autistic people with a learning disability (Hughes, 2021; Jaarsma and Welin, 2012) underlining the difference between the autistic populations with and without a learning disability. This study does not include autistic people with a learning disability because their experiences are different, they can access specialist services for learning disabilities which are not available to the autistic only population.

Autism does not always co-occur with learning disabilities; according to Lai *et al.* (2014) approximately 55% of autistic individuals do not have a learning disability, Autistica (2021) estimate this figure higher at 60%. Despite agreement that most autistic people do not have a learning disability these two conditions are put together under UK Government initiatives,

thus Building the Right Support for people with a Learning Disability and Autistic People (NHSE, 2022) and the NHS Long Term Plan (2019). “Building the Right Support” is an action plan to reduce reliance on mental health inpatient care, aiming to make health and social care support equitable in the community. The Transforming Care programme (DH, 2012), instigated after the Winterbourne scandal, was for people with a learning disability and/or autism. Until 2017 data included both learning disability and autism information together making it difficult to get a picture for the separate populations. Figures for autism only in inpatient settings is now collected separately (NHS Digital, 2021)

Since there are different definitions and ways of thinking about autism, it could be concluded that autism means different things to different people which could cause conflict and misunderstanding of expectations. Sarrett (2011) highlights that the information the public receive about autism is often from the media rather than scientific literature, these portrayals can be inaccurate and create unhelpful stereotyping. Lorna Wing introduced the idea of autism being a spectrum condition (Wing, 1988) because of the complex heterogeneous nature of the condition with each autistic person experiencing their autism differently. Therefore, first hand narrative from autistic people is particularly relevant for this project aiming to understand how being autistic in a non-autistic focussed world may affect mental health. That there is a link between autistic mental health and being misunderstood in society is suggested by Mitchell *et al.* (2021). They propose a social developmental, transactional model whereby behaviour influences the behaviour of others in cyclical interactions. This would affect self-knowledge, wellbeing, and outcomes, including attempts to access support.

Beliefs about autism as a condition will have informed legislation of the time that has perhaps developed slower than our knowledge of autism,

2.3.2. Autism legislation/policy guidelines

The Autism Act, 2009, was the first legislation related to a specific condition. It aimed to improve services for autistic adults. Despite this the “Autism Act 10 Years On” (APPGA, 2019) document found few autistic adults felt that professionals understood why they behave as they do. This causes barriers for accessing services (Mason, et al., 2019.) and leads to inequity in healthcare (Brice, *et al.*, 2021.)

2.4. Autism and Mental Health

2.4.1. Introduction

The relationship between mental health and autism is complex with mental health disorders increasing mortality risk (Prince, *et al.*, 2007). Life expectancy for autistic people is shorter

than for the general population (Hirvikoski, *et al.*, 2016; Smith DaWalt, *et al.*, 2019). Suicide as a cause of death is a higher risk for autistic individuals without a learning disability (Hirvikoski, *et al.*, 2016; Hirvikoski, *et al.*, 2020) than those with a learning disability, (Cassidy, *et al.*, 2014; Cassidy, *et al.*, 2018) and further raised if the individual also has depression. According to Kølves *et al.* (2021) nationwide Danish study over twenty-one years (n= 6,559,266., age ≥ 10 yrs.) autistic people are three times more likely to attempt or die by suicide than non-autistic people. This risk is associated with psychiatric co-morbidity, predominantly anxiety and affective disorders, and increased for autistic people who attained a higher educational level. NICE (2018) guidelines for preventing suicide in community and custodial settings recognise autistic people as one of the high-risk groups.

The WHO action plan (2013) acknowledges that a human rights approach is needed to address the discrimination experienced by people with mental disorders, presumably they are including autistic people due to their definition, but this is not made explicit. However, WHO (2014) specifically recognises the social stigma and barriers autistic people and their families may face in participating as equal members of society and the need for better mental health support (Resolution WHA57.8). Autistic people with mental health needs would experience stigma due to both mental ill health and autism which could have a cumulative effect in increasing health inequity and reducing quality of life (Reinka, *et al.*, 2020).

2.4.2. Prevalence

Co-morbid psychiatric disorders are prevalent in autistic children (Simonoff, *et al.*, 2008). Simonoff *et al.* (2008) found 70% of their population-derived sample of 112 ten- to fourteen-year-olds with an autism diagnosis had a co-morbid psychiatric disorder, with 41% having more than one, from parent report. UK “No Health without Mental Health” strategy (DH, 2011) also recognises there is an increased range of mental health problems for autistic people (p.61 i6.27). Co-morbid psychiatric disorders are prevalent across the whole lifespan, significantly higher than in the general population (Lai, *et al.*, 2019). From their findings, autistic people are 12.7% more likely to have an anxiety disorder than the general population, 3.5% higher prevalence of schizophrenia and 6.3% higher depressive disorders across ages. This systematic review and meta-analysis covered publications of original research over fifteen years up to 2019 looking into prevalence of co-occurring mental health conditions and concluded that increased age was associated with increased diagnoses of depressive disorders, bipolar and schizophrenia spectrum disorders. The time span includes the change in diagnostic criteria for autism spectrum disorder in 2013 to DSM5 (APA, 2013) when Asperger’s Syndrome was removed as a separate diagnosis to come under the autism

umbrella. Findings from Wigham *et al.* (2017) systematic review put the prevalence of depression in autistic people without a learning disability between 1% - 47% compared to 2.5% - 10.7 % in the general population (Wigham, *et al.* 2017). The reasons for such a wide variety of research results on the prevalence of co-morbid mental health conditions within the autistic population could depend on methodology of research (Hollocks, *et al.*, 2019), sample age or sampling, (Hossain, *et al.*, 2020). For example, a higher percentage of additional mental health diagnoses are found in participants from clinical settings. Lugo-Marin *et al.* (2019) found 95% co-morbid psychiatric disorders in their meta-analysis of autistic adults, 87% of whom from clinical settings. The variation could also be due to inconsistencies with regards to diagnosis and that people might be more likely to gain diagnoses in clinical settings. Mental health conditions could be experienced differently in autistic people (Underwood, *et al.*, 2015), and autistic individuals may have difficulties recognising and communicating what their symptoms are (Underwood, *et al.*, 2015) with overlap of symptoms of autism and some mental health conditions (Au-Yeung, *et al.*, 2019; Starling and Dossetor, 2009). Shepherd *et al.* (2019) suggest that autism and anxiety may originate from the same early developmental pathways rather than being distinct. This forms a question, particularly regarding service eligibility criteria, whether autism is an identity where co-morbid anxiety can be experienced like any other illness; or autistic anxiety is peculiar to autism and part of the condition. Anxiety is not included in the diagnostic criteria for autism spectrum disorder (ICD11, 2019; DSM 5, 2013). Kerns and Kendall (2012) cautiously put forward that anxiety is a co-occurring disorder distinct from anxiety-like autistic traits. This is confirmed by Montazeri *et al.* (2019) in their network analysis of anxiety in autism. Although prevalence varies, the literature agrees that a higher number of autistic people across the life span have co-morbid psychiatric disorders than the general population. These co-occurring mental health conditions impact on quality of life, functioning and wellbeing (Lai, *et al.*, 2019; Park, *et al.*, 2019).

2.5. Why mental health diagnoses may be higher in the autistic population than the general population

2.5.1. Introduction

From descriptions of mental health, it could be construed that autistic traits themselves could be risk factors. Indeed, psychiatric problems in autism did tend to be attributed to autism itself (Lainhart, 1999). Lai, *et al.* (2019) suggest that autism could be a risk factor for major psychiatric disorders such as depressive, bipolar and schizophrenia spectrum disorders. Nevertheless, according to Oshima *et al.* (2014) the traits in themselves need not cause

mental health problems, although it can be difficult to differentiate these core symptoms (i.e. social interaction and social communication differences, restricted, repetitive, and inflexible patterns of behaviour and sensory differences) from psychosis (Starling and Dossiter, 2009). As well as autistic traits, a risk factor for autistic people developing mental ill health could relate to ongoing difficulties with accessing support due to difficulty meeting eligibility criteria for services (No Health without Mental Health strategy, 2011). This could mean that support is not available early on for mental health needs such as anxiety, leaving symptoms to get worse. Anxiety has been associated with social difficulties, intolerance of uncertainty and sensory sensitivities (Johnston and Iarocci, 2017; Neil, *et al.*, 2016; Williams, *et al.*, 2021) which could influence diagnostic overshadowing (Au-Yeung, *et al.*, 2019). The next section reviews the literature on the possible factors that may impact on autistic mental health in a societal context.

2.5.2. Social interaction and social communication challenges

Within the neurodiversity view, the challenges an autistic person experiences are not solely due to their autistic traits but also the impact of the mismatch between themselves and their environment (Lai and Szatmari, 2019). Adapting the environment, the neurodiversity paradigm suggests, can accommodate the autistic individual and reduce distress, thus helping to lessen the risk of development of mental health problems (Leadbitter, *et al.*, 2021).

To consider this further the range of contexts that can be challenging needs to be reflected upon. For example, existing research has considered how this plays out in the context of home and school. An association between social skills and mental health in autistic children without a learning disability was found (Ratcliffe, *et al.*, 2015) in these contexts. This reflects the social model of disability which argues that barriers can arise from the environment and context not just the individual themselves (Clark and Adams, 2020). The research, however, did rely on parent and teacher report rather than the view of the child. A further quantitative study with adult autistic participants aged 18 – 36 years without a learning disability found that those with greater self-reported social impairments were at greater risk of depression (Day, *et al.*, 2020). This had a small sample size (n=33), so conclusions need to be treated with caution but results suggest that it is not the severity of the autistic trait that is the risk factor but perceiving themselves to be different and not fitting in. The conclusion that self-reported social impairment increases the risk of depression is supported by Smith and White (2020) who found that the lack of ability of socially motivated autistic adolescents and young adults to form and sustain successful interpersonal relationships led to loneliness which is a predictor of depression. The link between positive friendships and wellbeing in adolescents is

also supported by O'Connor *et al.* (2022). The connection between social competence and depression can influence both ways in that increased depression symptoms increase social difficulties and increased social difficulties increase depression (Johnston and Iarocci, 2017). Trusting relationships with schoolfriends were valued by young autistic participants (Cribb, *et al.*, 2019.) with quality not quantity emphasised, although may need support in maintaining (Calder, *et al.*, 2013). In the Johnston and Iarocci (2017) study autistic children aged between six to fourteen and their parents were recruited (n=67) with neurotypical sample (n=67) for comparison. A disadvantage of this study is that it relied on parent report which may not accurately reflect the individual's perception. Lord *et al.* (2020) in their longitudinal study into outcomes for autistic young adults found that parent report for depressive symptoms were lower than that of self-report (Lord, *et al.*, 2020). They found that more children showed depressive symptoms than were known to have diagnosed depression, warning that clinical features of depression such as withdrawal and social isolation can be confused with autistic traits and missed. Increased generalised social anxiety in female children increased the risk of depression in adolescence (Keenan, *et al.*, 2009). With anxiety often leading to the development of depression, treating anxiety disorders would protect against a later diagnosis of depression (Keenan, *et al.*, 2009). There is concern that treatment pathways for autistic mental health needs urgent attention (Camm-Crosbie, *et al.*, 2019; Crane, *et al.*, 2019; Hallett and Crompton, 2018).

Within another context it has been suggest that employment experiences are a key factor in promoting well-being for autistic people (Walsh, *et al.*, 2014). Research suggests that how the autistic person perceives their social anxiety and work ability can impact on how successful they feel in social situations and work (Woolard, *et al.*, 2021), the higher the perceived social anxiety the lower the self-reported view of social ability. A negative view of work performance is associated with lower success at work, putting gaining and sustaining employment at risk. This perception of poorer social and work outcomes could be a result of the actual social challenges faced and repercussions from colleagues in the workplace which can be located to and internalised by the autistic person (Bury, *et al.*, 2020; Thorpe, *et al.*, 2024). This can threaten their mental health and jeopardise their employment, despite likely mutual misunderstandings caused by lack of knowledge of autism and the double empathy problem (Milton, 2012). Bury *et al.* (2020) produced these findings from written online narratives from 29 self-reported autistic employees and 15 supervisors who directly supported autistic people from seven different continents and working in a variety of sectors. An advantage of the methodology is that the information was obtained from the autistic

employees and supervisors directly rather than from secondary data. There were 72 examples of autistic perceived social challenges and 56 from supervisors that were not the same. This reinforces the knowledge that autistic and neurotypical people perceive things differently and therefore misunderstandings between the two are likely to occur. In forming a resolution to the challenge, both supervisor and employee's first choice was for the employee to resolve it themselves. This resonates with Jordan *et al.* (2020) findings that autistic people tend to rely on themselves rather than seek help for problems. This could be due to a lack of trust (Robledo and Donnellan, 2016) if their problems have not been taken seriously in the past because of the different perceptions of what constitutes a challenge (Catala, *et al.*, 2021). The environment and attitudes of others could also exacerbate the challenges (Lai and Szatmari, 2019).

Social interaction and communication challenges, therefore, can have a negative effect on home, school and work life with peers, parents and colleagues interpreting behaviours incorrectly resulting in loss of friendships, threats to employment and expectations that the autistic person needs to change. To achieve that the autistic person may try to hide their autistic traits by social masking.

2.5.3. Social Masking

Experiencing social challenges are risk factors for employment and wider friendships (Calder, *et al.*, 2013; Finke, *et al.*, 2019) which should promote wellbeing (Kandalafi and DeBrabander, 2021) as could helping others (Oarga, *et al.*, 2015). If fitting in is important, it is understandable that autistic individuals will try to adapt to fit and be accepted as typical peers. Research suggests that this camouflaging is a common social coping strategy in autistic people but may have a detrimental effect on mental health (Cage and Troxell-Whitman, 2019; Hull, *et al.*, 2017). If autistic people feel a need to fit in, by inference, they must be socially aware to realise they do not, so possess theory of mind in relation to this.

Theory of mind (ToM), (Baron-Cohen, 1995; Frith, 1994) is the concept that autistic people struggle to understand the perspectives of others, often referred to as mind blindness (Roeyers and Demurie, 2010). However, like non-autistic people, adult autistic people without a learning disability generally succeed on false-belief tasks (Roeyers and Demurie, 2010). The one-way nature of ToM, as a deficit of autism rather than a shared challenge in understanding across neurotypes, is countered by the double empathy problem (Milton, 2012).

The double empathy problem furthers thinking by suggesting neurotypical people do not understand autistic theory of mind, as many people with very different experiences of the world would struggle to understand each other. This takes the impairment away from belonging to the autistic person, reconceptualising the difficulty in understanding as a shared problem (Heasman and Gillespie, 2018). It was thought due to observed aloneness of autistic people that they lacked social motivation (Chevallier, *et al.*, 2012) however this does not appear to be the case (Jaswal and Akhtar, 2019). Jaswal and Akhtar (2019) argue that social motivation does not lie within the individual but is dependent on how others interact with the individual. If neurotypical people are not recognising, or finding acceptable to their norms, social initiation from an autistic person that person may be rejected.

Jordan, *et al.* (2020) used an interpretative phenomenological analysis to explore the autistic experience of low mood and depression (n=8). Participants were predominantly male (n=7) and results showed that ‘acting normal’ was a theme that was felt important indicating masking is not just a female preserve. Hiding emotions and not being authentic was found to contribute to a feeling of lost identity and low mood (Jordan, *et al.*, 2020). Continued failure to engage in positive successful interactions when social motivated to do so would negatively affect mental wellbeing (Smith and White, 2020) with social self-efficacy supporting mental wellbeing (Camus, *et al.*, 2024). Fletcher-Watson and Crompton, (2019) refer to the principles of neurodiversity that acceptance of all, socially motivated or not, is what is important (Fletcher-Watson and Crompton, 2019).

There is a growing body of research that shows autistic people have a greater rapport with other autistic people and feel more comfortable and able to communicate better with them (Dachez and Ndobu, 2018; Crompton, *et al.*, 2020a and 2020b). Being with other autistic people removes the need for masking to pass as neurotypical (Crompton, *et al.*, 2020a) which can take a lot of energy and be exhausting (Hull, *et al.*, 2017). It could be that non-autistic observers of autism have made assumptions that may not truly reflect what it is to be autistic. The methodology of this research follows the move from a solely pathological view of autism to applying social theory and the human rights model, valuing experiential knowledge (Dirth and Branscombe, 2018). It takes a social construction approach considering that both the autistic and non-autistic person share responsibility in an interpersonal interaction and is underpinned by the human rights theory that all humans deserve respect and have a right to be heard.

2.5.4. Autistic and Social Identity

Considering social interaction as bidirectional and healthy schemas developing from experiences of self and relationships with others from childhood (Oshima, *et al.*, 2014), positive interactions with others from an early age is important for developing a sense of self. Piaget (1954) used the word schema to describe the active process that children use to acquire knowledge and understanding through thinking and interacting with their environment as well as categorising it to use to interpret the world. Social difficulties could mean autistic children may miss out on developing healthy schemas over time. It is generally agreed that schema development in the autistic population is different to that in neurotypical populations (Patry and Horn, 2019). Early maladaptive schemas (EMS) have been suggested to arise from not developing understanding of self and others through positive social interaction (Oshima, *et al.*, 2015), which can influence health and development of some mental disorders, e.g., post-traumatic stress disorder, eating disorders, (Oshima, *et al.*, 2014). Their study concluded that it was the development of EMS rather than autistic traits themselves that could predict mental health problems for autistic people.

It has already been considered that unusual attempts to socially initiate may result in rejection. Attempts to fit in or appearing to be vulnerable through unsuccessful interactions could result in the person being bullied (DeNigris, *et al.*, 2018; Haruvi-Lamdan, *et al.*, 2020; Humphrey and Hebron, 2015) or abused (Roberts, *et al.*, 2015). A purpose of autistic people camouflaging has been reported to be to avoid bullying (Hull, *et al.* 2017). Increased bullying and interpersonal trauma were found to be risk of developing post-traumatic stress disorder in autistic people (Rumball, *et al.*, 2021). Psychiatric disorders have been associated with adolescent experience of bullying and victimisation (Berney, *et al.*, 2014) affecting identity and self-esteem. Bullying is prevalent among autistic children and associated with various mental health problems (Cappadocia, *et al.*, 2012). Vulnerability could be considered not as a characteristic of autistic people to be pitied, but since all groups are vulnerable at some time, autistic or neurotypical, vulnerability can be construed as equality (Jaarsma and Welin, 2012).

Analysing interactions have a strong impact on making sense of self, comparing oneself to others. Feeling different affects how a person values themselves (Williams, *et al.*, 2019). A few studies have investigated self-concept and self-identity building through social interactions in autistic youth. Cresswell and Cage (2019) used three measures, the Twenty Statements Task (TST), Autism Identity Scale (AIS) and Strengths and Difficulties Questionnaire (SDQ) with 21 male and 3 female participants aged 12-18 and found no

connection between identity and mental health. Whereas Williams *et al.* (2019), through metasynthesis of seventeen qualitative studies with autistic participants aged between 5 – 21 attending mainstream education found a range in how they made sense of themselves, highlighting that mainstream school settings may increase the risk of developing poor mental health through a sense of themselves being different in a negative way.

In respect to adults, Maitland *et al.* (2021) explored self-concept through identification with social groups (n=184, ages 18-67) and suggest that autistic people most strongly socially identify with other autistic people and family. Some participants in the study socially identified with many groups, others with none but the results showed overall autistic people identified with a smaller number of groups than neurotypical people. The autistic people in the study who socially identified with a greater number of groups reported greater symptoms of good mental health (Maitland, *et al.*, 2021) demonstrating the importance of autistic people socially interacting, particularly with autistic peers. These results support Cooper *et al.* (2017) that adopting a positive autistic identity promoted wellbeing. Maitland *et al.* (2021) concluded that, like neurotypical counterparts, autistic adults who feel connected to many groups report a more positive feeling of well-being. This supports findings from Milton and Sims (2016).

Milton and Sims (2016) undertook a small study of what wellbeing and social belonging means to autistic people who contributed to twenty-one issues of Asperger United magazine. The results identified “mental health” as a sub-theme of “societal othering” and a further theme “Living with the consequences of an ‘othered’ identity”. They discuss the opposition between some autistic people finding that gaining an autism diagnosis, pathologising their identity, helped in being accepted by neurotypical people (Milton and Sims, 2016). This suggests neurotypical privilege and the problems relating to being other and not understood by the majority group. Since Dr. Milton is an autistic academic and author of the double empathy problem (Milton, 2012) it could be expected that the interpretation of these magazine contributions would be through a neurodiversity lens. Equally articles published in Asperger United magazine would have a particular stance; rightly, positionality is discussed in their article. In summary, Milton and Sims put forward that the focus of improving wellbeing of autistic individuals should be by reducing social exclusion through acceptance, rather than approaches to develop social skills (Milton & Sims, 2016).

Society’s view therefore of what autism is can affect interactions. The medical view of lifelong impairments that cannot be cured can be internalised and accepted as autistic identity in a way that would be negative. It has been argued that it would be helpful not to just think

of autism in this way but also through a social lens (Belek, 2019). Using a social model to autistic mental health, Cage *et al.* (2018) in their mixed methods study proposed that positively accepting autistic identity could lead to increased self-esteem. A quantitative study of 272 self-identified autistic adults and 267 neurotypical adult controls (Cooper, *et al.*, 2017) applied social identity principles to autistic people to investigate the relationship between autistic social identity and mental health. Social identity being shared characteristics with other groups and autistic identity the concept of self that is developed from personal characteristics. The results provided evidence of lower self-esteem and higher depression and anxiety in the autistic group, demonstrating a relationship between social identity, collective self-esteem and well-being. The benefit of the methodology is that the data was from self-report via a survey and the demographics of each group were similar, however, a disadvantage was that the autistic participants did not necessarily have a diagnosis of autism spectrum disorder. If awaiting a diagnosis that period of unknowingness could also be a variable in relation to identity. Autistic traits have an influence on identity formation (Ratner and Berman, 2015) with increased likelihood of identity distress and existential anxiety. This is endorsed by Mattys, *et al.* (2018) who associated identity, as a social construct, raising depression and anxiety, particularly for those autistic individuals who do not have a learning disability and their disability is hidden (Mattys, *et al.*, 2018). This previously called 'high functioning' group are expected more of by society and not fitting in could have a greater impact. Similarly to the general population, negative self-thoughts are associated with depression in autistic people and self-esteem could be a protective factor against depression (Gotham, *et al.*, 2014).

Van de Crujisen and Boyer (2020) put forward the idea that different self-esteem profiles may be implicated with co-occurring problems. Twenty-five autistic individuals were compared with twenty-four neurotypical individuals, all aged between eight and sixteen with an IQ over eighty. Explicit self-esteem is explained as "*how someone says their self-esteem is after reflecting on it*" (Van de Crujisen and Boyer, 2020 p.349) and implicit self-esteem as an automatic process without reflection. Their results showed no difference in implicit self-esteem between the groups but the autistic youth reported lower explicit self-esteem after they had reflected upon it. Lower explicit self-esteem was related to greater symptoms of depression, lower implicit self-esteem with externalising symptoms (e.g. disruptive behaviour or aggression). Although this is a tentative conclusion due to small sample size and age range it supports findings of McCauley, *et al.* (2019) who had 73 participants, age 9 – 17, IQ >75. McCauley *et al.* (2019) had an additional measure in their study, comparing ToM (Baron-

Cohen, 1995), concluding that autistic youth who were more skilful at recognising the perspectives of others could be more likely to develop low self-esteem with the associated risks of depression. The association between higher theory of mind and lower self-esteem was only found in the autistic group, not the neurotypical control (McCauley, *et al.*, 2019). This could be relevant to this study in answering the question why autistic individuals felt they went on to hospital admission for their mental health.

Botha and Frost (2020) continue the premise of autism as a part of identity. Their small-scale quantitative study of autistic adults without a learning disability used the minority stress model to explore the link between autism and mental ill health. Again, the participants were not required to have an autism diagnosis, self-identifying was sufficient to be eligible. However, the autism diagnosed participants were found to experience higher distress and it was postulated that this was due to the stigma of an Autism Spectrum Disorder (ASD) diagnosis and feeling the need to hide this. Conversely, Tan (2018) found diagnosis resulted in more positive affirmation of self and exoneration for previous misunderstandings, opening opportunities for engaging with autistic communities. This could be because the participants were recruited from autism activism organisations (Tan, 2018) so presumably had accepted their diagnosis. A late diagnosis was also found to be affirming and a relief in Dachez and Ndobbo (2018) qualitative study into coping mechanisms of adults without a learning disability. Hosozawa *et al.* (2021) found a positive relationship between diagnostic age in children and depression and self-harming behaviour that suggests early diagnosis is a protective factor in this group of children without additional learning disability against mental health problems.

George and Stokes (2018) hypothesised that belonging to two minority groups who experience poorer mental health, namely autistic and non-heterosexual or gender dysphoric groups, would additively worsen mental health. This quantitative study compared 261 neurotypical individuals (103 males and 158 females) with 309 autistic individuals (90 males and 219 females). The autistic group are not representative of the wider autistic population where more males than females have an autism diagnosis. The researchers contacted autism organisations and forums to recruit participants online. The female bias could have influenced findings. The results found that adding non-heterosexual minority group did not worsen mental health but adding gender dysphoric traits (GDT) minority group to autism, mental health did worsen (George and Stokes, 2018). This could be relevant to this doctoral research if the addition of GDT with autism compounds mental health adversity.

2.5.5. Lack of reasonable adjustments for communication

It is suggested that autistic pathways to mental health services need to be developed and that autistic people without a learning disability are more prone to risk of mental health problems but less likely to have services available to meet their need (Camm-Crosbie, *et al.*, 2019; Crane, *et al.*, 2019; Hallett and Crompton, 2018.) Jackson *et al.* (2020) used Interpretative Phenomenological Analysis (IPA) to explore parent experience of accessing mental health support for their autistic child. When parents did access support, relationships with professionals broke down as parents did not feel their concerns were validated, they felt the professionals had a lack of understanding of autism and blamed the parent for autistic behaviours (Jackson, *et al.*, 2020). Further research is suggested into understanding why so many autistic children also have a mental health condition. To some extent this research aims to add information to fill this gap by exploring autistic adults' experience of events leading to mental health crisis and inpatient admission.

Nicolaidis *et al.* (2015) qualitative study in the US found healthcare interaction a dominant theme for autistic people accessing services. It is not clear if this relates to physical or mental healthcare services or both. The study suggests that lack of professional knowledge to support communication with autistic people was a factor that restricted access. Autistic people needed more information and time to process language and a good experience would be being provided with the details of the expectations of the appointment by email first. It was how interactions were supported that made the difference. Further supportive reasonable adjustments could be longer therapy sessions to enable the autistic person and therapist to establish a rapport (Jordan, *et al.*, 2020). This research showed autistic people saw their inability to recognise and explain emotions as a barrier to accessing support. Therefore, visual aids to support communication of emotions both inside and outside therapy would be beneficial to meet autistic need (Jordan, *et al.*, 2020).

Brice, *et al.* (2021) also recognised clinician knowledge of autism and communication as an important factor that needs adjustment for autistic people to access mental and physical health services, along with sensory environment and clinical and service context. Their study is based on the foundation that autistic voices are paramount in understanding how to improve their accessing services and it includes an autistic researcher. Of relevance to this doctoral research are the responses to the mental health service survey (n=537 autistic adults) although the study also included a physical health service survey. The majority (69%) were not offered reasonable adjustments and felt that it would have been helpful if they had. Across both mental and physical health services the most important reasonable adjustments

identified by the autistic participants were under the professional's clinical knowledge and communication category. Just over half of the respondents to the mental health survey (51.0%) rated a health summary document (such as a hospital passport explaining their needs) to share with clinicians as 'very important' compared to just under a half (48.8%) for the physical health survey. Respondents to the mental health survey rated higher importance to mental health clinicians using previously provided information than for physical health clinicians in the physical health survey results (Brice, *et al.*, 2021). Difficulties accessing mental health services due to lack of reasonable adjustments could relate to this investigation into autistic perception of reaching a point where mental health inpatient admission was required.

The results of Jordan *et al.* (2020) qualitative study into autistic adults' experience of depression provides further evidence that autistic individuals are encountering difficulties in accessing therapeutic support. Their findings suggest that not only is there not enough mental health support, clinicians not understanding autism sufficiently, fears being dismissed or ignored, and support not being adapted to individual need, but the negative outcomes of the autistic person's experience of these factors (e.g. being misunderstood, experiences not validated, not feeling it possible to be helped) perpetuate their feelings of failure, isolation and hopelessness (Jordan, *et al.*, 2020). Results indicated that participants seemed to have a strong sense that they should be able to manage on their own. They mentioned reluctance to ask for help as not being confident about what experiences could be shared within social boundaries and having a fear of being judged. Withdrawing and trying to be self-reliant again reinforcing the feelings of being alone and isolated (Jordan, *et al.*, 2020).

This section has considered whether the social communication and interaction challenges associated with a diagnosis of autism are a risk factor alone for the development of mental health problems. From the wider literature it is emerging that it is a more complex interplay of the influence of broad social and society neurotypical norms that constitute the risk rather than features of the individual alone. A key tenet of neurodiversity is social acceptance, moving away from just a pathological view of autism to include the social disability model, social identity and minority stress to try to understand what it is to be autistic. It supports the human rights model of disability affording equal rights under the law for disabled people, choice and a right to be heard.

2.5.6. Restricted, repetitive patterns of behaviour and interests

In addition to social interaction and social communication challenges, rigid thinking and lack of flexibility of thought is the other core diagnostic criteria for autism. (DSM5, 2013). It is

thought that autistic individuals find change more stressful than neurotypical individuals (Gomot and Wicker, 2012) and have intolerance of uncertainty. Intolerance of uncertainty has been linked to increased internalising and raised anxiety in both autistic children (Ozsivadjian, *et al.*, 2020.) and autistic adults (Hwang, *et al.*, 2020; Robertson, *et al.*, 2018).

Perseverative thinking can worsen symptoms of mental ill health (Rumball, *et al.*, 2021). Rumination is indicated as unhelpful in managing negative thoughts and emotions and has been associated with the autistic trait of insistence on sameness in a sample (n=50) of autistic adolescents and adults (Gotham, *et al.*, 2014). It is suggested that rigid thinking could increase a sense of entrapment that is a predictor of suicide (Richards, *et al.*, 2019). Nevertheless, special interests can be a positive and these have been identified as a coping mechanism (Jordan, *et al.*, 2020) as well as a source of pride that their knowledge in the special interest exceeds that of others (Teti, *et al.* 2016). Matching interests to a career can result in employment success and a sense of fulfilment (DePape and Lindsay, 2016).

It is proposed that the autistic rigidity of reading unpredictable future events by using unrelated information that is not likely to repeat in other circumstances, can affect cognitive-emotional conflict control (Schreiter and Beste, 2020). This small study (n=47) of predominately male subjects aged 13 to 18 indicated that neurotypical controls used flexible emotional processing whereas the autistic adolescents relied on more inflexible cognitive learning to manage emotional control and conflict resolution. As emotional regulation is necessary for mental health this lack of flexible emotional processing will negatively affect the ability to regulate (Galderisi, *et al.*, 2015). Cognitive inflexibility is a mechanism that significantly predicts externalising behaviours such as autistic aggression (Ozsivadjian, *et al.*, 2020). Aggressive behaviour has also been linked to sensory differences (Van den Boogert *et al.*, 2021) which will be considered next.

2.5.7. Sensory sensitivities

Sensory processing and perception appear to be a common thread between autistic experience and mental health conditions (Harrison, *et al.*, 2019).

2.5.7.1 Exteroception

Sensory sensitivities have a long history with being connected with autism (Kanner, 1944) but it wasn't until 2013 that they were incorporated into the diagnostic criteria for ASD (DSM 5, 2013). It has been suggested that co-morbid anxiety in autistic adults is connected to sensory over-responsiveness (Amos, *et al.*, 2019). From this it would seem reasonable to conclude that access to sensory neutral environments could be a protective factor. Research

by Syu *et al.* (2020) found sensory sensitivity and avoidance was significantly correlated to behaviours that challenge in young adults, and this was mediated by anxiety. Recognising the association between increased behaviour that challenges and sensory over responsivity outside the neurotypical repertoire has implications for how that behaviour is responded to. Rather than a behavioural intervention, reasonable adjustments relating to the environment could be considered to support the individual and validate their experiences. Strategies for autistic individuals to promote self-regulation could also be useful instead of expecting acclimatisation to the neurotypical world. Involuntary admissions to a mental health hospital are to prevent negative behavioural outcomes such as aggression and violence towards self and to others Smith *et al.* (2020). Aggressive behaviour is associated with sensory differences (Syu, *et al.*, 2020; Van den Boogert, *et al.*, 2021) and cognitive inflexibility (Ozsivadjian, *et al.* 2020) highlighting the interconnectivity between many factors that may lead to the autistic person being admitted as an inpatient.

Results from these quantitative studies endorse findings from a study to gain autistic perspective of sensory experience (Robledo, *et al.*, 2012) that used interview as well as additional artefacts such as diaries, photos, poems and drawings to provide in depth qualitative insights into the lives of five participants. One participant described how some sounds made her feel angry, aggressive, and out of control which lasted much longer than the sound itself, evidence of association between sensory difference and behaviours that challenge. The data illustrated that sensory differences are not the same for all autistic people nor for the same autistic person all the time (Robledo, *et al.*, 2012). The study concludes that more in depth qualitative research would be sensible to illicit perceptions of individuals on their autistic experience to raise knowledge of its complexity and diversity. This requires listening to their story rather than judging from preconceived neurotypical notions.

Recognising the connection between sensory processing differences and aggressive behaviour in autistic individuals (Syu, *et al.*, 2020; Van den Boogert, *et al.*, 2021) is important when considering that criteria for detention under the Mental Health Act includes protection of the individual's safety or the safety of others, which could be due to aggressive behaviour. A medical assessment when detained in hospital for diagnosis of an underlying mental health condition is appropriate but the cause of aggression may not be pathological. Assessment of atypical sensory sensitivities would also be needed (Elwin, *et al.*, 2017) to inform support planning and interventions. The ideal would be that sensory needs are recognised promptly in life and strategies are offered as early intervention to prevent a build up to crisis (Clare, *et al.*, 2020).

2.5.7.2 Interoception

So far the discussion has focussed on exteroception, processing of sensory input from outside the body. Interoception, processing sensations from within the body, could also be interpreted differently by autistic individuals (Quadt, *et al.*, 2018). As well as autism, interoceptive impairments have been associated with anxiety, depression, disordered eating, borderline personality disorder and social connection (Quadt, *et al.*, 2018).

Recognising your emotions is not just linked to an external situation but recognising your body's internal response to that situation. This is linked to culture in that many mental states are socially constructed influencing how the feeling is interpreted, e.g. Asian individuals may be likely to experience physiological symptoms as an illness (somatic) whereas Americans as emotions (Feldman, *et al.*, 2024). If interoception is impaired it follows that recognising emotions may be affected. Alexithymia is the difficulty in distinguishing emotions through internal body sensations and is associated with interoception. As is the case with anxiety in autistic people, a high number of autistic people also have co-occurring alexithymia (Bird and Cook, 2013). It has been suggested that difficulties with emotion processing in autistic individuals could be a result of impaired interoceptive processing (Garfinkel, *et al.* 2016). Conversely, Shah *et al.* (2016) quantitative study found it was alexithymia not autism associated with impaired interoception. This suggests that reduced interoception ability in autism is simply because there are a high proportion of individuals with alexithymia in the autistic population (Shah, *et al.*, 2016). Alexithymia and autism are distinct from one another but alexithymia may elevate anxiety and depression in autism because of its link with emotional regulation (Morie, *et al.*, 2019). Difficulties with emotional regulation are associated with lower emotional intelligence that can lead to mood disorder. Lack of emotional insight and cognitive inflexibility could also affect processing of stressful incidents leading to trauma and Post Traumatic Stress Disorder (Rumball, 2019).

2.5.8. Trauma

Traumatic life events are associated with development of mental ill health in the general population and can lead to anxiety and depression and post-traumatic stress disorder (Rumball, *et al.*, 2021). Research indicates that autistic children and adolescents are vulnerable to experiencing more stressful and traumatic events (Kerns, *et al.*, 2015; Peterson, *et al.*, 2019). It is theorised that this could be due to the autistic traits described by the diagnostic criteria (APA, 2013) considered earlier in this chapter. For example, negative interactions experienced by the autistic individual due to difficulty with communication or adverse sensory experiences due to differences in sensory processing (Kerns, *et al.*, 2015).

Additionally, autistic children and young people may be more vulnerable to abuse and maltreatment. This maltreatment could be bullying, (Rumball, *et al.*, 2021; Cappadocia, *et al.*, 2012) as previously described, but also sexual abuse. Results of Gotby *et al.* (2018) study of 18-year-old Swedish twins (n=4500), showed autistic girls were three time more likely to experience sexual victimisation than their non-autistic peers.

In the UK, Rumball *et al.* (2021) compared rates of trauma between individuals with a self-reported autism diagnosis (n=38) aged 18 and over and non-autistic adults (n=44), results showed autistic people experienced increased trauma. The autistic group were of a slightly older age range, 18 years to 68, compared to 19 years to 57 in the non-autistic group, a greater age perhaps giving more time for repeated trauma to occur. However, the results not only showed increased trauma incidences but also that cumulative trauma exposure in the autistic group increased the likelihood of developing Post Traumatic Stress Disorder (PTSD) over the lifetime. This association was not found in the control group (Rumball, *et al.*, 2021). Similarly, Haruvi-Lamdan *et al.* (2020) found 32% of their autistic study participants (n=25) demonstrated possible PTSD, compared to 4% in the typical adult group (n=25) indicating a significantly higher risk of developing PTSD in the autistic population. This study also illustrated that autistic females were more vulnerable than autistic males and the general population to experiencing traumatic events and PTSD due to increased rumination and re-experiencing of the trauma (Haruvi-Lamdan, *et al.*, 2020).

Autistic children may be significantly less likely to report traumatic events (Hoch and Youssef, 2020) but recognising re-experiencing PTSD symptoms by professionals is more likely in individuals with an autism diagnosis when trauma is known (Kildahl, *et al.*, 2020). An autistic person's responses to trauma may be attributed to autistic traits if exposure to trauma has not been accounted for, consequently PTSD in the autistic population may be under-diagnosed. Knowing that an autistic individual has experienced trauma should trigger appropriate trauma informed practice (Reuben, *et al.*, 2021). Berger *et al.*, (2021) undertook a narrative review of trauma informed care models and autism interventions in schools. They concluded that a combined approach improved student emotional regulation, relationships and communication.

The need for trauma informed care in services that support autistic people is recognised in the Core Capabilities framework for supporting autistic people (Department of Health and Social Care, 2019). The literature provides increasing evidence that autistic children and adults are more vulnerable to PTSD (Haruvi-Lamdan *et al.*, 2020; Rumball, *et al.*, 2021) but diagnostic overshadowing, as with other psychiatric disorders, makes it difficult to diagnose. In addition

to confusion with autistic traits, symptoms could be put down to anxiety or depression (Rumball, *et al.*, 2021) with psychosocial needs relating to autism not addressed (Au-Yeung *et al.*, 2019). Childhood trauma is associated with negative outcomes and is a predictor for psychiatric illness (Kerns, *et al.*, 2015) so it is critical that trauma is not overlooked when supporting autistic individuals.

2.5.9. Lack of Support

Despite the literature, and data, showing that autistic people have a high incidence of mental ill health, autistic adults with mental health needs can often be excluded from mental health services due to lack of eligibility and lack of professional's understanding of autism (Camm-Crosbie *et al.*, 2019).

The report into Assessment and Treatment Unit (ATU) model (Clare, *et al.*, 2020) referring to UK transforming care group of adults and children with a learning disability and/or autism, find a theme of lack of support. The report suggests that the reason that children, young people and adults in their research were ending up in ATUs and as inpatients was because this crisis level response was the “first resort”. Neither planning nor support was available for transitions and life events in the community and parents were left without interventions to cope with challenging behaviour, all resulting in crisis rather than prevention support being provided. Family interventions could be useful as young autistic adults have identified a reason that they were unable to access support for depression was due to family not taking them seriously (Zheng, *et al.*, 2021). Involvement of family is also strongly highlighted in the Care Act 2014 guidance as updated 21st April 2021 to be considered in respect of wellbeing and family relationships.

2.6. Conclusion

This chapter has considered theories on associations between mental health and autistic traits from the literature with quantitative studies exploring risk factors to hospitalisation, although these mainly refer to children and adolescents (Mandell, 2008; Righi, *et al.*, 2018). The literature relating to prevalence of mental health conditions being associated to autistic traits, development of early maladaptive schemas, trauma and diagnostic overlap of symptomology have also been discussed. Results have varied which may be explained by the heterogeneity of autism or differences in methodology. Multiple reasons for autistic people to be disproportionately susceptible to mental ill health and admitted to mental health wards have been posited. These have ranged from autism being a risk factor for psychiatric disorders, lack of support, and inadequate national data. What has become evident is that there are

multiple factors associated with developing mental ill health in the autistic population, not just due to traits of the autistic person themselves but the culture of the community, school and workplace, knowledge of autism and societal attitudes. To develop understanding of why a disproportionate number of autistic people do find themselves on mental health inpatient wards a broad view of their life experiences will need to be taken.

The usefulness of life course study was suggested by Shattuck *et al.* (2020) to understand the interconnectedness of health, social and environmental factors alongside access and availability of differing services as needs change over time. What has not been evident from the literature review is first account stories of the autistic journey to mental health hospital admission. The aim of this doctoral research is to hear the stories of lived experience to mental health hospital admission, perceived risk and protective factors directly from autistic individuals, rather than relying on notes or data, to contribute to developing this understanding. Building on Mitchell *et al.* (2021) transactional model suggesting a link between autistic people being misunderstood in the neurotypical focussed world and their mental health, autistic life stories could provide further information from the individuals' perception of how outcomes could be determined through interactions between features of the self and the social environment.

The next chapter describes the methodology to gain a life course perspective of autistic individuals with the aim of gaining a holistic, person centric perspective that can contribute to the understanding of why crisis is experienced disproportionately by the autistic population in England. The intention being to gain a picture of where those with lived experience feel support would have been helpful to inform guidance on what could be taken into practice as early intervention to avoid hospital admission.

Chapter 3. Methodology

3.1. Introduction

This chapter starts by disclosing who I am as a researcher through my positionality and where my methodology is located in terms of ontology and epistemology. After explaining the rationale for the qualitative approach using Interpretative Phenomenological Analysis (IPA) to answer the research questions it moves on to how the research was undertaken, ethical issues, introduction of participants and suggested impact.

3.2. Positionality

Having been involved with autistic children as a teacher and being an ally for the local all age autistic community for many years I view autism through the social model of disability, that autistic people are disadvantaged through society rather than the autistic person being impaired and needing treatment. Considering autism through a human rights model of disability encapsulates values that are important to me, upholding equity under the law for all and equal respect for who the person is conceptualises fairness. As a practitioner researcher my current role within the local mental health NHS Trust sits in the Transforming Care Team which focusses on hospital avoidance and facilitating hospital discharge for autistic people and people with a learning disability. My perspective is from a white woman, with a professional background and educational privilege. I do not have an autism diagnosis myself, although have an autistic grandchild and stepdaughter who was diagnosed recently as an adult.

All the final participants came forward from a local Autism Advisory Panel (AAP). The AAP is an integral part of the Autism Champion Network (ACN) providing the autistic voice within a non-hierarchical group of cross organisational ‘Autism Champions’ dedicated to improving experiences for autistic people (Kirby and Payne, 2023). As part of my professional role as Autism Assurance Lead, I facilitate the ACN so all the participants were familiar to me, and I to them. Facilitation involves preparing agendas and speakers for meetings with dates and times ensuring this information is received by members in good time, keeping a list of members and checking in via email if I haven’t heard from them for a while. At online meetings aiming to create a kind, safe space where people can say what they want to say without fear of judgement, communicating either verbally, in the chat, text to speak or through emailing me, and guide the session along. After meetings I send out notes and slides from speakers with the monthly newsletter. In between meetings I am the conduit to share questions that come in for the group from members, acting as a gatekeeper to prevent

AAP members being inundated with individual emails at their request. Additionally, I accept apologies, answer questions directed to me and receive information sent in from members to compile into our newsletter. The relationships developed from this was kept at the forefront of reflections throughout to mitigate the risk of any pre-conceived suppositions about the individuals being interviewed. The benefit of knowing the individuals as members of the county AAP was that we already had a trusting relationship and participants seemed to genuinely want to share their experiences and be heard. Not knowing the researcher and their values has been described as a possible deterrent to autistic people taking part (Gowen, *et al.*, 2020). Due to the already established trusting relationship I knew that AAP members would be able to say “no” to me and feel confident to ask questions using their preferred means of communication so if they decided to participate it would be in a fully informed way. I trusted them not to feel obliged to take part if they were eligible and they trusted me that I wouldn’t want them to take part if they didn’t want to, so wouldn’t pressure them. Furthermore, I trusted them to tell the truth and they trusted that I would believe their stories and want to hear them.

3.3. Rationale

Autism, from a neurodiversity perspective, is described as a difference (Chapman, 2021; Kapp, *et al.*, 2013; Manalili, *et al.*, 2023), autistic people experience the world differently (APA DSM5, 2013) from people who are not autistic (Pellicano and Burr, 2012), therefore we are in the realm of more than one reality so a positivist approach in trying to understand autistic experiences would not seem relevant. This study takes the interpretative stance that reality is created by your own mind depending on your experiences and intersectionality (Botha and Gillespie-Lynch, 2022). Humans are organic, they change, grow, and adapt, so a flexible and reflective approach is relevant in developing understanding of how different autistic people have interpreted their experiences towards mental health hospital admission. It intentionally concentrates entirely on autistic interpretation; traditionally the majority of research to inform clinical practice and developments has focussed on non-autistic, professional opinion. This has come under criticism from autistic individuals as not providing a true reflection of issues experienced (Milton and Bracher, 2013).

The qualitative research design uses IPA, (Smith, *et al.*, 2022) during data collection and for analysis. This approach allows reflection on the significant experience of participants’ admission to a mental health ward, how they interpreted meaning relating to this, not just through consideration of immediate events leading up to it but a life history build-up of layers of previous experiences. IPA was felt more appropriate than thematic analysis because

it is concerned with interpreting how the participant has made sense of their experiences using a dynamic process (Smith, *et al.*, 2022). This study takes the double hermeneutic process a stage further, the autistic person is trying to make sense of their experiences and I, as a neurotypical interviewer, am trying to make sense of them making sense of their experiences, then I go back to the interviewee after analysis to check my interpretation matches what they intended. This provides a check for trustworthiness to counteract the autistic, neurotypical communication divide, i.e., the double empathy problem (Milton, 2012) and ensures a shared agreement of the interpretation. A risk of using thematic analysis could be that my neurotypical interpretation of the autistic experience may not counter the double empathy problem and thus be less reliable. Since the impact of the research should be to inform development of services to prevent autistic people going into mental health crisis it is important those who develop services understand the autistic perception of what autistic people need, not another neurotypical interpretation.

The research design was inspired by oral history methodology which is described by Janesick (2014) as an accessible approach to collecting data about issues of social injustice from marginalised voices, thus a good fit with the theoretical underpinning of the research to the human rights model of disability. Concerns, however, have been raised in the literature about autistic people being less able to elicit meaning from autobiographical memories, (Crane, *et al.*, 2010) and providing narratives with less detail and coherence than neurotypical counterparts (McCabe, *et al.*, 2012), therefore an oral history approach could be thought to be less powerful with autistic people. However, as Maras *et al.* (2020) describe, by structuring the telling of the story by separating it into smaller topic sections, executive function is supported and the autistic individual, and non-autistic individuals, give a more complete and detailed response. In Maras' "witness-aimed first account" for police interviews it is the witness that suggests the topic sections for the whole account (Maras, *et al.*, 2020) whereas in my proposed research design the participants would not. Pellicano *et al.* (2020) use a disability oral history methodology successfully to understand the experiences of late diagnosed adults (n=24), they undertook a series of interviews with a participatory approach using reflexive thematic analysis to analyse the interview data (Pellicano, *et al.*, 2020). Another advantage of the oral history approach is photographs and other artefacts can be used to help tell the story, this seemed particularly helpful for autistic participants with communication differences. Non-traditional research methods were explored whilst considering the final research design. Ultimately the research needed to fit time parameters and thesis requirements, with this in mind it was decided to interview a minimum of three

autistic participants who had experienced mental health hospital admission, offering the use of their own chosen artefacts to help communicate meaning. The small number of participants lent itself to IPA as the interpretative process. The interview schedule itself compartmentalised the story into sections, following the life course, rather than participants being supported to section their own narrative. The schedule provided a scaffold for the guided conversation to illicit rich data, with the option of flexibility if required for individual circumstances. Each participant would be interviewed once; the transcript checked with them and the analysis with personal experiential themes discussed with each individual to check validity.

3.4. Ethics

A great deal of thought went into ensuring participants were not distressed or suffered emotional ill effects from taking part in the study. Whilst highly valuing lived experience and wanting understanding to be shared to co-create knowledge it is recognised that the participants may be vulnerable to mental ill health having previously been inpatients. To check that it was the right time for individuals to take part without harm, a readiness guide (Appendix 1) was created, informed by and adapted from Autistica's readiness document and checked for accessibility by an autistic member of the local community. As well as potential mental health vulnerability, there may also be vulnerability regarding autism specific factors such as communication differences. The double empathy problem (Milton, 2012) may create a barrier to participants developing understanding of the intended information about the research, forming a concern that their agreement to participate may not be fully informed. This risk was mitigated against by co-designing the information sheet, consent form and debrief sheet with an autistic person (Appendix 2, Appendix 3, Appendix 4) also checking understanding with participants at an informal interview pre-meet as well as before the actual interview. Further reasonable adjustments to ensure the autistic interviewees were comfortable throughout their participation are described under 'Procedure' below. Ethical approval was obtained from the University of Northampton Research Ethics Committee (ETH2021-0127).

3.5. Procedure

3.5.1. Context

This research commenced November 2021 when ethical approval was granted. At this time the UK Government had moved from legislation to restrict contact by lockdown to protect the population from the COVID pandemic to offering advice and guidance as the country settled back into economic and social recovery (DHSC, 2021). The previous year, at the start

of the pandemic many groups stopped meeting and disruptions were of concern to the wellbeing of autistic people (Pellicano, *et al.*, 2020). Pellicano, *et al.* (2020) reported that a positive from COVID for autistic people was that the way services were accessed changed and video calls improved accessibility. Their study did, however, highlight the importance of social contact and maintaining friendships. Recognising the importance of this the ACN transferred to being an online community. After missing two monthly meetings (April and May 2020), meetings transferred to online and continued monthly due to the importance of maintaining relationships for AAP members. This meant that contact with the AAP was not substantially interrupted and thus COVID appeared not to impact on recruiting from the group nor impact on members participating in online interviews. It could be that recruitment might have been different without the shift to online platforms but since relationships were already established before this change there seemed no problem with participants coming forward indicating their interest in the study. Enough eligible participants were quickly recruited. There was a commitment to participant wellbeing throughout the study starting with the Readiness Guide (Appendix 1) to check that the participant was in the right place to take part in the study emotionally and mentally. Although this did not mention COVID specifically it took participants by the hand to lead them through thinking about why they wanted to take part, their support network and whether they recognised any of their own triggers which would naturally include wellbeing associated to COVID. They were encouraged to go through the document with a family member or friend or myself, whoever they felt most comfortable with, attesting to the need for trusting relationships to work things out together. The intention, specified in the ethical application, was that the interviews would take place online to enable the participant to have more control of their sensory needs in their familiar environment although they were encouraged to ask about the research using their preferred means of communication such as email, video call, phone, text or email. Conducting the interviews online had the additional benefit of protecting against a risk of transmission of COVID, it also meant face masks need not be worn. Professional experience led me to believe that wearing face masks would provide increased complexity of issues for autistic people from sensitivity to the feel of them to difficulty with communication as the mouth region is covered but as a protection against smell sensitivity being a positive. Since then research has increased understanding of the autistic experience of face masks (Clegg, *et al.*, 2024) indicating different opinions. However, it has confirmed that some autistic people found the wearing of face masks had a negative impact on their understanding of others and of them being understood in an interaction. 51.02% of respondents from the Clegg, *et al.* study (2024) experienced this and Baxter, *et al.* (2024) findings agree that autistic people

experienced greater interference in social interaction due to masks. This provides evidence of a further advantage of conducting the interviews online in the period of COVID recovery. The wrap around nature of ensuring wellbeing of participants, whether COVID related or not, also extended to the de-brief after the interview (Appendix 4) which included signposting to support if they felt distressed after talking about their experiences. It also informed about when they would be contacted again to talk through themes drawn from their story following the premise that communication and a feeling of inclusion is important throughout the research process to avoid any anxiety (Chapter 6, Recommendations).

3.5.2. Recruitment

In accordance with IPA practice (Smith, *et al.*, 2022) a small number of participants were sought with the aim of acquiring rich, in-depth data from each individual to answer the research questions. The plan was to seek three participants from the local Autism Advisory Panel (AAP), if not enough eligible participants came forward to recruit further through Autistica. It was also planned to recruit further participants if, after the three interviews, the data obtained was not substantial enough. The adult autistic members of the AAP had previously been consulted on the proposed research aims and confirmed that these were questions relating to an issue that was important to autistic people which needed answering from the autistic perspective to inform and create understanding for those who develop services. This corresponds with the messages from the Lancet Commission (Lord, *et al.*, 2022) on the need to tackle real life needs of autistic people through developing understanding of their lives and the factors that enable positive outcomes. This document suggests that negative outcomes may be socially induced and that community mental health systems may not meet the needs autistic people with mental health problems, both of which have the possibility of being elucidated in this study.

From the initial conversation with the AAP, an autistic individual who met the eligibility criteria was asked to be consulted on the research design, documents and take part in the pilot interview. After this they asked that their story be included in the study which was agreed so as not to lose their powerful data.

Autism, historically, has been connected with males, from initial recognition (Kanner, 1944; Asperger, 1994) to the extreme male brain theory (Baron-Cohen, 2002) but of the participants who came forward for this study only one was male. Another potential male participant was ineligible because he was admitted to a physical health hospital after a suicide attempt. Whether this reflects society view of expectations for males is beyond the scope of this study.

This predominantly female sample may reflect the findings of So *et al.* (2021) that reports an increase in use of psychiatric emergency services by autistic adolescents was greater for girls than boys. They found autistic girls had a higher suicide risk and greater incidence of anxiety disorders than boys, although boys had experienced mental health problems for longer (So, *et al.*, 2021). Martini *et al.* (2022) also found autistic females were at higher risk of psychiatric disorders and hospitalisation than males (Martini, *et al.*, 2022). Interestingly, studies have found that autistic women present more favourably than autistic men in first impressions with non-autistic people, although that may change when a diagnosis is known (Belcher, *et al.*, 2021). It is suggested that this is due to females being adept at masking autistic traits (Pearson and Rose, 2021) but masking takes its toll and forms an independent risk for suicide (Cassidy, *et al.*, 2018) as well as resulting in later diagnosis (Belcher, *et al.*, 2021). Therefore, a predominantly female sample can be justified.

Figure 3 Eligibility Criteria

What do I need in order to be in the study?

You can be in this study if

- You are at least 18 years old
- You have proof of a diagnosis of autism spectrum disorder or Asperger's Syndrome
- You have previous experience of admission to hospital for mental health needs
- You do not have a learning disability
- You are not currently experiencing mental health crisis
- You are not sectioned under the Mental Health Act

An email (Appendix 5) was sent to AAP members explaining the study and eligibility criteria (described in Figure 3) including the information sheet (Appendix 2) and readiness guide (Appendix 1) and participant interview sheet (Appendix 6) asking if anyone may be interested in taking part. Seven people came forward and their eligibility checked. Three potential participants were ineligible, one because she was the mother of an autistic son who had experienced mental health hospital admission rather than having the lived experience herself another because, although she had been admitted to the Crisis House, actual hospital admission had been avoided. The third because he had been admitted to a physical health hospital after an overdose and was not admitted to a mental health hospital.

The final four were sent the consent form (Appendix 3) and demographic questionnaire (Appendix 7) to complete and return. A pre-interview meet was arranged to check readiness, informed consent and to familiarisation with the Collaborate platform which would be used

for the interview. I spoke with one of the four at length as I was not sure they were ready to tell their story, they persuaded me otherwise and after their interview they said they had found it positive to be able to have their experiences listened to and to reflect on them themselves. This, with the pilot, provided five participants. There were no problems with recruitment, rather autistic people who had experienced mental health admission were keen to tell their story and hoped that by sharing it would improve experiences for others. A factor in the willingness to participate could be that I was a familiar person to the group (Gowen, *et al.*, 2020). When satisfied that all understood the purpose and expectations of being a participant, interviews were booked in on the online Collaborate platform.

3.5.3. Interview

It was agreed with participants that interviews would be held online enabling them to have more control of their sensory needs in their familiar environment. The online platform used was Collaborate, in line with the University of Northampton research policy and interviews were recorded via this platform.

A loosely semi-structured interview was used to gather data and the interview schedule was developed in consultation with an autistic volunteer to ensure accessibility. The questions followed a life history timeline, rooted at the start with where they were born. In the interviews the question order was not necessarily implemented verbatim throughout, but flexibly to follow the nuances of the individual's story. Participants were invited to use artefacts to help support them in getting their meaning across if they wished, communication support enables inclusion in research of minority autistic groups (Cascio, *et al.*, 2021). Photos of these artefacts are included in this thesis; this is appropriate as it demonstrates increased accessibility for autistic need since it is autistic members of society that this study hopes to benefit.

All interviews were held individually online and lasted between 1 hour 49 minutes and 3 hours 53 minutes, with a total of 14 hours 45 minutes of recorded interview time across the five participants. Each interview was transcribed verbatim. The participant interview sheet (Appendix 6) was sent to each participant in advance which, as well as the questions that were going to be asked, described what would happen at the interview, advising that they could have someone with them if they wished, to use their own sensory strategies during the interview, could take a break at any time and not answer any questions they didn't want to. No participant brought anyone with them and a need to take a break was checked throughout the interviews. One participant sent in the notes they had made in preparation for the interview to me, others just used their notes personally in the interview. Before each

interview started informed consent and readiness was re-checked referring to the readiness guide (Appendix 1)

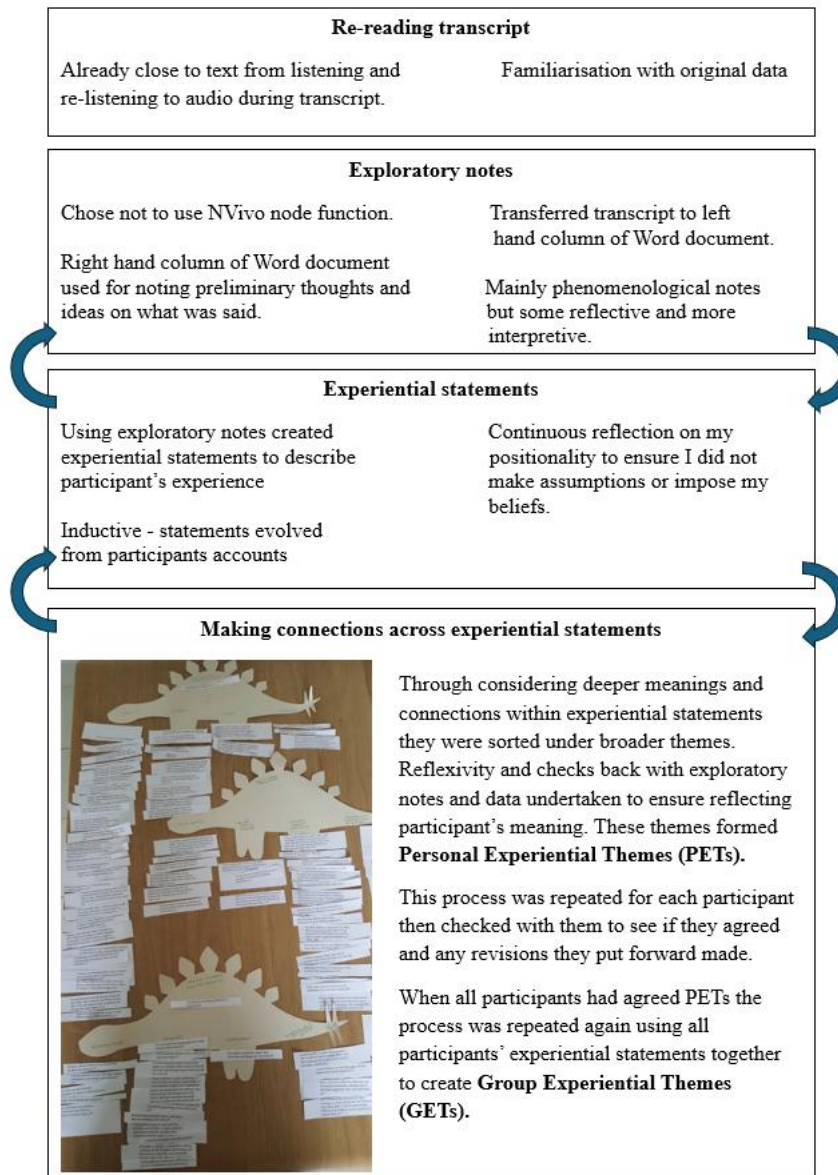
After each interview the de-brief sheet (Appendix 4) was gone through with the participant and wellbeing checked with a reminder of contacts listed on the readiness guide (Appendix 1) if they found it upsetting to talk about their experiences. The de-brief sheet was then emailed to the participant for them to refer to.

When the interview had been transcribed it was password protected and emailed to the participant. Participants were asked to respond within seven days of receipt if they would like anything changing or wanted to withdraw part or all of what they had said. Four out of the five participants confirmed that they were happy with the transcript. The fifth participant still did not reply after a reminder email and it seemed reasonable to take this as they didn't object so all five transcripts were analysed.

3.5.4. Analysis

Complexity of analysis arose from the detailed, iterative nature of constantly moving back and forth through the data analysis stages to build and refine meaning (Figure 4). The phenomenological nature of IPA demands that the participant's meaning making from their experiences is paramount and the iterative process ensures remaining close to original words. To achieve this the hermeneutic principle of the IPA approach involves checking assumptions are not being made by interpretation of what has been said from the researcher's world view of what is heard. This is to avoid straying from the first-hand interpretation whilst developing deeper meaning and thus creating a double hermeneutic which Howard *et al.* (2019) suggest may alleviate the double empathy problem (Milton, 2012). For this study a further third stage was included with the researcher's interpretation being checked by the participant with meaning further refined. As Figure 4 shows, the exploratory notes and experiential statements drawn from each interview are used to create personal experiential themes for each individual. This ideographic approach, focussing on each person at a time, makes it particularly appropriate for research with autistic participants as they are all unique. It is also relevant to the human rights model of disability as it can equally amplify minority and marginalised voices.

Figure 4 Analysis process



Each interview was analysed separately with the transcript copied into the left-hand column of a page numbered word document and 'exploratory comments' (Smith, *et al.*, 2022) added against the relevant part in the right-hand column. The exploratory comments recorded descriptive and language notes as well as immediate thoughts on issues that seem important to the interviewee and how they viewed those.

For each transcript a conscious effort was made to keep the interpretation separate and not be influenced or reflect on previous analysis of other participants experiences. After making the exploratory comments these were used to form 'experiential statements' (Smith, *et al.*, 2022). Each experiential statement was labelled with the page number that it arose from on the original document. When completed all experiential statements were cut out and moved

around in different ways to fit together those with connections. During this process the whole story was also reflected back upon, as well as the research questions that needed answering, to inform the different ways to group. When satisfied with the groupings they were named to describe their characteristics under ‘personal experiential themes’ (PETs) (Smith, *et al.*, 2022) that reflect that participant’s story. These were all brought together to form a table of personal experiential themes for each participant that stayed very close to the interviewee’s own words. The intention being that the autistic voice is clear throughout as they are in the best position to explain their experiences (Catala, *et al.*, 2021). Keeping close to the original words included close analytic reflection to make sure any underlying meaning was not missed whilst maintaining transparency (Nizza, *et al.*, 2021). The expectation of autistic communication to be direct and in an effort to not lose this in translation (Milton, 2014), as well as the use of images, provided reassurance for the interpretive claims. In addition, these results were shared with the participants to check that this interpretation matched their interpretation of their experiences. Four out of the five participants accepted the invitation to talk through their personal experiential themes; they all agreed and generally reinforced the themes with very minor alteration. This gave confidence that the fifth interpretation would also be acceptable.

The next step was to look for shared experiences across all five stories to create ‘group experiential themes’ (GETs) (Smith, *et al.*, 2022). Each story is unique and the intention was not to lessen the importance of individual personal experiences but to look for any similarities. Each participant’s PETs with the experiential statements they were built from were colour coded and cut out separately. These were again moved into groups of shared features and re-sorted in different ways to create a pattern of themes. Each section was checked to see how many participants experienced that GET, some were experienced by all, some not. The ones experienced by all were construed to be the strongest. All the group experiential themes were brought together under risk factors for deterioration of mental health that could lead to mental hospital admission and protective factors against deterioration of mental health (Appendix 8, Appendix 9), with quotes from the various participants to substantiate each.

3.6. Participants

All participants were white British, four out of five university educated and all diagnosed as adults. Two participants were students, two in part time employment and one was employed but COVID had changed the workplace significantly and put their employment at risk.

Intersectionality must be taken into consideration when answering the research questions, (Cascio, *et al.*, 2021). Autism cannot be isolated from the person any more than you can isolate or ignore gender (Moore, *et al.*, 2022), ethnicity and background, (Botha and Gillespie-Lynch, 2022; Montiel-Nava, *et al.*, 2023) this all makes up the person's lived experience and influences their personal creation of meaning from events. This is why the interview questions cover a life course time scale. Table 3 illustrates the demographic of the interviewees.

ID	Gender Identity	Ethnic Group	Highest Education Level	Work	Income (pounds sterling) p/a	Accommodation	Household	Faith	Age (years) at Interview	Age at Autism Diagnosis
221	Trans	White: British	College / University	Part time paid employment and volunteer unpaid work	£20,001 – 30,000	Rent from private landlord.	Live alone	No religion	37	27 & 34
222	Female	White: British	College / University	student	Rather not say	Rent from council	Live alone	No religion	26	25 (private diagnosis)
223	Female	White: British	College / University	Student. Not in paid work	Under £10,000	Supported living	Live alone	No religion	29	26
224	Male						Live alone			
225	Female	White: British	College / University	Part time paid employment	£20,001 – 30,000	Rather not say	Spouse/ partner and children	Christian	39	34

Table 3 Interview characteristics

3.7. Meet the Participants

As well as a demographics table (Table 3) an introduction to each autistic participant follows to give more of an insight into who they are. This is important for interpreting their stories at a deeper level. To protect their anonymity pseudonyms are used.

3.7.1. Introducing Ashleigh

As a child Ashleigh knew they were different from an early age, this wasn't accepted by their parents who wanted them to conform to be a typical child and ignored any suggestion of autism as they were anti-label. Ashleigh had a lot of sensory pain that was not believed. As they matured they realised they were queer, an added difference, and since it was the time of section 28 nobody could say it was acceptable to be them. Ashleigh was bullied at school, which was not a safe place for them, they were good academically but their way of working

didn't fit the marking scheme. University was their goal when they would come out and be them, but this turned out to be the time when they first made a serious attempt on their life. They got married but their wife caused added pressure and their divorce, along with difficulties at work, resulted in their first voluntary hospital admission, and an autism diagnosis. The autism team supported and there was provision of the reasonable adjustment of a tent in their room but apart from that there were no other reasonable adjustments nor understanding from the ward staff of them being autistic or of their behaviour and needs. The autism team intervened when the ward wanted to section Ashleigh after an incident but after that they were no longer involved. Subsequently the autism diagnosis was taken away and changed to borderline personality disorder. Ashleigh felt that the behaviourist approaches and medication were not helping and discharged themselves. After having everything done for them in hospital to having to do everything for themselves after discharge they didn't cope, resulting in multiple visits to Accident and Emergency after self-harm and suicide attempts and subsequently a further admission. Psychiatric medication was prescribed, Ashleigh explained to staff their feelings of dissociation from reality and fear that their urge to die was getting stronger particularly the idea of achieving this through smoke inhalation. Ultimately this resulted in a suicide attempt that put others at significant risk and a prison sentence. After a couple of months in prison, Ashleigh was transferred to a medium secure hospital under section 37. They were later re-diagnosed as autistic.

3.7.2. Introducing Rosie

Rosie lived with both her parents and her older sister until she was eleven when her Dad left overnight and her parents divorced. Her Mum concentrated on work and Rosie was left to look after her sister who developed an eating disorder which disrupted Rosie's schooling and damaged their sibling relationship. They chose not to keep in contact with their Dad after initial attempts. Rosie hated school and felt an outcast, as an adult learnt that autism had been suggested at junior school but her parents didn't want her to be treated differently so didn't want her to have a label. Rosie found this difficult to hear because she wonders whether having a diagnosis would have meant an easier time growing up. Sensory issues had a big impact at school and were not understood; pain was not believed. Rosie excelled at engineering at school and left school at the earliest opportunity for a successful career in commercial kitchen design. As an adult she has been diagnosed with Ehlers-Danlos Syndrome and is now a wheelchair user. This affected her mental health, which along with the constant feeling of being misunderstood and not able to explain herself, resulted in her not wanting to be in the world anymore and her first mental health admission at twenty-one.

Autism was suggested to Rosie at that admission and she went on to receive a private autism diagnosis. Rosie wonders whether her previous Emotional Unstable Personality Disorder (EUPD) diagnosis will be taken away now she has an autism diagnosis but worries that without that she may not be able to access the mental health team.

3.7.3. Introducing Polly

In her former, younger, life Polly was a victim of serious abuse being used by paedophiles at the arrangement of her father. As a result, Polly was not known to the system and didn't attend primary school, she started school at fourteen when her Dad left. Did very well academically but very anxious, had panic attacks and saw the school councillor but didn't understand why. Tried her best to blend in and didn't realise that her past experiences were unusual, nor that it was unusual to be the carer for her Mum, providing meals etc. When she started to realise that others didn't live in the same way and disclosed aspects she was not believed. After leaving school had a brief time in employment before deciding to leave home and live own life away from Mum at university. Put lots of pressure on herself over studies and found social aspect and shared accommodation horrendous. First mental health hospital admission at nineteen but discharged herself after a week because it was a mixed ward with forced loud communal area and bedrooms locked during the day so no space for yourself, Polly was terrified. Went back to university but not eating, Body Mass Index (BMI) dropped to twelve and was admitted to an Eating Disorder Unit. Polly was discharged after gaining weight to supported living accommodation where she was the only female amongst older males with drug and alcohol issues, she soon became mentally unwell again and has had repeated psychiatric admissions over the last eight years.

3.7.4. Introducing Max

Max had a transient childhood moving frequently as an army family, he feels this masked his social and communication issues. He found that warmer countries suited his sensory needs. His last year at school was in a warmer country that was going to be their forever place, Max felt he was fitting in better than in previous schools and felt secure in the routine of life there. Circumstances changed, his father left the army and after school finished, they came back to England. Max felt his life had been torn away from him, he didn't do well in his exams because of the impact of knowing they would be moving. University then was not an option. In England his parents supported him in getting a series of menial jobs where he was bullied and did not feel fulfilled. Things changed when he was employed in an area of interest where he could use his skill set. Through work Max was asked to play guitar in a band which opened his eyes to communicating without words, with the band he was able to access social

events and enjoyed being in a social group in a meaningful and artistic way. Work was Max's reason for existence, however, COVID and company changes ripped this apart and again Max is left bereft which affected his mental health. Serious physical issues meant Max had to make a decision about surgery that he struggled to do, in retrospect Max realises he made a poor decision due to not processing the implications, this decision threatened his life and has been significantly life changing. An autism diagnosis was given a year or so later which he took in a negative way, that things wouldn't get better, this went on to suicidal ideation and a mental health hospital admission. Max feels a 'bossy wife' would support him to socialise and enable him to succeed in having a 'normal life' in a natural way, which is what he craves, but he believes he is unable to form a relationship. Being part of society is important to Max but the pain of getting social contact wrong causes isolation.

3.7.5. Introducing Jenny

After Jenny's parents divorced when she was four there were different rules in different households which was challenging. Jenny had a strong need to know why things happened and remembers endless questioning and a sense of self blame. With her literal world view Jenny went to school to learn, she didn't see the point of any other aspect of school life and was soon bullied. Jenny was diagnosed as clinically depressed at nine but no autism diagnosis until adulthood when her children were diagnosed. Scouting was an important aspect of Jenny's younger life and being a scout leader suited her skills. After an incident with her new stepmother at her Dad's house Jenny stopped going to visit although her brother still did. Jenny internalised all the constant negativity and took a first overdose at fourteen, stopped eating at fifteen to take some control and as a form of self-punishment, whilst thinking that would be OK because she was still eating one apple a day. As a perfectionist Jenny put huge pressure on herself to achieve at school and by Lower 6 all these experiences led to another overdose and admission to a children's ward, then transferred to an adolescent ward as a voluntary admission. The challenge of the behaviours of others on the ward and the expectation to participate in group activities was overwhelming and Jenny often absconded; this resulted in restraint and increased medication and transfer under section 3 to a secure unit. Jenny was discharged back home aged seventeen when no longer a child but adult services were not open to her. This was not a success, afterwards there was a period when she had no contact with her mother and her brother still does not speak to her. At eighteen Jenny moved into supported living, stayed with a church family and then got her own flat building up her life, including volunteering at the church youth group. At nineteen knew the system

from their own experiences and wanted to use this to help others. To achieve this went to university and subsequently started their own successful charities.

3.8. Participant Involvement

Autism research advises that to address and remove power imbalance between neurotypical researcher and autistic participant it is crucial for studies to have continued consultation with participants (Fletcher-Watson, et al., 2019). That advice is employed in this research as illustrated in Table 4.

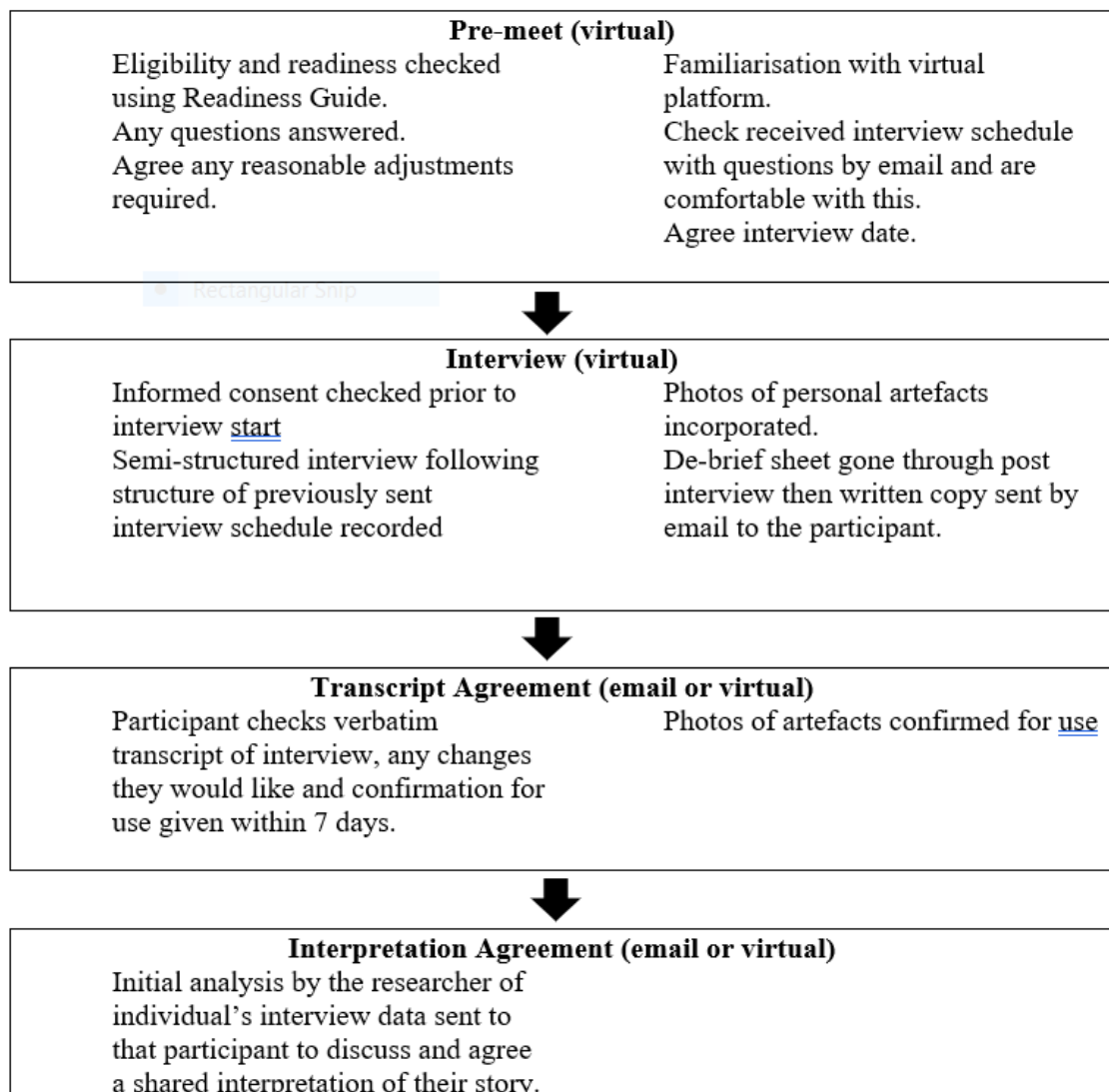


Table 4 Participants' involvement

3.9. Suggested Impact

Listening to autistic life stories during the interviews and keeping participants involved through the research process (Garfield and Yudell, 2019; Nicolaidis et al., 2019), gains understanding of the autistic perspective of how living as autistic in a non-autistic focussed world impacts on their mental health. This understanding from the autistic viewpoint is

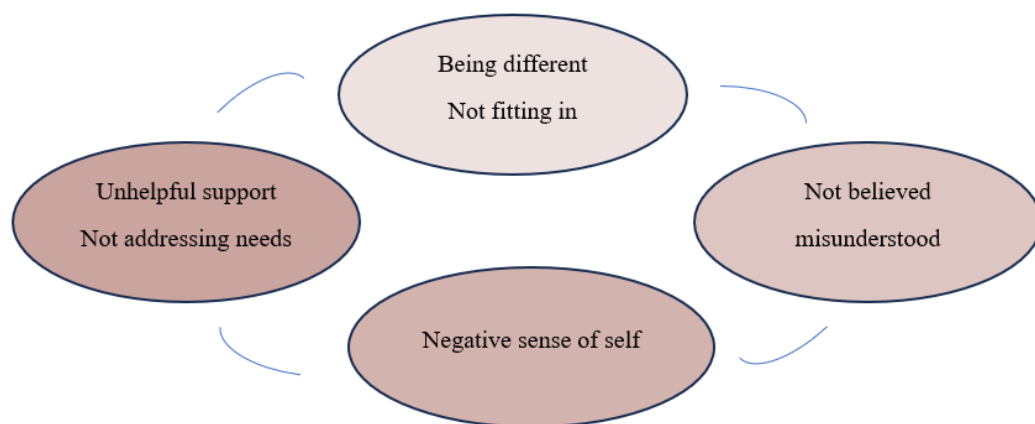
underdeveloped (Ince, *et al.*, 2022) but can be used in developing services, interventions, and processes to improve autistic access to the right support that meets their needs and helps divert crisis. Indeed, the interviewees' reason for participation was mainly because they believed there is a lot to be learnt from their experiences in terms of improving treatment of autistic people. This supports the idea of equal status of autistic people in research and the value of their lived experience knowledge (Milton, 2014).

Chapter 4. Results and Analysis – Risk

4.1. Introduction

All participant's stories were different but have some shared features (Table 5) which will be described in this chapter. The two strongest Group Experiential Themes for risk were a sense of “being different and not fitting in” and “unhelpful support”. As autism is a difference this was not surprising but the impact, being misunderstood, misjudged, bullied, isolated and the pressures of trying to fit in whilst not understanding why they don't, seems to give a sense of negative self-worth, in one case described as “self-loathing” (Jenny, p.13). These childhood experiences appear to follow into adulthood with lack of understanding or stereotypical understanding of autism by others resulting in not being believed and not receiving the right support (Max, p.46; Jenny, p.16). This leading to not feeling safe (Ashleigh, p.102) a loss of hope (Polly, p.55) that they will ever receive help (Ashleigh, p.16), that the world isn't equipped for them (Rosie, p.17) because they don't fit, creating a recurring cycle (Figure 5).

Figure 5 Recurrent cycle of being different & not fitting in, not being believed & being misunderstood, negative sense of self, unhelpful support not addressing needs, being different & not fitting in



Protective factors, which will be considered in detail in chapter 5, provide ways of breaking this cycle and can contribute to the development of practice. In this chapter quotations from participants illustrate the themes, extended quotes can be found in Group Experiential Themes, Risk (Appendix 8)

Group Experiential Themes	Sub-themes
Being Different and Not Fitting in	Being different
	Not belonging
	Not understanding why they don't fit in
	Family relationships

Not Being Taken Seriously and Misunderstood	Work relationships Accessing support Being labelled with a negative judgement
Internalising a Negative Sense of Self	
Unhelpful Support That Does Not Address Need	Mental Health Services set up to support neurotypical mental health only Mental Health Services not knowing what to do with autistic people Support not addressing need

Table 5 Group Experiential Themes (GETs) for Risk

4.2. Being different and not fitting in

4.2.1. Being Different

A feature of all the stories was the realisation by the participant that they were different from others and didn't quite fit in. In one case, Polly, significant childhood trauma in their past life meant the realisation happened later:

“at Uni you then live with people who have a boyfriend or get married or are saving up to buy a house and all these sort of like social norms that I didn't think I would ever achieve ... I think Uni was the time, the first time I compared myself to my peers, before I'd just floated around and not really thought about it” (Polly, p.16)

All others were describing feeling different from their family and peers during childhood, affecting their early interactions and relationships.

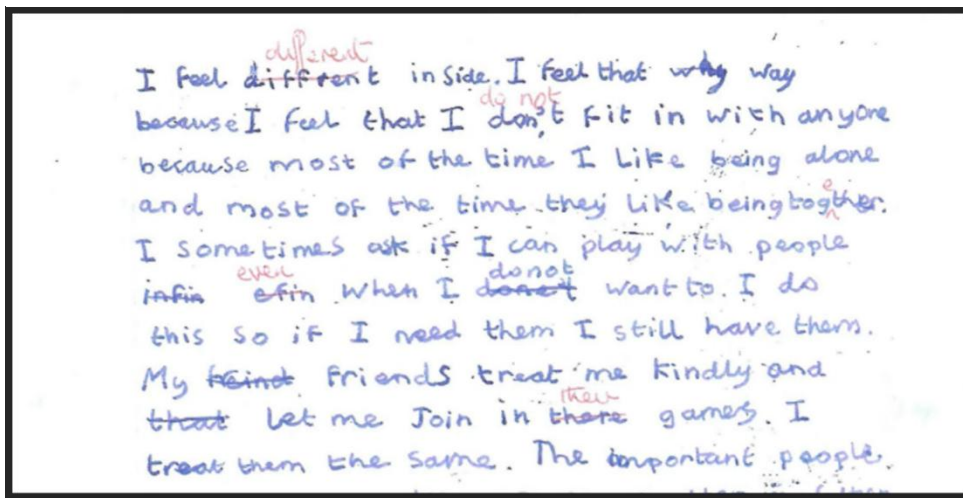
Ashleigh was aware that they were different in primary school and had to behave in a way that was not authentic to themselves to be accepted and maintain friendships. Their writing piece about 'our lives' (Figure 6) was displayed on the school wall and kept by their parents. Ashleigh says:

“I remember this went on the school wall ... it was a piece done about our lives which means my teachers were aware too and the fact that my parents

kept this as well um - meant other people were aware ... nobody ever offered me support or talked to me about it or acknowledged it apart from sticking it on the wall and my parents keeping it.” (Ashleigh, p.13/14)

There is a sense of incomprehension that although they had stated that they felt different inside and didn't fit in with anyone, no adult, either teacher or parent, had bothered to follow this up or appeared to notice it as a potential matter of concern. The content was dismissed and apparently didn't matter, so could be interpreted and internalised by Ashleigh that they didn't matter themselves.

Figure 6 Participant Image - extract from primary school literacy piece written by Ashleigh illustrating that they already recognised that they were different from peers



One participant, Max, describes his differences from peers being hidden as he moved with his family every two years due to his Dad's specialist skills in the army:

"I think it masked the fact that I had issues because because things changed so regularly um there wasn't a kind of base line to show that I wasn't fitting in because by the time I was kind of about wondering about that it would be on to somewhere different" (Max, p.2)

Jenny and Rosie explicitly say that they were bullied at school because they were different:

"I found school painfully difficult by the age of 7 I was being bullied ... I was very quickly identified as different um unusual, weird and that was really hard" (Jenny, p.7)

"I got bullied in school um because of the fact that I wasn't like everybody else and I was seen as a teacher's pet" (Rosie, p.9)

Interestingly, Jenny also describes being a teacher's pet:

“I was a teacher’s pet there is no other word to describe it really um I bonded with the adults not the children um I was there to learn I wanted to connect with the teacher” (Jenny, p.5)

This was not the case for Max or Ashleigh who did not always get on well with teachers because they asked too many questions or spoke about what they knew already in class:

“teachers don’t like a Know-it-all basically and I literally did know what they were trying to teach the class already um and I had no concept of the fact that if I sort of gave the right answers or explained or knew something beforehand um or sort of pre-empted something that it would actually go down pretty badly (laugh)... I wasn’t fitting into their (teacher’s) idea of how I should be responding you know in that sort of situation things got a bit unpleasant” (Max, p.10)

“my teacher either loved or hated me it seems I am that sort of person um and it is the fact that I ask a lot of questions and some people liked that cos they saw it was my interest and me wanting to clarify um but some people saw that as disruptive” (Ashleigh, p.12)

These features demonstrating interest and participation in lessons were misconstrued by teachers as being wilfully disruptive, underlining difference to the norm of children’s typical behaviour in class and furthering negative responses to genuine interactions. Max is also taking the blame for getting the interaction wrong when maybe the situation had not been explained to give other pupils a chance, or the thought that a good teacher could have differentiated the learning to match the stage that Max was on.

Polly had a different experience and didn’t attend primary school:

“I was 14 that was when I really formally started attending school and actually going...I didn’t really have that much experience of schooling until I was in my teens and when I did get there I absolutely loved it!” (Polly, p.4)

For Ashleigh the extent of difference from peers seemed to accentuate in teenage years:

“once we were teenagers obviously people become a lot more conformative ... the differences just grew a lot and in terms of things like the way I spoke I didn’t swear I spoke Queen’s English I spoke I had a different accent than

my family that kind of typical thing and I and I started to get picked up on on those things and bullied about those things” (Ashleigh, p.16)

Being different and not accepted is interpreted as not belonging by some participants.

4.2.2. Not Belonging

Rosie explains the feeling of not belonging and not having a place in the world:

“I kind of hated school all throughout um I always kind of felt like I was an outcast” (Rosie, p.5)

She goes on to say:

“I guess it saddens me a little bit to know that the world isn’t really equipped to deal with autistic people um and I I am part of that criteria that the world doesn’t understand that well and um doesn’t necessarily always know how to deal with in the best way.” (Rosie, p.17)

As well as being autistic, although not knowing it until an adult, Ashleigh had an extra layer of difference as Trans:

“I was a queer kid growing up under section 28 and I don’t think you can take that out of the equation in terms of me appearing different and being aware that being different wasn’t OK ... I was just getting these messages that I wasn’t OK to be myself and there was no one cos it was section 28 um no one was allowed to tell me it was OK to be me” (Ashleigh, p.17)

At that time, a sense of belonging was denied to Ashleigh as there was no place for them to belong. Ashleigh makes the connection between not belonging and it not being OK to be them having a negative effect on how you feel about yourself, your wellbeing and therefore your mental health.

The perception of not belonging to the human race as autistic is also interpreted by Max:

“I don’t think it (autism) has been presented to me as something being wrong but that is certainly my interpretation ... I’m missing abilities that er would enable me to be part of the human race (laugh)” (Max, p.32)

4.2.3. Not understanding why they don't fit in

Historically it was thought a feature of autism was 'aloneness' (Asperger, 1944; Kanner, 1944) and that this was a preference (Chevallier, et al., 2012). Listening to the lived experience accounts gives a different perspective (Jaswal & Akhtar, 2019).

Jenny describes her dilemma between wanting to be herself as an adult, because she is confident in her diagnosis, and needing to mask to fit in to avoid judgement:

"you can't be your true self necessarily um there are certain things that um you know even though I'm confident in who I am and my diagnosis now there's still um aspects of life you know when you still kind of feel the need to mask ... you want to be yourself but at the same time you want to fit and you don't know what people's judgements are like" (Jenny, p.44)

Before adulthood, however, Jenny struggled with a sense of who she was and was pleased to put on the mask of a school or scout uniform because that gave a visual representation of who she was supposed to be at that time, what to do and the part she needed to play:

"I liked the uniform for ... it's kind of the visual representation of putting on the mask um putting on that act putting on that demeanour that is my school demeanour rather than the bit of me that I am not sure who it is any more" (Jenny, p.10)

Polly wanted friends as a teenager and retrospectively realised that she didn't get on with her peers very well and that they probably didn't like her:

"I didn't necessarily get on very well with my peers and it's not until now that I realise that ... I wasn't bullied but they weren't, I think I was very easy to manipulate, quite vulnerable I suppose and I didn't realise that at the time I just wanted some friends ... they never did anything awful it was just that yeah I they didn't necessarily really like me I don't think (laugh) but there I was" (Polly, p.5)

Max was an outsider on the playground and couldn't understand why. He didn't fit in with army children or civilian children and this caused further negative interactions that Max experienced as not being accepted:

"you sort of need to fit in with the social group in some way and which is something I obviously never did but never realised quite why and I think

that kind of caused some problems because I was never part of the crowd or any of the crowds that were around and that was yeah quite unpleasant” (Max, p.8)

Rosie also couldn’t understand why she was so different to others:

“I was teased and stuff like that um and I guess it kind of especially in senior school it made me realise just how different I was to other people um but didn’t really understand why I was so different” (Rosie, p.9)

Later on in his story Max describes how he didn’t fit in with other staff in the workplace, again he seems to be taking the blame for missing cues that he wasn’t behaving in a way his colleagues approved of, even though he had no idea what he was doing wrong in their eyes:

“with me being oblivious to any kind of um (sigh) um well non-verbal sort of er expression of how they felt um I you know I sort of I guess didn’t get the hint for some stuff ... I wasn’t aware of doing anything that was actually bad but obviously some people didn’t like where I was how I behaved um and quite a few times I came out of work to find they had let my tyres down (laugh)” (Max, p.18)

Although Max himself doesn’t describe this as bullying and didn’t perceive it as such:

“I guess it’s there are good sides and bad sides to the autism in that er on the bad side I didn’t realise why that would be done and also on the plus side it didn’t have the effect that maybe people thought it would have um because it didn’t register with me that that was a thing to try and make me feel bad because it just didn’t make me feel bad and it was just a thing that had happened ... it quite possibly you know was to some extent my fault because I was not behaving in the way I should have done but had no idea I sh there was another way to behave,” (Max, p.18)

It does seem to be a matter that has caused reflection and regret with a negative connotation of himself in relation to others. Rather than perceiving them as unpleasant, Max regrets not having the ability to fit in.

When reflecting on their relationship with their Mum, Ashleigh thought they were doing things that were good e.g. helping out at the youth group at church, they couldn’t understand why they were not thought of as good:

“I was her problem child but I couldn’t understand how I was ... This is something that confused me quite a lot because like I got good grades and reports I was very well behaved very rule abiding um I was very involved in church” (Ashleigh, p.3)

There is a sense that Jenny feels a burden to her Mum:

“it was extremely challenging for my Mum she also had to deal with the fact that I was different” (Jenny, p.2)

Across the stories participants couldn’t seem to make sense of why they weren’t accepted, what they were doing differently and why they were different and not approved of.

4.3. Not being taken seriously and being misunderstood

In the previous section, for all five participants, an idea is formed that they feel a need to fit in somewhere but can’t work out why they are not accepted. Lack of understanding from both sides of relationships challenge togetherness. This corresponds to Damian Milton’s ‘Double Empathy Problem’ (Milton, 2012) which explains that people who experience the world very differently will struggle with mutual reciprocity in a social interaction. This, he argues, is neither of their faults but a disconnect due to differences across a neurological divide. Participants identified this problem across family, work and social relationships.

4.3.1. Family Relationships

Max describes a lack of understanding between them and his parents which resulted in a remote and undemonstrative relationship:

“I think I was more possibly more baffled by their responses than they were about er my behaviours um so yeah I th... essentially there was a lot of misunderstanding and um yeah the the the outcome of that was essentially um as I say quite a distant kind of relationship not a tactile one no hugs or things like that” (Max, p.14)

The hesitations in Max’s explanation seem to indicate a sense of regret:

“I think I came across as being er – not a very loving kind of person and that kind of kind of got reciprocated a bit” (Max, p.13)

He says that ‘he came across as’ not being very loving but there is an impression that he is not lacking in emotion and feelings of love and affection, with a need for that to be

reciprocated, however, he seems not to demonstrate it in the expected and typical way causing misinterpretation.

Jenny speaks of the intensity of her emotions and it being hard for her to let it show because it would create a feeling of being out of control:

“I find showing emotion really hard um so I was always I suppose and still am in many ways seen as someone who is quite together and quite um maybe almost cold in some situations because rather than expressing the emotion I will kind of go into a shutdownny freezy kind of very sort of fixed facial expression um which isn’t about not having emotion it is about having a really intense amount of emotion that I can’t display because if I display that emotion I’d feel out of control” (Jenny, p.11)

Both Jenny and Max speak of not showing emotion in facial expressions not meaning a lack of emotion:

“you see people who you know have a very kind of er expressionless or slightly grumpy expression when it is actually just their default state or they don’t show emotion in their face although they might be feeling things and so to other people it comes across as being quite negative” (Max, p.13)

Jenny experienced misunderstandings within her family which had negative repercussions:

“I had very strained relationships within my family um at different points which has been quite complicated and misunderstood um which is tricky” (Jenny, p.3)

For Jenny this resulted in not having contact with her Dad or Mum at various times and losing contact with her brother altogether:

“I then had a ... a time when I had no contact with my Mum and my brother I still don’t have any contact with so my brother won’t talk to me since then so ... 20 years I haven’t seen my brother to talk to he won’t engage with me at all um ... I do see I do have a relationship with Mum now ... but um ... we’re not close” (Jenny, p.28)

As a child a misconnect with her Dad’s new wife meant that Jenny felt unable to visit him at their house because she was there and consequently lost contact with him for a couple of years:

“I I didn’t feel understood um then I didn’t get on with the step-mum the the his new wife particularly well um I’m not saying that she necessarily did anything um wrong um but it was there was just a misconnect um and then it did kind of I would remove myself ... hid in the bedroom for a while she came in and and she kind of stood on me and I I um as I was sitting on the floor curled up on the floor pretty foetal I should think cos that’s kind of my go to and she just kind of stomped on me a bit and um and that was it for me I was just like I don’t want to go um and so I just refused to go anymore” (Jenny, p.3)

“I tried to maintain some level of contact with my Dad um but he ... wouldn’t make any adjustments to meeting me in a café or somewhere outside the home if he if I wanted to see him I would have to see him at their house um and yeah I just couldn’t so that was the end of that...” (Jenny, p.4)

Although not evident that it was due to misunderstanding, after a couple of years of Rosie and her sister staying for weekends with their Dad after their parents divorced they chose to stop because he was never there when they visited:

“we weren’t a massive fan of the new girlfriend um you know she took our Dad away um so yeah it was very very weird and I think we we did it (visited) for probably about 2 years and then it just got to the point where we said you know what enough is enough um you know if he really wants contact with us he is the adult he needs to make time ... we don’t want to keep visiting him and him not being there” (Rosie, p.3)

Ashleigh struggled to understand why their difficulties were not acknowledged nor recognised by their family. Their sister, who it appeared Ashleigh thought had a traditional, uncomplicated, comfortable family life to be envied, interpreted Ashleigh being in hospital as escapist rather than them being significantly mentally unwell:

“when I was in hospital I remember her (sister) saying to me Oh it’s alright for you you can just lay there and I’ve got to be at home with my baby um this was her healthy baby that she had in her lovely she’s got a lovely husband who is very supportive and provides everything she could need... she must have thought I was at some kind of weird celebrity retreat or

something but it was this strange attitude which I think my Mum has as well... ” (Ashleigh, p.6)

This attitude was incomprehensible to Ashleigh, as it seemed the way Ashleigh behaved was incomprehensible to their birth family. They have had years with no contact with their birth family:

“we’re getting to the point again where I’m looking again at cutting them out of my life again which I had done for years at one point” (Ashleigh, p.3)

Losing contact with family can make you vulnerable as Ashleigh describes after a safeguarding experience in hospital:

“I was vulnerable because I’d stopped contact with my family at that point the autism diagnosis stuff had been the last um and cos I felt I couldn’t deal with them (laugh) there was apart from my brother so there was no one to kind of to intervene not that they would have done anyway” (Ashleigh, p.61)

Although not necessarily family needed, Max reflects that his instinctive reaction to refuse having his gall bladder removed may have been different if he had someone to discuss it with:

“didn’t want to have er gall bladder removed um – bearing in mind that it was only me so you know I’d there was nobody there for me to talk to apart you know the consultant comes in and says we want to do this ah and yeah my er instinctive kind of reaction was that gall bladders do a function and I’d probably prefer to have it rather than not um if it if it was an option then and it was an option even though it was probably recommended so yeah I went with that” (Max, p.28)

This decision has had very serious repercussions, resulting in near death. It seems the information may have just been presented verbally rather than in a concrete way, without anyone advocating on his behalf for reasonable adjustments in communication, with the assumption by hospital staff that Max had capacity to make the choice of options independently (Mental Capacity Act, 2005). The consequence of his choice is that he now has impaired mobility, pain, nausea and a liquid diet. A dramatic result to possibly not having

anyone close to help with decision making or not having the time required for him to process and consider all the options:

“combination of the general isolation and then because of the hospitalisation and the weakness and the um the diagnosis um and the just the sort of chronic pain and you know and stuff whereas before I’d you know there’d nothing wrong and suddenly I was taking all these tablets and things were wonky I got completely suicidal and so bad basically that I literally reasoned with myself that I had nothing left to lose” (Max, p.39)

Polly has no contact with her Dad:

*“My, my Dad isn’t a very good person I have no contact with him now.”
(Polly, p.1)*

She recollects her Mum not understanding or sympathising with her response when she was ill and not able to go to school. Polly felt upset and was crying about it, Mum didn’t validate this feeling but commented unpleasantly that other children wouldn’t react like that, giving an impression of othering, inferring she is unnatural and behaving in a strange, abnormal way unlike other people rather than trying to understand:

“the most vivid memory I have of school is one morning crying because I was ill and couldn’t go to school and my Mum, not in a very nice way, but basically said you are a complete weirdo most children would be very happy to not have go to school (laugh) but, it took a while to realise but I think it was because my routine was being thrown and being ill wasn’t something I could plan for. I think I really liked school because of the structure and the routine” (Polly, p.4)

4.3.2. Work Relationships

Work can present a feeling of belonging and acceptance, (Kandalaft & DeBrabander, 2021; Walsh, et al., 2014) especially when using your skills for a joint purpose, see Chapter 5, 5.5. Unfortunately, it also can be a place where relationships break down due to misunderstandings (Bury, et al., 2020).

Ashleigh came across difficulties at work and felt they were not supported or understood by colleagues. A misunderstanding of something they said resulted in them being hated by a colleague which didn’t make any sense to them:

“someone decided they hated me because of something I said I did point out that she had misinterpreted once and I think it was something I said about my family too like in passing which actually was considering my relationship with my family quite mild (laugh) I and I didn’t understand why that would be kind of upsetting to her” (Ashleigh, p.28)

Max also describes not naturally picking up on the unwritten behavioural expectations of the work environment:

“although it wasn’t exactly traditional sort of office type stuff it was along those lines and there’s a whole culture and and er set of behaviours that goes with that which I guess people just pick on and it’s it’s grown up over time and as people join places they kind of their social bits of their brains pick up on the behaviours and whatever and again with me that didn’t register at all” (Max, p.18)

Again, there is a commonality between the experiences of Ashleigh and Max in that they both found expected interactions within the culture of work a mystery.

4.3.3. Accessing Support

Being different also seemed a shared issue that resulted in reducing the ability to access support. Since as autistic they were responding differently when struggling with their mental health they were not taken seriously because they were not demonstrating neurotypical signs.

Rosie tried to seek help before her mental health reached crisis point but she was not taken seriously:

“I guess it took a little while for anyone to actually notice how much I was struggling with my mental health because again it somewhat looked different to start off with you know I tried to seek help for it before it got to the point where I was taking attempts at my life but they didn’t understand, they didn’t really see that it was a big problem and it didn’t look like your typical you know I wasn’t crying I wasn’t you know, I was still doing my normal routines and things like that” (Rosie, p.20)

Ashleigh experienced the same struggle to get help as autistic and presenting differently:

“when I was struggling with the depression and I think it was with me that I shutdown emotionally and I maybe I presented differently and now I know

at burnout that people didn't I didn't present in the same way" (Ashleigh, p.21)

4.3.4. Being labelled with a negative judgement

There is shared experience of misunderstandings resulting in a negative judgement by others. This ranges from not being believed and thought of as attention seeking, intentionally awkward, uncooperative or difficult, to simply being a bad person.

Ashleigh found their sensory pain was not believed, this resulted in their doubting the signals that their body was giving them in addition to feeling insecure from interactions with others:

"I got pain from when I was walking um and from lights and as I say kind of yeah my senses can be very sensitive um and that was just hypochondria seen as it wasn't seen as real um by other people it was just me being attention seeking or that and that was quite difficult in that I think so I learnt to suppress pain and to mask it um and to not listen to my body" (Ashleigh, p.32)

Autistic traits in various contexts have resulted in these negative judgements:

at home:

"a lot of the sort of autistic was taken in quite a bad way as a as a fault in me communicating or as me being – being bad in some way" (Max, p.13/14)

"I couldn't talk after school when I was overloaded she (Mum) took that personally as me being rude to her and not involving her in my life and she just wouldn't accept or understand" (Ashleigh, p.4)

At school:

"People not thinking my questions as genuine and thinking that I'm just trying to be difficult when it's that I need clarification um because of not being able to read between the lines" (Ashleigh, p.12)

"teachers felt that I wasn't concentrating ... I tried to explain that to them that actually this is how I focus, this is how I concentrate, and I really struggle to sit still and stuff like that they just didn't get it and just saw it as me being awkward." (Rosie, p.11)

When trying to access support for mental health, different interpretations of behaviour could influence the diagnosis given. Ashleigh describes how patients who are perceived as difficult and uncooperative can be given a borderline personality disorder (BPD) diagnosis and that patients joke about this:

“I do say BPD for a reason um not EUPD (emotionally unstable personality disorder) because I think that fits my diagnosis more um (laugh) and the reason I say that and excuse the swearing is that um the patients say that it can stand for something else instead which is um Bitch Pissed off the Doctor and it was a diagnosis that everyone knew that was commonly given to people seen as difficult women who didn’t co-operate which I definitely came under the category of because I was seen as uncooperative because I didn’t respond to things ways in ways they expected um which I think was my autism” (Ashleigh, p.38)

Rosie also experienced being labelled as a difficult patient:

“Very much a lack of understanding of me and being put down as a difficult patient and um sometimes non-engaging and and things like that... how it tends to go is staff struggling to understand me needing to communicate in different ways at different times being able to cope with you know something one day but then maybe not being able to cope with it the next day” (Rosie, p.32)

And Polly as an absconder:

“you are being punished for running away and you’re running away because either you don’t want to be alive anymore or you because can’t tolerate the ward environment anymore and that’s another thing that’s sort of put on your notes ... I am down as an absconder risk but if they’d look both of the times I’ve ran from the ward I’d already been there for about 8 months and hadn’t tried that, hadn’t done that, it just it gets to that point where you think this is my only option I haven’t got any leave so I will leave in the only way I can.” (Polly, p.33)

4.4. Internalising a negative or unreliable sense of self

The negative messages that were being received externally seem to have had the impact, shared across all the participants, that they came to negative conclusions, in different degrees, about themselves and their self-worth.

Jenny explains that all the bullying caused her to have a very negative view and intense dislike of herself:

“the harm internally of of being constantly put down it becomes your own thought pattern um and I certainly took a very heavy dislike of myself um and internalised a lot of the messages I was given um as a child um and and that was really really hard” (Jenny, p.8)

She stopped eating, not to lose weight but rather to take control of an aspect of her life and as self-punishment:

“I think it was just general self-loathing um not being happy with who I was” (Jenny, p.13)

Polly, when trying to make sense of who she was worried she might be a psychopath:

“I spent a lot of time wondering if I was a psychopath um which was really scary (laugh) um but then I learnt that it wasn't that I didn't care, I cared very much, almost too much, I just wasn't quite the same (laugh) as everyone else and sometimes that did make me come across as quite cold or in a self-preservation kind of mode I suppose too” (Polly, p 13)

Professionals telling her they are doing all they can and she needs to try harder resulted in a loss of hope:

“(readmission) does leave you feeling like you're not getting anywhere because all you've done is circle the system and the hospitals for x amount of years and when professionals are saying they are doing all they can or that you're not trying hard enough or all these things, I think you lose hope and it almost that becomes your life and that's not a very good life” (Polly, p.55)

Rosie felt that she was continually being told she wasn't responding properly:

“I was always told how I should feel or how I should react to something and I often didn’t react that way” (Rosie, p.4)

Ashleigh felt that their differences were blamed as the cause of her Mum’s continuing difficulties and it was thought of as their fault:

“I think it (Dad would discreetly support Ashleigh but would always take Mum’s side because Mum’s mental health wasn’t stable) was around trying to make my Mum stable and happy um and she just I mean they were anti label was the way they put it um but she just couldn’t cope with being different she was very obsessed with appearances what will people think um that kind of person and had a lot of anxiety” (Ashleigh, p.1)

Ashleigh mentions ‘gaslighting’ four separate times in their interview showing their belief that their family and services deliberately misconstrued or denied things happened and that made them doubt their reality and judgements:

“impact of all the gaslighting and mistreatment and as I say my family still as well of kind of the mental health services of not believing me and pretending something didn’t happen or something isn’t happening if it makes them look bad (laugh) and it’s just the kind of like that isn’t the case when I know it is true and it makes me doubt my mental health ... unfortunately I don’t trust my own judgement and when someone does say to you like these memories aren’t real” (Ashleigh, p.112)

‘Scapegoating’ is another term used by Ashleigh throughout the interview. This is in relation to both their mother and sister who they feel projected their own problems onto them:

“my sister is very similar to my Mum in terms of not managing her mental health and scapegoating ... she even admitted I remember aft when we were teenagers like after she left home and we had a heart to heart at one point when I was struggling that she did scapegoat me it was kind of like if my Mum made her feel bad she would take it out on me” (Ashleigh, p.5)

Max concluded that his parents thought him bright but choosing not to bother to apply himself. Max explains that he did bother but his organisational skills were such that he wasn’t able to manage to complete homework for example. At that time this was just labelled as bad:

“I’m sort of being a little bit broad in the in the ah the explanation but I think it was essentially the um very bright but lazy or doesn’t apply himself which yeah looking back on it was this ADD executive function thing it’s just getting stuff done was just something I struggled with at a a biological level but at that time er I mean it just wasn’t a thing um and if you didn’t do your homework or you didn’t behave in the a certain way you were a bad person basically (laugh)” (Max, p.12)

After getting his diagnosis as an adult, Max searched online and discovered that his results were bad and meant that there was something seriously wrong with his ability to relate to others:

“my emotional quotient or whatever it is um I’d once I got the results back I started looking up online about you know where you were the various scores put you and I think ... if you score 25 or below then you’ve got a serious problem in terms of you know social er communication and and empathy with people um and I’d scored 5 on that (laugh) so um obviously there’s something yeah pretty wrong” (Max, p 31)

This interpretation has a big impact on Max, there is a sense of shame, he is aware when something goes wrong in a communication and blames himself:

“I can at least pick up on the fact that somethings gone horribly wrong socially um because there was a conversation going on even though it was pretty meaningless but it was going on and then all of a sudden it stopped and the person isn’t smiling (laugh) um” (Max, p.35)

The painful emotion resulting from the thought that he unintentionally hurts other people leads him to avoid interactions which contributes to further isolation:

“I go off my food and so um yeah I don’t have the option of ordering stuff online because that would mean I had to answer the door to somebody which again (laugh) which is kind of even worse than than um the possibility of maybe of messing up when I’m checking my groceries out” (Max, p.35)

4.5. Unhelpful support that does not address need

4.5.1. Mental Health Services set up to support neurotypical mental health only

A shared experience across participants was the confusion that having a co-occurring autism diagnosis caused services when they tried to access mental health support. Since services are set up to essentially address a primary need, there seemed to be a tendency for services to try to divorce autism from the support given to focus on just what was assumed the presenting need, ignoring that autistic people may show signs and symptoms of mental ill health differently and may require adaptations to treatment or reasonable adjustments to meet their needs. Another response from services being that autism doesn't fit their eligibility criteria so they can't offer any support.

Rosie categorically stated that her autism diagnosis was a barrier to accessing mental health support:

“having the diagnosis has got in the way of getting mental health support definitely.” (Rosie, p.18)

Jenny explains that she is testament to the fact that ignoring a person is autistic when trying to provide mental health support means that the support fails:

“if you treat somebody for mental health without acknowledging and understanding their autism you're doing it wrong and you'll be doing it for years and years and not actually getting to the bottom of it which I am testament to I started interventions at the age of 9 and didn't finish until I was about 23 / 22 um including an extensive admission and I think if I keep saying 'if' if the right support had been there if I'd been understood um it would have made a huge difference” (Jenny, p.38)

Polly, who, like Rosie, has had multiple admissions, describes the experience of professionals wanting to talk about her mental health and not her autism but they are inseparable. She explains that this can skew mental health diagnoses.

“I've had this in ward round before where I've answered something and they've said you're here for your mental health not for your autism or we're here to talk about your mental health not your autism like but I can't take the autism (laugh) away so yeah I think it skews your mental health diagnoses a bit I don't think they are the same, if you're autistic and you

have anxiety I don't think it's the same as anxiety I don't know I've never been neurotypical but (laugh) yeah." (Polly, p.59)

Rosie found that as autism is not a mental health diagnosis mental health hospitals refuse them even if there is a mental health emergency:

"mental health (support) um that's been more challenging because autism isn't seen as a mental health diagnosis so if you need to go into a mental health hospital they say Oh well we're not equipped to deal with autism so we can't have her um no matter what the mental health urgency is that is requiring it" (Rosie, p.18)

Jenny concludes that health services have decided that autism, as not a mental health condition itself means that autistic people can't have mental health support:

"I do think that you need to be able to um acknowledge that somebody with autism can be struggling with their mental health and need support um which at the moment I feel like we're almost not it's almost like we are saying OK so autism isn't a mental health condition therefore you can't have mental health services which is ridiculous" (Jenny, p.38)

There is a sense of frustration in these words from participants, the exclusion from mental health support does not seem logical.

Ashleigh speaks of the difficulties that arise when services focus on one thing when others are interlinked:

"I saw that the crisis team had come in once and written that like it's not depression they have always been like this it is just EUPD ignore them um as I say they hadn't used the word but they had said like don't treat it because I was saying I am depressed I am saying I am unwell like I knew it wasn't right that I was getting these urges and like that but um yeah and they would just dismiss it in that way" (Ashleigh, p.40)

They explain that mental health professionals were more dismissive of their need for support than other agencies:

"what was interesting was that the people who generally argued my care were not mental health professionals" (Ashleigh, p.41)

and that the crisis team denied that they had a mental health need:

“the police weren’t happy to interview me social er um the crisis team were just like oh just interview them it’s not health and the police they weren’t they weren’t buying that um so yeah we had the appropriate adult come” (Ashleigh, p.48)

This illustrates the position of not fitting into a service and not being believed, feeding into the cycle effect of low self-worth and unhelpful support.

Rosie shares this experience being turned away from crisis support:

“Crisis Cafes and things like that can quite often say Oh well it’s your autism so go and speak to somebody that knows about autism” (Rosie, p.18)

Her GP referred her to the community mental health team but she is not accepted by that service:

“I’d also spoken to my GP before who had contacted community mental health team um to try and get me more support but community mental health team didn’t want to give more support so yeah there was quite a few attempts to get more support.” (Rosie, p.26)

Rosie’s words reflect frustration at not being able to get the help she needs when she describes contacting the mental help hub in a time of crisis. She finds them dismissive, giving standard answers that were not helpful for her but also acknowledges that she believes this to be the experience of non-autistic callers too.

“I had spoken to the Hub a couple of times um and tried to get support from them but they were pretty dismissive um because of the fact I’m doing SCM (Structured Clinical Management) therapy they just said oh just wait for your next appointment for SCM um and things like that um and again just saying, it’s it’s the standard answer you get that I know it’s not just autistic people get, “Use your distractions”, “Go for a walk”, “Make a cup of tea” you know, “Take a hot shower”, and all those sort of things were the answers I was getting despite the fact that I was saying to them actually I need more help than this at the moment. Unfortunately, your distraction techniques aren’t going to cut it for me, I’ve been doing them, you know I know my distraction techniques and they are not working.” (Rosie, p.25/26)

Ashleigh explains further that as their mental health deteriorates their autistic traits become more prominent. They feel a need for them to be able to separate the two so that they can be believed by mental health services that they really do need support for their mental health, which seems to imply added pressure on themselves.

“when my mental health is worse my autistic traits become worse in that like my um sensory stuff and I’m more stuck to my routines I am less able to be flexible um as I say I get agoraphobic it always seems they link so much but then at the same time I think you need to be able to pull them apart um it’s really important to because in the way that otherwise you can have autistic people dismissed by mental health services because it’s like you are just being autistic and don’t believe that you’re in severe mental distress whereas obviously we can have mental health problems like anyone else”
(Ashleigh, p.103)

Even on admission the root of what is going on is not addressed and is superficially taken as risk behaviour. Polly, who has had multiple admissions, describes finding the experience unhelpful:

“I did self-harm a lot but it was always with objects that I’d brought in with myself from leave or OK they can’t really stop you head banging, well they can, um but it’s – it’s never getting to the root of what’s going on, or what’s happening or what’s causing it and they just see it as risk behaviour” (Polly, p.32)

Max also uses the word ‘root’ when describing his core need not being supported. There were no beds available when a second hospital admission was thought to be appropriate, so he had some day hospital sessions instead. This prevented isolation but didn’t address what he needed.

“the time when I was going to be admitted but they couldn’t find a place um I again went in for about a week maybe 2 weeks of of the day hospital um similar kind of drill um but again just partly just having a reason to get up in the morning and partly being just around some people um was a really helpful thing even again even though it wasn’t targeted or helping my root problem it was at least social contact” (Max, p.48)

Max explains that if problems related to being autistic aren't addressed, depression builds up and becomes a problem:

"if the problems caused by autism aren't addressed then the er... depression builds up until it becomes a problem um and stuff like hospital admission solves the mental health problem by taking away some of the pressure and giving you some routine and meaning which helps a little bit with the autism stuff like because of that um but it doesn't really address the root problem so it's not going to help me pay my bills on time it's not going to help me get my car into the garage um it's not going help me er particularly with socialising" (Max, p.52)

Like Polly, Ashleigh's risk behaviours continued in hospital, the behaviourist approaches they experienced didn't make sense to them and were detrimental:

"the behaviourism I encountered of the kind of not supporting me because that was seen as rewarding me when I was distressed um when I acted out and it was just bizarre and I just didn't it didn't make sense to me um it still doesn't and I don't see how and cos the thing is it wasn't there wasn't an alternative um and I was there because I was seriously unwell it wasn't like I was choosing to behave and it is that assumption that all your kind of behaviour is that and the thing is the rewards was being like being allowed in my room by myself I had to earn that through working through the system whereas that was something I needed" (Ashleigh, p.94)

Both Polly and Ashleigh found themselves on medication that did not suit them but from medical observation it seemed to be effective as their presentation was calmer, this meant professionals wanted to keep them on it:

"I came off it because I couldn't tolerate how different it made my body feel um which they then didn't understand and when I came back a few months later they were like ooh let's get you back on this cos it worked so well last time, yeah it does for you (laugh)," (Polly, p.31)

"I was put on psychiatric medication that caused me to dissociate and that's when things got really bad and I told them like I knew ... I was becoming less aware of reality um but they didn't cos understand because from the professional's point of view I was calmer they saw me as calmer from the outside because I was dissociated

(laugh) but that was seen as a good thing because I was calmer and I can see from their point of view that yeah although I was telling them that like I'm not calm inside (laugh) this is um it's just on the outside so they wanted to keep me on them"
(Ashleigh, p.42/43)

Polly reflects that medication could be experienced differently by autistic people:

"I still think you would experience it (medication) differently" (Polly, p.60)

Ashleigh could see no logic in not be able to access support for something until they had stopped doing it:

"all my risk behaviours had to stop before I was allowed therapy and you know some people they need something to replace that before which is what therapy skills teach you" (Ashleigh, p.95)

Ashleigh considers that their mistreatment around autism caused a lot of their mental health difficulties:

"lot of my mental health difficulties I would say have been directly or indirectly caused by my experiences as being autistic in environments that weren't good for me um and my family's response to that I mean there was a hell of a lot of gaslighting" (Ashleigh, p.102)

4.5.2. Mental Health Services not knowing what to do with autistic people.

Lack of understanding in how to support an autistic person, or a mistaken premise that you can ignore the fact that the person you are supporting is autistic, can unintentionally lead to mistreatment or the individual not being able to access any support at all. Polly describes an array of mental health teams not knowing what to do with them, including the Crisis Team:

"when I first came to Uni I spent about 5 or 6 months under the Crisis Team which isn't the norm, they normally (laugh) see you for about one or two weeks I think they just they didn't know what to do with me I wasn't getting any better. Eventually they put me in (hospital) um where I stayed for about a week because I asked to leave. That was my first inpatient experience, and it was horrifying." (Polly, p.19)

the inpatient teams:

“I’ve probably been what they would term a revolving door patient and I tend to stay about 8 or 9 months because they never know what to do”
(Polly, p.31)

as well as the psychiatrist not being able to identify a suitable long-term ward to send her too. This points to suitable services not existing, in addition to mental health professionals not knowing how to help:

“I managed to get away with not being sent to a long-term ward because the psychiatrist basically had to admit that he didn’t know which one he would send me to and he didn’t know what was wrong with me” (Polly, p.51)

This is an experience shared by Rosie:

“you get to the mental health team, the people who are supposed to have all the understanding in the world, um you know and support people with mental health issues, just had no idea! (laugh).” (Rosie, p.25)

Ashleigh, too, found that professionals did not know what to do with them:

“so they took me into hospital for that and also so they could figure out what to do” (Ashleigh, p.45)

That professionals don’t know how to help or only offer unhelpful support, fails the individual further in that if they don’t, or can’t, go along with the support offered that is not useful, they can be discharged from the service as not engaging and assumed to be not wanting help. This experience is shared by both Ashleigh and Polly:

“services are like call this number or go to this Crisis Café and then again it’s on paper that you are not engaging or you are not taking the options that are available to you but actually they they don’t meet your needs.”
(Polly, p.62)

“I ended up in A&E a lot because I was harming myself in this period and the doctors there were unhappy with the fact that the mental health team weren’t helping me um they tried to get me admitted to the hospitals but I got quickly kind of kicked out because what they did with people with BPD is they made you sign a self-harm contract and what that meant was that if you self-harmed when you were in hospital then you were discharged

*because it showed you didn't want their help, now, I thought this bizarre ...
I was like but that doesn't make any sense because you are self-harming
because you are unwell so surely it is just a sign that you need help"*
(Ashleigh, p.39)

4.5.3. Support not addressing need

Across participants there are experiences of the support they have received not addressing the problems they have. Both Jenny and Polly seem to have concluded that the right support would be not trying to change the autistic person to fit in with the rest of the world but being supported to accept themselves as different and those around them accepting this too. Jenny's weekly CAMHS appointments involved talking through lots of things and she had a good relationship with them but nothing improved:

"they were really really supportive and we talked through lots of stuff and we talked about strategies and stuff um... but nothing ever really improved we didn't necessarily talk about the right stuff um or recognised why I was different and I think that's what I needed it wasn't about changing me to fit the rest of the world it was about me learning to accept that I was different and that it was OK to be different and for the rest of the world to know that it is OK for somebody to be different um and so I just continued on a pretty downward spiral to be honest" (Jenny, p.16)

As a child they were the one identified as having the problem and were the one having therapy, there wasn't support for the whole family, which Jenny explains, meant the right issues weren't addressed:

"something that is really missing that tailored support that kind of individually focussed support and support for the whole kind of family because let's face it I was in a system I was in The system whatever it might be um but as a unit we weren't really getting the right support I was seeing someone once a week but it never really got to the bottom of the issues and the advice we were given wasn't that helpful or right even" (Jenny, p.26)

Polly also identifies the rest of the world needing to accept and respect autistic difference, that support is not solely needed for herself:

“the reason I think I need help for being autistic or autistic traits isn’t because of me or autistic people it’s because of the rest of the world (laugh) I need support to be able to function in this world” (Polly, p.61)

For Polly it seems a more two-way support is envisioned, with herself and those around her working to understand each other:

“sometimes I do need support with my thinking because I can get very lost or take things the wrong way, maybe neurotypicals aren’t always the clearest of people um (laugh)” (Polly, p.61)

Max talks of support not addressing the right things:

“there hasn’t been any er intervention that’s specific to the problems I have um it has been fairly general sort of sitting and talking about things ... while I’m getting attention um there’s nothing which is really changing stuff or allowing me to change stuff” (Max, p.46)

There is sense that he is taking responsibility for making the change to relieve issues, “allowing me to change stuff”. They are receiving some social care but that is not supporting the areas where he struggles:

“I’ve got some um some social care but it’s essentially um home help um so the people who are expected to come in and do a bit of dusting or er feed the cat or um maybe get some shopping for stuff that I can’t do when it’s I kind of need a a specialist in terms of the the problems I’ve got because again kind of like if they were there all the time then there would be stuff they could do which would really help they can’t do that if they are only coming for an hour sort of every day or so every other day and it you know it’s they’ve got tight schedules they’ve got to see other people and so they can’t really do things like booking me a skip or sorting out an appointment with the garage and stuff like that it’s not really in their job description” (Max, p.34/35)

Even on admission to hospital the support is not necessarily helpful. Max finds himself just left on the ward, not knowing what to expect and believes finding out what the routines are is harder for an autistic person:

“the first couple of days which were pretty awful um partly because of the time there was some really difficult patients in there as well um and I yeah didn’t know what to expect and basically got taken there and then left (laugh) um and and spent the first half a day just sitting in the corridor not knowing what’s going to happen next” (Max, p.43)

Being thrown into situations without preparation and understanding what to expect is not an issue specific to Max. Jenny, when describing her hospital admission, uses the term ‘thrown’ repeatedly:

“when you don’t do peers and don’t do people you are suddenly thrown into living with people” (Jenny, p.18)

“you were being thrown in to situations that were really uncomfortable and really difficult” (Jenny, p.20)

“I went to adolescent units as opposed to being an adolescent being thrown into adult wards” (Jenny, p.21)

Jenny had previously described how important it was for them to have a plan and know what was happening next.

Although being in hospital took away the pressures of everyday life that was a benefit, nothing changed for Ashleigh in respect to their ability to manage the problems they faced in society and their feelings of hopelessness, meaning that readmission was likely:

“there was that thing of hopelessness of thinking there’s no way my life is going to get any better it’s always going to be this hard no one will help me” (Ashleigh, p.35)

Ashleigh found themselves unprepared to manage in the community:

“I kind of got taken care of and there were no expectations kind of on me um but of course that didn’t prepare you for leaving and having to do everything for myself at all so I crashed as soon as I left again” (Ashleigh, p.37)

Polly found that the transition plans for leaving hospital didn’t work for her:

“it wasn’t even that there was any transition it was that none of the plans were followed through ... the only transition there’s kind of been is you get

I hour leave then 3 hour leave then 4 hour leave then 8 hour leave but I never know what to do with that time because I don't spend that much time in the community (laugh) as it is and with university it was like I'm coming back on that day therefore I come back on that day, I can't stay overnight or I can't do all of these other things that people might be doing um so there never really was a transition" (Polly, p.51)

Polly explains that her cycle of readmissions lasted about 10 years with nothing changing, it was when a suicide attempt that was supposed to be fail proof did not work along with other issues that she felt services finally took her seriously:

"I've just been around in services for a very long time and until September last year I think it took me making a very significant attempt on my life that they couldn't ignore or even say, are you sure you wanted to kill yourself because that was a supposed to be a fail proof and then being kicked out of Uni and being made homeless for them to go hah we might need to do something, it it had been 10 years and that it took them that long" (Polly, p.54)

4.6. Conclusion

Risks for mental health admission are complex and reflect a life lived. Common to participants in this study is the feeling of being different and not accepted but not really understanding why. Support has been hard to access, including due to not being believed or taken seriously and when support has been presented it has not necessarily addressed the problems, which can lead to a sense of hopelessness (Polly, p.35, 55; Ashleigh, p.30, 34, 35, 68). Autism diagnosis can be helpful in forgiving yourself and shifting blame from "yourself", reducing a negative sense of self, but also unhelpful in the thought that things won't get better. An autism diagnosis can also be experienced as a hindrance to getting mental health support bringing the cycle back to being different and not fitting into support systems.

All experiences did not necessarily appear to connect with autism, e.g. Polly's abuse as an undiagnosed small child to teenager, facilitated by her Dad, and being kept out of the Education system is hard to attribute to the vulnerability of autism although did influence a negative sense of self. The negative sense of self that resulted from the bullying experienced by Jenny and Ashleigh and feelings of not fitting in of Max and Rosie could logically be attributed to the difference of being autistic. Ashleigh had the further intersection of being

Trans adding to the level of their rejection by society, intensifying their feeling of hopelessness. For Ashleigh trauma did seem to arise from the vulnerability of being autistic and Trans in the Health and Care systems, e.g. their difficulty in using potentially helpful strategies learnt in hospital due to triggering memories (see chapter 5 s.5.4 p.102).

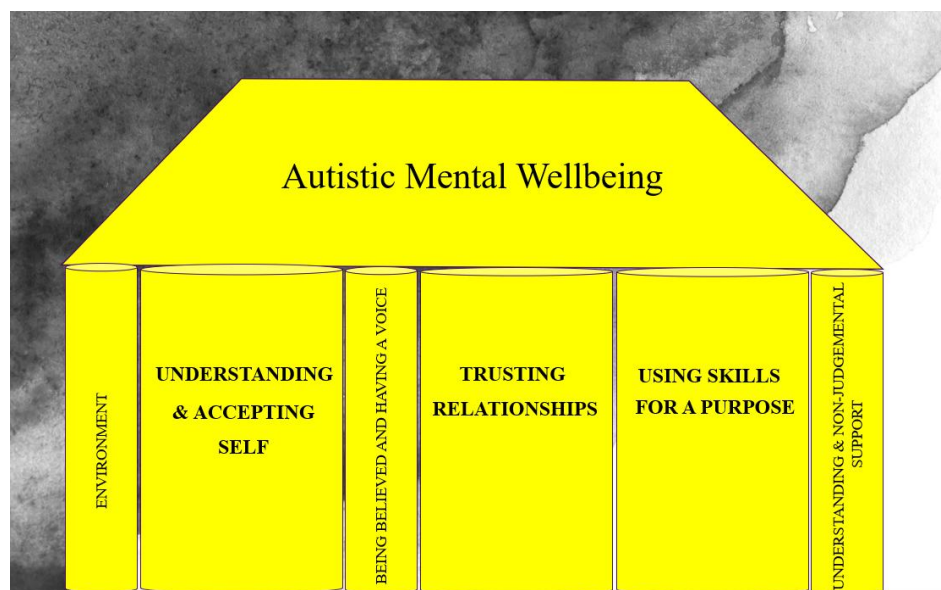
This chapter has considered some shared factors across participants' stories that could be risk factors predisposing them to escalating mental ill health and hospital admission. These factors do not appear to necessarily be due to being autistic per se, rather the problems of rejection or wrongness of being different and not fitting into social norms. This is not just society's assumptions and reaction to differences that are not physically manifested but also the way services are set up to serve the majority of the population and a lack of awareness and understanding of what it is to be autistic. The next chapter will consider protective factors that may help break the proposed cycle of risk and avoid autistic people being admitted into hospital with a mental health crisis.

Chapter 5. Results and Analysis - Protective

5.1. Introduction

In the last chapter it was identified that unhelpful relationships with people were risk factors to mental wellbeing, however, when looking at protective factors it is found that positive relationships with people who try to understand promotes wellbeing. Figure 7 shows the protective themes shared across the five stories. The broader column shapes represent the main shared themes supporting wellbeing, the narrower columns were not shared by all but were strongly represented in one or two stories so need recognition.

Figure 7 Protective factors for autistic wellbeing



The chapter is structured into three main sections (Table 6) containing autistic recount under themes that emerged as being protective for autistic wellbeing. The first describes the shared experience of trusting relationships being supportive and enhancing a feeling of acceptance and validation. The second explores the importance of understanding and accepting themselves. The final section provides insights into how using skills for a purpose is a protective factor. Each section contains illustrative quotes, extended quotes can be found in the appendices (Appendix 9).

Group Experiential Themes	Sub-themes	Sub-sub-themes
Trusting Relationships (All participants)	People Being believed Animals Having a voice	

	Understanding and non-judgemental support	<i>Environment:</i> Staff attitudes Reasonable adjustments
Understanding Self (All apart from Max)	Using understanding of self to know what support from others is helpful Using understanding of self to recognise own state of mental health and develop own strategies Diagnosis as a means of understanding self	<i>Environment:</i> Sensory (Max)
Using Skills for a Purpose (All apart from Polly)	Recognising and using skills Having interests	<i>Environment:</i> Predictability, structure and routine (Polly)

Table 6 Group Experiential Themes (GETs) for protective factors

5.2. Trusting Relationships

Polly had spent a long time finding that people created the problems in her life but had recently realised that although people make the problem some people help you get out of them:

“there are some people that help you to get out of the problem as well and yeah there are a few people who when you just see them or when you hear their voice you are like yep everything’s going to be OK or you can email them and you know that they will help or they will listen,” (Polly, p.64)

Polly goes on to explain that one of the most important things that supports her wellbeing is about five people in her life that she enjoys spending time with who allow her to be herself and speak freely. Her words capture how uplifting, warm and life enhancing she finds interactions with these special people who accept her:

“there are some wonderful like magical people in the world that I think that for the most part I find people draining or they make me grumpy or I don’t understand them but there are about 5 people in my life who I enjoy spending time with and I feel lifted afterwards or there is a quote that’s like, “Have you ever met someone who is sunshine in human form?” and like yes there are some people who are just, I think they get you that is the thing so I think having a space with a person or people who allow you to be yourself but also allow you to speak freely I think that is one of the most important things” (Polly, p.64)

Ashleigh finds the most positive influence that impacts all areas of their life is finding their own family who supports them out of love and love them for who they are. Ashleigh’s birth family had not been able to provide this for them:

“Learning you can choose your own family and one that does accept and support you and really loves you and that was something that’s been so healing and important for me to me to learn that there are people there who like me as I am and that will support me out of love” (Ashleigh, p.114)

In both examples there is the common thread of acceptance and appreciation of who they are, with no need to mask. If there are other people who think you are acceptable as you are then perhaps you can be able to feel more accepting of yourself.

When speaking about what has a positive effect on their wellbeing Rosie also identifies interactions with friends and the chosen people around them:

“I think it is people that I surround myself with and my friends and having positive influences around me” (Rosie, p.36)

Ashleigh found friends and the gay community, who supported their own, accepted them for who they were which was a new and positive experience:

“I found people who accepted me and I started to talk about my autism a bit I had one friend particularly whose brother was autistic and he knew that quite a lot about it and he saw it in me um and I started to talk about this more and people did my friends recognised it and accommodated” (Ashleigh, p.22)

Max explains that, rather than mindfulness exercises, it is positive contact with people that support his wellbeing:

“having contact with people who are helpful or trying to be helpful or trying to be understanding is better than nothing but talking to somebody even if it’s not um changing a lot but having the who understands about the issues and can suggest at least some appropriate ways of managing that would be good um but it’s definitely about having contact with a person rather than a um exercise or something like mindfulness” (Max, p.54)

Jenny gives many examples of positive interactions that have supported her from teachers at middle school, friend in 6th form to, importantly, her first husband who changed her way of thinking:

“he had the motto if life throws you lemons make lemonade you know such a positive person um and so that was a big turnaround for me um and as part of that you know things really moved forward um yeah made massive strides um in terms of my mental health still knowing that I didn’t fit the world quite as I might and should but um or could um but that actually I had a contribution to make um and I could achieve something” (Jenny, p.31)

He was an inspiration to her and his positivity in adversity helped her reframe some of her issues.

Jenny was fortunate in developing close relationships with some of her teachers at school who made person-centred reasonable adjustments for her, some of whom she is still in touch with as an adult. These teachers recognised that Jenny’s difficulties were real:

“they accepted um and acknowledged the real difficulties I had growing up um and the level of bullying these two teachers were really good at not forcing me out onto the playground um and making those adjustments for me” (Jenny, p.7)

Jenny now in her adult life has built a supportive network of people around her. This includes a professional ally who believes her and sticks up for her:

“having an ally who would actually stick up for you and um who believed in you even when you know the schools were being defensive or whatever is

massively massively helpful and I have been fortunate that I had an amazing person work with us and actually was involved in both my girls diagnosis and also involved in the school avoidance situation and I just am so grateful for that person so that's been a real Godsend" (Jenny, p.42)

There is also a trusted non-autistic friend who Jenny can use as a sounding board to provide a neurotypical viewpoint:

"my trusted friend um that's really important to me that I've got that sounding board that's somebody that will actually tell me honestly what they think and if I'm slightly misunderstanding but equally telling me when I'm not um because it's the trust in that that's really important cos I need to be able to trust that I'm going to be given the truth" (Jenny, p.41)

Jenny also has autistic allies through work and she describes the sense of belonging and peer support they get across the team:

"I do have autistic allies because I have those through my work so I've kind of described that within that the fact that my work and my life is surrounded by autistic people I'm fortunate I have that sense of belonging and community through that that's brilliant ... actually that sense of belonging and that peer support that we get through that ourselves is brilliant and the ease of communication" (Jenny, p.43)

Further evidence of the importance of support provided by connecting with others comes from artefacts that Jenny and Polly shared when telling their story and explaining about maintaining wellbeing. Both participants had small soft toys with them when they were inpatients that represented connections. Although Jenny didn't get on that well with her Dad he gave her a dolphin (Figure 8) that she took everywhere with her because it gave her a sense of connection and security.

Figure 8 Participant Image - dolphin giving Jenny a sense of connection and security!



“I didn’t have a good relationship with my Dad as I’d mentioned and he had sent me this dolphin and so I took to wanting to take this dolphin everywhere with me and it was around for me in my brain I guess it was around that connection and wanting to feel that connection and know that they’re there” (Jenny, p.21)

5.2.1. Being believed

Polly had a tiny little lion (Figure 9) that a counsellor she worked with for a long time when she was lacking courage and trapped in her past life gave her when she went to university. Polly took this as a comfort object to every lecture and with her when she was admitted into hospital. The lion was given to her to have something that was hers and to give her courage. For Polly the little lion also represents the belief her counsellor had in her, that she could see good in her that perhaps wasn’t clear to Polly herself at the time and held hope for a brighter future.

Figure 9 Participant Image - Matilda, the very small lion representing a very large amount of courage!



“I think she made all the difference because she believed in me and it wasn’t it didn’t matter what I threw at her, not literally I didn’t actually throw anything at her (laugh) but metaphorically, that she still sort of stayed solid and stayed in my life and kept telling me that she could see something in me that I couldn’t see and so she she always used to tell me she was holding the hope and I think that’s kind of what the lion represents as well is that sometimes people can see things in you that you can’t sometimes they’re not good things (laugh) but most of the time people do want good things for you” (Polly, p.66/67)

Another of Polly’s artefacts also represents the kindness people can show to her. She had a really bad day on the ward because it was very loud. She was stressed and rocking and bit a

hole in her tongue and had also, without realising it, ripped the head of her dinosaur which was a sensory object. A member of staff was going to throw the head away and Polly was so distressed and crying at the thought that the dinosaur's head was going. Their rationale that the head had to go was that Polly might swallow it or use it to harm herself. The cleaner then offered to mend the dinosaur for her but Polly couldn't believe that could be done. The cleaner asked one of the ward staff whether she could staple the head back on but was told no because Polly may ingest the staples or put them in her body. Polly said she wouldn't and had never done anything like that, the cleaner believed Polly and trusted her not to break it again and went ahead and mended it (Figure 10), putting herself at risk of getting into trouble. Polly felt touched that they had done this and argued for them over something that appeared insignificant.

Figure 10 Participant Image - repair of sensory dinosaur, staff believing and taking a risk on Polly



“you are so used to not being trusted at all like nothing you say nothing you do is trusted and to have someone yeah trust that is amazing.” (Polly, p.68)

Polly emphasises the difference it makes when people see good in her and take a risk in trusting her at different points in her story, including other examples when an inpatient:

“a nurse ... said to me are you going to go again if they let go? And by this point I just said No, I haven't got anything left in me to go and she told them to let me go and I don't think they knew what to do and at that point she was like she doesn't lie, she is not lying, let her go, and they did and I think that's like it someone trusted me someone saw a good thing about me and took a risk a big risk (laugh) on me that that makes such a difference” (Polly, p.34)

She also has found that the most understanding staff who make a big difference come from unexpected roles:

“when I was on the female ward before that for quite a long time she used to hide biscuits on her trolley and give them to me because there was only one biscuit that I liked and she would walk me up and down the corridor, she would let me push her cleaning trolley because I’d just I really like I think it was the weight of it the pushing through really helped um and if I was like really stressed and she could see that she would go in my room and get my blanket or my weighted blanket or get one of my sensory objects, staff didn’t notice, or she’d come and be like the fire alarm’s going to go off in 10 minutes we’ve just been told go in the garden, and you think she wasn’t clinical and she was the best member of staff without a doubt there and that made a big difference.” (Polly, p.44)

If other people go out of their way to care about her, believe that she won’t abscond or harm herself, see something good in her, perhaps she can then start to interpret herself in that way, see herself as someone who is trustworthy and a good person. From the previous chapter we hear Polly, when trying to work out who she was, worried she may be a psychopath. The way people react to her, showing trust, is a positive for Polly challenging a possible negative identity as she develops understanding of herself.

Max summarises what is beneficial from ward staff:

“it was just about you know um being a nice human being” (Max, p.51)

5.2.2. Animals

It was not just trusting relationships with humans that were found helpful. Polly and Max both used photos of animals (Figure 11, Figure 12) they felt a connection and bond with to explain their wellbeing in relation to non-judgemental relationships. There is no need to mask with an animal as they accept you as you are.

Figure 11 Participant Image - Sid, the chihuahua PAT (Pets as Therapy) dog.



“the amount of times that I have talked to that dog, cried at that dog, hugged that dog, patted that dog um and yeah it’s a soft sensory tactile thing but it’s just also a a creature that seems to just get you and won’t judge you” (Polly, p.44)

Max found the affection from the cat gave him hope for communication and a warm connection of reciprocal friendship:

“I’ve not really had a friend before whereas this was somebody that clearly wanted to be around and was was happy to interact and understood and I understood him” (Max, p.59)

Figure 12 Participant Image - semi-feral cat that used to live near Max's office.



Max refers to Cat as ‘somebody’ and in the photo (Figure 12) Cat has adopted a human type position. There appears to be some anthropomorphising of the genuine connection between

them into Cat being a human friend. Whether or not this is so, Cat and Max choose to be together because they take pleasure in each other's company which is affirming for Max. Max, like Polly, also appreciates the tactile bond, continuing the anthropomorphising:

“and perhaps the biggest thing was um just the contact like I was saying before about hugs um having somebody who was sort of physically affectionate and would sort of stick his arm around my neck and his face into my chin and purr and sort of be happy to see me” (Max, p.59)

Although Max and Polly specifically mention these animal relationships as protective factors for their wellbeing, spending time with animals does feature in all the interviews. Rosie being with her tortoise, Ashleigh with their cats and Jenny with the rabbit, all appearing to be positives in childhood.

Ashleigh explained that their relationship with their birth family was not satisfying but they enjoyed their cat's company and the comfort he gave,

“we got twin cats for our birthdays one year when I was six and he was like my best friend and I have always been that kind of as I say I think that is something that was quite stereotypically autistic or just kind of other child I always enjoy being with animals it is like now I just live with pets, I prefer pets to human housemates, um and yea that was the case even as a kid and I did take a lot of solace and like I would just hang out with my cat” (Ashleigh, p.4)

Jenny has positive memories of spending time with dogs when she was young:

“we had German Shepherd dogs like when I was a toddler um and um and I used to sit and read to the dog” (Jenny, p.5)

Jenny now uses support provided by her Assistance Dog rather than formal support from professionals. The dog gives confidence in going out, is a conversation starter and going out for walks not only encourages physical health but also promotes emotional wellbeing by providing time to regulate:

“Daisy, the dog (laugh) she's definitely a big support in terms of everything both for the girls and for me um and just the confidence to go places and then a conversation starter because actually those oh small talk's really frustrating get me talking about autism and I'm fine um making small talk

is not something I'm comfortable with at all but everybody talks when you've got a dog don't they um and everybody makes that initial contact that saves us having to do it for ourselves which does help ... I can just walk Daisy as well so that's always a good thing it's so she is good on a kind of to actually support you but also as an emotional wellbeing perspective of you know getting out and having that time and using it as a regulation strategy" (Jenny, p.40/41/42)

Trusting relationships with an understanding human who they can be themselves with or with an animal who connects with them can both support wellbeing. Being accepted by others promoting acceptance of self.

Ashleigh puts this in context, inferring that it is quality of relationships rather than quantity of interactions that benefit. These interactions may not be as often as typical for non-autistic people. They warn that neurodiversity needs to be understood more, difference being accommodated rather than judged with an expectation of conformity, so you can accept yourself or be accepted by society as you are:

"I see these wellbeing calendars sent round... like happiness project ... and stuff like that and they're all about kind of like a month of interacting with people cos interacting with people is good for everybody's happiness I'm just like if I interacted with people that much that would have a detrimental effect on me and there isn't that understanding of neurodiversity within that and the same things are not good for the same people and it does seem to be very much blanket assumptions ... and also my experience of it being based on yeah conformity which links into that it was like the thing of like dressing in a way making an effort with your appearance means you are well whereas actually that's not the way" (Ashleigh, p.109)

5.2.3. Having a Voice

Fitting within a trusting relationship theme for Polly was the difference to her now she has been given a voice:

"what's really changed is I have a voice now before I didn't have a voice at all and I was too scared of offending anyone or saying the wrong thing and, but I think that's changed in like the last year or the last 2 years it's having been given a voice I suppose or given a platform and having found people who are of similar opinions or finding legislation that backs you up there I

think that's made a big difference to me and I also know that I don't I don't 100% feel like I have what they call a meaningful life or a life worth living right now but I think more so than I ever have" (Polly, p.56)

This experience for Polly seems to have had such an impact on her wellbeing that it is important to include, even though having a voice was not mentioned specifically by any other participant. On meeting to discuss the analysis with the participant, Polly stated that she thought having a voice was the main thing and being interviewed as an autistic person was giving them that. She explained further that the opposite, which is not being heard, was detrimental to their wellbeing, for example disclosing her difficult situation at home was not listened to by school (3.7.3).

5.3. Understanding and non-judgemental support

Countering the unhelpful support not addressing needs in the risk section, what the right support people hope for is touched on. Max in particular often mentions that support should be understanding which links to establishing a trusting relationship:

"at the simplest level somebody who understands and can at least suggest appropriate help would be the biggest thing" (Max, p.54)

and non-critical,

"somebody was wanting to help me and doing it in a really positive and understanding way made a huge amount of difference you know just the fact that somebody wasn't criticising me but realised I might have difficulties with things um and was helping me through the process without being condescending" (Max, p.45)

This reflects the importance of staff attitudes, what is helpful is giving the feeling that they care, want to help and the person is not a burden, as well as believing the problems faced by the autistic individual. There is a sense that being patient is important and providing reasonable adjustments of breaking a task down and allowing time, illustrating understanding of the individual and person-centred care.

5.4. Understanding Self

All participants, apart from Max, found that understanding themselves was a protective factor. Out of these, three included getting their autism diagnosis as a feature towards that understanding. The importance of understanding self was the subsequent knowledge of how

to support themselves, knowing what helps, with an impact on self-efficacy and self-acceptance, as well as understanding how others can support them:

“I think the right support has to start with you knowing yourself so if you had a diagnosis then actually that’s about you having that knowledge of your own needs um and your own differences and from there you can build your self-acceptance which in turn enables you to move forward” (Jenny, p.24/25)

“I think I have a better understanding of myself and a better understanding of like when what I need to do so if I’m in burnout I can now recognise that and work out why, I’ve now got strategies like putting a colour for each day and then looking back on the week and be like well you’ve had 7 red days it’s no wonder you feel like this” (Polly, p.56)

Polly’s quote not only illustrates how understanding herself is of benefit in finding strategies to support herself but also self-acceptance and forgiveness for feeling a certain way. Self-forgiveness is also an important factor for Jenny:

“for me that self-acceptance was huge in terms of accepting the things that I find difficult and that being a stepping stone to overcome some of the things that I find hard I’m still having bad days but then actually forgiving myself for a bad day it’s OK” (Jenny, p.25)

Like Polly, Ashleigh also wasn’t recognising autistic burnout and this now adds to their understanding of themselves, and implications for their mental health:

“another thing was like that I didn’t even know was recognising autistic burnout um kind of the everyday stuff and the extreme stuff and how that differs from clinical depression or can go alongside clinical depression stuff where rather with me it was kind of like well it’s not quite depression so therefore that just means you are really not that ill whereas actually it was just that it was more of this extreme burnout which was that severe but it didn’t quite fit kind of other diagnoses um but was severe enough to have affected my mental health” (Ashleigh, p.89)

It is not just the understanding of self to recognise own needs but also the recognition that these needs should not be ignored if wellbeing is to be protected. This message is highlighted

by Ashleigh who explains that autistic need unrecognised by society can result in non-acceptance and trauma:

“it’s not healthy to condition someone to ignore their own needs I mean it is something my parents did a lot but they did even more in hospital and that has been really difficult for me to learn to unlearn some of that um where I had to because of the risk kind of learnt to ignore my pain to ignore signals from my body to ignore my own distress and to hide that and yeah it just leaves you traumatised” (Ashleigh, p.94)

Ashleigh found that learnt strategies were difficult to use because of the context in which they were learnt. Since they were associated with accusations of pretence and traumatic episodes in hospital, using potentially helpful strategies taught there brought back feelings of distress which were not easy to overcome:

“I found it really difficult to start using them again because although I find it helpful it is linked up with that this is you acting out and trying to be attention seeking and the thing of it and learn that actually it is OK to use something” (Ashleigh, p.92)

They found writing (Figure 13), which had a positive reintroduction for them, worked in a therapeutic way:

“writing ... is something I started again in an um it’s actually because my partner does it and she got me on to a writing conference with her creative writing and I remembered how much I used to enjoy it but that I got put off because I didn’t do it in the way school wanted to grade ... I started then using it doing some morning pages exercise where you write just a stream of consciousness um and it’s supposed to be a writing warm-up therapy but I wrote it down actually in a therapeutic way it helped well” (Ashleigh, p.110)

Reading words they have written themselves enables processing, allowing the opportunity to move on rather than getting stuck in negative spirals:

“when I write I mean I’m a visual processor so it helps me process by having it in words even written by myself but yeah I can be clearer and I don’t get stuck on one point in the same way because I’ve seen I’ve written that point that point is clear on the paper I don’t it’s easier for me to move

on from it if that makes sense I don't get as stuck like I do on a thought or even speaking it um so I'm able to work through things helpfully so I do use journaling now for working through anything" (Ashleigh, p.111)

Figure 13 Participant Image - Ashleigh's journal



As Ashleigh's therapy was coming to an end it was realised that they were able to figure things out for themselves after talking for an hour, so replicating this in writing could work the same way. The success of this was empowering for Ashleigh and gave them confidence that they could work through things themselves without relying on professional support:

I write on a page and I found I could do that I could take something I'd feel it and write in it ... it's the empowering thing of being able to deal with it myself too and that I'm not reliant on finding a carer who has some understanding of me (laugh) and to support that so it gives the kind of confidence to work through" (Ashleigh, p.111)

Jenny describes needing support but also knows that she is capable and can achieve things in her own way:

"I think I utilise a lot of support I still need a lot of support for various aspects of my life but I am also conscious that I'm also very capable and have lots to give but it's just that I have to find my way of doing those things sometimes" (Jenny, p.40)

Jenny understands that she needs to protect herself from situations that can be very emotive as this could cause an escalation of emotion resulting in feeling out of control. Knowing herself in this way enables her to be prepared and put strategies in place, such as having the right people around her, to keep herself safe.

“I have to ... be mindful of putting myself into those positions where um I kind of feel that the emotion might take over um so but it’s something that I can more easily manage or I try to put support strategies in place or the right people to support me in this moment if that makes sense” (Jenny, p.11)

Both Ashleigh and Rosie, although they find friends can support their wellbeing, stated that they didn’t want to be with friends all the time. They feel more comfortable with a small group of friends rather than a large crowd that caused sensory challenges and need to be selective to the amount of input they expose themselves to protect their wellbeing:

“I could find somewhere quiet to go there and kind of with my group of friends” (Ashleigh, p.9)

“(had friendship group) much later in secondary school um probably like the last two years. Um but even still I was quite selective as to when I’d sit and you know have breaks with them and stuff like that. I’d still spend a lot of my time in the library and using that as my excuse not to sit with them as they would sit in a noisy area normally.” (Rosie, p.12)

On meeting with Ashleigh to discuss the analysis of their interview they took this point of needing time alone further, explaining that living on their own is a protective factor and is what enables them to have healthy relationships.

Since school days Rosie has been able to use strategies to support her sensory needs:

“I always wore leggings underneath my like school trousers always wore a T-shirt or like a vest top underneath um my uniform cos I just couldn’t stand the touch of it it would you know by the time we got to the end of the day I would literally want to be ripping the clothes off me” (Rosie, p.7)

She made her own packed lunch for school so she was able to ensure food was separated, packed lunches also avoided noise of cafeteria and uncertainty of what food would be available there:

“I’d pack my own kind of packed lunch um because I eat the same foods the uncertainty of what the cafeteria might be kind of making was always kind of too challenging for me ... I could pack it in the way that I liked it meant that I knew that certain foods weren’t going to be touching and all of

kind of those kind of those sort of things that add an extra element of anxiety to the day. It ... also meant that I could avoid the cafeteria ... having a packed lunch meant that I never had to go in there um so it kind of got rid of something that would have been extremely stressful for me.”

(Rosie, p.9)

When Jenny was in hospital, she was introduced to distraction to maintain wellbeing and regulate and still uses this.

“I was allocated a one to one ... I really enjoyed them the distraction element the playing games so they’d play cards and stuff we’d do that sort of thing that worked well for me and it’s something that I’ve that was the one thing I really learnt from that hospital admission was that um I use distraction to maintain my mental health or my regulation um ... and I still do although you know in different ways so you know the reason that my diary is is full is because I don’t allow myself that time um to just sit with I have to fill every moment because that’s how I cope” (Jenny, p.18)

However, as Rosie reminds us, (4.5.1 Rosie p.25) there can become a point in deterioration of mental health when distraction techniques may no longer work. Jenny has also found that food is a helpful strategy for her in managing social occasions but realises that this could be a barrier for others:

“things that involve food um are usually my safe coping strategy food is my um my way of coping with social situations and um and I make a bit of a joke about it ... for me it works as a as a something to help me cope with that interaction and it breaks things up, for other people it’s a stumbling block and I get that” (Jenny, p.44/45)

For Jenny, food, in a social situation is helpful because it takes the focus away from completely being on conversation and gives brief respite from the intensity of interaction while you eat.

5.4.1. Understanding self to know what support from others is helpful

Part of understanding yourself includes being able to tell professionals what works for you.

Ashleigh keeps a close eye on what medication is prescribed because they have had such bad experiences:

“obviously something I’m very aware of is (laugh) what medication I should be given um (laugh)” (Ashleigh, p.101)

5.4.2. Understanding self to recognise own state of mental health

Along with understanding self is the recognition of when mental health is deteriorating:

“I think the test for me is how in control of my mind to I feel ... if my mind feels very full and chaotic and I can’t concentrate very well or things like that are signs of my mental wellbeing not being great ... if like I can’t quieten my mind down then actually I need to do something to look after it” (Ashleigh, p.110)

“I guess the one thing that I can kind of use to explain it is my autism versus my OCD um like every day I’ll put on a pair of socks and those socks need to feel right for my autism um and if they don’t feel right I might have a meltdown or simply decide not to wear socks. Um however like for my OCD I could put on those socks and then intrusive thoughts come in which will make me panic and um think that something bad is going to happen and then I’ll act on those. Um and it will be more kind of catastrophic um when it’s my mental health than my autism” (Rosie, p.34)

Figure 14 Participant Image - Rosie's perfect sock



“an example of my perfect sock (Figure 14), one where seams aren’t too big and the seam at the top is very tall, as well as being a sock that comes high up the leg so there’s no gap between trousers and sock.”

Both Rosie and Ashleigh recognise that when their mind is feeling out of control, “chaotic” or “catastrophic” it is probably more of a mental health issue than autism, and with that comes the recognition of what support strategies may or may not be helpful. Rosie finds it takes a lot of effort to keep everything in balance and not let things get too much, to support herself she finds routine and structure very useful:

“I think having my routine and structure and you know knowing what’s going on and things like that is probably most important to me because without those everything seems to go a little bit, bit the wrong way should we say (laugh)... so I tend to make a schedule for the week and factor everything in that needs to be factored in” (Rosie, p.35)

5.4.3. Diagnosis as a means of understanding and accepting yourself

As described in the previous chapter receiving an autism diagnosis can be negative, connected with a feeling that things aren’t going to get any better, the stigma of stereotyped understanding, and can be a barrier to receiving mental health support.

The other side of this is that a formal diagnosis can promote self-acceptance, Jenny explains:

“you can’t access self-acceptance if you haven’t actually had it confirmed that you’ve got a diagnosis” (Jenny, p.25)

This infers that self-diagnosis would not be a means of self-acceptance as it is not endorsed by a professional diagnostician, it could rather be construed as an excuse, or not be true, so a negative rather than positive aspect of themselves.

Rosie also found self-understanding came with her autism diagnosis:

“I think the main thing for me was getting a better understanding of myself and being able to put the pieces together to understand why I’m different” (Rosie, p.15)

She did say that most of the people around her thought she may be autistic before she did and the diagnosis didn’t make any difference to relationships:

“I’ve always been autistic so they’ve only known the autistic version of me it’s just that now there’s a name to it.” (Rosie, p.17)

Ashleigh experienced both sides of the feelings around diagnosis having been diagnosed autistic twice, they concluded after the second diagnosis that it helped with self-understanding and was protective:

“I’ve not had any big mental health crises or admissions or anything since then because it was so specific around a lot of stuff from then but I think a lot of it too is that I’ve learnt a lot about myself as I say some therapy was

helpful despite all this um and knowing having my re-diagnosis helped as well and knowing triggers” (Ashleigh, p.100)

Connected to the self-acceptance comes self-forgiveness and a more positive sense of autistic self. Polly particularly mentions that her diagnosis enabled her to give herself “*a bit of a break*”, shifting her feelings about herself as someone who is broken and wrong to someone with permission to make mistakes because they are autistic and think differently:

“give myself a bit of a break and to have words for things like learning things like meltdowns, shutdowns, um just burnout, autistic burnout that I wish I’d have known um because it all just went down as not being able regulate or then is that a personality disorder, is that emotional difficulties...” (Polly, p.25)

Like Polly, Jenny found that accepting herself as autistic, and being comfortable with that, stopped her being as hard on herself. Being autistic gave her an explanation of what had happened in the past, enabling her to release feelings of self-blame and enhance self-acceptance:

“there was this kind of realisation that actually yes autism is the answer um is the explanation it is the the kind of reason behind everything” (Jenny, p.33)

Jenny also considers that her feeling comfortable in her diagnosis and others accepting and feeling comfortable with it, can allow support to be effective. Disclosing her diagnosis can make other’s perception of them change and hence their expectations of how she will behave and how they may interpret that:

“I think that knowledge of having the diagnosis and being comfortable in that and other people being comfortable in that is the key to getting the right support in the first place” (Jenny, p.25)

Polly warns:

“some people seemed less difficult when you’ve got the diagnosis, some people (laugh) seemed a lot more difficult” (Polly, p.22)

this is presumably because of the different knowledge and interpretation of autism that people have who interact with her.

It is Polly who describes the most positives of receiving her autism diagnosis however, she outlines how it enabled her to find like-minded people,

“It allowed me to kind of find my people online and through other means, autistic people” (Polly, p.25)

access education more successfully:

“I get an autism mentor ... she helps me with peer relationships, she helps me just think things through, to work through my To Do lists and all of that, it’s amazing. Um I also get Study Skills, someone to help break down my assignments and things.” (Polly, p.23)

access the local NHS autism team:

“it’s given me access to ... the Autism, ADHD and Tourette’s Team ... being able to see the autism OT and having had those sessions um. In terms of like psychology with the counselling psychologist who works for them was very different experience” (Polly, p.23)

people understanding them more when known as autistic:

“having people who understood that I can’t talk to you right now because my socks feel wrong on my feet and them saying, “OK, shall we take them off?” Just this understanding and empathy that came from it was incredible!” (Polly, p.25)

also, able to have a Care and Treatment review (CTR):

“I’d never had a CTR before because I hadn’t had the diagnosis and just knowing that there are those things in place or yeah that was it it really I I genuinely think getting an autism diagnosis has been one of the best things that has happened for me, to me, however I want to phrase that um I just wish (laugh) it hadn’t taken so long.” (Polly, p.22)

Polly wishes she had had an autism diagnosis at the beginning and wonders whether things would have been different for her if she had:

“I think the thing that would have helped me at the beginning was to have an autism diagnosis (laugh) and to have people around me that were better understanding because I think since since I’ve been diagnosed I think I’ve

had less - less admissions (laugh) who knows I mean I might not have but... ” (Polly, p 56)

Instead of Polly thinking the answer to not fitting in and the world not working for them is killing themselves, understanding that they are autistic gives them permission not to try and do what others do and society expects if it is not for them, which was liberating:

“having it explained to me that you don’t have to fit that kind of mould and it makes sense the DBT didn’t work it makes sense that their sleep hygiene stuff doesn’t work because for me I go to bed at about 6pm and I will get up at 3 or 4am and that works for me because I’m exhausted (laugh) by that point after having peopled but then in the morning my brain is so alert and the world is so quiet that that works for me yet I’m sure if that was written down somewhere they would say that was an unhealthy sleep pattern or something I don’t know I get enough hours that’s all that matters” (Polly, p.56)

“a really eye opening thing for me was the first time to have someone going well stuff it you don’t have to do that, normally it’s people being like well have you got a boyfriend yet are you ticking this box yet and have you done this yet and this is how things are so you need to fit that mould to have someone going, no, do what makes you happy and yeah I think having that, if I’d have had that when I was 14, 18 I don’t think I would be in this position today” (Polly, p.57)

An important aspect of understanding self in this theme is that the understanding of self is positive in that it is forgiving and accepting, as well as acknowledging that help may be needed and what help is likely to be effective, whether self-help or outside support.

Even though you understand what helps you, if that is not available to you it is not protective. Max realised some sensory needs and what suited him as a child:

“with sort of all the moving around the places I sort of felt most at home were perhaps coincidentally the (laugh) places where I used to wear the least amount of clothing so um basically sort of hot places and the life style that goes with that um were something I particularly kind of fitted ... and with all the sort of little cultural things that go with with having extreme temperatures in the day and um and you know the fact from May to

September you're not going to see any rain it's just a fact um yeah it just I I mean kind of thinking about it now maybe it was the predictability of stuff like the weather seasons and the way the day goes that help a lot as well but um either way sort of physically and and and to a limited degree socially (Max, p.15)

but wasn't in control of where the family settled and they came back to England with unpredictable weather, varied seasons and not consistent warmth to wear minimal light clothing. Max also found military school worked better for him as the families had a shared existence with a rigid societal structure. There was an emphasis on physical activity that also suited him:

"just the whole the fact that everybody's Dad wore the same uniform and went to work and did the same sort sorts of things um and you kind of knew that everybody had a common sort of essentially everybody's parents were kind of like sort of the same um so you kind of knew everybody had a shared experience of that um and so just just existing in that environment was much more comfortable um but also there was a bigger emphasis on um more adventurous sporting kind of things so um because it is a big thing in the military" (Max, p.7)

Action and doing practical things were where Max was in his element rather than in the classroom. This self-knowledge didn't seem to influence his adult life apart from finding structure and routine in the world of work:

"go to work leave work come back go to sleep go to work thing it just life went on" (Max, p.39)

5.5. Using skills for a purpose

Another protective factor mentioned by Rosie, and particularly Max and Jenny, was finding your niche, what you did well, and using that skill for a purpose.

For Max, his interest in early computers from his schooldays not only was a cause of fascination but also instigated social interaction and ultimately his working life. Max describes this fascination in school led him to be part of interest groups with peers whereas outside this he did not feel accepted:

"it was people that I had some kind of shared interest with um that we'd sort of get together because of that so um it was sort of early days of

computers um sort of swapping games tapes and things like that and sort of because it was such a new thing sort of passing knowledge between us um but um yea that was very much more a practical thing than a personal thing” (Max, p.6)

His interest had a positive impact on other aspects of his school life in that he was able to do well in lessons such as Design and Technology which involved creativity and working things out yourself rather than being taught. As the technology was emerging it was new to everyone including the teachers:

“Design and Technology was a sort of a thing that was taught which was kind of a combination of woodwork and metalwork but also of actual inventing of things and then and then making the things that you thought of ... there was more a kind of creative side to it um and particularly with the computers because effectively the teachers weren’t that much more clued up than anybody else” (Max, p.11)

Max took advantage of opportunities to get more involved and started developing the skills that led him to his career:

“it was a chance to quite involved with that um and helping out with the sort of computer based side of things and maybe having a bit more exposure to it than than um just in the lessons um so sort of combination of technical um creation and then also dealing with computers something that sort of er (laugh) has put me where I am today if you like in that it’s - took a while to sort of focus things down but um I’ve ended up sort of using those particular skills um where I am now and that seems to be where I kind of fit” (Max, p.11)

When Max was in between jobs, the transition was helped by his keen interest in computers and computer animation:

“one of the things that kind of smoothed the transition from the TV to the games thing was that I had always been interested in computers and a big thing that was taking off in the sort of early nineties was er computer animation was becoming something that you could do with machines that didn’t cost hundreds of thousands of pounds ... there were some sort of

leaps in the technology and the software and I started to get into post production through the animation stuff” (Max, p.21)

Figure 15 Participant Image - Max's first computer



This early computer (Figure 15) represents for Max the idea that autistic thought processes can be restrictive in managing life but are very positive in creative thinking patterns for innovation and this is what he is good at:

“I started to realise that I had an ability which could be which I was good at and could be used for things um and which now at this stage in my life I am making a difference by applying it um so it was kind of um a practical um example of how autistic thinking can actually be a really powerful thing because um the sort of logic and analysis that’s required ... I seem to have an aptitude for it that’s based on my er on my thought processes that otherwise seem like quite restrictive but actually this is one case where they’re actually very positive things” (Max, p.61)

Max explains that the most positive influence in his life has been realising his strengths, which is part of knowing himself, and using these capabilities in a purposeful and useful way:

“realising what my capabilities can’t think of the right word skill set isn’t quite the right thing but kind of understanding what I can do that’s useful is probably the biggest thing that makes a difference in that it helps give structure and meaning and pleasure um and what’s the word ... um ...a sort of feeling of safety if you like that you understand the issues rather than you just be pushed around by events that you know that you’ve certain

things that you can control and they will help in a positive way for at least some parts of your life” (Max, p.55/60)

It appears for Max’s wellbeing it is important for him to feel he is useful and not a burden, using his skills for a purpose promotes this giving self-worth, confidence, a sense of security and of being in control.

In his TV job he describes, *“I kind of like found a niche there”*, (Max, p.9) working in computer games for 25 years he found, *“it was a situation that I kind of fitted”*, (Max, p.20) this implies the importance for Max of belonging, being part of a group with a purpose and giving something useful to the whole,

“(work) giving me a reason for existing um and was making me feel like I had a use” (Max, p.40)

Like Max, Rosie did not experience success in lessons at school apart from in engineering where the teachers’ opinions of her were the opposite to those for other subjects:

“I went to a specialist engineering college well secondary school and yeah, I loved it. I understood it, it makes sense you know something either works or it doesn’t and um I guess it was my chance to excel in school um which I very much did. I was the first student to get 100% on the double engineering GCSE and I was recognised as one of the top engineering students in the UK” (Rosie, p.12)

This skill led Rosie to a successful career in kitchen design from an early age:

“I think it was quite easy for me to transition into work um because I had a job I knew what I needed to do um and it was something that I enjoyed.” (Rosie, p.12)

Rosie enjoyed the routine of work and although kitchen design is not what she does any more her skills are still sought, indicating a positive sense of worth and purpose:

“ten years I was doing it um but I did about four years doing commercial kitchen design um and then the rest of the time I was doing domestic um so and yeah I whilst I don’t do it any more ... somebody that I used to work with in commercial kitchens and started up his own business um and he still comes to me and says, “Ooh, could you do me a visual?”” (Rosie, p.14)

Both these examples of working life involve using the person's skills and interest, for Polly working in a Garden Centre interacting with customers was a negative experience causing anxiety. The stories from the participants in this study indicate that it is not work or employment per se that is protective but rather using your skills for a purpose.

The theme of using skills for a purpose is not just limited to paid employment or the world of work either. For Jenny and Rosie using their experiential knowledge to help others is important to them:

"it's (autism diagnosis) also given me a chance to help other people um which has been really really nice" (Rosie, p.15)

Jenny explains that a coping strategy of hers is to intellectualise and learn about mental health and disability and use that to help others:

"one of my coping strategies in life is intellectualising and learning um about um those things that I've experienced so I will you know do everything I can to learn all about those experiences and the pathways and the um the strategies and then use that to help others that's the kind of way I operate" (Jenny, p.31)

Ashleigh experienced success working in a care home, they connected with autistic clients and wanted to help them be understood as staff were not seeing their potential:

"I did get on with autistic people and like I went in to work working with young adults um with learning disabilities and autism into a care home and I was kind of ended up being the autism expert in some ways that I came to in that if something had upset one of our clients ... like a break to the routine that someone else thought was insignificant I understood how significant it was or a sensory experience or um something else I could spot what was upsetting" (Ashleigh, p.25)

These enjoyable interactions with autistic people and a wish to upskill staff inspired Ashleigh to pursue a career in Speech and Language Therapy, showing self-determination:

"it did fuel me to like do my speech and language therapy particularly I wanted to educate staff and for people to understand that it wasn't communication wasn't all about speech and that a lot of what people saw

as behaviour, challenging behaviour, was because of miscommunication um and often people not understanding” (Ashleigh, p.26)

For Max, he could play the guitar (Figure 16) and was invited to play in a band from work when their bassist left. Again, Max describes the sense of belonging with everyone working together as a team with their own discrete role to create the whole process to performance:

“everybody taking a role whether it was a PA or a cameraman or a vision mixer whatever um you’d put it you’d plan it put it together execute it ...that was a really good experience” (Max, p.23)

Also, matching Max’s skill set, was that the band created its own material rather than playing other people’s compositions:

“being sort of creative was a was a in a sort of artistic way rather than anything else was a good experience” (Max, p.23)

Figure 16 Participant Image - Max's guitar, represents finding out about non-verbal communication, creating a sense of belonging and connection through using music as communication within the group



“finding out about not verbal communication that I was capable of it that it was a thing yeah that was that was quite a huge um a huge discovery that um before I’d kind of not even realised that there was non-verbal communication if you like and all of a sudden was able to speak and listen without actually saying anything or you know could communicate information” (Max, p.57)

For Max, his guitar symbolises the revelation that you can share communication with others non-verbally, to be able to speak and listen and share information two way without words was a profound discovery for him.

As a band member Max had a link into social groups and went to quite big parties and pub gigs with a purpose and a positive role:

“being in a social group of some kind in a meaningful way for once” (Max, p.23)

Jenny found scouting a positive experience, it had a clear purpose in that it had badges to earn:

“I read the proficiency badge book on the first night pretty much from cover to cover um I wanted to earn all of those badges um that was the mission for my scouting um which I set about and did pretty much” (Jenny, p.15)

She was able to use her strengths, such as organisational skills and communicating with adults, to experience success not only in achieving proficiency badges but also as a patrol leader:

“had the patrol leader’s council meetings so I was able to be the minute taker in meetings I’d naturally take minutes anyway ... that was just who I was it fitted really well I was able to represent at county Patrol Leader’s Council PLC um even went to national PLC um and it was those roles were then you representing young people with adults um so from 12 I’d been doing that I was giving a voice to young people but with adults so it was communicating with adults love it always really liked it it was the peers that was the problem ... I was able to kind of organise the activities all of that stuff um and I can do that well um so I became quite popular within my scouting because I generated a good programme and got them all badges and all that sort of stuff” (Jenny, p.15)

These achievements were recognised and celebrated and there is a sense of pride in Jenny’s recount of scouting:

“I got my um one of my er scouting awards and a couple of people came over and presented it to me in hospital cos I wasn’t able to go to the

presentation like they wouldn't give me day release because they considered me still too much of a risk I was in ICU at the time um but they um they allowed them to come onto the hospital and present them there so that was really nice" (Jenny, p.15)

That the award was presented in hospital seems important to Jenny and a reminder that she is not just a mental health inpatient but a valued and successful member of the scouting community.

As an adult Jenny has founded her own charity to support autistic families, she has found this an enormous positive, feeling proud and fulfilled to hear feedback that they are making a real difference for people:

"it means a lot to me to see those reviews that feedback see kind of things changing and people's appreciation for something um you know it's brilliant so I'd say that's had a massive influence and it's also given me you know selfishly it's given me a job and a purpose" (Jenny, p.46/47)

5.6. Conclusion

The protective factor that seemed to come through all the stories was understanding and trusting relationships with others, how they themselves may not really understand others and how others may not understand them, but how others interpret and interact with them translates to how the individual interprets themselves. It was the understanding and acceptance that creates the trust as Polly described when checking the analysis of her story. In addition, the importance of using their skills for a purpose and not being a burden also impacts on how they feel about themselves; this is very strong for Max and Jenny, but also Ashleigh speaks of feeling empowered by occupation that brings success and Rosie of positive and worthwhile activity, Polly too when reflecting on living apart from traditional norms spoke of volunteering. Furthermore, understanding their own needs enables recognition of what is supportive for them even if not typical, this support being a self-directed strategy or support from others was found to be protective. These notions will be discussed further in chapter 7.

Chapter 6. Findings: towards best practice in researching with autistic people

6.1. Introduction

There are a growing number of useful articles on researching and coproducing with autistic people (Cascio, *et al.*, 2020; Stark, *et al.*, 2021; Albert, *et al.*, 2023; Aidonopoulou-Read, 2025). This chapter adds an additional contribution towards best practice and is primarily intended for researchers and people who want to do any sort of coproduction work with autistic individuals. It is structured to guide the reader, step by step, through the process of researching with this group. ‘Think pieces’ using extracts from participant interviews along the way give an opportunity for true reflection on the reader’s own practice and values. It invites researchers to join in a reflexive journey through this study to examine their own purpose and principles. The aim being that the reader is encouraged to think about how to move towards better practice in their work.

From the inductive nature of this research, it emerged that many participants had encountered adverse childhood experiences (Felitti, *et al.*, 1998) indicating a history of trauma. High incidences of trauma in autistic people is confirmed in the literature (Haruvi-Lamdan *et al.*, 2020; Rumball, *et al.*, 2021), see s.2.5.8. This points to using a trauma informed approach when researching with autistic people (Isobel, S., 2021; Alessi, E. and Kahn, S., 2023). Brake, *et al.*, (2024) note that the importance of trauma awareness when researching with autistic people is not well recognised. This piece highlights the importance of trauma awareness and is different to other pieces in that it uses instances of autistic participant voices from the study to invite the reader to reflect on their views and values when preparing or considering a research project with autistic people.

This study has supported evidence that autistic people frequently find themselves not listened to and not believed (Camm-Crosbie, *et al.*, 2019; Shaw, *et al.*, 2023) when trying to access healthcare. This has a negative impact on their wellbeing and can result in a loss of hope that things can get better (Camm-Crosbie, *et al.*, 2019). It could be construed that this would cause a reluctance to take part in autism research due to experiences of being let down, however, participants also expressed that they find using their experiential knowledge to help others fulfilling (*Jenny, p.31; Rosie, p.15*). This supports Pellicano, *et al.* (2022) who found their participants responded very positively to telling their life history and concluded that the benefits of a coproduced approach extended to the participants as well as the quality of the research. Trusting relationships were found to promote wellbeing in this study in line with

Crane, *et al.* (2019). As a researcher being familiar with autism theory and interacting with autistic people is an advantage in developing trust, being an autistic researcher would support that and immediately give that assumption but researching with autistic people need not be the sole preserve of diagnosed autistic researchers (s.3.2). To encourage a wish to take part in a coproduction project, developing a trusting relationship between the researcher and the participant from the start is crucial (Aidonopoulou-Read, 2025; Cascio, *et al.*, 2020; Fletcher-Watson, *et al.*, 2019; Nicolaidis, *et al.*, 2019; Pickard, *et al.*, 2021). Any sense of a power imbalance needs to be addressed.

To do this the researcher has to allow themselves to be vulnerable (Thompson-Hodgetts, 2022) and relinquish sole control. It could take more confidence for the researcher to surrender this power. There is also a need to acknowledge and validate any past bad experience the participant may have had in interactions. This could lead them to mask and not tell the whole story because of a feeling that it may be unsafe to do so (Pearson, *et al.*, 2023). In the current study where the autistic participants have experienced hospital admission for their mental health, meaning they have been some of the most distressed people in society, the trusting relationship is paramount. This is to safeguard their wellbeing and enable them to feel safe telling their story. A joint wish to improve experiences for autistic people as equal partners is a good basis for co-creation of research, or any project for developing services. Reflexivity is important throughout the process; this includes considering your motivation in conducting the research before starting interaction with potential participants. Self-reflection, such as questioning yourself as to whether your main focus is your career development and getting papers published i.e. selfish, or concern for the participant's experiences for the participant's sake, selfless, leads to considerations on whether your motivation comes across in your researcher/participant relationship? Might this influence the amount and quality of data you gain at interview? Affect trustworthiness? Historically, it was thought that autistic people lacked empathy (Baron-Cohen, *et al.*, 1995), the double empathy problem (Milton, 2012) reframes this as not a lack of empathy on the part of the autistic person but a shared failure between communication partners to develop understanding (Williams, *et al.*, 2021). We now understand that some autistic people may feel emotional empathy more deeply (Gillespie-Lynch, *et al.*, 2017) therefore autistic participants may be likely to feel a connection with the researcher or not. In this research Polly (5.2 p.64) talks of some people being "*sunshine in human form*" allowing her to be herself and speak freely. As researcher this seems the environment to aim for, where the participant is comfortable and can blossom. Although this chapter is focussing on the relationship between

researcher and autistic participant it would seem relevant for any relational connection across a neurotypical / neurodivergent divide (Crompton, *et al.*, 2020b).

You are invited to engage with this chapter in a reflective and reflexive vein. Throughout the chapter you will find input from participants and boxed 'Think Pieces'. These Think Pieces have prompts for your own reflections from your practice and experience and provide opportunities for consideration of your own values and possible biases. You may prefer to do this on your own or as part of a group but your participation in the Think Pieces is valuable.

6.2. Preparation

Before starting the research design, it would be good practice to check the topic of the research with representatives of the local autistic community to ensure the focus aligns with what is important to them. In this case it was the local Autism Advisory Panel (AAP) who agreed the topic for research, they also contributed to checking the research questions to ensure they reflected what is needed to be found out. After ethical approval had been gained a member of the AAP, as an autistic person who met the eligibility criteria, checked through the interview schedule and information for participants documents to make sure that they were accessible. This was done via email exchange as this was their preferred communication method. Due to communication differences participants were invited to use props to help tell their story and enhance meaning. These were suggested as diary entries or songs or objects or any other media that represented times in their life, particularly related to feelings of wellbeing, or lack of wellbeing, which may be harder to put into words than a recount of an event. Ashleigh took part in the pilot interview and shared the screen to show their writing piece from primary school. This disrupted the flow of the interview and rather than sharing props on screen it was decided that interviewees would email photographs of their props in advance of the interview. This was a more straightforward method and removed any anxiety about managing the technology associated with the video call in real time.

Every autistic person is different but having an autistic person check accessibility of the documents and interview process made it more likely that interviews would be successful. It increased confidence that the level of detail and specificity of language in the documents would enable clear understanding of the expectations of taking part in the study; what would happen when, with whom and who to ask if there were any questions. In addition, that the interview questions were unambiguous to remove as much anxiety in answering them as possible so autistic people could feel confident in taking part if they should wish.

The Think Piece below invites you to consider Max' experience of being hospitalised without any understanding of what life on the psychiatric ward would entail. Perhaps you can reflect on a parallel scenario from your practice when you invite autistic people to take part in something? Do you consider autistic need without stereotyping?

Think Piece.

Max, when talking about his inpatient admission explained, *“I didn't understand um so from that sense because I didn't know what was going on that was the negative part of it but having if I'd had it explained to me from the start but I guess the people working there take it as granted because they do it every day um so yeah but basically the the sudden change and the oddness of it could have been better for somebody with autism if it had been if it had been if there had been some explanation um so that I knew what was going to happen but you know from being strip searched to having cameras over the my bed all things that I didn't know I just had to experience them as they happened I didn't everything you know was a surprise”*

Consider what impression of Max is gained from this quote.

Reflect on how you would feel if it were you rather than Max in this situation

Thinking about your own practice, how do you ensure an autistic person is prepared for the experience you invite them to take part in? How would you know they have understood the information and it makes sense to them?

The initial contact established with the autistic community in checking relevance of the topic and the accessibility of information you are going to provide about the study starts the interactional relationship. It illustrates that you are willing to listen and act on their advice so already you are starting to develop trust and address power distribution which may be a factor in a decision whether to take part in the research project. Rosie said,

“I think I wanted to take part because it actually represents autistic voices, you made me feel comfortable and I have experience that I felt could be beneficial to you” Rosie, feedback.

6.3. At the start

In the preparation stage a connection has been made with members of the autistic community and you are now known to each other. You have started a coproduction process in agreeing

that the research is important to autistic people, that the research questions are appropriate and the interview schedule and information documents are accessible and provide the necessary detail for informed consent.

The next Think Piece invites you to extend your thinking further in relation to what detail of information would be helpful to provide for an autistic person to be comfortable in joining you in a project, you might want to consider how you would present this information to ensure it is clear and accessible. Perhaps you would need to present it in more than one way?

Think Piece.

“needing to know a plan so I would send everybody mad with not being able to enjoy the moment um and having to have a plan for the next thing and I think that was quite a difficult dynamic” Jenny

To enable Jenny to consider being a participant in a research or coproduction project you are planning what information would you need to provide for the potential experience to be predictable i.e. not anxiety provoking so participating seems possible?

At this stage you have ethical approval and are ready to start seeking participants. For this research an email was sent to all members of the Autism Advisory Panel with information on the study, eligibility criteria and a request for participants to indicate their interest to take part. The information sheet (Appendix 2) included my photo so potential participants knew who they would be speaking to and a visual representation of the choices regarding informed consent. I contacted each individual separately who expressed an interest using their preferred means of communication, email or telephone or Teams call, no face to face as COVID restrictions still in place. After establishing eligibility and readiness to take part a date was set for the participant to meet with me, the researcher, on Collaborate before the interview to familiarise ourselves with the platform we would be using for the interview. This also gave another opportunity to answer any questions, make sure they were fully informed about taking part and still wanted to, and to discuss any reasonable adjustments. Max chose to have his camera off during his interview, whereas the others had their cameras on.

Date and time for the interview was agreed with each individual taking into account their routines to ensure that it would be a time when they were comfortable to take part. Due to this research topic, it is known that participants will be vulnerable having had experienced past mental health inpatient admission and that ethically it is a high-risk study. It is

imperative to do no harm but is also an important area for research as recognised by the autistic community themselves. In order to mitigate the risk of recruiting a participant who was not in the right place in their recovery journey to tell their story safely a ‘readiness guide’ was produced adapted from Autistica’s work (Appendix 1; see s.3.4)

Owing to the levels of distress autistic people who have experienced mental health hospital admission have encountered they have often been traumatised (Quinton, *et al.*, 2024). You may find what you hear upsetting or you may not want to believe it. It can be useful to adopt a non-judgemental trauma informed approach (Brake, *et al.*, 2024). Using a relational based trauma informed approach includes reflection on why you are undertaking the research (p.120) to avoid participants loss of trust in the research process (Isobel, 2021), redressing the power imbalance between researcher and participant (p.120, 122) to avoid replicating the power differential that occurred in trauma which could trigger a psychological reaction for the participant (Alessi and Kahn, 2023) and ensuring safety and trust (p.119, 120, 122) throughout the whole research process (Alessi and Kahn, 2023). The Think Piece below invites you to consider how you can present yourself as a safe person to share sensitive recollections with.

Think Piece.

“a lot of the staff some of them were vindictive but I don’t believe, I believe the vast majority of them did not mean me any harm they genuinely saw me as the problem”

“I strongly distrusted staff because of my experiences”

Ashleigh

This quote from Ashleigh speaks to us of trauma she has experienced when accessing a service and the power staff hold. Consider how you could establish trust with someone who has had these experiences.

6.4. During

With virtual interviews the participant can control their physical space within their own familiar environment. As the interviewer you just need to show acceptance of any fidgets the participant may use and respect any need to move and rock, depending on the individual, so they do not have to be concerned about supressing these sensory needs whilst telling their

story. For this study there is a written reminder in the interview sheet (Appendix 6) sent with the initial information documents for participants to use their personal sensory strategies during the interview.

We had already agreed, as stated in the information sheet (Appendix 2) and interview sheet (Appendix 6), that participants could have someone with them to support them, but no participant took that offer up. In the information sheet it was also explained that they could have a break at any time. In most interviews when I asked if the participant was ready for a break they asked me the same question back. The decision felt like a negotiation or joint agreement (Table 7).

Interviewer: <i>"I am thinking about moving and things are you OK? Do you want a stretch and a move round?"</i> Transcript p.32 Ashleigh: <i>"Yeah I might do if that's OK? It's probably a good point to do it..."</i> Transcript p.32 Ashleigh: <i>Are you OK to keep going?</i> Transcript p.95 Interviewer: <i>Yes please if you are?</i> Transcript p.95
Interviewer: <i>"I think this leads us on rather nicely to the next question. How are you feeling though do you want a walk around and a stretch and get a drink?"</i> Transcript p.17 Rosie: <i>"Um I've got a drink I'm going to have a sip of my drink. How are you feeling, do you want to have a walk round and get a drink?"</i> Transcript p.17 Interviewer: <i>"Well, I'm alright at the moment but perhaps in ten minutes or so it might be nice, if that works with you?"</i> Transcript p.18 Rosie: <i>"Yeah, yeah"</i> Transcript p.18
Interviewer: <i>"How are you feeling? Do you need a break?"</i> Transcript p.24 Polly: <i>"I'm OK, I'm used to 2 to 3 hour lectures! I'm fine but if you need a break (laugh)"</i> Transcript p.24 Interviewer: <i>"No I'm alright, we'll carry on a bit longer if that's OK with you?"</i> Transcript p.24 Polly: <i>"Yes that's fine"</i> Transcript p.24
Interviewer: <i>"I was just wondering how you are feeling whether you are OK to carry on or would you like a stretch or a pause or anything?"</i> Transcript p.23 Max: <i>"um I'm fine if you are yea um"</i> Transcript p.24
Interviewer: <i>"Perfect how are you feeling um did you want a break a stretch a drink or anything?"</i> Transcript p.22

Jenny: *"I could probably do another one and then go and get a cup of tea and then carry on"* Transcript p.22

Table 7 Extracts from transcripts to show agreement between researcher and interviewee over when to take a break.

These quotes give a sense that any potential power imbalance, with the interviewer holding the power, has been mitigated. There seems to be equality in the decision making about a break implying that the whole interview was conducted on an equal footing between researcher and researched. In the first example with Ashleigh I am suggesting that I may need to move myself, this addresses the power imbalance by indicating I have needs too and is leading by example. In the last example Jenny feels empowered to take the lead, she indicates when the break will happen and what it entails.

If you look at the words I use to see if someone wants a break, page 125, I am often saying lots of things at once in different ways e.g. *"How are you feeling (one question) though (unnecessary word) do you want a walk around (second question) and a stretch (third question) and get a drink (fourth question)?"* This is the reverse of the recommended communication style, however, it appears to be accommodated. Without the trusting relationship I would have to be much more careful to be specific and explicit and use less words because more anxiety would be present. The dialogue shows that I am relaxed in the interaction, offering and not instructing, which seemed to promote a calm and purposeful atmosphere for the interview. Although not used in this study, a reasonable adjustment of participants having a visual card to hold up to indicate when they would like a break could be offered. Reasonable adjustments are personalised to the individual and would be agreed at the pre-interview meet stage but could be shared and adopted at any time in the process depending on participant need. Although some participants explained in the interviews that there were occasions when they were unable to communicate verbally this seemed to be in situations of high anxiety. That all were able to use verbal communication effectively throughout the interviews is a further indication that they felt empowered to do so in the researcher participant relationship. Communication through visual systems can limit the warmth and connection in an interaction but is vital to connect with those who don't use verbal language typically.

My aim was to make the interview call a safe, kind and non-judgemental space. I believe that the detail and candid nature of the interview data so generously provided indicates that I was successful in that. Opening up about personal experiences can be hard and adds to

anxiety of being interviewed, it is important to not only consider the physical environment in which you are collecting data but also the emotional environment you generate.

As a professional you can feel that you need to know all the answers and alleviate challenges people face, if a healthcare professional your training was probably based on the medical model so your focus is looking at things that are not going well and making them better (Jeanneret, *et al.*, 2022) with the power held by you. The next Think Piece asks you to question yourself about how you interact with an autistic person and how that could influence how they feel about themselves.

Think Piece.

“he is the first professional that didn’t treat me like I was stupid or I was just a patient, yeah, I think he valued me as a human being and sometimes he asked me what I thought or asked my opinion and just made all the difference.” Polly

Could there be occasions when the medical model may cause a barrier?

As stated throughout the most important thing is for the participant to tell their story safely, if they want to tell it. It can be hard to know in advance what emotions this can bring up and important for the interviewer to be alert and vigilant in detecting any changes in the participant’s demeanour, also being aware that an autistic person may not show emotions typically (Brewer, *et al.*, 2016). For example, they may have a monotone way of talking and facial expressions that may not be readable (*Polly, p.13; Jenny, p.11; Max, p.13*). Cassidy, *et al.*, (2021) developed a Research Wellbeing Plan which asks the participant how the researcher would know if they were becoming distressed and how best to support. Although the document was not used in this study, an individual’s completed Research Wellbeing Plan would be useful information for the researcher to have to hand to ensure safe participation, particularly if there is not a pre-established relationship. Trust and relationships were identified as important by participants and highlights the importance of an informal interview pre-meet.

“already had trust with you which made it easier, you weren’t just some random stranger asking me questions!” Rosie

Autistic voices being heard and using autistic experience to help others seemed a motivation to take part and became a protective theme from analysis in this study. Counteracting the

possible adverse effects of telling distressing personal stories, being listened to during interview could be positive and promote wellbeing, especially if the findings from research go on to influence societal understanding and develop practice to improve experiences for autistic people.

The Think Piece below honours Ashleigh's wish that their side of their story is shared in connection with their relationship with their family. There can be tension between what a parent wants for their autistic child and what the young person wants themselves (Cribb, *et al.*, 2019) with the voice of the parent heard rather than the young person (Taneja-Johansson, (2023). The human rights model of disability (UN, 2006) upholds the right for disabled children's voices to be heard.

This Think Piece invites you to consider Ashleigh's fears about being perceived by their parents as a problem child and the distress that caused them along with not having a voice themselves. Ashleigh points out the possible repercussions of this from past news stories giving the sense that they would be powerless and blamed should this have happened to them.

Think Piece.

"I can talk about this because I don't want other people to go through what I went through in that way or worse um because I mean the real and I know this makes it very dramatic thing going round is where you have parents who well there are parents who openly talk about wanting to kill their children um autistic children and there are parents who do it and what's really scary is like in our media that the sympathy is with the parents" Ashleigh

Should Ashleigh be scared? What evidence do you have to support your opinion?

6.5. After

After checking that the participant hadn't got anything further to add the de-brief sheet (Appendix 4) was gone through together whilst still on the video call. This covered what was going to happen next, what to do if they didn't want some or all of the information they provided included in the study, how their information was going to be kept private, what to do if they had a complaint and signposting to where support could be obtained from if they found it distressing to talk about the issues relating to the study. The de-brief sheet was then emailed to the participant with thanks for taking part and researcher's contact details for any questions.

As an example of good practice, the transcript of their interview was sent to the participants, which included photographs of props they had used to explain their points. They were given seven days to check that the words they had said imparted what they wanted to say, allowing processing time to consider and advise of any additions or modifications they would like made. This addresses the known communication issues autistic people may have and allows for clarification and agreement as to whether they are happy for the information to be used. Not only that, it also avoids any anxiety as to remembering what they said in the interview and keeps participants active in the research. Since no one requested their interview information be withdrawn analysis started. As stated on the de-brief sheet I contacted the participant after analysis and formulation of person experiential themes (PETs) to agree a good time to meet virtually again to check whether my interpretation matched theirs. The PETs were emailed to each participant before the discussion meeting to allow time to read and process. Not only did the discussion meetings provide a check to avoid misunderstandings thus addressing the double empathy problem, they also allowed further discussion and thoughts to be shared adding to the data, keeping the autistic person at the centre of the process.

This was a new experience for Polly and something she clearly appreciated. The next Think Piece suggests you take some time to consider Polly's response and connect it to current theory.

Think Piece.

"Never had someone come back and check interpretation, everyone should do it"

Polly, (when checking personal experiential themes together)

Reflect why Polly may feel this way, how this connects with the double empathy problem (Milton, 2014) and triple empathy problem (Shaw, *et al.*, 2023)?

6.6. Recommendations

Aidonopoulou-Read (2025) stresses the importance of building relationships before starting the research in her framework for researching with non-speaking autistic individuals. Participants in this study did use verbal communication to take part but some reported times when they were unable to speak, for example, *Jenny p.24*. The importance of valuing communication in other ways than speech is honoured in this study by use of photographs of objects of significance to the individual. It appears that these recommendations for

researching with non-speaking autistic individuals are also of benefit when researching with speaking autistic people.

Through undertaking this study the following suggestions are put forward to work towards best practice in researching with autistic people. These recommendations reflect a trauma informed approach which is an area that is often ignored when researching with autistic people (Brake, *et al.*, 2024).

1. Be trustworthy - build a trusting relationship with the group you hope to recruit participants from.
2. Establish your credibility as someone who values and wants to hear autistic lived experience knowledge.
3. Be aware of what issues are important to autistic people, if you are addressing these autistic people are more likely to be willing to participate (makes sense and is worthwhile).
4. A trauma informed approach can be helpful, recognising that the autistic person has most likely experienced trauma in their lives and the impact that may have had.
5. Validate and accept the individual autistic experience giving opportunity to communicate this in ways other than speaking, e.g. use of artefacts, photographs.
6. Make your best effort to establish whether it is the right time for the autistic person to take part in a collaborative project with you, e.g. using a Readiness Guide (Appendix 1) considering their wellbeing.
7. Check in to ensure autistic wellbeing throughout.
8. At the start, during and after the participation, communicate clearly and transparently with the autistic person using their preferred means of communication, differentiated to individual need, to enable them to be fully informed throughout with reasonable adjustments made to reduce any anxiety associated with taking part.
9. When practical, at analysis stage, check your interpretation of the information the autistic person provided is what they meant and take feedback, this is when you know who has provided what information, not for e.g. anonymous survey.
10. At the end of the research, or other project, provide the autistic participants with the outcomes and any actions and reports with opportunity to feedback on any changes they have seen as a result of the work.

6.7. Conclusion

My experience of researching with autistic people has been rewarding, enlightening and humbling. Hopefully autistic participants have found the experience positive too and would be happy to take part in other research studies. The findings from my study into why autistic people are overrepresented on mental health wards stressed the importance of relationships, both negatively as a risk factor for mental ill health and positively that understanding relationships were protective for wellbeing. Best practice in researching with autistic people is about relationships too (Pickard, *et al.*, 2021). The autistic person has, in all likelihood, experienced adverse relationships in their life, chapter 2 literature review provides information on prevalence of bullying, trauma and social interaction and social communication challenges. From Løgstrup's (2007) ethical thinking they would have lost trust and are coming from a position of distrust (see chapter 7). This means you may need to make more effort to establish yourself as a trustworthy and safe person to talk to. A remote method of collecting data via survey or questionnaire may enable you to reach more autistic people and your choice of methodology will reflect the research questions you aim to answer. To obtain deep and rich qualitative data, opening our eyes to what it is to live as autistic, trying to interact with others as well as processes and practices of e.g. education, health, care and justice systems, committing the time to establish a relationship and having a more open interview schedule where both partners in the interaction trust each other seems well worth the effort.

The final Think Piece roots us back into our shared humanity which seems a suitable way to conclude this chapter. You are invited to be reflexive when considering what Max is telling us.

Think Piece.

"... there wasn't anything particularly um that needed er psychiatric qualifications to do it was just about you know um being a nice human being and er being there to talk to..."
Max,

The concept of neurodiversity is that all human brains work differently, is interacting with an autistic person a specialist area? Why?

The next chapter will discuss the findings from this research study connecting them with the wider literature and considering theoretical and practical implications.

Chapter 7. Discussion and Conclusion

7.1. Introduction

This research set out to answer the questions,

1. What is the autistic lived experience perspective of the precipitating and predisposing risk factors for mental health hospital admission?
2. What is the autistic lived experience perspective of the protective factors that promote resilience to avoid mental health hospital admission?

The aim being to understand what autistic people interpreted from their life experiences led to mental health crisis. In turn this may elucidate why this population is overrepresented in mental health inpatient settings, a national priority is to reduce the number of autistic people in mental health hospitals (DHSC&Ed., 2021). Previous chapters have examined the stories from five participants, all of whom had experienced hospital admission to keep themselves safe. Four precipitating and predisposing risk factors for reaching the level of distress requiring a mental health hospital admission for these autistic individuals were identified from their personal stories:

1. Being different and not fitting in
2. Not being taken seriously and being misunderstood
3. Internalising a negative sense of self
4. Unhelpful support that does not address need.

Protective factors that promoted resilience and autistic wellbeing emerged as:

1. Trusting relationships
2. Being believed and having a voice
3. Understanding and accepting self
4. Using skills for a purpose
5. Understanding and non-judgemental support
6. Environment (reasonable adjustments).

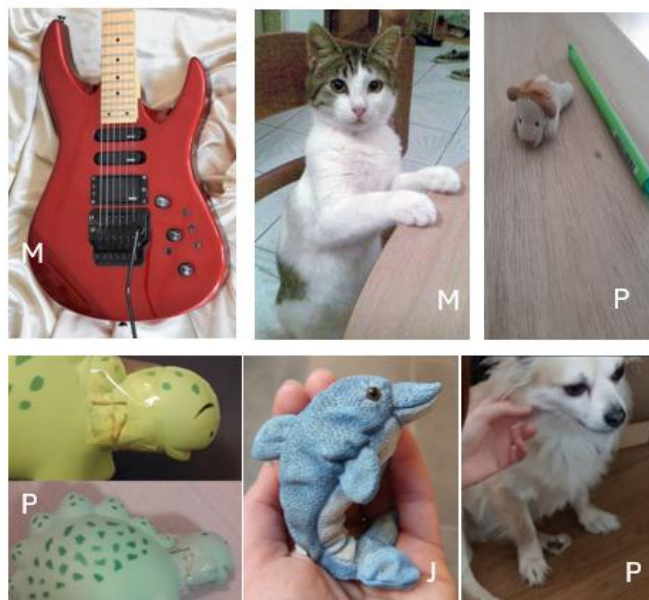
As Trew, (2024) found in respect to relationships with autistic adolescents and their families, external responses to autism significantly affect their mental health and wellbeing, findings from this study indicate that these consequences of autistic people being made to feel different extends throughout life. This indicates that for autistic people to be less likely to be admitted to hospital due to mental health crisis, the way services and society respond to, and understand autism, needs to change to be more accepting, agreed and consistent. Reflecting on this piece of research, the findings are also relevant to other interactions with autistic people and have implications when considering best practice in designing and conducting

research in this field. This chapter will discuss the findings, connecting them to the wider literature and consider some of the issues.

7.2. Interpretation

When reflecting on the themes, the majority are associated with relationships. This is further illustrated by the images participants provided and how they can be grouped. Three out of the five participants sent in images which related to connecting with others, two more than one image (Figure 17). The images either represented a connection with another person or people, or a direct connection with an animal. Finding animals non-judgemental and not needing to mask in an interaction with a pet is in keeping with Howe *et al.* (2023) and supports a sense of being accepted for themselves and a shared connection. Feeling of empathy towards animals is also found as a positive autistic advantage in Russell *et al.* (2019) qualitative study (Russell, *et al.*, 2019). Shoib *et al.* (2022) considers the role of Animal Assisted Therapy in suicide prevention. They proposed that for autistic people the interactions with a pet had two positive effects, one that the animal depends on them for their care giving a sense of purpose and being needed, and secondly that the animal showing them affection gives a sense of acceptance and of not being a burden (Shoib, *et al.*, 2022). This strongly echoes Max's interaction with Cat and Jenny with her therapy dog. All the images below were associated with feelings of acceptance.

Figure 17 Participant Images representing connections to others. M = Max, P = Polly, J = Jenny



Considering a sense of self evolves from how others interact with you (Oshima, *et al.*, 2014; Williams, *et al.*, 2019), the theme feeling different and not fitting in is directly linked to relationships. All participants in this study had a difficult family relationship. Family conflict

is associated with trauma (Hoch and Youssef, 2020) whereas feelings of connection with family are a positive for mental wellbeing (Maitland, *et al.*, 2021). Not fitting into the family and not understanding why appeared difficult and emotionally stressful for participants in this study, also associated with a feeling of self-blame (Max) linking to the theme internalising a negative sense of self. Jenny clearly spoke of self-loathing due to not being happy with who she was. Most participants were now estranged from members of their family which is another factor that is inconsistent with society norms (Barnwell, 2024) and has an associated impact of extended aloneness. For Ashleigh lack of belonging was accentuated by the additional intersection of being in a sexual and gender minority in addition to neurotype minority (George and Stokes, 2018; Moore, *et al.*, 2022; Strang, *et al.*, 2023) which they have had to overcome. Emile Durkheim (1897) spoke of suicides being connected to weak social integration, so the risk connected to a sense of not belonging has long been known. The interpersonal theory of suicidality (Van Orden, *et al.*, 2010) suggests the characteristics that may lead to someone wanting to end their own life are ‘perceived burdensomeness’ and a ‘thwarted sense of belonging’. A thwarted sense of belonging clearly connects with the idea of ‘being different and not fitting in’ that arose from the life stories in this study. There was a misconception that autistic people may not want or need a social identity or relationships with others (Chevallier, *et al.*, 2012) but an increased sense of belonging for autistic people is evidenced as a protective factor against suicidality (Cassidy, *et al.*, 2018).

Relationships with school peers and later employment colleagues seemed often to consolidate a feeling of disconnection which can affect how someone values themselves (Williams, *et al.*, 2019) and be a risk factor for mental ill health (Day, *et al.*, 2020). Being different also led to bullying and not feeling safe. Bullying is well documented as being a cause for psychological damage (Berney, *et al.*, 2014; Cappadocia, *et al.*, 2012; Rumball, *et al.*, 2021). On the other hand, acceptance and positive relationships were important in keeping safe and giving a feeling of shared connection that promoted wellbeing. Unfortunately, not fitting in also extended to not fitting into services, not being understood by health staff or not being eligible for support, compounding rejection. Being dismissed perpetuates feelings of failure, isolation and hopelessness (Jordan, *et al.*, 2020). The theme "not being taken seriously and misunderstood" has to involve a relationship because you can't not be taken seriously or misunderstood in isolation with no one to misunderstand you. Non-autistic people misunderstanding autistic people could prevent them being included in society (Alkhalidi, *et al.*, 2021). Misunderstanding links with Milton's (2012) double empathy problem which recognises that there are two sides to an interaction and people from very different

backgrounds and outlooks will find it difficult to understand each other, such as autistic and neurotypical. It also links to society's view and stigma which influences the relationship. A further factor is what Shaw *et al.* (2023) describe as the 'triple empathy problem' where health professionals with their medical knowledge find it hard to see a patient's perspective who is without medical knowledge. This adds the third layer to the double (autistic / non-autistic) empathy problem by adding in a further medical / non-medical divide.

In Chapter 2, (2.5.8) literature relating to autistic people and traumatic life events was discussed, that autistic children and adults were more vulnerable to PTSD but trauma in autistic people often goes undiagnosed or misdiagnosed. Kerns, *et al.* (2015) associated childhood trauma as a predictor of psychiatric illness. Adverse Childhood Experiences (ACEs) (Felitti, *et al.*, 1998) as potentially traumatic events can impact the person through adulthood and have lasting effects on mental health. When considering what are described as Adverse Childhood Experiences by Ellis, *et al.*, (2022) and experiences that participants disclosed in this study (Table 8), even though this was not a specific question, there seems a connection. This warrants further investigation to explore whether autistic young people experience adverse childhood experiences at a higher rate than the general population, whether ACEs are a predictor of mental ill health and psychiatric admission in the autistic population, and interventions that may help.

ACEs (Ellis, <i>et al.</i> , 2022)	Ashleigh	Rosie	Polly	Max	Jenny
Maternal depression	✓	? threw herself into work, relying on Rosie			
Emotional & sexual abuse			✓		
Substance abuse			✓		
Domestic violence					Perceived?
Homelessness					
Incarceration			?		
Mental illness	✓	Sister: eating disorder	✓		
Divorce		✓			✓
Physical & emotional neglect		?	✓		

Table 8 Possible Adverse Child Experiences encountered by participants

Although from the interview Max did not disclose any of the above ACEs, he did experience disruption due to regular moving but particularly not fitting with his family and throughout life was an issue that caused him much emotional distress as he felt excluded from a 'normal' life that he desperately wanted. Reflecting on Max's story within an army family it seems to reflect an attitude to maleness associated with being strong mentally and physically.

Appearing to be picky and struggling to eat everything put in front of him, to not organise himself to do his homework, could have been construed as a weakness that needed to be overcome. This could affect Max's interpretation of himself as this was not something he could do. In fact, he stated that his fear of hospitals as a child was to do with hospital food indicating the significance of this difficulty to him. Yau, *et al.*, (2023) put forward that psychological wellbeing of autistic women is impacted by societal, gendered and cultural expectations, this study hints at the same being possible for autistic men and warrants further investigation.

When considering protective themes to wellbeing and avoiding mental health admission, trusting relationships were key. Understanding self was important too, this results from interactions with others (Williams, *et al.*, 2019) and the groups belonged to, therefore relationships again. The social identity derived from that impacts mental health (Jetten, *et al.*, 2017). Helpful support was described as being kind and non-judgemental which fits with trauma informed practice (p.38), a relational approach, rather than standard behavioural interventions (Fuld, 2018). Non-judgemental relationships extended to animals who accept people as they are and there is no need to mask. This was positive for wellbeing of participants with the added advantage of the animal being a talking point and thus could help with human social relationships. A further helpful factor that promoted feeling good about oneself was using skills for a purpose. This ranged from helping others, taking enjoyment from achievements to creating connections. This links to the previous chapter as a reason for wanting to take part in research. Of particular importance was self-acceptance that seemed difficult to achieve due to attitudes of others. Some participants found an autism diagnosis aided this (Polly, Jenny) although it did seem to depend on whether a diagnosis was given during a period of mental ill health which then resulted in a negative outlook (Ashleigh, Max). Farahar, (2022. p.237) maintains that discovering that you are autistic should happen when wellbeing is high because when a diagnosis is given at a time of distress, that distress can be linked to being autistic and be viewed as negative, isolating and damage wellbeing.

Taking a lifelong approach to answer the research questions has illustrated the impact of family and society expectations of how one should belong and behave has on an autistic

individual over time. All participants were diagnosed autistic as adults at a time when our Western culture was starting to accept that autism is related to a different way the brain works with traits relating to social interaction, monotropic and sensory experience, rather than a sense that someone with that medical condition could ever amount to much having impaired communication, impaired social interaction and rigid inflexible thinking. As children their parents probably perceived how they behaved as a choice, apart from Jenny who was diagnosed with clinical depression aged nine. The majority of parents were described as anti-label and wanted to protect their child from stigma so didn't pursue an autism diagnosis. Unfortunately, not having an autism label but just being marked as different were not protective in these instances. Jenny and Polly had eating disorders and hospital admissions relating to that, all spoke of depression and bullying, Ashleigh and Rosie had borderline personality disorder diagnoses, Polly experienced significant abuse as a child, all attempted to end their lives which resulted in psychiatric hospital admission. Jenny explained what she had needed was to learn to accept that she was different and for the rest of the world to know it is okay for somebody to be different too. Fundamentally, therefore, it could be acceptance of difference that is needed by society rather than acceptance of a medical diagnosis of autism (without co-occurring conditions). Pathologising difference (autism) tends to indicate a perception that the person is not okay, depathologisation could alter society and autistic individuals' notion of what it is to be autistic (Farahar, 2022. p.238).

Over years we have moved away from the perception that the autistic person needs to be 'fixed' to fit in with society and cultural norms (Botha & Gillespie-Lynch, 2022). We are recognising the impact of constantly being perceived as wrong, being part of a minority group and masking on wellbeing (Pearson, *et al.*, 2023). The importance of a positive relationship with healthcare staff has been highlighted in this study but it has also shown that this is not enough alone. Types of treatment given to autistic people but evidenced with non-autistic people may not have the same result. It may not address the need of the autistic person and can have a negative effect. This can be further problematic if the autistic person is not believed or can't communicate their symptoms effectively and the healthcare staff are relying on making judgements on signs and observations alone. Both Ashleigh and Polly describe being given medication that had adverse effects on them but made them appear calmer. For this reason professionals wanted them to stay on that medication (s.4.5.1 p.81/82) The autistic person may take not being able to be supported successfully as a personal failure, particularly since the attitude of the healthcare system seemed to be that autistic people have to fit in with what is on offer pushing them towards EUPD "structured clinical management" (Rosie) or not being able to accommodate what they recommend (Polly). Ashleigh decries the

use of behavioural approaches, corresponding to Fuld (2018) that these do not address issues relating to mental health and wellbeing, and describes sensory pain from group therapy sessions. Max also found sensory aspects of group meditation sessions difficult and the anxiety of talking in front of others in group therapy for Jenny was “*hell on earth*”.

All participants indicated that mental healthcare staff didn’t seem to ‘get’ them. Max seemed to be the most positive being very grateful for activities such as step-by-step cake making but did say the root difficulties weren’t addressed. Ashleigh, Polly and Jenny indicated an “us and them” attitude between staff and patients on the ward. Polly explained feeling most comfortable with the cleaner who seemed to understand and support her best. This could be because the cleaner was not a threat and would not be part of any restraint for example so would feel safer. A professional view could be that Polly is saying the cleaner is good and other staff are bad to cause a split in the team, however, Polly didn’t give this impression in the interview, only her appreciation for the cleaner’s interactions with her.

7.3. Integration with literature

The findings from this study emphasise understanding and acceptance as key factors supporting autistic wellbeing (Yau, *et al.*, 2023). A review by McKinlay, *et al.* (2024) found having a good relationship with staff, positive relationships with peers and a sense of belonging indicated a positive school experience. Whereas poor therapeutic relationships can result in trauma (Ashleigh, *p.112*), internalising low self-esteem and feeling shame for being yourself (Darazsdi and Bialka, 2023). Negative sense of self corroborates Lilley, *et al.* (2021) subtheme ‘negative self-conceptions’ that linked stigmatising attitudes to negative self-conception, also repeated negative experiences being internalised as there being something inherently wrong with them (Pearson, *et al.*, 2023). The benefits of relationships with like-minded and other autistic people to enhance autistic mental health is widely acknowledged (Crompton, *et al.*, 2020a; Maitland, *et al.*, 2021; Cooper, *et al.*, 2023) where there is no need to try to mask to conform to neurotypical expectations to be accepted (Pearson and Rose, 2021).

As this study, high rates of psychological distress, unmet support needs and a sense of aloneness without someone to support and guide decisions were found by Jeanneret, *et al.*, (2022). Max wants ‘a bossy wife’ to enable social participation and felt he might have made a different decision about his physical health care if he had someone to discuss it with. Jenny explains the importance of her support network of trusted friends and colleagues both autistic and non-autistic who can act as a sounding board to check her understanding as a protective factor for her wellbeing. Like Jeanneret, *et al.*, (2022), the social and relational aspects of maintaining good mental health are evident. This supports the idea that spending positive

time with others where there is a sense of belonging enhances wellbeing (Maitland, *et al.*, 2021) and that positive interactions from an early age creates a healthy interpretation of self (Oshima, *et al.*, 2021). As Milton and Sims (2016), wellbeing of autistic people could be improved by reducing social exclusion by acceptance.

This research has added to the literature recognising the importance of positive relationships in maintaining wellbeing and good mental health for autistic people. Positive interactions with family and accepting people contribute to self-esteem and a sense of belonging. Good relationships with mental health staff who accept and acknowledge autistic need promotes a better experience. Sadly, in the stories told here, mental health staff were perceived as less accepting than physical health and police indicating possible anti-autistic bias (Darazsdi and Bialka, 2023). Training in learning disability and autism for health and social care staff only become statutory under The Health and Care Act 2022 for all providers registered with the Care Quality Commission (CQC) so many staff would not have knowledge of autistic presentations and the individual nature of these. The Oliver McGowan Mandatory Training in Learning Disability and Autism is being rolled out to healthcare staff. Future research should investigate the impact of this training on autistic people accessing or attempting to access mental health care.

7.4. Limitations

Focussing on hospital admission may have been a limitation as well as a strength. Due to my professional role concentrating on psychiatric admission avoidance for autistic people, gaining an understanding of risk and protective factors relating to mental health admission for autistic adults is pertinent. There are many possible reasons for autistic people to reach mental health crisis and be admitted to a mental health hospital, I could have chosen from the literature an area that could be a risk to investigate. This would have been more straightforward and contained but ultimately it is the autistic viewpoint of the reasons that are central. Any recommendations informing practice to support autistic people must start from listening to their experiences. The human rights model of disability stresses the importance of listening to lived experience voices and I wanted to find out through the story of autistic people's journey to mental health hospital admission, their perception of what may have precipitated that. When themes emerged, these areas could be targeted for further research and support in the community. From the literature review (Chapter 2) it was found that there were a lack of autistic voices on this topic and double (Milton, 2012) and triple empathy (Shaw, *et al.*, 2023) warn that neurotypical interpretation may result in misunderstanding. This highlights the importance of really understanding and truly reflecting the autistic experience when aiming to avoid hospital admission for this group.

Although acknowledging intersectionality, a limitation could be not exploring it further within the participant group. Focussing on autism is necessary to answer the research questions but there are many other factors that influence the way we experience the world. Each individual story is unique but these are all constructed within Western sociocultural context. Autistic people from other cultures may have different beliefs about autism, with different or similar experiences, their stories would form an interesting comparison. Although the five participants included different genders the sample is predominantly female, all are white British and received their autism diagnosis as an adult. All apart from one were educated to college/university level and three out of the four who declared had no religion. Again, people from different educational and/or religious backgrounds may find different protective and risk factors. For example, Kølves *et al.* (2021) found increased prevalence of self-harm within the autistic population with higher educational attainment. Furthermore, it doesn't shed any light as to whether those diagnosed as autistic in childhood have a different trajectory. Reflecting on why the individuals who came forward were all white British, it may be because that is my ethnicity. It seemed that an important factor in a decision to take part was a feeling of trust with the researcher. Being of the same ethnicity may contribute to feeling comfortable with the researcher and people from other cultural backgrounds may feel more comfortable and relate better with a researcher from a similar origin. This is valuing and respecting different cultures and experiences, in the same way autistic people seem to relate better with other autistic people, not a negative. Another reason is the AAP, where participants were recruited from is predominantly white British (Kirby and Payne, 2023) which could be due to differences in cultural norms (Hussein, *et al.*, 2019).

7.5. Recommendations for practice

The striking finding from this research is that relationships featured as both a protective and risk factor for mental health. This underlines the importance of a good relationship between the autistic patient and the mental health practitioner whether they are practising in the community or in a hospital. The ideal is to reduce the risk of mental ill health through greater acceptance of this group of autistic people who do not visibly appear to need support navigating societal norms. A practical way of improving the relationship with health and care staff that could aid access to support is for services to adopt a culture of trauma informed practice. The person shouldn't be made to feel blame for being autistic in the same way that someone who has experienced trauma should feel blame for what happened to them. Reuben, *et al.*, (2024) confirm that autistic adults with PTSD have more mental health symptoms and difficulties with daily tasks, they advocate that autistic people are screened for PTSD to see

who would benefit from trauma focussed treatment. This seems sensible advice, however, there seems no harm in health and social care staff using a relational based trauma informed approach in their everyday interactions with autistic people whether or not they have been professionally diagnosed with PTSD to address the protecting factor of understanding and non-judgemental support. Every autistic person is different but an acceptance of autism, of it being okay to be different and to not judge from a neurotypical lens will be helpful in developing trust for the positive relationship to form. An understanding and compassionate approach to autistic people seeking support early on may reduce mental health decline. The health and social care staff should also keep in mind double empathy (Milton, 2012) and triple empathy (Shaw, *et al.*, 2023) to guard against misunderstanding. It is hoped that the current drive in England for health and social care staff to undertake the Oliver McGowan mandatory training in learning disability and autism, or equivalent with outcomes matched to the Core Capabilities Framework for supporting autistic people, as appropriate to their role may raise their awareness of autism from a stereotyped view and improve experiences for autistic people in these areas. The evaluation of whether the Oliver McGowan training is meeting the needs of autistic people is awaited with interest.

Moving away from concentrating on the emotional environment a further practical recommendation would be consideration of the sensory environment and communication environment and making reasonable adjustments to enable the autistic person to engage fully. This will be dependent on the individual, not on a diagnosis of autism, so will be an aspect of person-centred care needed by the autistic person. These recommendations are also relevant for researching with autistic people (Chapter 6).

Gaining the right support is not just centred on relationships but also resources and processes. Participants identified that there wasn't support available that addressed the root of the problems they faced (unhelpful support that does not address need), therefore it is recommended that the structure of health and care services is reviewed to locate where this gap could be filled. Further research needs to be undertaken to inform approaches that would provide suitable support in the community that addresses this autistic need, looking beyond standard behavioural interventions (Fuld, 2018).

7.6. Contribution to theory

This study collected autistic stories to illuminate the autistic perspective of experiences to mental health hospital admission. What was learnt was the importance of relationships as both precipitating and protective factors. A lack of understanding, not being believed and not validated reduced wellbeing and mental health over time. A sense of being understood,

accepted and respected increased wellbeing leading to autistic people feeling they were safe not to mask and be their authentic selves. The human rights model as set out in the CRPD (UN, 2006) focuses on the importance of disabled people influencing policies that affect their lives. Governments are expected to involve disabled people, including autistic people, in planning how to implement the Convention. The learning from this study indicates that to be effective this involvement must come from a place of trust and respect. A major contribution of this thesis is how to engage autistic people in an equal, purposeful and empathetic way to achieve this (Chapter 6). Autistic voices from this study highlighted trusting relationships as important for wellbeing and what is needed to get equitable health care but a protective factor was also using skills for a purpose. The findings and method gave insights into the importance of purpose, understanding the point and expectations of the study and the positivity associated with using their skills and knowledge for a purpose. This learning translates into a recommendation to ensure autistic people understand the purpose of a project when asked to engage and be involved in it. From the double empathy theory (Milton, 2012) we know that meaning may be interpreted differently between the autistic and neurotypical mind, this means it is not sufficient to simply offer information on the purpose of a project but to also check understanding and encourage questions (6.6 nos.8,9,10). For this to be successful the trusting relationship is needed (6.6 nos.1,2). For policies to be effective the human rights model identified that autistic voices need to be listened to, without having the autistic voice policies aimed to protect and support autistic people may not be successful. Not only are autistic voices needing to be heard and listened to but consideration has to be taken to ensure the autistic person feels safe and comfortable with the researcher to unmask and speak authentically to provide genuine, purposeful and useful data. This thesis has contributed ways that this may be achieved, see recommendations 6.6.

This contribution to theory that offers a ‘how’ to include autistic people in research transcends the human rights model of disability and applies to any approach requiring hearing genuine lived experience. The trusting relationship and an understanding of the point of the participation is fundamental, whatever the theoretical underpinning of the approach. Equally, an ethical and reflective approach to the needs and perspectives of participating lived experience individuals is relevant outside the field of research to include any coproduction project.

7.7. Conclusion

This study set out to better understand why autistic people are overrepresented on mental health wards from the autistic lived experience perspective through emphasising autistic

voices and lived experience. In keeping with highlighting autistic voices it is appropriate to sum up with a quote from a participant:

“nothing ever really improved we (Child and Adolescent Mental Health Services, CAMHS, appointments) didn’t necessarily talk about the right stuff um or recognised why I was different and I think that’s what I needed it wasn’t about changing me to fit the rest of the world it was about me learning to accept that I was different and that it was OK to be different and for the rest of the world to know that it is OK for somebody to be different”

(Jenny when reflecting on why their mental health continued to negatively spiral to psychiatric admission)

The above quote encapsulates the need for change in the way services and society respond to and understand autism to protect autistic wellbeing. It captures the essence of the human rights model of disability to accept and respect all. Rather than society and services requiring autistic people to follow strategies to fit in with the majority, a more inclusive, accepting, non-judgemental approach would be beneficial, with a shared and consistent understanding of what it is to be autistic. Acknowledgement is needed that autism cannot be put to one side when supporting mental health of an autistic person or interacting with them, autism may affect the way a medical condition is experienced and responded to. Findings illuminated the importance of the autistic minority having their voice heard, believed and their experiences used to improve services to meet their needs, following the expectations of the human rights approach.

This research has highlighted the importance of relationships in our human lives, autistic needing positive connections with others just as non-autistic people do. It is interactions with people that provide risk factors to autistic mental wellbeing but also can provide protective influence meaning that this is not just a clinical concern but needs a relational approach (7.5). As Shaw *et al.* (2023) it suggests that preventative solutions will need an adjustment in both societal and cultural practices. Health and social care practitioners developing their awareness of autism away from a stereotypical view and adopting a trauma informed approach to their interactions with autistic people may support the development of trusting relationships to aid access to support before escalation to mental health crisis. Further research is recommended to establish whether that is the case.

From what participants revealed in this study and through the process of the research, a trusting relationship is also identified as being important in researching with autistic adults (Chapter 6). A background of understanding autism theory and interacting with autistic people may help with developing trust as participants talk about the value of being understood (*Jenny, p.3; Max, p.59, Polly p.25*), however, the researcher can make an autistic person feel safe and comfortable without an autism diagnosis themselves (Rosie, 6.2). In addition, a contribution towards best practice to researching with autistic people is to clearly provide the purpose of the research. It emerged from the findings of the study that using skills for a purpose was a protective factor for wellbeing and there was a wish from participants to use their experiences to benefit others (Jenny, Rosie, Ashleigh). It follows that individuals came forward to indicate an interest in taking part in the study because they felt they had something to contribute (Rosie, 6.2). The ethical tenet to do no harm to participants could be extended to do some good by promoting self-esteem in autistic participants taking part in ethical research by using their knowledge for a purpose. What this study has exposed is how essential the fundamental basics of positive human interaction are in maintaining autistic wellbeing. This is the foundation of inclusion and good support. Ironically autistic people were labelled as having no empathy, from participants' stories non-autistic empathy towards autistic could be questioned. Key contributions of this study for research and practice, therefore, are that numbers of hospital admissions for autistic people due to mental health crisis is not simply a clinical concern but a relational, rights-based issue that requires societal and systemic change to align with statutory commitments to inclusivity; plus methodological implications for further research and projects coproduced with autistic people providing recommendations towards best practice.

The concluding statement relating to the importance of relationships and accommodating personal need, both towards best practice in interacting with autistic people from a research perspective and in providing mental health support to avoid hospital admission, I leave with Max,

“it was just about you know um being a nice human being” (Max, p.51).

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Appendix 1 Readiness Guide

Readiness Guide

TITLE: Why is the hidden disability of autism so visible in mental health inpatient services? The autistic view from personal stories

Researcher	Louise Kirby
Reviewed by	University of Northampton & Northamptonshire Healthcare NHS Foundation Trust

INFORMED BY AND ADAPTED FROM AUTISTICA'S READINESS DOCUMENT:

Is taking part in this study right for you, right now?

There are lots of reasons why someone may want to tell their story, for example they might want to help others, or they may want to feel seen. It's important to make sure that you are ready to share your experiences. This guide is to help you work through that decision. It is for anyone who is thinking about talking about their lived experiences, whether they're talking about big or small issues.

Before you make your decision, here are some questions to consider, either by yourself via self-reflection or with a trusted family member, loved one, or friend. You can also talk through these questions with the researcher, Louise via video call, face to face, email Louise.Kirby@northampton.ac.uk or phone 07712543118, whichever you would feel most comfortable with.

Talking about Autism:

1. What is your motivation for being involved in this work? Understanding why you want to share your experiences will help you decide if this project is right for you.
2. Has there been enough time between your diagnosis and now for you to process what this means for your past? This time period may well

reset after a medical diagnosis, even if you have known you are autistic for a long time before.

3. How do you feel when you are talking about your experiences as an autistic person? Are there certain topics that you find more upsetting than others?

Talking about Mental Health and distressing incidents:

1. What is your motivation for being involved in this work?
2. Has there been enough healing time between now and your experience?
3. What impact does talking about mental health challenges or distressing incidents have on you, mentally and emotionally, in recent times?
4. Are there any particular times or dates when you feel more vulnerable?
5. Are you aware of any particular words, conversations, or triggers around mental health challenges or distressing incidents that affect you?
6. What self-care practices do you have in place to nurture yourself when you are feeling more vulnerable?
7. Do you feel ready for the next step in this process, and do you have any concerns? If you have questions you can ask Louise Louise.Kirby@northampton.ac.uk or phone / text 07712543118,

Before you decide to take part, here are some of the signs that demonstrate you might be truly ready for the next step. Completing the table below, either on your own or with a trusted family member, loved one or friend, may help you reflect on whether you are truly ready to share your experiences.

Signs that you are ready!

Signs	Yes	No	Maybe	My Notes
You are at a point in your life, emotionally and mentally, where being involved in this work won't set back your own healing.				

You are motivated to tell your own story and participate in the study for reasons other than solely for your own healing.				
You understand your own triggers and have self-care strategies and practices in place to support you when you are feeling more vulnerable, you also know when you need to reach out for more support. Do you have a support network or someone in your life that you can turn to when needed?				
You are doing this for you! You are gentle with yourself as a result of the healing that has taken place so far.				
You have considered the emotional and mental impact of taking part in the				

interview and it feels right for you at this point in your life.				
You have considered what taking part involves – the interview and reading the researchers understanding of your interview, and you have the capacity and time to dedicate to this without overwhelming yourself.				
You have considered the implications of involvement to yourself, your family and your friends.				
You are at a point in your life where you have allowed adequate personal healing time.				

Don't worry if you have got this far and have decided that you are not ready to share your experience. It is important to the researcher that you would be able to tell your story safely and that you make an informed choice about whether or not to take part.

Please remember that if you've found it upsetting to think through issues related to the study you can reach out for support from:

- Mental Health Navigators: 0800 448 0828 (Lines available 24 hours a day, 7 days a week)
- Crisis Cafés: drop in,
<https://www.nhft.nhs.uk/download.cfm?doc=docm93ijjm4n8848>
- Samaritans: 116 123 free from any phone

Appendix 2 Information Sheet

Information Sheet

TITLE: Why is the hidden disability of autism so visible in mental health inpatient services? The autistic view from personal stories

Researcher	 Louise Kirby
Reviewed by	University of Northampton & Northamptonshire Healthcare NHS Foundation Trust

What is this for?

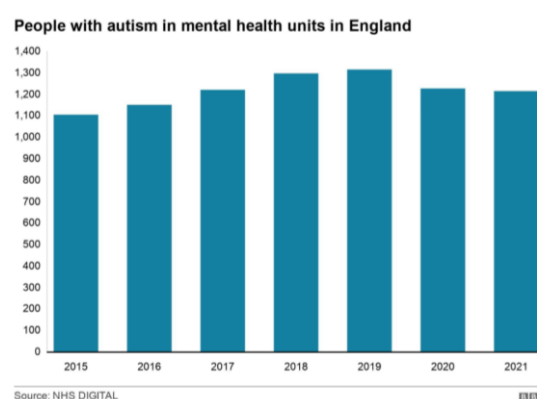
This information sheet is about a research study. Please read this document and the 'Readiness Guide' carefully so you can decide whether or not you want to be in the study. You can share this information sheet with a trusted family member, loved one, or friend to help support you in your decision. Louise would be happy to go through the information with you too. You don't have to be in this study.

What is the study about?

The study wants to find out why so many autistic people are admitted to hospital mental health wards.

We want to better understand:

- Your experiences that may have been a risk to your mental health.



What do I need in order to be in the study?

You can be in this study if

- You are at least 18 years old
- You have proof of a diagnosis of autism spectrum disorder or Asperger's Syndrome
- You have previous experience of admission to hospital for mental health needs
- You do not have a learning disability
- You are not currently experiencing mental health crisis
- You are not sectioned under the Mental Health Act

What will happen if I do the study?

If you decide to do the study you will do a virtual interview with Louise, the researcher. You will be sent the questions before.

During the interview you and Louise will go through the questions together. If you choose, you can also have someone you know with you to support you. You can also use props such as photos and diary entries to help you answer questions if you wish.

The interview will be recorded and after the interview Louise will type everything up and send it to you to check.

You will be able to take a break at any time. You don't have to answer any questions you don't want to. You will be able to stop the interview at any time. Please remember that you can use any of your personal sensory strategies e.g. fidget objects, chewees, and communication tools that help you during the interview.



It will take about two hours to complete the interview.

How will my information be kept private?

- Your name or other personal information will not be used in any public way such as when the study is written up.
- A written copy of your interview will be kept and archived at the UK data archive for future researchers to use. Your name will not be on that copy. Instead a code will be used.

- You will not be asked any questions about violence or abuse. However if you tell Louise you have been abused and this has not previously been reported that can not be kept private. Evidence of terrorism cannot be kept private either.
- The only information for the study from you will be what you choose to tell Louise during the interview

Could doing the interview cause any problems for me?

- Telling your story in the interview could be triggering. Before agreeing to take part and before the interview you can chat with Louise about whether this is the right time for you to share your experiences. You can also discuss this with others. (Please see 'Readiness Guide' for questions to think about to help you decide whether this is the right time for you to share your experiences)
- Everything we can is done to keep your identity private. However, there is a small risk of loss of confidentiality

Will doing the interview help me?

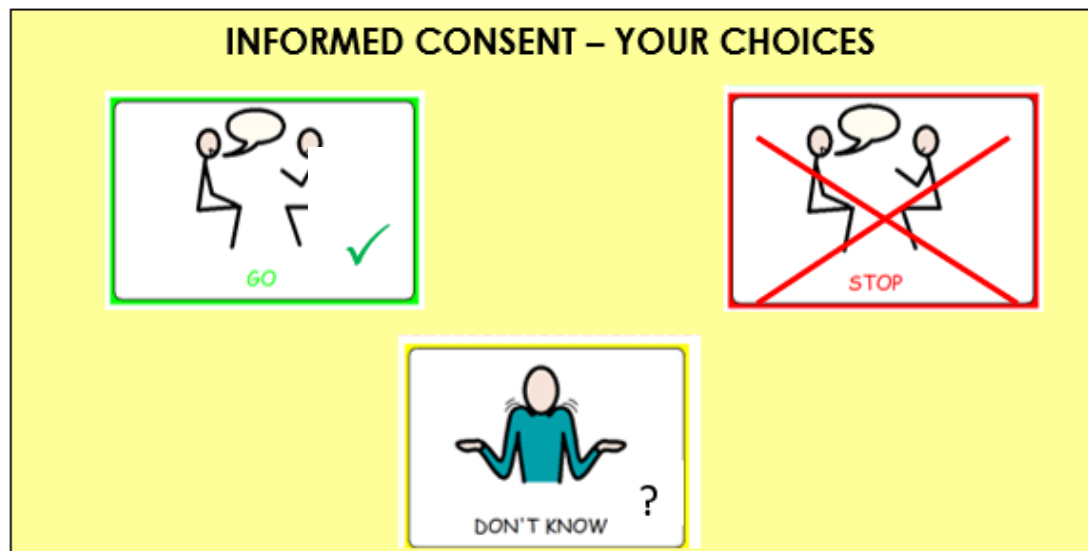
- Doing the interview may or may not help you, however your answers may help make it be easier for other autistic people in the future to get support to prevent mental health crisis.

What are my rights? Who do I contact if I have questions?

- Being in this study will not affect any care or services you might receive from NHFT.
- Being in this study will not affect your involvement within the Autism Advisory Panel in any way.
- You do not have to be in this or any research study. If you choose to do this interview and then change your mind you can cancel it without giving a reason. If you take part in the interview and change your mind you can have all or some of the information you have given removed within 7 days from getting the write up of your interview. You will not experience any bad consequences because of changing your mind.
- If you have any questions about the study or taking part you can ask Louise Louise.Kirby@northampton.ac.uk or phone / text 07712543118
- If you have any concerns about the way you are treated during the study, you can contact Michelle Pyer, Doctor of Professional Practice in Health and Social Care programme leader at the University of Northampton - michelle.pyer@northampton.ac.uk

What are my choices now?

- You can decide to do the interview
- You can decide not to do the interview
- You can take more time or ask more questions and decide later



Informed by and adapted from AASPIRE 1c consent Autistic doc <https://aaspire.org/wp-content/uploads/2021/10/Consent-qual-HealthcareV2.pdf> Symbols: Communicate in Print 2 from Widgit Software

Informed Consent

Why is the hidden disability of autism so visible in mental health inpatient services?

The autistic view from personal stories.

If you are willing to take part in this project, please complete this consent form and return to Louise Kirby, Louise.Kirby@northampton.ac.uk

If you would like to discuss any of the points or need any further information before completing this consent form, please ask Louise, Louise.Kirby@northampton.ac.uk

Please read each statement below and then confirm that you agree or disagree by **placing your initials** in the appropriate box.

	YES	NO
I have read and understand the information provided to me in the information sheet.		
I have had the opportunity to ask questions about this project.		
I agree to the interview being recorded.		
I understand that I can decline to answer any questions.		
I understand that I can withdraw my answers in part or full, anytime up to 7 days after receiving the write up of the interview		
I agree to artefacts (props) that I may use to answer the questions being photographed.		
I agree to anonymised quotations and photographs of artefacts being used in any presentations or publications of this work.		
I agree for the data I provide to be archived at the UK Data Archive.		
I understand the limits to confidentiality in the project e.g. the researcher will let someone know if a safeguarding concern is disclosed or evidence of terrorism; the researcher has explained that there is a small chance that my anonymised contribution may be identifiable to someone else.		
I agree to my data being used in any subsequent work that builds on the current project.		

Signature and date of person giving consent (the participant).

Signature and date of person obtaining consent (the researcher).

Appendix 4 Debrief Sheet

Debrief Sheet

TITLE: Why is the hidden disability of autism so visible in mental health inpatient services?

The autistic view from personal stories

Researcher	Louise Kirby
Reviewed by	University of Northampton & Northamptonshire Healthcare NHS Foundation Trust

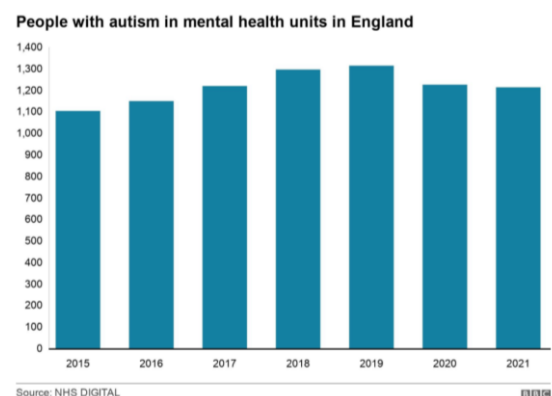
Thank you for taking part in this study, it is greatly appreciated. It is hoped that the results of this study will help inform development of support in the community to meet autistic need

What was the purpose of this study?

The study wants to find out why so many autistic people are admitted to hospital mental health wards.

We want to better understand:

- Your experiences that may have been a risk to your mental health



What happens next?

- Now you have taken part in the interview Louise will type everything up and send it to you to check
- If you used props to help tell your story, photographs of these will be included in the write up of your interview
- You will receive the write up of your interview within one month of the date you were interviewed
- You are invited to read the write up of the interview to check that it says what you wanted to say
- Louise will ask, within 7 days of you receiving the write up, if you are happy with it or not
- If you are happy with the write up of your interview Louise will analyse it and then check with you that she has interpreted what you meant correctly

- It will be about 2 months until Louise contacts you to check the interpretation. She will let you know when it is ready and you can agree a good time for you to talk through this with Louise
- If you have any questions about any aspect of this study, please contact Louise: Louise.Kirby@northampton.ac.uk or phone 07712543118

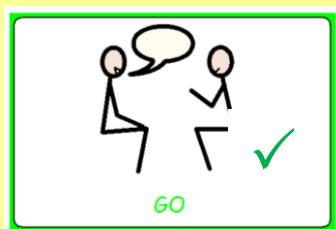
What do I do if I don't want some (or all) of what I said in the interview included in the study?

- If you are not happy with the write up of your interview and you want to change your mind about what is included tell Louise
- Louise will ask, within 7 days of you receiving the write up, if you are happy with it or not
- If you are not happy with part of what you said in the write up of the interview you can withdraw that part without giving a reason and it will not be used in the study. You have 7 days from receiving the write up to choose whether to do this or not
- If you are not happy with any of what you said in the write up of the interview you can withdraw it all without giving a reason and it will not be used in the study. You have 7 days from receiving the write up to choose whether to do this or not
- If you withdraw part of your information from your interview that part will be deleted and no record kept of that information
- If you withdraw all your information from the interview it will all be deleted and no record will be kept of that information or your previous involvement in the study
- You will not experience any bad consequences because of withdrawing some or all of what you said in the interview from the study



You have 7 days from receiving the write up of your interview to tell Louise if you are not happy with it.

INFORMED CONSENT – YOUR CHOICES



Symbols: Communicate in Print 2 from Widgit Software

How will my information be kept private?

- Your name or other personal information will not be used in any public way such as when the study is written up
- The only information for the study from you will be what you choose to tell Louise during the interview and agree to keep in the write up of what you said
- A written copy of your interview write up, that you previously agreed, will be kept and archived at the UK data archive for future researchers to use. Your name will not be on that copy. Instead a code will be used
- If you have any questions about any aspect of this study, please contact Louise: Louise.Kirby@northampton.ac.uk or phone 07712543118

What can I do if I have found it distressing to talk about issues relating to this study?

You can reach out for support from:

- Mental Health Navigators: 0800 448 0828 (Lines available 24 hours a day, 7 days a week)
- Crisis Cafés: drop in
<https://www.nhft.nhs.uk/download.cfm?doc=docm93jjm4n8848>
- Samaritans: 116 123 free from any phone

What do I do if I have a complaint?

If you have any concerns about any aspect of the way you have been approached or treated during this study, then please contact Dr. Michelle Pyer. Doctor of Professional Practice in Health and Social Care programme leader at the University of Northampton
michelle.pyer@northampton.ac.uk

Thank you for taking part in this study

Appendix 5 Email Request for Participants

Email to AAP requesting applicants.

On Friday, April 1, 2022, 6:18 pm, Kirby Louise wrote:

Dear Autism Advisory Panel members,

Autism Acceptance week seems a good time to seek participants for my research study:

Through listening to autistic life stories this study aims to understand the autistic perspective of how living as autistic in a non-autistic focussed world impacts on their mental health:

1. To explore through autistic lived experience risk factors for mental health admission
2. To explore through autistic lived experience protective factors that promote resilience to avoid mental health admission

To be a participant you need to meet all the following criteria:

- Be at least 18 years old
- Have a confirmed diagnosis of autism spectrum disorder or Asperger's Syndrome
- Have previous experience of admission to a mental health hospital
- Do not have a learning disability
- Not currently experiencing mental health crisis

It will involve an online interview with me – I have attached the questions so you know what to expect to help you make a decision whether you would like to take part.

There is a lot of other information attached to help you understand what it is all about.

There is a readiness guide to have a look through too, to help you reflect on whether now is a good time for you to tell your story. It can be quite hard to know what emotions this might bring up.

If you have any questions about anything before you decide please do ask 😊

If you decide you would like to take part I will send you a consent form and demographic questionnaire to complete and return.

We will also arrange a pre-meet on the Collaborate platform we will be using for the interview to get familiar with that.

Finally, you don't have to just rely on talking -you can bring along 'props' or 'artefacts' to help you answer a question. This could be anything really and we will take a photo of it to add to the interview words, maybe a diary entry, a poem, a pet, a sensory item ...

Thank you for considering taking part, please ask if you are unsure of anything.

The most important thing for me is that you are able tell me your story safely - if you want to tell it at this time.

Thank you.

The Interview

TITLE: Why is the hidden disability of autism so visible in mental health inpatient services? The autistic view from personal stories

Researcher	Louise Kirby Louise.Kirby@northampton.ac.uk 07712543118
Reviewed by	University of Northampton & Northamptonshire Healthcare NHS Foundation Trust

Before the interview please check that:

- You feel confident about the answers to the consent form that you completed.
- You have been through the 'Readiness Guide' and are confident that now is the right time for you to tell your story.

What will happen during the interview?

The interview will be between you and Louise and be held online.

The online platform will be Collaborate, in line with the University of Northampton research policy.

During the interview you and Louise will go through the questions together.

You can use props such as photos and diary entries to help you answer questions if you wish. Providing a digital photograph of your props will be helpful to include in the interview write up.

If you choose, you can also have someone you know with you to support you.

Please remember you can use your personal sensory strategies, e.g. rocking, fidget objects etc. during the interview.

You will be able to take a break at any time.

You don't have to answer any questions you don't want to.

You will be able to stop the interview at any time.

The interview will be recorded and after the interview Louise will type everything up and send it to you to check.

Some information can't be kept confidential if it is a safeguarding issue e.g. abuse, terrorism.

It will take about two hours to complete the interview.

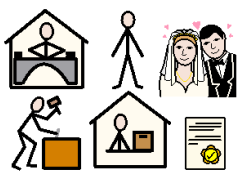
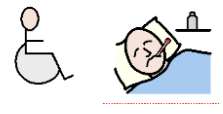
If you have any questions you can ask.

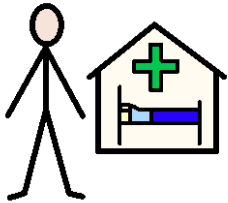


It will take about two hours to complete the interview.

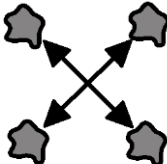
The Interview Questions

	Main questions	Secondary questions and prompts
	1. Where was your place of birth?	Demographic details not received previously
	2. Who did you grow up with?	Parents? Carers? Siblings? Extended family? How did you get on with them?
	3. Please describe what your schooling was like?	How did you get there? School uniform? School dinner? Friends? Favourite aspects? Least favourite aspects? Any difficulties you remember having, if any? Any areas where you excelled, if any?

		Any experience, if any, that had particular impact that influenced your life? How? Why?
	4. What did you do after you left school?	Further study? jobs? Hobbies? Marriage? How did you decide? What did you particularly enjoy doing? Any difficulties you remember having, if any? Any experience, if any, that had particular impact that influenced your life? How? Why?
	5. Please describe how you received your autism diagnosis?	What led to this? Where were you diagnosed? How old were you? How long did diagnosis take? How did you feel about receiving a diagnosis? Do you believe having an autism diagnosis had an impact on your care and support? If so, how?
	6. What physical health problems do you remember having, if any?	What was this like? How were they addressed?
	7. In addition to physical health, can you describe any episodes of being mentally unwell, if any?	What was this like? How was this addressed? What support, if any, did you receive? What support was successful? Helpful? If you didn't feel you received the right support, what do you

		consider the right support should be? Do you consider you experienced particular difficulties due to being autistic? If so, what were they? Were you diagnosed at that time?
	8. Please could you describe your experience as an inpatient?	Was this a voluntary admission or not? Why were you admitted? Had you had / did you have a Care and Treatment Review? If so, how did you find it? How long were you admitted for? If there were reasonable adjustments what were they? What helped you as an inpatient? Do you consider you experienced particular difficulties due to being autistic? If so, what were they? Is there anything you would like mental health wards to do differently? If so, what?
	9. Where did you go after discharge from hospital?	How was the transition? Have you had more than one admission? If so, what were the reasons for admissions? Can you identify any triggers for admission?

 V 	10. How are you able to, if you can, differentiate between your autism and mental health needs?	In your opinion, is it necessary to differentiate? Do you need support for these? Which or both? How do you access support? Who or what provides this support? Does it meet your needs? If not, what would meet your needs? What would make support more successful?
 Image https://www.libf.ac.uk/	11. What do you understand by the term mental wellbeing?	What does mental wellbeing mean to you?
	12. What would you consider to be the most important thing that supports your wellbeing?	Explain this. <i>You are invited to provide an artefact (a photo, an object, a song or something else) to show what you consider to be the most important thing that supports your wellbeing rather than solely providing a verbal description</i>
	13. What do you consider to be the biggest problem you face in maintaining your wellbeing?	Explain this <i>You are invited to provide an artefact (a photo, an object, a song or something else) to show what you consider to be the biggest problem you face in maintaining your wellbeing</i>

		<i>rather than solely providing a verbal description</i>
	14. What would you say has had the most positive influence on your life?	Describe this. Any other positive influences? <i>You are invited to provide a photo or other artefact, any media, to support you in answering this question</i>
	15. Is there anything else you would like to add?	No prompts at this stage.

Symbols: Communicate in Print 2 from Widgit Software

Appendix 7 Demographic questionnaire

Demographic Questionnaire

This information is requested to provide clarity about the characteristics of the participant group. It will enable consideration of how culture and context could influence findings.

If you would like help to complete this form please ask Louise

Kirby: louise.kirby@northampton.ac.uk

Age

How old are you? Click here to add ☐ years

How old were you when you received your autism/Asperger's diagnosis? Click here to add ☐ years

Ethnic Group

Please indicate which ethnic group you consider yourself to belong to (you can choose more than one answer)

White English, Welsh, Scottish, Northern Irish or British ☐ Irish ☐ Gypsy or Irish Traveller ☐ Roma ☐ Click here to add ☐	Mixed or Multiple ethnic groups White and Black Caribbean ☐ White and Black African ☐ White and Asian ☐ Click here to add ☐	Asian or Asian British Indian ☐ Pakistani ☐ Bangladeshi ☐ Chinese ☐ Click here to add ☐
Black, Black British, Caribbean or African Caribbean ☐ African ☐ Click here to add ☐	Other ethnic group Arab ☐ Click here to add ☐	Rather not say ☐

Sexual Orientation

How would you describe your sexual orientation?

Bisexual/Pansexual ☐	Gay/Lesbian ☐	Heterosexual ☐
Asexual ☐	Rather not say ☐	Other – please state: Click here to add ☐

Gender

How would you describe your gender?

Female ☐	Male ☐	Non-binary ☐
Agender ☐	Rather not say ☐	Other – please state: Click here to add ☐

Gender identity

Are you trans? (different gender than that assigned to you at birth)

Yes ☐ No ☐ Rather not say ☐

Faith

Which group below do you most identify with?

No religion ☐	Hindu ☐	Buddhist ☐
Christian ☐	Muslim ☐	Jain ☐
Jewish ☐	Sikh ☐	Agnostic ☐
Rather not say ☐	Other – please state: Click here to add ☐	

Educational Attainment

What is the highest level of education you have completed?

Secondary school up to 16yrs ☐	Higher or secondary or further education (e.g. 'A' levels, BTEC) ☐	College or University ☐
Post-graduate degree ☐	Rather not say ☐	Other – please state: Click here to add ☐

Work

Please indicate all the choices that apply to you.

I am in full time paid employment (35 hours or more) ☐	I am in part time paid employment (work a few hours up to 35 hours) ☐	I do volunteer unpaid work ☐
I am a student (full time or part time) ☐	I am a full time carer or parent ☐	I am not in paid work but would like a paid job ☐
I am not in paid work (e.g. due to long term condition or retired) ☐	Rather not say ☐	Other – please state: Click here to add ☐

Income

Which amounts best represent your total household income before tax and deductions but including allowances and benefits?

Under £10,000 ☐	£10,001 – 20,000 ☐	£20,001 – 30,000 ☐
£30,001 – 40,000 ☐	£40,001 – £50,000 ☐	£50,001 + ☐
Rather not say ☐		

Accommodation

In which way do you occupy your current accommodation? Please select one only.

Owned outright ☐	Buying on a mortgage ☐	Rent from private landlord ☐
Rent from council ☐	Rather not say ☐	Other – please state: Click here to add ☐

Household

Who occupies your accommodation with you? Please indicate all the choices that apply to you.

No one, I live alone ☐	My spouse / partner ☐	My parent/s ☐
My child/children ☐	My stepchild / stepchildren ☐	Share with 'flat mates' who are no relation to me ☐
My carer ☐	Rather not say ☐	Other – please state: Click here to add ☐

Thank you for completing this questionnaire

All the information collected for this study will be kept confidential and stored on a password protected computer. At the end of the study the completed demographic questionnaires will be deleted.

Appendix 8 Group Experiential Themes - Risk

A. BEING DIFFERENT & NOT FITTING IN

Being different

Bullied at school from age 7 as different, this carried on after moving schools

"I was very quickly identified as different um unusual weird and that was really hard"
(Jenny, p.7)

Recognises that circumstances must have been very challenging for Mum which included them being different

"it was extremely challenging for my Mum she also had to deal with the fact that I was different" (Jenny, p.2)

Felt different because didn't respond to things in the same way as the rest of the family

"family would say you know on the phone oh were you excited to see everyone and I'd say 'no' um and they'd be like oh you should be excited" (Rosie, p.4)

Moving every two years, and not with the same regiment or battalion due to Dad's specialist skills, camouflaged difficulties fitting in

"I think it masked the fact that I had issues because because things changed so regularly um there wasn't a kind of base line to show that I wasn't fitting in because by the time I was kind of about wondering about that it would be on to somewhere different" (Max, p.2)

Didn't fit in with other staff and missed cues that their behaviour was not approved of

"with me being oblivious to any kind of um (sigh) um well non-verbal sort of er expression of how they felt um I you know I sort of I guess didn't get the hint for some stuff so um and yeah so I mean it it what I was going to say er I wasn't aware of doing anything that was actually bad but obviously some people didn't like where I was how I behaved um and quite a few times I came out of work to find they had let my tyres down (laugh)" (Max, p.18)

Appreciated that being made Head Girl was a privilege but as Head Girl they stood out more as different.

"I was made Head Girl which should have been a great privilege (laugh) but it really wasn't it was another way of standing out and I think because they'd learnt that I had absolutely no issue with talking in assembly, that didn't bother me at all, but putting me on a one to one I

really struggled with. I think they were trying to help me become more confident but it just alienated me slightly further (laugh) from my peers.” (Polly, p.5)

Different in junior school, bullied and seen as teacher’s pet

“I got bullied in school um because of the fact that I wasn’t like everybody else and I was seen as a teacher’s pet” (Rosie, p.9)

Differences more pronounced as a teenager, bullied for not fitting in, would mask to avoid being bullied not because they wanted to fit in

“once we were teenagers obviously people become a lot more conformative in some way a lot more kind of worried about what they look like and um yeah the differences just grew a lot and in terms of things like the way I spoke I didn’t swear I spoke Queen’s English I spoke I had a different accent than my family that kind of typical thing and I and I started to get picked up on on those things and bullied about those things” (Ashleigh, p.16)

Always known different, autism suggested first suggested to them during their first mental health admission at 21

“I’d always kind of known that there was something different um but I got admitted into [REDACTED] hospital and staff picked up very quickly that I was struggling to cope with the fact that I no longer have my routine and all the noises and the different smells and all of those sort of things that staff started say, “Ooh, are you are autistic?” (Rosie, p.14)

Uni was the first time they compared themselves to others who were going through normal societal rites of passage, these didn’t feel achievable to them

“at Uni you then live with people who have a boyfriend or get married or are saving up to buy a house and all these sort of like social norms that I didn’t think I would ever achieve and I think I am still slightly in that camp. I don’t know if I’m going to be able to do that or if I will do that. I think Uni was the time, the first time I compared myself to my peers, before I’d just floated around and not really thought about it” (Polly, p.16)

Don’t fit in with other patients on mental health wards.

“don’t know how much I fit in either as an inpatient because for the most part people tend to be not in employment, not in education and I’m trying to finish I was trying to finish my undergrad degree while I was there, or I was doing a module for my Masters while I was there and I don’t think they, I don’t know if they don’t expect it” (Polly, p.55)

In group mindfulness sessions realised that their sensory experiences were different to others

“was some mindfulness sessions um with a sort of group of 6/8 something like that would sit down and sort of be taken through um the process um that was interesting but possibly for the wrong reasons because I kind of realised that I wasn’t experiencing it in the same way that other people were in that I had all my all the inputs switched on at once so I didn’t need to concentrate to realise I was feeling pressure from the seat or to hear the clock ticking in the background I was getting that all the time um and it but it was useful in that going through it to concentrate on each one individually was a thing but it kind of realised that for most if not all the other people there they were oblivious to a lot of stuff which I was getting all the time” (Max, p.45)

Not belonging

Although not sure autism has been presented to them as something wrong but interpreted that way as missing abilities to be part of the human race is a wrongness

“I don’t think it has been presented to me as something being wrong but that is certainly my interpretation and I you know I’ve heard a lot of people say that it’s a difference in mental processing rather than a wrongness but certainly the way I feel at the moment I’m missing abilities that er would enable me to be part of the human race (laugh)” (Max, p.32)

Hated school and didn’t fit in

“I kind of hated school all throughout um I always kind of felt like I was an outcast” (Rosie, p.5)

Couldn’t find their place as there was no place for them affected their mental health

“I was a queer kid growing up under section 28 and I don’t think you can take that out of the equation in terms of me appearing different and being aware that being different wasn’t OK I don’t think you can separate it out from that um and in terms of like my mental health and stuff like that it obviously that came into it as well that I was just getting these messages that I wasn’t OK to be myself and there was no one cos it was section 28 um no one was allowed to tell me it was OK to be me” (Ashleigh, p.17)

Very much alone since familiar universe of work destroyed

“my work has always been my reason for existence and pretty much all of my um er all of my life and with COVID and changes to the current company um that’s been taken away from me permanently now so um where I am at the moment is in a um yeah lost (laugh) I kind of don’t my universe that I used to fit in however badly has gone now and um I’m sort of fating

trying to work up from scratch and even then it's no longer a place where I can I can fit ... and the what made me not alone has sort of exploded into lots of different pieces which are never going to come back together um which yeah is just quite a difficult place to be" (Max, p.25)

Awareness that they had to behave in a way that was not what they necessarily wanted to be accepted and maintain friendships

Figure 6 *"I remember this went on the school wall um the wall it was a piece done about our lives which means my teachers were aware too and the fact that my parents kept this as well um - meant other people were aware but as far as I am aware as of I can remember nobody talked to me about this, nobody ever offered me support or talked to me about it or acknowledged it apart from sticking it on the wall and my parents keeping it."* (Ashleigh, p.13/14)

Sadness that the world isn't equipped to deal with autistic people, and they are one of those people

"I guess it saddens me a little bit to know that the world isn't really equipped to deal with autistic people um and I I am part of that criteria that the world doesn't understand that well and um doesn't necessarily always know how to deal with in the best way." (Rosie, p.17)

Not understanding why

Outsider on the playground but couldn't understand why, didn't fit in with army children or civilian children and this caused problems

"you sort of need to fit in with the social group in some way and which is something I obviously never did but never realised quite why and I think that kind of caused some problems because I was never part of the crowd or any of the crowds that were around and that was yeah quite unpleasant" (Max, p.8)

Knew they weren't like other humans.

"I wanted to understand humans because I knew I didn't understand them and I knew I wasn't like them, I didn't I just didn't know." (Polly, p.13)

Difficult teacher/learner relationship and difference from peers caused worry that the interactions were wrong but not understanding why

"I wasn't fitting into their (teacher's) idea of how I should be responding you know in that sort of situation things got a bit unpleasant as well um but um just just generally that it was

more kind of things going socially wrong but not quite really me understanding why they were going badly but knowing enough or or er having enough of a feeling that they were going badly to be worried about it” (Max, p.10)

Bullied and teased for not doing social aspects of senior school

“I was bullied I was teased and stuff like that um and I guess it kind of especially in senior school it made me realise just how different I was to other people um but didn’t really understand why I was so different” (Rosie, p.9)

Incomprehension in that despite doing all the things that would be described as good they were still perceived as a problem

“I was her problem child but I couldn’t understand how I was” (Ashleigh, p.3)

Wanting to fit in (Add into not belonging)

Feel excluded from society and missing the ability to integrate despite wanting to

“I’m excluded from society I don’t have what it takes to integrate even though I want to I don’t I’m not sure whether I can ever actually have enough well I don’t know but (laugh) er essentially I am pessimistic at the moment but I am open to change” (Max, p.32)

Wanted friends, didn’t realise at the time that they didn’t really get on with peers.

“I didn’t necessarily get on very well with my peers and it’s not until now that I realise that. I think I, I wasn’t bullied but they weren’t, I think I was very easy to manipulate, quite vulnerable I suppose and I didn’t realise that at the time I just wanted some friends. I wanted them to be my friends they never did anything awful it was just that yeah I they didn’t necessarily really like me I don’t think (laugh) but there I was” (Polly, p.5)

Confident in who they are and their diagnosis but has a dilemma between wanting to be themselves and the need to mask to fit in and avoid judgement

“you can’t be your true self necessarily um there are certain things that um you know even though I’m confident in who I am and my diagnosis now there’s still um aspects of life you know when you still kind of feel the need to mask because you want to fit you want people to accept you you don’t want to stand out and it’s a dilemma isn’t because you want to be yourself but at the same time you want to fit and you don’t know what people’s judgements are like” (Jenny, p.44)

B. NOT BEING TAKEN SERIOUSLY & MISUNDERSTOOD

Family Relationships

Lack of understanding both ways between them and their parents resulted in a remote and undemonstrative relationship

“I think I was more possibly more baffled by their responses than they were about er my behaviours um so yeah I th essentially there was a lot of misunderstanding and um yeah the the the outcome of that was essentially um as I say quite a distant kind of relationship not a tactile one no hugs or things like that” (Max, p.14)

Was ill and not able to go to school so felt upset and crying about it, Mum commented unpleasantly that other children wouldn't react like that

“the most vivid memory I have of school is one morning crying because I was ill and couldn't go to school and my Mum, not in a very nice way, but basically said you are a complete weirdo most children would be very happy to not have go to school (laugh) but, it took a while to realise but I think it was because my routine was being thrown and being ill wasn't something I could plan for. I think I really liked school because of the structure and the routine and I also I'm very academic” (Polly, p.4)

Had a strained relationship with family and didn't feel understood

“I had very strained relationships within my family um at different points which has been quite complicated and misunderstood um which is tricky” (Jenny, p.3)

“relationships generally have been a bit tricky with family not really understanding” (Jenny, p.3)

Not understanding why their difficulties are not acknowledged or recognised

“when I was in hospital I remember her (sister) saying to me Oh it's alright for you you can just lay there and I've got to be at home with my baby um this was her healthy baby that she had in her lovely she's got a lovely husband who is very supportive and provides everything she could need... she must have thought I was at some kind of weird celebrity retreat or something but it was this strange attitude which I think my Mum has as well...” (Ashleigh, p.6)

Work Relationships

Difficulties at work, not supported or understood by colleagues.

“someone decided they hated me because of something I said I did point out that she had misinterpreted once and I think it was something I said about my family too like in passing which actually was considering my relationship with my family quite mild (laugh) I and I didn’t understand why that would be kind of upsetting to her” (Ashleigh, p.28)

“although it wasn’t exactly traditional sort of office type stuff it was along those lines and there’s a whole culture and a set of behaviours that goes with that which I guess people just pick on and it’s it’s grown up over time and as people join places they kind of their social bits of their brains pick up on the behaviours and whatever and again with me that didn’t register at all” (Max, p.18)

Accessing Support

Tried to seek help before things got as bad as they did but not taken seriously because their struggles with mental health didn’t look the same as neurotypical

“I guess it took a little while for anyone to actually notice how much I was struggling with my mental health because again it somewhat looked different to start off with you know I tried to seek help for it before it got to the point where I was taking attempts at my life but they didn’t understand, they didn’t really see that it was a big problem and it didn’t look like your typical you know I wasn’t crying I wasn’t you know, I was still doing my normal routines and things like that” (Rosie, p.20)

An autistic presenting differently, struggling to get help

“when I was struggling with the depression and I think it was with me that I shutdown emotionally and I maybe I presented differently and now I know at burnout that people didn’t I didn’t present in the same way” (Ashleigh, p.21)

By secondary school accepted they wouldn’t be listened to, they would be bullied, people didn’t care and would not act on any cry for help

“by that point I think I in my secondary school I wasn’t expecting anyone to (listen) I was used to kind of um not being listened to um and not people not caring how I felt” (Ashleigh, p.16)

Mental health ward didn’t accept private autism diagnosis, said it was irrelevant

“they said because of the fact it was private, um it doesn’t matter it’s irrelevant um and they wouldn’t take it into consideration um despite the fact I I made the point that the person that I went with um for my diagnosis works within the NHS” (Rosie, p.22)

Of the opinion that mental health team didn't want to accept autism diagnosis as they didn't want to bother to provide reasonable adjustments

"I think they knew that it meant that they had to make more allowances and they didn't want to have to make the allowances, you know such as giving extra time and you know maybe not having quite so many people in a room and all of those sort of things um and yeah I think it was they didn't want to accept it because they then know they've got to make some allowances and they didn't want to have to make those allowances." (Rosie, p.23)

Not understood by staff

"he arranged for me to go into supported living accommodation cos I wasn't coping at home by myself um and I wanted that I knew I needed that and that's what the autism team the one who before she was taken off my case had been arguing for um and like having my own bit I didn't need like hands-on care but yeah that side of it um so he arranged for me to go into supported accommodation um but there wasn't the understanding there either, again I was just seen as kind of a problem" (Ashleigh, p.42)

Being labelled with a negative judgement

Sensory pain not believed and interpreted as attention seeking

"I got pain from when I was walking um and from lights and as I say kind of yeah my senses can be very sensitive um and that was just hypochondria seen as it wasn't seen as real um by other people it was just me being attention seeking or that and that was quite difficult in that I think so I learnt to suppress pain and to mask it um and to not listen to my body" (Ashleigh, p.32)

Not understood by staff, labelled as difficult and not engaging but finding staff make it difficult for them to communicate with them

"Very much a lack of understanding of me and being put down as a difficult patient and um sometimes non-engaging and and things like that... how it tends to go is staff struggling to understand me needing to communicate in different ways at different times being able to cope with you know something one day but then maybe not being able to cope with it the next day" (Rosie, p.32)

Not understood but labelled disruptive

"teachers felt that I wasn't concentrating um and that I was doing it to be disruptive rather than seeing it as an actual need and this is something that is helping me focus and helping me

concentrate and it didn't matter how many times I tried to explain that to them that actually this is how I focus, this is how I concentrate, and I really struggle to sit still and stuff like that they just didn't get it and just saw it as me being awkward." (Rosie, p.11)

Traits which were due to being autistic not understood and negatively construed

"a lot of the sort of autistic was taken in quite a bad way as a as a fault in me communicating or as me being – being bad in some way" (Max, p.13/14)

Communication differences caused problems at school as were construed as bad behaviour when trying to do the right thing

"People not thinking my questions as genuine and thinking that I'm just trying to be difficult when it's that I need clarification um because of not being able to read between the lines" (Ashleigh, p.12)

Their autism caused them to respond differently which was interpreted as being uncooperative, not intentionally uncooperative, medics unwaveringly decided BPD and autism diagnosis removed.

"I can't say what their reasons are cos I don't know um they had the system this was in [REDACTED] where um they wouldn't deal with people with a diagnosis of BPD or EUPD emotionally unstable I do say BPD for a reason um not EUPD because I think that fits my diagnosis more um (laugh) and the reason I say that and excuse the swearing is that um the patients say that it can stand for something else instead which is um Bitch Pissed of the Doctor and it was a diagnosis that everyone knew that was commonly given to people seen as difficult women who didn't co-operate which I definitely came under the category of because I was seen as uncooperative because I didn't respond to things ways in ways they expected um which I think was my autism" (Ashleigh, p.38)

In some circumstances and when under stress can experience situational mutism, this can be hard for others to believe

"if I am upset by something or um feeling threatened in some way and shutdown and struggle then to to give any eye contact and become quite hard faced not in an aggressive way but just in an emotionless way um it can just look like I'm having a strop um can be perceived like I'm having a strop whereas actually I've got all these repetitive thoughts about how useless I am going round in my head and um I've got lots of things that I want to communicate but can't and it's not about being difficult and defiant and awkward it's a genuinely really horrible place to be" (Jenny, p.35)

Not being able to speak when overwhelmed construed as deliberate rudeness

"I couldn't talk after school when I was overloaded she took that personally as me being rude to her and not involving her in my life and she just wouldn't accept or understand"
(Ashleigh, p.4)

Ran away from the ward because don't want to live any more or can't stand the environment, when you are brought back it feels as though you are being punished.

"you are being punished for running away and you're running away because either you don't want to be alive anymore or you because can't tolerate the ward environment anymore and that's another thing that's sort of put on your notes, I've run from ... twice so now I am down as an absconder risk but if they'd look both of the times I've ran from the ward I'd already been there for about 8 months and hadn't tried that, hadn't done that, it just it gets to that point where you think this is my only option I haven't got any leave so I will leave in the only way I can." (Polly, p.33)

C. INTERNALISING A NEGATIVE SENSE OF SELF (shame?)

Bullying caused them to have a very negative view and intense dislike of themselves

"the harm internally of of being constantly put down it becomes your own thought pattern um and I certainly took a very heavy dislike of myself um and internalised a lot of the messages I was given um as a child um and and that was really really hard" (Jenny, p.8)

"when your constantly being put down by your peers and disliked to such an extent it does have a very negative impact in you" (Jenny, p.8)

Stopping eating wasn't about weight, rather control, mental health and self-punishment

"I think it was just general self-loathing um not being happy with who I was" (Jenny, p.13)

Worried they might be a psychopath

"I spent a lot of time wondering if I was a psychopath um which was really scary (laugh) um but then I learnt that it wasn't that I didn't care, I cared very much, almost too much, I just wasn't quite the same (laugh) as everyone else and sometimes that did make me come across as quite cold or in a self-preservation kind of mode I suppose too" (Polly, p.13)

Felt their parents thought they were very bright but didn't bother to apply themselves and this was bad.

“I’m sort of being a little bit broad in the in the ah the explanation but I think it was essentially the um very bright but lazy or doesn’t apply himself which yeah looking back on it was this ADD executive function thing it’s just getting stuff done was just something I struggled with at a biological level but at that time er I mean it just wasn’t a thing um and if you didn’t do your homework or you didn’t behave in the a certain way you were a bad person basically (laugh)” (Max, p.12)

Looked online and interpreted themselves as having serious problems with social interactions and there was something very wrong with them

“my emotional quotient or whatever it is um I’d once I got the results back I started looking up online about you know where you were the various scores put you and I think ... if you score 25 or below then you’ve got a serious problem in terms of you know social er communication and and empathy with people um and I’d scored 5 on that (laugh) so um obviously there’s something yeah pretty wrong” (Max, p.31)

Professionals tell you they are doing all they can and you need to try harder, makes you lose hope.

“(readmission) does leave you feeling like you’re not getting anywhere because all you’ve done is circle the system and the hospitals for x amount of years and when professionals are saying they are doing all they can or that you’re not trying hard enough or all these things, I think you lose hope and it almost that becomes your life and that’s not a very good life” (Polly, p.55)

Feeling they were always told that they were not responding to things properly

“I was always told how I should feel or how I should react to something and I often didn’t react that way” (Rosie, p.4)

Can pick up from the expressions and manner of other people if they have done something terribly wrong socially

“I can at least pick up on the fact that somethings gone horribly wrong socially um because there was a conversation going on even though it was pretty meaningless but it was going on and then all of a sudden it stopped and the person isn’t smiling (laugh) um” (Max, p.35)

Knowing that can unintentionally hurt people through a social interaction results in avoiding interactions

“I go off my food and so um yeah I don’t have the option of ordering stuff online because that would mean I had to answer the door to somebody which again (laugh) which is kind of even worse than than um the possibility of maybe of messing up when I’m checking my groceries out” (Max, p.35)

Sense that they were blamed and assigned responsibility for Mum’s continuing difficulties

“I think it was around trying to make my Mum stable and happy um and she just I mean they were anti label was the way they put it um but she just couldn’t cope with being different she was very obsessed with appearances what will people think um that kind of person and had a lot of anxiety” (Ashleigh, p.1)

D. UNHELPFUL SUPPORT THAT DOES NOT ADDRESS NEED

Mental Health Services set up to support neurotypical mental health only

Professionals want to talk to you about your mental health and not your autism but you can’t take the autism away so it can skew your mental health diagnoses

“I’ve had this in ward round before where I’ve answered something and they’ve said you’re here for your mental health not for your autism or we’re here to talk about your mental health not your autism like but I can’t take the autism (laugh) away so yeah I think it skews your mental health diagnoses a bit I don’t think they are the same, if your autistic and you have anxiety I don’t think it’s the same as anxiety I don’t know I’ve never been neurotypical but (laugh) yeah.” (Polly, p.59)

Can’t ignore autism if treating someone for their mental health, they had interventions for about 13 years and a prolonged admission so are testament to this

“if you treat somebody for mental health without acknowledging and understanding their autism you’re doing it wrong and you’ll be doing it for years and years and not actually getting to the bottom of it which I am testament to I started interventions at the age of 9 and didn’t finish until I was about 23 22 um including an extensive admission and I think if I keep saying ‘if’ if the right support had been there if I’d been understood um it would have made a huge difference” (Jenny, p.38)

“I firmly believe that my mental health crisis was a lack of the appropriate support as a young person growing up and had I had the right support I’m sure I would have had challenges but I wouldn’t have needed mental health crisis intervention” (Jenny, p.22)

If problems related to being autistic aren't addressed, depression builds up and becomes a problem

"if the problems caused by autism aren't addressed then the er... depression builds up until it becomes a problem um and stuff like hospital admission solves the mental health problem by taking away some of the pressure and giving you some routine and meaning which helps a little bit with the autism stuff like because of that um but it doesn't really address the root problem so it's not going to help me pay my bills on time it's not going to help me get my car into the garage um it's not going help me er particularly with socialising" (Max, p.52)

As autism is not a mental health diagnosis mental health hospitals refuse them even if there is a mental health emergency

"mental health (support) um that's been more challenging because autism isn't seen as a mental health diagnosis so if you need to go into a mental health hospital they say Oh well we're not equipped to deal with autism so we can't have her um no matter what the mental health urgency is that is requiring it" (Rosie, p.18)

Services only look at one thing at a time when they are interlinked

"see what they had written on my medical charts and I saw that the crisis team had come in once and written that like it's not depression they have always been like this it is just EUPD ignore them um as I say they hadn't used the word but they had said like don't treat it because I was saying I am depressed I am saying I am unwell like I knew it wasn't right that I was getting these urges and like that but um yeah and they would just dismiss it in that way" (Ashleigh, p.40)

Mental health professionals more dismissive than other professionals of them needing support

"what was interesting was that the people who generally argued my care were not mental health professionals" (Ashleigh, p.41)

Crisis team saying no health need

"the police weren't happy to interview me social er um the crisis team were just like oh just interview them it's not health and the police they weren't they weren't buying that um so yeah we had the appropriate adult come" (Ashleigh, p.48)

Crisis Cafes assume the problem is their autism and tell them to go to someone who knows about autism

“Crisis Cafes and things like that can quite often say Oh well it’s your autism so go and speak to somebody that knows about autism and stuff like that” (Rosie, p.18)

No beds available meant second hospital admission was avoided, had some day hospital sessions which prevented isolation but didn’t address what they needed

“the time when I was going to be admitted but they couldn’t find a place um I again went in for about a week maybe 2 weeks of of the day hospital um similar kind of drill um but again just partly just having a reason to get up in the morning and partly being just around some people um was a really helpful thing even again even though it wasn’t targeted or helping my root problem it was at least social contact” (Max, p.48)

Have made attempts on own life when an inpatient, the root of what is going on is not addressed it is just seen as risk behaviour.

“I did self-harm a lot but it was always with objects that I’d brought in with myself from leave or OK they can’t really stop you head banging, well they can, um but it’s – it’s never getting to the root of what’s going on, or what’s happening or what’s causing it and they just see it as risk behaviour” (Polly p.32)

Autistic traits become more prominent when mental health declines but need to be able to separate them otherwise there is a risk of being dismissed by mental health services

“when my mental health is worse my autistic traits become worse in that like my um sensory stuff and I’m more stuck to my routines I am less able to be flexible um as I say I get agoraphobic it always seems they link so much but then at the same time I think you need to be able to pull them apart um it’s really important to because in the way that otherwise you can have autistic people dismissed by mental health services because it’s like you are just being autistic and don’t believe that you’re in severe mental distress whereas obviously we can have mental health problems like anyone else” (Ashleigh, p.103)

Referred to CMHT from GP but CMHT didn’t want to give more support

“I’d also spoken to my GP before who had contacted community mental health team um to try and get me more support but community mental health team didn’t want to give more support so yeah there was quite a few attempts to get more support.” (Rosie, p.26)

When tried to get support from mental health hub prior to first admission they were dismissive and gave standard answers that were not of help

“I had spoken to the Hub a couple of times um and tried to get support from them but they were pretty dismissive um because of the fact I’m doing SCM therapy they just said oh just wait for your next appointment for SCM um and things like that um and again just saying, it’s it’s the standard answer you get that I know it’s not just autistic people get, “Use your distractions”, “Go for a walk”, “Make a cup of tea” you know, “Take a hot shower”, and all those sort of things were the answers I was getting despite the fact that I was saying to them actually I need more help than this at the moment. Unfortunately your distraction techniques aren’t going to cut it for me, I’ve been doing them, you know I know my distraction techniques and they are not working.” (Rosie, p.25/26)

Behaviourist approaches didn’t make sense

“the behaviourism I encountered of the kind of not supporting me because that was seen as rewarding me when I was distressed um when I acted out and it was just bizarre and I just didn’t it didn’t make sense to me um it still doesn’t and I don’t see how and cos the thing is it wasn’t there wasn’t an alternative um and I was there because I was seriously unwell it wasn’t like I was choosing to behave and it is that assumption that all your kind of behaviour is that and the thing is the rewards was being like being allowed in my room by myself I had to earn that through working through the system whereas that was something I needed” (Ashleigh, p.94)

No logic in not being able to access support something until you have stopped doing it

“all my risk behaviours had to stop before I was allowed therapy and you know some people they need something to replace that before which is what therapy skills teach you” (Ashleigh, p.95)

Experienced mistreatment around autism

“lot of my mental health difficulties I would say have been directly or indirectly caused by my experiences as being autistic in environments that weren’t good for me um and my family’s response to that I mean there was a hell of a lot of gaslighting” (Ashleigh, p.102)

Autism diagnosis got in the way of getting mental health support

“having the diagnosis has got in the way of getting mental health support definitely.” (Rosie, p.18)

Mental Health Services not knowing what to do with autistic people

Crisis team didn’t know what to do with them

“when I first came to Uni I spent about 5 or 6 months under the Crisis Team which isn’t the norm, they normally (laugh) see you for about one or two weeks I think they just they didn’t know what to do with me I wasn’t getting any better. Eventually they put me in (hospital) um where I stayed for about a week because I asked to leave. That was my first inpatient experience, and it was horrifying.” (Polly, p.19)

Inpatient teams don’t know what to do with them

“I’ve probably been what they would term a revolving door patient and I tend to stay about 8 or 9 months because they never know what to do” (Polly, p.31)

Didn’t go to a long-term ward as psychiatrist didn’t know where to send them

“I managed to get away with not being sent to a long term ward because the psychiatrist basically had to admit that he didn’t know which one he would send me to and he didn’t know what was wrong with me” (Polly, p.51)

Mental health team had no idea how to support them

“you get to the mental health team, the people who are supposed to have all the understanding in the world, um you know and support people with mental health issues, just had no idea! (laugh).” (Rosie, p.25)

Professionals not knowing what to do with them

“so they took me into hospital for that and also so they could figure out what to do” (Ashleigh, p.45)

Lack of a service that offers the right support can result in the person being discharged as not engaging

If you don’t call a number or go to a Crisis Café that doesn’t offer help that meets your needs it is recorded that you are not engaging

“services are like call this number or go to this Crisis Café and then again it’s on paper that you are not engaging or you are not taking the options that are available to you but actually they they don’t meet your needs.” (Polly, p.62)

Criteria for hospital admission due to contract not to self-harm didn’t make sense

“I ended up in A&E a lot because I was harming myself in this period and the doctors there were unhappy with the fact that the mental health team weren’t helping me um they tried to get me admitted to the hospitals but I got quickly kind of kicked out because what they did

with people with BPD is they made you sign a self-harm contract and what that meant was that if you self-harmed when you were in hospital then you were discharged because it showed you didn't want their help, now, I thought this bizarre when I first met people when I was first in with my autism diagnosis who had one of this contract and I was like but that doesn't make any sense because you are self-harming because you are unwell so surely it is just a sign that you need help"(Ashleigh, p.39)

Supported Living

In supported accommodation the mix of people can create a risk factor

"I suppose there's always that ... how much you fit in with everybody in terms of those with enduring mental health issues um versus a young person on the spectrum that is ... intelligent and capable in the most part um and I suppose there's a different sort of need there ... as a young person I'd have been a rescuer and wanting to help and try and do and actually there's a vulnerability in that and then being in those situations and having needy people surrounding you so ... it's tricky you need to kind of manage who you put together in many ways um and there is definitely a risk factor in that" (Jenny, p.28/29)

Supported living rather than going back to Mum again was an awful experience

"the supported living they put me in was absolutely awful it was um I was the only female there, everyone else was male and adult, they all pretty much had issues with drugs and alcohol, psychosis, it was horrifying, it was my first time living independently cos I don't really class Halls (laugh) as independent living and I didn't last very long, I just became really unwell again" (Polly, p.29)

Support not addressing need

No interventions for the specific problems that have been going on for years

"there hasn't been any er intervention that's specific to the problems I have um it has been fairly general sort of sitting and talking about things" (Max, p.46)

Getting attention now but things not getting better

"while I'm getting attention um there's nothing which is really changing stuff or allowing me to change stuff" (Max, p.46)

Weekly CAMHS appointments involved talking through lots of things but not the right things, that it was OK to be them and different.

"I was under CAMHS from the age of 9 um I had really good relationship um with the first person that I saw still remember still remember their names and you know from when I was 9 who I saw week on week um and um they were really really supportive and we talked through lots of stuff and we talked about strategies and stuff um... but nothing ever really improved we didn't necessarily talk about the right stuff um or recognised why I was different and I think that's what I needed it wasn't about changing me to fit the rest of the world it was about me learning to accept that I was different and that it was OK to be different and for the rest of the world to know that it is OK for somebody to be different um and so I just continued on a pretty downward spiral to be honest" (Jenny, p.16)

When they were a child support for the whole family was not given which meant the right issues weren't addressed

"I think if there was more understanding of that genuine understanding um that would be massively helpful um and I think that more one to one support um is also something that is really missing that tailored support that kind of individually focussed support and support for the whole kind of family because let's face it I was in a system I was in The system whatever it might be um but as a unit we weren't really getting the right support I was seeing someone once a week but it never really got to the bottom of the issues and the advice we were given wasn't that helpful or right even" (Jenny, p.26)

Found group therapy type sessions where expected to speak in front of others very hard

"there was like the group therapy type things the group exercises where you go round the room and then everyone would say like I don't do talking in front of people that sounds like hell on earth um... so that was really hard" (Jenny, p.18)

Have some social care but it is more like a home help and what they actually need is not in their remit

"I've got some um some social care but it's essentially um home help um so the people who are expected to come in and do a bit of dusting or er feed the cat or um maybe get some shopping for stuff that I can't do when it's I kind of need a a specialist in terms of the the problems I've got because again kind of like if they were there all the time then there would be stuff they could do which would really help they can't do that if they are only coming for an hour sort of every day or so every other day and it you know it's they've got tight schedules they've got to see other people and so they can't really do things like booking me a skip or sorting out an appointment with the garage and stuff like that it's not really in their job description" (Max, p.34/35)

First experiences on the ward awful as just got taken there and left not knowing what to expect, harder to find out things as autistic

“the first couple of days which were pretty awful um partly because of the time there was some really difficult patients in there as well um and I yeah didn’t know what to expect and basically got taken there and then left (laugh) um and and spent the first half a day just sitting in the corridor not knowing what’s going to happen next” (Max, p.43)

“the thing that could make it less bad for somebody who is autistic is more explanation and um er being told about the structure of the way things work so so while I had the day planner which was really kind and helpful it didn’t cover things like when the pharmacy is going to be open to give people medication and that it only happens at certain times and that it is a limited time you can’t do it any time you want um finding about things like that was even more difficult for me I think” (Max, p.49)

Need support with their thinking as can get lost and take things the wrong way.

“sometimes I do need support with my thinking because I can get very lost or take things the wrong way, maybe neurotypicals aren’t always the clearest of people um (laugh)” (Polly, p.61)

Don’t need support for being autistic, support is needed not for them but for others outside of them.

“the reason I think I need help for being autistic or autistic traits isn’t because of me or autistic people it’s because of the rest of the world (laugh) I need support to be able to function in this world” (Polly, p.61)

Transition out of hospital

Reason for readmission was that nothing changed.

“I’ve just been around in services for a very long time and until September last year I think it took me making a very significant attempt on my life that they couldn’t ignore or even say, are you sure you wanted to kill yourself because that was a supposed to be a fail proof and then being kicked out of Uni and being made homeless for them to go hah we might need to do something, it it had been 10 years and that it took them that long” (Polly, p.54)

Plans from hospital to community not followed

“it wasn’t even that there was any transition it was that none of the plans were followed through. Um and the only benefit of the doubt I can give them was that it was still lockdown but that is a very small (laugh) thing. I think for the most part the only transition there’s kind

of been is you get 1 hour leave then 3 hour leave then 4 hour leave then 8 hour leave but I never know what to do with that time because I don't spend that much time in the community (laugh) as it is and with university it was like I'm coming back on that day therefore I come back on that day, I can't stay overnight or I can't do all of these other things that people might be doing um so there never really was a transition" (Polly, p.51)

Care plan didn't happen and felt like a box ticking exercise

"the worse thing procedure really that happened was that my care plan didn't really happen they kept saying that they were going to do it and there was a nurse who was going to do it for me and it kind of got written down or there was a care plan written down but there wasn't really much of a consultation and basically the first time that there was a meaningful sit down and talk about it was very soon before I was discharged so by that time there was (laugh) it was just done so it sort of felt like it was a bit of a box ticking exercise" (Max, p.43)

Couldn't manage when came out of hospital back to the pressures of everyday life and crashed straight away

"I kind of got taken care of and there were no expectations kind of on me um but of course that didn't prepare you for leaving and having to do everything for myself at all so I crashed as soon as I left again" (Ashleigh, p.37)

Appendix 9 Group Experiential Themes – Protective

A. TRUSTING RELATIONSHIPS

Recently realised that although people make the problem some people help you get out of the problem

“there are some people that help you to get out of the problem as well and yeah there are a few people who when you just see them or when you hear their voice you are like yep everything’s going to be OK or you can email them and you know that they will help or they will listen,” (Polly, p.64)

One of the most important things that supports their wellbeing is about 5 people in their life that they enjoy spending time with who allow them to be themselves and speak freely

“there are some wonderful like magical people in the world that I think that for the most part I find people draining or they make me grumpy or I don’t understand them but there are about 5 people in my life who I enjoy spending time with and I feel lifted afterwards or there is a quote that’s like, “Have you ever met someone who is sunshine in human form?” and like yes there are some people who are just, I think they get you that is the thing so I think having a space with a person or people who allow you to be yourself but also allow you to speak freely I think that is one of the most important things” (Polly, p.64)

Most positive influence that impacts all areas of life is finding own family who support you out of love and love you for who you are

“Learning you can choose your own family and one that does accept and support you and really loves you and that was something that’s been so healing and important for me to me to learn that there are people there who like me as I am and that will support me out of love” (Ashleigh, p.114)

Friends and chosen people around them have a positive influence on their wellbeing.

“I think it is people that I surround myself with and my friends and having positive influences around me” (Rosie, p.36)

Support from friend and gay community who supported their own, people accepting them for who they were for the first time

“I found people who accepted me and I started to talk about my autism a bit I had one friend particularly whose brother was autistic and he knew that quite a lot about it

and he saw it in me um and I started to talk about this more and people did my friends recognised it and accommodated” (Ashleigh, p.22)

“I just remember like I was running a meeting at uni for one of our societies, I end up chairing things, um and I just stopped talking at one point and they kind of people looked round to see what I was looking at and one of the people one of my friends at the meeting just got up moved the poster that was wonky fallen off the wall to put it straight and they all sat down and carried on like nothing had happened because they knew by then that something like that would had distracted me too much to be able to carry on talking and it was little things like that where they went yeah that’s yeah acted like that was completely normal that that would stop me being able to function and then (laugh) kind of and just sorted it and carried on without any big deal um so I think that was kind of my first taste of people being more accepting of me” (Ashleigh, p.22)

What supports mental wellbeing is contact with people who try to understand and be helpful, better than mindfulness

“having contact with people who are helpful or trying to be helpful or trying to be understanding is better than nothing but talking to somebody even if it’s not um changing a lot but having the who understands about the issues and can suggest at least some appropriate ways of managing that would be good um but it’s definitely about having contact with a person rather than a um exercise or something like mindfulness” (Max, p.54)

Relationship had a massive positive impact on their mental health due to his positivity and their achievements in the face of adversity

“he had the motto if life throws you lemons make lemonade you know such a positive person um and so that was a big turn around for me um and as part of that you know things really moved forward um yeah made massive strides um in terms of my mental health still knowing that I didn’t fit the world quite as I might and should but um or could um but that actually I had a contribution to make um and I could achieve something” (Jenny, p.31)

Developed close relationship with teachers from middle school who made person-centred adjustments for them and is still in contact with them

“developed some really close relationships with um some teachers which was really nice um I’m still in touch with two teachers from my middle school so my teacher from when I was 10 years old who was my class teacher is still a contact and a friend now and again when I was in Yr8 which is while I was 12 again the last year of middle school I’m still in touch with her and still see her um so you know that’s that’s unusual shall we say um to still have that kind of close um contact um I wrote to them following my me leaving middle school um so there was nothing inappropriate about it to clarify it was nothing inappropriate you we wrote to each other and then as I became an adult you know I have had actual contact and you know visited and been involved in meeting my family which has been really lovely um and I think my diagnosis has made sense to them for sure they accepted um and acknowledged the real difficulties I had growing up um and the level of bullying these two teachers were really good at not forcing me out onto the playground um and making those adjustments for me” (Jenny, p.7)

Had one close friend who was the year above them in 6th form and their teacher allowed them time together

“I had one close friend um and she was really close um really when I went into the Lower Sixth she was doing she was the year above me and she um she was doing the same subjects as me um but a year ahead so that was quite nice she wanted to be a teacher well she is a teacher um and our teacher was really good um at giving us that time together and allowing us to to sort of um stay in together” (Jenny, p.13)

A professional ally who believes you and sticks up for you is extremely helpful

“having an ally who would actually stick up for you and um who believed in you even when you know the schools were being defensive or whatever is massively massively helpful and I have been fortunate that I had an amazing person work with us and actually was involved in both my girls diagnosis and also involved in the school avoidance situation and I just am so grateful for that person so that’s been a real Godsend” (Jenny, p.42)

Without a service that provides long term support for autism they have made their own through trusted friendship that can provide a neurotypical viewpoint and act as a sounding board

“I have a very very good close friend who understands autism really um and well so I will I will sound her out on things that I’m not sure on or if I’m having a conversation and I’m not sure if I’m handling it right or if I need a just if I need a neurotypical standpoint because I I’m very self-aware that um I’m not neurotypical so I won’t necessarily think about things in the same way or I might misunderstand or misinterpret” (Jenny, p.39)

Trust is really important, that they can rely on their friend to be honest and tell the truth in their role as a sounding board

“my trusted friend um that’s really important to me that I’ve got that sounding board that’s somebody that will actually tell me honestly what they think and if I’m slightly misunderstanding but equally telling me when I’m not um because it’s the trust in that that’s really important cos I need to be able to trust that I’m going to be given the truth if if I’m... if I’m to trust when they say when somebody says to me no you’re you’re right no your absolutely right I also need to trust when they tell me that I’m not right um and that’s really important um so that sounding board” (Jenny, p.41)

Has autistic allies through work, there is a sense of belonging and peer support across the team and they get on well

“I do have autistic allies because I have those through my work so I’ve kind of described that within that the fact that my work and my life is surrounded by autistic people I’m fortunate I have that sense of belonging and community through that that’s brilliant ... actually that sense of belonging and that peer support that we get through that ourselves is brilliant and the ease of communication” (Jenny, p.43)

Need to feel sense of belonging with others

“I didn’t have a good relationship with my Dad as I’d mentioned and he had sent me this dolphin and so I took to wanting to take this dolphin everywhere with me and it was around for me in my brain I guess it was around that connection and wanting to feel that connection and know that they’re there” (Jenny, p.21)

Being Believed

Having someone who believes in you consistently, ‘holding the hope’

“I think she made all the difference because she believed in me and it wasn’t it didn’t matter what I threw at her, not literally I didn’t actually throw anything at her (laugh)

but metaphorically, that she still sort of stayed solid and stayed in my life and kept telling me that she could see something in me that I couldn't see and so she she always used to tell me she was holding the hope and I think that's kind of what the lion represents as well is that sometimes people can see things in you that you can't sometimes they're not good things (laugh) but most of the time people do want good things for you" (Polly, p.66/67)

People seeing good in them trusting them and taking a risk on them makes such a difference

"a nurse came up to me who I knew for a while she's now the manager of one of the wards she is absolutely brilliant and she said to me are you going to go again if they let go? And by this point I just said No, I haven't got anything left in me to go and she told them to let me go and I don't think they knew what to do and at that point she was like she doesn't lie, she is not lying, let her go, and they did and I think that's like it someone trusted me someone saw a good thing about me and took a risk a big risk (laugh) on me that that makes such a difference" (Polly, p.34)

"you are so used to not being trusted at all like nothing you say nothing you do is trusted and to have someone yeah trust that is amazing." (Polly, p.68)

The most understanding staff who make a big difference come from unexpected roles

"when I was on the female ward before that for quite a long time she used to hide biscuits on her trolley and give them to me because there was only one biscuit that I liked and she would walk me up and down the corridor, she would let me push her cleaning trolley because I'd just I really like I think it was the weight of it the pushing through really helped um and if I was like really stressed and she could see that she would go in my room and get my blanket or my weighted blanket or get one of my sensory objects, staff didn't notice, or she'd come and be like the fire alarm's going to go off in 10 minutes we've just been told go in the garden, and you think she wasn't clinical and she was the best member of staff without a doubt there and that made a big difference." (Polly, p.44)

The most benefit gained from hospital admission was being in a communal environment with people available to help who understood, human contact and routine

"essentially just having a communal normal life somewhere where you can go and do that with some understanding people that can help"

“it was just about you know um being a nice human being and er being there to talk to or to showing you how to make cakes or um yeah discussing the video that you’d just shown just from my point of view just some human contact and some fairly normal routine” (Max, p.51)

Animals

PAT Dog visits to the ward were a highlight

“the amount of times that I have talked to that dog, cried at that dog, hugged that dog, patted that dog um and yeah it’s a soft sensory tactile thing but it’s just also a a creature that seems to just get you and won’t judge you” (Polly, p.44)

Need for mutual companionship

“I’ve not really had a friend before whereas this was somebody that clearly wanted to be around and was was happy to interact and understood and I understood him” (Max, p.59)

“and perhaps the biggest thing was um just the contact like I was saying before about hugs um having somebody who was sort of physically affectionate and would sort of stick his arm around my neck and his face into my chin and purr and sort of be happy to see me” (Max, p.59)

Loved the tortoise and spent a lot of time outside rather than in, good relationship with tortoise.

“I had a pet tortoise he was called Rocky because he had a rocky back very creative I know um and yeah I loved him to pieces I I spent a lot of my time outside with him rather than inside the house um because he lived outside” (Rosie, p.4)

Trained the rabbit, in charge.

“the rabbit came to us um and I trained up this little rabbit and it used to hop around the garden and and follow me around which was super cute” (Jenny, p.5)

Relationship with family not satisfying but enjoyed their cat’s company and the comfort it gave

“we got twin cats for our birthdays one year when I was six and he was like my best friend and I have always been that kind of as I say I think that is something that was quite stereotypically autistic or just kind of other child I always enjoy being with

animals it is like now I just live with pets, I prefer pets to human housemates, um and yea that was the case even as a kid and I did take a lot of solace and like I would just hang out with my cat” (Ashleigh, p.4)

Enjoyed spending time with dog.

“when I was about 14 um my Mum was connected with the police force and things and there was a dog brought in um a lovely German Shepherd big dog um so we had the German Shepherd um so that was lovely um really enjoyed really enjoyed that um when I was much much younger um we had German Shepherd dogs like when I was a toddler um and um and I used to sit and read to the dog” (Jenny, p.5)

Uses support provided by assistance dog rather than formal support from professionals

“█ the dog (laugh) she’s definitely a big support in terms of everything both for the girls and for me um and just the confidence to go places and then a conversation starter because actually those oh small talk’s really frustrating get me talking about autism and I’m fine um making small talk is not something I’m comfortable with at all but everybody talks when you’ve got a dog don’t they um and everybody makes that initial contact that saves us having to do it for ourselves which does help um so █’s a great support ... um and I can just walk █ as well so that’s always a good thing it’s so she is good on a kind of to actually support you but also as an emotional wellbeing perspective of you know getting out and having that time and using it as a regulation strategy” (Jenny, p.40/41/42)

Need to understand neurodiversity more and that the same things are not useful for everybody

“I see these wellbeing calendars sent round... like happiness project ... and stuff like that and they’re all about kind of like a month of interacting with people cos interacting with people is good for everybody’s happiness I’m just like if I interacted with people that much that would have a detrimental effect on me and there isn’t that understanding of neurodiversity within that and the same things are not good for the same people and it does seem to be very much blanket assumptions ... and also my experience of it being based on yeah conformity which links into that it was like the thing of like dressing in a way making an effort with your experience means you are well whereas actually that’s not the way” (Ashleigh, p.109)

Having a voice

Being given a voice

“what’s really changed is I have a voice now before I didn’t have a voice at all and I was too scared of offending anyone or saying the wrong thing and, but I think that’s changed in like the last year or the last 2 years it’s having been given a voice I suppose or given a platform and having found people who are of similar opinions or finding legislation that backs you up there I think that’s made a big difference to me and I also know that I don’t I don’t 100% feel like I have what they call a meaningful life or a life worth living right now but I think more so than I ever have” (Polly, p.56)

Understanding and non-judgemental support

Someone else’s help or perspective can prevent a lot of problems

“at the simplest level somebody who understands and can at least suggest appropriate help would be the biggest thing” (Max, p.54)

Importance of support being understanding and non-critical

“somebody was wanting to help me and doing it in a really positive and and understanding way made made a huge amount of difference you know just the fact that somebody wasn’t criticising me but realised I might have difficulties with things um and was helping me through the process without being condescending” (Max, p.45)

The importance of being listened to

“my social worker is great the first one I got and he believed I was autistic and he even when they took my diagnosis away he kept telling people I was he arranged my supported accommodation and um yeah he was quite clear that I was and he actually talked to me and actually listened to me and believed what I say what I said” (Ashleigh, p.41)

Importance of having feelings validated

“actually for me it’s being able to ask for help I think is a big point and trust and kind of and admit to when I do um and I get a lot of support from my chosen family um and a big part of that is validating my feelings as well rather than gaslighting me of kind of like makes such a difference in that is having that level of support. (Ashleigh, p.105)

Validation is important when asking for help

“My trauma therapist I can text her, I can email her and there was a time where I was struggling to get from my car to the building because because it didn’t feel that safe it was a new environment and she would walk me from the car to the building and there have been times when I have been in the Campbell House car park text my CPN and said I can’t physically get myself in the building and she replied saying sure you can you’ve been here before your like right (laugh) I think it’s a validation thing as well that when you are someone that doesn’t necessarily find it that easy to ask for help or doesn’t ask for help and when you do it doesn’t happen and then you just use that as evidence as why you are not going to do that again because it takes so much”

(Polly, p.62)

Better that difficulties are recognised even if haven’t any help for them than being thought of as deliberately awkward when trying so hard to fit in

“I haven’t managed to get access to any specific help for my difficulties but at least there’s a recognition that I have difficulties (laugh) um and which yeah is much better than it was previously” (Max, p.33)

Psychiatrist accepted autism diagnosis and put it on the system so everyone else had to accept it too.

“my GP accepted it instantly, um they were very very good about it um it wasn’t until I spoke to my psychiatrist and said to my psychiatrist look I’ve got a private diagnosis the letter is on the system but the mental health team seem to be refusing to acknowledge it um she then pulled up the letter; turns out she actually knew the consultant and she said I I absolutely accept this” (Rosie, p.23)

Misconception that if people don’t communicate in the typical way they have nothing about them, interactions with Cat showed that there is something there if you look for it and respond in the way that is right for them, gives hope for interactions with people if they adapt

“I mean a lot of people um go on about cats being sort of aloof and whatever but from my experience it’s basically because you’re not listening to what they’re saying if you actually respond to their their language which is mainly body language and facial expression um they appreciate that um in the same ways you know with old people if you just shout at them and ask if they’d like a cup of tea love they just switch off and you think they don’t have an internal life um if you actually bother to communicate and interact as if they’re you know people then um you suddenly find

out that they are not just sort of sat there staring at the TV but they've got stuff"
(Max, p.60)

Friends were found by Mum, group of 'geeky' friends they got on with

"And I did have friends like a small friend group I used to hang out with they were my Mum's friends kids so they were originally friends that were made for me um but that is not to say that I didn't like them and they were and some of them filtered off but it was the geeky kids I was left with who I fit in with to some degree in that I always did and although they didn't necessarily get me" (Ashleigh, p.10)

Special relationship with grandparents, particularly grandmother, fond memories of childhood all involve them

"my fond memories of childhood all involve my grandparents my grandparents just so so important to me um there was a real connection and there still is my nan's still alive she is 95 um and there is a real connection between me and my nan um we absolutely love each other so much and that's been really special" (Jenny, p.2)

Met future husband on placement after having had a difficult time and had jumped out of a first-floor window and was on crutches, he was in a wheelchair and they instantly bonded

"I met [REDACTED] who was a young chap that was doing his drama degree at Uni and he was staying in Halls and he was in Year 3 and um he'd got multiple sclerosis um and so we got chatting um the first time we'd met I'd actually just had a spell at [REDACTED] and um I was really having a tough time struggling with things and had jumped out of a first floor window um and broken my ankle and so I got to this I was doing this meeting where I met [REDACTED] um and I'd got my I'd got crutches because I was with broken leg and he was in his wheelchair and so we swapped and I gave him my crutches and I had a go in his wheelchair um and we just really clicked" (Jenny, p.30)

Helped husband and married after he moved into the flat, got their own house and fostered together (purpose?)

"he moved into my first floor flat which was equally inaccessible um but he he the council put him in a house in a hotel that didn't have access to any meals um it was had a step up to the front door but no care so he came and stayed with me and then I could help him up the stairs and all of that sort of stuff um and we managed and then we yeah we got married and bought a house together and made it accessible and

things and that was that was all good um we ended up fostering together um so um despite my mental health and everything else we did fostering you know it was it really did help to turn a corner” (Jenny, p.30/31)

First husband was an inspiration and his positivity helped them reframe some of their issues

“it was horrible to see him deteriorate especially at the speed that he did um but the attitude and the positivity that surrounded him the joking the banter the nurses said to him you know we need to we need to insert a catheter I’m afraid we’re going to have to do it he said you don’t my wife takes the piss um (laugh) exactly exactly um you know he said to the consultant he said did you know latest scientific discovery diarrhoea is hereditary the consultant looks at him it runs in the jeans doesn’t it he was just so positive though even in like really difficult situations he was so so positive um and I think that helped me with reframing some of my stuff which was good” (Jenny, p.46)

Trampoline coach wanted to understand

“trampolining to me it was like OK this is technically a sport but it’s not but also I can’t possibly be in a team or have to talk to anyone while (laugh) I’m on a trampoline cos everyone’s too far away, and it worked really well for me. I, the coach he was actually really good because he tried to get me to do some things and I I tried to begin with but I am not co-ordinated I was awful, absolutely awful, I’m not even being mean to myself I really was. Um and he pulled me aside once and he was like I can kind of see you enjoy it but I can also see that you are getting really anxious and some weeks you are not coming and I was honest with him and just said I just wanted to bounce, I just came to bounce (laugh) and from then on he just let me bounce. Every time it was my turn I just bounced (laugh) so that was very much new a new hobby that came in.” (Polly, p.14)

Police showed understanding not experienced from the mental health team

“I must admit I was brought back by the police once, was caught by staff the other time, the police were lovely (laugh) they were really friendly um I had a female officer, she sat in the back with me at this point I was also going through like um forget what you call it, police investigations and um witness not well it’s not really the witness if you’re the person, I think they’re still called a witness or um victim impact statements and court proceeding stuff for my Dad, not for anything I’d done, um and

she was like I've seen on our system that you're um what d'you say, that you're having contact with DC L and I know what you're going through I know what what's happening for you, and you just think gosh if this person from the police who is supposed to not have empathy, not do any of that because she works for the police, can sit and just be like I get it, it's OK; and I begged her not to take me back to (hospital), I said I'll do anything (laugh) I'll go anywhere but do not take me back there and unfortunately she said she had to." (Polly, p.33)

Hospital was a positive experience because of the routine and the social interactions with staff when they were fulfilling their purpose

"it turned out to be somewhere that I really felt comfortable um because there was a routine and there were people who'd come and poke me with thermometers and things and talk to me and people would come round and bring you drinks and yeah there were just interaction there um and and a real routine so aside from anything else it was a really positive experience" (Max, p.27)

B. UNDERSTANDING SELF

The right support is developing understanding of yourself as autistic and self-acceptance.

"I think the right support has to start with you knowing yourself so if you had a diagnosis then actually that's about you having that knowledge of your own needs um and your own differences and from there you can build your self-acceptance which in turn enables you to move forward" (Jenny, p.24)

"for me that self-acceptance was huge in terms of accepting the things that I find difficult and that being a stepping stone to overcome some of the things that I find hard I'm still having bad days but then actually forgiving myself for a bad day it's OK" (Jenny, p.25)

Understanding themselves as autistic has enabled them to work out helpful strategies

"I think I have a better understanding of myself and a better understanding of like when what I need to do so if I'm in burnout I can now recognise that and work out why, I've now got strategies like putting a colour for each day and then looking back on the week and be like well you've had 7 red days it's no wonder you feel like this" (Polly, p.56)

Importance of understanding self and risks

“I think another thing was like that I didn’t even know was recognising autistic burnout um kind of the everyday stuff and the extreme stuff and how that differs from clinical depression or can go alongside clinical depression stuff where rather with me it was kind of like well it’s not quite depression so therefore that just means you are really not that ill whereas actually it was just that it was more of this extreme burnout which was that severe but it didn’t quite fit kind of other diagnoses um but was severe enough to have affected my mental health” (Ashleigh, p.89)

OK to use sensory calming strategies

“I found it really difficult to start using them again because although I find it helpful it is linked up with that this is you acting out and trying to be attention seeking and the thing of it and learn that actually it is OK to use something” (Ashleigh, p.92)

Importance of not ignoring own needs

“all the kind of controlling access to what you were allowed to do and what you were allowed to have um and yeah I have serious concerns about how it’s used um and it’s just not I don’t think and I think a big part of it is it’s not healthy to condition someone to ignore their own needs I mean it is something my parents did a lot but they did even more in hospital and that has been really difficult for me to learn to unlearn some of that um where I had to because of the risk kind of learnt to ignore my pain to ignore signals from my body to ignore my own distress and to hide that and yeah it just leaves you traumatised” (Ashleigh, p.94)

Writing helps maintain wellbeing for them

“writing ... is something I started again in an um it’s actually because my partner does it and she got me on to a writing conference with her creative writing and I remembered how much I used to enjoy it but that I got put off because I didn’t do it in the way school wanted to grade and stuff and because I can communicate easier in writing kind of as well um and I started then using it doing some morning pages exercise where you write just a stream of consciousness um and it’s supposed to be a writing warm-up therapy but I wrote it down actually in a therapeutic way it helped well” (Ashleigh, p.110)

Reading written words helps process things

“when I write I mean I’m a visual processor so it helps me process by having it in words even written by myself but yeah I can be clearer and I don’t get stuck on one

point in the same way because I've seen I've written that point that point is clear on the paper I don't it's easier for me to move on from it if that makes sense I don't get as stuck like I do on a thought or even speaking it um so I'm able to work through things helpfully so I do use journaling now for working through anything" (Ashleigh, p.111)

Empowering being able to manage self and gives confidence

"when I was tailing towards the end of my therapy so we were getting to the point of not being sure I needed her anymore um we used journaling to replace that cos she said we got to the point where I could figure things out for myself she'd say like you just talk for an hour and you've figured it out yourself you didn't need me here so actually using a page to do that where I write on a page and I found I could do that I could take something I'd feel it and write in it ... it's the empowering thing of being able to deal with it myself too and that I'm not reliant on finding a carer who has some understanding of me (laugh) and to support that so it gives the kind of confidence to work through" (Ashleigh, p.111)

Needs a lot of support but also aware that they are very capable and have a lot to give just has to **find their own way of doing things**

"I think I utilise a lot of support I still need a lot of support for various aspects of my life but I am also conscious that I'm also very capable and have lots to give but it's just that I have to find my way of doing those things sometimes" (Jenny, p.40)

Developed strategies to avoid and manage situations that they may find very emotive

"I have to ... be mindful of putting myself into those positions where um I kind of feel that the emotion might take over um so but it's something that I can more easily manage or I try to put support strategies in place or the right people to support me in this moment if that makes sense" (Jenny, p.11)

Removing self from unhelpful environments

"I went to university as my way of getting out of home and kind of my escape and that was what I had been focussed on and kept me going all the way through kind of when I was a teenager and then when I got there it all came I think I relaxed and it all came rushing in and I started seeing a counsellor um and talking about things like my family and from there and I think that brought it all to a head to some point um and I ended up having a big mental health crisis my first kind of well it was my first suicide attempt I wouldn't say it was my first big burn out like that um and I think that was

just as I say that was bound to happen I think it was I held on to get there um so I took the time off and went on leave from university because of that um but didn't end up going to that course but what I did was I stayed where I had gone to university I never went back home I didn't go back in the holidays or anything like that I would probably for periods um but I was someone who lived at university all year round um because as I say that was my point of (laugh) that was my main reason for going"
(Ashleigh, p.20)

Feeling more comfortable with a small group of friends than in a large crowd that caused sensory challenges

"I could find somewhere quiet to go there and kind of with my group of friends"
(Ashleigh, p.9)

Some friends in secondary school but chose when to be with them to avoid noise.

"(had friendship group) much later in secondary school um probably like the last two years. Um but even still I was quite selective as to when I'd sit and you know have breaks with them and stuff like that. I'd still spend a lot of my time in the library and using that as my excuse not to sit with them as they would sit in a noisy area normally." (Rosie, p.12)

Wore leggings and vest top under school uniform to manage the touch of it.

"I always wore leggings underneath my like school trousers always wore a T-shirt or like a vest top underneath um my uniform cos I just couldn't stand the touch of it it would you know by the time we got to the end of the day I would literally want to be ripping the clothes off me" (Rosie, p.7)

Making own packed lunch for school ensured food was separated, avoided noise of cafeteria and uncertainty of what food would be available there.

"I'd pack my own kind of packed lunch um because I eat the same foods the uncertainty of what the cafeteria might be kind of making was always kind of too challenging for me um so yeah I always took my own packed lunch meant that I could pack it in the way that I liked it meant that I knew that certain foods weren't going to be touching and all of kind of those kind of those sort of things that add an extra element of anxiety to the day. It meant that I could avoid um also meant that I could avoid the cafeteria which obviously was ridiculously noisy because we had like the cafeteria and then there was all the seat seating and stuff in there and there'd

probably be about 300 students in this one sort of hall um having a packed lunch meant that I never had to go in there um so it kind of got rid of something that would have been extremely stressful for me and meant that I could just do my own thing.”
(Rosie, p.9)

Learnt to use distraction to maintain wellbeing and regulate when in hospital and still use this

“I was allocated a one to one ... I really enjoyed them the distraction element the playing games so they’d play cards and stuff we’d do that sort of thing that worked well for me and it’s something that I’ve that was the one thing I really learnt from that hospital admission was that um I use distraction to maintain my mental health or my regulation um ... and I still do although you know in different ways so you know the reason that my diary is is full is because I don’t allow myself that time um to just sit with I have to fill every moment because that’s how I cope” (Jenny, p.18)

Food is helpful for them in coping with social interactions but aware that could be a barrier for others

“things that involve food um are usually my safe coping strategy food is my um my way of coping with social situations and um and I make a bit of a joke about it um because every meeting I do there’ll be food cos that is how not every meeting no that sounds terrible every um (laugh) every but every meeting like so [REDACTED] has pizza or food because actually I for me it works as a as a something to help me cope with that interaction and it breaks things up for other people it’s a stumbling block and I get that um but then will find things that do work” (Jenny, p.44/45)

i. Using understanding of self to know what support from others is helpful

Importance of keeping a close eye on medication

“obviously something I’m very aware of is (laugh) what medication I should be given um (laugh)” (Ashleigh, p.101)

“someone actually showed me the criteria for a personality disorder emotionally unstable personality disorder doesn’t fit um in terms of the long term nature and that although I showed some signs while in that severe crisis it wasn’t long term enough and as soon as I had was on the right medication it all disappeared” (Ashleigh, p.54)

ii. Using understanding of self to recognise own state of mental health

Need to be alert to signs that own mental wellbeing is deteriorating as an individual and have some strategies to support that

“I think the test for me is how in control of my mind to I feel um and that’s partly me being controlling but yeah it is like I know that how easily I burn out and if my mind feels very full and chaotic and I can’t concentrate very well or things like that are signs of my mental wellbeing not being great um how easily I can go to sleep things like that... for me it’s my brain not working how it usually would um and it’s those kind of things that I can see and I know if that’s the case if like I can’t quieten my mind down then actually I need to do something to look after it more with that.”

(Ashleigh, p.110)

Feel they understand their autism triggers – sensory, loss of routine, more than their mental health triggers – could be family or lots of stresses.

“I guess the one thing that I can kind of use to explain it is my autism versus my OCD um like every day I’ll put on a pair of socks and those socks need to feel right for my autism um and if they don’t feel right I might have a meltdown or simply decide not to wear socks. Um however like for my OCD I could put on those socks and then intrusive thoughts come in which will make me panic and um think that something bad is going to happen and then I’ll act on those. Um and it will be more kind of catastrophic um when it’s my mental health than my autism um I guess that’s probably the way, the only way that I can kind of differentiate and I guess I know my autism triggers and more of some of my mental health triggers um so it’s looking at what’s triggered what’s going on to try and work out the difference.” (Rosie, p.34)

Routine, structure and predictability important for mental wellbeing

“I think having my routine and structure and you know knowing what’s going on and things like that is probably most important to me because without those everything seems to go a little bit, bit the wrong way should we say (laugh)... so I tend to make a schedule for the week and factor everything in that needs to be factored in” (Rosie, p.35)

Military school worked better as the families had a shared existence with a rigid societal structure and there was an emphasis on physical activity that also suited them

“in the military schools um there’s a very kind of rigid structure societally or um which to my brain just worked and you know just the whole the fact that everybody’s

Dad wore the same uniform and went to work and did the same sort sorts of things um and you kind of knew that everybody had a common sort of essentially everybody's parents were kind of like sort of the same um so you kind of knew everybody had a shared experience of that um and so just just existing in that environment was much more comfortable um but also there was a bigger emphasis on um more adventurous sporting kind of things so um because it is a big thing in the military as well um sort of sports um we had a in when I was in [REDACTED] we had a dry ski slope just down the road from the school and one of our PE options was to go skiing basically um and then in the winter time when there's sort of a couple of metres of snow on the mountains we had sort of school trips up there to go skiing and the sailing club was probably my favourite part of that um because it involved sort of technical stuff and ropes and pulleys and whatever but also sort of action and doing things um so yeah that sort of non non-school stuff was particularly sort of happy place for me.” (Max, p.7)

Final 4 years at school fitted in better and was where they felt the greatest sense of belonging, the stability gave confidence and was beneficial in managing the future

“I somehow managed just to sort of fit in to the whole er the whole the school um so it was a place I felt I belonged more than I had anywhere else really ... final 4 years was quite a positive experience in terms of er getting with people um possibly you know it's if I hadn't have had had those 4 years things might have gone even sort of worse for me because I'd um I didn't have that period of some stability that kind of gave me a bit more confidence” (Max, p.14/15)

Final 4 years at school were in a warm place, clothes worn, predictability of the weather and the way the day was spent gave a feeling of security

“with sort of all the moving around the places I sort of felt most at home were perhaps coincidentally the (laugh) places where I used to wear the least amount of clothing so um basically sort of hot places and the life style that goes with that um were something I particularly kind of fitted with and so again for my sort of final 4 years to be in that kind of situation and with all the sort of little cultural things that go with with having extreme temperatures in the day and um and you know the fact from May to September you're not going to see any rain it's just a fact um yeah it just I I mean kind of thinking about it now maybe it was the predictability of stuff like the weather seasons and the way the day goes that help a lot as well but um either way

sort of physically and and and to a limited degree socially it was kind of a sort of stable amount of time” (Max, p.15)

Work provided routine and structure

“go to work leave work come back go to sleep go to work thing it just life went on” (Max, p.30/39)

Positive part of being in hospital was the routine, meals, shower, laundry, felt more of a normal home environment than they have at home

“one of the most positive parts of the whole experience was the fact there was a routine somebody would come and find me for breakfast and dinner you know um and I could get a shower and um yeah wash my clothes and um it was just sounds a bit sad but it was a lot more of a home environment than what I normally have um and that yeah was really positive um er just yeah the routine and the normality of having fairly normal things there and also having a strip down kind of um living responsibility I guess so that I didn’t have many things so sort of making your bed in the morning was a thing to do and um yeah um it just once I’d kind got used to things particularly once I was able to get out to um for sort of to walk down to the shops and back um it was a genuinely helpful experience” (Max, p.43/44)

“just getting up at the same time and yeah one of the biggest things was just having yeah having 3 meals a day rather than what I do normally is just eventually late at night I get hungry and I have something to eat but just having that going for breakfast you know and just having this 3 parts in the day where there is a reason to be there and to break the day up and to make you feel like you were doing something that was just normal” (Max, p.51)

What was good on the ward was being cared for, a break from managing everyday life

“I was feeling calmer I think from having been taken away from the world because that’s the thing the thing I liked about it was like yeah there was no pressure I got the feeding and cleaning and I kind of got taken care of and there were no expectations” (Ashleigh, p.37)

Schedule of what happened when was provided in hospital after a couple of days which was really helpful but if it included more information it would be even better

“did me a print out of the er schedule for what happens so that in my room I could have that up on the wall and I would know what would be happening at what time on what day which was really helpful” (Max, p.43)

“more explanation and um er being told about the structure of the way things work so so while I had the day planner which was really kind and helpful it didn’t cover things like when the pharmacy is going to be open” (Max, p.49)

Needing time to regulate and decompress between things

“it was overly structured without time to decompress in between like that and you had to be in activities all the time and they had to be set activities too that they’d chosen which didn’t suit everyone and it was kind of like I think there’s an in between that having something in between and having some choice and it is that recognition that not everything suits everyone and that time out to decompress um and the recognition of with me I found that difficult too because I was constantly over-stimulated I needed that decompression time that will allow I needed more decompression time” (Ashleigh, p.94)

Takes a lot of effort to keep everything in balance and for things not to get too much.

“sometimes my autism may not get in the way of my day too much and then other days my my whole day is ruled by it and then obviously other days it could be that my physical health is getting in the way of things um it takes an awful lot of work to kind of stop the tip of the iceberg from you know getting too much and tipping those weighing scales over” (Rosie, p.36)

iii. Diagnosis as a means of understanding and accepting self

Need a confirmed autism diagnosis to gain self-acceptance

“you can’t access self-acceptance if you haven’t actually had it confirmed that you’ve got a diagnosis” (Jenny, p.25)

A diagnosis helped them understand themselves (main benefit) and get support in workplace and at uni.

“I think the main thing for me was getting a better understanding of myself and being able to put the pieces together to understand why I’m different” (Rosie, p.15)

People around them supportive of diagnosis, didn’t make any difference.

“I think most of the people around me knew I was autistic before I even did um so it completely didn’t phase them at all. They were all super-duper supportive um and yeah they were just completely fine with it you know they made the joke well you always knew you were different, you know you are a weirdo, you’re this, you’re that. You know obviously from them it’s it’s endearing, I get on very very well with them and you know to them it’s no different um because I guess you know like I’ve just said, I’ve always been autistic so they’ve only known the autistic version of me it’s just that now there’s a name to it.” (Rosie, p.17)

Importance of understanding self, including autism diagnosis

“I’ve not had any big mental health crises or admissions or anything since then because it was so specific around a lot of stuff from then but I think a lot of it too is that I’ve learnt a lot about myself as I say some therapy was helpful despite all this um and knowing having my re-diagnosis helped as well and knowing triggers” (Ashleigh, p.100)

Didn’t need to be as hard on themselves when they knew they were autistic

“give myself a bit of a break and to have words for things like learning things like meltdowns, shutdowns, um just burnout, autistic burnout that I wish I’d have known um because it all just went down as not being able regulate or then is that a personality disorder, is that emotional difficulties or you think not not in the same way,” (Polly, p.25)

Instead of them being broken or wrong others need to adapt

“it helped me to give myself a bit of a break like when I obsess over things or when I don’t understand people before it was like I am wrong, I am broken, I am a problem, now it’s like I’m autistic and I will continue (laugh) to be a problem until you do something about it” (Polly, p.56)

Having a diagnosis gave permission to accept that they find social communication difficult and disclosing the diagnosis can make the expectations of others change

“I think that knowledge of having the diagnosis and being comfortable in that and other people being comfortable in that is the key to getting the right support in the first place” (Jenny, p.25)

Some people seem less difficult when you have a diagnosis, some more

“some people seemed less difficult when you’ve got the diagnosis, some people (laugh) seemed a lot more difficult um but yeah yeah it did change things”
(Polly, p.22)

Pleased to receive autism diagnosis because it provided an explanation for the past

“there was this kind of realisation that actually yes autism is the answer um is the explanation it is the the kind of reason behind everything”...

“I was pleased to get the diagnosis because it did give me the explanation it made things make sense” (Jenny, p.33/34)

Meant could find own people when they knew they were autistic

“It allowed me to kind of find my people online and through other means, autistic people” (Polly, p.25)

Autism diagnosis made a positive difference in support with education and gaining access to local NHS adult autism team for support.

“the first is education, I now have access to so much support um so I get and autism mentor I see her for an hour a week I have been at a point where I have seen her for two hours a week. Um She helps me to like this week I said to her there’s someone in my class and they’re my kind of my friend or they’re a positive acquaintance in the classroom, they keep touching me, not in a horrible way just like they tap you to get your attention, I don’t know how to explain to her that I don’t want to be touched so she helps me with peer relationships, she helps me just think things through, to work through my To Do lists and all of that, it’s amazing. Um I also get Study Skills, someone to help break down my assignments and things. The lecturers are great with it, I can’t fault them at all, so education it’s helped tremendously.” (Polly, p 23)

“it’s given me access to who are now the (Adult Autism) Team (laugh) I noticed they’ve changed the name um and yeah being able to see the autism OT and having had those sessions um. In terms of like psychology with the counselling psychologist who works for them was very different experience” (Polly, p.23)

People understand them better when they are known as autistic

“having people who understood that I can’t talk to you right now because my socks feel wrong on my feet and them saying, “OK, shall we take them off?” Just this understanding and empathy that came from it was incredible!” (Polly, p.25)

Having an autism diagnosis really helped, able to have a CTR, wished they had the diagnosis sooner

"I'd never had a CTR before because I hadn't had the diagnosis and just knowing that there are those things in place or yeah that was it it really I I genuinely think getting an autism diagnosis has been one of the best things that has happened for me, to me, however I want to phrase that um I just wish (laugh) it hadn't taken so long."

(Polly, p.22)

Would have helped to have an autism diagnosis at the beginning, feel they have had less admissions since diagnosis

"I think the thing that would have helped me at the beginning was to have an autism diagnosis (laugh) and to have people around me that were better understanding because I think since since I've been diagnosed I think I've had less - less admissions (laugh) who knows I mean I might not have but..." (Polly, p.56)

Autism provides a reason why some interventions didn't work for them

"having it explained to me that you don't have to fit that kind of mould and it makes sense the DBT didn't work it makes sense that their sleep hygiene stuff doesn't work because for me I go to bed at about 6pm and I will get up at 3 or 4am and that works for me because I'm exhausted (laugh) by that point after having people but then in the morning my brain is so alert and the world is so quiet that that works for me yet I'm sure if that was written down somewhere they would say that was an unhealthy sleep pattern or something I don't know I get enough hours that's all that matters" (Polly, p.56)

Instead of thinking the answer to not fitting in and the world not working for them is killing themselves, being autistic gives permission to not do what others do if it is not for them

"I think I still spend a lot of time wondering if I will ever fit in the world or the world will work for me and all of these worries that previously would have been like well if you can't function in the world then the easiest and quickest solution is to kill yourself because why would we prolong this for 30 years or whatever but now it's more like OK the world isn't working for me I don't know if I will ever have a full time job but there is there is no shame on living on Universal Credit and doing some voluntary work, and why would you want to get married (laugh) you don't need to"

“that was a really eye opening thing for me was the first time to have someone going well stuff it you don’t have to do that, normally it’s people being like well have you got a boyfriend yet are you ticking this box yet and have you done this yet and this is how things are so you need to fit that mould to have someone going, no, do what makes you happy and yeah I think having that, if I’d have had that when I was 14, 18 I don’t think I would be in this position today” (Polly, p.57)

C. USING SKILLS FOR A PURPOSE

Had shared interest groups at school which had a practical purpose of sharing knowledge

“it was people that I had some kind of shared interest with um that we’d sort of get together because of that so um it was sort of early days of computers um sort of swapping games tapes and things like that and sort of because it was such a new thing sort of passing knowledge between us um but um yea that was very much more a practical thing than a personal thing” (Max, p.6)

Lessons such as Design and Technology and Computers worked better than other lessons where you invented and made rather than being taught how to, this interest in the emerging technology eventually put them on their career path

“Design and Technology was a sort of a thing that was taught which was kind of a combination of woodwork and metalwork but also of actual inventing of things and then and then making the things that you thought of um rather than just sort of you know being taught how to make an ashtray or something and then just doing it there was more a kind of creative side to it um and particularly with the computers because effectively the teachers weren’t that much more clued up than anybody else um it was a chance to quite involved with that um and helping out with the sort of computer based side of things and maybe having a bit more exposure to it than than um just in the lessons um so sort of combination of technical um creation and then also dealing with computers something that sort of er (laugh) has put me where I am today if you like in that it’s - took a while to sort of focus things down but um I’ve ended up sort of using those particular skills um where I am now and that seems to be where I kind of fit and work well um so yeah I was kind of lucky in that the you know it was an emerging technology and the fact that somebody who was interested in it got to play with it a bit more than otherwise they would do and kind of yeah focussed me in in along those lines which useful back as I say further down the line” (Max, p.11)

Transition between TV job to the games one was helped by their interest in computer games and computer animation

“one of the things that kind of smoothed the transition from the TV to the games thing was that I had always been interested in computers and a big thing that was taking off in the sort of early nineties was er computer animation was becoming something that you could do with machines that didn’t cost hundreds of thousands of pounds ... there were some sort of leaps in the technology and the software and I started to get into post production through the animation stuff so so that and computer games were really my only two outside of work hobbies” (Max, p.21)

Autistic thought processes can be restrictive in managing life but very positive in creative thinking patterns for innovation

“I started to realise that I had an ability which could be which I was good at and could be used for things um and which now at this stage in my life I am making a difference by applying it um so it was kind of um a practical um example of how autistic thinking can actually be a really powerful thing because um the sort of logic and analysis that’s required and the thought patterns that I have make it er particularly suited to me to to do programming I can sort of I seem to have an aptitude for it that’s based on my er on my thought processes that otherwise seem like quite restrictive but actually this is one case where they’re actually very positive things” (Max, p.61)

The most positive influence on their life was realising their strengths and using them in a purposeful and useful way

“realising what my capabilities can’t think of the right word skill set isn’t quite the right thing but kind of understanding what I can do that’s useful is probably the biggest thing that makes a difference in that it helps give structure and meaning and pleasure um and what’s the word ... um ...a sort of feeling of safety if you like that you understand the issues rather than you just be pushed around by events that you know that you’ve certain things that you can control and they will help in a positive way for at least some parts of your life” (Max, p.55/60)

Fitted in and has worked in computer games for 25 years

“um the person I was living with um saw a job in I think it was in the Guardian actually um basically making computer games and because I was obviously really

interested in that fiddling around with computers and things um er yeah I ended up applying for that and got the job um and that's pretty much where I got to now ... again it was a situation that I kind of fitted" (Max, p.20)

"my work has always been my reason for existence and pretty much all of my um er all of my life" (Max, p.25)

"(work) giving me a reason for existing um and was making me feel like I had a use" (Max, p.40)

Enjoyment and success in identified skill that leads to career, with skill being sought by others

"I went to a specialist engineering college well secondary school and yeah, I loved it. I understood it, it makes sense you know something either works or it doesn't and um I guess it was my chance to excel in school um which I very much did. I was the first student to get 100% on the double engineering GCSE and I was recognised as one of the top engineering students in the UK and stuff like that." (Rosie, p.12)

"I think it was quite easy for me to transition into work um because I had a job I knew what I needed to do um and it was something that I enjoyed." (Rosie, p.12)

"ten years I was doing it um but I did about four years doing commercial kitchen design um and then the rest of the time I was doing domestic um so and yeah I whilst I don't do it anymore it's been about two years since I've personally designed a kitchen um I still do the visuals side of it um somebody that I used to work with in commercial kitchens and started up his own business um and he still comes to me and says, "Ooh, could you do me a visual?" "Could you do me this?" "Could you do me that?"" (Rosie, p.14)

Satisfaction from helping others.

"it's (autism diagnosis) also given me a chance to help other people um which has been really really nice" (Rosie, p.15)

A coping strategy is to intellectualise and learn about mental health and disability and using that information to help others

"one of my coping strategies in life is intellectualising and learning um about um those things that I've experienced so I will you know do everything I can to learn all

about those experiences and the pathways and the um the strategies and then use that to help others that's the kind of way I operate" (Jenny, p.31)

Connected with autistic people they befriended, wanted to help them be understood as staff not seeing their potential (**experiencing success**)

"I did get on with autistic people and like I went in to work working with young adults um with learning disabilities and autism into a care home and I was kind of ended up being the autism expert in some ways that I came to in that if something had upset one of our clients and, I mean often you just have to listen to them people don't, but um if it was somebody who was non-speaking or people found it harder to interpret what they are saying I could spot what had upset them because (laugh) if it was anything like in terms of like a break to the routine that someone else thought was insignificant I understood how significant it was or a sensory experience or um something else I could spot what was upsetting and I did was able to like the in terms of the way I interacted like I bonded with them in a way other people don't I am not sure if bonded is the right word because they were clients but um I don't know the way to describe it I could communicate them and got on with them and they interacted more" (Ashleigh, p.25)

Good at the job, enjoyable interactions with autistic people, inspired them to be a SaLT (**empowering/inspired**)

"it did fuel me to like do my speech and language therapy particularly I wanted to educate staff and for people to understand that it wasn't communication wasn't all about speech and that a lot of what people saw as behaviour, challenging behaviour, was because of miscommunication um and often people not understanding or things so and that was a positive experience" (Ashleigh, p.26)

Enjoyed working together as a team with own discrete role to create the whole process to performance (**belonging?**)

"the fact that it sort of with in in television was quite good in that um it meant that we had access to sort of recording studios and things and also um on courses um we basically er trained at the BBC um er training establishment um and so we'd have there'd be occasional sort of um residential courses where you'd sort of go and learn some of the technical stuff and and practice and one of the big things was with that was um in order to put into practice what you'd learnt um academically was making

a programme from scratch sort of deciding what it was going to be and everybody taking a role whether it was a PA or a cameraman or a vision mixer whatever um you'd put it you'd plan it put it together execute it and of course if you're making a programme you need content um so we got a couple of sort of invites to go and basically go and be the the band um and so you know the people that were doing the course would set up the studio with all the lights microphones and everything and we'd turn up and effectively it was sort of Top of the Pops thing but er so yeah that again that was a really good experience" (Max, p.23)

Enjoyed creativity in composing their own work as a band rather than copying work of others

"being sort of creative was a was a in a sort of artistic way rather than anything else was a good experience" (Max, p.23)

"We sort of did most of our own stuff so you know it was making it up rather than just copying stuff from other people" (Max, p.23)

As a band member had a link into social groups and went to quite big parties and pub gigs with a purpose and a positive role

"being in a social group of some kind in a meaningful way for once"

"the main things we did were sort of er sort of birthday parties for people that um within the company it was a very sort of social place um I think quite unusual um it may be something to do with the fact that it's the entertainment industry but um so yeah we had some quite big parties basically where we'd go along and and play those and er yeah got a bit so essentially pub gig kind of kind of things" (Max, p.23)

Mission for scouting was to earn all the badges

"I read the proficiency badge book on the first night pretty much from cover-to-cover um I wanted earn all of those badges um that was the mission for my scouting um which I set about and did pretty much" (Jenny, p.15)

Became a patrol leader so had control which worked very well for them

"it worked really well because I could become the patrol leader so I'd have my little group of 6 and managed that and um had that control had there was an expectation that I would give orders give instruction give um organisation um as a patrol leader" (Jenny, p.15)

Fitted well in their scouting role and proud of their achievements

“had the patrol leader’s council meetings so I was able to be the minute taker in meetings I’d naturally take minutes anyway hence the pen um so I’d constantly um that was just who I was it fitted really well I was able to represent at county Patrol Leader’s Council PLC um even went to national PLC um and it was those roles were then you representing young people with adults um so from 12 I’d been doing that I was giving a voice to young people but with adults so it was communicating with adults communicating with adults love it always really liked it it was the peers that was the problem um so that was fantastic it was um really good and I was able to kind of organise the activities all of that stuff um and I can do that well um so I became quite popular within my scouting because I generated a good programme and got them all badges and all that sort of stuff” (Jenny, p.15)

Scouting achievements were recognised (**experiencing success**)

“I got my um one of my er scouting awards and a couple of people came over and presented it to me in hospital cos I wasn’t able to go to the presentation like they wouldn’t give me day release because they considered me still too much of a risk I was in ICU at the time um but they um they allowed them to come onto the hospital and present them there so that was really nice” (Jenny, p.15)

Founding [REDACTED] (charity) has been an enormous positive, proud of achievement and means a lot to hear feedback that they are making a positive difference for people

“I mean from a tiny idea of wanting to well it wasn’t really that tiny always dream big but um that idea of and um I remember chatting to you way back now about you know wanting to set this up and create something that was around kind of connecting people and ensuring people knew where support was and and look where we are in a relatively short amount of time um and that’s been fantastic and we do get lots of feedback and those reviews are fabulous um and it means a lot to me to see those reviews that feedback see kind of things changing and people’s appreciation for something um you know it’s brilliant so I’d say that’s had a massive influence and it’s also given me you know selfishly it’s given me a job and a purpose” (Jenny, p.46/47)

Successful and positive experience being employed as a trainee technical operator

“something called a technical operator which is a television er post where basically it’s back in the in the sort of er late 80s sort of 90s where multi-tasking was a big thing um it was basically a job where you could do camera work and lighting and

video editing and sound mixing and stuff like that um and it was a trainee position so it didn't need any qualifications um and it was also working for a company that had associations with the military so there was a kind of familiarity there with some of the er the procedures and the work involved um and yeah so that actually suited me very well um it involved a lot of sort of initiative and fiddling around with things and sort of creativity" ... "I kind of like found a niche there" (Max, p.19)

Fell into playing in a band because could play the guitar

"so I was invited to be the bassist in the group and um got an old second-hand bass and it's effectively a subset of playing guitar so I was able to sort of pick that up fairly well" (Max, p.22)

Different social rules where they started scouting

"I did get into scouting so at the age of 12 I started scouting um scouting was absolutely brilliant for me um it was in a different town to my um schooling so it was quite interesting um because once again there was these different social rules I don't know how well you know the county um but [REDACTED] is renowned for being perhaps a more tracksuit type town in terms of what you wear and [REDACTED] is much more jeans and smarter kind of what you wear (laugh) um for want of a better way of putting it um and so you had to kind of adjust depending on what you were doing which was interesting" (Jenny, p.15)

Launched various county wide groups including befriending project, [REDACTED] to support parents with autistic children who don't have a learning disability

"I was approached by a group of parents um and they asked me if I would mind helping them facilitate and set up a group um for parents of children with youngsters with high functioning autism by which they meant exactly what it is you know those that are cognitively able those if kind of are in the mainstream environments and are able academically but they still have lots of challenges because rightly or wrongly they felt um that it was very difficult to be open about the challenges they have when they are so very different to the challenges that of a child with kind of more classic autism of learning disabilities potentially incontinent potentially non-verbal those children have they have they felt it was difficult at times to express their own challenges and so I said yes of course and that was the birth of [REDACTED] so that group still run" (Jenny, p.31)

“ [redacted] was set up um with this group of parents and um and I listened to them and we chatted and um I learnt more and investigated more and ... essentially listening to all these parents I was just thinking gosh you’re describing my childhood you are describing me you know this is you know totally me” (Jenny, p.31)

Benefit in working in their own charity is they have control over working environment and the flexibility to accommodate the complexities of their own family

“I couldn’t have just gone and applied for a job in somewhere I needed the flexibility um I needed to be able to work it around my own family and the complexities around my own family um I I I like having the control of my um working environment and how to kind of manage that um and I’m doing what I love and I couldn’t just go and work anywhere with anyone and I know that um you know so this has enabled me to achieve for myself but also to be doing what I love doing which is helping other people” (Jenny, p.46)

Employed running their own charity based on their passion to help autistic people and their families so has that team of understanding support around them

“I live and breathe the autism world ... I am employed running my own charity um living and breathing what I absolutely love so I work my special interest um and I’ve got a fantastic board of trustees um I’ve got a fabulous team of staff now um some great volunteers um and so I mean there’s support in that respect um that perhaps other people on the spectrum wouldn’t have because they’ve they’re not quite so um wrapped in um services that get it understand and know and that sort of thing” (Jenny, p.40)

Talkative and confident in talking to others in gatherings

“he (little brother) also it’s quite funny hide behind me in like family gatherings and stuff like that because I was more talkative kind and stuff like that” (Ashleigh, p.7)

Began speaking out which couldn’t do with parents. Experienced respect and admiration for this

“in the queer community I had to argue for the fact that I wasn’t what they wanted me to be and where I hadn’t been able to argue back with my parents so much or get away with that I could there and there were people who respected me for it and friends who respected me and people who liked me for it um so that was quite formative I think in some ways.” (Ashleigh, p.23)

Army bases good places to see tanks and helicopters which was a positive as mechanical things a favourite interest

“science type things were particularly um important but yea definitely um sort of mechanical gadgety things like sort of um well tanks and helicopters I mean it’s kind of the environment meant that there’s a sort of thing called Families Days where sort of it’s like the Army’s equivalent of a village fete um where they’ll sort of have put tents out and have tombolas and Bat the Rat and sort of things but also sort of show off things like the sort of the tanks and er they had a um when we were in there was a helicopter display team that was one of my favourites” (Max, p.4)

D. UNDERSTANDING AND NON-JUDGEMENTAL SUPPORT

Paramedics and police understanding their needs e.g. not waiting in A&E waiting room.

“I have found paramedics are amazing, um and they knew that I couldn’t cope in the hospital environment so they were like they would keep me on the ambulance until there was a room available knowing that I would just run away if I wasn’t in a room um so ended up spending a few hours on the ambulance at the hospital. They put me into a room then the A and E staff decided that I didn’t need the room so forced me to sit in the waiting area. I ran away from the hospital, police found me, um because it was ridiculous at a and e and I couldn’t cope, it was freezing outside. Um got found by police, got taken back, um police had said to them look she can’t cope with sitting in the waiting area you need to put her back into a room, that’s the whole reason she waited hours on an ambulance um because she can’t cope with it, she’s autistic um and they again didn’t put me in a room and said No she can just wait in the waiting area so I ran away again.” (Rosie, p.24)

Staff need to just ask what is going on for them in an accessible way.

“I think had staff have actually spent a bit more time and sat and spoke to me um and asked you know some simple questions you know Are you OK? What’s going on for you? Um you know it’s all about communication um and I think all too often hospitals miss doing the whole communicating with patients especially an autistic patient who may sometimes struggle to communicate um rather than find an accessible way to communicate they just leave off the whole communication thing and step in as they feel appropriate um which isn’t necessarily always appropriate for somebody with autism.” (Rosie, p.30)

To help with autism side: what to do when overwhelmed, understanding what is going on, daily living support if struggling.

“I think sometimes it can just be help with understanding what’s going on and um like you know when I’m overwhelmed and learning about things to kind of help with that and stuff like that really and um you know if I’m struggling with daily living things having that extra support with those and stuff” (Rosie, p.35)

Negotiating with teachers, self-advocacy

“I remember arguing I think I was the first kid in my schools who got to wear culottes rather than a skirt in middle school” (Ashleigh, p.12)

“I had to negotiate with my maths teacher for my maths exams and stuff” (Ashleigh, p.12)

School responded to change in behaviour and able to open up and a solution to moving out of home formulated

“my teachers started to take notice then and I did get pulled aside by teachers asking if everything was OK at home and I did open up to I started my behaviour got worse kind of in class and stuff and I started and it was cries for help (laugh) now I can see it that way and as I say my teacher my psychology teacher I did to start to open up to a bit and he was the one that arranged with one of my friends (about?) leaving home” (Ashleigh, p.17)

Disclosed feelings of self-harm to Occupational Health who recognised need for mental health support and voluntary admission

“I couldn’t cope with going outside because of the sensory input from going outside and I got so anxious around that um but yeah I did admit thought about these urges to harm myself and this kind of that and after I had this meeting um with my work colleagues said they wouldn’t provide any reasonable adjustments I just melted had a meltdown um and I was weirdly luckily supported by occupational health and some my autism team person who was really good and they recognised that they needed to get me help for my mental health and so they arranged for me to go into the um just the usual the NHS mental health open ward I’m not sure how to describe it not secure services just general admissions” (Ashleigh, p.36)

Benefit of supported accommodation is knowing there are people around but able to be by yourself

“I was given a room on my own which is then why I wanted to the stay or could manage to stay longer um just having knowing that there’s people are around but at the same time as kind of being on my own and having the freedom to you know go down to the swimming pool and go to the gym and you know build up a life and start to kind of do some of that kind of just building some activities and structure to my life” (Jenny, p.28)

Correct support for autism would help sustain positive mental health

“I think they’re (mental health and autism) closely interlinked in the sense that um when you don’t put the correct support in place then your mental health will suffer um but also on the flip side if you do put the correct support in place for your autism then that would help to sustain positive mental health um er I think that’s really important” (Jenny, p.38)

When professionals realised about their sensory differences there was an effort to talk about strategies which was positive

“they realised that I had different perception of the world to what they thought and there was an effort made to discuss with me things about you know whether to turn the lights off or to shut the window to stop the traffic noise and stuff like that so that was a really positive turn around” (Max, p.46)

Having somewhere to go that is supportive and safe and away from the pressures of life is very useful

“I wouldn’t be too unhappy if I was institutionalised and if I had to and forget about the rest of the world and live a fairly normal existence even though it wasn’t um quite as free um that would be a very attractive place to be um and also from the actual mental health side of things having the ability to be somewhere that is supportive and safe and takes you away from the pressures that are making it unbearable in the first place is a really useful thing um I’m not quite sure where the balance lies in terms of the time for how long you are there or not but um um yeah I mean for instance if I could if I could be an inpatient now and there weren’t any masks involved and there was the ability to get out occasionally and I could go to work in between that would tick most of the boxes for me” (Max, p.52)

Having an advocate made a huge difference

“Advocate was the best thing I did because not only did she fight for me every ward round (laugh) and made sure they wrote things down and it was the only way I could get a time for my ward round. If you have someone coming they give you a time otherwise they just grab you whenever um but she also stayed with me afterwards which she shouldn’t necessarily have done or didn’t have to do” (Polly, p.51)

E. THE ENVIRONMENT

Sensory

OT provided reasonable adjustments and sensory support on the ward

“I had the most incredible OT on the ward and she liaised with the Autism OT, they made like their own plan and she took me out for a walk every single day apart from the weekend cos she wasn’t working. Um she also got a trampette put on the ward that was locked away but when she came in I was able to use it once a day, um ice, ice cubes, is something that is really helpful for me that I wasn’t allowed because they were like well if you put salt with them you can burn yourself, well I didn’t know that so thank you for that information but also (laugh) I just wanted to crunch them. Um and even things like plastic cutlery and pla, I find plastic so much easier or straws are really a straw wasn’t allowed any of that but yeah what the new OT did for was just so helpful, um groups happened on time and she told me how many people were going to be in the group and who was going to be in the group and such small things that can really turn it around.” (Polly, p.37)

An autistic person available on the ward to talk to would be helpful.

“there somebody started working on the female ward and she was called like an SCM worker, or she basically saw the people with a personality disorder and they didn’t so I I used to sit outside her office and talk to her just because she was a new person to talk to and she had three cats and I wanted to know about the cats and now and then she would invite me in because she didn’t have anything to do so I could squish her squishy things (laugh) she had like a sensory box and I wish that they had that for an autistic person so like an autistic person on the ward who works with autistic clients or service users because again it’s it’s so needed” (Polly, p.48)

A psychiatric admission to the Eating Disorder Unit felt very different.

“I almost don’t class the Eating Disorder Unit as a psychiatric admission, which it obviously is, but it was just it was so different and I think there is there is no (laugh) there is no nice way of saying this, I think because nobody or everybody seems to be totally sane, like other than the eating disorder everyone is sort of quote unquote normal. There was nobody like self-harming, nobody psychotic, nobody wanting to end their own life, you were purely there because you needed to put some weight on um which obviously isn’t the case because eating disorders stem from trauma and all of the above but it just really felt like I’d gone on, (laugh) holiday’s not the right word because it was not that good (laugh) um but everyone was my own age and they were all female and I was very lucky that we all got on very well my my best friend now is someone who I met there and we stay friends, that is the only long term friendship I have and I think it’s because she she saw the real me she saw me at my worst she saw obviously the eating disorder, she saw what would have been autism, all the trauma stuff, there was nothing I could throw at her now that she hasn’t (laugh) experienced” (Polly, p.26/27)

Way of life in hot countries suited better

“the best sort of option from in the really hot places basically school started about 7 o’clock in the morning and then finished just after 1 so you’d go home at lunchtime and eat at home um and yeah and from a freedom point of view as a kid it was really great because you get the entire afternoon to yourself” (Max, p.5)

Before you get full independence a transitions house on site would be good

“again thinking back to not an Eating Disorder ward I’ve been in but one that I visited a friend on and there’s the main ward or the main house and then there’s one to the side where it’s kind of like your transitions house where you have less support you’re still on the site um and I think that works a lot better because, well they tend to be long admissions er but you get that independence before you get the full independence.” (Polly, p.54)