Mental Health Inpatient Experience of Patients with Autism Spectrum Conditions:

A phenomenological study

Paul Maloret

Submitted to the University of Hertfordshire

in partial fulfilment of the requirements of the degree of Doctorate in Health Research

June 2019

Contents

		Page
Abstract		i
Acknowledgements		ii
Glossary		iii
Chapter 1: Introduction		
Chapter overview		1
1.1	Background: How this study evolved	4
	a) My social constructionist stance	5
1.2	Autism and psychiatric comorbidities	8
	a) Stress and physical illness	8
	b) Autism and violence	9
1.3	Deconstructing the problem: policy, power and choice	10
1.4	The history of mental health inpatient units	11
1.5	Contemporary inpatient services for people with ASC	13
1.6	Narrowing the focus	16
1.7	Conclusion	18
1.8	Research question	19
Chapter 2: Critical literature review		
Chapter overview		20
2.1	Literature search strategy	20
2.2	Inclusion/exclusion criteria	21
2.3	Mapping of the literature	23
	2.3.1 Analysis of included studies	25
2.4	Service user views	27
	a) Summary of main studies	27
	b) Inclusion	27
	c) Vulnerability and safety	28
	d) Relationships with carers and support staff	28
	e) Relationships with other inpatient service users	30
	f) Environment	31
	g) The admission	31
	h) Treatment	32
2.5	Carers' and support staff views	32
	a) Summary of main studies	32

b) The admission 33
c) Concerns regarding safety 33
d) Relationships with unit staff 34
2.6 Examination of mental health inpatient units 35
a) The culture of risk management 37
2.7 Autism and mental health 38
2.8 The challenges of an autistic life 41
2.9 Grey literature 42
2.10 Summary of literature review 44
a) Conceptual and theoretical underpinning 44
b) Literature limitations 45
c) Literature impact 47

Chapter 3: Methodology

Chapter overview 50

3.1 Research design 50
3.2 A qualitative approach 53
3.3 Phenomenology 53
3.4 Interpretative Phenomenological Analysis 54
a) Suitability of IPA in autism research 55
3.5 Other considered qualitative methodologies 56
3.6 Population 57
3.7 Research participants 57
a) Inclusion criteria 57
i) Service criteria 57
ii) Participant criteria 58
b) Biographies 59
c) Sample and recruitment 71
3.8 Ethical considerations 74
3.9 Informed consent 74
3.10 Confidentiality 76
3.11 Potential distress 76
3.12 Data collection 76
3.13 Transcribing 79
3.14 Data analysis 80
a) Emergent themes 80
3.15 Quality, reliability and validity in qualitative research 82
a) Reflexivity 83
b) Research as contributory 83
c) Defensible in design 84
d) Rigorous in conduct 84
e) Credible in claim 84

3.16 Summary 84

Chapter 4: Findings

Chapter overview 86

4.1 Superordinate theme *The experience and management of anxiety* 87
- a) *Main theme Reasons and responses* 87
  - i) Sub-theme *Powerlessness and the emotional reaction to anxiety* 89
  - ii) Sub-theme *Responses to anxiety and powerlessness* 92
- b) Main theme *Strategies for coping* 95
  - i) Sub-theme *Developing positive coping strategies* 96
  - ii) Sub-theme *Negative coping strategies* 99

4.2 Superordinate theme *Sense of self and connectedness* 102
- a) Main theme *Relationships* 102
  - i) Sub-theme *Connections with other patients and unit staff* 102
  - ii) Sub-theme *Disconnection and reconnection* 105
- b) Main theme *Communication* 107
  - i) Sub-theme *Deciphering understanding and meaning* 107
  - ii) Sub-theme *Recognition of emotions of self and others* 110

4.3 Summary 111

Chapter 5: Discussion

Chapter overview 113

5.1 The experience and management of anxiety 114
- a) Powerlessness and the emotional reaction to uncertainty 115
- b) Responses to anxiety and powerlessness 118
- c) Development of positive coping strategies 120
- d) Negative coping strategies 121

5.2 Sense of self and connectedness 126
- a) Connections with patients and unit staff 127
- b) Disconnection and reconnection 128
- c) Deciphering understanding and meaning 128

5.3 Summary 129

Chapter 6: Conclusions and recommendations

Chapter overview 131

6.1 Answering the research question 131
- a) Using an appropriate methodology 132
- b) The interviewer's experience 132

6.2 Original contribution to the field of mental health 134
- a) Non-engagement 136
- b) Clinical implications 138

6.3 Recommendations 140
6.4 Research limitations 142
6.5 Future research 144
6.6 Conclusion 145

References 148

List of figures

Figure 2.1 PRISMA flow diagram 26
Figure 3.1 Research design framework 51
Figure 3.2 Summary of recruitment 75
Figure 3.3 Summary of process *Organising themes across cases* 82
Figure 4.1 Theme Map *The experience and management of anxiety* 88
Figure 4.2 Theme Map *The sense of self and connectedness* 103

List of tables

Table 1 Keywords searched 21
Table 2 Inclusion/exclusion search criteria 22
Table 3 The Quality standards framework 23
Table 4 Outline of IPA procedures 54
Table 5 Summary of inclusion and exclusion criteria 59
Table 6 Participant characteristics 72
Table 7 Superordinate themes, main themes and sub-themes 87
Table 8 The *energy bank* - life outside the mental health unit 97
Table 9 The *energy bank* - life inside a mental health inpatient unit 97
Table 10 Original contribution to the field 135

List of appendices

Appendix 1 Literature review characteristics table 169
Appendix 2 Research consent form 177
Appendix 3 Participation information sheet 179
Appendix 4 Debriefing guidance sheet 181
Appendix 5 Interview schedule 182

Abstract

Aims

This study is pertinent to the current political and policy driven climate regarding increasing rights, choices, inclusion, independence and awareness for people with autism spectrum conditions (ASC). Since the implementation of Transforming Care (NHS England, 2015), commentators have focused upon the reduction of hospital beds within learning disabilities and mental health services. This qualitative study explored how patients with ASC, a group known to be extremely vulnerable to psychological issues, experience admission to acute mental health inpatient facilities in the United Kingdom (UK). Anxiety is a common characteristic for people who live with ASC, but its recognition can be compounded by the difficulty in disentangling features of ASC from those of anxiety disorders. Despite growing acknowledgement that admission to acute mental health facilities should be a last resort, reported figures on admissions continue to rise (NICE, 2014) and there remains a dearth of research highlighting how those who are most vulnerable in the inpatient setting experience this environment. The lived experiences of those with ASC could nonetheless help to inform service development.

Method

During 2015-2017 phenomenological enquiry using qualitative methods facilitated one-to-one semi-structured interviews to capture the experiences of 20 adults from the East of England who were former psychiatric inpatients with an established diagnosis of ASC. Verbatim transcripts of audio recordings from each interview were analysed using Interpretative Phenomenological Analysis (IPA).

Findings

IPA enabled the identification of broad themes, which explained in rich detail participant reflections on the situations and events within the acute care mental health facilities that triggered responses such as anxiety, fear, agitation and social avoidance anxiety. It was then possible to establish the broad behavioural patterns associated with their responses some of which has been reported by other commentators i.e., isolating themselves from others, including other patients and staff; ceasing to eat and sleep adequately; and, all too often, self-harming or exhibiting aggressive and violent behaviours (Lidstone et al., 2014; Donna et al., 2010; Bunyan et al., 2017). Emergent new themes were discovered in the same way and the original contribution of this research includes; creative self-help strategies to deal with anxiety, the notable impact of the sensory environment, interesting relational patterns with family/friends, staff and peers, including the disconnection from family and friends and confused connections to staff and peers.

Implications

This study provides further evidence that hospitalisation of a person with ASC should be the last resort. However, it is inevitable that in the future some people will need a mental health inpatient bed and the reductionist approach to inpatient services and the emergence of single person community services, whilst warranting applause, will leave gaps in service provision. Therefore, the thesis contends that instead of minimising inpatient availability to an unrealistic level, mental health care providers should concentrate on the emotional and psychological experiences of the inpatients aiming to improve their service experience,

raise awareness of ‘different’ service users; highlighting the ‘different’ issues for them, i.e. elsewhere their vulnerability due to relationship problems with their family and friends, and building relationships with staff which many have indicated as crucial to their feelings of safety and security. Equally, understanding the sensory profile of the inpatient environment from an autistic perspective can provide the practitioner with some easily implemented reasonable adjustments which can have a significantly positive impact with the help of highly motivated staff who are person-centred in their approach. Additionally, increasing the practitioner’s awareness of the causes and coping mechanisms to anxiety will contribute significantly to helping inpatients with ASC to cope with their situation and find improved ways to manage and look forward.

Acknowledgments

In completing the study, I have received considerable support from a number of people: although only a brief mention of this is possible, I would like to convey my appreciation for all the help and assistance which has been so generously given over the past seven years.

Firstly, I am totally indebted to those who agreed to participate so freely and so enthusiastically in this study; without their involvement the research would not have been possible. The participants' contributions were supported by their families, friends and, in particular, their support workers from the Hertfordshire County Council Asperger's support group; I thank them very much for making time in their exceedingly busy lives to allow me to enter briefly into their world.

I am extremely grateful for the advice and guidance which has been given during each stage of the study by my supervisors, Dr Patricia Scott and Dr Shivani Sharma – they have been true facilitators of my learning and their words of wisdom have been invaluable. Thank you both so much. Thank you also to the entire Doctorate in Health Research (DHRes) staff who have provided the support and education that has underpinned my whole Doctoral journey. I must also thank my fellow students – we have shared our experiences, and our 'ups and downs' as well as our understanding of each other's challenges.

I would also like to acknowledge the support given from my line managers in the School of Health and Social Work at the University of Hertfordshire: I thank you for providing me with the opportunity and ongoing support which has been crucial to my work/study balance. Equally, I would like to thank the Learning Disability Nursing academic team - I could not have asked for more support.

Finally, I would like to thank my family, especially my wife Jennie, my children Rebecca and Maddie and their grandparents for their patience and endless encouragement. Thank you.

Glossary

Autism spectrum conditions- Over the years, different diagnostic labels have been used, such as *autism, autism spectrum disorder (ASD), autism spectrum condition (ASC), classic autism, Kanner autism, pervasive developmental disorder (PDD), high-functioning autism (HFA), Asperger syndrome and Pathological Demand Avoidance (PDA)*. This reflects the different diagnostic manuals and tools used, and the different autism profiles presented by individuals (National Autistic Society, 2018). Primarily, within this current study *autism spectrum condition* (ASC) has been used, as favoured by the National Autistic Society (NAS) and the Asperger's Support Team in Hertfordshire County Council, who have supported this research project: however, on occasion, specifically disclosed diagnostic terms may have been used, such as *Asperger syndrome.*

Anxiety- The American Psychological Association (APA, 2018) defines *anxiety* as '*an emotion characterized by feelings of tension, worried thoughts and physical changes like increased blood pressure*.' The terms used in this study to describe anxiety are the words of the participants: *fear, worry, apprehension* and *nervousness*. On occasion, the diagnostic term is used when specific information about the clinical diagnosis has been shown, for example *generalised anxiety disorder* or *social anxiety disorder*.

Inpatient services- The term *inpatient service* has been used to describe any inpatient service to which adults with mental health problems may be admitted in order to receive support in relation to their mental illness or presenting difficulties. The term *inpatient admission* refers to any period of stay within such a service, different models of inpatient service, and including services specific to adults with learning disabilities and/or autism spectrum conditions.

Learning disability / intellectual disability- A range of different terms are used interchangeably, including *learning disability, intellectual disability, mentally disordered* and *mental retardation*. This current study uses both the terms *learning disability* and *intellectual disability*, the former mostly being used to refer to services in the UK for which the majority are using the term *learning disabilities. Intellectual disabilities* has been emerging for many years and is now used more commonly within UK literature.

Mental health problems- A number of terms including *psychiatric disorder, mental ill-health, mental disorder and mental health difficulties* are commonly found in the literature to describe somebody who has suffered from mental health problems. Within this current study, I have chosen to use the term *mental health problems*, which is used by the services mentioned in this study and is favoured by Mind and The Mental Health Foundation.

Mental well-being- It is defined as a state of well-being in which every individual realises his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to contribute to her or his community (MIND, 2013).

Chapter 1: Introduction

Chapter overview

This doctoral research provides an interpretive phenomenological analysis (IPA) (Smith, Flowers & Larkin, 2013) of the emotional and psychological experience of being a mental health inpatient with an Autism Spectrum Condition (ASC) in the UK.

Autism was first described academically in an article by American psychiatrist Leo Kanner in 1943. The following year, Austrian physician Hans Asperger referred to a group of children he had observed showing some of the same impairments as Kanner's children. Kanner (1943) refers to the following impairments, which can all be observed during the interviews of this current study's participants:

1) The person with autism finds difficulty with social contact, and he or she often shows more interest in objects rather than in persons.
2) Development of language is relatively late, or they simply do not want to talk to others.
3) Their play behaviour as a child is monotonous; as they grow older, their movements and actions remain repetitive.
4) The person with autism is against major changes (Kanner, 1973).

In 1978, Wing and Gould examined children in relation to their ability to socially interact, communicate and imagine. They found many similarities with these children that Kanner and Asperger had found previously, and these three areas of examination are still prevalent in diagnostic criteria and psychological assessments for ASC (Wing & Gould, 1978). This *triad of impairment* is ingrained within my thinking and understanding of ASC and I use it intermittently to help to group characteristics that I have observed when meeting people with ASC for the first time. I find this quick process of consideration of their social functioning, communication and imagination to be effective and helps me to understand their differences and needs in an efficient way which may help our continuing social interactional experience. Many participants within this current study had obvious impairments socially, communicatively, and with their imagination and 'flexibility of thought'.

Because of the increased incidence of and concerns about overdiagnosis, in May 2013 new guidelines for identification of ASC were introduced in the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-V) by the American Psychiatric Association (APA) (Lobar, 2016). DSM-V reduces the previous triad of impairment to two dimensions, recognising that 'social' and 'communication' cannot be disentangled. The National Autistic Society (2018) describe the new criteria as clearer and simpler for diagnosing clinicians and others to understand; additionally, sensory behaviours are now included. In DSM-V the previously used terms, such as '*autistic disorder*', '*Asperger disorder*', '*childhood disintegrative disorder*',

and '*pervasive developmental disorder-not otherwise specified (PDD-NOS)*', have been replaced by the collective term '*autism spectrum disorder'*. For many people, the term '*Asperger syndrome*' is part of their day-to-day vocabulary and identity, so it is understandable that there are concerns about the removal of this term and distinct diagnostic pathway from the DSM-V.

In the last 20 years, a single psychological theory has become widespread and popular within the autism research, the *theory of mind,* which argues that the child at the age of four usually knows that others may have thoughts, wishes and representations different from their own. Baron-Cohen (1996) argues that children with autism, on the other hand, have difficulty in understanding the minds of other people and, as a consequence, they appear to have little interest in other people's thoughts and opinions, which Baron-Cohen argues is fundamental to social interaction and reciprocal conversation. In Baron-Cohen's (1996) words: '*They are mindblind, in other words, they do not understand that other people have their own thoughts and beliefs'* (Pg. 10).

According to the NAS (2017), an ASC is a lifelong developmental disability that affects how people perceive the world and interact with others. People living with autism see, hear and feel the world differently and live with this condition throughout their life. Autism is not a disease and therefore it cannot be 'cured'. ASC refers to a range of conditions characterised by challenges to social skills, repetitive behaviours, speech and non-verbal communication, as well as by unique strengths. The term '*spectrum'* refers to a wide and varied group of differences and unique strengths possessed by each person with autism.

The Autism Support Network (2018), frustrated with the media perception of ASC and their concentration upon the challenges those with ASC face, decided to publish a list of positive strengths which can be associated with many people with ASC. The Autism Support Network (2018) claim that those with ASC value the truth and rarely lie about anything; many people in society tell lies, albeit mostly they can be perceived as little white lies, but not people with ASC for whom truth is truth: therefore, if you ever want an honest answer to a genuine question then ask somebody with autism. People with autism live in the moment: how often do atypical people fail to notice what is in front of their eyes because they are too distracted by social cues or random small talk? Those with ASC rarely judge others and are far less likely to attach any importance to people's personal characteristics; in fact, people with ASC often see through such surface appearances and thus discover the 'real' person. Autistic people are extremely passionate about their interests and, not being tied to social expectations and judgements, these interests can be pretty much anything they desire. Additionally, people with autism have phenomenal memories, including those for finer details. People with ASC are less likely to be materialistic, i.e., are far less worried about brand names, hairstyles and other expensive but unimportant externals than most people are concerned with. Finally, it is suggested that having an autistic person in your life has a profoundly positive impact on your perceptions, beliefs and expectations.

The variations in presentation that are possible with people who are on the autistic spectrum are demonstrated well by this current study's participants. Although the participants possess a current clinical diagnosis of ASC and they share traits consistent with the core features of the condition, as mentioned above, none of them could be considered as having a considerably similar presentation and, even within the relatively short time that I spent with them, I observed differences in their mannerisms, ability to communicate and

behaviours. They all clearly have their own personalities and their total behaviour could not be forced entirely into any of the above theories.

The global prevalence of ASC is not clear due to the varying degrees of awareness and diagnostic practices found across different countries. Elsabbagh et al (2012) have provided greater insight by undertaking a systematic worldwide review of epidemiological studies of ASC and pervasive developmental disorders. Based upon the evidence reviewed, the median prevalence estimates of ASC were 62 in every 10,000 people. The World Health Organisation (2017) suggests that ASC affects one in 160 people around the world. Baxter et al (2014) estimated that in 2010 there were 52 million cases globally of ASC, equating to a prevalence of 7.6 per 1000, or one in 132 people. In the USA, one of the leading nations in autism research, *The Autism and Developmental Disabilities Monitoring Network* reviewed epidemiological surveys concentrating on children across 14 States in America and found a prevalence rate as high as one in 88 children, with five times as many boys being diagnosed as girls (Autism and Developmental Disabilities Monitoring Network Surveillance Year, 2012).

A study of 0 to 17 years' old residents in Stockholm between 2001-2007 found a prevalence rate of 11.5 in 1,000 and suggested this is similar to the rate found in other prevalence studies in Western Europe (Idring et al, 2012; Williams et al, 2006; Baron-Cohen et al, 2009). In the UK it would appear that this rate is comparatively similar as the National Autistic Society (2018) estimated that people living with an ASC diagnosis comprise around 700,000 people, or one in 1,001. In South Korea, however, Elsabbagh et al (2012) claimed that a much higher prevalence rate of 2.64% was discovered in their study, where the researchers found two-thirds of the people on the autism spectrum were in the mainstream school population and had never been diagnosed (Elsabbagh et al, 2012).

When you consider the support networks and families of those affected by ASC that are impacted upon, ASC is a part of their daily life for 2.8 million people in the UK alone (NAS, 2018). It is also important to note that families are concurrently affected by the high prevalence of mental illness that exists within ASC groups with at least one in three adults experiencing severe mental health problems (NAS, 2018). Zablotsky et al (2013) provided evidence that parents raising children with ASC have been shown to experience high levels of stress and report a lower quality of life. Their study examined the association between child autism symptomatology, the mothers' quality of life, and the mothers' risk for depression in a sample of 1,110 mothers recruited from a web-based registry of families with children with an ASC. Higher autism symptomatology and a greater number of co-occurring psychiatric disorders in the child were associated with an increased risk for current treatment of maternal depression and a lower maternal quality of life. The results highlight the importance of screening for depression, particularly in mothers of children with ASC, mental health and behavioural challenges.

Although empirical studies on mental health inpatient hospital admissions do not give details of specific diagnosis and therefore we cannot clearly ascertain how many people with ASC have been admitted to an inpatient unit in the UK, we do know that 3,235 people with learning disabilities and/or ASC were in hospital at the end of September 2017, of which 1,530 were in a secure setting, i.e. an inpatient service. The total number of people in contact with mental health services at the end of September 2017 was 1,214,870, and

many of these would have an ASC diagnosis without the comorbidity of an intellectual/learning disability. Of those people in hospital with learning disabilities and/or autistic spectrum disorders at the end of September 2017, 33% (n=1,060) had been in hospital for over two years and a large number experienced a delayed discharge. There are a further 82,042 children and young people within mental health services, learning disability and autism services (NHS Digital, 2017).

This introduction will provide background information on current policy and service contexts: the psychological experience of being a mental health inpatient, how the inpatient environment impacts upon patients with ASC, and the strategies employed by the patients themselves to deal with this potentially distressing experience. Evidence suggests that admissions to mental health inpatient services for those affected by autism spectrum conditions, although seen by many practitioners as a last resort, are in fact increasing (Narendorf et al, 2011). Howlin (2005) noted that the mere thought of an inpatient admission for a person with ASC can cause an acute escalation of the severity of their mental health condition. Their desire for 'sameness' can be seriously compromised when someone with ASC is placed in unfamiliar surroundings and away from people they know and trust. Other studies have considered this phenomenon; however, their perspective has been for carers or members of staff, i.e., front-line caregivers (Donner et al, 2010; Dunn, 2012; Chaplin, 2004). Whilst those studies did also consider the service user perspective, the service users mostly had mental health or learning disability diagnoses. Some participants in these studies were assessed as having autism, but the researchers were not necessarily looking at the perspective from an autistic viewpoint i.e., what is different about the mental health inpatient experience for patients with ASC (Bee et al, 2008; Bunyan et al, 2007; Parkes et al, 2007). This makes a case for the need for this current study: whilst some of the experiences that have been reported within this study are comparable and not dissimilar to those experienced by patients without ASC, its overarching focus is to consider the 'autism' experience. I will elaborate on the rationale, justification and aims of the current study, including the decision to adopt a qualitative approach.

1.1 Background - How this study evolved

When embarking on this research, I brought to it my own experiences, values, ethics, attitudes and assumptions: therefore, by adopting a first person rhetorical writing style I can demonstrate how I inhabit the research process. By positioning myself within the process, I was able to get closer to the experiences of the participants. My interest and relative expertise within this field was informed by my experiences of working in roles such as Support Worker, Registered Learning Disability Staff Nurse, and Charge Nurse working alongside inpatients with autism.

More recently, my experience of working as a Clinical Reviewer in Clinical Treatment Reviews (CTRs) under the Transforming Care Agenda (NHS England, 2015) has exposed me to many cases of people with ASC who have been inpatients for long periods of time. Usually, people are referred via NHS England with a request for a CTR, which takes one full day to complete and comprises a multi-disciplinary panel reviewing cases. Often, inpatients have been referred to NHS England and have requested a CTR if they have been in hospital (i.e., inpatient mental health, learning disability or autism unit) for a period of more than one year. If the inpatient is considered to be a child or an adolescent, then the period of time before they are entitled to a CTR is less than three months. Under the leadership of the Clinical Reviewer, the panel provides a

comprehensive review of the patient's clinical case and agrees recommendations which encourage a discharge plan from hospital as soon as is feasibly possible. Additionally, CTRs are used to prevent admissions, and they thus help to reduce the number of people going into hospitals. For example, of the 552 Community CTRs recorded between April 2016 and January 2070, the outcome decision not to admit was almost three out of four (n=403) reviews. A CTR cannot take place without the inclusion of an *expert by experience* i.e., a person with a learning disability or autism, or a family carer, with the lived experience of services: the views and expertise of those who have first-hand experience is recognised and highly valued by the Transforming Care Agenda (NHS England, 2015).

During these experiences, I have witnessed at first-hand the intense, poignant and powerful impact that the admission to hospital can have on a person with a diagnosis of an ASC. As I paused to reflect on these experiences and my own personal reactions, what I found to be most striking was the frequent heightened states of anxiety which were highly prevalent and overly expressed by patients during their admissions. Equally as vivid in my memory were the reactions of the frontline care team who were required to support the patient with ASC through this traumatic time and on many occasions, they struggled to understand their own observed responses to the patient's anxiety, which can include violence or aggressive outbursts, and they invariably responded in a negative way towards the patients with autism. However, without the benefit of knowledge and understanding of autism, or the potential for certain responses to situations which are the cause of the patient's anxiety, then there is little surprise that a negative response from the staff is an outcome. This is clearly far from ideal, and in my recent years as a lecturer and as a trainer in Autism, I have delivered training to hundreds of mental health practitioners, including nurses, support workers, clinical psychologists, psychiatrists and a range of therapists; and both I and my co-trainers/lecturers have been struck by the general lack of knowledge and understanding of patients with ASC. With admissions to mental health inpatient facilities on the rise (DoH, 2016), a great deal of work needs to be undertaken to ensure that mental health services are credible and safe for people with ASC. It is this relationship with my clinical background which I believe has led me to identify strongly with the subject matter of this thesis and to pursue this research; and such research could contribute well to an understanding and realignment of values to improve the inpatient experience.

a) My social constructionist stance

There are numerous epistemological, ideological and theoretical stances from which I could attempt to answer the questions raised above. However, I chose a social constructionist approach to influence my research. "Constructionism is an ontological position (often also referred to as constructivism) that asserts that social phenomena and their meaning are continually being accomplished by social actors" (Bryman, 2012, pp. 33). This position urges researchers to take a critical stance towards taken-for-granted knowledge, to appreciate that all understanding is culturally and historically specific, but that knowledge and understanding is constructed between people and therefore the primacy of language is the vehicle by which we understand and make sense of life (Creswell, 2013). Social constructionist approaches propose that meaning, experience and identity are constructed, and may therefore be understood, within the context of relationships, interactions and patterns of behaviour (Burr, 2003).

Creswell (2013) describes paradigms or worldviews, whilst others (Bryman, 2012; Mason, 2014) called them *epistemologies* or *ontologies* (Crotty, 2013): essentially, they are the general orientations about the world and the nature of research that the researcher holds. Before deciding upon a chosen epistemological stance for this current study, it was important to consider this study alongside others. Postpositivist assumptions have represented the traditional and scientific form of research and these assumptions hold true for quantitative research and therefore could be ruled out for this type of study (Creswell, 2013). Pragmatism as an epistemology arises out of actions, situations and consequences; it is not necessarily committed to one system of philosophy or reality and one can often see researchers using a range of methodologies, including mixed methods approaches to enquiry, to draw liberally from both qualitative and quantitative assumptions. The pragmatist researcher will apply multiple ways of extracting data as well as to analysing data. Whilst this paradigm would not be ruled out easily for this type of research, I felt that, as a relatively novice researcher within the field of ASC, and when considering the complexities that I expected to be presented with during the data collection and analysis stages, a more definitive approach and stance was more appropriate and was ultimately decided upon.

Personally, I am increasingly cognisant of the authority of language, from its ability to shackle and disempower individuals and groups, to reshaping understandings and thus liberating people. Having worked alongside people with intellectual disabilities who in many cases express very limited communication skills, I have come to realise the importance of language and how inhibition of language can strip a person's sense of autonomy and agency, leading to disempowerment and resignation.

Constructionist approaches assist the researcher to challenge and develop some of the existing research grounded in empiricism and seek understanding of the world in which they live. They develop some objective meanings of their experiences; these meanings are varied and multiple. This leads the researcher to look for complexity of use rather than the narrow meaning and in terms of practice, their questions become broad and general so that the participants can construct a meaning to the situation, a meaning typically forged in discussions or interactions with other persons (Creswell, 2013). In this study the construction of understanding and meaning is influenced by the service user's views of themselves, their identity, their relationships and experiences, as well as by the beliefs held about them by others. Strauss and Glaser (1975) provided a good example of using a social constructionist stance when observing the organisation of a psychiatric hospital. Instead of taking the view that order within the hospital was a pre-existing characteristic, they argued that it develops within a constant state of revision. Further, rules that existed in the hospital, which appeared to be rigorously imposed, were less so and described as much less like commands, and more like general understandings. Therefore, the social order of the hospital was an outcome of agreed-upon patterns and action that were products of negotiations between the different parties involved, i.e. doctors, nurses and patients. The social order of the hospital is in a constant state of change in that numerous agreements are continually established, renewed, reviewed, revoked and revised.

Similar points have been made about the idea of culture. Instead of seeing culture as an external reality which acts on and constrains people, it can be taken to be an emerging reality in a continuous state of construction and reconstruction (Bryman, 2012). Therefore, it cannot be expected that one cultural

understanding can provide a perfectly applicable solution to any problem people have to solve during the day they must remake solutions which are adapted by their understanding of the new situation and what has changed from their pre-existing cultural understanding. For example, on one day the cultural understanding of an inpatient unit could be completely different from the next, to be able to flexibly exist within the new situation and there would be elements of these changes that would be difficult to understand and cohabit with particularly if the inpatient has an ASC. However, it could be argued that because elements of the organisational infrastructure do not change, i.e. the physical building remains the same, the beds will usually be in the same place, the nurses' station, the room and other rooms for therapeutic sessions and activities will be in the same place. Equally, nursing shift patterns, doctors' rounds and scheduled sessions are generally consistent, all of which could help patients establish much-needed structure and routine, essential to feel safe and secure. Interestingly, the above conditions could be perceived as social constraints which could frustrate neurotypicals but could potentially have the opposite effect on inpatients with ASC. Constructionism invites the researcher to consider the ways in which social reality is an ongoing accomplishment of social actors rather than something external to them.

Constructionism also suggests that social actors use categories to help them understand the social world. The categories do not have built-in essences; instead, their meaning is constructed in and through interaction. For example, a category like 'authority' might be treated as a social construction and rather than being perceived as a distinct and permanent characteristic of a person's personality, authority is construed as something whose meaning is built up during interaction which can differ depending on the interactional situation (Denscombe, 2004). Within the context of this study authoritarian approaches to managing the inpatient environment were witnessed by the participants, it was also noted that the presence of other staff could influence their authoritarian stance. Perhaps this shift of approach was a result of the social actor, in this case the nurse, attempting to give the impression of authority in front of their colleagues because this was the norm or perceived expectation. Similarly, the patients themselves exhibited different categories in different situations, e.g. 'masculinity' was a category that was demonstrated by social actors/inpatients when they required it to be and could be interpreted as a defence mechanism perhaps or a way of fitting in with other inpatients who displayed similar traits.

As a constructionist I have listened to the participant's realities as they constructed them and the implications of those constructions for their lives and interactions with each other. Through their own experiences the participants have created their own individual personal constructs around what it means to experience mental health problems and be admitted to an inpatient unit and how they responded to the challenges posed. Similarly, I have acknowledged that the participants would all have had different experiences and I have tried to be mindful of my previous experience of witnessing inpatient admissions and what I previously perceived the realities to be. The constructionist philosophy fits comfortably with my quest to capture the authentic accounts of the participants' experiences and it is through this phenomenological lens that this research has been undertaken.

1.2 Autism and psychiatric comorbidities

Comorbidity is defined as the co-occurrence of two or more disorders in the same person. A comorbid condition is a second order diagnosis, which offers core symptoms that differ from the first disorder (Mannion & Leader, 2013). People living with ASC are particularly vulnerable to mental health problems such as anxiety and depression, especially in late adolescence and early adult life (NAS, 2018). Ghaziuddin et al (1998) found that as much as 65% of their large sample of patients with Asperger syndrome presented with symptoms of psychiatric disorder e.g., depression and generalised anxiety disorders. More recently, Bakken et al (2010) found that 53% of their sample of people with autism and intellectual disabilities suffered from a psychiatric disorder. Bradley et al (2004) compared psychiatric and behaviour disorders in individuals with severe intellectual disabilities, with and without ASC, concluding that individuals with ASC presented four times as much psychiatric comorbidity as those without. Joshi et al (2013) found significantly higher levels of psychiatric comorbidity in ASC populations when compared with non-ASC populations, including major mood/depressive disorders, bipolar disorder and psychosis. Particularly high were multiple anxiety disorders including phobias, separation anxiety disorder, agoraphobia, social phobias, obsessive-compulsive disorder, post-traumatic stress disorder and generalised anxiety disorders. Mannion et al (2013) found that 46% of individuals with ASC had a comorbidity of psychiatric disorder, with this number rising to 79% in individuals who also had an intellectual disability; a potential reason is that those people with ASC who are more high functioning intellectually have greater potential in finding coping strategies to deal with chronic anxiety levels which impact upon their mental well-being. Simonoff et al (2013) estimated a figure as high as 70% of 12-year-old children with ASC who met the criteria for at least one psychiatric disorder, while 40% of their sample had two or more additional disorders.

The high prevalence of psychiatric comorbidity in ASC is largely due to the constant anxious state of mind with which many with the condition live their lives. People with ASC will go to great lengths to minimise stress for themselves and create a very predictable world in which they feel confident and can function adequately. This may well mean isolating themselves for long periods and detaching themselves from, as one participant described, '…*the most unpredictable element of society, namely people*'. This can have a significant impact upon their mental wellbeing; additionally, most people with ASC fail to eradicate stress from their lives and over a sustained period this can cause acute and chronic mental and physical illness (Steensel et al, 2012). It is crucial to understand the aetiology of anxiety within ASC populations: a great deal of anxiety experienced by those with ASC can be linked to the core features of the condition itself. Although this current study mostly considers the psychological effects of anxiety, it is also important to consider the diverse manifestations of stress, including vulnerability to physical illness.

a) Stress and physical illness

Stress has been associated with a wide range of biomarkers, none more damaging than cortisol, a steroid hormone activated as a response to stress. Cortisol is produced in humans within the adrenal cortex and the adrenal gland. It functions to increase blood sugar through gluconeogenesis which suppresses the immune system, representing mechanisms that are believed to be the cause of a range of physical health problems (D'Andrea, 2011). Exposure to chronic stress has been associated with an increased risk of a wide range of chronic physical conditions where effect sizes are similar in severity to stress-consequent mental health outcomes (Atwoli et al, 2016).

The physical health conditions affected by the release of cortisol comprise poor bone growth and repair, abnormal thyroid function, loss of muscle mass, irregular menstrual periods, arthritis, respiratory disease and Addison's disease (Atwoli et al, 2016). Suglia et al (2015) additionally suggested that cortisol also impacts upon cardiovascular disease, pulmonary problems, type II diabetes and digestive problems.

A participant in this current study explained during interview that, due to her perpetual experience of stress, her General Practitioners (GPs) diagnosed her with Addison's disease as her symptoms included low energy, joint pains, difficulty waking in the morning, weight loss, diarrhoea and electrolyte deficiencies. She also suffered from regular headaches, which her GP also associated with her high levels of stress on a daily basis. Many of the participants in this current study have reported high levels of stress, which has been an ongoing issue for them, normally starting in childhood.

b) Autism and violence

It is not suggested that people with ASC are more aggressive or violent than people without ASC, and most people with an ASC diagnosis will lead their lives very peacefully. However, according to Ambler (2015), specific traits relating to the core features of ASC such as social functioning deficits, life events causing change and intolerance of uncertainty, mood disturbances, impulsivity, poor emotional regulation and poor coping skills can contribute to violence, aggression and offending when people with ASC are in certain situations and circumstances which they cannot control. Experiencing poor emotional regulation can cause an inability to quickly and appropriately inhibit the expression of strong emotions, and this may manifest in poor impulse control, aggression and negative peer interactions.

Im (2016) reviewed prevalence studies, case studies and review articles of violence perpetration towards others and property within ASC, from 1943 until 2014. The evidence suggests that individuals with ASC may engage in violence and aggressive threats and actual physical harm towards others, which could lead to injury and damage to property (Im, 2016). Im (2016) noted that methodological issues in prevalence studies included selection biases due to their recruiting from forensic services, and limited numbers of studies that included comparison groups, i.e. groups of those with ASC and those without. Within community studies, there was no significant difference in rates of violence between ASC and non-ASC samples (Mouridsen, Rich, Isager & Nedergaard, 2008).

Im (2016) suggested that impaired theory of mind abilities, i.e. one's ability to understand the mental state of others, to interpret social intentions and to understand social nuances, also contribute to the increased likelihood of violent acts. Such impairment may cause confusion and feelings of being overwhelmed, especially when under duress and, pressurised by social information, people with ASC cannot process and may not recognise the emotional impact of their actions on others.

Lerner et al (2012) acknowledge that an influential factor to aggression within ASC is the propensity to struggle with moral reasoning. Moral reasoning is a social cognitive process by which a person judges an action to be worthy of positive or negative responses. This can be viewed as a fundamental in evaluating our own actions and the actions of others.

Studies that have investigated the severity of violence and aggression in individuals with ASC have yielded mixed results. Ambler et al (2015) compared adolescents with ASC with their non-ASC peers: self-report measures of anxiety and anger and teacher ratings of behaviour were significantly higher within the ASC sample. Teacher-related verbal and physical aggression was also reported to be higher within the ASC participants. May et al (2015) found in a sample of children aged 7 to 12 years that aggression measured on the Connors Third Edition scale (Connors, 2003) was significantly higher in children with ASC than in their non-ASC counterparts.

Studies that investigated if a comorbidity of an intellectual disability had an impact upon the prevalence of violence and aggression also yielded mixed results. De Giacomo et al (2016) found no differences in aggression between children with ASC who were high functioning and low functioning, or verbal and non-verbal, whilst Adler et al (2015) found that individuals with ASC and comorbid intellectual disability were more likely to meet the criteria for drug refractory aggression than those without intellectual disability.

1.3 Deconstructing the problem: Policy, Power and Choice

The question emerges: to what degree are national strategies impacting upon the lives of people with ASC? To explore this question, attention must be focused and attuned to the idiosyncratic processes of enabling choice over issues of personal concern. The problems of translating policy goals of choice and autonomy into practice for people with ASC have been hindered by poor communication, discriminatory attitudes and a lack of understanding of this vulnerable group (DoH, 2009). The Autism Act (2009) discusses the need for support to match individuals, rather than people with autism being expected to fit into existing services which tend to create dependency by focusing on incapacity, inability and risk. However, since the implementation of the Autism Act (2009) little has changed in the type of service provided to people with ASC who have the need for inpatient mental health care and determining the location of care and treatment largely depends upon whether they have an intellectual disability. With very few specialist ASC services available, the majority of those with an intellectual disability who need inpatient care will be referred to inpatient learning disability services. Those who do not have a verified intellectual/learning disability will have their mental health inpatient needs met by generic mainstream psychiatric services.

The Autism Strategy (DoH, 2010) demanded higher quality services, particularly for those who have trouble accessing services that meet their needs. The report discussed the ability of 'personalising services' i.e., making services to fit everyone's needs, not just those people who fit specific criteria. Despite best efforts by some services, and there are examples of person-centred care and reasonably adjusted services, an experience of mental health inpatient care for someone with ASC is described by many of the voluntary candidates in this study as being '*poor*'.

From an international perspective, the World Health Organisation (WHO) (2013) declare a global consensus to urgently strengthen strategies for comprehensive and integrated mental health services to care for people with ASC, in alignment with the WHO Comprehensive Mental Health Action Plan 2013-2020 (WHO, 2013). Although specific global data on people with autism being hospitalised for psychological reasons is not

available, autism is included within the Mental Health Atlas Series (WHO, 2017) which is considered to be the most comprehensive resource on global information on mental health and is an important tool for developing and planning mental health services within countries and regions around the world. The report highlights that most children with intellectual disabilities, mental health problems and autism still live in 'Asylum-type institutions', with Europe having the highest statistic of over 70% (WHO, 2017). Asylum-type institutions were highly prevalent within lower income European countries, and community facilities were more developed in middle and high income European countries (WHO, 2017).

People with intellectual disabilities and/or autism who reside within Europe's lower income countries should expect to experience marginalisation, and government policy which is focused on segregation in education, employment and housing. Although there are reported movements towards integration and inclusion including day-care centres, occupational therapy workshops, vocational training, group times, supported employment and sheltered employment, these are at their early stages of development only. Health provision for people with intellectual disabilities and autism remain the domain of the specialist services which are attached to the long-stay hospitals (WHO, 2017).

In the USA, services to persons with intellectual disabilities and autism are managed at the State level. These services vary greatly in quantity and quality from State to State. The national government plays a major part in financing services provided to persons with intellectual disabilities and autism, but it has a modest role in specifying the nature and quality of the services provided by the States. In Canada, services to persons with intellectual disabilities are completed on a Provincial level. The federal government makes health transfer payments to the Provinces in the yearly budget, but these are administered and prioritized on a Provincial level. There is not a national federal policy for the care of individuals with intellectual disabilities and autism in Canada. Consequentially, services vary considerably, with inpatient care being more highly prevalent within lower-funded localities, and improved community facilities more likely to be in operation within higher-funded areas of the country. Additionally, there are no set curricula for professionals working in intellectual disability or autism across Canada. Instead, local pockets of interests within university settings offer courses in disciplines in the intellectual disability and autism field; however, these are not mandated by either a Provincial or federal training mandate, which again causes significant variation in quality and quantity (WHO, 2017). The message used consistently within WHO publications regarding guidance for care within the autism services is to avoid institutionalisation/hospitalisation wherever possible (WHO, 2010; WHO, 2017).

1.4 The history of mental health inpatient units

The term 'inpatient service' is used to describe any inpatient service to which adults may be admitted receiving support for mental health problems. The term 'inpatient admission' refers to any period of stay within such a service. However, before the current literature on mental health inpatient services is explored, it is important to consider their historical context, and what we now refer to as Mental Health Inpatient services have had a long and complex history.

Wolfensberger (1972) summarised some of the terminology used historically to describe this group of people: *subhuman organism*, *unspeakable object of dread*, *menace*, *object of ridicule*, and *eternal child*: it can be

argued that these terms are indicators of people's attitudes at the time and marginalisation of a subsection of the population. Society seemed very willing to listen to solutions to the 'problem' of the feeble minded, which by many accounts would allude to anyone with psychological problems including alcoholics, those with dementia, the learning disabled, those people with mental health conditions, and many more (Gates, 2007).

Foucault (1961) examined the way in which society perceived people with psychiatric conditions, insanity being a social construct, i.e. insanity does not have an absolute identity in itself but is defined as a society wishes to define it. As a result, myths and stories, often negatively biased, were attached to this group. His vision was to learn from history and to be analytical about the way society should care for its mentally ill. He saw the notion of institutionalisation and shutting people away from society as purely brutal and pointed to previous times in history where people who were different were more likely to be revered in society, or at very least allowed to be seen so that others could judge for themselves.

This institutional model became increasingly popular in the early to mid-1800s and led to a re-naming of 'madhouses' to 'asylums' i.e. sanctuaries/asylums grew in popularity, with bed capacity in the UK peaking at 154,000 beds in the 1950s (Fakhoury & Priebe, 2007). During the 1950s, criticism of the asylums had taken hold, their being described as 'total institutions' (Goffman, 1961) which induced dependency and institutionalisation. By this time, asylums were becoming overcrowded, often being used to house petty criminals or people within society who were seen as morally defective e.g. mothers who had children outside of wedlock. Reports of abuse and mistreatment were increasingly frequent (Fakhoury & Priebe, 2007).

In the 1960s, a steady process of deinstitutionalisation began to take place, initially announced in the UK by Enoch Powell in his 'Water Towers Speech'. Speaking to the National Association for Mental Health in 1961, the then Minister of Health, Enoch Powell, outlined his desire to see greater community care provision for mental health patients. Powell estimated that within 15 years the number of psychiatric beds could fall by 75,000 and that many of the existing institutions would need to close. Powell described the buildings as '*not to purpose', isolated* and *daunting*. He instructed society to try to alter its mentality about mental hospitals and their patients and did not underestimate the challenges and resistance with which the movement to close hospitals would be met (Powell, 1961).

The Mental Health Act (1959) repealed the Lunacy and Mental Treatment Acts of 1890 to 1930, and the Mental Deficiency Acts of 1913 to 1938 to make fresh provision for the treatment and care of mentally disordered persons; it has been described as influential in changing society attitudes and in accelerating the pace of change towards eventual closure of long-stay hospitals and to a shift to community care. Although it took the publication of the two White Papers entitled 'Better Services for the Mentally Handicapped' (1971) and 'Better Services for the Mentally Ill' (1975) to begin the transition to community care in earnest, it was not until the 1980s that the first hospitals closed (Ellis, 2017).

As the inner-city workhouses of London closed, people were relocated to the country, and the immediate countryside around London (sometimes referred to as the 'green belt') became the chosen location for many new long-stay hospitals. The economic impact of the closure programme on the Home Counties was considerable: they acquired an over-representation of both learning disabilities and mental health long-stay

institutions, and consequently had to rehouse vast numbers of former inpatients, both within the community and in residential care.

The impact on Hertfordshire was comparable to other Home Counties: Leavesden Hospital in Watford was the last to close, in the late 1990s, due to the huge undertaking of rehousing its 3,000 inpatients. The smaller hospitals of Hill End, Cell Barnes, Shenley and Napsbury closed sooner, and land on which Harperbury Hospital was situated has been used for building new inpatient facilities for people with learning disabilities, autism and mental health illnesses.

Psychiatric hospitals became 'Psychiatric Inpatient Units' and aimed to provide short-term care for people with acute mental health episodes. The implementation of the 'NHS and Community Care Act' (1990) altered funding structures and resulted in more short-stay admissions, relocating mental health care within the community. Psychiatric institutions have always been places of paradox, being viewed as acting to control those individuals thought too precarious or dissimilar to remain free members of society, but also as providing sanctuary, a '*brick mother*' (Rey, 1994 pp 65). Bentall (2009) suggests that these historically situated dual roles continue in modern services, where elements of both control and care are expected and the balance of these roles is continually changing, with social and political influences serving to initiate changes of attention. In more recent years, following the move to community care, the balance in hospitals has shifted to place greater value on the role of risk management and less on developing an understanding of, or resolution to, people's problems (Radcliffe, 2006; Bee et al., 2006). As more people with more acute needs, who pose greater levels of risk to themselves and/or others, are admitted to units, so staff time is increasingly spent striving to manage these risks and the associated administrative paperwork (Hall, 2004; Bee et al., 2006).

1.5 Contemporary inpatient services for people with ASC

Inpatient services for people with ASC should ideally offer short-term, highly focused assessment and treatment of behavioural problems and mental health issues within the context of the wider care pathway. Three models of inpatient services are currently available within the UK to complement and support community services and are provided by both the public and private sectors (DoH, 2010).

- Firstly, the title ***mainstream*** is used to explain inpatient care, which is provided by mainstream acute adult mental health services where service users are supported by staff trained from within a generic adult mental health model (DoH, 2016)
- Secondly, the term ***specialist learning disability*** inpatient services are provided by dedicated multidisciplinary learning disability professionals i.e., staff within the services who have undergone learning disability training and have received additional training specific to the needs of the population, for example, in challenging behaviour or communication support strategies. Specialist services are sometimes located some distance from people's homes or within purpose-built units in the grounds of old long-stay hospitals (DoH, 2016).
- Thirdly, small numbers of ***specialist autistic*** inpatient services have emerged since the statutory legislation within the field of ASC, i.e., the Autism Act (2009) and the Autism Strategy (2010), although a few were established before this time. Commonly, these units employ learning disabilities and mental health practitioners; for the most part they are within the private sector and will treat people with and

without an Intellectual/Learning Disability (DoH, 2016). The National Autistic Society offers an Autism Accreditation Certificate which evidences that an organisation is committed to understanding and to setting the standard for autism practice; NAS is the only organisation within the UK to offer such an accreditation process which is rigorous and assures quality for any service that is claiming to be a *specialist autistic* service. These can include adult services, colleges, inclusion units, local authorities, playgroups, prisons, schools, inpatient units, and others (NAS, 2018).

Each model of inpatient service provides a service differing from the next. The stark difference between the generic mental health inpatient service and the others is that there is greater emphasis on getting people back into the community as quickly as possible, whereas within the *autism* and *learning disability* Services there is a managed expectation that the discharge process will take longer and hence locating the most appropriate community facility is problematic (NHS England, 2015). Specialist *autistic* services and specialist *learning disability* services attract criticism, are accused of 'bed blocking' (where patients who may be considered ready for discharge, remain in hospital because there is a lack of community provision for them to go to). This results in service users experiencing longer admissions to specialist services similar to those experienced before the closure of long-stay hospitals and remaining in hospital longer than is necessary (Slevin et al, 2008). This disruptive timeframe is supported by findings that the average length of admissions to *mainstream* units tends to be shorter (Chaplin, 2004; Hall et al, 2006).

All model of Inpatient units in the UK employ a psychosocial model of care. Psychosocial support involves the culturally sensitive provision of psychological, social and spiritual care (Jury et al, 2019). Nurses play a unique role in supporting patients; by building dialogue nurses can begin to understand how patients view themselves as individuals, what is important to them, and how their relationship with others may affect their decisions and their ability to live with those decisions during their treatment and beyond (Barlow et al, 2000). Good communication and assessment skills are essential to building a rapport with patients and can help the nurse develop a clinical relationship with the patient and their family.

Providing good psychosocial care is dependent on good communication skills, both verbal and non‐verbal. Communication in the context of psychiatric care includes general interactional skills to convey empathy and support and to provide medical information that is understood and retained. A relationship of health care providers with patients is based on trust, being open and honest, understanding, being present, respect, setting mutual goals and providing social support. This relationship can be an important support and buffer for mental health patients experiencing distress (Butler et al, 2014). Mental health nurses strive to make relationships with inpatients with or without autism, lots of the nurse's role being psychosocial care and provision of resources and education particular to the individual patient's needs. To be able to do this effectively nurses need to create an environment in which the patient feels comfortable and safe to relate and communicate (Jury et al, 2019).

Bowers et al (2009) developed a conceptual model of aims and functions of acute inpatient psychiatry, drawing on a literature review of the reasons for admission to acute inpatient services (Bowers, 2005) and qualitative research with key inpatient staff (Bowers et al, 2005). The conceptual model (Bowers et al, 2009) identified a range of elements of operation within inpatient services. Management in inpatient settings involves

not only delivering interventions to address admission problems, but also providing basic living needs such as food and access to outside space, a daily routine and activities suitable for different patients. Treatment can involve more intensive or potentially risky interventions than are possible in the community because closer monitoring and more sustained staff presence are possible. Inpatient care provides a setting where coercion has a legal basis for detained patients and the social context of a hospital with rules and customs, staffed continually by nurses and doctors, helps encourage compliance through a legitimate authority. This can involve direct containment of patients using seclusion or continual staff presence to observe the patients or forcibly administering treatment. Finally, inpatient care provides continuous staff presence: tasks are less prescribed by staff availability and opportunities for interventions can be identified and capitalised on whenever they present. The close proximity of staff and patients in inpatient settings and spending time with patients not always in a goal orientated way allows relationships to develop which may potentially aid assessment and persuasion to accept treatment or be therapeutic in their own right.

The recovery model is central to the mental health inpatient nurse strategies and approaches, it indicates that despite the symptoms and disabilities, mental illness need not irrevocably impede people's life goals and psychological well-being (Young et al, 2018). Those who are dealing with their recovery consider themselves to be in recovery rather than recovered, implying a developmental process. Such definition of recovery doesn't exclude the possibility of having further psychotic episodes or other experiences of mental distress. It is about managing the experience and finding ways of dealing with crisis that may occur (Baksheev, 2012).

In 2015, NHS England acknowledged that without evidence of the recovery model demonstrating the same success with patients with ASC/learning disabilities and mental illness as it has with mental health patients without ASC and/or learning disabilities, they published a new national plan under the *Transforming Care Agenda*, to ensure that people with ASC and/or a learning disability and complex needs do not inappropriately *live* in inpatient units. The plan proposed a 50% reduction in the number of inpatient beds, so it was inevitable that some units would close altogether. The units that have been targeted by this plan exist in both the NHS and the private sectors (NHS England, 2015).

The ongoing closure of mental health inpatient services has received political and media attention recently. On *Prime Minister's Question Time,* Jeremy Corbyn (Leader of the Opposition) challenged the Prime Minister over failings in mental health services, saying:

> *'Too many of our fellow citizens suffer alone because there are not enough staff to help them at a moment of crisis'* (British Broadcasting Corporation, 2018).

The Labour leader accused Prime Minister Theresa May of failing to live up to the government's promise to treat mental health as seriously as physical health. '*Despite legislating for parity of esteem, the government has failed to fund it*,' he said (British Broadcasting Corporation, 2018). Jeremy Corbyn urged the Prime Minister to ensure that a fair share of any new funding should be allocated to mental health provision, by '*ringfencing NHS mental health budgets to support those going through a mental health crisis, at a time when they most need our help and our support*' (British Broadcasting Corporation, 2018).

There is clear evidence that people with ASC, with or without a learning disability, are vulnerable to bed shortages. The allocation of inpatient beds to those who desperately need them is further complicated by long admissions in inpatient units. All three of the service models discussed above can have occupants holding beds for long periods, but particularly within specialist autistic and learning disability services (NHS England, 2015). An additional impact on these lengthy admissions was highlighted by some participants in this current study, who indicated that they deliberately sabotaged discharge plans because of their fear of leaving a place with which they had become familiar and where they had begun to trust the people who cared for them.

The social constructionist perspective argues that choice and control arise in the manner with which people talk to each other. Emancipatory and disabling discourses emerge through options being offered and preferences being expressed, how such information is presented, and how spaces are opened for people in which to express their preferences and how such spaces are closed off (Creswell, 2013). Expressions of recognition of preferences in everyday interactions are acutely important for people with communication difficulties, who may have restricted access to exercising control over their lives (Beardon & Worton, 2011). Government policy must not just promote choice, autonomy and independence as solitary aspirations, but act within the context and understanding of the difficulties of learning and communication.

The problems of translating policy goals of choice and autonomy into practice for people with communication problems have been discussed by commentators (DoH 2016, Hall et al, 2006). Obstacles include poor communication strategies, discriminatory attitudes and a lack of understanding of this vulnerable group (DoH, 2010).

1.6 Narrowing the focus

The challenges facing staff in mental health inpatient units is where the focus of this current research begins to emerge. Both the Autism Act (2009) and the Autism Strategy (2010) offer a number of recommendations about the care and support that adults with autism should receive to enable them to access mainstream healthcare services. These are similar to the acknowledged improvements to public services that have already occurred for people with learning disabilities and mental health problems. There has been feedback to suggest that people with autism are missing out due to not being able to fit into either the learning disability or the mental health models of care (Public Health England, 2016).

> *'I want staff in health and social care services to understand that I have autism and how this affects me'.* (Contributing service user, Department of Health '*Think Autism*', 2014)

The key component to the recognition and personalisation of people's individual needs is that services can be configured to meet them. Luke Jackson spoke at an Autism Conference in 2016 and outlined his vision or dream for services and people to change drastically and for their understanding of autism to improve considerably:

> *"I believe that the greatest contributing factors to mental ill health for people with AS is a lack of understanding of the needs of the individual alongside a lack of willingness, or inability, to adjust the environment to suit those individual needs. If the world changed overnight and, all of a sudden, the general public understood AS and adapted their roles to suit individuals, then I am convinced that mental health problems for people with AS would pretty much disappear. Of course, this is unlikely to ever happen – but gradually, with a greater understanding, lives of those with AS should improve. I would like to think that any professional who reads this will be moved to change their practice to better suit the individual and, thus, reduce the potential for mental health issues."* (Jackson, 2016, unpublished conference paper).

If 'personalised services', which promote enablement as presented within the Autism Strategy (2010), are to be realised then there is a need to develop the skills of frontline staff within inpatient units. Policymakers recognise that even with making service structural changes and increasing the types of services available, without a sensitive and skilled workforce these broader values will not be achieved (DoH, 2010). Therefore, it follows, in my opinion, that the policy change must address experiences of choice and power at a one-to-one level, namely the relationship and interaction between the people using the service and those working in it. If real, meaningful and profound changes are to be accomplished then this dynamic is crucial. If 'person centred care 'is to be a meaningful aphorism, as opposed to a superfluous promotional slogan, then the spotlight must be switched to the value, emotional and meaningful insights of the service users.

Much of the face-to-face care experienced by this study participants have been conducted by Registered Mental Health Nurses (RMNs) and support workers. The Autism Strategy (2010) stipulates that services which care for people with ASC must ensure that their staff are adequately trained: I have trained many mental health inpatient practitioners on either one-day or two-day workshops/training days; the challenge for the trainer in these instances is how to impart sufficient knowledge of ASC within a very restricted timeframe. Understanding ASC has been a lifelong journey for me, and I am consistently learning new information and developing new understandings, which have been challenged and re-developed on many occasions. The NHS, Local Authority and other services belonging both to private and voluntary sectors send their staff for ASC training and do so with good intentions and to meet the requirements of the Autism Act (2009). However, it can be argued that this is a tokenistic gesture and cannot seriously prepare practitioners to work with people with ASC in a way that is informed and that can impact positively upon the inpatient experience.

Equally, it is important to consider the number of theory and practice-based hours that are devoted to ASC content within a pre-registration Mental Health Nursing curriculum, compared with that of a Pre-Registration Learning Disabilities Nursing curriculum. Student nurses undertaking a learning disability qualification will encounter considerably greater content on ASC in their curricula. Alongside the theoretical component of their studies, they will work with many people with ASC when in their clinical practical placements. Kennedy (2015) suggests it is an ongoing concern that registered Mental Health nurses are attempting to meet the mental health needs of patients with ASC within mainstream mental health inpatient services, without ASC being an integral part of their theoretical Nursing curriculum.

1.7 Conclusion

This introductory chapter conveys the predominant focus of research to date into the mental health inpatient experience for patients with ASC, the reasons why ASC and mental ill-health commonly co-exist, how the activity or service model impacts upon their experiences and the philosophical underpinnings which have been considered in driving the focus of this current study forward. It also argues the case for constructionism which will be addressed further in the methods chapter.

This current study aims to elaborate on the inpatient experience reinforced by the theories belonging to two critical sociologists: Foucault (1972) and Goffman (1961). Foucault (1972) argues that power in a mental hospital is an aspect of interrelationship, or social interaction between human beings. One person will have the capacity to have an impact on another's thoughts, thus exercising their power perhaps because of a heightened display of knowledge. People will not always submit to the exertion of power from others; often resistance is shown which suggests that they are able to act with autonomy. However, the impact of power between people is often inhibited by their environments, for example doctor-patient or nurse-patient relationships provide clear examples of power existing within the roles of healthcare professionals due to their status and heightened knowledge. Foucault (1972) suggests that the exercise of power can significantly reduce or limit the actions of others and restricts their freedom to act or to resist. Psychiatric patients are in an environment where their movements are limited, and their mental health is fragile, impacting upon their confidence and capabilities: they have little or no knowledge of what is happening to them or how long they will be there, and they are resigned to putting their trust in the people who are looking after them. Foucault (1972) would argue that these people are one of the most vulnerable societal groups and therefore would potentially hold the least power in their relationships with others.

Goffman (1961) argued that stigma within society is caused by psychiatric diagnosis, i.e., once you have been labelled as having a mental health problem, it is especially difficult to have your views, opinions and experiences taken seriously. Stigmatised patients frequently become self-fulfilling prophecies: institutional life demolishes the identity of an individual, and the experience of being a patient in a mental hospital has a more profound effect on the individual than their actual psychiatric illness.

Weiss et al (2006) described stigma as being typically a social process, experienced or anticipated, characterised by exclusion, rejection, blame or devaluation. It results from experience, perception or reasonable anticipation of an adverse social judgement about the person or group. Goffman (1963) recognises that the stigmatisation of a person is not the property of the person themselves but instead belongs in the pattern of social control that is exerted upon them by those around them. The stigmatised self therefore is the product of an institutional relationship with performances within a mental hospital. Scambler (2009) describes stigma as an ontological deficit, which reflect infringements against norms of shame, fuelled by the discrimination of others on grounds of being imperfect. Giddens (1991) argued that stigma can impact upon 'ontological security' and a stable mental state which is derived from a sense of continuity regarding the events in one's life i.e., a sense of order which is reliant on people's ability to give meaning to their lives. 'Meaning' is described by Elias and Dunning (1986) as experiencing positive and stable emotions, by avoiding chaos and anxiety. If an event occurs that is not consistent within the meaning of an individual's life, for example, a period of poor mental health and the consequential admission to an inpatient unit, then this may threaten that

individual's ontological security. The work of Goffman and Foucault, and other commentators upon the theories of power and stigma in mental health care, has provided this study with a theoretical framework and an established grounding from which this study has grown.

1.8 Research Question

Recognising that individuals with ASC have increased vulnerability to mental health difficulties, coupled with my own experience of the lack of professional readiness to meet the needs of those with ASC within an inpatient setting, this thesis will aim to examine the following research questions, keeping in mind the current social and political contexts surrounding both ASC and mental health care, and the development of mental health services over time:

Principal research question: How does admission to a mental health unit impact the psychological well-being of adults affected by Autism Spectrum Conditions?

Primary research aims:

- To explore the experiences of adults affected by ASC who have been admitted to a mental health inpatient unit.
- To explore how adults affected by ASC make sense of their thoughts and feelings in relation to having been treated as an inpatient.

It is hoped that a study addressing the lived experiences of inpatients with a diagnosis of ASC will lead to outcomes that help to better inform service commissioners and developers about the needs of individuals and how care is better when personalised.

The next chapter provides an in-depth review of relevant literature relating to the current study's research question and aims. A comprehensive and thorough search of relevant literature, including grey literature, is critically appraised and a quality standard framework is applied to ensure that research considered within this current thesis are rigorous and contribute to existing knowledge and understanding of the phenomenon. As well as exploring the perspectives of service users, the studies within the literature review consider the views of their carers and frontline caregivers within mental health institutional settings.

The areas of interest which are considered within the papers that met the criteria for this study include the inclusivity and feelings of empowerment, which were rare amongst participants; the feelings of vulnerability and lack of safety, or relationships with support and nursing staff; indifferent relationships with fellow patients; the intimidating physical and social environment of the inpatient units; the negative perceptions of their admissions and the treatments they received. The grey literature portrays problems for services more generally for people with ASC, including health and social care provision which appears to be failing to keep them out of hospital and supporting them to maintain positive mental health well-being.

Chapter 2: Critical Literature Review

Chapter overview

The literature review for this study is a comprehensive summary and critical appraisal of the literature that is relevant to the research question and research aims (section 1.8), examining the key areas encapsulated in the discussion that was presented in Chapter 1. This chapter will initially provide an overview of the strategies that were undertaken to ensure that a comprehensive and thorough search was conducted to facilitate the retrieval of relevant literature, including grey literature, within an appropriate timeframe. This will be followed by a mapping of the literature retrieved and a critical discussion of each key area underpinning and influencing the theoretical foundation of the research. This chapter also includes the theoretical and methodological contributions to research in the field to ensure the selection of a research design which is of relevance to the conceptual approach.

2.1 Literature search strategy

An extensive literature search was required to understand the range of seminal texts, research studies and supporting literature to ensure full coverage of the subject area. At the outset of this doctoral journey, my understanding of inpatients with ASC's experiences of mental health inpatient care was limited to my personal observations and experiences. In order to develop a pertinent research question, I sought to connect with the distinct nature of this experience by a critical reading of the relevant literature. A preliminary search was undertaken in 2014 to identify the possible range of relevant search terms in preparation for a robust literature review. Further literature reviews were undertaken on a regular basis until June 2018 to ensure current research was included. Furthermore, since the first submission of this thesis in 2018 further studies have come to light, some of which have been considered within this review, the new literature was engaged with using the same approach and model that has been used for the previous sections of the literature review, as highlighted in the PRISMA flow diagram in figure 2.1.

Search engines such as Google Scholar, PubMed, and online databases Scopus, PsychINFO and the Cumulative Index of Nursing and Allied Health Literature (CINAHL) were used to search the period from 2002 to 2019 to allow for ensuing discussions to incorporate the Autism Strategy (DoH, 2010) and the Transforming Care Agenda (NHS England, 2015). Medical Electronic Subject Headings (MeSH) terms such as 'mental health', 'inpatient' and 'autism' were searched for, in conjunction with different phonetic word formations such as psychiatry, psychiatric, mental ill-health, mental well-being, autistic spectrum conditions, autistic spectrum disorders and abbreviations such as ASD and ASC, and sentences using words and terms such as 'lived experience' and 'inpatient' (Table 1). The Boolean operators comprised of AND, OR and NOT. All items were in English since the complexities of managing papers in multiple languages is beyond the remit of this thesis. The question: 'how does admission to a mental health unit impact the psychological well-being of adults affected by Autism Spectrum Conditions?' identified keywords that would cultivate the search. The combinations provided only a small number of hits and many of those comprised 'grey literature'.

Supplementary grey literature was gathered from a range of organisations which contributed to the research process, including policy documents, local service-side material and patient information from Hertfordshire Partnership Foundation Trust, 2016, National Development Team for Inclusion, 2012 & Asperger's team – Outreach, Hertfordshire County Council. According to Whitaker and Williamson (2011), a literature review is an organised investigation and interrogation of relevant material; the parameters that identify the search are a key component to the overall credibility of the literature review. Creswell (2013) suggests that the parameters of a search will eventually indicate the parameters of a framework that is produced by the literature reviewed.

Table 1: Keywords searched

Main keyword	Potential variations included:
Autism	**Autistic spectrum conditions (ASC)** **Autistic spectrum disorders (ASD)**
Mental health	**Psychiatry** **Psychiatric** **Mental illness** **Mental well-being**
Inpatient	**Lived experience**

All references from the literature review were stored methodically using a software system (Endnote version 8). Literature was continually reviewed throughout the research process, and small-scale studies as well as additional literature were uncovered with the help of networks developed throughout the doctorate journey, including attending and participating in relevant conferences.

2.2 Inclusion / exclusion terms

To be included in this focused review of the literature, studies were required to have qualitatively examined participants' subjective views and experiences of inpatient services, although studies utilising a mixed methods approach, or systematic reviews (including qualitative studies) also meet the criteria. An initial scoping of the literature highlighted a shortage of research specifically investigating service users' views in the area of inpatient experiences, and therefore it was decided that research exploring the views of family members and paid carers, including direct support staff, would enhance the literature search. Additionally, Community Learning Disability/Mental Health Nurses would be included because it was felt that their close working relationships with inpatients would further enhance the literature review. Equally, there was a paucity of research specifically within the field of ASC, and therefore research from the fields of learning disabilities and mental health were included. This more comprehensive range of possible fields assisted in the emergence of a conceptual framework and identification of the current literature to underpin the study design.

Any studies which focused on physical health inpatient experiences, community services, forensic inpatient services and non-UK services were excluded to ensure that clear study parameters were established as service provision varies from country to country. The selected papers were UK-based and better to inform experiences from a UK perspective. Research papers, theoretical articles, books and systematic reviews that were generated within the search and identified as relevant to the current study, but which did not meet inclusion criteria for this focused literature review, contributed to the overall understanding, insight and subsequent write-up of this research and were used to support or offer contrasting views of the studies included in this literature review. **Table 2** illustrates the inclusion/exclusion search criteria.

Table 2: Inclusion/exclusion search criteria

Inclusion	Exclusion	Limitation
English language only	Non-English-language	Potential to admit relevant studies
Primary research- qualitative/mixed method examination of experiences of inpatient services.		Potential to admit relevant quantitative only studies.
Systematic reviews (inclusive of qualitative studies)		Not primary research and potential for author bias.
Papers reporting on the views of family members and paid carers		Risk of detracting from the views of the inpatients with autism.
Papers reporting on the views of Community Learning Disability/Mental Health Nurses		Risk of detracting from the views of the inpatients with autism
Research from the fields of learning disabilities, mental health and autism.		Potential for different patient perspectives
	Papers reporting on physical health inpatient experiences	Potential to admit relevant studies
	Community services	Potential to admit relevant studies
	Forensic inpatient services	Potential to admit relevant studies
	Non-UK services	Potential to admit relevant studies
	Pre 2002	Potential to admit relevant studies

2.3 Mapping of the literature

I conducted a literature mapping exercise to organise and present the literature using a conventional approach. Unlike systematic reviews, which provide an in-depth analysis and critically appraise research, a mapping exercise can demonstrate the types of studies that exist, answer questions about what evidence is available and identify gaps in research (Bryman, 2012). It focuses on the following main question: What research has been conducted that relates to the experiences of adults affected by ASC who have been admitted to a mental health facility? However, due to a dearth of published research which has specifically addressed the inpatient experience from an autistic perspective, I widened the mapping and asked the following question: What research has been conducted that relates to the experiences of adults who have been admitted to a mental health facility?

The electronic database searches, which included the topic areas related to the questions above, identified 112 records. Titles and abstracts were screened to determine whether they met or came close to answering the questions above. Qualitative studies were prioritised if they employed methods such as focus groups, in-depth semi structured or unstructured interviews or participant observation and used appropriate qualitative approaches to data analysis. Quantitative studies were defined as those that reported evaluations of inpatient experiences or other analytical designs such as audit approaches and surveys. The Search strategy employed within this study is illustrated with a PRISMA Flow diagram in figure 2.1 below.

In total, 33 key research papers were identified through the mapping exercise. Studies were included based on their relevance to the research topic, which led to a critical appraisal of the full text articles using a quality standards framework based on Spencer et al (2003) and Northcote (2012). An illustration of how the quality standards framework was applied is given in **Table 3** below, for the purpose of presentation shortened titles for each criterion have been used, the full title is outlined below.

Table 3 The Quality standards framework, adapted from (Northcote, 2012).

The Quality standards framework used the following criteria:

1. Study has clear aims and objectives / statement of purpose
2. Previous literature is reviewed and provides a rationale for the study
3. Design is clear and appropriate
4. Context and setting are clearly described
5. Sampling and participant characteristics are clear and suitable
6. Data collection and analysis is systematic, clearly described and is UK-based.
7. Trustworthiness: results are supported by the data and steps were taken to ensure credibility / triangulation / reflexivity
8. Study contributes to existing knowledge/practice and addresses original aims
9. Study considers the experiences of patients with mental health and/or ASC and/or intellectual disabilities.

The Quality standards framework (QSF) scores 1-5 (5 being the highest and indicating the highest quality with 45 being the maximum score overall), the score was taken as an indicator rather than a definitive measurement of quality.

Study	1) Aims and objectives	2) Previous literature reviewed	3) Design	4) Context and setting	5) Sampling	6) Data collection and analysis	7) Credible	8) Contribution	9) Patient experiences	Total Score
Bee et al (2008)	5	5	3	3	2	2	3	3	2	28
Bunyan et al (2017)	4	4	5	3	3	2	3	3	5	32
Chaplin et al (2006)	3	4	4	3	5	5	5	5	5	39
Donner et al (2010)	2	3	4	4	2	4	4	3	3	29
Dunn (2012)	5	4	3	3	2	3	4	3	5	32
Hall et al (2006)	2	3	3	4	5	4	5	5	2	33
Murphy and Mullens (2017)	4	2	3	4	5	3	3	3	4	31
Parkes et al, (2007)	4	4	3	3	3	2	3	3	4	29
Slevin et al, (2008)	4	5	4	5	4	4	5	5	4	40
Spencer et al (2019)	4	5	5	4	2	4	5	5	4	38
Malfait et al (2017)	3	4	3	3	2	2	3	3	0	26
Gordon et al (2015)	2	3	5	3	2	2	3	3	3	26
Robertson et al (2018)	4	5	4	1	3	4	4	4	3	32
Acker (2018)	4	3	4	1	3	4	5	4	3	32

The studies shown in **table 3** are of the selected papers only, as shown in **figure 2.1** below other papers were assessed using this framework. Further information regarding the selected papers can be found in **Appendix 1**. 11 studies did not meet the inclusion criteria for this review as they were not primary studies or systematic reviews and consequently they were not reviewed in detail; however, they contributed to the wider psychological literature that informs the analysis and synthesis stage (Vos et al, 2007; Palucka & Lunsky, 2007; Narendorf et al, 2011; Wyder et al, 2017; Beckett et al, 2013; Delaney et al, 2018; Cambers, 2016; Clifton et al, 2017; Slemon et al, 2017; Gooding, 2016 & Harris and Panozzo, 2014). The studies authored by Palucka and Lunsky (2007), Narendorf et al (2011), Wyder et al (2017), Bryson et al (2017), Sherwood, (2015), Benedictis et al, (2011) Malfait et al (2017) & Andvig and Biong, (2014) were excluded as they were not entirely UK-based, and services and participants from overseas were considered within them. This review therefore focuses on 12 papers which met the quality standards outlined above, all selected papers scored between 28-40, each category carries the same weight and a score lower than 28 would signpost an average of below three being scored in each category, this is an indication rather than a definitive scoring system, however it does show that some of the categories are fairly poor if an average of three is not met (Northcote, 2012). Malfait et al (2017) and Gordon et al (2015) scored below 28 and were therefore excluded. There was a diversity within the scoring, showing that the selected papers were stronger in some areas than others, for example their overall contribution to the field (Chaplin et al, 2006; Hall et al, 2006; Slevin et al, 2008; Spencer et al, 2019; Robertson et al, 2018 & Acker, 2018). Whilst others scored highly for their inclusion of patients' experiences (Bunyan et al, 2017; Chaplain et al, 2006; Dunn, 2012; Murphy and Mullens, 2017; Parkes et al, 2007; Slevin et al, 2008; Spencer et al, 2019 and Robertson et al, 2018).

2.3.1 Analysis of included studies

The majority of the included studies adopted a qualitative approach using semi-structured interviews or focus groups to explore a range of aspects of service user admissions (Bunyan et al, 2008; Donner et al, 2010; Parkes et al, 2007; Spencer et al, 2019; Robertson et al, 2018 & Acker, 2018). Four studies used mixed methods to provide qualitative as well as quantitative data (Chaplin et al, 2006; Dunn, 2012; Hall et al, 2006 & Murphy and Mullens, 2017;).Bee et al (2008) provided a systematic review of the current evidence base at the time of their study, suggesting that service users expect Mental Health Nurses to demonstrate sufficient flexibility to fulfil a range of different roles. Bunyan et al (2017) and Donner et al (2010) used focus groups, Bunyan et al's (2017) focus groups were led by former service users (experts by experience) to explore the experiences of current service users of inpatient mental health care. Donner et al (2010); Spencer et al (2019) and Acker (2018) used an Interpretive Phenomenological Analysis to examine the experiences of 11 service users across five mainstream inpatient settings.

Using a thematic analysis approach, Parkes et al (2007) analysed data from 12 service users who had been admitted to mainstream inpatient services, and 19 service users admitted to an integrated inpatient unit i.e., a mental health unit with a small number of beds allocated to patients with a diagnosed learning disability and/or ASC. Dunn (2012) used a combination of focus groups and semi-structured interviews and a thematic analysis to explore the experiences of 19 participants, who had been cared for within NHS inpatient units. Robertson et al (2018) used semi-structured interviews and a thematic analysis to explore the views of participants with ASC and their supporters, providing insights into the drivers and impact of anxiety in autistic

adults. Bee at el (2008) systematically reviewed 90 papers in which service users' experiences of Mental Health Nurses had been observed via the use of qualitative methodologies. Murphy and Mullens (2017) used the analysis of hospital data to compare the experiences of 127 patients with and without ASC in a high secure mental health setting. A detailed summary of the study designs, participant demographics and methodologies can be found in Appendix 1. The following sections discuss the emergent themes and concepts which have been developed through an in-depth analysis of each of the study's perspectives of the main points they convey.

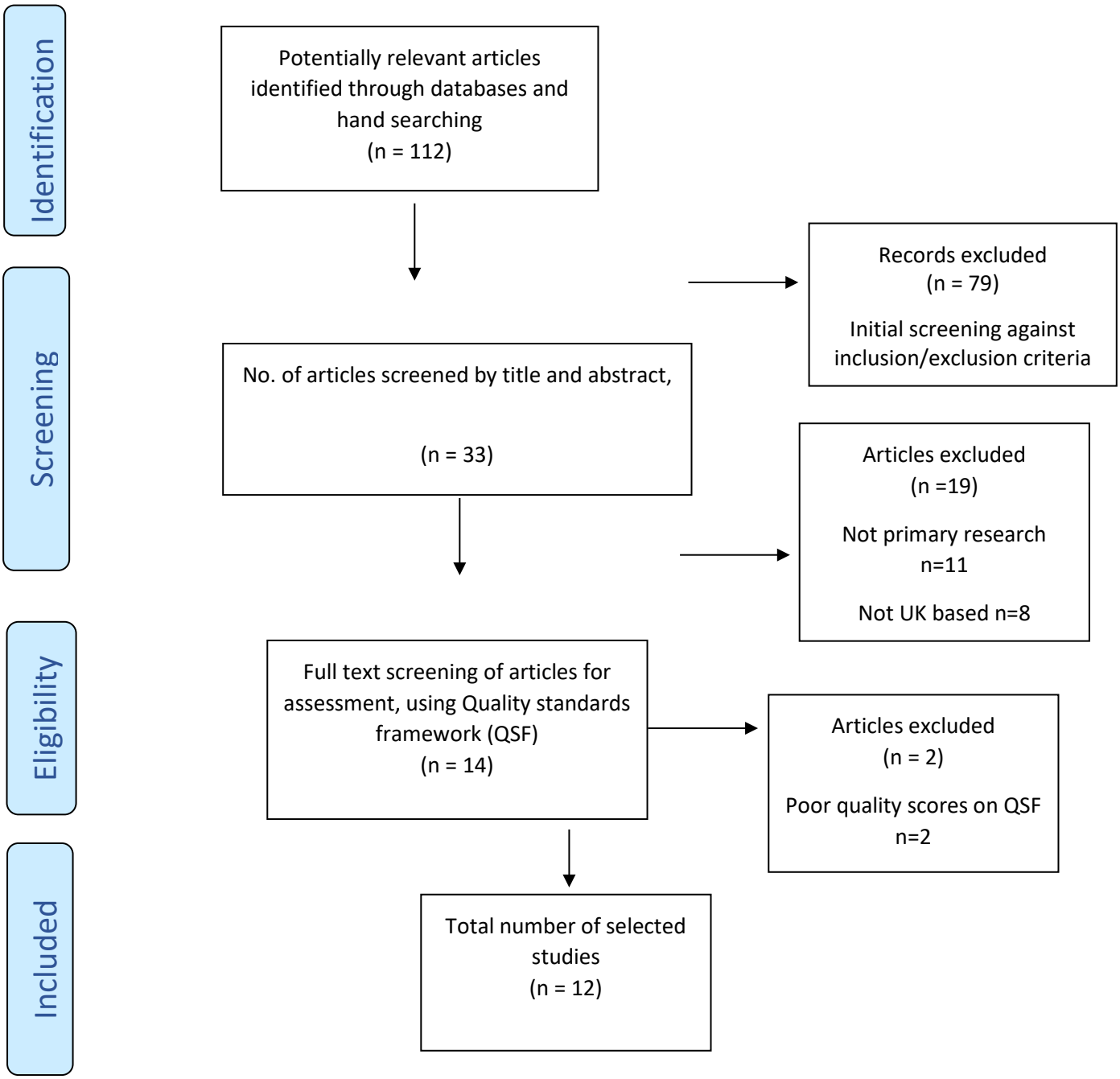


Figure 2.1: Search strategy with a PRISMA Flow diagram (adapted from Moher et al, 2009)

2.4 Service User Views

a) Summary of main studies

Researching the views and experiences of service users offers a robust way of understanding how to ensure services there needs. The reviewed research has included a range of questions, methodologies and participants to produce data that is credible and able to make a contribution to the field. Although some studies have attempted to understand the experiences of people with ASC by using methodologies which are not entirely of a qualitative nature (Chaplin et al, 2006; Dunn, 2012; Hall et al, 2006; Murphy and Mullens, 2017 & Slevin et al, 2008), it could be argued that those studies who have embraced purer qualitative methodologies have been able to understand the lived experience to a greater level. Robertson et al (2018) combined the views of both participants with ASC and supporters of the people with ASC, whilst both experts by experience, the views of those with ASC offer the greater insights and enable this paper to be an important contributor to its field.

b) Inclusion

Expressions of feelings of disempowerment, lack of control and being excluded from decision-making processes as a patient within inpatient services were prevalent throughout the literature. Service users described their fears of punishment, and of inflexible rules which engendered feelings of disempowerment, together with staff opinions that compliance with medication was synonymous with recovery. Submissiveness also characterised some service user accounts, with descriptions of them saying or doing things just to satisfy staff (Donner et al, 2010; Bunyan et al, 2017). Furthermore, the research indicated that the service users' propensity to comply and acquiesce generated feelings of neglect or of being put at risk (Donner et al, 2010). This observation is supported by research within general healthcare settings where inpatients identified that their reliance on staff, and the power imbalance that this can generate, had resulted in significant feelings for them of injustice, discrimination and inequality associated with having a variety of needs, i.e., communication difficulties, or difficulties in processing information (Hoole & Morgan, 2011).

Exercising control over an immediate situation or environment is a critical factor in minimising anxiety for many people with ASC. Intolerance of uncertainty (IU) is regarded as one of the main driving forces behind the high levels of anxiety experienced by patients with ASC (Maisel et al, 2016; Boulter et al, 2014; Wigham et al, 2015; Robertson et al, 2018; Spencer et al, 2019). The less in control the person with ASC feels, the more anxiety they will inevitably experience (Lidstone et al, 2014; Robertson et al, 2018, Acker, 2018). The studies reviewed suggested that feeling out of control was associated with service users lacking information and having doubts about the fundamentals of their treatment, such as length of admission and post-discharge plans (Chaplin, 2004; Bee et al, 2008). This may in part be due to a failure to recognise the cognitive and communication needs of such service users, which was reported by Chaplin (2004) to have been caused by information not being made accessible to them, and by their active involvement in their own treatment being partial and limited. Similar difficulties

experienced by service users in trying to achieve a collective understanding with staff have also been expressed by service users in general hospital settings (Hoole & Morgan, 2011). Those service users who reported being well-informed about their care identified this as being a substantial causative factor in feeling included (Donner et al, 2010).

Parkes et al (2007) reported service users' experiences of not feeling heard or listened to. Although there was evidence that service users were in attendance during ward rounds, Care Programme Approach (CPA) meetings and Clinical Treatment Reviews (CTRs), many of them experienced these inclusions as tokenistic gestures and rather intimidating experiences. These meetings comprise in-depth discussions regarding the patient's past and present clinical presentations, the evaluation of clinical interventions and decisions regarding new clinical interventions and plans for discharge if appropriate. Parkes et al (2007) suggested that service users struggle to feel involved in decision-making despite being present at and invited to contribute to these important meetings. Within inpatient settings, service users described feeling a lack of control in managing their relationships with potential advocates and other people who could speak on their behalf, such as friends and family (Bee at al, 2008; Bunyan et al, 2017). Achieving a sense of control, equality, inclusion and involvement in their own care may therefore be precluded for service users because of difficulties they experienced in accessing and upholding contacts with their carers, who provide an important role as advocates.

c) Vulnerability and safety

Service users interviewed in the reviewed studies also described feeling vulnerable because of the absence of control they experienced in not knowing what was going to happen to them following admission to a unit (Parkes et al, 2007). They also reported that the unit environments often felt unsafe due to violence and theft of personal possessions, citing accounts of assault by other patients which led them to feel they were in danger (Donner et al, 2010; Parkes et al, 2007). Beardon and Worton (2011) found that service users described their reliance on staff to keep them safe; however, staff did not always meet those needs. Some reports from service users indicated experiences of staff being unfriendly and unavailable, which exacerbated their feelings of vulnerability and ultimately heightened their anxiety; they expressed the feeling of being anxious, which many with ASC describe as constant and unwavering. Unfortunately, self-harm is a common strategy used within ASC populations to deal with acute anxiety, with various degrees of severity, the most usual being causing short-term pain by cutting, burning or hitting themselves (Lidstone et al, 2014).

d) Relationships with carers and support staff

Social relationships are impaired for many people with ASC due to their feeling insecure: such insecurity is caused by many factors, including low self-esteem, having insight into their own poor communication skills, and not being able to trust others (Jones & Meldal, 2001). Relating to others, according to Johnson et al (2011) is an essential part of our human experience, and it is at the core of our emotional and social abilities. Therefore, when a psychiatric patient experiences distress and pain, the need for another person to provide compassionate care and reassurance becomes increasingly desperate. Where these actions are performed positively by Mental Health Nurses, psychiatrists and healthcare support workers, their impact can improve the patient's mental health outcomes. Department of Health (2012) published

the ‘6C’s’ which are embedded into everything nursing, midwifery and care staff do, measuring outcomes and experiences and being able to demonstrate regular value to those for whom they care. It can be used by everyone, whatever your role, wherever you work: two of the 6C’s referred to are *compassion* and *communication*, highlighting the importance for nurses to relate to their patients in a caring and compassionate manner. MIND (2004) asked 364 recipients of mental health nursing care how much face-to-face contact time they had with their named nurse: 82% reported spending less than 15 minutes per day, with only 20% of this large sample feeling that they were treated with dignity and respect. Further studies (Stenhouse, 2011; Gilburt et al, 2008) reported that patients expected nurses to initiate conversations and guide relationships; others expected clear signs of approachability from the nursing team, such as acting in a non-threatening and non-authoritarian manner, taking the time to listen, not being rushed, being flexible, smiling, taking a sincere interest in the ideas of the patient, having a positive relationship with the family of the patient, allowing the patient to partake in decision-making when appropriate, and utilising language that is developmentally appropriate.

Relationships with the staff were reported, in this literature review, as being particularly important to service users as they contribute towards feelings of security, access to activities/therapies and maintaining contact with friends and family (Bee et al, 2008; Bunyan et al, 2017). These relationships were characterised across service settings both positively and negatively. Donna et al (2007) reported accounts from service users who defined negative interactions with a range of front-line caregivers who were considered hostile and uncaring, as well as mocking, threatening and frightening which service users with ASC experienced as distressing and anxiety-provoking. This is supported by evidence from local community Mental Health services and forensic inpatient settings where negative staff characteristics such as unfriendliness, the use of punitive measures, and antagonising service users have also been described by those with ASC (Clarkson et al, 2009; O’Brien, 2010). Additionally, Maisel et al (2016) suggest that poor emotional recognition i.e., the inability to distinguish and understand emotions expressed by others, are commonly experienced by people with ASC: this can lead to confusion and mistrust of relationships, as others without ASC struggle to understand why their emotional qualities are not reciprocated.

Hopkins et al (2009) reviewed 10 studies and found that therapeutic relationships were not always obvious within the mental health inpatient units. The service users interviewed placed high value on a consistent connection to the staff and peers within the units and described them as an important component of their treatment programmes. Catty et al (2012) found that the most important relationships were formed with patients’ key workers and named nurses, rather than their psychiatrists, psychologists or therapists. Gilburt et al (2008) noted that patients expected at the very least opportunities to talk through their problems, enabling them to express their emotions and move towards solutions.

Howlin (2005) also observed that even on the units where the inpatients were extremely unwell, there would generally be relationships formed between the staff and patients, ‘*…some displays of good humour and sharing of experiences were common place…*’ (p103). However, a patient with ASC is unlikely to take part in these interactions and their general lack of response in social situations form a

continual source of irritation for staff as well as fellow patients. Additionally, their failure to respond to therapy was at times viewed as deliberate, with very little understanding being shown of their impairments in the social functioning which is crucial to the success and accessibility of the therapy. The National Autistic Society looked at child Mental Health services: their report, 'You Need to Know' (2010) noted that more than half of parents with children with ASC do not think that professionals within mental health services know how to communicate with their child. The report cited serious problems within psychiatric services where parents found it very difficult to access appropriate services for their children, waiting months for appointments and finding that the professionals had very little understanding of their child's needs.

High staff turnover was cited by service users to have impaired their ability to get to know staff (Donner et al, 2010; Bunyan et al, 2017). Furthermore, service users often reported feeling let down, angry or frustrated as a result of staff unavailability which led to them having to wait or failing to have their needs met at all (Parkes et al, 2007).

However, there were also positive accounts of relationships with staff detailed in the research reviewed, and examples given by service users of staff being caring, sensitive and available to talk to (Parkes et al, 2007). This is supported by Clarkson et al (2009) who reported that service users in forensic inpatient settings found staff to have a nurturing parental role and were positive about their experiences of familiarity and alliance with staff.

e) Relationships with other inpatient service users

Relationships between patients have been found to be characterised by incidents of aggression and, at times, violence (Donna et al, 2010; Bunyan et al, 2017). Howlin (2005) observed that other mental health inpatients did not understand the behaviours of those with autism. The unpredictability of other patient's behaviours left service users feeling vulnerable, upset, stressed; in addition, the noise on the unit presented a problem for them (Donna et al, 2010). Wood and Pistrang (2004) suggested that the most fearful were those patients who were being admitted for the first time: their fears were mostly around other patients and their responses to their behaviours. Murphy and Mullens (2017) reported that within a high security psychiatric setting, a higher number of formal seclusions for patients with ASC compared to those without ASC. The higher proportion of incompatibilities with other patients was an influencing factor which led to many problems with other patients including violent exchanges.

Parkes et al (2007) also reported that service users had difficulty in getting to know other patients, which contributed to their feelings of isolation. It has been noted that in specialist learning disability or autistic inpatient units this was less of a problem than for those patients with ASC residing in mainstream mental health facilities, where service users with ASC and/or intellectual disabilities were seen as having limited communication skills and as having a disability.

f) Environment

Howlin (2005) noted that the mere thought of an inpatient admission for a person with ASC can cause the severity of their mental health condition to escalate, and the desire for sameness can be seriously compromised when someone with ASC is placed in very unfamiliar surroundings. Service user views of the physical environment in inpatient settings were largely negative, including the general atmosphere within the units, and their personal frustration at the lack of privacy - including limited personal space in which to spend time alone and for receiving visitors (Bee et al, 2008). The literature reviewed in this study shows clearly that meeting the mental health needs for adults with ASC by admission to hospitals should be only a fall-back position. The experience of such a drastic change of environment can have a traumatic effect on people with ASC, equalling that of the mental illness itself (Howlin, 2005; Dunn, 2012; Donna et al, 2007; Narendorf, 2011).

Furthermore, service users also reported that being placed in facilities far away from home contributed to forceful feelings of isolation from family and friends and caused difficulties in maintaining these important relationships. Service users therefore wanted more contact with family and friends and to return closer to home (Chaplin, 2004; Hall, 2004; Bunyan et al, 2017). Additionally, sensory processing abnormalities, which are highly prevalent in ASC, had an impact upon how the service users experienced the physical environment: the issues they reported as causing anxiety included high-intensity strobe lighting, beeping of fire alarms, and the humming of air-conditioning units (Wigham et al, 2015; Bee et al, 2008; Robertson et al, 2018).

g) The admission

It was reported by service users that they viewed their admission to an inpatient unit as a form of custodial sentence and, inevitably, they perceived the inpatient unit as being like a prison (Bee et al, 2008). This perception appeared to be influenced by the service users blaming the cause of their admission on the behaviours and/or responses to certain circumstances that they presented prior to admission, which resulted in them being admitted via a court recommendation following incidents of violence or aggression (Parkes et al, 2007; Donna et al, 2007). Some service users believed that their negative feelings were aggravated by feeling that their admission was unfair (Beardon & Worton (2011).

Wood and Pistrang (2004) noted that the most fearful of service users were those patients being admitted for the first time: their anticipatory fears were mostly related to other patients and how they might behave towards them. This fear and anxiety would often increase the likelihood of service users displaying uncharacteristic violent responses.

Service users in inpatient settings also described difficulties in adjusting to the environment with their experiences of anxiety been linked to unfamiliarity (Parkes et al, 2007). This is supported by analogous narratives from adults with ASC experiencing general hospital care, which identified that feelings of anxiety and fear were commonly reported and were influenced by previous experiences (Beardon & Worton, 2011; Gibbs et al, 2008).

h) Treatment

The aims of inpatient services have been described as providing a wide range of therapeutic modalities, coalescing psychiatric, educational, recreational and behavioural support perspectives (Bee et al, 2008). The research reviewed suggests that activities might be considered as an important aspect of service user treatment plans with a range of activities being identified which offered opportunities for growth of independence, choice and control in inpatient and community settings (Donner et al, 2007). Some service users reported opportunities for engagement in activities as providing both enjoyment and a sense of purpose, e.g. a modular learning programme designed to meet the specific development needs of each individual patient, and meaningful one-to-one sessions with their nurse or therapists; others discussed the monotony they experienced in inpatient facilities where there were few activities (Bee et al, 2008; Beardon and Worton, 2011). It was highlighted by the service users that activities relating to independent living within the community were linked to increased self-worth, independence, motivation and well-being (Donner et al, 2007).

The use of typical and atypical psychotropic medication as a therapeutic intervention has received mixed reviews from service users: while some viewed medication as a helpful factor in their treatment strategy, others perceived it as being disciplinary and given without their consent. and resulting in undesirable side-effects. Some service users reflected upon their own knowledge of medication, and reported that increased understanding of medication resulted in service users being more able to recognise its benefits; however, other service users reported anxieties about taking medication, citing experiences of disempowerment aggravated by feelings that they were compelled to take the medication and the nurse would watch to ensure they did so (Parkes et al, 2007).

In addition to activity-based interventions and medical treatments, service users have discussed their experiences of psychological treatments. They identified the benefits they find in talking about and addressing issues from the past; however, the availability of psychological interventions has been identified as being limited (Parkes et al, 2007; Narendorf et al, 2011; Bunyan et al, 2017).

2.5 Carers' and support staff views

a) Summary of main studies

The views of the people who support and care for service users offer important insights into how we might best comprehend the experiences of service users in inpatient settings. The research reviewed has observed the views of family and paid carers, including direct support staff and Community Learning Disability/Mental Health Nurses. This section of the literature review complements and builds upon the previous section by providing an examination of the findings that relate to key themes represented within research exploring carers' views and experiences of inpatient services.

Using an Interpretive Phenomenological Analysis, Donner et al (2010) explored the views of nine family members, four Community Nurses and seven other professionals from Community Learning Disability Teams in relation to mainstream inpatient services. Dunn (2012) used mixed methods to attain the views of 14 parents/carers on their personal journeys of supporting inpatients through mental health systems

and pathways to diagnosis and treatment. Chaplin (2004) used mixed methods approaches to establish an understanding of violent behaviours: many support staff were interviewed and provided important insight into this experience. Robertson et al (2018) provided comparisons between participants with ASC and the supporters of the same participants with ASC, there were similarities of their views in some cases but also some stark difference in their perceptions, for example when questioned about miscommunications the participant with ASC proportioned blame to those he was communicating with, citing that they struggle to understand his directness and seem to take offence and sometimes this is interpreted as rudeness. Whilst, the participant who supported this individual cannot understand why he sees this as the other person's problem and cannot take responsibility for the way communicates. A summary of the study designs, contexts, participant demographics and methodologies are summarised in Appendix 1.

b) The admission

Family and paid carers have generally found the process of admission to be a positive experience for service users (Donner et al, 2010). Some carers, however, have described the inaccessible and difficult routes they had to travel to secure admission for service users, where the situation had to escalate to a crisis before services would accept the service user for admission (Donner et al, 2010; Dunn, 2012). This was particularly problematic for service users with high functioning autism or Asperger's syndrome, who seemed unable to meet the criteria for either learning disability or mental health inpatient services; very few specialist ASC inpatient units were available to fill this gap (Slevin et al, 2008; Dunn, 2012; Beardon & Worton, 2012). Once admission was secured, however, carers and support staff described positively the respite that the admission provided for themselves *and* the service user. In addition, carers reported a sense of being supported and cared for by the unit staff during the admission process and emphasised the honesty of communication between themselves and the unit staff (Donner et al, 2010). Mixed views were expressed by carers about the length of admission (Hall et al, 2006; Slevin et al, 2008). In some instances, carers expressed their desire for longer admissions and for greater advice on how to support service users once they were discharged (Chaplin, 2004).

c) Concerns regarding safety

Some carers and support staff support the accounts made by inpatient service users, that they have observed service users fearing other service users and describe threats and incidences of violence that make the environment intimidating (Donner et al, 2010; Beardon & Worton, 2012). Additionally, the carers' views of the physical environment echoed those expressed by service users (Beardon & Worton, 2011; Gibbs et al, 2008): the mainstream mental health inpatient units were described as being bleak in appearance, including poor natural lighting and dreary decor (Donner et al, 2010).

Dunn (2012) noted that service users felt that minor adjustments could be made to the physical environment, i.e. busy waiting rooms with fluorescent lighting and loud, sudden, unpredictable noises are also barriers to accessing services for many autistic adults who suffer from sensory processing disorder. Specialist ASC and learning disability inpatient services were viewed more positively and were

described by one parent as ‘home-like’. This highlights the importance of the physical environment and how carers and family members evaluate the service (Dunn, 2012).

A recurring theme throughout the research studied was the perceived notion that staff did not or could not spend enough time with the service users, although it was acknowledged by some carers that this was a hunch rather than an observed fact (Chaplin, 2004). McCrae (2014) supported this notion and recognised the barriers to one-to-one patient/nurse contact, suggesting that nurses spend too long in offices completing administrative duties. Allowing space for Mental Health Nurses to offer protected time within their daily schedules in which to spend real-time with service users is a necessity and impacts positively upon patient recovery. Längle et al (2003) supports the theory that relationships with nursing staff, social workers and doctors are, from the patient’s perspective, very important within the mental health inpatient experience.

d) Relationships with unit staff

The nature of carers’ and support staff’s relationships with the inpatient unit staff was a recurring theme throughout the research reviewed. Carers described difficulties in communication with staff, inadequate contact, frequent use of agency staff and lack of continuity as barriers to ensuring effective care planning (Slevin et al, 2008). Lack of continuity and the consequential difficulty of knowing with whom to liaise created difficulties in establishing trusting relationships with and among staff, which was experienced as confusing and disappointing (Slevin et al, 2008). Dunn (2012) noted carers’ frustration in relation to their perceived knowledge of ASC and particularly in how to communicate effectively with a patient with ASC. Dunn (2012) undertook an assessment to ascertain the level of knowledge and understanding of issues relating to patients with ASC and described how 70% of the mental health care staff who took part admitted to having little or no knowledge about autism, and 77% felt that they would benefit from autism awareness training.

While service users were inpatients, the level of involvement in their care from their carers and support staff varied considerably within the reviewed literature. Some considered that attendance at Care Programme Approach (CPA) and Clinical Treatment Review (CTR) meetings provided an important opportunity for carers to be involved in their service users’ care (Donner et al, 2010); others believed that their attendance at CPAs, CTRs and Mental Health Act Tribunals were tokenistic, and their views were not always listened to. Additionally, some felt that the reporting of their service users’ responses to treatment plans was overly positive and unrealistic (Hall et al, 2006).

In relation to experiences regarding out of area placements where service users have been placed in inpatient units a long way from their families and homes, Donner et al (2007) found that some carers felt as if their relationships with service users had been damaged for good and they expressed beliefs that service users would never be able to return to their care. Carers also described how the distance between themselves and service users rendered contact and support difficult to maintain.

2.6 Examination of mental health inpatient units

Since the inpatient environmental impact upon the participants in this study was so pronounced and described in detail, it is imperative that a greater breadth of understanding be established with regard to the inpatient units themselves. By understanding the nature of the units, it will better elucidate the challenges that individuals with ASC may face within them. Spencer et al (2019) explain the restricting effects of policies, procedures, routines and rules enforced by staff in a mental health inpatient unit. Adding to the complexity is the milieu of an acute inpatient unit with interactions being with multiple health and education staff and the young people who present with different mental health problems. All these factors add to the complex environment that impacts on health outcomes of people who receive care in hospital.

Acute mental health inpatient units have been criticised as unsafe, unpredictable, and chaotic, not providing therapeutic benefits and stressful environments for both patients and staff (Beckett et al, 2013). Spencer et al (2019) suggested that hospitalisation itself impacts negatively upon the recovery process, including dramatic unit dynamics, exposure to aggression and violence and a disconnection from primary support networks. Furthermore, Bryson et al (2017) explained that being the recipients of coercive interventions such as seclusion and restraints, and exposure to aggression, violence and self-harming behaviours from other inpatients can increase the likelihood of trauma during an admission. Delaney et al (2018) indicate that inpatients' experience of distress present one of the biggest challenges for mental health clinicians. Although strategic treatment plans are formulated, clinicians also need to be able to respond quickly and effectively to unanticipated immediate, often life-threatening or dangerous situations on inpatient units.

Beckett et al (2013) describe efforts to improve culture and practice within mental health inpatient units, citing ineffective leadership, staff assistance, and unresponsive organisational culture identified as common barriers to change. Changing culture has been notoriously difficult. Although there is an increasing emphasis for mental health services to provide care that is person centred and supportive of recovery, and not withstanding existence of effective psychosocial interventions, it remains the case that improving nursing practice in acute inpatient mental health settings continues to present significant challenges (Bryson et al, 2017). The experience of both staff and consumers in inpatient settings continues to be an issue of significant concern (Delaney et al, 2018). Person centred care promotes respect for collaborative partnerships between patients, carers and clinicians, and is recognised as being vital to the developments of high quality, safe and effective healthcare (Beckett et al, 2013). These principles have been further reinforced through the revolution of the recovery movement and increased understanding of the iatrogenic effects of health care institutions and practices (Malfait et al, 2017). Spencer et al (2019) argue that in order for clinicians to practice the principles of person centred, strengths-based and recovery focused care, they must experience the same for themselves, therefore transformational leadership principles which emphasise staff empowerment, respect and mutual appreciation, match the practice of person centred care (Malfait et al, 2017).

Clifton et al (2017) suggest that recovery approaches have been widely adopted for working with people with long term mental health problems. For people with autism a full clinical recovery from the mental health issues that are associated with their ASC may not always be achievable. The principles of recovery therefore focus on a person-centred approach that acknowledges the wider impact of having both an ASC and a mental health problem. Therefore, the recovery goals might include improving social outcomes through meaningful employment and strengthening their social networks and engagement within wider society which could require a change. For example, recovery orientated interventions could include education, transport and leisure services. In general, people with long term conditions do better when offered interventions that help to develop their skills, knowledge and confidence to actively participate and to personally manage their conditions. An example a successful intervention of this nature would be the 'PEGASUS' post-diagnostic psychoeducational group, which aims to increase the awareness of strengths that it's autistic participants can align to their ASC specifically (Gordon et al, 2015). Cambers (2016) suggests that mental health practitioners supporting mental health recovery with patients with autism should be flexible enough to adjust their practice to working in partnership with patients and wider community networks. Yet, given Spencer et al (2019) observations it is clear that the therapeutic milieu of the inpatient facility has not yet been realised where people continue to be exposed to damaging encounters.

Despite a paucity of studies observing the characteristics and experiences of ASC inpatients during periods of admissions, there are a number of papers reviewing the predictive factors for psychiatric hospital admission within this group (Palunka and Lunsky, 2007; Dunn, 2012; Mandell, 2008; Siegal and Gabriels, 2014; Righi et al, 2018).

Palucka and Lunsky (2007) examined the predictive factors of 36 patients with ASC who had been admitted to a mental health inpatient unit. 13/36 were admitted with an established diagnosis of ASC, of these the majority were male (69%). The mean age at admission was 28 years with the range from 17 to 52 years. The most frequent diagnosis of ASC was autistic disorder (69%), followed by Asperger's syndrome (15%) and pervasive developmental disorder not otherwise specified (15%). Almost 40% of patients had severe intellectual disability. 15% of patients were at the moderate and mild level of intellectual disability. 31% function at the borderline level of intelligence, i.e. an IQ of 70-75. Almost half (46%) of the patients had a confirmed or tentative diagnosis of bipolar mood disorder. Psychotic spectrum disorders were diagnosed in three cases and involved schizophrenia (1) and psychosis not otherwise specified (2). 23% of the patients had no comorbid psychiatric diagnosis. Serious physical aggression was identified as the reason for seeking inpatient admission in 77% of the sample. For the remaining patients, the reasons involved behaviours difficult to manage by families/carers (15%) and risk of self-harm (7.7%). Dunn (2012), Mandell (2008), Murphy and Mullens (2017) and Slevin et al (2008) concur that aggressive behaviour was the main reason for inpatient admissions with many also citing self-injurious behaviours as highly prevalent.

Palucka and Lunsky (2007) further reported the length of hospitalisation ranged from approximately two months to 4 years, with 295 days being the average length of stay. Following discharge, 4 patients were readmitted, of those, two were readmitted for a very brief stay during the transition process, whereas

the other two were readmitted following serious incidents of aggression. Locked seclusion rooms were used at some point during the admission to manage incidents of aggression, this occurred for 69% of the sample. PRN medication for agitation and aggression was used with all except one patient. All patients received behavioural consultation and interventions as part of their care plan. Long lengths of stay were often related to the inability to discharge the patient back to the original primary care provider, who, in over 50% of cases was the family. The majority (71%) of individuals who lived with their families prior to admission were not able to return home and were subsequently placed in group homes or other community-based facilities. Two of the patients, who before coming to hospital lived in residential homes, lost their placements as the providers felt that they could no longer support them due to the potential of their aggressive behaviours.

Siegal and Gabriels (2014) reviewed details of over 700 children and young people with ASC who had been psychiatrically hospitalised between 5 and 21 years. The strongest predictors for hospitalisation were; aggressive behaviours (40%), coming from a single parent home (28%), depression (15%), obsessive-compulsive disorder (12%), and self-injurious behaviours (5%). During admission psychiatric diagnosis was recorded in the following way: specific phobia (44%) obsessional compulsive disorder (37%) attention deficit/hyperactivity disorder (31%), separation anxiety disorder (12%) and major depressive disorder (10%). Righi et al (2018) acknowledge that there may be a variety of other factors that have not been measured, for example the effectiveness of outpatient psychiatric care, community-based behavioural services, school settings and day programming.

a) **The culture of risk management**

Slemon et al (2017) argues that within current psychiatric inpatient environments, safety is maintained as the predominant value and risk management remains the cornerstone of nursing care and this situation is unacceptable. Across healthcare environments, the notion of safety invokes a cluster of concepts including patient safety, quality assurance and quality improvements (Hall et al, 2008). Safety in nursing practice constitutes protecting patients from harms arising from adverse events in care such as medication errors, poor communication in handover, insufficient staffing and inadequate education on technologies (Sherwood, 2015). Gooding (2016) suggests that those involved in risk management also have a moral duty to protect the patient population, health care providers and the general public, which perpetuates the continuation of risk management strategies from a bygone era of institutionalisation, including containment (i.e., locking doors to inpatient units) and seclusion. De Benedictis et al (2011) acknowledge that the more unpredictable an inpatient's behaviour is, the more likely nurses are to implement risk management strategies, for example, physical restraint and seclusion. Slemon et al (2017) proposes that safety discourse, grounded in fear of individuals with mental illness, continues to legitimise the use of these practices in the name of protection and risk management.

Clifton et al (2017) describe concepts of the therapeutic relationship as one that centres upon positive personal interaction between the nurse and the patient, with the patient's needs and goals as the focus of the relationship. Therapeutic relationships have been integrated as a fundamental principle of mental

health nursing. Indeed, Slemon et al (2017) argue that the upholding of safety as the 'highest aim' of mental health nursing may contradict the therapeutic relationship and cause conflict between nurse and patient which are unhelpful to the development and maintenance of a relationship deemed crucial to their recovery. Harris and Panozzo (2019) propose that mental health nurses find barriers to therapeutic relationship between nurses and some patients, such as time constraints, communication issues and the requirements of practice policies. Nurses tend to limit communication and interaction with patients whose presentation can be unpredictable, due to potential escalation and fear of being physically hurt.

Recovery-focused care is considered best practice mental health care and is fundamentally relational, requires nurses and other providers to acknowledge the personhood of the consumer, their unique abilities and limitations, and to collaborate with them within a relationship to maximise recovery opportunities at all levels of care (Andvig and Biong, 2014). As demands for recovery-focused care grow and empirical evidence of its effectiveness mounts, mental health nurses need to draw upon their strong position providing care within contexts of therapeutic relationship to meet these demands. Being aware of the aforementioned barriers is important, as are our strategies to overcome them. Exercising too much emphasis upon risk management can be counter-productive when working with an autistic patient who thrives on maintaining control.

2.7 Autism and mental health

Since mental health has been so pronounced in the profiles of the participants in this study it is crucial to establish a robust understanding of the literature which connects the relationship between ASC and mental health issues. As highlighted in section 1.2, the high prevalence of psychiatric comorbidity in ASC is associated with the equally high prevalence of anxiety experienced by inpatients and people generally with ASC. Anxiety is a word used to describe inpatients with or without autism within this literature review (Bunyan et al, 2017; Chaplain et al, 2006; Donner et al, 2010; Acker, 2018; Robinson et al 2018). Anxiety disorders being the most common mental health diagnosis for people with ASC (NAS, 2018) approximately 40% of people with ASC suffer from an anxiety disorder, compared with 15% in the general population. Dunn (2012) recognised that people with ASC who were being admitted for anxiety related disorders commonly found their anxiety exacerbating further upon admission and often reaching fever point during the admission process.

Dunn (2012) identified a range of anxiety disorders including general anxiety disorder, social anxiety disorder, panic disorder, obsessive-compulsive disorder and post-traumatic stress disorder, within her study. Significant difficulties in diagnosing inpatients with ASC due to emotional recognition and communication problems were noted numerous times (Dunn, 2012). Hall et al (2006) and Murphy and Mullens (2017) also noted high levels of post-traumatic stress disorder and social anxiety disorder in inpatients with ASC, again difficulties in establishing a correct diagnosis were indicated. Robertson et al (2018) considered the impact of anxiety in autistic adults and reported that the causes of much of this anxiety can be explained by three main themes of their research: *uncertainty and change, miscommunication* and *being accepted.* Robertson et al (2018) reported that social interaction is impaired for many people with autism because of the unpredictability of the interaction, a participant

claiming, '*people are very difficult because people are unpredictable'.* Participants within Robertson et al (2018) also discussed miscommunication as an influencing factor upon their general anxiety, i.e. not being clearly communicated with, as well as misunderstanding the intentions of others, and these factors were likely to impact anxiety symptoms. Additionally, Robertson et al (2018) discussed the importance of feeling accepted and the positive impact that this could have on their anxiety. Comparisons to Acker et al (2018) can be drawn upon, exploring the lived experience of anxiety with adult participants in their study who reported a strong urge to make and maintain social connections, but were continuously frustrated by their apparent inability to feel accepted. Relationships were perceived as 'treasured 'and 'fragile', with persistent concerns that they would not last very long, much of this is explained by internal pressures or self-criticism, driven by a concern about letting others down (Acker et al, 2018).

Parkes et al (2007) and Slevin et al (2008) highlighted a number of patients with ASC affected by depressive illness. NAS (2018) suggests that around 20% of the UK population will experience a period of depression within their lifetimes, but it is even more common in people with ASC. Parkes et al (2007) describes observations of inpatients with ASC and learning disabilities and found it was especially difficult for them to describe their depressive symptoms. Feelings of concern were cited due to the fear that their expressed help would lead to a daunting change which could be further anxiety provoking.

Au-Yeung et al (2019) reported high levels of diagnosis in autistic adults for depressive disorders, anxiety disorders, obsessive-compulsive and related disorders, trauma and stress related disorders, feeding and eating disorders and personality disorders, many of which the recipients disagreed with. There were two major reasons for their disagreement, firstly ASC characteristics were confused by psychiatrists with symptoms of a mental health condition and secondly, mental health difficulties were perceived to be resultant of the core features of ASC. The autistic participants also spoke about the clinical barriers that hinder accurate diagnosis and support which include healthcare professionals' lack of awareness and understanding of autism, poor communication between autistic adults and healthcare professionals and treatment deemed unsuitable for their needs. The term 'criterion contamination' is used readily in psychology to describe the entanglements of the core features of ASC and the core features of anxiety related disorders.

Recent studies suggest that ASC difficulties could increase the likelihood of being exposed to risk factors for developing mental health conditions. For example, higher autistic traits were associated with self-reported loneliness in autistic adults (Hedley et al., 2018) and the experience of social disconnectedness, and feeling a burden on others in the general population (Pelton and Cassidy, 2017); these factors in turn increase the risk of both depression and suicidality. Lever and Guerts (2016) established that 79% of autistic adults met the criteria for some form of psychiatric co-occurring condition during their lifetime, with mood and anxiety disorders being the most common, and at a significantly greater rate compared to non-autistic adults.

Despite increased risk factors for, and incidents of, mental health conditions in ASC, conditions such as depression may still be under diagnosed given the lack of validated assessment tools to accurately detect the unique presentation of mental health difficulties in this group (Cassidy et al, 2018). The

characteristics of ASC can overlap with many indicators of mental health conditions; for example, social withdrawal, appetite and sleep disturbance are common characteristics in both ASC and depression (Stewart et al, 2006). This would suggest that an established diagnosis of ASC could overshadow the presence of mental health symptoms potentially leaving co-occurring mental health conditions unrecognised (Matson and Williams, 2013). The consequences of misdiagnosis and/or missing diagnosis of co-occurring mental health conditions are potentially devastating and increase the risk of dying by suicide (Hirvikoski et al, 2016).

It is also possible that symptom overlap could lead to overdiagnosis of mental health conditions in autistic individuals (Lai and Baron-Cohen, 2015). Recent case reports (Luciano et al, 2014; Van Schalkwyk et al, 2015) indicate that mental health professionals' failure to collect information about developmental history, as well as their lack of understanding about ASC presentation, contributed to mental health misdiagnosis. Misdiagnosis of ASC as a mental health condition could lead to unnecessary treatment (e.g. antipsychotic medication), which could preclude the possibility of having another intervention which could be more appropriate to their needs.

Cooper et al (2017) suggest living with autism is likely to negatively impact on an individual's ability to develop a positive social identity, thereby reducing psychological well-being. For example, people with ASC face the challenge of maintaining a positive sense of self despite their membership of a stigmatised group. Cage et al (2018) acknowledge that the challenge of acceptance of autism from external sources as well as personal acceptance significantly increases the potential for depression. Additionally, their study highlights that experiences of 'camouflaging' i.e. attempts to disguise their autistic traits, could also relate to higher rates of depression.

Sasson et al (2017) found that non-autistic individuals tend to make 'rapid unfavourable judgements' about those on the autistic spectrum. In their study, neurotypical participants rated pictures and videos without knowing that some of the people in the videos had been diagnosed with ASC. Their findings showed that autistic people were rated as less likeable, less attractive and that the participants would be less likely to engage with them socially, suggesting that societal acceptance may be poor. It is therefore likely that people with autism experience negative reactions from neurotypicals. Milton and Sims (2016) suggest that social acceptance is important to ASC and a lack of understanding from the public impacts upon mental well-being. Studies examining autism acceptance additionally indicate that although non-autistic people are aware (Dillenburger et al. 2013), misunderstandings and misconceptions are common, nonetheless. Further, unconscious bias towards autism can still be prevailingly negative even in those who work regularly with autistic children (Kelly and Barnes-Holmes, 2013).

Detrie and Lease (2007) propose that due to the social stigma that surrounds autism 'social identity groups' that have a membership for only autistic people can improve psychological well-being, as demonstrated in a range of social groups including lesbian, gay, bisexual and transgender (LGBT). MacLeod et al (2013) counter argue that although social situations can be positive for mental health, having a diagnosis of ASC and being in a group is not necessarily perceived as positive, as this group

membership also reinforces stigma. Also, the social and communication deficits may interfere with the social identity process. However, a sense of belonging is thought to be important to the well-being of people with ASC (Cage et al, 2017; Kelly and Barnes-Holmes, 2013; Cooper et al, 2017). Indeed, sense of belonging is argued to be vital to the well-being of all individuals, irrespective of autism (Baumeister and Leary, 1995). Longitudinal studies have also shown that autistic individuals believe supportive family and friends help them to develop greater feelings of self-worth (Hurlbutt and Chalmers, 2002; Weiss et al; 2012). Correspondingly, in a study where loneliness was positively correlated with anxiety and depression, individuals with ASC who reported having more friends experienced fewer feelings of loneliness, as well as fewer anxious and depressive symptoms (Mazurek, 2014). As such, it may be that feeling accepted by others could act as a protective factor against mental health problems.

To remain safe from anxiety or depressive related disorders, the many challenges and different pathways that have been discussed in this section demonstrate that there are many obstacles for people with ASC to overcome in order to remain safe from poor mental well-being and inevitable mental illness. It is crucial therefore, that society generally but more specifically those who work in mental health services, are encouraged and taught to develop a greater breadth of understanding of how mental health manifests itself within this group.

2.8 The challenges of an autistic life

According to the American Psychiatric Association (2013) characteristics of ASC fall into three main categories: social interaction and communication problems, difficulty relating to people, things and events and, restricted and repetitive patterns in behaviours, interests or activities. When the potential challenges of these categories are considered, the inevitability of a different inpatient experience becomes clearer.

The outcome of experiencing difficulties with relating to people can lead to people with ASC having little or without any social networks which can lead to isolation and increased vulnerability (NAS, 2017). It is often the case that relationships are desired and, in many cases, needed, but impaired social functioning and limited communication skills are often too profound to enable this (Howlin, 2005). Chin et al (2017) suggest that emotional intelligence is the key to impaired social functioning and the key to developing relationships, understanding the responses of others and the potential psychological impact of their communication is often missing, consequently the conversation and relationship becomes one dimensional which is intolerable to many.

Rodgers et al (2012) suggest that the need for sameness, control and the intolerance of uncertainty impacts upon the person with ASC's ability to speak freely and flexibly about topics that are instigated by the other person, again this can be difficult to tolerate and impacts upon relationship building. Maloret and Scott (2017) suggest the need for sameness challenges every aspect of the lives of people with ASC, including; controlling conversations, developing rituals and routines, being antagonised by the unpredictability of other people and the resistance to change. Rieffe et al (2011) highlighted that often routines and rituals are established to protect them from sensory stressors which can impact upon their

lives considerably. A number of the participants that I interviewed in their own home indicated a very well-managed sensory profile of their living environment, which often took a long time to develop and eradicate the known sensory stressors. Van Steensel et al (2012) identifies that the need for sameness often relates to the sensory issues that may prevail if strict routines and unpredictability is not adhered to.

2.9 Grey literature

The Autism Act (2009) identified a sensible approach moving forward but not, unfortunately, for all services to become more autism friendly: instead it called for Local Authorities to have a single identifiable point of contact with people with autism who could then find autism-friendly entry points to access a wide range of local services (DoH, 2009). Hertfordshire County Council (2011) designed an 'Asperger's Support Team' which inherited the responsibility for adults with ASC from community mental health teams and started to become the single identifiable point of contact for people with ASC in Hertfordshire, i.e., those who required health or social care provision (Hertfordshire County Council, 2017). However, according to Public Health England (2016) only 22% of Local Authorities in England and Wales have appointed such a single identifiable point of contact; and, since the Public Health England (2014), Local Authorities with a recognised pathway for people with autism but without learning disability to access care assessment and other support was down by 7%, indicating clearly that the picture for accessing services for people with ASC is still confusing and not easily identifiable. The Local Authority in Haringey, London, was asked, 'do you have a recognised pathway for people with autism but without a learning disability to access care assessments and other support?'. They answered:

> *'We are developing an autism pathway. Currently if you do not have a learning disability, physical disability, mental health or are an older person then there is no pathway for you. The proposal is to have an autism pathway in adult social care.'* (Public Health England, 2016).

The Asperger's Support Team within the Hertfordshire Local Authority only consider referrals for people with Asperger's syndrome and/or high-functioning autism, referring others with ASC and the comorbidity of a learning disability to the Learning Disability Team. The Asperger's Support Team was developed in response to feedback from people with Asperger's and high-functioning autism, and their carers who were saying consistently that they could not fit into traditional learning disability and mental health services and they wanted and needed to be supported in a different way. The Team's goal is to provide support that improves the quality of life for its 400 service users and supports future planning, housing, further education, employment, daytime opportunities, financial problems and access to healthcare (Hertfordshire County Council, 2017).

When the expert by experience from the Asperger's Support Team within the Hertfordshire Council addressed a group of Registered Mental Health Nurses and other frontline caregivers within mental health services in 2017, he said:

> *"Without the support of the Asperger's support team many of its 400+ service users will not be able to cope independently. The team comprises of social workers, transition coordinators, employment offices, community care officers and experts by experience. Without these people to contact many of our service users would reach breaking point very quickly and ultimately end up in your care* (the care of mental health services). *Everybody in the team has had specialist training in autism and now many years of experience of working with people with ASC and a diverse range of personalities and needs."* (Philip Hanscombe, personal communication, August 12, 2017).

The Asperger's Support Team in Hertfordshire County Council has this year (2018) been disbanded due to lack of funding, leaving Hertfordshire as one of the 88% of Local Authorities who do not have a single identifiable point of contact, which potentially puts greater pressure on mental health services. The Team had developed as a reputable group of experts within the field of ASC since they went live in 2013: they will be significantly missed by their current service users and those who have been on a waiting list to access them.

The 'experts by experience' (who are either carers or people with ASC) within Hertfordshire Local Authority and I will continue to develop and deliver training packages for mental health frontline caregivers via short courses and workshops delivered by the University of Hertfordshire. It is encouraging that 7% more frontline caregivers, including Registered Mental Health Nurses, have received autism training since the previous autism self-assessment in 2014 (Public Health England, 2016).

The progress report, *Think Autism: the updated strategy for adults with autism in England*, states that from April 2015, Section 2 of the Care Act (2014) placed a statutory duty on all Local Authorities to provide or arrange '*preventative services*' (pg. 3) for people with autism within their communities. The most recent progress report identifies that Local Authorities have interpreted what 'preventative services' means and how this can be actioned within their local communities.

According to the National Development Team for Inclusion (2012) much work has been done to enable easier access for people with learning disabilities and autism. The report, '*Reasonably Adjusted? Mental Health Services for People with Autism and People with Learning Disabilities*', highlights many services that can demonstrate and provide examples of reasonable adjustments; for example, services have created accessible information sheets and video materials, have redesigned buildings and processes, and have obtained feedback from people and their family carers. However, upon examination it becomes evident that the vast majority of adjustments made are for those people with learning disabilities, and very little is written about the changes made to accommodate those with ASC and without a learning disability.

The author and autism commentator Luke Jackson spoke about his experience of having Asperger's and explains, from his own perspective, why people with ASC and without a learning/intellectual disability are often not seen as a vulnerable group within our society:

> "*People have always seen me as the same but different, the same in that I'm not disabled, and different because I am autistic. I recall a social worker saying to me that I have my*

own home, a career and I am high functioning, therefore why would I need a social or healthcare needs assessment? I told her because I spend huge amounts of time every day in a perpetual state of anxiety, but I was stressed out by pretty much everything! Running my own home and holding down a job may look easy, but I can assure you it is not!" (Jackson, 2016; unpublished conference paper).

Think Autism: the updated strategy for adults with autism in England (2016) reported that awareness of autism within public services has increased significantly (DoH, 2016). Much of the credit for this increased awareness lies with the NAS and other national charities and organisations which have worked tirelessly to make a difference and to raise awareness. The Autism Alliance UK for example, have worked across eight geographical areas to provide activities with the aim of increasing autism awareness for people who work in retail, leisure and public services. They have focused on developing partnerships with Local Authorities, other partners, local services, businesses, retailers and people with autism. NAS target places of work and businesses every year during their 'World Autism Awareness Week', when they acknowledge that awareness has been significantly raised over the last 10 to 15 years; however, with only 16% of autistic adults in full-time paid employment, there remains a great deal more to do (NAS, 2018).

2.10 Summary of literature review

The research reviewed, undertaken from both service users' and carers' perspectives, highlighted many factors which appear to have influenced service users' views and experiences of inpatient admission. However, previous studies have focused upon providing thematic or phenomenological accounts of service user experiences and, in doing so, have not considered psychological theory in order to make sense of them. For example, the importance of relationships with inpatient staff has been highlighted by both carers and service users, but this is not explored from a theoretical perspective, which might contribute to a greater psychological understanding of how these factors impact upon the service user inpatient experience. It is therefore proposed that the factors contributing to service users' experiences as identified in the existing literature may be understood by drawing upon social constructionist, systemic and attachment theories: these approaches are considered useful in making sense of the results obtained within the current study.

The grey literature in this review identifies the need for specialist services, and different consideration for people with ASC, within public services. Whilst there is endeavour by national government and several Local Authorities to enhance service provision and improve upon the service user experience for users with ASC, there remains a great deal to be done. The challenge for the future is to spread these pockets of good practice into every mental health service and every encounter between staff and the people with ASC whom they support.

a) Conceptual and theoretical underpinning

The literature reviewed indicated that service users' understanding of different parts of their admissions, and the perceptions attributed to them, influenced their reflections on their experience. Service users' thoughts were influenced by a range of factors, including their relationships and interactions with other service users, staff and family (Donner et al, 2010; Parkes et al, 2007; Bunyan et al, 2017; Spencer et al, 2019; Robertson et al, 2018; Acker, 2018). Social constructionist approaches propose that individuals

develop subjective thoughts and meanings to their experiences; these meanings are varied and multiple, leading the researcher to look for the complexity of use rather than to narrowing the meanings into a few categories or ideas (Mason, 2014). The goal of the researcher, then, is to rely as much as possible on the participants' views of the situation, which are not simply imprinted on individuals but are formed through their interaction with others (Creswell, 2013). In the current study, 'the others', mentioned (Creswell, 2013) above, refers to other service users, unit staff and carers. The impact upon the service users' relationships with staff, influenced by their experiences of control, inclusion and being heard, was also indicated in the research reviewed (Donner et al, 2010; Dunn, 2012; Spencer et al, 2019; Bunyan et al, 2017). In accordance with social constructionism thinking, systemic approaches propose that individuals are connected in relationships with one another and that experiences are constructed and understood in relation to a given context (Creswell, 2013; Berger & Luckman, 1966).

Attachment theory (Bowlby, 2005) also underlines the influence of relational factors upon experiences, particularly experiences of separation, loss and safety. Bowlby (2005) proposed that, in response to periods of feeling threatened or anxious, individuals seek out attachment figures. This model may therefore provide a useful framework for considering service users' and carers' responses to being separated as a result of admission, their desire to maintain contact, and the emotional and spatial proximity involved in the service user experiences (Bee et al, 2008; Bunyan et al, 2017; Spencer et al, 2019).

The nature of relationships between service users and inpatient unit staff may also be considered within an attachment perspective. The research reviewed suggests that some inpatients have significant dependence on staff to meet their social and emotional needs: it may therefore be considered that these could be conceptualised as attachment relationships for the service users (Chaplin, 2004; Parkes et al, 2007). However, the research reviewed also suggests that there is a problem for service users with ASC to formulate such relationships that could be deemed as dependent or therapeutic (Beardon & Worton, 2012; Bunyan et al, 2017; Narendorf et al, 2011). These theories form the underpinning of a framework for the research and will be expanded upon in Chapter 3.

b) Literature limitations

The literature review uncovered a scarce number of qualitative studies related specifically to the inpatient experience, there is a critically unanswered question of why there is a shortage of research exploring inpatients experiences, albeit in mental health, learning disability or ASC specialist services in the UK. Many studies recommend that perceptions of the inpatients be sought yet the larger scale research studies tended to focus on staff viewpoints.

Whilst critically evaluating my own literature search strategy, it is apparent that my initially selected search terms limited my ability to unearth relevant areas of research. This was an attempt to stay as close to the phenomenon and therefore as relevant as possible. Retrospectively it is clear that this strategy limited the literature review and consequentially more recent additions have been included, i.e. research papers that may not be as specific to the inpatient experience intrinsically and therefore may

not have entirely met the inclusion criteria which allowed them to progress to final selection, but instead are included to enhance the discussion within this chapter which has given this research project greater rigour of examination in areas important to the relationship between autism, mental health and mental health inpatient units in particular.

Limitations of the selected papers in this literature review are summarised in **Appendix 1** with specific issues identified in relation to methodological confines and limited description of service settings and sample bias as examples. The following limitations were highlighted by using the Quality assurance framework used in **Table 3 (**Northcote, 2012). From the health services and inpatient facilities reviewed within the studies, (Murphy and Mullens; 2017 ; Parkes et al, 2007; Spencer et al, 2019; Bunyan et al, 2017; Donner et al, 2010), whilst others had similarities, for example learning disability inpatient units and specialist autism inpatient units (Bee et al, 2008; Chaplin et al, 2006; Hall et al, 2006; Slevin et al, 2008). Dunn (2012), Robertson et al (2018) and Acker (2018) considered autistic experiences away from inpatient services and they provide important insights into the lived experience of those with ASC who suffer from anxiety. However, the reported anxieties in these studies were not necessarily driven by inpatient experiences. Additionally, there are distinct differences between the different types of inpatient and healthcare facilities discussed which would come with their own unique set of challenges; learning disability services would utilise a different model of care for example, which could alter the lived experience significantly compared with the reviewed mental health inpatient units.

The notable difficulty in undertaking qualitative research with people who have either an ASC, learning/intellectual disability or mental illness is the ethical requirement for participants to have a level of cognitive and communicative ability to provide informed consent to participate in the research process. Consequentially, the findings discussed chiefly reflect the views of service users who can give consent; the generation of themes identified in these studies may be specific to this population, therefore run the risk of excluding those with more significant intellectual disabilities or cognitive limitations who may be less able to consent or to communicate to a level in which they can engage in such research. Acker (2018) justifies only focusing upon adolescents with 'high functioning' ASC by claiming that the existence of anxiety is more prevalent than people with ASC who have lower intellectual ability, the evidence provided for this claim is challengeable. This is particularly relevant in understanding the differences between service users' experiences of mainstream mental health services compared with those of specialist ASC or learning disability services where the wider service user population is more likely to have a greater degree of learning disability compared to the participating service users. In addition, interviews in several studies were conducted with service users at three years post discharge, thus introducing the potential for limited recall associated with the duration of time elapsed since admission (Donner et al, 2010; Parkes et al, 2007).

Of the 12 selected studies discussed within this review, two provided an interpretive analysis of the data using IPA (Donner et al, 2010; Acker, 2018) with other studies providing thematic investigation of the data (Slevin et al, 2008; Bunyan et al, 2017; Chaplin, 2004; Dunn et al, 2012; Hall et al, 2006; Parkes et al, 2007; Murphy and Mullens, 2017; Robertson et al, 2018). However, critical appraisal exposed that only four papers provided an appropriately thorough and transparent description of the process of

analysis and inclusion of strategies to safeguard credibility checking (Donner et al, 2010; Acker, 2018; Murphy and Mullens, 2017; Robertson et al, 2018). Furthermore, whilst the main studies offered a thematic understanding or interpretation of service users' and carers' views and experiences, there has been little attempt to synthesise this into a theoretical model or framework to enhance understanding of this phenomenon and/or its surrounding topics.

A further methodological constraint emerges from the sampling bias, which has occurred because of service providers managing the recruitment process. Whilst it is recognised that it would be unethical for researchers to make an initial approach to service users, Donner et al (2010) and Dunn (2012) may have been influenced to some degree by the presence of support staff during interviews. This review of the literature identifies that the carers offer a useful perspective and can contribute meaningfully towards understanding service users' experiences. However, it is important that the carers can provide a dependable account of the service users' experiences if they are to contribute to our understanding of this, at times when perspectives were compared, they differed considerably, which can question the extent to which the carers can accurately describe autistic experiences (Robertson et al, 2018). The extent to which carers in the research reviewed were involved with services and service users during periods of admission were limited, and therefore their ability to comment on the service users' experiences remains limited (Slevin et al, 2008; Chaplin, 2004).

Five of the studies included only participants with ASC (Dunn, 2012; Murphy and Mullens, 2017; Robinson et al, 2018; Acker, 2018; Donner et al, 2010). Whilst other papers acknowledged having people with ASC within their sample but did not specify how experiences differed between their autistic or non-autistic participants. For example, Chaplin et al (2006) used a mixed methods approach to question 156 inpatients/former inpatients of learning disability and specialist autistic inpatient units, a large sample with the potential to provide credible and useful information, but it is reported generically without specifics relating to autistic participants and therefore little is understood of the autistic experience and how it may differ from others. Others failed to specify how many of their participants were diagnosed with ASC (Hall et al, 2006; Slevin et al, 2008). Although more recent studies made suggestions that people with ASC were involved in designing and/or been involved in undertaking the research. However, there is a lack of clarity when describing the impact this may have had on the overall study (Spencer et al, 2019; Acker, 2018).

c) Literature impact

The current study supports the statutory guidance that is afforded to local authorities and the NHS by the Autism Strategy (DoH, 2010). The policy states that achieving greater knowledge and understanding is crucial to the impact of delivering accessible and meaningful services to people with ASC (DoH, 2010). Bunyan et al (2017) explored patients' experiences in mental health hospitals and this paper helped me to understand the potential pitfalls of generating data using focus groups with inpatients. The authors were not satisfied with the data engendered by the focus groups alone and decided to follow up the groups with individual semi structured interviews in order to gain greater insight into their experiences. I had previously considered using focus groups as the tool for generating data within this current study, but instead decided upon pursuing pilot face-to-face interviews for which I don't

have any regrets and feel much of the in-depth disclosures would not have been offered in a group situation.

Chaplin et al (2006) provides evidence that inpatients struggle, whether they have autism or not, with the physical environments which they found problematic and violence is commonplace. The current study builds upon this evidence and looks deeper into the issues that result in extreme behaviours which many of the practitioners in the study by Chaplin et al (2006) accept as part of the inpatient culture. Dunn (2012) demonstrated the need for staff training and greater awareness of autism. Interestingly, despite a further five years after the Autism Strategy (DoH, 2010), which indicates strongly that front line caregivers should undertake mandatory training, this current study provides evidence that little has been advanced in this area of need.

Parkes et al (2007) explored the views of service users who had a learning disability and occupied a bed dedicated to patients with a learning disability within a unit which was predominantly used by mental health patients without learning disabilities. Comparisons to the current study can be drawn as these few inpatients with LD felt different and frightened, as did the participants in the current study. However, Parkes et al (2007) describe participants as being in possession of social skills which allowed them to overcome the feeling of being different and make positive relationships with staff and fellow inpatients, the stark difference to most of the participants in the current study who were not able to overcome the feeling of being an outsider and experienced isolation and fear continuously throughout their hospital stay. Murphy and Mullens (2017) whose ASC participants were without a comorbidity of a learning disability also found relationships with other inpatients to be poor, with a high incidence of reported aggression between them. In some cases, conflict was frequent enough for the nursing teams to effectively segregate the patients with ASC.

Slevin et al (2008) described their participants with learning disabilities as becoming calmer following an admission to an inpatient unit i.e. challenging behaviours and mental health problems were significantly reduced after the patient had been admitted. Again, this is unambiguously different from the experiences of many of the participants within the current study whose behaviours increased dramatically when first admitted. Robertson et al (2018) and Acker (2018) increases understanding of the drivers of anxiety in people with ASC, finding that uncertainty and change have a significant impact often resulting in unmanageable behaviours.

In summary, this Chapter 2 has provided a structured review of literature on inpatient experiences. It has highlighted the dearth of existing research that specifically aims to highlight the perspective of service users with ASC about their inpatient experiences, thus strengthening the need for the proposed research. In undertaking a review of the literature, key methodological issues have also been uncovered, which the design of the current study will aim to address. The following Chapter 3 now moves on to provide a methodological overview, including the naturalistic paradigm which has been fundamental to my initial thoughts and developments of this current study. It will explain how the process has been influenced by the thoughts and philosophies of social constructionism, systematic dynamics and attachment theories and how using interpretive phenomenological enquiry has influenced the research design, data collection and data analysis. Chapter 3 also provides a discussion of the theoretical frameworks employed within the current study and those which have not been directly implemented but

which have had an influence upon thinking and research construction. The qualitative and interpretive phenomenological analytical processes are explained step by step, with a rationale for each stage, each supported with an evidence-based structure. Consideration has been afforded to how the data for this current study have been interpreted and influenced by external and internal factors. The research participants and their characteristics are described in detail together with the sampling and recruitment strategies undertaken by this current study. Additionally, the ethical considerations are discussed and explored, including how the participants consented and were adequately informed of this study and its implications for them and future practice.

Chapter 3: Methodology

Chapter overview

This study uses qualitative research in the naturalistic paradigm, influenced by social constructionism and using interpretative phenomenological enquiry to explore the emotional and psychological experience of inpatients with ASC. Face-to-face semi-structured interviews facilitated access to participant experiences for inductive analysis. The overall aim was to explore the emotional and psychological experiences of patients with ASC during their time in mental health inpatient units. I have selected the qualitative methodology of Interpretive Phenomenological Analysis (IPA), as developed by Smith and Osborn (2008), to meet these research aims. This Chapter 3 explains the rationale for the use of the employed methodology, detailing participant recruitment, data collection, data analysis, and summarising the steps I have taken to adhere to ethical and quality guidelines.

3.1 Research Design

The overall approach to this research lends itself to phenomenology within a naturalistic *worldview*: I am interested in how patients with ASC experience the inpatient units and their time spent there, with a view to get as close as possible to their perception of events and experiences within the inpatient unit. Lincoln and Guba (1985) describe naturalistic research as 'pattern theories', i.e., rather than a theory deducted from data, as in qualitative studies, pattern theories or generalisations represent interconnected thoughts or parts linked to a whole. Changing views are subjective and are concepts, rather than facts, which are integrated into a theory which can be considered as highly applicable but as not always factual. The Research Design Framework schema (Figure 3.1) below helps to identify the flow of research design, epistemology and theoretical perspectives considered.

Figure 3.1: Research design framework (adapted from Crotty, 2013)

A variety of possible theoretical frameworks could be used to contextualise this study and position it theoretically. According to Burr (2003), social constructionism maintains that we need to take a critical stance towards taken-for-granted knowledge and to be cautious about the idea that there is an objective, un-biased view of the world. The ways in which we commonly understand the world, the categories and concepts we use, are historically and culturally specific knowledge which is sustained by social processes, and our

knowledge of the world is constructed between people. Knowledge and social action go together, suggesting that each construction brings with it, or invites, a different kind of action from human beings.

Additionally, the widely considered founding fathers of social constructionism, Berger and Luckmann (1966), suggest that the central concept of the Social Construction of Reality is that persons and groups interacting within a social system create concepts or mental representations of each other's actions, and that these concepts eventually become habituated into reciprocal roles played by the actors in relation to each other. Therefore, we should assume that a sudden change of environment, i.e. an admission to a psychiatric unit, would alter the process of institutionalisation considerably and, essentially, the process would begin again, potentially presenting very different behaviours and actions which could be due to the environment rather than to a person's neurological or psychiatric condition. Early indicators from the data analysis suggest that the early part of the admission process, i.e. the first few days spent on the unit, are the most stressful. There are clear patterns within the data that demonstrate the existence of heightened anxiety and aggressive behaviours during this time. With or without autism, this would be a confusing time for most of us: many of the participants have discussed the need to find their place within the unit and this new social system in which they find themselves.

Burr (2015) suggests social constructionism forces us to examine our own understanding of social constructs and consider how they may differ between social actors involved in the same scenario and social situations. For example, the inpatient experience through my eyes, or the perspective of the inpatient nurse would potentially be very different to that of the inpatient themselves. Therefore, it is important to understand my own perspective and understand the impact that perspective has on this research and its participants.

Bryman (2012) highlights the uses of reflexivity as a way of attending systematically to the context of knowledge construction, a researcher's background and position will affect what they choose to investigate, the angle of investigation, the methods judged most adequate for this purpose, the findings considered most appropriate, and the framing and communication of conclusions. Crotty (2013) Suggests that social constructionism emphasises the hold our culture has on us: it shapes the way in which we see situations and gives us a definitive view. This would include all the people who are participants in this study. Whether they have or have not, shared the same experiences they would almost certainly hold different views of the world especially with regards to inpatient mental health care.

Burr (2015) indicates that language is central to the ideas of constructionism. Because our understanding of the world and each other is socially constructed through our interactions with each other, especially in our use of language, and that our thinking rests on the rhetorical use of concepts and assumptions which are embedded in language. Social constructionists hold the idea that language is structured into a number of discourses and that people can only construct their world according to the discourses available to them. These discourses are described as systematic, historically and culturally specific and therefore dependent on gender, age, social class and personal experiences. In this sense, constructs and language can be interdependent rather than one driven by the other. Therefore, my constructed view of an inpatient experience would be influenced by my experiences as a worker within such environments, but also by my gender, social class and understanding of mental illness as well as my rhetorical articulation of my understanding of the

experience. Some of these perceptions have altered with experience, increased knowledge and understanding. It is my belief that mental health is becoming a less taboo topic of conversation and as a society in the UK we are more sympathetic to mental health sufferers today than previously. Perhaps unwittingly this has impacted upon the views of myself and the participants perceptions so as a researcher I tried to limit the impact by being fully attentive to the participants' stories.

3.2 A qualitative approach

As demonstrated within the literature review in Chapter 2, there is a dearth of qualitative research into experiences that cause mental health instability for people with ASC; the studies that do exist are largely reliant upon others observing differences in behaviours and very little is known and understood about the views of the patients with ASC themselves.

The aim of this study is to capture, in-depth, the experiential nature of the inpatient experience. For this I have adopted a qualitative methodology, due to the inherent benefit of allowing a detailed study of phenomena that are not easily quantifiable by quantitative methods, but which are more accessible to explorative research that also promotes the emergence of anticipated findings. To best facilitate an exploration of the patients' experiences, I have used semi-structured interviews, which Smith et al (2013) argued encourages flexibility and yields in-depth data, thus allowing exploration of interesting, important ideas that are expressed by the participants in the interviews. The semi-structured nature of the interviews may also be best suited to allow the researcher flexibility in aiding participants with ASC to engage effectively with the topics of enquiry.

3.3 Phenomenology

Phenomenology is concerned with how knowledge of the world is grasped by human beings (Ricoeur & Embree, 1967). It is interested in lived experience, what the experience of being human is like in the numerous aspects that are significant to us and which constitute our lived world (Smith et al, 2013). The founding principle is that experience should be examined in the way that it occurs and in its own terms. Bryman (2012) suggests there are many different emphases and interests amongst phenomenologists, but they all have a shared interest in thinking about what the experience of being human is like, in all its various aspects, but especially in terms of the things which matter to us and which constitute our lived world. Phenomenology is significant to this current study's participants as it offers an opportunity to express themselves as a sole voice which is not diluted or impaired by the voices of others, to give the true account of the phenomenon that only they are qualified to give.

Ree (1997) explains Martin Heidegger's theory of the 'they-self' instead of 'our-self', i.e. Heidegger felt that people had forgotten how to live their lives for themselves and instead lived for others and adapted their personalities to suit the needs of others. It could be argued however that people with ASC would often fit into Heidegger's 'our-self' description of people being able to live their lives for them and not others. Howlin (2005) describes people with ASC as 'a law unto themselves' meaning that they behave in an independent way, ignoring laws, rules, or conventional ways of doing things. This is influenced by Baron Cohen's (1996) theory of mind which indicates that people with ASC are unable to recognise and understand the thoughts,

beliefs, desires and intentions of others and therefore less inhibited by them (Howlin, 2005). However, if you remove somebody's freedom and stop their independent way of doing things and place them into a narrow social milieu surrounded by rigid attitudes then there is a requirement for them to become in Heidegger's eyes 'they-say', in order to survive within their new unfamiliar surroundings, in this case a mental health inpatient unit.

Husserl and Welton (1999), argued the importance of 'going back to the things themselves', the experiential content of consciousness, alluding that this approach allows us to circumvent people's tendency to 'fit things' within our pre-existing categorisation systems. This issue is particularly relevant and significant to the experience of inpatients with autism, which exist in an environment dominated by pre-existing classifications and labels such as 'self-injurious' or 'challenging behaviours'.

3.4 Interpretive Phenomenological Analysis

Interpretive Phenomenological Analysis (IPA) aims to explore, in detail, how participants make sense of their personal and social world. According to Smith (2008), the main currency for an IPA study is the meaning that experiences and events hold for participants. Using this approach in this study, I will aim, as far as possible, to understand the phenomenon from an insider's perspective. The use of the six steps of IPA as identified by Smith et al (2013) – i.e. reading and re-reading; initial noting; developing emergent themes; searching for connections across emergent themes; moving to the next case; and looking for patterns across cases, assisted in the formulation of a planned examination of the generated data.

Table 4- Outline of IPA procedures

Stage	**Procedures**
1	Formulate research questions based on experiences and/or understandings of a certain phenomenon and acknowledge researchers' subjective perspectives.
2	Choose a homogenous sample with experience of the phenomenon.
3	Conduct semi-structured interviews with participants and transcribe the interview data.
4	Analyse interview data by: a) reading first transcript line by line; b) noting descriptive comments in the left-hand margin; c) noting emergent themes in the right-hand margin; d) repeating the same process of all transcripts; e) identifying emergent themes across accounts; f) clustering themes into a list of master (superordinate) and sub themes.
5	Produce narrative accounts of experiential themes using excerpts of participants own words to exemplify their attitudes and experiences.
6	Link identified themes back to existing research and read acknowledge researchers' subjective perspectives.

IPA is embedded within three philosophies of knowledge: phenomenology, hermeneutics and idiography (Smith & Osborn, 2008). In this section, I will illustrate how these underpinning ideas are both relevant to the experiential focus of the patients with ASC and their experiences within psychiatric care. Hermeneutics is the theory of interpretation (Schleiermacher & Kimmerle, 1977), focusing the researcher on the methods and purposes of interpretation itself to uncover the intentions or original meanings of the author or, at least, as 'closely' as possible. For example, any data interpreted from interview transcripts can be influenced by the notions of grammatical and psychological interpretation, the former being concerned with exact and objective textual meaning, the latter with the individuality of the author or speaker. It is very true to say that data drawn upon from interviews with people with ASC are at a high risk of being misinterpreted by a researcher who is external to the group and the experiences being studied (Elwin et al, 2012). Schleiermacher (1998) describes ideography as being concerned with the particular and the individual: this entails a commitment to detail, depth, and that analysis must be systematic. It also refers to understanding how particular experiential phenomena (a process, relationship, or event) are understood from the perspective of people within a context, thus avoiding universal generalisations (Faulkner & Bee, 2017). We should not assume that all the experiences of the participants in this study are negative or alike as the individual perceptions are very different, although some nomothetic patterns may exist. This in-depth consideration will increase the relevance to this study, which exists in a field dominated by generalisations across people and services.

Finally, at its simplest level, the participant experience is a subjective process. Who the patient/service user is, how they perceive their role, whether they make sense of it as being treated, cared for or incarcerated, how they relate to health care professionals, carers and other service users, how this relationship is experienced, and where their sense of identity lies, will all make the experience multi-faceted and personally exclusive to them. Furthermore, the qualitative framework described above connects firmly with the social constructionist nature of this research and undertakes a detailed examination of the individual's personal experiences and perceptions, whilst considering the social context of these experiences from a critical psychological perspective.

Social constructionist philosophy is compatible with IPA methodology, as IPA explores the participants 'interpretations' of their experiences, whilst acknowledging that this is being interpreted by the interviewer and analyst. My questions have highlighted certain areas above others and participants have talked about some aspects of their experiences and not others. I view the experiences as being constructions of something that has happened in an objective reality.

a) Suitability of IPA in autism research

Prevalent amongst ASC theory is the concept that autistic people have impaired 'theory of mind' i.e. the ability to imagine the thoughts and feelings of others, in order to comprehend and predict their behaviour (Baron- Cohen, 2014). Whilst it is true that autistic people can struggle to process and understand the intentions of others within social interactions, when one listens to the accounts of autistic people, one could say such problems occur in both directions. The theory of the 'double empathy' suggests that when people with very different experiences of the world interact with one another, they will struggle to

empathise and understand each other (NAS, 2017). MacLeod et al (2017) validated the use of IPA with autistic students by suggesting that IPA necessitates a respect for the participants and their perspective, providing a strong platform to understand the 'double empathy' problem. The application of the IPA procedures illustrated in **Table 4,** gives the researcher the opportunity to consider data from different perspectives and allows the researcher to focus on the particular, I anticipated some varied experiences between the participants I would be interviewing, and I wanted a method that would capture the individual voices as well as the experiences they have in common.

Within its small and purposive sample IPA research does not aim to be generalisable to whole populations but may illuminate autistic experiences in a way that other qualitative approaches do not (Howard et al, 2019). This may be challenging to researchers who have trained in empirical methods that emphasise a positivistic approach to epistemology (Willig, 2008). While IPA shares many characteristics with grounded theory, which seeks to generate a theoretical explanation of a phenomenon or process, the frameworks differ in key areas. IPA arguably offers the researcher greater flexibility and creativity in a choice of methods and broadly speaking seeks to answer psychological rather than sociological questions (Willig, 2008). In this sense IPA may provide a more useful framework for understanding how individuals experience autism, focusing on the lived experience and, using language as the medium of expression poses greater depth of insight but also challenges (Howard et al, 2019).

The challenge of using language as the medium may be particularly true for research conducted with the autistic population. Dewinter et al (2017), for example highlights that limited expressive language and overly formal language of some participants in their study restricted the richness of their data. Therefore, if IPA is so fundamentally bound to the elicitation of the voice, questions may well be raised as to whether it can be a justifiably useful tool for autistic individuals with language difficulties. To that end, it is acknowledged that while traditional forms of IPA may represent a useful methodological framework for some autistic participants it will not be appropriate for all. Instead other methods of data collection such as diaries and drawings, as well as photo elicitation (Williams, 2004; Stephenson and Adams, 2016; Petales et al, 2015), may be increasingly useful methods in IPA studies with autistic participants and though I considered these, I decided to limit my data collection to interviews due to being a relatively inexperienced IPA researcher, this appeared to be a safer option.

3.5 Other considered qualitative methodologies

This current study considered the following qualitative methodologies before a decision was made to move forward with IPA: Grounded Theory, Discourse Analysis and Narrative Analysis were all considered earlier in the process. IPA was preferred over Grounded Theory, which attempts to draw upon wider conceptual and theoretical explanations of psychological phenomena as opposed to capturing the personal experience (Smith et al, 2013). IPA was preferred over Discourse Analysis, although there are similarities in regard to the importance of language to IPA and the attention to detail required in the analysis of transcriptions. IPA undertakes a different analytical angle to conceptualise sense-making and meaning-making in experiences (Smith et al, 2008). Narrative Analysis was considered, given its focus on how people construct their own accounts (Barber, 2014); however, because of its strong focus on the narrative and only one way of meaning-

making, IPA was chosen as it can take narrative into consideration as part of a wider process of sense-making without being inhibited by essentiality (Smith et al, 2013). As IPA requires a reflexive attitude from the researcher, language used in IPA research may be expressed by using first person, personal and informal (Shaw, 2010).

3.6 Population

The national profile of people with ASC who need psychiatric inpatient care and who are without intellectual/learning disability is described as a group who are potentially vulnerable to exclusion from health and social care services (Department of Health, 2014). Consistently, within this population people live largely independent lives: many live on their own, undertake employment or education opportunities and interact with support networks, whether family members or advocacy/support groups. Many are not known to health and social care professions until the point at which their mental health needs becomes a crisis (National Autistic Society, 2012).

The demographics of this population are wide and varied i.e., there is no higher prevalence of people with ASC from different economic, cultural or specific ethnic backgrounds (NAS, 2012). There are, however, some reported gender differences, with commentators reporting on a higher male: female ratio (Baron Cohen, 2009; Howlin, 2005). The ratio has been reported as 4:1 in favour of males (Baron Cohen, 2009; NAS, 2012). NAS (2015) reported the ratio of men to women supported by the population within their adult services was approximately 3:1 in favour of males, and the ratio of boys to girls in their charity's schools was approximately 5:1.

Dean et al (2017) suggest that care must be taken when making assumptions in regard to lower numbers of women being diagnosed with ASC. Their study examined the extent to which gender-related social behaviours can help girls with ASC to mask their symptoms. The results indicate that the female social landscape supports the camouflage hypothesis; girls with ASC use compensatory behaviours, such as staying in close proximity to their peers and weaving in and out of activities, which appears to mask their social challenges. Comparatively, the male landscape made it easier to detect the social challenges of boys with ASC: typically, developing boys tend to play organised games; boys with ASC tend to play alone. The results highlight a male bias in this perception of ASC. If practitioners look for social isolation on the playground when identifying children with social challenges, then our findings suggest that girls with ASC will continue to be left unidentified. Based upon the premise that in this population there are four males to every one female and using the NAS (2018) approximated figure of 700,000 people with ASC in the UK, then 560,000 of them are male, and 140,000 are female.

3.7 Research Participants

a) Inclusion criteria

i) Service criteria

The inclusion criteria for services were that they must be a nationally registered inpatient unit, with a Care Quality Commission (CQC) certification, providing 24-hour care which is specifically designated to care for people with mental health problems, and admitting patients between the ages of 18 and 65 years. The unit cannot have a specialist designation, for

instance being a dedicated service for people with ASC, learning disabilities, physical problems or dementia. The unit must be part of a charity, private organisation or the NHS. The rationale for this narrow focus is that this current study is designed to examine the experiences of mental health inpatient services and not of those belonging to other related fields.

(ii) Participant criteria

Participants must be formally diagnosed with an ASC, most patients with ASC in the UK will have been diagnosed according to the Diagnostic and Statistical Manual - Fifth Edition (DSM-V) (American Psychiatric Association, 2013) or the International Classification for Diseases (ICD-10) (World Health Organisation, 1990), or previous versions of these. Specialist clinical psychologists or psychiatrists are the only healthcare professionals who can diagnose ASC formally in the UK, although other members of the multidisciplinary teams can be involved in the diagnostic process (NAS, 2018). The latest edition of the DSM-V was published in 2013 and has made some important changes to the classification of ASC: one of the most significant changes is that the separate diagnostic labels of Autistic Disorder, Asperger's Disorder, and Pervasive Developmental Disorders Not Otherwise Specified (PDD-NOS) are replaced by one umbrella term, '*Autism Spectrum Disorder*.' It is also important to note that, in the UK, the terminology of *Autistic Spectrum Conditions* is preferred by those with the condition as compared to the DSM's terminology of '*Autism Spectrum Disorder*' as noted within both the Autism Act 2009 and Strategy (DoH, 2009, 2010); therefore, ASC is used within this current study.

Currently, the World Health Organisation is reviewing their diagnostic manual, the *International Classification of Diseases* (ICD-10) and the new version (ICD-11), published in June 2018, includes a category as follows: '*Autism spectrum disorder without disorder of intellectual developments and without impairments of functional language*'. This category would typically apply to the participants in the current study. Generally, the autistic diagnosis for this group would be Asperger's syndrome or High Functioning Autism, although six have declared their diagnosis as *Atypically Autistic with a mild to moderate Intellectual Disability*. Their mental health diagnoses are varied, but most prevalent within this current study's sample are generalised anxiety disorders and depression.

The participant would have spent longer than two consecutive weeks in a mental health inpatient unit: the rationale here is that less than two weeks would not give a person enough time to be able to explain their experiences and thus provide sufficient meaningful data. The participant must have been admitted to the unit either informally or formally under the Mental Health Act (1983) and they can have been admitted for any mental health-related reason. Participants must be English speaking: as qualitative research relies heavily on language, there is a concern that the richness and meaning of language may have been lost if using a translator; also, on economic grounds, there was limited finance available to support this student research.

There were no disability, gender, religion or sexual orientation restrictions for participants: therefore, the sample did not exclude those with a comorbidity of a learning disability, and provisions were put in place to ensure that additional communication needs were met, among other potential requirements. Due to the potential distress that being involved in this study may have caused, those who were receiving mental health treatments or who were unable to provide informed consent were excluded from the study. Additionally, the age of the participants was over 18 years, and their diagnosis of an ASC, although self-disclosed, would need to have been given by an appropriate health professional, (i.e., clinical psychologist or a psychiatrist) and this was verbally verified by the participants themselves. A summary of the inclusion and exclusion criteria is provided in ***Table 5*** below:

Table 5- Summary of inclusion and exclusion criteria

	Participants	**Service**
Inclusion criteria	formal ASC diagnosis spent longer than two consecutive weeks in a mental health inpatient unit admitted to the unit either informally or formally under the Mental Health Act (1983) can be admitted for any mental health related reason. participants must be English speaking as 1st language, or fluent.	nationally registered inpatient unit with a Care Quality Commission (CQC) certification providing 24-hour care specifically designated to care for people with mental health problems admit patients between the ages of 18 and 65 belong as part of a charity, private organisation or the NHS
Exclusion criteria	those who were receiving mental health treatments at the time of the study unable to provide informed consent	specialist designation, e.g. being a dedicated service for people with ASC, learning disabilities, physical problems or dementia

b) Biographies

The following section presents a biographical presentation of each participant in the study, has captured the character of the person and embedded this uniqueness within the context and anonymity of their unique story. Each person's illustration forms part of the person behind the lived experience of their inpatient involvement and includes a range of information which could be useful for the reader to contextualise this experience within their lives.

Lucas

Lucas is a 24-year-old man who had been diagnosed with ASC in his early teens, although he believed that his "mental problems" started on his first day at school. His recollection of

early school experiences was being “systematically bullied by teachers and pupils alike” and by the time he left school he felt completely traumatised, had no self-esteem, no sense of self-worth and no self-confidence. Lucas regarded himself as very bright and academically able, but left school without any qualifications and has struggled to hold down meaningful employment ever since.

He lives alone, although before the latest of his three admissions to mental health inpatient facilities, he lived with his mother with whom he has a close relationship. Prior to his recent admission he experienced increased anxiety leading to suicidal ideation, his mother felt unable to support him and it was agreed that upon discharge he would move into a supported living environment, essentially a self-sufficient flat within a supported unit. We conducted the interview for this current study in his flat which was very presentable and well-kept. Lucas seemed very proud that he had moved away from his family’s home and was now living a life with more independence.

Charlie

Charlie is a 22-year-old female who is well known to police having been arrested on numerous occasions for aggressive, sometimes violent behaviours, some of which she has been charged. Her complex diagnosis including Asperger’s syndrome, bipolar disorder, eating disorders and depression, are in her opinion to blame for her erratic behaviour and constantly finding herself “in trouble with the law”.

Charlie had five previous mental health facility episodes on five separate occasions and each time she told me that she picks up a new diagnosis but doesn’t seem to lose any. She had an apparent distrust for doctors and clearly disbelieved much of her diagnosis. At the time of the interview Charlie appeared to be calm and without anxiety, she claimed to be “in a good place at the moment”.

Charlie lives in a shared house with four other people, two of which she works with and had met via her employment at the time of the interview. The interview was conducted in the house which was well looked after and a sense of pride about her living environment was easy to detect.

Davy

Davy is a 58-year-old man who is well known to the police and mental health facilities having a reported ten admissions to inpatient facilities all of which have involved the implementation of the Mental Health Act (1983). Davy met me in his own housing association flat which had been partly funded by a vulnerable adult’s charity, Davy explained that the other flats in his block are also occupied by people who are vulnerable, and they looked after each other.

Davy spoke very quickly and in a way that seemed as if he was very anxious to tell me his story, asking me on several occasions during the interview whether I needed to leave soon? He explained to me that he is always “running here and there, and I find it difficult to sit down and relax”. He described his autistic diagnosis as a “Godsend”, explaining that it allowed his very active mind to keep busy, when he stops is “when things start to go wrong in my life and other people’s “. He claims to not be able to work and has not been in meaningful employment for a number of years but has previously worked as a train operator and engineer but lost his job due to his criminal record.

Delta

Delta is a 75-year-old man who was born in Western Europe and has resided in the UK for over forty years. He met his wife, with whom he is still happily married, when she was working in Europe and he moved back to the UK with her. He has never been back to his homeland and has had no contact with his family there. He was diagnosed with Asperger’s syndrome in his early 50s, although his wife said she always knew he was “on the spectrum”. They have a grown-up son who has a wife and two children of his own, all which Delta has a “fantastic relationship”.

He showed me his ‘gaming room’ where he spends many hours of his day playing video games on his Xbox ©, his favourite game being ‘Tour of Duty’©, which is certificated ‘18’ due to its violence content. He claims to use his video games to stop him from acting in a violent way and often acknowledges that they are not reality. Delta worked as a car mechanic before he retired. Cars are clearly his passion and he spent a long time after the interview telling me about the cars he has owned and the alterations he has made to them.

Garry

A 20-year-old man at the time of the data generation and was diagnosed when he was 16. He described himself as “a loner” and explained that he didn’t have any friends, lives with his parents, without employment or education and the only social events he has in his calendar are the local Asperger’s monthly support group meetings where I met Garry for the first time and discussed this study with him. I noted at the meeting he was very quiet and didn’t seem too willing to interact socially. It was also difficult to engage Garry in a conversation beyond the interview schedule, interestingly the data generated from the interview was very rich and the desire for Garry to tell his story was evident.

Garry has a mild learning disability, autism and suffers from a generalised anxiety disorder. He regularly “loses control” of his anxiety, but this has been the only occasion when it resulted in a hospital admission. He was referred for an assessment to be admitted by his father, for which he has not been able to forgive or trust his father since.

Jacob

Jacob is a 35-year-old man with mild learning disabilities and suffers with anxiety which on this occasion resulted in a hospital admission. Jacob works in a warehouse and blames a change in shift patterns to the disruption which ultimately caused rapid escalation anxiety. Without warning the warehouse foreman changed Jacob's shifts from five shorter shifts per week that saw Jacob attending the warehouse Monday to Friday, to three long days per week- Monday to Wednesday. Jacob explained that he felt "at a loose end" on Thursdays and Fridays and didn't know how to occupy his time and establish some structure on those days which was now not at work.

Jacob lives alone in a supported living flat and from Thursday to Monday he told me he felt isolated and "quite depressed", by the time Monday came around and it was time to return to work he described feeling a lack of social confidence to be able to do so. Eventually he began missing days and "got in trouble with the boss", he lost his job two weeks before he was admitted to hospital.

Jan

Jan is a 42-year-old woman who's fifteen-year marriage finished and caused her anxiety to "spiral out of control" which resulted in an admission. She explained that her husband helped her with many aspects of her life, many of which she hadn't realised until he had gone. She told me that she does not blame him for moving away and leaving her as she acknowledged that living with her was "a long way from easy". This was largely due to her autism and the need for sameness and unpredictability, leaving both of their lives to be "very routined" without much "out of the ordinary and interesting experiences". Jan explained that her husband apologised but he could no longer "take it".

Jan continues to live in their married house alone and this is where I met Jan for the interview. I had noted that Jan had photographs of herself and her husband together in the living room and she explained that she had not been able to remove them or any of his belongings that he had left behind. It was clear from the way she was explaining the situation that she was still trying to come to terms with the separation. Jan was able to return to work at her local library after her 4 months as an inpatient, she described her appreciation to her employers for keeping her job open for her, as she values her work very highly.

Olivia

Olivia was 50 years old at the time of our meeting, she is married to her husband of 28 years and has two grown-up sons who have now left home. We conducted the interview in the family home which was very salubrious. Olivia worked as an accountant, she worked from home mostly apart from the occasional meetings with her customers. She describes herself as a "workaholic, who simply loves her job", but her three-month stay in hospital saw her lose her main customer and the account which gave her the most work and the most financial reward. This unfortunately has forced her and her husband to put their house on

the market as they look to “downsize” and make some money to deal with the shortfall caused by the loss of the account.

She spoke of her two sons with great pride, one of them had recently been diagnosed with Asperger’s syndrome the same diagnosis as his mother. She described herself as a good role model for her Asperger’s diagnosed son who has seen his mother largely unaffected by her ASC and explained her love of mathematics which makes her “damn good at my job”.

However, Olivia has now been admitted to hospital for heightened anxiety on three separate occasions, her latest admission was due to a GP referral which resulted in a three-month admission.

Malkey

Malkey was 26 at the time of the interview; he lives in a residential home with 24-hour support with three other young men with learning disabilities and autism. Malkey describes himself as someone with “a good work ethic” and “has high standards” of others. He described others around him, both at work and at home as “lazy” and “they don’t give a shit”. He explained that it is these people that impact upon his mental health as they “really wind me up”.

He was admitted for his most recent of the three mental health inpatient admissions he has experienced, when the police had been called to Malkey’s home. A support worker who works closely with Malkey in his home had been violently attacked by him, causing significant injury. The police had physically restrained him, and he was admitted to a local hospital under the MHA (1983).

Despite claiming to have a strong work ethic, Malkey had been unemployed all his adult life and put this down to people discriminating against him because he has mental health issues. Without any structure to his day, he told me he gets very bored and this is when he finds himself in “trouble”.

Damien

Damien was 50 years old at the time of the interview, he is a family man and lives with his wife and four young children. Damien has been admitted on two separate occasions to mental health inpatient services, both times his wife alerted the local mental health team and asked for her husband to be assessed.

His wife attended the first part of the interview and my feeling was that she thought I was a nurse from the team mentioned above and I was there in a professional capacity. When I explained the purpose of my visit to their home, she left us to it.

Damien works in heavy industry and he owns a building company and described himself as a builder, he was only diagnosed with Asperger's syndrome seven years before the interview and explained that he carries a lot of shame and struggles to "look his mates in their eyes". He has been subjected to verbal abuse regarding his Asperger's diagnosis from both work colleagues and "blokes down the pub", he told me he regretted telling people about his diagnosis. Damien explained that in a working class/building trade culture people didn't have time to worry about other people's problems and mostly he was now perceived as "odd".

Winston

Winston was 25 years old at the time of our meeting, to conduct the interview in his family home which he shared with his parents. Winston comes from an Afro-Caribbean background and described his parents and siblings, who have now left home, as "being very supportive and understanding".

Winston is unemployed but takes on voluntary work which is organised by his church, the work varies and includes helping elderly members of the congregation with shopping and gardening. Winston described himself as "very religious" and explained that his faith acted as a "guiding light" during his admissions and "mental breakdowns". Winston and his family are regular church attendees and he sees them as important members of the church community, a community which overall has been very supportive of Winston through his more troubling times.

However, he has experienced discrimination at the hands of other church goers. An example he gave was being asked not to take part in the Nativity play which he has been a part of since he was a child. The reason given was that his behaviour was too erratic, and he was at risk of scaring the children. Whilst he accepted their position on this, he explained how frustrated and upset he was as a consequence.

Jason

Jason is a man who was 32 years old at the time of our meeting for the interview. Jason is a successful entrepreneur who owns his own security company who specialise in home security systems. He proudly informed me that he had started his own business at the tender age of 21, 11 years later it had grown beyond his expectations and now he employs a team of manufacturers and sales personnel which are big enough to call themselves market leaders. He describes himself as a "tough boss "who is willing to make "tough decisions", citing his businesses success on his ability to "let people go" if they are not performing at the high level that is expected. Interestingly, Jason spoke about his ASC in a positive way when it comes to running a business, explaining that his employees understood his position and "boundaries never got blurred".

However, Jason blames a significant profit decrease for his company as the beginning of an episode of heightened anxiety that ultimately ended with an admission to a mental health inpatient facility. He described the feeling of “losing control” when his profit margins began to take a direction that he had not experienced previously and had not predicted.

Jason lives alone and does not desire a family or a relationship, he is close to his mother who he described as a “worry guts”. Following his discharge from hospital some months before our meeting, his mother would contact him every day and he has appreciated her support.

Maggie

Maggie is a woman who at the time of our meeting was 52 years old and had experienced five separate admissions, all of which have involved the police and the use of the Mental Health act (1983). Maggie didn’t want to conduct the interview in her own home and explained the reasons for this, as she didn’t want me to know where she lived. Her mistrust of the authorities was clear from the outset of our meeting and although she seemed to understand my position as a researcher, she wasn’t detaching me from other professionals that she had dealings with previously.

Maggie explained that she felt her family have disowned her, she had not seen her two children or estranged husband for “years”. Maggie described her behaviour as “anxious, suicidal and continuously in a crisis or another”, which impacts on her ability to hold down a regular job, pay her bills and has experienced some time “living rough on the streets”. Maggie’s experiences of homelessness were “very difficult” and although short lived their psychological impact has been significant and cause Maggie a great deal of anxiety as she is concerned that it will happen again. Maggie describes this cycle of events as being “perpetual” and “impossible to break”.

Prima

Prima is a man who was 45 years old at the time of our meeting. The interview took place in his flat, in which he lives alone. Prima works part-time in a local retail store, a job which was organised for him with the support of the local county council and a team of employment advisers whose aim is to find vulnerable adults meaningful employment. Prima spoke of his gratitude to the team who have been extremely helpful when looking for work upon discharge from hospital, he has been admitted four times.

Prima is from a Pakistani family and was born in Pakistan. He told me of his experience of an “arranged marriage” which brought him to the UK in his early 20s. Prima described the marriage as an “unmitigated disaster”, which broke down “fairly quickly” but not before his wife became pregnant with his son. Prima explains that the breakup of his marriage was the cause of his first admission to a mental health facility.

Prima's parents followed him to the UK shortly after his divorce and although his mother died recently his father remains an important person in his life. Prima was not diagnosed with ASC until is late 20s despite being admitted to hospital in this time period. He described his relationship with his son as "hit and miss", explaining that he doesn't feel his son respects him.

Shannon

Shannon is a woman who was 52 years old at the time of the interview. Shannon met with me and her psychotherapist in a local community centre. She described herself as living in an abusive relationship, with her husband being the abuser. The anxiety caused by the abuse, in Shannon's opinion, has resulted in two hospital admissions, despite the obvious anger she displayed within the interview regarding her abusive relationship, she informed me that she does not plan on moving away from her husband. Shannon described herself as 'vulnerable and without many skills to cope on my own'.

Shannon and her husband had a daughter, who was removed at an early age due to concerns regarding the aggression in the household. Shannon explains that their daughter had been adopted and apart from the occasional letter, they have no contact with her.

Mnamdi

Mnamdi is a black African and at the time of our meeting was 41 years old. His diagnosis was atypical autism, mild learning disability, obsessional compulsive disorder and attention deficit hyperactivity disorder. He described himself as 'a bit of a hermit' and maintains that in his own space and comfortable environment he is an 'enormously placid individual'. His problems therefore seen to stem from times when he needs "reach out to the outside world" and Mnamdi explains that "chaos becomes the expectation" at these times.

Mnamdi arrived in the UK from Africa with his parents and siblings when he was 10 years old. He described his childhood in both Africa and UK as being difficult, bullying was prevalent as was problems with authority. Mnamdi wasn't diagnosed until he was 25 years old and on his 3rd admission to a UK based mental health inpatient facility. When the psychologist first suggested I might be autistic I said, "I can't be autistic, how ridiculous!". He explained that he had always known something was different, but "doesn't everyone think they're different or special in some way"?

Mnamdi has now been admitted 5 times, the last admission lasted 6 months and was described by Mnamdi as "the most horrific and violent so far". He blames his increasing levels of anxiety and inability to cope on his ongoing problems with mental health. But also noted that he feels the mental health units do not know how to treat him.

Francesca

Francesca was a 35-year-old woman at the time of the interview and describes herself as being from a “mixed/dual heritage” with an English mother and an Afro-Caribbean father. Francesca lives with her parents who made the referral to her local mental health team with a view to being assessed for admission. Francesca acknowledges her behaviour is too “disorderly” for her parents to cope with her. They have told Francesca that if the behaviour does not improve significantly then she will have to find alternative living arrangements.

Francesca described herself as having “high functioning autism” and an “extremely high IQ” which her parents found “threatening”. Despite Francesca’s self-described talents she explained that her education and employment experiences have been a “disaster”. Currently she is without employment and has been for over 10 years. Her parents are both working full-time and Francesca explains that she looks after the house, i.e. house work, cleaning and laundry.

Emeka

Emeka is a black African woman who was 38 years old at the time of the data generation for this study. Emeka along with her autistic and learning-disabled diagnosis she is schizophrenic. She described herself as “a nuisance to the police” stating she is “often aggressive to people of authority”. Her latest admission, her fourth, saw her admitted for 6 months on a section 3 of the Mental health act (1983).

I met Emeka in her house which is a residential home for women with autism and learning disabilities, she shares her home with 3 other women, and they enjoy 24-hour support. Emeka explained that this is more support than she requires, and she would welcome a less supported environment which would allow her more independence and autonomy. But she has been informed that due to her ongoing mental health concerns she will be staying there for the foreseeable future. She described the other women she lives with as “stupid” and “far less able than me”.

Emeka also attends a supported daytime service most days, where she has a full timetable of activities. She also spoke negatively about the other people who use this service, again using the word “stupid” to describe them and clearly feels she has been misplaced with a group of people who are dissimilar to her.

Habika

Habika is a black British woman who was 48 years old at the time of our meeting. She presented as a very friendly and socially confident individual who made me laugh throughout our time together. She describes her views on her autistic diagnosis as being “very philosophical” and had decided a long time ago that this was not going to impact on her life negatively, in fact the opposite and she was going to embrace the core features of her condition and use them to her advantage.

She explained that despite her positivity she "comes a little unstuck at the seams from time to time". She describes her relationship with her GP as "crucial" and she "completely trusted his judgement". It was the GP who referred her for assessment prior to her most recent mental health inpatient admission, her 3rd. Habika describes each of her admissions as a "huge build-up of anxiety". Each time her anxiety is caused by something 'very small', e.g. "missing a bus or a bus being late, the supermarket running out of my brand of butter or the bananas not being just how I like them".

It was interesting to listen to Habika mocking herself and seeing the humour in her explanations, demonstrating her ability to understand a different perspective of these "small things" that had triggered a much larger problem for her. Habika lives alone in her own housing association flat and works part-time as a cleaner for a large company which cleans corporate buildings.

Anne

Anne is a white British woman who was 42 years old at the time of the interview. Having a mild learning disability and a long history of community placements breaking down due to aggressive behaviours, Anne is well known to the local community learning disability team. It was the local community learning disability team who made the referral to be assessed for a potential period of admission.

Anne lives in a residential home, which she shares with 4 other women with learning disabilities and/or autism. She has been there the longest and spoke with pride about the house and how well the other residents have done since they arrived, indicating that she feels that she has played her part in their development. I met Anne with her key worker in the home which was a warm and welcoming place. Despite Anne's self-confessed "challenging nature" it was clear that her key worker and other staff I met were fond of Anne with good relationships being obvious to observe. Anne describes her mental health problems as "getting really low sometimes" although could not specify why this happens, Anne explained "I get nervous that I am becoming unwell again and I get angry with everyone".

There were considerable similarities between the participants, including reported issues around self-esteem, accommodation, employment, misdiagnosis and criminal activity. There were also notable similarities between those who had reported to be suffering from low self-esteem and some likenesses to those who had not reported issues around self-esteem and/or told me that they experience healthier self-esteem and self-worth. For example, participants who had informed me that they had issues around their self-esteem were the same participants who told me they experienced poor family and friend networks. Those with higher self-esteem appeared to be the ones who spoke most positively about their autistic diagnosis, were more accepting of their condition and were able to embrace the core features of their condition with more positivity.

Unemployment correlated closely to low self-esteem and was highly represented within the cohort, but many were employed in some capacity before their mental health issues had made it problematic to continue, with few continuing to work and an even smaller number with successful careers. A number of those who are unemployed reported a desire to work but found getting and holding down a job was consistently reported as difficult, some citing societal discrimination as a further challenge. Furthermore, several of the participants now have criminal records which undoubtedly contributes negatively to their chances of gaining meaningful employment. There was a consistent level of blame attributed to their mental health issues when questioned about their criminal activity. Chaplin et al (2013) suggests there are a number of factors that are believed to independently increase the likelihood of offending in individuals including unemployment, mental disorder, substance abuse, being young, male gender and socioeconomic status. However, little is known about how these and other risk factors are associated with people with ASC who offend. Much of the literature on criminality in this group is restricted to case studies often reporting atypical offending that has caught the imagination of the media such as stalking and Internet crime (Langstrom et al.,2009: Gunasekaranand Chaplin, 2012).

Hayward et al (2019) acknowledge gaining or sustaining employment is challenging for many people with autism despite other productivity advantages to the labour market, these include: reliability, attention to detail and excellent visual skills. The technology sector has recognised and responded to the valuable contribution individuals with autism can make to organisations and, importantly, a businesses' productivity (Hedley et al, 2017). There are many global examples, such as those from Auticon (Germany; 2016), AutonomyWorks (US; 2017), Microsoft (global; 2017), Passwerk (Belgium; 2017), SAP (2017) and Willis Towers Watson (2016), who have all engaged in targeted recruitment of people with autism. However, despite such initiatives, and evidence indicating people with autism could be employed in a wide range of industries (Ohl et al., 2017), these potentially productive individuals continue to report high levels of under and unemployment (Hayward, et al, 2019).

As early as 1938, Eisenberg and Lazarsfeld (1938) were able to review the results of over 100 studies examining links between unemployment and personal adjustment. Their conclusion from this review of evidence was that "unemployment tends to make people more emotionally unstable than they were previous to unemployment" (p. 359). More recently several studies have suggested that unemployed people are more likely to have poor physical health (Brydsten et al, 2016), including increased risk of cardiovascular disease (Herbig et al, 2013) and increased alcohol consumption and substance misuse (Fergusson et al, 2001). However, the health issues that unemployed people face the most are a wide spectrum of mental health problems, including increased stress (Bjarnason et al, 2003), decreased mental well-being (Bacikova-Sleskova et al, 2007), increased risk of depression (Crowe and Butterworth, 2016), anxiety (Virtanen et al, 2016), other psychiatric disorders (Power et al, 2015) and decreased mental health later in life (Strandh et al, 2014).

Although there is strong evidence to suggest that unemployment or underemployment are contributors to poor mental well-being and ultimately mental health problems (Bjarnason et al, 2003; Bacikova-Sleskova et al, 2007; Crowe and Butterworth, 2016; Virtanen et al, 2016; Power et al, 2015; Strandh et al, 2014 and Chaplin et al, 2013) and there is little reason to suggest this differs in ASC populations. However, there is a

paucity of literature that explores the relationship of unemployment, mental health in relation to autism specifically, and an area that requires further research to understand the psychological impact for people with ASC not reaching their potential within their professional lives.

Nearly half of the study participants lived alone, interestingly there wasn't an observable correlation between those living alone and reported low self-esteem and it was clear that a number of the participants have actively made a conscious decision to live alone, Charlie for example lived confidently with others in shared accommodation, whilst others lived with their families. A smaller number lived alone as a consequence of failed relationships and family disputes indeed many of those who lived alone acknowledged that they would be difficult to live with and require their own living space. The participants who had reported being diagnosed with an intellectual disability lived in small group homes with other people with learning disabilities. Garry, Winston and Francesca, remain at home with their parents. Francesca told me that as her parents were becoming elderly and she would need to move out within the next year or two, but without a job this was going to be difficult. Garry and Winston were also unemployed at the time of their interviews.

Mis-diagnosis was a re-occurring theme for many of the participants, for example Charlie, who had five admissions and a new diagnosis each time she was admitted, without losing any from previous admissions which accumulate an extensive list of diagnoses which eventually ended in her only current, at the date of the interview, diagnosis of ASC. Schalkwyk et al (2014) reported substantial conceptual and clinical difficulties associated with diagnosing comorbid psychiatric illness in individuals who have ASC. Several participants within this study had informed that at one time or another they were considered to be displaying symptoms consistent with psychosis and, for the most part, medicated accordingly. Charlie's experience of collecting a new diagnosis upon each admission without formally having previous diagnoses dismissed or discredited is similar to the cases reported in Schalkwyk et al (2014), where it is considered clinicians lack confidence to change previous diagnoses especially when presentations and behaviour patterns are complicated with ASC.

Several of the participants reported that they have criminal records for offences such as arson and grievous/actual bodily harm. King and Murphy (2014) conducted a thorough review of the research in this area. They found that overall, there is no evidence that people with autism are more likely to engage in criminal activity than people without autism. The studies they reviewed presented conflicting information, however, some studies have found that people with autism are less likely to commit offences such as probation violations and property offences (Cheely et al., 2012; Kumagami and Matsuura, 2009), and another study reported that people with autism are no more likely to commit violent crime than the general population (Woodbury-Smith et al., 2006). On the other hand, some people with autism may be more likely than the general population to commit certain types of offences such as arson (Hare et al., 1999; Mouridsen et al., 2008), sex offences (Cheely et al., 2012; Kumagami and Matsuura, 2009) and assault and robbery (Cheely et al., 2012). Critical analysis would avail that most of these studies rely on information from small samples representing the general autistic population; equally these studies rarely include people without autism for crucial comparison. It is likely, therefore, that as many of the participants in this current study have suggested, their mental health status at the time the crime was committed, is more than a contributory factor.

Despite these similarities the participants were very much their own people, individualised and with different characters and personalities. From the quietest (Garry) to the most outgoing (Habika) and even with Jason's determination to not let his condition and associated mental health problems 'get the better of him', they all shared a palpable sense of vulnerability, despite some attempts to mask it.

c) Sample and recruitment

Purposive sampling (Crotty, 2013) was used to identify former mental health unit inpatients with an established diagnosis of ASC. Recruitment was evidently easier and felt safer for the participants if the study had been recommended to them by a member of the local Asperger's Support Team, in Hertfordshire County Council. A small group of participants were identified by the Manager of the Asperger's Support Team and approached by the members of the Team who knew them personally. They were given contact details and information in the form of a Participant Information Sheet (PIS) (Appendix 3) explaining the nature of the study and what was asked of them: potential participants were then invited to contact the researcher.

A snowball sampling technique (Crotty, 2013) was used, whereby those initially sampled proposed other participants who had had similar experiences and who they thought may be willing and able to share them. During invited sessions with the Autism/Asperger's Social Groups in Hertfordshire and North London, the researcher distributed a Participant Information Sheet (Appendix 3) and explained the nature of the research. The reaction was positive and a number of attendees who had experienced mental ill-health and subsequent admission to an inpatient unit volunteered their involvement within the current study, all the participants came for either Hertfordshire or North London. A few individuals wanted to learn more about the study before giving consent, and further communication took place either face-to-face, by telephone or by online discussion. On initial contact, there was an open discussion about the methodology and the research process and how the information would be used, and the semi-structured interview was explained. Following discussions and the answering of any questions, two weeks' 'thinking time' was facilitated to allow participants to consult with family and friends. Agreement to participate in the current study was mostly communicated to me directly, either via email or telephone conversation; some communicated their desire to be involved via their support group facilitator/manager, and some asked a relative or carer to contact me.

Due to the nationally higher male to female ratio in ASC diagnosis (National Autistic Society, 2012) a male-dominated sample was perceived to be a likely outcome of the recruitment. **Table 6** below demonstrates a healthy representation of 9:11 female to male participants: although this ratio is out of sync with the general profile in the UK, it has provided this study with a balanced perspective, and the voices of female participants, who are often less represented in ASC research, are heard. The 20 participant profiles are detailed in **Table 6** below: any names used have been changed to protect the participants' anonymity.

Table 6 - Participant characteristics

Participant alias*	Gender	Age	Ethnicity **	Length of last admission	Number of admissions in total	Diagnosis***	Reason for last admission	Mental Health Act status
Lucas	Male	24	White British	Four months	3	Asperger's syndrome, Generalised anxiety disorder	Increased anxiety and suicidal ideation - GP referral	Informal
Charlie	Female	22	White British	Three months	2	Asperger's syndrome, bipolar disorder, eating disorder and depression	Aggressive behaviours - referred by police	Section 2/3
Davy	Male	58	White British	Five months	10	Asperger's syndrome, depression	Aggressive behaviour - referred by police	Section 2/3
Delta	Male	75	White German	Six months	1	Asperger's syndrome	Aggressive behaviour - referred by police	Informal
Garry	Male	20	White British	Three months	1	Atypical autism, mild learning disability, generalised anxiety disorder	Increased anxiety - family referral	Informal
Jacob	Male	35	White British	Two months	1	Atypical autism, mild learning disability	Increased anxiety - GP referral	Informal
Jan	Female	42	White British	Four months	2	Asperger's syndrome, depression	Increased anxiety due to relationship breakdown - GP referral	Informal
Olivia	Female	50	White British	Three months	3	Asperger's syndrome	Increased anxiety - GP referral	Informal
Malkey	Male	26	White British	Six weeks	3	Atypical autism, mild learning disabilities	Violent behaviour, community placement breakdown	Section 2/3
Damien	Male	50	White British	Three months	2	Asperger's syndrome, depression	Increased anxiety - family referral	Informal
Winston	Male	25	Black British	Two months	2	Asperger's syndrome, generalised anxiety disorder, depression	Increased anxiety - GP referral	Informal
Jason	Male	32	Asian British	One month	1	Asperger's syndrome	Violent behaviours - police referral	Section 2/3

Participant alias*	Gender	Age	Ethnicity **	Length of last admission	Number of admissions in total	Diagnosis***	Reason for last admission	Mental Health Act status
Maggie	Female	52	White British	Three months	5	Asperger's syndrome, generalised anxiety disorder	Increased anxiety, obsessional behaviours, suicidal ideation, crisis intervention Mental Health Team	Section 2/3
Prima	Male	45	Asian British	Six months	4	Asperger's syndrome	Increased anxiety, violent behaviours	Informal
Shannon	Female	52	White British	Three months	2	Asperger's syndrome	Increased anxiety, inability to cope	Informal
Mnamdi	Male	41	Black African	Six months	5	Atypical autism, mild learning disabilities, obsessional compulsive disorder, ADHD	Violent behaviours - police referral	Section 2/3
Francesca	Female	35	White British/ mixed	Two months	1	High functioning autism, generalised anxiety disorder	Challenging behaviours - family referral	Section 2/3
Emeka	Female	38	Black African	Six months	4	Atypical autism, mild learning disabilities, schizophrenia	Aggressive behaviours - police referral	Section 2/3
Habika	Female	48	Black British	Two months	3	Asperger's syndrome, depression	Increased anxiety - GP referral	Informal
Anne	Female	42	White British	Three months	2	Atypical autism, mild learning disabilities, depression	Aggressive behaviours, community placement breakdown - Community Learning Disability Team referral	Informal

* All Participant names have been replaced with aliases to protect identity

** Ethnicity was self-identified by the participants

*** Diagnosis was self-declared by the participant

3.8 Ethical Considerations

Favourable opinion was granted by the National Research Ethics Service London South East Committee on 26th August 2015 (HSK/PG/NHS/00284). To minimise distress when asked to recall their mental health unit experiences, the participants were informed in advance of the type of questions they would be asked, that they may take a break if they wish, especially if they became upset, and they could choose to decline answering questions or withdraw from the study at any time without repercussion. A debrief followed each interview in which the participants were asked their opinion of the process: then they were offered a debrief sheet (Appendix 4) outlining support available to them.

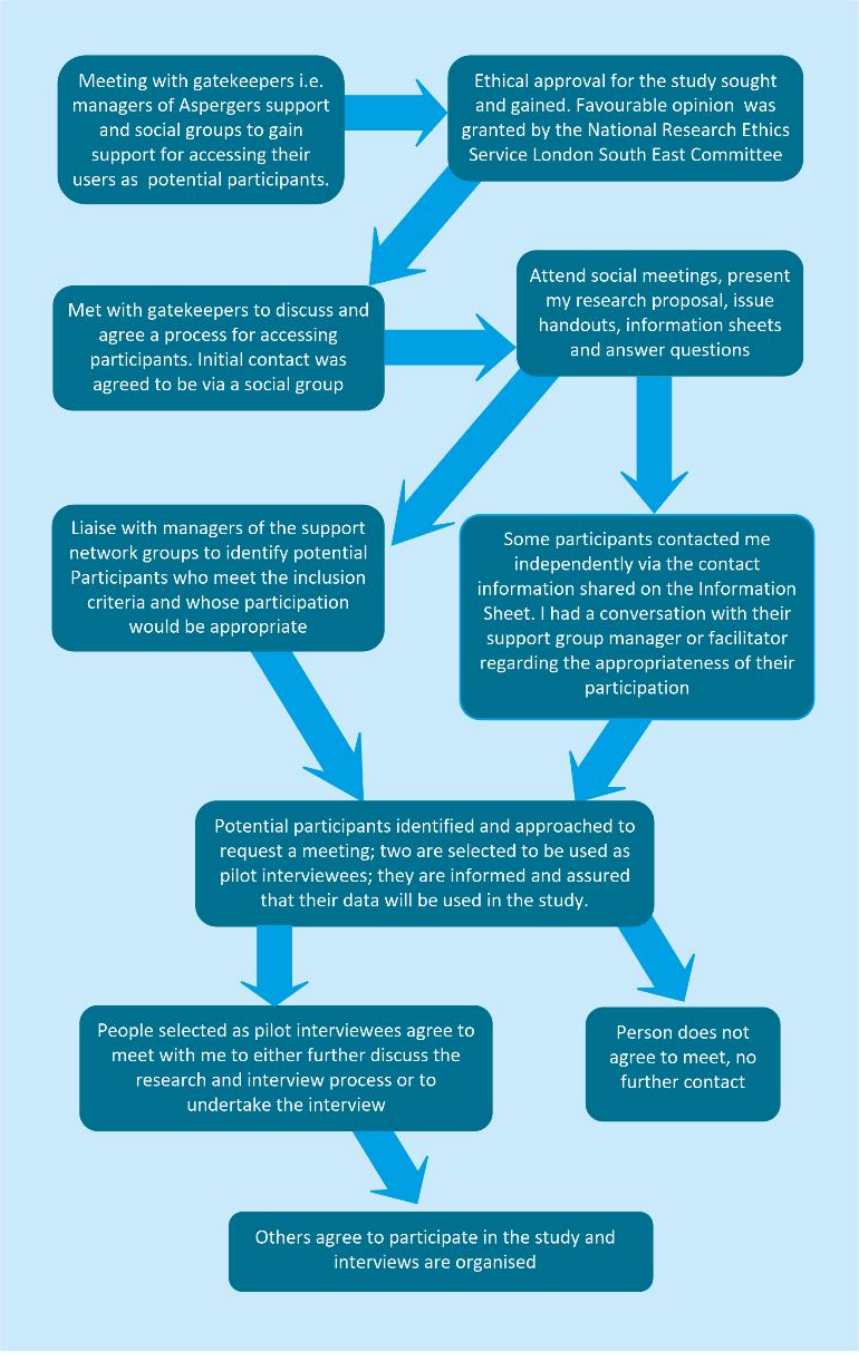
3.9 Informed consent

Informed consent to participate was ensured by providing a Participant Information Sheet (Appendix 3), which sets out information about the current study, including the purpose of the research, what taking part would involve, who would have access to the data and how it would be stored. The Participant Information Sheet was used as the basis for invitations to take part: potential participants could take as long as they needed to consider this information before deciding to make contact.

On meeting a participant, I ensured that they had read and understood the contents of the Participant Information Sheet (PIS) and gave them the opportunity to ask any questions. If they had not had the opportunity to read the PIS, then I devoted the first five minutes of the interview to explain the research before I asked for their consent. They were then given the Consent Form to read (Appendix 2). If they agreed to continue, they were asked to sign the form to give written consent before being interviewed. A signed copy of the Consent Form was given to the participant and another was kept for my own research records. As stated in the PIS, the participant was able to ask another person to be present during the initial meeting when gaining consent, and/or during the interview itself: this person would also sign a Consent Form and was informed that any contributions they made would also be transcribed and used as part of the data.

In line with the core principles relating to consent within the Mental Capacity Act (2005), attempts were made to help the participants to make an informed decision about whether to participate within this study. Reasonable adjustments and time allowances were made for individuals who had mental health problems or intellectual impairments. It is equally important that the participants were not treated as unable to make a decision, and capacity to consent was assumed unless established otherwise (National Research Authority, 2017).

Figure 3.2: Summary of recruitment



3.10 Confidentiality

All participants were informed verbally of the limits of confidentiality prior to partaking. In particular, I explained that if anything were to arise during discussions that would put themselves or others at significant risk, then I was obligated to tell the relevant professional, namely their support officer from the Asperger's Support Team and/or a relevant outside body. Additionally, the participants were aware that formal supervisors and representatives from academic bodies would look at the anonymized transcripts, including a member of the Asperger's Support Team. Participants were informed that any quotes selected for thesis documents or journal articles would be fully anonymised. Furthermore, transcripts and other data collected would be kept on a secure encrypted laptop which nobody else had access to apart from myself as the chief investigator of the study, the audio data would be destroyed on the completion of my doctorate and anonymised data would be kept for five years post thesis submission, in accordance with University of Hertfordshire *Good Practice in Research guidelines* (University of Hertfordshire, 2017).

3.11 Potential distress

There was the potential that partaking in this research may be distressing for participants, for example when describing the range of emotions that they experienced as inpatients during and after the event. This was addressed by providing information prior to interviewing regarding the types of questions to be asked and any areas of anticipated exploration, thus giving potential participants the opportunity to make an informed choice regarding their decision to take part. This technique was used successfully by Carrington et al (2003) who conducted face-to-face interviews with teenagers with Asperger's; the interviews followed a semi-structured format, allowing the teenagers time and the flexibility they needed to answer the questions which were based upon their friendships and their views on relationships. The interview questions were developed in consultation with the special needs support teacher from the participating school and two adults with Asperger syndrome from a local Asperger Syndrome Support Network. The questions were sent out either by post or email to the participants a week before the interview date, thus allowing the students time to think and formulate ideas about the answers they would give, as well as ensuring that they knew what to expect on the day.

A debrief followed each interview, in which I reviewed how participants experienced the process, and provided a Debrief Sheet (Appendix 4) detailing sources of support, should they be interested, primarily provided by the Hertfordshire County Council Asperger's Support Team.

3.12 Data Collection

The social anxiety that is experienced by many people with ASC means that an interview experience can be paralysing, causing some individuals to freeze up and be unable to think on the spot and, ultimately, to be unable to respond in ways that can communicate their knowledge and experience (Whetzel, 2014). This can be challenging for people with ASC in many aspects of their lives, including interviews for educational courses, employment, and Police enquiries, as well as, as in this case, enabling them to be active participants in research. The criminal justice system is taking autism seriously: in 2015 there was a debate in the House of Lords in which Baroness Uddin expressed her disappointment regarding the '*extraordinary difficulties*' people with autism can face in obtaining justice, and outlined the need for specific training for police officers at all levels and including their interviewing processes and approaches, aimed at improving police practice when dealing with autistic victims, witnesses and perpetrators. (Network Autism, 2015).

In 2002, the UK's Home Office published guidelines that recommended the use of *cognitive interviewing* for all vulnerable witnesses. *Cognitive interviewing* is a technique developed by psychologists and is based on several important memory processes: it is effective in increasing the number of correct details that a witness reports with fewer errors made. The instruction is to report absolutely everything, no matter how small or how trivial it may seem: by reinstating the context at the time of the event, the witness is encouraged to think back and to visualise the environment in which the event happened, i.e., objects, people, sounds, and so on (Network Autism, 2015).

However, Maras and Bowler (2010) compared the use of *cognitive interviewing* against structured police interviews and found that adults with autism made more errors with the use of *cognitive interviews:* they warned investigative professionals to be cautious when considering the accuracy of the evidence produced from *cognitive interviews* with witnesses with ASC. The reported issues were: deficits in the recognition of people's faces, especially those who are not known to the interviewee; the information can become disorganised within their memory, with some participants reporting difficulties in binding elements of an experience together in their memory, causing frustration and anxiety during the interview process. The criminal justice system continues to grapple with effective methods for interviewing people with ASC (Network Autism, 2015).

Additionally, people with ASC find interviews a stumbling block to gaining meaningful employment. Zwanenberg (2016) reflects upon his own experiences of being a person with ASC seeking employment. Generally speaking, interviews are poor indicators of future performance for people with or without autism, but for an autistic candidate it is simply setting them up to fail. Jobseekers are expected to demonstrate in interview a high degree of competency in performing tasks that are exactly what autistic people are bad at, including looking someone in the eye for an appropriate amount of time, engaging in small talk, shaking hands with the interviewers, feigning enthusiasm (when in fact they are very anxious and have every expectation that they will not be offered the job), and smiling when not particularly happy. During the interview an autistic person could tap their leg, rub their head, look distressed and preoccupied throughout and inevitably they do not get the job.

The Autism Empowerment Kit is a comprehensive resource with useful tips on helping employers to adjust their interview approaches to meet the different needs of candidates with ASC. The tips include: flexibility in asking questions, rewording questions if at first, they are not understood, and ensuring that the candidate is allowed a moment to collect his or her thoughts before giving a response (Global Impact Sourcing Coalition, 2017). Zwanenburg (2016) agrees that an all too regular occurrence is for the interviewer to speak when the interviewee is trying to concentrate and think about the question they have been asked - this invariably will cause confusion and uncertainty about which of the questions or comments they should be responding to.

The Autism Empowerment Kit also encourages employers to reflect carefully on their own understanding of some of the characteristics and behaviours that they may observe in their interviewees. Some of these may include inconsistent eye contact, lack of interest in aspects of the conversation which are not directly related to the job or the interview, uncommon greetings (e.g. avoidance of shaking hands) and unusual voice tone

or manner of speaking. Employers should understand that this is part of being autistic and should not be judged as part of the selection process (Global Impact Sourcing Coalition, 2017).

Pellicano (2016) spoke of her extensive and challenging experiences of interviewing autistic participants during her research and identified the importance of finding ways to overcome difficulties when communicating directly with the participants, rather than inviting third parties into the interview process to assist with information processing and interpretation. Pellicano (2016) drew upon her earlier experiences of allowing a third person to sit in during a face-to-face semi-structured interview with the participant with ASC. The third person would often be a family member somebody who knew and understood the participant or, on some occasions, another healthcare professional, such as a speech and language therapist. Many of these interviews had failed to elicit the depth of information that was required; the impact upon the interview by the third person had been evident and, on many occasions, they had significantly altered the direction and line of the conversation.

The semi-structured interview schedule (Appendix 5) used in this study was developed and enhanced through a process of assessing relevant literature, and discussions with my supervisors. It was further informed by Barbour's (2014) guidance on semi-structured interview development and was assisted by The National Autistic Society's *Tips for interviewing people with Autism and Asperger's syndrome* (2012). This Guide highlights the need for structure and for the interview to be well organised. It discourages the use of open questions, for example, instead of asking: 'Why were you admitted to the inpatient unit?', a more directed question was needed such as: 'What was your understanding of why the decision to admit you had taken place?'. This type of questioning helps the interviewee to consider a more specific answer. The interview schedule was thus designed to be adaptable, with the order of questions being flexible based on the direction of conversation from the participants: this enabled the interviewer to facilitate the probing of any anticipated areas, and a selection of brief questions was placed alongside more structured questions to engender this. Interviews lasted between 45 minutes and 90 minutes.

The NAS Interview Guide acknowledges that people with ASC often find it very difficult to gauge how much information is required when questioned and suggests that answers can be halted tactfully by simply saying, 'Thank you, you've told me enough about that now, and I'd like to ask you another question.'. This was needed for some of the questions used in this research schedule, as was the occasional prompt to redirect the interviewee to the question asked; also, care was taken to interrupt only very occasionally, perhaps when the conversation was moving away from the subject matter.

To test the validity and reliability of the interview schedule and its approach, two pilot interviews were conducted on people already known to the interviewer and who met the inclusion criteria. In response to the pilot interviewees' comments, some changes were made. For example, a suggestion that it helped the interviewees to remember and organise their thoughts by 'starting at the beginning' (Charlie), questions were made more accessible by opening the interview with questions about the initial parts of the admission process. Other feedback given that it would help the interviewee if the interviewer went back to previous questions if relevant information was later remembered, indicated that the schedule should be used as a guide rather than an order which must be adhered to (Lucas).

Other participants offered advice along the way, which I took on board and used to improve upon my interview technique as the research unfolded. For example, Participant 4 asked me politely to 'stop fidgeting', explaining that fiddling with my trouser pocket, scratching my head and moving regularly within my seat was causing sensory issues for the interviewee to the point that she had to raise it because it was impacting upon her ability to concentrate on the question and her answer. Fortunately, once I had become aware of my movements, I was able to stop fidgeting; additionally, I remained conscious of this during future interviews and ensured that these small but significant actions were limited.

Great effort was needed to bring almost all the interviewees back to the questions if they went off track and lost focus and relevance to the questions being asked. Concentration appeared to be an issue for a number of the participants and I tried to make every attempt to minimise distractions. Interviews were carried out at a location chosen by the interviewee where they would feel comfortable, e.g. their own home, a day centre or college. Data transcription was carried out by the researcher so that a familiarity with and identification of inflections within the data would begin to develop from the outset.

3.13 Transcribing

Willig (2008) recommends that researchers do their own transcribing as this allows the researcher to become immersed in the data. I transcribed all the interviews, making field notes along the way. The interviews were transcribed word-for-word, with field notes making insightful inceptions which helped to remind me of my interpretation of what I was being told at the time. For example, the field notes reminded me that Participant 16 had scoffed and laughed (I wrote, *in a sarcastic way)* when I asked her: '*How were difficult emotions managed/supported by the care team?'*. This confused me a little as she had informed me earlier in the interview that her behaviour was 'crazy' and 'completely out of control', and she had indicated that she felt remorseful and was sorry for the care team who invariably became the target for her aggressive and abusive behaviour. I returned to this line of questioning at the end of the interview because I wanted to clarify why she had laughed at the suggestion that the care team had helped to support her at these difficult times. Participant 16 explained that she was laughing because my question had reminded her of a funny comment that another patient had made about the care team, and this was not related to her impression of the care team or the question I asked.

It was for this reason, and other examples of misinterpretation or difficulties with communication, that I requested a second conversation with the participants after transcribing the interview, and which I used with effect to clarify their meanings and my understanding of the transcriptions and related field notes. The transcript was then read through again, with the right-hand margin being used to document emerging themes such that my initial field notes were condensed into concise phrases which captured what had been found in the text. This stage of analysis involved moving to a higher level of abstraction and making connections with concepts from the literature, albeit with explicit links to what had been said during the interview (Silverman, 2014).

3.14 Data Analysis

I began to interrogate the data further and moved towards reflecting upon my preliminary thoughts or pre-understandings of the phenomena and began to make descriptive comments from the transcripts by identifying key words, phrases or explanations of relevance which structured the participants' thoughts and experiences. Subsequently, linguistic comments were added to the transcripts about the participants' tone or whether they had expressed humour, their degree of fluency, hesitancy and ability to articulate their thoughts. Further, data interrogation identified conceptual comments (Smith et al, 2013) which often represented a shift in the researcher's focus on the questioning of recognised thoughts and the interpretation of the data. There is often an element of personal reflection to conceptual coding and the interpretations which you develop, and this stage will inevitably draw on your own exponential and professional knowledge (Crist & Tanner, 2003). This in-depth thoughtful process of your own pre-understandings and your newly emerging understandings of the participants' world has been described as the 'Gadamerian dialogue', after the hermeneutics writer Hans-Georg Gadamer (Schleiermacher, 1998). Gadamer (1990) described a necessity for the researcher to be continuously aware of the distractions that can originate in the interpreter themselves: the researcher is always trying to project a meaning as soon as they can. Therefore, a continued reflection upon my pre-understandings is crucial to enable me to interpret and penetrate to the true meaning of the participants' words. In noting my preconceived ideas clearly in the margins of the transcripts and creating a notes section within my chosen qualitative data analysis software, I have provided a fluid reviewing process of my pre-understanding thoughts, some of which I only became aware of once the interpretation was underway.

Valuable comments were received following a blind review of four transcripts by an 'expert by experience', a person with a diagnosis of Asperger's syndrome and my research supervisors which also helped to challenge my pre-understanding. The emerging themes were then listed, and possible connections between the themes were explored. Connected themes were clustered together, and the researcher then returned to the interview transcripts to confirm that these were applicable to the verbatim text in the transcripts. NVivo qualitative data analysis software (NVivo version 11, 2017) was used to establish two superordinate themes comprising 'the experience of anxiety' and 'sense of self and connectedness'. The analysis was approached idiographically, with each interview analysed separately, facilitating the in-depth analysis and detection of reoccurring patterns whilst being cognisant of new themes developing (Smith et al, 2013). Shaw (2010) suggested that the analysis of transcriptions, field notes and consequential comments into emergent themes entailed moving to a level of construct general enough to allow theoretical influences to be made across themes and ideas. This process is rooted within the system of constant analysing and linking between the transcripts and concepts, to ensure that emergent themes remain grounded in the text.

After coding one interview, I asked one of my research supervisors to code the same transcript blind and then we met to compare our notes. This helped me to review my coding framework and further challenged me to think more deeply about was being said and the points the interviewees were making.

a) Emergent themes

A number of emergent themes were generated: the next stage entailed making sense of connections and associations between those themes, and their subsequent organisation to form main themes and

sub-themes. Smith et al (2013) detailed how main themes and sub-themes can be identified through: *abstraction*, collecting like-for-like and developing a name for the emerging cluster; *subsumption*, where an emergent theme itself becomes a superordinate theme as it draws other related themes towards it; *polarisation* which examines transcripts for oppositional relationships; *contextualisation* which identifies the contextual and narrative elements within an analysis; *numeration* which views the frequency with which the theme is supported; and *function which* analyses how the themes function, whether independently or collectively.

The next phase entailed an exploration and identification of connections across transcripts and participant cases. This was achieved by drawing up a table incorporating the sub-themes and emergent themes from all interviews. A similar process to the individual analysis was conducted, whereby I examined and subsequently clustered the sub-themes, main themes and superordinate themes, representing shared higher-order qualities. Transcripts were re-reviewed to ensure the thematic accuracy of the themes, and thus a framework to represent the participants' experiences of inpatient care was developed.

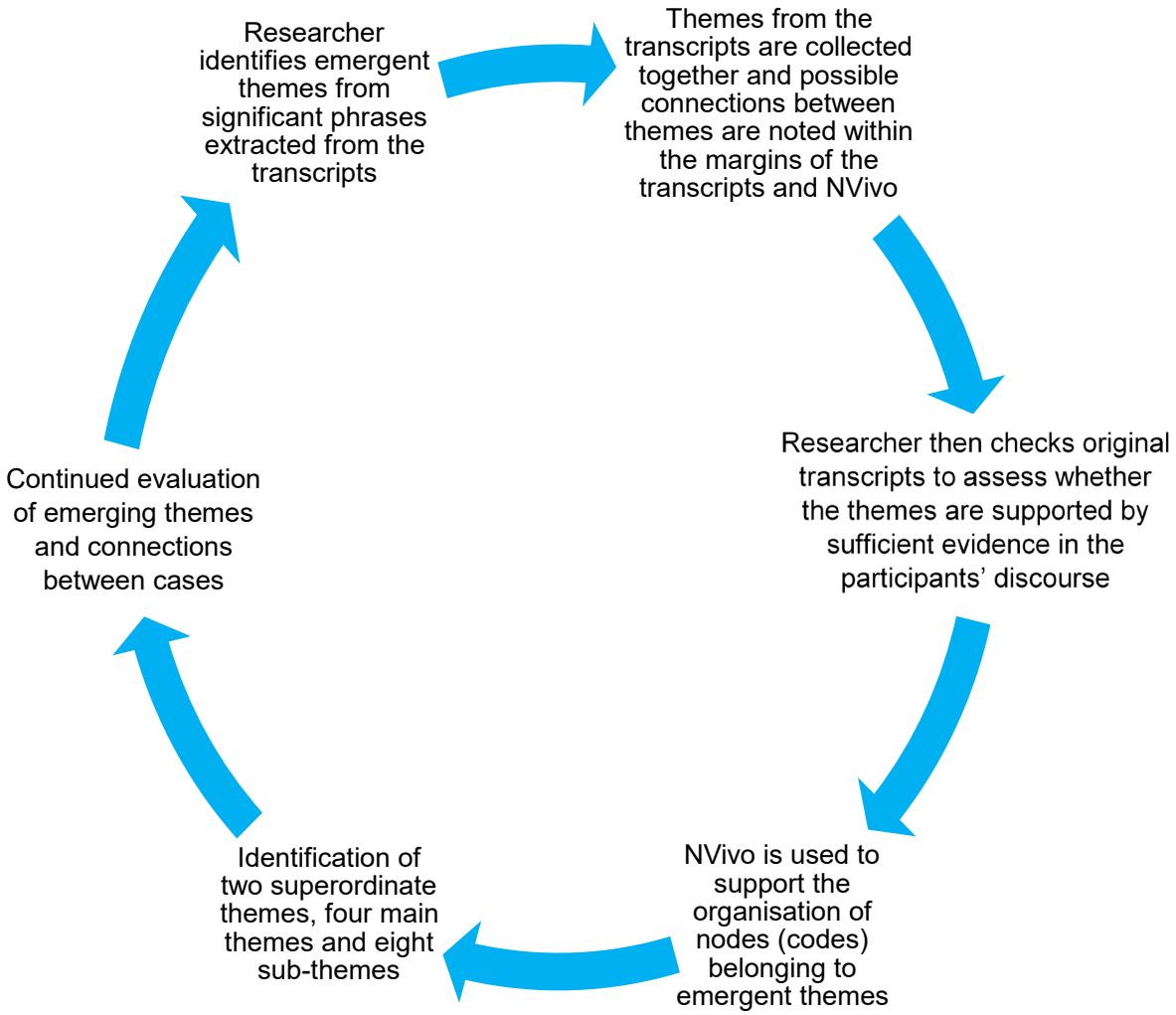


Figure 3.3: Summary of process - organising themes across cases

Chapter 4 will discuss the themes in more detail and will discuss the emergence of two superordinate themes, four main themes and eight subthemes. **Table 7** in Chapter 4 will demonstrate how the superordinate, main themes and sub-themes are connected.

3.15 Quality, reliability and validity in qualitative research

To demonstrate the quality, reliability and validity of my study, I have referred to published criteria by Spencer et al (2003) on best practice in qualitative research. There are four central principles: research as contributory, defensible in design, Rigorous in conduct, and Credible in claim.

a. Reflexivity

According to Keller et al (2014) it is impossible to separate the researchers from their research or to be neutral or unbiased. It is therefore important for researchers to be honest about their histories and reflect upon how that might influence the research. To allow the reader to fully understand my position and my interpretation of this research it is important to describe myself. I am a white British male who is 47 years old at the time of writing this thesis. I am the middle of three children and were raised in a non-graduate and non-professionally qualified two-parent family. Growing up, my mother undertook most of the caring and housekeeping roles, whilst my father would be involved in the more practical elements such as maintaining the car and house, when he was not at work. I am now a parent myself with two daughters and married for 13 years.

I generated this research idea through my interest in ASC. Most of my work following my undergraduate degree has been with people with ASC and/or intellectual disabilities. I have met some incredible people and recognise that I tend to focus on the positive aspects of their personalities. I tend to overlook and perhaps not understand some of the more negative behaviours which can be a consequence of the core features of ASC or other conditions. Additionally, I noted that have I tended to view people as 'on the spectrum' if I noticed certain behaviours or ways of thinking and I found this helpful in my understanding of the person. As my experience and exposure has grown, I have virtually abandoned this strategy of attempting to notice certain behaviours which could be perceived as autistic, the reason for this is that I have met such a wide and varied autistic population with ranging characteristics, many of which are too broad to characterise within the understood core features of ASC and my image of an autistic person has been shattered on too many occasions.

Throughout the interviews and analysis, I have tried to 'bracket' my preconceptions. Starks and Trinidad (2007) notes that the researcher:

> … must be honest and vigilant about their own perspective, pre-existing thoughts and beliefs, and developing hypothesis and engage in the self-reflective process of 'bracketing', whereby they recognise and set aside (but do not abandon) their priori knowledge and assumptions, with the analytic goal of attending to the participants' accounts with an open mind.

I have noticed at times, particularly in the transcription process, where I have felt a strong reaction to something a participant said about their front-line caregivers and have noted these reactions for reflection and attention during the interpretive analytical process, so I can return to them. The IPA process allows for such reflection, reflexivity and flexibility, the further steps to ensure the quality of analysis are further discussed below.

b. Research as contributory

The fundamental rule of all research is that it should contribute and advance existing theory and knowledge (Spencer et al, 2003). This was addressed within this study by demonstrating sensitivity to context, namely existing literature, theory and the sociocultural setting of the study (Barbour, 2014). I strived to demonstrate these aspects by situating the research in the context of the current policy agenda

and existing mental health and ASC services; and by exploring the relevant literature on the experiences of inpatients. I was keen to attend to issues arising around communication and interactions between myself and participants, namely being aware of the potential challenges and limits of an interview process for people with problems with social interaction, their anticipatory fear of how other people may respond to their comments, and the limitations of confidentiality. Finally, I aimed to embed sensitivity into the data through rigorous and in-depth interpretational processes, including verbatim text extracts.

c) Defensible in design

A defensible design relates to how the overall research strategy appropriately meets the aims of the study (Spencer et al, 2003). This relates to the chosen and preferred methodology, including the naturalistic paradigm which has been fundamental to initial thoughts and developments, which I have explored in detail and have provided a robust rationale within this Methods chapter.

d) Rigorous in conduct

Spencer et al (2003) describe the commitments to qualitative data collection, analysis and interpretation as being systematic, transparent and applied to the complete research process. I endeavoured to achieve such rigour through a process of reflection and reflexivity regarding my underlying research motivations, formulations, interpretations and reporting of data. This entails acknowledging and being aware of the impact of my own personal position in the research process.

Attending taught lectures facilitated by IPA researchers, and seeking support from academic team members with extensive IPA experience, helped to develop my chosen process of data analysis. My supervisors agreed the themes produced and they could see how they had emerged from the transcripts. Finally, I considered all aspects of the research in a thorough, reflective and careful way drawing upon available training and supervision en-route.

e) Credible in claim

Spencer et al (2003) argued that the credibility of evidence generated from the study needs to be reinforced by well-founded and plausible arguments. In the Findings Chapter (4), I have provided an observable connection between the themes and the transcripts by providing verbatim extracts in the form of direct quotations. External verification of themes was sought and came about using my supervisors and peer supervision from an Expert by Experience (EbE), who has a diagnosis of Asperger Syndrome. I asked the EbE to read a small number of randomly selected anonymised participant transcripts, without previously seeing relevant coding or field notes belonging either to myself or to my research supervisors. Additionally, the EbE role was extended to that of a 'data analysis consultant', by sending elements of data to the EbE and seeking further clarification of meaning and understanding from him. This process has helped to unearth information either unseen or only superficially understood, prior to their involvement.

3.16 Summary

The methodological overview provided within this Chapter 3 has captured the thoughts and philosophies which have influenced the research design, its implementation, and analysis. I have reflected upon my

performance as a researcher, which I believe has improved along the study journey, i.e. the research schedule has been amended in line with improvement recommendations and observations from the pilot interviews. Furthermore, I felt that my approach, attention to detail and ability to further enquire into the thoughts and feelings of the interviewees has improved and enhanced the quality of data that has been generated.

The implementation process of the stages of IPA assisted in the in-depth analysis of the data and helped me to manage and structure the data to allow for understanding and thematic development.

Chapter 4 provides the findings/results of this study. Following the in-depth data analysis described in this Chapter 3, the findings have been organised thematically within superordinate themes, main themes and sub-themes, many of which are interlinked and discussed in connection with one another. The themes include: the experiences and management of anxiety; the responses to the anxiety experienced and the range of coping strategies employed by the participants to deal with their anxieties; relationships experienced and the importance they placed upon them; issues around communication, understanding and meaning, including understanding and recognising emotional responses in themselves and others. Chapter 4 is rich with vivid accounts of the lived experience of the participants, brought to life by verbatim quotes and comments.

Chapter 4: Findings

Chapter Overview

This chapter presents the findings of an Interpretive Phenomenological Analysis of the experiences of people with ASC who were admitted as mental health inpatients. Twenty interviews, two of which were pilots, resulted in the emergence of two superordinate themes, comprising two main themes, each with two sub-themes. This is represented in **Table 7** below. Detailed exploration and deconstruction of these superordinate, main, and sub-themes will form the focus of this chapter. Each theme will be illustrated and supported by verbatim extracts from the participant interviews. I have provided rich and vivid accounts of the lived experience of the participants, both to capture the essence of their experiences and to do justice to the meaningful contributions that all the participants have made.

The research construction and intent were never to declare an all-encompassing exploration of the experience of the patients, nor was the intent to incorporate a complete exploration of the participants' experience. Instead, the intent, as my research question states; is an in-depth exploration of the emotional and psychological experiences of people with ASC who were admitted as mental health inpatients. Quotations, comments and emergent themes were selected due to their relevance and proximity to the research questions. Moreover, the selection process was impacted by my own constructions, interests and reflexive responses, thus adding to the subjective and hermeneutic nature of this study (Bryman, 2012). I have, to some degree, become inhabited within the research and undoubtedly the data has been affected by my own identity as the researcher with experience of working with inpatients with ASC; however, I have endeavoured to present a rigorous and systematic account of the analysis by demonstrating my rationalisations and deductions.

Table 7: Superordinate themes, Main themes and Sub-themes

The experience and management of anxiety	Reasons and Responses	Powerlessness and the emotional reaction to uncertainty
		Responses to anxiety and powerlessness
	Strategies for coping	Developing positive coping strategies
		Negative coping strategies
Sense of self and connectedness	Relationships	Connections with other patients and unit staff
		Disconnection and reconnection
	Communication	Deciphering understanding and meaning
		Recognition of emotions of self and others

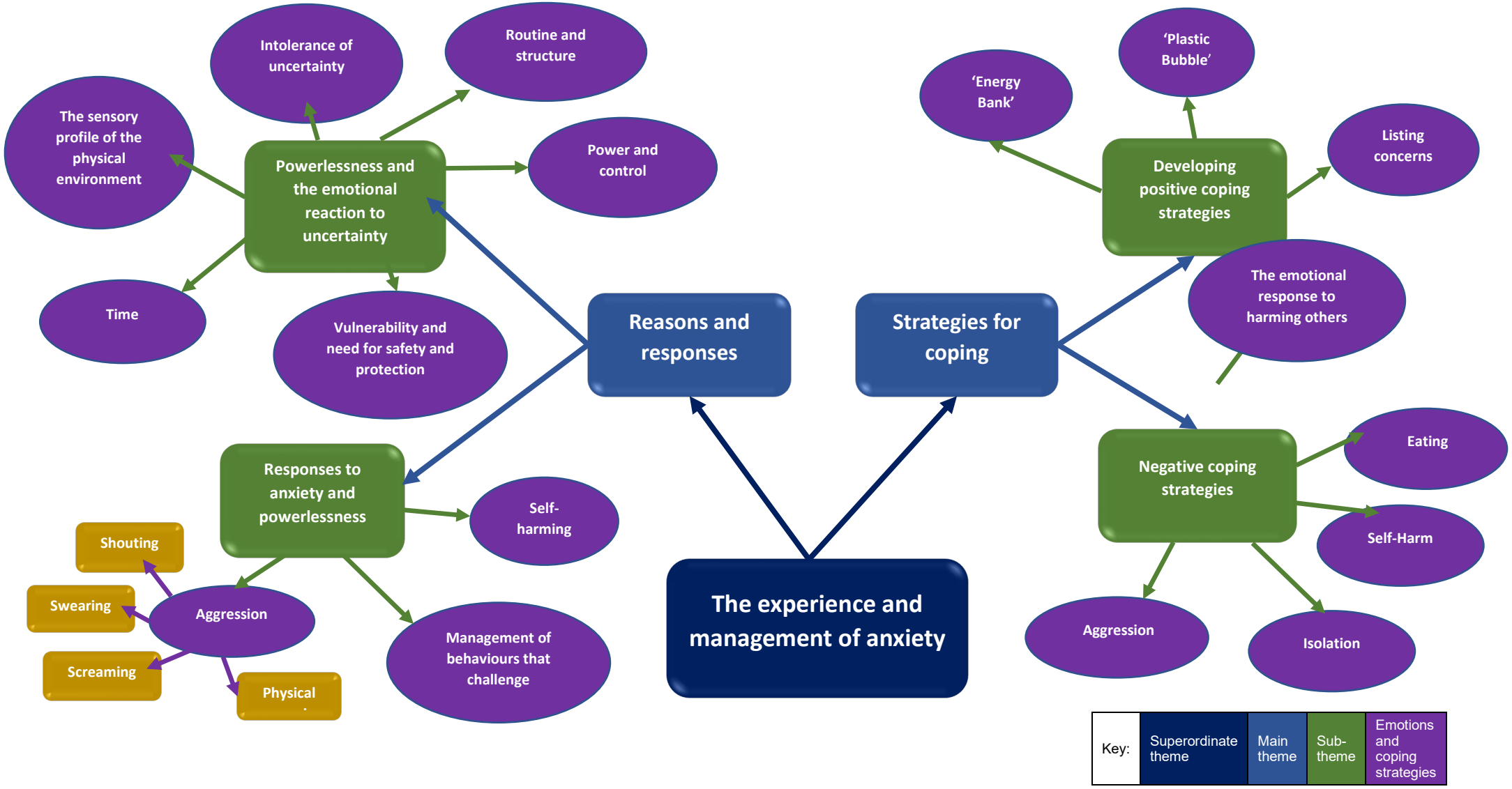
4.1 Superordinate Theme - *The Experience and Management of Anxiety*

This superordinate theme captured the variety of the participants' emotional experiences and explored the underlying factors of anxiety that was so highly prevalent for all the participants during their time as inpatients. Furthermore, the participants endeavoured to formulate a range of strategies that were employed to deal with their anxiety and stress, which will be presented below.

a) Main Theme - *Reasons and Responses*

This main theme captured the reasons why inpatients with ASC consistently reported feelings of anxiety and stress. For many of the participants the experience of being admitted entailed a profoundly deep and disturbing sense of powerlessness and an inability to exercise control over their lives in any way. Notably, participants aspired and endeavoured to understand their feelings and described periods of fear, uncertainty, anger, guilt, distress, failure and identity collapse.

Figure 4.1 Theme Map - The Experience and Management of Anxiety



i) Sub-theme - *Powerlessness and the Emotional Reaction to Anxiety*

This sub-theme captured the participants' vivid descriptions of their anxiety, the reasons for their heightened anxiety and their recognised emotional reaction. Their anxiety derived from many areas, including: the intolerance of uncertainty; fear of change and unpredictability; inability to make sense of the change in their environment; the mistrust and poor relationships of the people around them, including front-line caregivers, the multi-disciplinary team and other patients; the sensory profile of the inpatient unit; a loss of routine and structure; a loss of identity and self-worth; and the feeling of vulnerability and the need for safety and protection.

Power and control

There were numerous accounts of service users not being able to act of their own volition through experiencing external forces of control and responsibility over their lives during their stay. The participants generally experienced the staff as being in a position of control and authority, one participant stating:

> *"Everything I wanted to do and anywhere I wanted to go had been negotiated through my named nurse, invariably the answer would be no. Even when my family asked on my behalf, the answer would still normally be no. Sometimes I felt that the staff would enforce restrictions just to ensure that we knew who was in charge*." (Delta)

A number of participants reported that they also felt they were being treated in an authoritarian way when they were first admitted: this caused them stress and anger and resulted in aggression on their part. The same participants noted that, after a period, it would become very clear that any elements of control would return to them when the staff felt they could be trusted. One respondent (Mnamdi) describes this feeling as "*being rewarded by getting some of your life back*".

Intolerance of uncertainty

I recall hearing the anxiety returning in some of the participants' voices as they explained to me the fear that they had felt because they were uncertain when they could regain control and begin to take back their lives, so that life became more predictable once again. One participant explained:

> *"The pain of not knowing what is going to happen next, or who is going to decide what is going to happen next, was far too much to bear. It forces you to go into yourself, to try and take yourself to a place where they can't get to. Control is everything to me, my life on the outside of hospital is very predictable, routines and structures without any surprises. I control every aspect of my life. If this stops, my anxiety increases rapidly."* (Jacob)

Routine and structure

Many people with ASC manage their anxiety through daily routines. Much of the discussion during the interviews was based on a fear of not being able to re-establish beneficial routines whilst in

their new environment, and this shaped how they spent their time on the unit. This participant explained:

> *"After the first four to five days of my admission, my stress levels began to decrease as I began to understand what I was there for and how I should spend my time. I used the activities available to me to help establish a routine, for example I took a yoga session, which was always on Tuesday mornings and then a group session would follow in the afternoon. Once I established a pattern or routine, I started to manage my anxiety much better."* (Davy)

This person was not alone in reporting that his stress levels began to decrease over a period of days or the initial weeks following their admission. Rodgers et al (2012) recognised the need for sameness for people with autism, and repetition is never more apparent than at times of significant anxiety. Some reported that establishing routines and structure into their lives on the units helped, whilst others reported that they had simply '*given up the fight*' and realised they were not in a situation where they could take back control by force, a strategy employed by participants who demonstrated aggression towards their front-line caregivers.

The sensory profile of the physical environment

Participants reported specific sensory aspects of the physical environment as problematic and therefore a source of anxiety: this included the bright fluorescent lighting used in the well-lit parts of the units such as the corridors or social areas; the smell of cleaning products used throughout the unit; the continually loud air-conditioning systems; and the taste, smell and texture of the hospital food. The impact that the experience of a hospital admission can have upon someone suffering from sensory processing disorder is articulated here by one participant:

> *"I know that I am sometimes hyper- and hypo-sensitive to certain things, but often it is not until afterwards when I sit down and think about it that I realise that the sensory issues have caused me problems and anxiety. On the unit, I found it extremely difficult to sleep, the buzzer on the door of the unit really irritated me and sounded really loud, but it didn't seem to affect anybody else. The beeping noise of the fire alarms will keep me awake at night. I found myself in a situation where every night I spent in hospital my sleep was wrecked. There is also a constant humming noise that, when I felt anxious it sounded louder than it did when I wasn't feeling so anxious, I think it might be the air-conditioning or the heating system, not too sure. The medical room was near to my bedroom and if the fridge was left open too long it would buzz, again not a problem for anybody else seemingly apart from me."* (Shannon)

Another participant explained the difficulty she faced with her personal hygiene; this caused much conflict with the care team, who were very keen for her to be cleaner:

"I had problems with my personal hygiene on the unit because I did not like the water in the shower, it fell harder than the water I had at home and it was actually quite painful to have a shower or bath or even wash, so much of the time I chose not to." (Jan)

Speaking about the staff, one nurse was described as '*…a proper chatterbox*' who would talk quickly without pausing to allow people to digest and understand what she was saying. Somebody with a sensory processing disorder would always be trying to catch up in the discussion. The participant explained:

"I could keep up with the nurse for one or two sentences at the most and then I felt that my brain could take no more, I would stop trying to follow what she was saying and simply close down. I remember hearing nothing, but still see her mouth going up and down." (Jacob)

Vulnerability and need for safety and protection

Participants described several issues regarding their vulnerabilities and need for protection and how they developed strategies to ensure their personal safety. Primarily the participants identified the need to rely on staff to keep them safe from other patients; this was highlighted in the data extracts below:

"As soon as I had been targeted by another service user, whom I had been warned about, I had this overwhelming need to be friends with the staff. I felt that I needed them at all times and I needed to be safe." (Anne)

Bullying was an issue that emerged from the data, with one participant reporting that they expected to be bullied by other patients on the unit, and when this was explored further it arose that these expectations were based upon previous experiences, mostly from their younger years at school, when bullying was a part of their day-to-day life:

"I was one of the weaker boys at school and couldn't talk myself out of situations, although sometimes I would lash out mostly until I became tearful and then get bullied again and again. I had very much a feeling of being a victim of school and those exact feelings were replicated within the mental health unit. I felt very vulnerable and some of the other patients would tease me, and even some of the staff. I remember the Charge Nurse laughing at me when I broke down in tears one day, perhaps he wasn't used to seeing men in their forties cry." (Prima)

Time

Many participants reported that poor time-keeping would escalate their anxiety levels whilst on the unit. The lack of punctuality, particularly at times of potential stress, such as ward rounds or multidisciplinary meetings, was a concern for participants:

"The ward round could take hours, so if I was told to be near my bed to meet the psychiatric team at 10 am, then there at my bed at 10 am I will be. Sometimes they would turn up two to three hours late, in that time I wouldn't have moved even if I needed to go to the toilet. I was already anxious about the ward round and whether the psychiatrist would allow me any leave or even to go home. By the time they arrived at my bedside I was quite literally climbing the walls, needless to say I wasn't discharged that day!" (Lucas).

Additionally, the desire to confirm the anticipated duration of their inpatient stay led to a question regularly asked by the participants:

"*Outside of hospital I live my life by the clock, I know what I'm doing and when I'm doing it. On the unit I called it flexitime because time wasn't really time, things just happened when they happened, and it used to drive me insane! I needed to know how long I will be there for and nobody ever gave me a straight answer. I now understand that was a tricky question for them and there probably wasn't an answer. But they need to understand that people with autism exist within blocks of time and things need to fit in to those compartments of time. Anything that doesn't fit in is either ignored or causes anxiety until it does fit in to a timeslot or period."* (Jason)

ii) Sub-theme - *Responses to anxiety and powerlessness*

During the generation of the sub-themes, *Responses to anxiety and powerlessness* emerged somewhat surreptitiously. When initially analysing the data, the actions of the participants, which arguably could have been a consequence of the participants' anxiety, or the situation that they found themselves in more generally, were seen simply as a response or a behaviour. However, after further analysis there were clear indications from the participants' narratives that many of the reported incidents were swift responses and reactions to situations without too much thought about what they were doing or how the consequences of their actions might affect themselves and others. Other responses, however, were described as *pre-planned* or a strategic course of action to deal with a specific problem. To that end, these actions have been separated into two different sub-themes: *4.1a) ii)* '*responses to anxiety and powerlessness*', and *4.1b) ii)* '*default to negative coping strategies*'.

Aggression

Often, when fear and anxiety become exhausting, participants might resort to violent acts towards other people, and the front-line caregivers were very much in the firing line. The data demonstrated that the severity of aggression exhibited by the participants varied from the verbal shouting, swearing and screaming to physical aggression causing injury. Most of the violence reported would appear to be short-lived and limited to an outburst rather than a sustained attack; however, even a short-lived violent outburst, caused by a build-up of anxiety, could be destructive and cause serious physical injury.

One participant explained how the sensory conditions of the physical environment, coupled with a nurse talking to him, simply overloaded his capacity to absorb more information. Once breached, he needed to stop the source of the information, in this instance, the nurse herself and he attacked the nurse, causing serious injury resulting in a visit to the Emergency Department. Numerous incidents of aggressive responses emerged from the data; the following example is from a participant who would normally describe himself as passive and who was shocked to learn that he was capable of such a response to her anxiety:

> *"I remember the fear within me and how it pushed me into a rage. I felt very paranoid about the people around me and considered that it was them against me. I remember on numerous occasions being very loud and aggressive and, on less frequent occasions, physically violent towards the members of staff. I don't think I've ever tried to hurt anybody in my life and I am sorry for how I behaved, but this was undoubtedly the most anxious time of my life and I felt completely out of control."* (Garry)

I was continuously surprised by the acts of violence that the participants reported to me during the interviews: the majority of the participants came across as extremely mild-natured and courteous, so imagining them undertaking the acts that they described was a difficult thing to do. This is explained by a number of participants:

> *"It's very out of character for me but I became very aggressive and couldn't calm down".* (Habika)

> *"During the first two days of my admission, I continuously saw red (metaphor for fury) and vividly remember feelings of absolute anger".* (Prima)

> *"I can't remember a time in my life when I felt so scared and I couldn't find any other way of dealing with it than to be very aggressive and fight my way through it*". (Jacob)

> *"I'm not an aggressive person and never want to hurt anybody but in desperate situations, especially those that I don't have any control over, I do seem to have a problem with unqualified rage".* (Lucas)

> "*My behaviour was so bad that the nurses had to restrain me and give me an intramuscular injection to calm me down. I work in a library and I wouldn't hurt a fly".* (Jacob)

> *"My parents came to visit me but were told they couldn't see me because my behaviour was too aggressive and too unpredictable.".* (Jan)

I was struck by the level of detail that the participants were able to recall, even those who described episodes of 'rage' and who would theoretically expect blank spots within their memory, were able

to articulate detailed and painful recollections. There were also words of remorse and shame that emerged from the data:

> *"I feel ashamed of my actions and feel that they belong to somebody else other than myself,".* (Charlie)

> *"If I could wind the clock back and not hurt those nurses, I would".* (Delta)

However, when considering these quotes as well as other similar extracts alongside the linguistic notes, and listening to the participants' tone of voice, often their words of sorrow and remorse appeared shallow and without authenticity. These comments of remorse may well be genuine and should be considered so; however, Lerner et al (2012) suggest that people with ASC can often mimic language and learn to use appropriate words at certain times, without real depth or understanding of what the words mean within a context. To be able to evaluate the normative of the actions or spoken language can only be achieved by possessing the social cognitive process of moral reasoning, which is a challenge for many with ASC (Im, 2016).

Francesca described herself as a 'social actor', i.e. someone who has to not be themselves in order to survive certain social situations. She explained that this is very tiring and can lead to complete exhaustion if one is constantly being called on to take part in social situations where one is not comfortable. Similarities could be drawn upon when considering the 'managed heart theory' of Hochschild (2012), i.e., the emotional labour which is required for certain professions which Hochschild's (2012) study considered, including flight attendants and other service providers who are involved in face-to-face customer care interactions. Hochschild (2012) explores the theory that such professionals are required to mask their true emotions with those that are needed to do the job, i.e. customer courtesy demands that under no circumstances should the customer ever have to consider whether you are having a bad day: any troubles you may be experiencing should be masked with a smile and pleasantries. This necessitates an employee to suppress feelings and, in addition to the mental and physical labour that is already exists, this adds emotional labour. From a nursing perspective, I have often found myself using emotional labour, none more so than when I have been called upon to deal with a critical incident involving a violent patient. At such times it is evident that a nurse is not only interested in managing the emotions of the patient but is also mindful that their own emotions need to be regulated.

Self-harming

Unfortunately, self-harm is a common strategy used by people with and without ASC to deal with acute anxiety, and this will be explored in more detail under the main theme *strategies for coping*, both in this Findings chapter and the Discussion Chapter 5. One participant reflected on an extreme response where he would bang his head against the walls. His aim, quite literally, was to '*knock the fear and anxiety out of his head*'. Others reported cutting their bodies: whilst most made superficial cuts at various anatomical locations e.g. on the upside of the forearm, one participant articulated fluently the need for many people with ASC to regularly hurt themselves.

Management of Behaviours that Challenge

A range of staff-led strategies were identified which contributed to managing service users' challenging behaviours and emotional distress. These strategies seem to form an important aspect of the admission process. There are a variety of negative and positive perceptions of this from participants, which are outlined below.

They expressed positive opinions about identified anonymous staff who were skilled at escalating aggressive outbursts:

> *"Staff talk to me about trying to run away or take overdoses".* (Delta)

> *"Some staff spoke to me and tried to comfort me, whilst others really can't be bothered".* (Olivia)

There is clear evidence of feelings of resentment towards staff emerging from the data: this was mostly directed at those members of staff who had been involved in physical restraint:

> *"I remember the staff being very heavy-handed with me and during physical restraint, one of the male nurses gave me an intramuscular injection. It must have been very powerful because it knocked me out almost immediately. I very much disliked the nurse who gave me injections from that point onwards.".* (Shannon)

> *"Being physically restrained was one of the most torturous experiences of my life, I know now that they were trying to protect me and others from my behaviours, but at the time it felt like punishment. I have heard since that some guidelines suggest that physical restraint should not be used on patients who are known to have ASC, due to the sensory stuff I guess?"* (Prima)

Participants also reported that they saw the use of antipsychotic medication regimes as forms of chemical restraint and that their only purpose was to manage behaviours:

> *"My question for the psychiatrist was that if you don't think I am psychotic why am I on antipsychotic medication? The answer was never satisfactory, and I feel very much that the medication was prescribed to keep me down."* (Habika)

b) Main Theme - *Strategies for Coping*

This main theme described the strategies employed by the participants to cope with the all too apparent anxiety issues. Their struggles appear relentless and unyielding as they attempt to get a handle on their anxiety and reduce it to a level where it can be managed.

i) Sub-Theme - *Developing Positive Coping Strategies*

This sub-theme represented the creative ability of the participants and their insights into where their anxiety has come from, why it continues to be a problem for them and how to manage it as best they can in an environment which is unfamiliar to them. Participants reported that managing anxiety within a comfortable environment, i.e. their home, is far easier than managing anxiety in an environment which is unfamiliar. Broadly, the participants were aware of specific situations when their anxiety might become unmanageable and would try to be proactive to avoid such escalation. Predicting these occasions was less likely during the early admission phase, and more likely when the participants became more experienced and alert to potential moments of anxiety on the units.

> *"Mealtimes were the worst for me, the hustle and bustle of the dining room, people bumping into you and wanting to get to the food first so that there is more choice. Eventually I found myself holding back and not wanting to get involved in the hullabaloo."* (Charlie)

> *"I found evenings to be particularly tricky, there was less routine and activities going on after dinner and I found myself getting quite stressed just thinking about getting through the evening to bedtime. Everybody else seemed to relax and watch television and do the right thing, but for some reason I can't find anything to do and really just killing time until bedtime. However invariably I would be so anxious at this time it would impact upon my sleep."* (Maggie)

The participants described making notes to help them understand when these times and situations arose, so that they could learn and make differences that could help to alleviate their anxiety and improve their time on the units. Winston described how he took notes and used them on a daily basis, in or out of mental health units; he formulated lists which contained aspects of his day-to-day life which were either perceived as positive or negative, and called this an *energy bank:*

Energy Bank

> *"The energy bank is like any other bank, in that it receives deposits and withdrawals and when the bank is in the red I feel physically and mentally drained, at this point my ability to control what is happening around me reduces, then my world becomes more unpredictable and then the anxiety increases. It is then that I feel at most risk of mental illness".* (Winston)

The identified Withdrawals and Deposits by Winston outside of a mental health inpatient unit, are detailed in **Table 8** below:

Table 8: The Energy Bank - life outside of a mental health inpatient unit* (Winston*)

Energy Bank	
Withdrawals	**Deposits**
Socialising Change Making a mistake Sensory sensitivity Daily living skills Coping with anxiety Over analysing Being teased or excluded	Solitude Special interest Physical activity Animals and nature Computer games Meditation Routines Nutrition Favourite food

This *Energy Bank* concept was explored with this participant during the interview process, when he had been admitted to a mental health unit, at which point the 'Withdrawals' began to outweigh the 'Deposits' and, consequently, he lost control of many aspects of his daily life, thus causing unpredictability and, ultimately, high levels of anxiety. See **Table 9** below:

Table 9: The Energy Bank - life inside a mental health inpatient unit (Winston)

Energy Bank	
Withdrawals	**Deposits**
Lack of familiar environment and change Lack of trusted people Socialisation Daily Living skills Being teased or excluded Lack of control Not being allowed to isolate himself Side effects of medication Making a mistake Eating weird food Loss of sleep	Talking about his special interest Having meals prepared Physical activity

The importance of physical exercise when dealing with or avoiding anxiety was highlighted by participants and having access to a gym was a priority for some. However, a gym was seldom available. Another participant described how using progressive relaxation and breathing recordings on her iPhone helped her to relax in the evenings. Another reported that she would identify the main potential stressors of the week and write down objectives to how she could limit the anxiety

surrounding these situations as much as possible. She noted that nearly all the unpredictable situations involved other people: meetings involving other professionals were described as extremely stressful for this participant.

Plastic bubble

Participants also reported the ability to be able to *zone out* when life on the unit became too stressful; this was articulated by Damien:

> *"I call it my plastic bubble, it's my imaginary wall between myself and the world. The wall can appear when I need it to and it conceals my thoughts and protects me from other people and the sensory world which scares me. For others who can't see my plastic bubble, all they see is an individual shutting down, in other words going into oneself and zoning out completely. People have told me my presentation is that of a person in a trance. But it works, and I stay in my plastic bubble for as long as I need to."* (Damien).

This can be considered alongside psychological theories that relate to introversion. Grimes et al (2011) developed a four-factor model of introversion, divided into: social introversion (prefers solitude to people); thinking introversion (reflective and introspective); anxious introversion (shy and ruminative); and inhibited introversion (resists new experiences); however, the example given by Damien appears to be more extreme than any of the four factors described within the model. Baron Cohen (2014) uses the term '*extreme introversion'* to describe social behaviours belonging to groups of people with ASC.

Listing concerns

Jacob reported that his strategy for dealing with his anxieties was to reflect upon what it was he was worried about, write it down in a 'list' format and systematically find solutions and "check them off the list one by one".

> "I take my list with me everywhere I go, I fold it up and keeping in my back pocket, that way I can tick things off or add to the list if I need to." (Jacob).

Before the implementation of this strategy Jacob told me he simply had "a load of anxiety, without any reasons or ways to get rid of it." Solutions to the listed concerns are found by asking somebody for advice, Jacob named the Asperger's support group that he attends as a useful place to bring his list and speak to the volunteers and others who may share his anxieties. Also, he has been known to use *Google* to find solutions, with mixed reports of success. Jacob had a list in his pocket and was willing to show me how it works, I recall being surprised at the level of detail and the perceived complexity of the list and asked Jacob to explain in more detail.

> "I look for common elements, sometimes worry issues are strangely connected, I call them anxiety spirals, in other words there could be one central cause for my anxiety, but in my

head, I have created lots of different connections or spirals to the central cause. I find it useful to note these down and use arrows directing them to the central cause because that's the most important one and if I deal with that one as a priority, the other connected anxieties go away as well as the central concern." (Jacob).

Jacob demonstrated a simple example of this during the interview. He was disturbed by some noise outside in the street and identified that this was causing him anxiety. After writing it down he then spoke to me about it and I suggested closing the windows for the duration of the interview. Which he did and then duly ticked the concern off his list. Jacob reported that during his time as an inpatient there were too many causes of anxiety to write down, although he did try, the success of this strategy during this time was further hindered by a fellow inpatient continually "pinching" his list in an attempt to encourage Jacob into a confrontation.

ii) Sub-Theme - *Negative coping strategies*

This sub-theme represented the participants' described attempts to manage their periods of anxiety with employed strategies, which have been observed by myself and others who have commented upon the data. It is important to note that the participants themselves and the users of these strategies do not always perceive them to be negative. This dichotomy exists because the presentation of the act, i.e. the externally observed behaviour, is the only part that anyone other than the strategy user themselves will see. The participants described feelings of safety, comfort and release from acutely anxious moments in their day-to-day lives, and they can only see these feelings as positive.

Aggression

Most of the reported behaviours of violence and aggression were responsive, short-lived and without consideration of their consequences both for themselves and others: they are therefore more suitably reported within the sub-theme: *4.1 a) ii) 'Responses to anxiety and powerlessness*'. However, one participant explained the use of aggressive behaviour differently, with evidence that she had pre-planned verbal attacks on an identified other service user:

"I discovered early in my admission that aggression, both verbally and physically, helped to get a lot of my frustration and built-up anxiety out of my system. During these earlier times my aggression would be a result of a situation that I would find myself in. However, over the weeks and months I developed an understanding that if I was aggressive earlier, i.e. during the build-up of my anxiety or frustration, then I could manage it more quickly. There was a young lady with learning disabilities on the unit and I knew that I could get away with shouting at her and not fear any repercussions, as she would be too scared to challenge me. Therefore, I would actively seek her out when I felt that my anxiety was building up and yell at her, and it made me feel a whole lot better." (Charlie)

Self-harm

A good example of an action perceived as a positive and negative dichotomy is the description of a *worry cycle,* which Jacob clearly perceived as a positive strategy:

"I use short sharp pain to interrupt my anxiety and my worries. I call it my worry cycle and I have a couple of techniques that I know work, for example I flicked my earlobe really hard and it gives me a sharp pain which makes me think very quickly about the pain and I then tend to forget what I was worried about in the first place! Another thing I do is to wear elastic bands around my wrists and I snap it against my more sensitive underside of the wrist, again this sharp but short-lived pain interrupts the train of thoughts. In hospital, I was constantly trying the strategies but none of them worked, that's mental illness pure and simple, the stark difference between anxiety relating to the core features of autism and something that is much harder to control." (Jacob)

Isolation

Isolation is a coping strategy reported by many participants. One participant needed to isolate himself from others to cope with his rising anxiety levels.

"In my normal living environment, I have my flat, which is my own space which I have designed to meet my needs. The key component of this design is that there is nobody else in it! I know that I can find solitude and quietness, I can listen to my music, watch my own television or play on my PlayStation. Additionally, over a long period of time I have been able to eliminate all the sensory aspects of my living space which could cause me stress. On the unit, finding a quiet area was impossible, even the areas which were called 'quiet areas' were always quite busy, and I can never find time just to be on my own. There were four beds in my dorm, even with the curtain around my bed I was never alone. I found this unbelievably difficult to deal with and consequently I spend my entire time on the unit on the edge of my nerves." (Delta)

Another participant described her frustration at not being allowed by staff to be on her own at certain times of day:

"Nearly everybody with autism including myself needs periods of time on their own and away from social situations, this is used to rid themselves of anxiety, gather their thoughts and spend some well-needed time on their own. On the units the staff simply did not understand this, and it caused endless problems, not just for myself but for other patients with ASC. I remember one nurse saying to me that, "if I leave you in your room, then I'm not doing my job properly". I believe that this nurse and others saw engaging with their patients as an important part of their role, which is fair enough, but they need to understand the impact of social situations upon people with autism. For me there was a significant lack of understanding and empathy on their part." (Anne)

For the most part, participants reported seeking out isolation; however, one participant used the word '*isolated'* to explain how he was made to feel on the unit by other service users and staff.

Service users described difficulty in getting to know the other service users, which contributed to feelings of being alone, not having others to talk to and feeling isolated.

Eating

Eight of the 20 participants reported they had little or no desire to eat during their admission and reported significant weight loss. One participant explained:

> *"I was feeling so worried all of the time, I simply didn't have an appetite. The nursing staff would always be on at me to eat. They would watch me at mealtimes and record how much I had eaten. I didn't want to annoy them, so I would force myself to try and eat something at least, but this seemed to cause me digestible problems. I have been out of hospital now for just over a year, but my appetite is still not as it was, and I don't think it will be."* (Olivia)

Another participant put her considerable weight loss down to her continual pacing up and down the unit in an attempt to alleviate the stress that she was feeling:

> *"The only way I could maintain an anxiety level that I could manage, was to pace and keep yourself moving all the time. I wore headphones or ear defenders mostly to block out noise, but also to make myself look busy so people wouldn't talk to me. I must've walked miles every day, without actually leaving the unit."* (Emeka)

I consulted an Expert by Experience (EbE) who works for the Asperger's Support Team, and who himself has ASC, and asked him to review a small number of transcripts belonging to those participants who had reported weight loss. He felt there needed to be greater analysis and asked me to return to the participants and ask them if this could be related to sensory issues. His rationale was that he knows of many people with ASC who eat the exact same food, in the exact same format, normally in three set meals each day. They rarely alter from this concrete routine, going out for dinner only on special occasions, do not order takeaways or allow others to prepare meals for them, unless this is what they normally do. He suggested:

> *"The taste of the food is the all-important part, the fear of not knowing how the food will taste, because it hasn't been prepared in exactly the way it needs to be, can cause great anxiety to the point where going hungry is an easier option. But it's not just the taste, the texture is also very important. It could well be that the person eats Shepherd's pie three times a week and Shepherd's pie is on the inpatient unit menu, however it will not be their Shepherd's pie and it will not taste exactly the same*." (Expert by experience, Asperger's Support Team, 2016)

By returning to the participants and exploring their eating habits and the reasons why they make the choices they do, the EbE had opened a new line of enquiry which I would not have thought

about without his input. I discussed this with the participants, six of whom agreed that this had been an issue for them.

The emotional response to harming others

words of remorse were seldom heard during the interview processes and instead many of the participants appeared unable to take responsibility for their own actions, even when they had clearly remembered and understood that they had caused another person on. Garry however use the word 'sorry' on numerous occasions during the interview:

> "I'm sorry that I put my family through what I did." (Garry).
>
> "When I think back to the three months of my admission I realise now that it was 3 months of hell for my poor mum and dad, I am sorry for that". (Garry).
>
> "My mum particularly panicked about my admission to hospital and was really scared that I wasn't going to come home, I felt sorry for her, but was unable to reassure her because I was also scared about the future". (Garry).

4.2 Superordinate Theme - *Sense of self and connectedness*

This superordinate theme encapsulates the participants' construction and perception of self and connectedness to others, including unit staff, other patients and external parties. It explores how participants view themselves and the impact this perception has upon making relationships; additionally, it will explore the effectiveness of the participants' communication styles and the impact this may have had upon their inpatient experience.

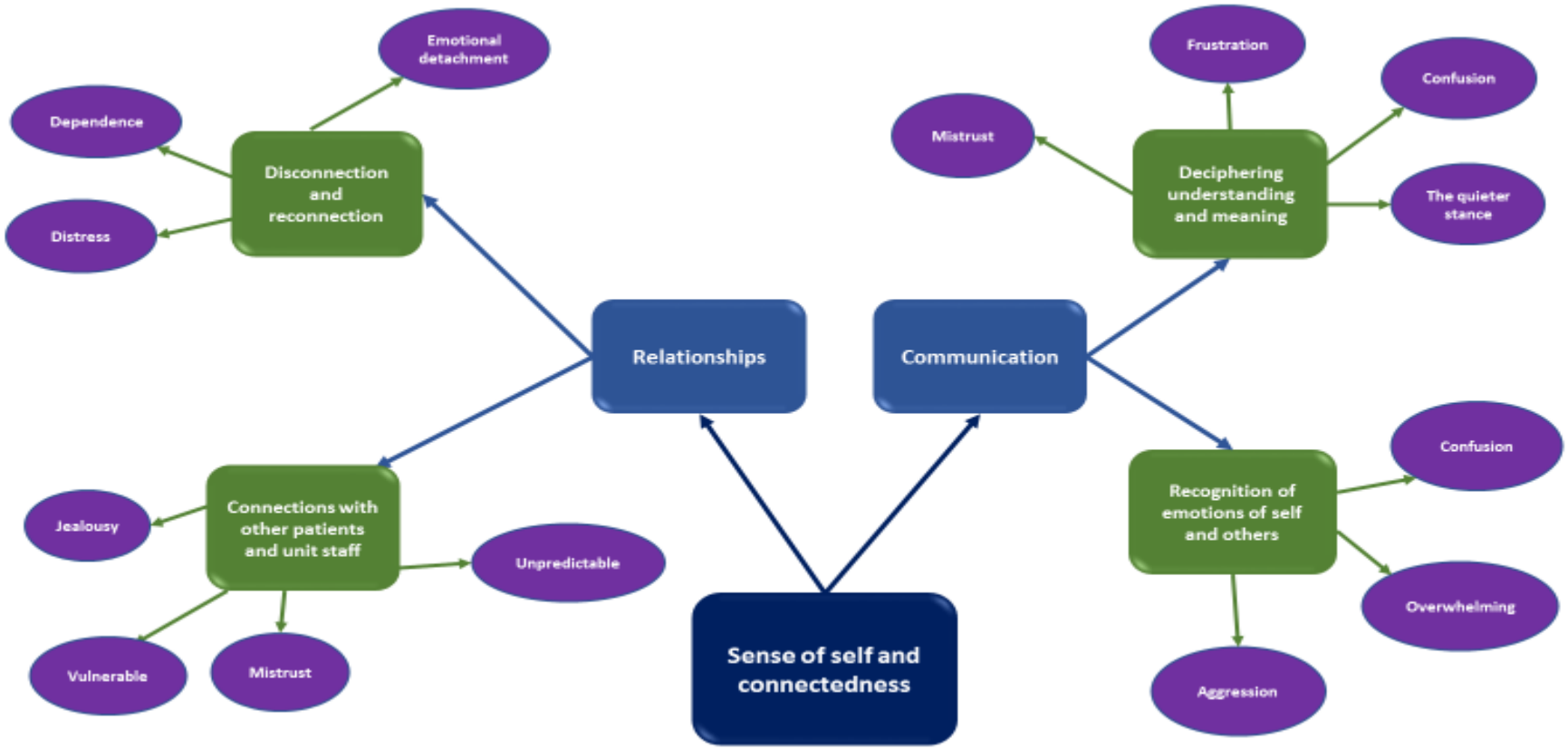
a) Main theme - *Relationships*

This main theme explores the participants' experiences of relating, and how successful or unsuccessful these may be and how their experiences impacted upon their feelings.

i) Sub-theme - *Connections with Other Patients and Unit Staff*

Service user views of themselves and their relationship with staff, carers and other service users influenced how they experienced their admissions. The current study reports that service users experienced difficulties in relating to staff and other service users, thereby isolating themselves. Several participants reported that they felt different from those other service users without ASC and that they could observe better relationships between the care team and those patients without ASC. They explained the powerlessness was created by not being able to develop meaningful relationships with others on the units.

Figure 4.2: Theme Map – The Sense of Self and Connectedness



Key:	Superordinate theme	Main theme	Sub-theme	Emotions and coping strategies

Jealousy

> *"There always seems to be banter between the staff and other patients, but the jokes seem to be private jokes exclusively between them and therefore difficult to join in. Much of the banter was of a teasing nature and the patients appear to find most of the teasing funny, but I struggled to see the funny side of a lot of what was said."* (Prima)

There seemed to be a desire on both sides, i.e. the members of staff and patients, to engage in a more successful way, but this was not easily achieved. Another participant recalls an early attempt by a support worker to begin a humorous discussion:

> *"On my second day a member of staff walked into my room to have a chat, he was friendly and started to talk about being on the unit and what I could do during the day. I could tell he was being funny but unfortunately, I didn't get any of his jokes and he didn't get the response he was looking for. The conversation ended, and I didn't speak to that particular member of staff again, although I would see him on numerous occasions laughing and joking with other patients."* (Jan)

Mistrust

Due to the prevalence of violent incidents reported by the participants, particularly during the initial few days of admission, some participants felt that the staff resented them for these acts. One participant explained:

> *"One of the nurses said to me, which I didn't like very much, that there was some resentment towards me from the nursing staff because I had physically hurt some of the care team during the initial period on unit."* (Jacob)

Shannon described her feelings that the care team thought she was being '*socially awkward on purpose'* and appeared to be suggesting that the unsuccessful building of relationships was being caused by the participant, and that greater effort was needed.

> *"Their inability to build relationships with me was taken personally by the nurses and impacted upon the level of care they offered me, they would come across as cold and uncaring. Eventually I grew to dislike and mistrust them."* (Shannon)

Vulnerable

The poor relationships many of the participants experienced with staff and other patients was noted to have had an impact upon their feelings of powerlessness:

"If you don't have friends in these places, you can't say anything, you can't talk, you can't challenge, and you can't stand up for yourselves". (Anne)

The sense of powerlessness and sense of vulnerability is also evident when the participants spoke of being bullied by other patients:

"The way I felt on the ward was very like how I felt at school, I was one of the weaker boys and felt like a victim. Some of the other patients would tease me and occasionally threaten me." (Prima)

"Some patients would tell me that others had it in for me, just to wind me up I expect, but this made me feel very scared." (Damien).

Unpredictable

The unpredictability of the other patients' behaviour and ways in which they communicate, would cause the participants to avoid them. The participants clearly interpreted the other patients' actions and communications as being threatening and even intimidating, but on occasions I felt that there had been the potential for misinterpretation and the way actions and communications had been perceived by the participants were not necessarily the way they were intended.

"One guy threw a boiling kettle at another patient, the one who threw it was someone I got on with and we were becoming friends, but after that I didn't trust him and no longer wanted to be around him." (Mnamdi)

"The ward would be so loud and chaotic, I would keep out the way and keep myself to myself." (Davy)

ii) Sub-theme - *Disconnection and Reconnection*

Relationships with family were also significant to the service users during the admission. The traumatic experience of being admitted to an inpatient unit may partially be attributed to service user experiences of being separated from their families, which some perceived as rejection and which contributed to feelings of distress and loneliness. Maintaining and increasing contact with family and friends was therefore important:

Distress

"Being separated from my family was extremely painful, as they are the only ones who understand me, my quirkiness and how to keep me focused and calm." (Lucas)

"My family put pressure on me at times, but I didn't realise how much I needed that and really missed it, I felt directionless." (Jan)

"I desperately needed to see a familiar face and someone I could trust, that is really only my family." (Francesca)

"I guess I rely heavily on my parents and not seeing them was a scary experience." (Emeka)

Dependence

The suggestion was of need, i.e. they needed their family rather than that they missed them in an emotional way. It was interesting that there was a suggestion of surprise within their voices, which indicated that they had not realised how much they needed their family, whether parents, siblings or, in one instance, their children. Having family as a strong advocate was valued by Habika, who acknowledged:

"I strongly believe that I would never have got out of that mental hospital if it wasn't for my Dad, he pushed and pushed for a proper diagnosis and if I hadn't had that support I don't think I would have got the help I needed." (Habika)

Emotional Detachment

Participants experiencing longer admission periods reported a disconnection with family and friends: they were more likely to maintain regular contact during the early periods of the admission, compared with the latter period:

"Maintaining relationships with people within my current environment, seemed more important than preserving contact with people whom I see very seldom and are not part of my day-to-day life." (Charlie)

"During the first few weeks the only thing that kept me going was ringing home, this became less and less important and I don't think I spoke to my family at all during the last few weeks." (Delta)

The matter-of-fact way that this participant explained the process of disconnecting with family and friends gave the impression that there was little consideration for their feelings. The notes I took during the interviews consistently reminded me that I had the same feeling at the time I heard these comments, a feeling that they were either unaware of or were disinterested in the feelings of those closest to them at these significantly stressful times for everybody concerned.

"I got used to my current surroundings, routines, structures and the people in it, everything else goes out the window." (Delta)

The same participants who discussed the process of this with family and friends also discussed the process of reconnection once they came closer to leaving, or had been discharged:

> *"My family took my lack of contact to heart, they could not understand why I didn't need them during my time as an inpatient. This caused problems on discharge, when I felt the need to reach out to them, there was a reluctance on their part at first to speak with me"*. (Charlie)

Another explained the desire to reconnect with his family after a period of very little contact that lasted approximately six months:

> *"As my anxious state of mind began to diminish, I became more able to see the world beyond the inpatient unit and the day-to-day survival that I had endured for most of my inpatient stay. I suddenly felt the need to attach once again with my family and some of my friends, they have been out of sight and completely out of my mind for a long time. It is almost as if I didn't need them in there, therefore couldn't see the point in keeping in touch with them if they were unable to help me."* (Jacob)

My interpretation of this final quotation was that the nurses and the other frontline caregivers had assumed responsibility for their everyday psychological support and care which was previously provided by the family.

b) Main theme - *Communication*

Clear and concise communication was an essential part of the inpatient experience for the participants. An understanding by frontline caregivers of the need for individualised communication strategies and an associated estimation of the participants' communicative abilities, appears apparent. This main theme explores the difficulties of communication which lacks clarity and precise meaning, and how misinterpretations can lead to a variety of powerful emotions.

i) Sub-theme - *Deciphering understanding and meaning*

The participants held in high value clear and concise communication from the front-line caregivers. Often the relationship between the health professionals and the participants suffered due to inaccurate information being given. Participants referred to their carers as '*liars'* and being '*dishonest'*; some of the evidence would suggest that the care team had attempted to communicate in a way that they perceived appropriate, but that the patients did not.

Mistrust

Charlie claimed that the staff had '*blatantly lied*' and consequently they could no longer trust that member of staff.

"The blatant lies the people say to you, for example the nurse who looked after me on the unit was always very happy and very positive, would always say that things are going to be okay for me not to worry because things would be all right in the long run. However, they weren't okay, actually most my time on the unit things were a long way from okay, since she lied to me in this way I can't trust her again." (Charlie)

"Problematic encounters for people with autism and as you would expect can lead to stress and anxiety. Nearly every mental health practitioner I worked with within the psychiatric inpatient unit could have made relatively simple changes to the accuracy of their language, which will have enhanced my experience twofold. Until people realise that being falsely positive, or have a laugh, or making fun of to relax them and make them feel better, has extensive repercussions, the likelihood is that communication used by the staff on the units will only increase anxiety and not help or assist with recovery." (Mnamdi)

Frustration

It may well be that the extracts above are examples of misinterpretation on the part of a person with ASC, rather than the practitioner trying to mislead them. People with ASC interpret language quite literally; for example, irony, sarcasm, figurative language, rhetorical questions, idioms and exaggeration can all be extremely misleading and confusing to the autistic ear (NAS, 2018).

The next extracts raise the question of the staff's ability to interact with people with autistic spectrum conditions in an informed way. The National Autistic Society (2018) offers guidance on how to communicate with people with autism; their online *Communication* e-learning module offers guidance on supporting the listener and not overloading them with the information they are trying to process. An autistic person can find it difficult to filter out less important information: therefore, it is important to try to keep to the most important information, '*say less and say it slowly*'. The following extracts are clear examples of what can happen if simple guidance is not followed:

"Everybody I know apart from a very few people have no idea how to communicate with people of autism. Therefore, the care team on the psychiatric unit were no different. I have processing issues, is not to say I'm thick, it's just that I need time to keep up with the level of conversation and the speed of a conversation. Sometimes there can be gaps or silences when I speak to people. For example, a nurse on the unit would ask me a question, and before I had a chance to reply or process what she was asking me properly, she has become uncomfortable with the silence and filled the gap with another comment or question. At this point I'm still thinking about the first sentence she said and can't concentrate on the second. Sometimes people have told me at this point I look very dazed and confused, I'm not confused or dazed I'm just trying to keep up the conversation and thinking very hard about how to respond to the first question and if you then hit me

with a second and you'll probably lose me. Many people with Asperger's and high functioning autism, very clever people suffer from the same processing disorder." (Jan)

"She (the nurse) was very busy and I understand she had to move quickly, it was too quick for me and I think she just thought I was completely thick." (Francesca)

"If my named nurses talking to me and not waiting for me to catch up I quite often get stuck on something she asked me, and because she was a bit of a chatterbox she will fill that gap with another question and I would be lost." (Anne)

Garry questioned whether the care team in this particular inpatient unit had received training in communication strategies and approaches for ASC. Since the implementation of the Autism Act in 2009, many mental health practitioners undertook autism training which encompasses strategies for communication (Public Health England, 2016). The training will typically be guided by the communication principles offered by the National Autistic Society, i.e. how to use less non-verbal communication, use of visual supports (e.g. symbols, timetables and social stories), and sentence construction, and avoiding open-ended questions (NAS, 2018). Further details of communication recommendations can be found in Chapter 6.

"Some simple rules of how to communicate with people of autism could have been taught to the care team and I think they will get a lot more out of me, the main rule is to check your pace of your conversation and make sure that I'm able to keep up with you". (Garry)

Confusion

Howlin (2005) suggests that avoiding eye contact is a quick and easy way to automatically improve your achievements when talking to a person with ASC; the person with ASC themselves will often avoid eye contact as they can be distracted by facial expressions from the person talking to them and trying to maintain eye contact is difficult. Attempting to read the non-verbal communication which is being conveyed via facial expressions are notoriously difficult for people with ASC to decipher.

"Sensory processing disorder can sometimes slow down the way you communicate because you get hung up on people's facial expressions or the way they are talking, for example accent or the tone of voice." (Olivia)

Other participants' accounts describe the use of medical language and the need for further clarification:

*"This is a brand-new experience for me and I have no concept or rule of understanding of the world of mental health and the terminologies used within it." (*Delta)

"When the nurse is talking to me about cognitive behaviour therapy, you might as well be talking to me in Chinese." (Malkey)

The non-engagement of therapies reported by Lucas, Jacob, Prima and Anne who identified various types of interventional therapies that were on offer to them and why they decided not to engage. The overarching reason given for this was that the participants could neither understand nor see the potential benefits of engaging. For example:

"The psychologist invited me to attend an 'anger management' group, which would meet three times per week on the unit. It was explained to me that the group would be facilitated by an assistant psychologist and would be a good opportunity to discuss the triggers and responses to my agitation and behaviour. I did try hard to understand, but I could not see how this could help." (Prima)

"My thoughts were that psychotherapy was for people with mental health problems, I am autistic not mentally ill and therefore could not understand how therapy could help, as there isn't a cure for autism." (Lucas)

"I find it hard to imagine how talking about the problem can make it better." (Anne)

The quieter stance

In a small number of the interviews I had a sense that the participants were providing me with only brief and succinct answers. This could have been for a variety of reasons, for example when I questioned Delta about his treatment on his unit, he replied: '*that's just the way it was'*. Or when I asked Shannon to elaborate upon the perceived power held by other inpatients she replied; '*there are some things that you can't do anything about*'. Emeka replied in a similar way when I asked her if she challenged the way in which the nurses spoke to her, she said; '*there is a limit to what you can do'.*

ii) Sub-theme - *Recognition of emotions of self and others*

This sub-theme aimed to capture the participants' descriptions of ways in which emotions are recognised and the impact these have upon interaction and meaning.

Overwhelming

The following extract explains the confusion which existed for this participant when he found himself in an emotive exchange with his named nurse:

"My named nurse was a flamboyant character who used lots of facial expressions and hand gesturing to help accentuate what it was he was talking about. I would normally begin the conversation with an attempt to try to read some of the unspoken communication which will take place, but after a while I find this too overwhelming. I

would then look away and tried to concentrate on just the spoken communication. Every now and again he raised the tone or the volume of his voice. I was always confused by these changes and would try and guess whether he was angry with me or not?" (Malkey)

Aggression/Confusion

The same participant went on to explain how guessing at the emotions attached to the interactions from the nursing team lead to misinterpretations as there was a lot of guesswork going on:

"When the nurse raised his voice and heightened the tone, I assumed he was being aggressive with me and I responded by being aggressive back! I pushed him over and screamed at him. In a debriefing discussion about the incident afterwards, the nurse explains he was raising his voice to demonstrate his passion for the programme of therapy that he was proposing to me. I remain confused but, he didn't appear to be an aggressive person and wasn't before this incident or after, I think I did interpret his emotions incorrectly." (Malkey)

Another participant explained further the importance of the care team understanding the difficulties people with ASC are faced with when attempting to understand their emotions and feelings towards their mental well-being:

"On the unit I was constantly asked how are you feeling today? I could never work out the answer. Did I feel depressed? If so, do I feel more depressed or less depressed than I did yesterday? It is more important to instead of asking us what's the matter? Ask us, what matters?" (Francesca)

4.3 Summary

Chapter 4 has presented the findings and results of this current study following an in-depth data analysis and the development of thematically presented superordinate themes, main themes and sub-themes. The vivid recollections of the participants' experiences help to bring their experiences to life and allow the reader to begin to understand the reality of the phenomenon. The participants have given this study a vast amount of data which contains many well-articulated insights into their rationalisations and reasons for their responses to the difficulties and challenges that they faced, how they overcame the challenges and faced up to their difficulties.

In summary, the key findings as illustrated in Table 4 begin with the superordinate theme 'the experience and management of anxiety' which includes the participants' responses to feelings of heightened anxiety and powerlessness; including responses such as aggression and self-harming. Additionally, the emotional reaction to uncertainty was reported as feeling vulnerable and in need of safety and protection, coupled with the desire to recapture control in their lives, ensuring that routine and structure exist as this assisted in feelings of security and safety. The intolerance of uncertainty is explained in great detail, as is their reaction to the sensory stressors within the inpatient environment and their reaction and felt anxiety when time is not

completely understood, particularly including the lack of clarity regarding their length of stay on the units and exactly when things may happen for them. This superordinate theme also captures their created coping strategies, some of which are insightful and effective, whilst others are more difficult to comprehend for those who are not experiencing.

The superordinate theme ‘sense of self and connectedness’ encapsulates the participants’ recollections of relationships with both staff and fellow patients, the challenges that impeded and the rewards gained when they were possible. The emotional dependence and detachment issues which existed with family and friends upon admission and then similarly with staff and patients upon discharge. The communication challenges are comprehensively reported within this superordinate theme, including encounters with deciphering understanding and meaning, which generated mistrust, frustration and confusion. The internal struggles with recognising emotions and the feelings of others proved to be overwhelming and often led to further confusion.

Their accounts of how they see themselves and their role as an inpatient and a person with ASC and their relationships with others will be examined further in Chapter 5. Additionally, Chapter 5 provides an in-depth exploration of these key findings in relation to the existing theory and evidence base. The significance of the study i.e., the clinical and methodological implications and suggestions for future research, will also be key components.

Chapter 5: Discussion

Chapter overview

This study set out to convey the lived experiences of psychiatric inpatients, with a focus on the experience of adults affected by ASC and from the perspective of being an inpatient and experiencing hospitalisation. The previous Chapter 4 goes some way to achieving this, by providing an in-depth and multi-dimensional analysis of the inpatients' experiences. This discussion chapter explores the key findings in light of the following research questions and in relation to existing theory and prevailing literature. The significance of the study, its clinical implications, arising methodological issues, suggestions for future research and reflections on the study will subsequently be explored.

Additionally, the impact of implementing a social constructionist stance and an IPA framework will be discussed and evidenced. Using IPA has given me the opportunity to bring to the forefront the experience of inpatient units for adults with ASC, using their own language to share their inner world. The IPA framework also allows for acknowledgement that subjective experience is itself embedded within a history of personal, cultural, and social-economic history, which all shapes how people make sense of or construct their reality the two cannot be de-coupled. I can see that the careful examination of claims and concerns can be valuable and revealing. For example, being able to understand Prima's experiences of vulnerability (i.e. being bullied and laughed at school) is an important precursor to been able to understand how he felt when he thought the charge nurse on his unit was laughing at him. That is, it is easier to recognise that the anxiety born from this feeling of vulnerability is not simply an inevitable consequence of being autistic, but instead the interpretation of previous events which influence perceptions of future similar situations.

The analysis has demonstrated, first and foremost, that observed behaviours are rarely what they seem and the majority of such require deeper examination. Whilst IPA offers much as a guiding framework, the focus of the IPA researcher can be thrown into some considerable uncertainty; the claims made by participants can be extremely varied, contradictory and confusing making them difficult to comprehend and this can easily lead us away from simply making sense of them and towards causality or veracity. You can find yourself wondering what really happened. It may even prompt us to become excessively absorbed in trying to understand our own experiences and reactions, not very helpful when you have very limited or no experience of being autistic and experiencing the core features of ASC. A certain amount of reflection was helpful and a necessary part of phenomenological and hermeneutic enquiry, so was the use of an inter-coding reliability strategy, i.e. eliciting the help of people who live with the condition, which helped to understand elements of the emerging themes such as the eating habits and consequential weight loss for Olivia and others. Inter-coder reliability was useful to ensure that the analysis was meaningful and importantly placed participant narrative within broader social-cultural contexts and added extra scrutiny to how language is used to convey meaning. Within the following section, I will move on to consider more fully how a social construction approach to IPA has informed analysis and the drawing of meaning from the research.

The primary research question in this study was:

How does admission to a mental health unit impact the psychological well-being of adults affected by Autism Spectrum Conditions?

This question was explored by further subsidiary questions:

- What are the experiences of adults affected by ASC who have been admitted to a mental health inpatient unit and how do they make sense of their thoughts and feelings?
- How do inpatients with ASC make sense of their emotions and experiences whilst in the unit?
- What coping strategies do these emotions and experiences evoke?
- What motivations and values do such patients experience during their time as inpatients?

5.1 The experience and management of anxiety

Coping strategies are commonly classified into *approach* and *avoidance* responses. Approach strategies are actions or behaviours that are taken by an individual to directly alter stressful situations. Examples include active problem solving by the individual or social support seeking when others' insights and support are sought to address the issue. Conversely, avoidance strategies are those that enable an individual to manage their personal physiological and psychological reactions to a negative stressor (Altomare et al, 2017). Studies that have embraced the lived experience have can offer a greater depth of understanding and exploration of the psychological reasoning behind certain acts, for example the employed coping strategy to manage anxiety. (Robertson et al, 2018; Spencer et al, 2019).

The participants in this study have described three avoidance strategies that they often use in the context of anxiety-provoking situations: (a) cognitive distancing, or resistance to thinking about the negative experience; (b) internalising emotional reactions, directed toward oneself for bringing on the negative situation; and (c) externalising, or focusing one's emotions on other people or objects (Kochenderfer-Ladd & Skinner, 2002). Combinations of these strategies are often implemented, with their selection and application varying depending on environmental and situational demands. In general, approach strategies are related to improving the psychological outcome and producing the desired change, i.e. stopping the anxiety (Altomare et al, 2017).

Recent studies have identified several strategies employed to deal quickly with anxiety, including self-harming, physical and verbal aggression, repetitive motor behaviours, sameness behaviours and avoidance (Robertson et al, 2018; Wigham et al, 2015; Lidstone et al, 2014; Rodgers et al, 2012). Of note, in this current study a number of participants explained their anxiety avoidance strategies in detail. Some were quite creative, whilst others would be considered dangerous, involving self-harm and violent responses. Broadly, the participants were aware of specific situations when their anxiety might become unmanageable and would try to be proactive to avoid escalation. Predicting these occasions was less likely during the admission phase, and more likely when the participants became more experienced and alert to potential moments of anxiety on the units.

Evidence from the interviews emphasises the presence of coping strategies organised in the following themes: isolation, stopped eating, and self-harm. Once again from a social constructionist perspective it is also important to acknowledge the impact that such behaviours have upon the social order in general. Spencer et al (2019) explain the restricting effects of policies, procedures, routines and rules enforced by staff in a mental health inpatient unit. However, Strauss et al (1973) describe the social constructs of a hospital environment as more like 'general understandings' rather than a list of commands that have been orchestrated by doctors, nurses and other hospital personnel. The social order of the hospital was an outcome of agreed-upon patterns of action that were themselves the products of negotiations between the different parties involved. Therefore, the social order is in a constant state of change because the hospital is a place where numerous agreements are continually being terminated or forgotten, but also as continually being established, renewed, reviewed, revoked and revised. The participants who exhibit actions such as isolation, stopping eating and self-harm amongst others, are impacting upon the social order of the inpatient unit. Their actions will often be followed by responses from the hospital staff, namely risk management interventions, including increased observations and limitations placed upon their movements. Bryson et al (2017) explain that being the recipient of such coercive interventions can increase the likelihood of trauma during an admission.

The participants in Acker et al (2018) reported that negative responses to anxiety would often result in self-criticism which in turn would create internal pressure, often the result would then be further anxiety. Similarly, the participants in Robertson et al (2018) discuss the inevitability that their actions have a negative impact upon their need and desire to be accepted. Highlighting that not being accepted or judged can be a fear and again result in anxiety (Robertson et al, 2018). Bryson et al (2017 explained that being the recipient of interventions such as seclusion and restraints can cause trauma due to the aggressive nature of the event, but also self-criticism when reflecting upon the incident afterwards.

a) Powerlessness and the emotional reaction to uncertainty

Of all the themes arising about inpatient life, the most concerning and worthy of attention is the feeling of powerlessness and uncertainty, described by one participant as 'the dehumanising effect of the patient care and treatment' (Lucas). The participants have used comments such as 'I had forgotten that I had rights as a human being', 'just because I am unwell, I am not less of a person', 'I felt completely powerless and your life and choices are taken away'.

But more disturbing for them was the lack of control they were able to exercise which caused long periods of anxiety and fear. They observed that the service focused on control or containment, with little regard for the patients' individual experiences and circumstances. The psychological impact of hospitalisation and sectioning of patients included: feeling restricted; controlled; objectified; disconnected; disempowered; not being understood or heard.

Anxiety for many people with ASC is driven by the intolerance of uncertainty i.e. being unsure of what is going to happen, how long the uncertainty will exist and the insistence of sameness which, when compromised, can be anxiety-provoking. Without being able to exercise any control over their day-to-day lives, anxiety is a highly likely outcome (Maisel et al, 2016; Boulter et al, 2014; Wigham et al, 2015; Robertson et al, 2018; Spencer et al, 2019). Their feelings of powerlessness interrupted their willingness or ability to be able to ask for help to improve their situation, and therefore it simply continued until such time that they felt confident and mentally competent enough to be able to gain back some of the control they had forfeited.

The lack of control over the sensory profile of the inpatient unit was central to the way in which participants reported on sensory aspects of the physical environment, and how they impacted on their anxiety. Acker (2018) describes extreme reactivity to sensory stimuli which can become an obstacle to daily functioning, employment and community access. The NAS (2018) suggests that the clear majority of people with an autism diagnosis suffer from sensory processing disorder, with Chang et al (2014) suggesting that over 90% of children with ASC demonstrate atypical sensory behaviours, i.e. hyper or hypo-activity to sensory input, or unusual interest in sensory aspects of the environment. This is becoming a far greater researched feature of autism and has been included in the Diagnostic Statistical Manual-5 diagnostic criteria since 2013. Any of the senses (sights, sounds, smells, tastes, touch, balance and body awareness) may be over or under-sensitive, or both, at different times. These sensory differences can affect behaviour and can have a profound effect on a person's life (NAS, 2018).

This study's participants reported sensory differences in sound, touch, smell, taste, body awareness (proprioception) and oversensitive proprioception. For example; sounds impacted upon Shannon's inpatient experience significantly, as articulated in Chapter 4. She reported having very little sleep during her time as an inpatient, continuously irritated by the closing of one of the doors which she claimed sounded louder to her than it did to the other patients, who appeared to pay very little attention to it. Commonly for people with ASC, noise can be magnified, and sounds become distorted and muddled; they may be unable to cut out sounds, notably background noise, which leads to difficulties in concentrating (NAS, 2018). Jacob described how he would shut doors and windows to reduce external sounds and would wear earplugs or ear defenders if he went to a noisy or crowded place. The problem with the inpatient unit was that often noise would be unpredictable and virtually impossible to prepare for, and '*who wants to wear earplugs or ear defenders all day?*' (Jacob).

The sensation of touch became an issue for Jan, as she explained her dislike of the water as it flowed through the shower, claiming it felt hard and caused her pain. NAS (2018) suggests it is common for people with ASC to have difficulty in brushing and washing their hair because the head is sensitive, and touch can be painful and/or uncomfortable. Prima and Shannon complained that the staff would often touch them, sometimes in a friendly gesture and sometimes to restrict or limit their movements, with the most severe touch being a full restraint.

I have witnessed first-hand the implementation of a full restraint process on patients with ASC, and for many I would have been part of the restraint team. We had little or no knowledge of the sensory differences experienced by patients with ASC, and certainly did not realise that placing one's hands on a patient with ASC who is already in a very anxious state and exhibiting aggressive behaviours, can and probably will make the situation even worse. However, the development of research in the area of sensory processing disorder and its relationship with ASC started over 20 years ago in America. Gillingham (1995), in his book appropriately entitled, *Autism: handle with care,* began to give researchers and practitioners insights into this added challenge for people with ASC.

> *'Every time I am touched it hurts; it feels like fire running through my body.'* (Gillingham, 1995).

Chang et al (2014) suggest that some people with ASC can also be under-sensitive to touch, have higher pain thresholds and need to work harder to feel a sensation that they enjoy. Weighted blankets for example have been used to create a heavy sensation which can be calming and relaxing. Weighted blankets are heavier than the kinds of blankets people usually buy. They typically weigh anywhere from 4 to 30 pounds, making them heavier than the average comforter or down quilt. For many people who have disorders such as anxiety, insomnia, or autism, weighted blankets may provide a safe alternative to medication or other types of treatment. They can also be used to complement existing therapies. Research has shown that weighted blankets can help reduce symptoms and manage these conditions (NAS, 2018). Commonly, self-harm is used to create the sensation of pain, with some going to great lengths to overcome under-sensitivity (Chang et al, 2014).

Maisel et al (2016) identified the sense of smell to be variable within autistic groups. Whilst some report having little ability to smell, and fail to notice extreme odours, others reported the additional need to taste to help to get a better sense of identifying foods. Others with ASC report issues around smells being intense and overpowering. Jacob described the mornings on the inpatient unit as being particularly stressful, and much of this stress was being caused by the overpowering smell of cleaning products being used to wash the floor.

Similarly, the sense of taste can be both under-sensitive and over-sensitive; some experienced under-sensitivity and reported their desires for very spicy foods; and more extreme examples have seen those with ASC eat or mouth non-edible items such as stones, dirt, soil, grass, hair and faeces, this behaviour is known as Pica (NAS, 2018). The main issues relating to taste that have been noted by the participants of this current study concern the inability to maintain a consistent and healthy diet during their time as inpatients. This however appears to be more about the unpredictability of the taste of the food being prepared by the hospital kitchen staff. With few reported opportunities to cook their own food, participants found that if they were unable to eat food provided by the unit, then they had no choice but to stop eating altogether or to eat as little as they could.

Maloret and Scott (2017) acknowledge that it is not only the taste of the foods that can cause problems; equally important is the texture of the food. Olivia would agree, and her 'shepherd's pie example'; highlighted within Chapter 4 clearly demonstrates that even the smallest change to texture and taste can have a large impact upon how palatable the food is for someone who suffers from sensory processing disorder. Olivia also explained that her appetite and ability to eat regularly had been considerably impaired: this continued to cause her problems for a long period of time after she was discharged from the inpatient unit.

Body awareness (proprioception) can also cause problems for people with ASC. Our body awareness system tells us where our bodies are in space, and how our different body parts are moving. Those who experience under-sensitive proprioception could find themselves standing too close to others because they cannot measure their proximity to other people and judge personal space. This could also cause issues with navigating rooms, avoiding obstructions and other people (Magiati et al, 2016). Mnamdi and Winston reported comments made to them by fellow patients and staff that they stood too close to them when interacting. Winston recalls being accused of continually invading the personal space of others.

Oversensitive proprioception could involve difficulties with fine motor skills, for example manipulating small objects like buttons and shoelaces. Prima remembers a mental health nurse commenting upon his amazement that somebody who is clearly intelligent and articulate would struggle to tie their own shoelaces. Prima explained his embarrassment at not being able to undertake tasks which involve the use of fine motor skills, and which appeared to be very easy for others, saying he 'often goes to great lengths to ensure he is not seen dressing or attending to personal care', not always easy to do on a busy mental health unit with little privacy. He also noted a clear correlation between anxiety and being less able to undertake such tasks.

b) Responses to anxiety and powerlessness

Expression of feeling disempowered, lacking control and being excluded from decision-making processes as a patient within inpatient services are not exclusive to the participants of this study or others living with autism (Donner et al, 2010; Bunyan et al, 2017), but what is more pronounced in this group and reported in this study is the need for control at a higher level and a clear difference of ability to cope when this has been withdrawn. A number of participants expressed their fear of losing control over their lives and questioned whether they were in hospital to be cared for or to be controlled. They reported feeling anxiety directly resulting from a lack of control. Many of the participants drew comparisons upon their day-to-day lives outside of the inpatient unit, and how they are successful in managing potentially stressful situations and consequently containing their anxiety. Detachment from their regular routine and their inability to access personal coping strategies is the root cause for their feeling of being out of control: the inevitable anxiety that follows, and their responses to the anxiety, is a consequence of their situation. Some participants were able to re-establish a structure and routine within the inpatient units which helped immensely with their day-to-day subsistence. A small number reported that they had become so comfortable with their

inpatient routines, comprising three mealtimes a day with activities or therapeutic sessions in the morning and afternoon, that they found it difficult to leave them behind, and discharge planning discussions were to be avoided because the thought of losing their new routine exacerbated their anxiety. It has been noted in previous studies that exercising control over an immediate situation or an environment is critical to minimising anxiety for many people with ASC. IU is regarded as one of the main drivers behind the high levels of anxiety experienced by patients with ASC (Boulter et al, 2013; Maisel et al, 2016; Wigham et al, 2015).

According to Burr (2015) medical doctors are perceived in society to be a powerful group and therefore can make decisions which impact upon mental health patients' lives significantly. This sense of not knowing or being confident enough to challenge such decisions, has been further impacted by the participant's high levels of anxiety and/or elements of the core features of their ASC. Slemon et al (2017) describes risk management and safety as the cornerstone of nursing care but challenges the acceptability of this notion. The evidence in this current study suggests that there is a direct conflict between risk management strategies and the amount of control the participants were able to enjoy. Andvig and Biong (2014) suggest that there is a need for providers to demonstrate greater acknowledgement of the personhood of the consumer, their unique abilities, limitations and different needs.

The Care Quality Commission (2017) describes a significant variation between mental health wards, and how frequently staff use restrictive practices and physical restraint to de-escalate challenging behaviour. Adult secure services are committed to ensuring that the least restrictive practice is observed always, and several important national documents recommend this: e.g., the MIND Report, 'Restraint in Crisis' (2013); Restraint and Restrictive Intervention (DoH, 2017); the revised Mental Health Act Code of Practice (2015). NICE guidance (NG10) Violence and Aggression: Short Term Management in Mental Health, Health and Community Settings (2015) highlighted the need for services to review and reduce restrictive practices. The NICE guidance (NG10) is a framework used to anticipate violence and aggression in inpatient psychiatric wards, exploring ways to reduce violence and aggression and the use of restrictive interventions that may infringe a person's human rights and freedom of movement, including observation, seclusion, manual restraint, mechanical restraint and rapid tranquillisation (NICE, 2017).

Whilst the interventions of mechanical restraint and seclusion were not required to deal with the management of risk exhibited by the participants of this study, limitations placed upon freedoms of movement, including continual observation, manual restraint and rapid tranquillisation were reported. Prima, for example, described his physical restraint as being 'one of the most torturous experiences of my life'; evidencing that patients with ASC often find this approach more traumatic than their neurotypical counterparts. Gooding (2016) suggests that risk management strategies are often from a bygone era and not enough changes have been implemented within inpatient care to allow for positive risk to be a widely practised.

Delaney et al (2018) acknowledge that inpatients' experience of distress which can lead to aggressive behaviours, presents one of the biggest challenges for mental health clinicians. NICE (2016) offers guidance on the use of alternative approaches to deal with dangerous situations involving people with ASC, including de-escalation techniques using verbal and non-verbal communication skills to defuse anger and aggression. Consideration should be given to using pro-re-nata (PRN) medication on its own to handle challenging behaviour only when psychosocial or other interventions could not be delivered because of the severity of the challenging behaviour. Commissioners are required to monitor the use of antipsychotic medication for the treatment of behaviour that challenges. My personal experience as a Clinical Reviewer within Clinical Treatment Reviews (NHS England, 2015) has demonstrated that the information on antipsychotic medication use for inpatients does not necessarily reach the Commissioners who have responsibility to ensure best practice is being observed for the clients. Too often, in my experience, patients receive one, two and sometimes three neuroleptic medications concurrently and remain on the prescribed regime for long periods of time. The participants in this current study have agreed that this is an issue. Terms such as 'chemical restraint', 'trying to knock me out' and 'to keep me down', have been used by the participants, many of whom experienced sedating side effects.

c) Development of positive coping strategies

The employment of the positive coping strategies identified within this current study had been designed and developed by participants who are able to demonstrate their insights into the causes of their anxiety and the ways in which they can realistically take back control and, in some cases, minimise the levels of stress experienced. Examples highlighted within Chapter 4, i.e. the '*energy bank'* and the '*plastic bubble'* theory, have both taken a long time to develop. Both Winston, who described the '*energy bank'* concept and Damien, who explains his '*plastic bubble'* theory were keen to develop their ideas. Both acknowledged that these strategies were not completely robust and therefore cannot be fully relied upon. Winston spoke about his inability to be able to '*balance the books'* in their '*energy bank'*, particularly as an inpatient, and sometimes did not know when to stop *'*spending'; whilst Damien explained that sometimes the '*plastic bubble'* works just a little too well, and the temptation is to stay within the walls of the '*bubble'* for too long, whilst acknowledging that those looking on will only see a '*mental health patient in a daze'*.

Damien spoke about the need to rehearse the process of 'getting behind the walls of the *bubble'* and would spend time psychologically going through the process, even if it was not required. Chin et al (2017) consider *cognitive rehearsal* as a crucial coping strategy for people with ASC; rehearsal or practise in advance before approaching unfamiliar territory was a practical way to ease anxiety. Jacob explained how he would make a list of what the predicted stressors may be for the week ahead, an exercise that was undertaken both inside and outside of hospital. He would then note ways of dealing with the situations, which were nearly entirely social situations, and practice his response if they occurred. He described this as an '*internal role-playing exercise'*.

(d) Negative coping strategies

The perception of the coping strategies discussed in this section have been interpreted as negative by myself, and by others who commented upon the data for this study, and there is little doubt that most observers would also draw the same conclusions. In some instances, the behaviours could be described as 'challenging'. The original term *challenging behaviour* was defined by Emerson (1995) to reflect the challenge to services that managing an individual's behaviour may present. More recently, it is commonly used as a label, both diagnostically and anecdotally. Once a label of *challenging behaviour* is applied to an individual, it will be recounted descriptively to allow others to judge what may be expected from them (Kiernan, 2017). For many patients with intellectual disabilities, autism or mental illness whose behaviour are described as *challenging*, they are characterised by the behaviours identified and so described by their peers and professionals within services.

The participants within this current study reported negative reactions towards their 'coping strategies' which were perceived as challenging by the nursing team within the inpatient units, and the wider multi-disciplinary team. It was reported within the data that nursing teams had voiced their concerns about the safety of the environment during times of observable aggression, even though most of the violence reported by the participants in this study appeared to be short-lived and limited to a quickly resolvable verbal or physical outburst, rather than sustained attacks on members of the nursing team or fellow inpatients. However, some of the damage caused was destructive and serious in nature.

There is an apparent link between periods of the admissions, which caused more anxiety and concern for the participants, and the frequency and severity of the aggressive behaviours reported by those who undertook them. For some participants, the initial process of admission was '*traumatic, scary and unsettling'*. In response to the trauma and anxiety of admission, and in relation to the benefits of participants being familiar with the units and staff, participants described the importance of a 'settling in' period. The term '*settling in'* was consistently referred to by the participants. Malkey suggested that, 'The nursing staff should expect heightened anxiety, aggression and even self-injurious behaviours, when they are made aware of the new admission with autism'.

The beliefs the participants held about the reasons for their admission appears to have contributed to their views and feelings regarding their admission. Some acknowledged that they needed to be hospitalised, whilst others were clearly angry. This anger contributed to their disturbed behavioural issues during the initial days of their admission and, for some, throughout their inpatient experience. Delta described that relinquishing autonomy and control over his life was something he fought vehemently, but over a period he describes the feeling of being 'battered down*'* and eventually becoming more accepting of the situation and understood that his power and control would not return until he left the inpatient unit.

Equally as apparent within the data was the increased anxiety and consequential behavioural difficulties at the time of discharge or when staff began discussions of discharge planning. In several cases the participants acknowledged that their increased behavioural difficulties leading up to a planned discharge often hindered, delayed or as Jan explained 'postponed until I learn to manage my anxiety about

returning to the world outside and everything that it may have in store for me*'*. As Puddicombe and Lunsky (2007) explained, '*aggression is the main ticket into hospital and the main barrier to getting out'* (p 192).

Garry reported that he was '*sorry'* for how he behaved, demonstrating remorse for his actions and for physically and verbally attacking others. However, most of the language used by the participants of this study was of a blaming nature, seeing their own behaviour as being caused by other people and therefore not owning or taking responsibility for the way they had behaved towards others. Even after a systematic review of the data and the application of IPA processes, there was little indication of Gary's remorse and that any of the other participants were able to articulate those emotions.

ASC has long been associated with impairments in processing one's own and others' emotions (Kanner, 1973). More recent studies focused upon the extent to which individuals understand or have knowledge of their own emotions and investigated their ability to differentiate between different emotions or, indeed, whether they felt any emotion at all in response to emotion-eliciting events (Barrett et al, 2001). To be able to feel remorse or guilt for one's actions involves understanding the emotional response of others to your actions, and one's own emotional response to be the cause of it. Rieffe et al (2011) suggests that the complexity of understanding both another person's emotions and how we feel about those emotions belonging to others is too complex for most people with ASC and they would lack the ability to apply such knowledge in these emotional situations. Howlin (2005) suggested that many people with ASC attempt to use the correct words when they find themselves in situations that they recognise as difficult or as having caused an emotional response in others. Wang and Hamilton (2012) suggested that this is achieved by mimicking and attempting to deliver words that could offer an opportunity to defuse the situation, but often these attempts are received as disingenuous and insincere. Therefore, expecting an inpatient with ASC to have the ability to understand or demonstrate remorse with any real depth is unrealistic, and not something I would expect to be explicit in the interviews in this current study.

Self-harming or self-injurious behaviours is used commonly to deal with acute anxiety and these acts vary considerably in severity (Lidstone et al, 2014). Although almost entirely perceived by the onlooker as a negative coping strategy for dealing with stress and anxiety, the participants who reported such acts during their time as inpatients, and at other times, disagreed with the negativity that surrounds them. Jacob spoke about his need for a '*short sharp shock'*, a flick of his earlobe or a snap of his elastic band upon the underside of his wrist, which he would use every day with a good level of success, achieving what these acts set out to do and describing it as a '*necessary evil'*. Although they hurt physically, the alternative is far more mentally painful. He could not understand my concern regarding these behaviours, when he told me about them in the interview.

Charlie cut herself on a regular basis; the more anxious she felt, the more frequent the cutting would become. Although she also agreed that this was necessary, and the alternative would potentially be far worse and even life threatening, she appreciated the negativity surrounding her actions and she acknowledged the unconstructiveness of these acts and understood why others, particularly mentioning

the nurses on the unit, were concerned. The abrasions caused regular infections, pain and discomfort, but did not seem to derail her opinion that this was a positive and successful coping strategy.

Watching individuals harm themselves to the point of causing visible injury, and not knowing the reasons why or how to stop it, is both frightening and frustrating, and in my nursing and caregiving experience it is the most difficult behaviour to work with. Summers et al (2017) suggest that self-injurious behaviour is frequent in children and adults with ASC (occurring in up to 50% of the population) and can be understood as existing on a continuum in relation to frequency and intensity, ranging from 'mild and infrequent' to 'severe and chronic'. Symons (2011) describes the more severe and chronic self-injurious behaviours as involving forceful and intense contact with specific body sites which have the potential to cause lasting physical damage. Maggie explained that she would often return to previous cutting sites on her arms and legs as re-opening old wounds causes more pain, necessary during times of extreme anxiety. The initial days of her inpatient experience was an example of those times of extreme anxiety.

Kahng et al (2002) explained that, within the ASC/learning disability populations, head hitting is one of the most common forms of self-injurious behaviour. Nissen et al (1997) reported post mortem examinations conducted on the brains of two individuals with ASC, aged 24 and 27 years, who had a long history of head hitting behaviours. The brain scan images showed neuropathological changes, including neurofibrillary tangles similar to boxers who suffered chronic repetitive head injury. Maggie described banging her head with force and velocity to maximise pain. She explained the process of graduation, from her comparatively minor displays of self-injurious behaviours, such as flicking her earlobe, to biting her wrists, hitting herself in her face and on her head, to eventually head-butting the wall. This process of graduation was described as incremental in terms of the pain received, again indicating a pattern of increasing anxiety equals an increase in severity and frequency of self-injurious behaviours. Upon returning to the interview transcripts for further analysis it became apparent to me some participants tone of voice indicated a level of frustration regarding the way their self-injurious behaviours were spoken about by the professionals involved in their care. Additionally, terms such as 'they don't get it' and 'why would they understand' were interpreted as a sense of frustration and a feeling that unless the healthcare professionals experience autism and/or serious anxiety then their understanding would be minimal, and expectations should be managed accordingly.

Several of the participants spoke of their need to spend time alone, a behaviour which in this current study I have described as 'isolating'. The word *isolation* conjures undesirable implications with feelings of being cut off from society and communities (O'Brien, 2010). The participants discussed the problems they caused for the inpatient units when they decided to spend long periods of time in their room or own personal space, usually because the unit was too noisy or unpredictable within the communal areas. The act of isolation appeared to be more of an issue for the staff than for the inpatients. The participants described this isolation as being consistent with their behaviour outside of the inpatient unit. Delta explained that, ordinarily he would spend long periods of time in his flat on his own, and these times would often be the most relaxing for him and the least anxious parts of his day.

Davy accused his care team of '*significantly lacking understanding and empathy towards patients with autism'*, claiming his time spent on the inpatient unit would have been improved and been more conducive to his mental health recovery if he had been allowed to spend more time alone. He explains that this self-managed coping strategy was continually being interrupted by the nursing team's desire to remove him from his bedroom and insisting upon social interaction with the patient community. He claims that the nurses he spoke to had very little or no understanding of the problems that social interaction can cause people with autism. MIND (2018) stress the point that being alone is not the same as being lonely, and there is nothing wrong with being on your own if you are comfortable with it. People usually describe feeling lonely for the following reasons: they simply do not see or talk to anyone very often, even though they are surrounded by people, and they do not feel understood or cared for.

Francesca explained that, when she is in a social situation, she becomes an 'actor', i.e. playing the part which is not herself but instead somebody who she feels can 'handle the situation'. She acknowledged that a certain amount of mimicry was required in social situations with an attempt to 'fit in and be appropriate'. Wang and Hamilton (2012) suggested that people with ASC commonly mimic the use of language and even facial expressions of neurotypicals, but usually fail to modulate their mimicry according to the social context. Wang and Hamilton (2012) proposed that these mimicry differences are caused by difficulties for people with ASC to use social cues, and mimicry is modulated according to the social context. Lakin, Chartrand, and Arkin (2008) suggested that people are more likely to mimic others' social behaviours when they feel socially excluded or are interacting with people whom they are attracted to and those of whom they are socially envious. Francesca admitted to mimicking the people she admired who seemed to be popular and sociable, and she gave examples of this inside and outside of the inpatient unit. She explained that, inside the unit she had a selection criterion in her head of the kind of person she wanted to mimic/copy in terms of their social behaviours. The example given was a young woman of Italian origin whose first language was Italian and who therefore spoke English with an accent - she was an inpatient at the same time. Francesca began to speak in the same way and, because they spent a lot of time together, she found it easy to mimic her friend's accent and effectively change the way she spoke; she recalls without any embarrassment or shame that she was mimicking another patient whom she admired.

I had not considered eating as a coping strategy before this study, nor during the majority of the data analysis: I had neither understood nor appreciated entirely the participants' thoughts and feelings around the subject, particularly the notion that these behaviours could be aligned to their sensory differences. Whilst returning to the data for further analysis within the processes of IPA, I felt there was more of an explanation for this pattern of behaviour, but alone I was unable to ascertain exactly what that might be. Then, in using an inter-coding reliability strategy, I had the privilege of discussing elements of the data that required further expert clarification. This was offered by a colleague, an *expert by experience* with an ASC diagnosis. He highlighted the importance of taste and its relationship to anxiety for people with ASC, recommending that I return to the participants to explore a different line of enquiry and examine further their normal eating habits and how these may have been affected during their inpatient experience.

Six of the eight participants who had reported significant weight loss during the time they spent in hospital explained their normal/everyday eating habits in very similar ways. Typically, this comprises a limited diet to consume certain foods on specific days of the week. For example, on a Monday, Malkey would normally eat: toast for breakfast with only *Anchor* butter which had to be salted; cheese on toast for lunch with mature Cheddar, *Tesco's* own make; fish fingers for dinner, *Birds Eye* only, with oven chips, *Tesco's* only and *Heinz* baked beans. Olivia explained that using frozen or processed food made it easier to predict their taste as they invariably contain commonly-used ingredients, and therefore there was less potential for the food to taste different from the previous meal. The need for sameness in both taste and texture was apparent for these six participants; however, some also alluded to the routine of the weekly food shop and their personal satisfaction that their meals were organised and prepared for the week ahead.

None of the participants in this current study suggested that they had access to the kitchen or opportunity afforded to them to prepare their own food while on the units. Their food therefore was being prepared entirely by others and it always tasted, smelt and felt textually different from the way they had expected and hoped for. Olivia explained her frustration with the unit staff and how they seemed to think she was making a 'mountain out of a mole hill'; she explained that they would watch her at mealtimes and record how much she had eaten. She explained that it was not her intention to cause 'a fuss' and would try to eat to 'keep the staff happy'; the consequence of this would normally be an increased state of anxiety which sometimes would result in her vomiting or having digestive problems.

Refusing to eat or eating as little as possible to survive, was a strategy used by some of these participants to further reduce levels of anxiety caused by the processing of sensory information. Smith (2016) explained that sensory processing difficulties can manifest themselves in a diverse range of ways including auditory, visual, vestibular or proprioceptive stimuli. Sensory processing disorders can have a profoundly negative impact upon a person's ability to engage fully in many aspects of daily living, including feeding and eating. People with ASC often display problematic behaviours around the activity of feeding and eating, with many demonstrating idiosyncratic food preferences, restricted diets limited in variety, aversion to certain textures, and excessive mouthing of unusual or inedible objects i.e., enjoying the sensory aspects of having objects in their mouth but without swallowing. Prima explained his desire to feel the texture and taste of coal in his mouth, explaining that the taste was '*comforting'*. He remembered his childhood when his parents had an open coal fire in his house and he therefore had easy access to lumps of coal which he would hide and mouth until his parents caught him and reprimanded him.

Smith (2016) suggested that people with ASC can go to great lengths to seek out or avoid sensory stimuli. Martins et al (2008) explained that children with ASC are almost twice as likely to experience feeding difficulties when compared to neurotypical children. A review of scientific studies, Autism Speaks (2013), found that children with autism are five times more likely than neurotypical children to have mealtime challenges, such as extremely narrow food selections, ritualistic eating behaviours and meal-related tantrums. Autism Speaks (2018) are currently planning research projects that aim to

address the underlying issues related to eating challenges and autism, e.g. anxiety, inflexibility and sensory issues.

5.2 Sense of self and connectedness

Services which represent the views of service users and other government agencies (Mind, 2006; Care Quality Commission, 2017) found that patients repeatedly criticised the options for acute mental health inpatient provision in the UK. Patients' reactions to their experiences of psychiatric hospitalisation include feelings of alienation, exclusion, dehumanisation and abandonment. Such findings are similar to earlier claims by Goffman (1961) that *mental hospitals* or *institutions* have their own agendas and, in the desire to achieve their own objectives of containment and exclusion, they are likely to destroy inpatients' self-esteem and threaten their self-concepts, such as identity and dignity. Bunyan et al (2017) suggest that admissions to mental health hospitals are disabling; the wards are often crowded, unpleasant and noisy, there are many clearly disturbed patients and there is often violence. The service users' views in some studies reviewed also described feelings of vulnerability due to the environment not feeling safe because of violence and theft of personal possessions, citing accounts of assault by other patients which impacted upon individuals feeling in danger (Donner et al, 2010; Parkes et al, 2007; Beardon and Worton, 2011). In this current study the participants have strongly acknowledged the need for a connectedness to others, including unit staff, other patients and external parties. The participants have repeatedly noted that their perception of self which has been impacted upon by their experiences of psychiatric hospitalisation has a role to play in their ability to make meaningful connections to others. Johnson et al (2011) suggest that when a psychiatric inpatient experiences distress and pain, the need for another person to provide compassionate care and reassurance becomes increasingly desperate, the difference being that their participants did not have an ASC diagnosis. However, the need for compassion remains with the autistic participants in this study, though on numerous occasions the opportunity seems to elude them. Lucas explained this when he said, 'I don't necessarily like people or social contact, but I do appreciate that I need them'.

A survey from the Care Quality Commission (2017) raised the following issues, highlighted by inpatients regarding the overall quality of care being received: they include inadequate physical health care; lack of involvement in the development of their own care and care plans; lack of information and communication between services and professionals; lack of activities; and therapeutic interventions. The results from the current study clearly show that the participants with ASC are enduring negative and distressing experiences during their time on inpatient units. There is evidence of a lack of understanding generally of autism, and communication was difficult and limited with staff, who appeared to be too busy to engage in communication, or who preferred to connect with those patients who did not have communication difficulties. The dominance of the medical model was strongly evident: people were being channelled into obtaining a diagnosis and pressured into taking medication. The participants felt that they were treated within a rigid, hierarchical framework, with little autonomy for the patients. The utilisation of a social constructionism framework has enabled me to develop the data into social constructs which reflects the determinacy of their knowledge of the social world, in this instance the psychiatric inpatient unit, from the autistic participant perspective.

a) Connections with patients and unit staff

Previous research in the field of nursing has highlighted a problem with the interpersonal skills of nursing staff: McSkimming et al (1999) studied the actual experiences of patients with life-threatening illnesses in the United States; the results showed dissatisfaction with care, often of an interpersonal nature. Reeve et al (2009) studied the impact of interactions with healthcare professionals and patients living and dying with cancer. This study concluded that patients found poor interactions, with healthcare professionals failing to provide emotional support. Consequentially, the relationships with the front-line caregivers was sporadic, to say the least. Relationships with unit staff were reported in studies included in the literature review as being particularly important to service users as they contribute towards feelings of security, access to activities/therapies and maintaining contact with friends and family (Bee et al, 2008; Bunyan et al, 2017).

There was a consistent suggestion that the participants felt victimised and treated differently from other patients. Many of them spoke of their desire to develop relationships with members of the front-line care giving team, having observed other patients enjoying these relationships and seeing them being treated as equals rather than objects or just mental health patients. Howlin (2005) observed patients/nurse relationships with patients without ASC and found that, even on the units where the inpatients are extremely mentally unwell, there will generally be relationships formed between the staff and patients, 'some displays of good humour and sharing of experiences were common place' (p13). However, a patient with autism is unlikely to take part in such interactions and their general lack of response in social situations is a continual source of irritation to both staff and fellow patients alike (Howlin, 2005). Other studies reviewed and reported in the literature review (Clarkson et al, 2009; O,Brien, 2010), reported similar characteristics such as unfriendliness, the use of punitive measures and antagonising service users with ASC.

As Prima explained, 'there always seemed to be banter between staff and other patients, much of the banter was of a teasing nature and patients appeared to find most of the teasing funny, but I struggled to see the funny side of a lot of what was said.' Previous research in psychiatric hospitals indicates that patients' relationships with nursing staff receives a high-ranking position of importance, whereas other factors such as psychopharmacotherapy, group therapy and even autonomy are ranked lower in importance (Längle et al, 2003). Others reported relationships with staff as one of the most important factors when measuring patient satisfaction (Schröder et al, 2006). Many of the participants noted that they felt most of the staff had little understanding of autism and how to communicate with patients with ASC, and this left them feeling less confident and experiencing a sense of powerlessness.

In most cases, the most powerful moments for patients were when professionals were explicitly and genuinely helpful, where they were stepping out of their prescribed roles and relating to the person in distress on a reciprocal human level. For example, Habika was accompanied by a nurse to a supermarket to buy a banana with the same ripeness that she was used to, as she could not eat her favourite fruit if it was different; or when a support worker brought some CDs from her home to

help Garry to fall asleep at night. However, in line with our understanding of the core features of ASC, building, developing and then maintaining relationships is difficult. Definitions of relationships both professional and personal vary, but the qualities of closeness, helping, sharing, sympathy and empathy are fundamental to most. A real understanding of such abstract and even allusive concepts may be almost impossible for many people with autism (Narendorf et al, 2011). Commonly, people with ASC demonstrate their perceived importance of relationships and friendships, but without any true appreciation of the complexities that are involved e.g. caring and/or understanding the feelings and emotions of others. Many adults with autism will describe themselves as having friends, but generally they are referring to acquaintances; much less frequently is there evidence of shared experiences or mutual understanding (Stoddart et al, 2012). Winston explained that relationships with other patients were only built if the patients wanted to socialise and, as the same participant explains in Chapter 4 within the concept of the '*energy bank'*, socialising can be an exhausting activity for people with ASC.

b) Disconnection and reconnection

The participants in this study reported traumatic experiences of being separated from friends and family when admitted into an inpatient unit. However, the data demonstrates their feelings of frustration were due to not having people around that understand them, are able to communicate with them and that they can trust and rely upon. Little is mentioned of the emotional attachment with these key people in their lives. Additionally, some participants explained that, as time went on, they experienced a disconnection from the people who were important to them outside of hospital and instead put their social energies into trying to develop new relationships with people in their new environments.

Some of the participants explained that, because they had effectively disconnected with their family, when discharge plans starting to emerge they were encouraged to reconnect once again. For example, Francesca described how she refused to speak to her family when she realised they were unable to help her. She had been sectioned within the Mental Health Act (1983) and her parents were powerless to prevent her admission, and neither were they able to be involved in the decision-making process regarding her discharge afterwards. She can recall both her parents becoming visibly emotional when she asked them not to visit her in hospital, but she could not see the point of maintaining the relationship if they no longer had a function in her life.

c) Deciphering understanding and meaning

Another dehumanising aspect of inpatient treatment was psychiatry's power over individuals and its insistence on explaining people's illness/difficulties in terms of the medical model, thus ignoring people's personal meanings and explanations for their behaviours and characteristics. O'Brien (2010) suggested the medical model has long been criticised for being inflexible. One of the

criticisms that came through the participants of this study was that the people's own explanations about their difficulties had been dismissed and, instead, psychiatry had imposed its own model upon them.

The medical model of psychiatry has long been challenged; Laing (1965) claimed that any attempt to understand madness as a pathological process was doomed to failure because it inevitably treated the patient as an object. To prove this point, Laing (1965) studied the meanings that individuals gave to their experiences by using an existential approach. In this way, Laing was able to provide insights into why people labelled as 'schizophrenic' behave the way they do. These insights further shed light upon the types of anxieties and fears that all humans are plagued with and, more importantly, how the transition from 'normal' to 'mad' can occur in anyone's life.

Delta explained that 'mental illness for people with autism was an extreme outcome of our anxiety about being in the world and interacting with others'. Therefore, being diagnosed with a generalised anxiety disorder and being prescribed antidepressants in the hope that this will deal with the anxiety, seems ill-considered. Many of the participants in this current study regarded their psychiatric diagnosis as secondary at best. Some participants spoke about their consideration of psychiatric explanations for their symptoms and behaviours, but most perceived this to be far less important than the autistic diagnosis. However, the current study found that patients did not have much choice but to accept the psychiatry/medical model and subsequent medical treatments, including involuntary hospitalisation: for some this made them feel belittled and not listened to.

5.3 Summary

This chapter has provided an in-depth synthesis and considered interpretation to arrive at a greater understanding of the significant impact of hospitalisation for patients living with ASC and acute exacerbation of mental health comorbidities. Most participants highlighted issues that impact upon their mental well-being which were perceived by mental health staff as being small, even trivial. Nevertheless, despite the perceived scale of the issue, anxiety and a need for sameness can be a significant problem for such patients. To some extent, the above comments reveal why people with ASC adopt extreme responses in this situation: there is no doubt that some of these responses can be particularly challenging to mental healthcare professionals, too; however, with greater insight into the root causes, practitioner reactions could be more sensitive and accommodating.

The social constructionist stance has enabled this study to explore the discourses which can be seen to be embedded in power relationships. Burr (2003) suggests that the hallmark of the social constructionist view is that it theorises a close relationship between knowledge and power, such that relatively powerful groups in society can give certain discourses the stamp of truth. For example, our understanding of health and illness is based on a biomedical discourse and the medical profession remains powerful through its ability to systematically marginalise and discredit alternative conceptions.

Foucault (1972) believed that people do not hold power implicitly but that it is an action that is exercised, and that where there is power, there always must be resistance to that power. As a social constructionist I have explored how inequalities of power exist between the inpatient with ASC and the healthcare professionals who care for them and if so, and the discourses which instigate and maintain them. The social constructionist stance used in this study has attempted to capture different perspectives through open-ended (semi structured) interviews, and to examine the implications of these multiple realities within inpatient settings.

The use of IPA enabled the in-depth analysis which was required to explore the data and provide evidence of emergent themes displayed within the thematic maps (figure 4.1 and figure 4.2). The purpose of the analysis was to provide a rich interpretation of the participants' inpatient experiences, all the time being mindful of how they have come to construct their version or meaning of reality. In accordance with a phenomenological approach, the focus was on how the participants experienced their hospital life and the impact of these experiences. Such a rigorous analytical approach has enabled the construction of social actions which has assured a comprehensive contribution to the field and future inpatient care experiences.

In the following section, **Chapter 6**, I discuss conclusions and recommendations arising from this doctoral thesis. I take the opportunity to reflect on the contents of the thesis while asking questions of its ability to answer the research questions proposed in Chapter 1. It evaluates whether the chosen methodology was appropriate to examine the thoughts and feelings of inpatients with ASC, and whether this current research study makes an original contribution to the field of mental health practice. It also highlights recommendations with potential impact on education and clinical practice, including the need for greater emphasis on teaching and training on the core features of ASC and their relationships to mental ill-health, the monitoring of the use of antipsychotic medication, and an enhanced understanding of psychosocial interventions. Communication guidelines for frontline caregivers in mental health inpatient units are evaluated, as is guidance on the importance of relationship-building to overcome the complexities which challenge the development of such relationships. Empowering people with ASC to gain greater ownership of their mental health recovery is imperative, and greater partnership working between the patients and the practitioners will enhance opportunities to develop and maintain more appropriate coping strategies, particularly at times of increased stress and anxiety. Chapter 6 also considers the potential limitations of the study. Critics of the interpretive phenomenological analysis approach to the research question whether participants and researchers both have the required communication skills and understanding to deliver successfully the main points of the data in a coherent and accurate way. Such factors will be considered in more detail, together with how they may have impacted the outcomes of the study.

Chapter 6: Conclusions and Recommendations

Chapter overview

In concluding this work, in which a range of issues have been raised and methodologies used, I have reflected on the contents of the thesis while asking myself three questions:

- Was my chosen methodology appropriate to examine the thoughts and feelings of previous inpatients with ASC in mental health units?
- Did I answer my research questions, which were outlined in the introduction to this thesis?
- Have I made an original contribution to the field of mental health practice?

Additionally, this final chapter will include recommendations for practice and future research, and personal reflections upon the experience of being the primary researcher within this current study.

6.1 Answering the research question

The principal research question, 'how admission to a mental health unit impacts the psychological well-being of adults affected by Autism Spectrum Conditions', was based upon my experience as a caregiver within the field of learning disabilities, autism and mental health, and my expectation and *a priori* assumption was that of a negative perception by the participants. For the most part, the inpatient experience reported on within this study was generally poor and negative; however, I had not expected this study to highlight the wide and varied aspects of this experience in the way that it does. The literature review highlighted that there was a lack of empirical evidence related to the experience of patients with ASC. This current study demonstrates the psychological effects of being an inpatient included a wide range of feelings such as anxiety, distress, anger and guilt. Equally as wide-ranging were the self-constructed and self-managed strategies employed by inpatients to deal with these psychological effects; for example, the *energy bank*, the *plastic bubble*, self-injurious behaviour, and isolation, amongst others. Some of the participants could easily recall and articulate their thoughts and feelings from the time of admission, whilst others found this to be a profoundly painful process, and yet others struggled to remember what it was like and what they were thinking at the time.
The first primary research aim, 'to explore the experiences of adults affected by ASC who have been admitted to a mental health inpatient unit', created the emergent themes, which mostly adhered to the core features of ASC. For example, Intolerance to Uncertainty, the need for routine and sameness, the fear of unpredictability, issues with relationships, building trust in those who are employed to care for them, and issues with the sensory profile of the physical environments in which they found themselves.

The second primary research aim 'explore how adults affected by ASC make sense of their thoughts and feelings', has been achieved by an in-depth analysis and exploration of the participants' explained reasons

for their responses to the situations, and the coping strategies they developed to avoid or deal with the inevitable resulting stress and anxiety.

a) Using an appropriate methodology

Chapter 3 offered an in-depth discussion of the methodology which supported this research study, and the different methodological frameworks which could be appropriate for this type of enquiry. A naturalistic framework was appropriate for this study because of the subjective nature of the participants' reality: through the inductive generation of relevant and authentic data to explain their experiences and feelings, whilst expecting the challenges when approaching and eliciting data from this cohort. Also, Chapter 3 demonstrated awareness of the key concepts of interpretive phenomenological analysis (IPA), my chosen methodology, as well as locating its approach coherently within my epistemological framework. I have offered a rationale for this choice, which I believe has allowed me the opportunity to delve deep into the data and create a detailed understanding of this complex human phenomenon, which has then been discussed in an authentic and meaningful way.

This study has allowed the voices of this vulnerable group of psychiatric patients to be heard and studied comprehensively. In common with other qualitative research, the sample size was relatively small; however, the wealth and richness of the data is considerable. In the body of this thesis, I have disclosed my own values and expectations as well as my epistemological assumptions. I have ensured reflexivity to allow readers to see the influences behind my thinking and my way of approaching the research. I have also described how I interpreted the data so that readers can see that this was just one way of thinking, and that there could be alternative interpretations of the same data.

Additionally, I have foreseen potential limitations within the data analysis process. Notably, I as the primary researcher and data analyser, do not have an autism spectrum condition diagnosis; therefore, the aim to truly understand the experience, and the perception of that experience, belonging as it does to a person with ASC who is also suffering additional anxiety and associated mental illness, is not realistic and should not be claimed as such. The valuable contributions of an expert by experience, who has supported this study and enhanced the reliability of the data analysis, have assisted in bringing certain aspects and different themes to the surface which, without his intervention, may well have been missed. Gaining assurances from the participants that I could return to them for clarification on certain parts of the data once transcribed and analysed, provided me with a valuable 'safety net', which was used on numerous occasions to avoid misrepresentation or misinterpretation of their spoken words.

b) The interviewer's experience

I was deeply privileged to be given permission by the participants to explore aspects of their life which I am sure most would just want to forget. Conducting the fieldwork for this current study was one of the most enjoyable and fulfilling periods of my professional life. I had the opportunity to meet some wonderful people and learnt a great deal from them. I now have considerable new knowledge, which I will disseminate through publications and conferences, and especially in my teaching, both as a trainer for frontline care-giving staff in Mental Health, Learning Disabilities and Autism Services, and as a

Principal Lecturer at the University of Hertfordshire, where I teach on undergraduate Pre-Registration Nursing programmes.

This is the first opportunity I have had to interview people with autism as part of a research project. I have, however, had the experience of interviewing people with ASC for employment and educational opportunities which was very much about me gaining information about people and making assessments of them as to whether I and the other interview panel members felt they were suitable for the role in question. The research interviews in this current study were very different: this was for them and not for me, i.e. this was their chance to tell their story and an opportunity to enhance future hospital inpatient admissions for people with ASC.

Most of the participants saw the opportunity for what it was - the one chance to get their point across - and they were not going to miss out or waste the opportunity. The interviews with these participants were the most fulfilling and produced the richest data: the only challenge was to stop them talking for quite literally hours. The timing of the interviews was also significantly impacted upon by participants either being very reserved initially until they became more comfortable with me and my questions, or by their desire or need to talk about subjects which they felt more comfortable to discuss but which, unfortunately, bore very little relevance to my research focus.

Other participants seemed more reluctant to talk and participate, or perhaps it was that they had difficulties with processing the questions I asked, or the answers they wanted to articulate. These types of interviews were certainly far more challenging, and the results are not quite as revealing: I found myself having to work much harder to gain information required. It was felt on reflection that, in these interviews, I needed to do a lot of the talking, and certainly the transcriptions reflect the amount of speaking I did during these interviews; it was then difficult not to influence both the proceedings and the data.

As I reflected upon each interview, I made notes both physically and mentally, to learn from mistakes I had made and to remember aspects of the interview which had been successful. During the pilot interviews, I practised my technique and tried different ways to engage the interviewee in conversation and to encourage a more fluid, interactional and relaxed interview style. I learnt, eventually, to allow the interviewee to take the lead in the interview, to process information and to answer in their own time, and to allow them the flexibility to return to previous questions when they had remembered relevant information which previously had eluded them. Having studied guidelines from the National Autistic Society on interviewing techniques, I knew it was important to avoid unnecessary eye contact (NAS, 2016). I found this difficult to do and, for the most part, and despite my best efforts, my eyes would invariably meet theirs frequently. This had varying degrees of impact upon the interviewees: some were clearly very uncomfortable when it happened, and on one or two occasions I noted that the interview had been impacted upon in a negative way.

However, after a few hours of interviewing participants with ASC, I felt that I became more comfortable, more relaxed and had built more personal confidence that together we would be able to explore their

experiences in detail and unearth their true feelings. By the end of the interviews - and nearly 28 hours of interviewing - my feelings of competence had grown unrecognisably from the initial pilot interviews. For example, I was able to recognise and question patterns of responding such as 'the quieter interviewee'. Whilst exploring the main theme 'coping strategies', it became apparent that there was a particular tendency by some of the participants to be constricted or unelaborate with their responses. The question therefore emerges, why would inpatients hold such a position? One theory is that this constricted style of responding provides protection and a way of coping with the anxieties or the memories that the experience holds. For example, the main theme reasons and responses describe a range of challenging and painful emotions that the participants were forced to experience, contain and cope with. It is apparent that these emotional experiences would have been unmanageable had it not been for the creation of a system of coping. Therefore, the patients needed a coping structure to prevent these experiences from becoming overwhelming and debilitating. It could, therefore, be understood that the sense of being constricted or explorative provides a level of protection for the participants against painful emotions, such as powerlessness and hopelessness. This was echoed in some brief and succinct answers from numerous participants, 'that's just the way it was' (Delta); 'there are some things that you can't do anything about' (Shannon); and 'there is a limit to what you can do' (Emeka). Reflecting on meaning as an interviewer is essential to be able to make sense of these descriptions which could otherwise be taken at face value as participants having little to offer in terms of insight. I needed to think about their history within the world and structures around them to unpick this type of responding and why this may be. An important lesson for anyone doing research more broadly but especially in the case of individuals with a diagnosis of ASC where there may be varying levels of insight into the factors that come to shape an individual's meaning making.

6.2 Original contribution to the field of mental health

The impact of this research needs to be clearly defined so others can build upon the evidence it represents which is crucial to the understanding and ultimately improving the lives and experiences of people with autism. Additionally, understanding a study's original contribution to research and its theoretical positioning helps to make informal decisions about where to focus new research projects and unearth gaps in knowledge and ideas for improvements.

This study has contributed several fresh insights into the psychological impact of being an inpatient with an ASC. The literature review highlighted that the experience evoked strong feelings for many inpatients, but little was known about the perception of this experience for those with ASC. **Table 10** below illustrates the contribution to the field made by this current study compared to previously published studies. It is important to note that many of the previously considered studies, discussed within the critical literature review in Chapter 2, do not entirely include people with autism, however many of the experiences of inpatient care noted by non-autistic participants have been shared by the participants with ASC within this current study. This is important as it highlights that there are some issues that are inherent to inpatient units that are likely structural and even objectively reality as opposed to a subjective experience of people with ASC only. In addition to the comprehensive and largely negative list of experiences, the participants have also had to

endure the collection of experiences pertaining to the new and original knowledge which appears to be exclusive to inpatients with ASC.

Existing knowledge of inpatient experiences	Shared with current study	New/original Knowledge
Importance of relationships	Yes	Coping strategies:
with inpatient staff	Yes	Routine/Structure
Feelings of disempowerment	Yes	The energy bank
Intolerance of uncertainty	Yes	plastic bubble
Lack of control	Yes	listing concerns
Being excluded	Yes	self-harm
Fear of punishment	Yes	isolation
Inflexible rules	Yes	controlled eating
Submissiveness	Yes	Time and anxiety
Power imbalance	Yes	Control and anxiety
Discrimination/inequality	Yes	Poor communication- confusion and frustration
Feeling vulnerable	Yes	Overwhelmed by over friendly staff
Aggression from other	Yes	Mistrust of staff
patients		Family detachment and distress
Self-injurious behaviour	Yes	Fear of discharge
Uncaring/hostile staff	Yes	Need for safety and protection
Caring and sensitive staff	Yes	Jealous of other patient's relationships with staff
Unpredictable behaviour of other	Yes	Need for relationships
patients		
Feeling of isolation	Yes	
Lack of privacy	Yes	
Anxiety:		
Change of environment	Yes	
Sensory issues	Yes	
Aggressive to staff	Yes	
Lack of autism knowledge	Yes	
	Yes	

Table 10 Original contribution to the field

My findings build upon the current knowledge in concluding, as did Ambler (2015), Maisel et al (2016), Boulter et al (2014), Wigham et al (2015), Robertson et al (2018), Spencer et al (2019), Rodger et al (2012) and Carleton (2012), that people with ASC often experience heightened anxiety caused by the intolerance of uncertainty and a general lack of control. This study develops further our understanding of how anxiety can be influenced by others, for example not understanding the importance of time, the essential need to control their immediate environment, to minimise the sensory impact of the environment, to experience the notion of safety and security, the absolute need to establish routines and structure to enhance the feelings of security.

The feelings of disempowerment (Donner et al, 2010), feeling excluded (Bunyan et al, 2017; Parkes et al, 2007), the fear of punishment and discrimination (Hoole & Morgan, 2011) also determined in this study, whilst

further acknowledging the importance of relationship building with staff, clear and effective communication which can avoid confusion and consequential frustration and the importance of trusting members of staff. Correspondingly this study concluded, as did Parkes et al (2007) and Donner et al (2010) that feelings of vulnerability can lead to social isolation, this study further considered the act of isolating and detaching oneself and acknowledges the participant's positions that isolation is not necessarily a negative action, but instead a necessary coping strategy which helps alleviate anxiety often caused by social situations.

Likewise this study deduced, as did Lidstone et al (2014), Symons (2011), Kahng et al (2002), Nissen et al (1997) and Adler et al (2015), that people with ASC exhibit self-injurious behaviours more commonly than other mental health patients who are not affected by ASC. My research extends our understanding of the phenomenon by analysing the participant's explanations of using self-injurious behaviours as coping strategies, often well considered and controlled and not perceived by them as dangerous or negative, although their perception of how their behaviours are received by others is usually very different.

Comparably this study determined as did, Howlin (2005), Dunn (2012), Donner et al (2010) and Narendorf (2011), that a sudden change in environment that an admission often causes can result in psychological trauma which can take a considerable time to recover. This study exposed similar results at the other end of an admission period and considered the impact of discharge and the transition back to their homes and families, especially difficult when their relationships with family and friends have often diminished during their time as an inpatient.

It is important to consider how interactions, relationships and patterns of behaviour between service users and staff, and between the service users themselves, influence the construction of meaning, understanding and experience within the context of an inpatient unit. Indeed, many different systems and relationships have been seen in this study to have contributed to the service user's experience. These can be observed within two relational concepts of 'sense of agency' and 'creating safety and protection' due to their vulnerability as highlighted in the '*vulnerability and need for safety and protection' section in the findings section (Chapter 4)*. Sense of agency refers to the capacity of a person to act or control their actions in a given environment (Längle et al, 2003). These elements represent important factors in how service users make sense of their experience within the context of a social scene or their relationships with others. Relating, according to Johnson et al (2011), is an essential part of our human experience and it is at the core of our emotional and social abilities. Therefore, when a psychiatric patient is experiencing distress and pain then the need for another person to provide compassionate care and reassurance becomes increasingly urgent. The factors affecting participants 'sense of agency' relate to a sense of personal responsibility and control over what happened during their admission and their feelings of involvement and inclusion; these were also highlighted as being generally negative throughout participant narratives in this study.

a) Non-engagement

In my experience of working both as an inpatient nurse and as a clinical reviewer within Clinical Treatment Reviews, I have been continuously reminded how challenged care teams have been in their attempts to engage with patients with ASC, whether in clinical interventions, (i.e. talking therapies, psychodynamic interventions) or even in leisure activities, and when formulating care plans. The

participants in this study have commented upon their difficulty in understanding the benefits of engaging in these activities. Lucas explained how difficult it is to acknowledge how a psychodynamic intervention such as music therapy could assist positive mental well-being. It is not easy for many of us to comprehend and imagine how this could be of benefit: when a person's *flexibility of thought* is further impaired and affecting their ability to imagine how this could work as with people with ASC - then it is an even harder to sell to the service user. The non-engagement of therapies reported by participants Lucas, Jacob, Prima and Anne who identified various types of interventional therapies that were offered to them and why they decided not to engage. The main reason for this was that the participants could neither understand nor see the potential benefits of engaging.

The NAS (2018) suggests that the person with ASC is far more likely to engage if the information is coming from a single person, preferably in a one-to-one approach from somebody who is known to them and with whom they have a relationship. In my experience, this often cannot be somebody within the care team, as success largely depends upon how established a relationship is with the patient, or on how quickly and completely such a relationship can be developed to enable a trusting person-centred relationship. Therefore, thinking beyond the team to involving family members or an advocate is advisable, involving them in every aspect of the care plan and ensuring that their relationship is utilised to enhance the patient experience.

Additionally, engagements can be enhanced when the recipient of a new activity receives the information in an accessible way. Too often in this current study the participants complained that they were being asked to join therapy in either one-to-one sessions or in groups, without any understanding of how this could help them. Mnamdi acknowledged that the only reason they attended the group sessions was because they felt it would aid a quicker discharge and so they were 'playing the game'.

Person centred care planning is creating a plan with the patient at its centre and involving family and friends as partners in planning: the plan shows what is important to the person now and in the future (DoH, 2010). As Francesca explained, *'Instead of asking us, "What's the matter?", ask us, "What matters?"'.* She was making the point that, as it is unlikely for patients with ASC to be able to understand their emotions and feelings regarding their mental state, why use valuable time exploring this with patients when questions should be asked instead about *what matters* to the patient.

Längle et al (2003) suggest that once a clear understanding of a person's interests, and the motivators behind their interest, are established they can be used as *building blocks* to enable the psychiatric patient to *climb free* of their mental illness and begin to gather motivation and momentum which will assist their recovery. Francesca gave the example of her collections, of which she has many, including stamps and coins from across the world and ages. She wanted to talk about them and perhaps even get involved with them once again while she was an inpatient, but she was told by her named nurse that she could pursue these interests again once she was home, and for now her concentration should be upon *getting better*.

Within the concept of 'vulnerability and need for safety and protection', participants described several issues regarding their vulnerabilities and need for protection, and those strategies employed to ensure their safety. Incidents of verbal and, less commonly, physical aggression reported in this current study, contributed to the difficulties in relationships between service users, and the participants acknowledged being drawn to other patients who were quieter and less likely to impact upon their stress levels. Equally, during periods of being the recipients of aggressive behaviour, participants reported their need to befriend members of the care team. Anne explained that when she became a target for another inpatient, she decided that she required the protection of the staff and immediately worked towards building a relationship with them.

b) Clinical Implications

This study is pertinent to the current political and policy-driven climate of increasing rights, choices, inclusion, independence and awareness. Since the implementation of Transforming Care (NHS England, 2015), commentators have focused upon the reduction of hospital beds within Learning Disabilities and Mental Health services. This includes those hospitals belonging to the private and voluntary sectors, as well as Local Authority and NHS provisions. This study provides further evidence that hospitalisation of a person with ASC should only be considered when all other options have failed. It is inevitable, however, that some people with ASC in the future will need a mental health inpatient bed, and the reductionist approach to inpatient services and the emergence of single person community services - although this should be applauded - will leave gaps in service provision. Therefore, I contend that, instead of minimising inpatient availability to an unrealistic level, we should instead concentrate on the emotional and psychological experience of the inpatients, with an aim to learn and improve service experience, an awareness of 'different' service users, and provide adequately 'reasonably adjusted 'units with highly motivated staff who are person centred in their approaches. Simply asking patients with ASC to engage in a one-to-one session with their named nurse in order to discuss their care plan and, when they refuse, a box is ticked to say that they tried, is not good enough.

This study also provides evidence that the training and awareness that is currently required for a qualified nurse mental health nurses and other front-line caregivers in mental health settings to adequately provide care of a high standard to a patient with ASC, is currently not good enough. Improving training around autism is at the heart of the Autism Strategy for all public service staff, but particularly for those working in health and social care. This includes not only general autism awareness training, but also different levels of specialist training for staff in a range of roles, where this is needed to enable them to fulfil their responsibilities (DoH, 2010).

The Autism Strategy in 2010 gives statutory guidance for Local Authorities and the NHS that *basic* autism training should be available to all staff working in health and social care. This remains a key requirement of the Strategy: when professionals do understand autism, the positive impact on the lives of adults with autism can be immense (DoH, 2016).

Clark et al (2016) found that Learning Disability Nurses had a good basic understanding and knowledge of autism, and staff in learning disability teams generally had good knowledge about the difficulties

people with autism can experience with sensory issues, understanding emotions, repetitive speech, seeing 'the big picture', and language processing.

Although similar studies focusing on Mental Health Nurses and frontline caregivers within mental health services are currently not available, my experience of developing and delivering curricula within Nurse education in Higher Education Institutions that I have worked in directly, and in others in which I have externally examined, shows clearly that autism coverage within Mental Health Pre-Registration Nurse Education is minimal and tokenistic, to say the least.

Within my current role at the University of Hertfordshire, the geographical area where I have delivered autism training to meet the requirements of a range of NHS, Local Authority and private organisations is expanding across Hertfordshire, Thames Valley, North London and Wessex. Some of these organisations have encouraged their staff to undertake a short course consisting of five days of face-to-face learning and supplementary e-learning activities. again, I have been personally involved with developing and delivering these. The short courses are well evaluated and provide the recipients with a good level of practical knowledge and understanding of autism. However, many organisations have offered their mental health workers who are front line caregivers for patients with ASC, only a one-day training package without any supplementary e-learning activities or required reading. Many of these organisations have made this training mandatory for all their caregivers, including psychiatrists, psychologists, nurses, support workers, administrators, and others. The trainer's challenge in delivering a single training day to a varied multidisciplinary participation group, is to pitch the training at a level which will cover the basics of autism whilst keeping the interest of those in the group who have greater expertise and experience. The findings (Chapter 4) indicated a diverse range of experience with regards to staff awareness, no doubt impacted upon by the variety of training packages on offer.

The Autism Strategy's guidance on autism training has been interpreted differently across services and organisations, but it is a positive for people with autism that most frontline staff that they encounter have had their awareness increased by receiving some form of training.

The promises of specialist service provision in autism (DoH, 2010) has not materialised to the extent where it can adequately impact upon the lives of people with ASC who require specialist inpatient mental health provision. Reporting on the lack of services for people with ASC who do not have a comorbidity of an intellectual disability is nothing new (Marriage et al, 1993; Marston & Clark, 1999). Previously to the Autism Strategy (DoH, 2010) people with ASC and without an intellectual disability, who needed mental health input, were being refused access by both Learning Disabilities and Mental Health services (Carrington & Graham, 2001). It is generally acknowledged that Learning Disability services contain the expertise for nursing in ASC, while Mental Health services will now accept people with ASC more readily but seem ill-equipped to deal appropriately with them - this fundamentally is due to the preparation and training of the front-line caregivers. It is for this purpose that the main audience for the dissemination of this current study and its findings are the Mental Health Nurses and frontline caregivers within psychiatric inpatient services who are finding it problematic to implement their care to the standard they want to achieve.

Several participants within this current study have indicated that they felt their psychiatric team were treating their ASC diagnosis as secondary when considering their treatment options. Garry noticed that the psychology team were far more focused on the core features of autism and how they were impacting upon his mental health presentation, whilst his psychiatrist seemed to be interested only in medicating his symptoms, in this case extreme anxiety. His psychiatrist prescribed antidepressant and antipsychotic medications early on into his admission, continuing for a period of months afterwards. He remembers his psychologists remarking on his frustration because he was not able to assess the roots of his anxieties, as the symptoms had been masked by neuroleptic medication.

6.3 Recommendations

Several of my recommendations are for areas of education and clinical practice. The following are suggested:

- A greater emphasis on teaching and training of the core features of ASC and their implications to a high prevalence of mental ill-health must be considered for Registered Mental Health Nursing BSc degree programmes and other Pre-Registration Mental Health Nursing programmes. The findings chapter has clearly demonstrated a concern from the participants of this current study that the nurses had considerable problems understanding which approaches and communication strategies should be employed and how best to implement them.

- Acknowledgement of the need for Mental Health Service User-led interventions, because previous inpatient experiences have highlighted how the lack of ASC-specific knowledge can lead to detrimental emotional and psychological effects on patients. Understanding the lived experience has become an integral part of this study, seeing the inpatient experience from the perspective of the inpatients with ASC is not being noted or experienced by the participants. Figure 4.1 demonstrates the emotional distress experienced by the participants and reasons why are discussed within chapter 4 and 5, a number of these are environmental and could be largely eradicated with the correct implementation of expertise.

- On-going robust training in ASC for existing Mental Health Nurses and front-line caregivers in mental health inpatient and community settings. This is highlighted within the Autism Strategy (DoH, 2010), but too often is delivered only in a one-day workshop, which is tokenistic at best: such training should be co-produced or entirely prepared and delivered by people with ASC and *experts by experience*. For example, as research from service user perspectives gains momentum, such CPD practices could help staff to better include the lived experiences of patients to guide their own practice.

- Service Commissioners to:
    - require providers to monitor the use of antipsychotic medication with patients with ASC and the treatment of behaviours that challenge. The findings chapter indicated strongly that there was a substantial use and reliance on antipsychotic medication. The comment by Habika '*If you don't think I am psychotic why am I on antipsychotic medication?'* being particularly poignant and justified;

- look for evidence to ensure that, before antipsychotic medication was prescribed, psychosocial or other interventions had been attempted or considered but they had been insufficient or could not be delivered because of the severity of the behaviour.

This information is vital as the current suggestion is that either it is not provided or that it is not being acted upon, leaving too many inpatients with ASC on regimes of antipsychotic medication for lengthy periods of time.

- Nursing staff to develop policies, care plans and procedures that offer guidance on how best to support inpatients with ASC. The guidance should include reasonable adjustments, and be introduced to strategies used in communication, engagement, allowing privacy and personal space, adopting a '*hands off approach*' and minimising physical restraint. Prima described the experience of being restrained as '*punitive*' and '*torturous*'.

- Practitioners implementing psychological interventions to consider ways of engaging patients with ASC and developing person-centred strategies. It is clear from the results of this study that strategies commonly used on other mental health patients are not working for ASC patients. Certain psychological interventions that are employed to assist patient recovery - i.e., helping patients to regain a positive *sense of self*, which could lend itself to work on self-esteem/self-efficacy, emotional coping strategies and goal attainment - appear to be out of reach for many people with an ASC due to their issues of non-engagement and not being able to imagine the benefits of such engagement. Equally, a greater understanding of such patients 'interests and motivators in their lives could help to re-engage patients through a person-centred caring approach. Francesca's comments '*Don't ask us what's the matter? Ask us, what matters*? Which interpreted as, because Francesca finds it virtually impossible to understand and describe her feelings and emotions it is not a good use of time to try to discover how she is feeling at a moment in time or compared to other moments in time. Therefore, it is a better use of time in Francesca's opinion to find out what *matters* to her and use this information to support her to build upon these motivating aspects of her life, because this will enable her to recover from her mental distress/illness.

- Nursing staff to promote therapeutic relationships and to take the initiative in developing and maintaining relationships which patients with ASC value, but may not be able to actively seek out. It has been strongly emphasised within the findings chapter that there is a correlation between enjoying relationships with staff and feeling less vulnerable and observing a greater sense of safety and protection. It is also noted by participants that they are unable in many instances to initiate these relationships and instead experience poor communication resulting in feelings of paranoia and not feeling trusted.

- The multidisciplinary team to work collectively to instil hope and to empower people to believe in and take responsibility for their own recovery. Holding out the hope that recovery is possible is an essential principle of the recovery model. The recovery model emphasises patient-centred care and encourages professionals to recognise the importance of the patient's authority in their own well-being: therefore, greater emphasis must be placed upon the recognition of empowerment. The comments of Delta '*Everything I wanted to do and anywhere I wanted to go had to be negotiated',* is concerning and the

need for *power and control* is evident within the findings chapter, and perhaps the most important point that the participants wanted to share.

- This current study has demonstrated the need for patients with ASC to develop strategies to cope with anxiety. These strategies can be hugely diverse, but many are not developed from a positive position. Psychology staff and others to make greater efforts to support the development of such strategies and coping mechanisms to ensure they influence them to positivity and make attempts to steer patients away from negative outcomes.

- Frontline caregivers in mental health services need to have a greater understanding and awareness of the intolerance of uncertainty that is experienced by patients with ASC. Increases in anxiety have been widely reported within this current study, caused by a variety of changes that are often perceived as small and insignificant by the care team, but the effects of which can be significant and damaging for the patient. As Jan suggested '*it's the little big things that count*'.

- The build-up of anxiety as patients edge closer to discharge is evidenced: the multi-disciplinary teams need to work harder at desensitising inpatients with ASC to the impact that exiting the inpatient unit causes. Although initially the unit was uncomfortable and unpleasant, it has now become the norm and, as Jacob described, '*home'*.

Furthermore, there are lessons for researchers in the area in their attempt to make sense of how people with ASC attribute meaning to their experiences and why a social constructionism perspective is a useful epistemology. In other words, because none of our realities are free from the histories of social, political and cultural circumstances that we find ourselves in, researchers would benefit, therefore, in questioning themselves at a high level about why individuals have the interpretations that they do. What is it about society and their previous interactions within that may have given rise to how they described their current experiences?

6.4 Research limitations

This study is subject to both methodological and contextual limitations. Criticisms that are commonly aligned to qualitative research are also applicable here. The findings from this study can be considered as unscientific, not generalisable and subjective. This is the product of a single researcher using an inter-reliability framework, which in practical terms means that a colleague and an expert by experience within the field of ASC both reviewed the data and made comments upon their interpretation.

Phenomenology as a research approach relies on the accounts of participants and the experiences of the researcher/s. Critics of IPA question whether both participants and researchers have the requisite communication skills to successfully communicate the nuances of experiences (Tuffour, 2017). Shinebourne and Smith (2010) suggest phenomenological research is only suitable for the most eloquent individuals and great care should be taken when used with people who find it difficult to articulate their thoughts and feelings in a way that can be easily understood by others. Within this current study there cannot be any assumptions made on the level of fluency that the participants possessed to enable them to describe their experiences,

i.e. we understand that the core features of ASC are associated with social and communication impairments; however, a large percentage of the sample for this current study were able to articulate their thoughts and feelings in a very comprehensible way. It should also be acknowledged that for other participants this was not as straightforward, and extra attentiveness was required to collect the required richness of data.

All the participants in this current study showed an interest in the area of exploration; many expressed their gratitude to be given the chance to have '*their voice heard'*. Charlie (one of the pilot interviewees) assured me that I would not have any problems with recruitment to this study as people with ASC would be '*climbing over each other*' to give me their point of view and accept an opportunity to allow their story to be heard. This was the case, and recruitment to a viable cohort was relatively straightforward.

For a few participants, the level of engagement could have been stronger, and the data received therefore richer. On reflection, I have considered whether I could have been more explicit regarding my interest in their experiences. Although I sent information in advance of interview, including the participant information sheet and, for those who requested them, the questions also, I could have been more explicit about my interest in the emotions, motivations and fulfilment they experienced; i.e. more clarity about my expectation of being able to delve deep and analyse their feelings and emotions, may have helped. Although I did return to a few participants to gain clarification on meaning and additional thoughts expressed during interview, as had been agreed from the outset with all participants, this invariably took me back to those participants who had engaged and interacted well in the interview and who had a great deal to say on the subject. In retrospect, it might have been useful to conduct follow-up interviews with all participants, which focused on their in-depth thoughts and feelings about their admissions.

I feel it is important for me to take some reflexive ownership in this research. In Chapter 1, I have described my experiences as a nurse working within inpatient environments and experiencing at first-hand numerous admissions of people with ASC. I have been conscious of the negative nature of my experiences and how they may have impacted upon my expectations upon the content of the data in this current study. Being conscious of this potentially made it easier to recognise my doubts and therefore easier to ensure that they were not seen by the interviewee, but realistically it was difficult to remove this from the interviews entirely.

Additionally, it is important to reflect on my performance as an interviewer. With many years' experience of working and communicating with people from across the autistic spectrum, I have been able to call upon many of those strategies and developed techniques that I use when working and implement them into the interview schedule and my interview approach. However, I found the interviews to be very challenging and it struck me during the early interviews that it was unlikely that there was going to be a 'typical' interviewee; and yet I have been astonished by the diversity of people I have met during the journey of this research study. Keeping the interviewee focused on the subject matter of this study has been challenging, and not to let them move off onto a subject which is more comfortable to them, or they are more motivated to talk about. It was obvious during the data analysis process that I had not always been entirely successful in this, and the occasional interview transcript contained large amounts of text that were not wholly relevant. An honest reflection would be that I improved as a research interviewer of people with autism and impaired communication skills and, as the data collection phase grew, I tried to learn from previous mistakes and

develop my technique: therefore, the interviews that produced the richest data are further down the data collection timeline. This can also be said of my growing ability to understand the participant's viewpoint and to make more accurate *field notes* or ask more appropriate questions that could help clarify meaning quickly and effectively. This is not to say that the earlier interviews did not produce good insights into the phenomenon, but as a researcher I am aware that I needed to work harder to get the data I needed.

It was not possible to carry out credibility checks on all the participants, about their diagnosis and their claims to have spent enough time within a mental health unit to meet the inclusion criteria for this study. However, I am assured in the knowledge that I contacted all the participants via the central gatekeeper of this study - the local Asperger's Support Team in Hertfordshire County Council. All the participants are known to the Team, who only support people with an ASC or those who are under assessment for a formal diagnosis and therefore have access to their service user's clinical records: they only included those who had already been formally diagnosed.

This study has argued that my chosen research approaches of qualitative research in general, and IPA specifically, offer the flexibility and versatility that has been a requirement of understanding people with ASC and their experiences. However, it is an understandable limitation of this study that a different researcher with a different background and experience of their own, could apply the same research strategy and formula and produce different data, which in turn could be interpreted very differently. My influence upon the outcomes of this current study should not therefore be misjudged.

6.5 Future research

The findings from the current study provide valuable insight into the experiences of adults with ASC in mental health inpatient services. The findings, implications and limitations of the research indicate several potential areas for future research.

Although two participants explained to me that they consider themselves to be 'borderline intellectually disabled', none of the participants for this current study had a confirmed diagnosis of a learning disability/intellectual disability. Future studies should consider those inpatient experiences belonging to adults with intellectual disabilities and autism. Hamilton et al (2017) suggest that this group is excluded from participating in health and healthcare research. Understanding study information, which is an important aspect of demonstrating capacity to give informed consent, can be a challenge. I believe that using accessible communication would aid participants with intellectual disabilities and, when also utilising the opinions of carers and staff who know the patient well, this type of research is achievable. Mengoni et al (2016) used picture-aided consent forms to help inform potential participants with moderate to severe learning disabilities. The forms were sent through the post with an invitation pack containing standard and easy to read information. This was then followed up by a researcher visiting the interested participants and their carers in person.

My extensive experience of working with people with learning disabilities and autism, including my research field experience in this current study, would place me in a good position to achieve some very useful insights

into the inpatient experience seen through the eyes of patients with intellectual disabilities and autism. It could be argued that many of the themes that emerged within this study could well exist for those on the autistic spectrum with different intellectual ability; for example, the manifestation and causes of much of the anxiety described by the participants in this study could well be similar or even the same.

It has become apparent throughout the research process for this study that there cannot be enough emphasis placed upon the research methodology and the tools at the researcher's disposal, which need to be fit for purpose but flexible enough to meet the varying needs of the interviewees. Technology could play a useful part in enhancing the accessibility and engagements of future research projects for participants with ASC. Many adults with ASC are enthusiastic users of technology and often their interest and ability in computer use grows with age (Moor, 2008). To eradicate some of the issues surrounding the social situation of face-to-face interviews in research, future research studies could benefit from the use of alternative online formats to engage with interviewees. For example, *Second Life* is an online virtual world and a three-dimensional modelling tool that can allow interaction with different users by using avatars (Ross, 2009). Participants within this current study discussed *Second Life* and other online platforms, suggesting that they would enjoy using them in research; this was also mentioned during the initial exploratory discussions with the Asperger's Support groups. However, utilising an online forum such as *Second Life* within this current study was rejected at the Ethics Committee stage. The rejection was based upon the questionable security of the *Second Life* platform and the uncertainty of who the participants may be; i.e., as they would be using avatars there can be no certainty that the person who is interacting with the researcher is the person that has consented to the study. Additionally, there were concerns about other people who were not connected to the study being able to listen to the interviews without consent.

Future research could consider how best to include service users in service design and delivery, with better guidance on adapting information and facilitating discussions that could both increase accessibility and impact upon future services.

6.6 Conclusion

This study employed an IPA methodology to explore the emotional and psychological experience of being an inpatient with ASC in a mental health unit. The research recognised that there is a high mental health burden in adults with a diagnosis of ASC, and that many individuals require inpatient support, yet the lived experience of the same is rarely heard. Involving service users in this way has much to teach us about tailoring support to their needs: reflecting on the overall process used, I return to my initial explanation of '*How this study evolved*' (Section 1.1) - namely, an empathic connection with the patients and their challenging experiences. The empathic connection has not diminished - if anything, it has grown stronger. When starting out on this research, I had always expected to hear about negative experiences, which I imagined would be shrouded with anxiety and fear with a great deal more negativity arising besides. Synthesis of participant experiences in the inpatient setting highlighted a range of individual and often shared issues that impact upon mental well-being: some of these issues may be perceived by mental health unit staff as small, or even trivial, but, nevertheless, anxiety and the need for sameness were found to be consistently significant barriers to the effectiveness of available support for all the participants, and helps to

explain why people with ASC adopt extreme coping responses in this situation. There is no doubt that some of these responses can be particularly challenging to mental healthcare professionals, but with greater insight into the root causes, practitioner responses could become more sensitive and understanding.

This study has increased the understanding of the inpatient experience of people with ASC, their experiences have been thematically grouped in superordinate, main and sub-themes which have been systematically analysed and discussed and ultimately influenced the main clinical implications and recommendations for this research project. Previously reviewed studies highlighted in chapter 2 that explore the service user's views of inpatient care, described variable experiences. For example, Slevin et al (2008) described the experiences of people with learning disabilities and ASC in inpatient assessment and treatment services as positive and impacting upon the reductions in challenging behaviours, claiming to have reduced distress. A complete contrast to the findings of this current study whose participants claimed to have behaved far more erratically and on occasion more dangerously after they had been admitted.

Other studies demonstrated similarities to this current study for example the views of service users upon the mental health nurses that cared for them in Bee et al. (2008) which demonstrated some concerns around the lack of collaborative care, poor communication and inadequate information sharing. Although this study did include participants with ASC it did not differentiate their views from other service users. Mental health inpatients expressed some similar concerns to the participants of this current study in Bunyan et al (2017) also, highlighting uncertainty and fear exacerbated by too many restrictions imposed by the inpatient staff. These emotional feelings were only reported superficially without any real depth or understanding as to how these feelings impacted upon their psychological well-being and how they coped. Most of the participants within Bunyan's study were diagnosed with personality disorder and schizophrenia without any mention of autism.

Chaplin et al (2006) again found some similarities to this current study in that the inpatients reported insufficient physical environments, poor communication and low staff morale impacted negatively upon the inpatient experience. However, similar to the previous studies it pays little attention to the psychological impression upon the inpatient experience. Another study also found the inpatient experience disempowering and lacking in flexibility (Donner et al, 2010). Similar to this current study, Dunn (2012) found after a training needs assessment that 70% of the staff in services which catered for people with 'high functioning' autism had little or no knowledge about autism prior to working with them. The overarching statement from this study was that the majority of the services were deemed unsafe due to the lack of skills and knowledge of the front-line caregivers. This is a statement which many participants who had commented upon their feelings of vulnerability and need for safety and protection in this current study, would undoubtedly agree with.

Murphy and Mullens (2017) also found incompatibilities and poor relationships with patients in high security hospitals with ASC and their neurotypical counterparts. Again, the psychological impact and feelings of vulnerability and insecurity were not explored, this current study has explored the connection that relationships with other patients and caregivers are crucial to the psychological impact of the inpatient experience. However, their ability to build relationships are reportedly hindered by impaired social functioning and general social confidence, often resulting in them actively managing their expectations and concentrating on only one member of staff, normally a front-line caregiver i.e. a nurse or support worker. Leaving other

disciplines frustrated and observing non-engagements with therapies and other aspects of the care formula which has been devised by the multidisciplinary team.

The qualitative approach adopted in the current study has provided several insights that can aid the improvement of services to meet the needs of people affected by ASC. The findings are of value to mental health professionals, service commissioners and developers, and further highlight the need and value of involving patients in the planning and refinement of care that is designed to help the most vulnerable.

The experience and management of anxiety is at the forefront of this current study's most valuable insights. The sense of powerlessness and the emotional reaction to uncertainty, which is understood to a greater depth than previous studies have enabled. The participants have informed us that their sense of powerlessness can be readdressed by allowing more control and cohesion within the care given. Offering support to inpatients in gaining control over their daily structure and routine as quickly as possible can help to alleviate anxiety, as well as control over the sensory profile of their immediate physical environments. Being very clear communicators and ensuring there is as little uncertainty as possible, again helps to alleviate the nervousness and worry which is very unhelpful.

Additionally, the participants have informed us better than before about the importance of relationship building and what we as nurses and caregivers should expect and how best we can support this need in a managed way. Equally this thesis has enabled the development of our understanding of the responses to anxiety and powerlessness. Better understanding of behaviours such as verbal and physical aggression and those that are self-injurious, are crucial to the role of the nurse and other disciplines. Crucial as the greater our understanding the more able we are to assist the patients in developing positive coping strategies, the examples given by the participants in this study are extremely insightful and can have a positive impact upon our ability to co-design and co-implement others. Overall, the thesis has exemplified the relationship between society and its value placed on mental health units, how they are structured, and how individual interactions within society and culture come to shape experience of mental health units. Some of this sense making is shared with other inpatients without a diagnosis of ASC, whilst much is unique to interacting with the world when living with ASC.

References

Acker, L., Knight, M., & Knott, F. (2018). 'Are they just gonna reject me?' Male adolescents with autism making sense of anxiety: An Interpretative Phenomenological Analysis. *Research in Autism Spectrum Disorders, 56*, 9-20. doi:10.1016/j.rasd.2018.07.005.

Adler, B. A., Wink, L. K., Early, M., Shaffer, R., Minshawi, N., McDougle, C. J., & Erickson, C. A. (2015). Drug-refractory aggression, self-injurious behaviour, and severe tantrums in autism spectrum disorders: A chart review study. Autism, 19(1), 102-106. doi:10.1177/1362361314524641

Altomare, A. McCrimmon, M. Cappadocia, J. Weiss, T. Beran, & Smith-Demers (2017). When Push Comes to Shove: How Are Students with Autism Spectrum Disorder Coping with Bullying? Canadian Journal of School Psychology, 32 209–227.

Ambler, P. G., Eidels, A., & Gregory, C. (2015). Anxiety and aggression in adolescents with autism spectrum disorders attending mainstream schools. Research in Autism Spectrum Disorders, 18, 97-109. doi: https://doi.org/10.1016/j.rasd.2015.07.005

Andvig, E., & Biong, S. (2014). Critical reflection on practice development- Recovery oriented conversations in a milieu therapeutic setting. *International Practice Development Journal, 4*(1).

Atwoli, L., Stein, D. J., Williams, D. R., McLaughlin, K. A., Petukhova, M., Kessler, R. C., & Koenen, K. C. (2013). Trauma and posttraumatic stress disorder in South Africa: analysis from the South African Stress and Health Study. BMC Psychiatry, 13. doi:10.1186/1471-244x-13-182

Auticon. (2016). Retrieved from https://auticon.com/

Autism and Developmental Disabilities Monitoring Network (2012). Morbidity and Mortality Weekly Report. Surveillance summaries, Prevalence of autism spectrum disorders - autism and developmental disabilities monitoring network, 14 sites United States, 2008. Retrieved from USA: http://www.cdc.gov/mmwr/preview/mmwrhtml/ss6103a1.htm

Autism Empowerment Kit (2017). New York: Global Impact Sourcing Coalition.

Autism Speaks (2013). What is it about autism and food? Retrieved from: https://www.autismspeaks.org/blog/2013/09/27/what-it-about-autism-and-food

Autism Speaks (2018). Future research. Retrieved from: https://www.autismspeaks.org/

Autism support network (2018) What You Can Do When Faced with Autism? Retrieved from: http://www.autismsupportnetwork.com.

AutonomyWorks. (2017). AutonomyWorks. Retrieved from http://www.autonomy.works/

Au-Yeung, S. K., Bradley, L., Robertson, A. E., Shaw, R., Baron-Cohen, S., & Cassidy, S. (2019). Experience of mental health diagnosis and perceived misdiagnosis in autistic, possibly autistic and non-autistic adults. Autism, 23(6), 1508-1518. doi:10.1177/1362361318818167

Bacikova-Sleskova, M, van Dijk, JP, Geckova, AM. (2007) The impact of unemployment on school leavers' perception of health. Mediating effect of financial situation and social contacts? Int J Public Health; 52: 180–187

Bakken, T. L., Helverschou, S. B., Eilertsen, D. E., Heggelund, T., Myrbakk, E., & Martinsen, H. (2010). Psychiatric disorders in adolescents and adults with autism and intellectual disability: A representative study in one county in Norway. Research in Developmental Disabilities, 31(6), 1669-1677. doi: http://dx.doi.org/10.1016/j.ridd.2010.04.009

Baksheev, G. N., Allott, K., Jackson, H., McGorry, P., & Killackey, E. (2012). "Predictors of vocational recovery among young people with first-episode psychosis: Findings from a randomized controlled trial." Psychiatric Rehabilitation Journal 35(6): 421-427.

Barbour, R. (2014). Introducing Qualitative Research (2nd ed.). London: Sage.

Barlow, K., Grenyer, B., & Ilkiw-Lavalle, O., (2000). "Prevalence and precipitants of aggression in psychiatric inpatient units." Australian and New Zealand Journal of Psychiatry 34(6): 967-974.

Baron-Cohen, S. (1996). Mindblindness. London: MIT press.

Baron-Cohen, S. (2014). Autism and Asperger Syndrome: The Facts. Oxford, United Kingdom: OUP Oxford.

Baron-Cohen, S., Scott, F., Allison, C., Williams, J., Bolton, P., Matthews, F., & Brayne, C. (2009). Prevalence of autism-spectrum conditions: UK school-based population study. British Journal of Psychiatry, 194(6), 500-509. doi:10.1192/bjp.bp.108.059345

Barrett, L. F., Gross, J., Christensen, T. C., & Benvenuto, M. (2001). Knowing what you're feeling and knowing what to do about it: Mapping the relation between emotion differentiation and emotion regulation. Cognition and Emotion, 15(6), 713-724. doi:10.1080/ 02699930143000239.

Baumeister, R. F., & Leary, M. R. (1995). The need to belong: Desire for interpersonal attachments as a fundamental human motivation. Psychological Bulletin, 117(3), 497-529. doi:10.1037/0033-2909.117.3.497

Baxter, A., Brugha, T., Erskine, H., Scheurer, R., Vos, T., & Scott, J. (2015). The epidemiology and global burden of autism spectrum disorders. Psychological Medicine, 45(3), 601-613. doi:10.1017/S003329171400172X.

BBC (2018). Prime Minister's Question Time. British Broadcasting Corporation.

Beardon, L., & Worton, D. (2011). Aspies on Mental Health. London: Jessica Publishers.

Beckett, P., Field, J., Molloy, L., Yu, N., Holmes, D., & Pile, E. (2013). Practice what you preach: developing person-centred culture in inpatient mental health settings through strengths-based, transformational leadership. Issues in mental health nursing, 34(8), 595-601.

Bee, P., Playle, J., Lovell, K., Barnes, P., Gray, R., & Keeley, P. (2008). Service user views and expectations of UK-registered mental health nurses: A systematic review of empirical research. Int J Nurs Stud, 45(3), 442-457. doi: 10.1016/j.ijnurstu.2007.02.008

Bentall, R. (2009). Doctoring the mind: Is our current treatment of mental illness really any good? New York: University Press.

Berger, P., & Luckmann, T. (1966). The Social Construction of Reality. London: Cox and Wyman.

Bjarnason, T, Sigurdardottir, TJ. (2003) Psychological distress during unemployment and beyond: Social support and material deprivation among youth in six northern European countries. Social Sci Med; 56: 973–985.

Boulter, M. Freeston, M. South, & J. Rodgers (2013). Intolerance of Uncertainty as a Framework for Understanding Anxiety in Children and Adolescents with Autism Spectrum Disorders. Journal of Autism Development and Disorder, 44, 1391–1402. doi:10.1007/s10803-013-2001-x.

Bowers, L. (2005). Reasons for admission and their implications for the nature of acute inpatient psychiatric nursing. Journal of Psychiatric and Mental Health Nursing, 12(2), 231-236. doi:10.1111/j.1365-2850.2004. 00825.x

Bowers, L., Chaplin, R., Quirk & Lelliott (2009) A conceptual model of the aims and functions of acute inpatient psychiatry, Journal of Mental Health, 18:4, 316-325, DOI: 10.1080/09638230802053359.

Bowlby, J. (2005). A Secure Base - Clinical Applications of Attachment Theory. London: Routledge.

Bradley, E. S. J., Wood, H., and Bryson, S. (2004). Comparing Rates of Psychiatric and Behaviour Disorders in Adolescence and Young Adults with Severe Intellectual Disability and With and Without Autism. Journal of Autism and Developmental Disorders, 32(2), 151-161.

Breeze, J. A., Repper, J., (1998). Struggling for control: The care experiences of 'difficult' patients in mental health services. Journal of Advanced Nursing, 28, 1301-1311. doi:10.1046/j.1365-2648.1998. 00842.x

Brydsten, A, Hammarstrom, A, San Sebastian, M. (2016) The impact of economic recession on the association between youth unemployment and functional somatic symptoms in adulthood: A difference-in-difference analysis from Sweden. BMC Public Health; 16: 230.

Bryman, A. (2012). Social Research Methods (4 ed.). Oxford: Oxford University Press.

Bryson, S. A., Gauvin, E., Jamieson, A., Rathgeber, M., Faulkner-Gibson, L., Bell, S., Burke, S. (2017). What are effective strategies for implementing trauma-informed care in youth inpatient psychiatric and residential treatment settings? A realist systematic review. International Journal of Mental Health Systems, 11(1), 36. doi:10.1186/s13033-017-0137-3

Bunyan, M., Cashen, A. (2017). A look at inpatients' experience of mental health rehabilitation wards. Mental Health Practice, 20(6), 17-23. doi:10.7748/mhp. 2017.e1163

Burr, V. (2003). Social Constructionism (2nd ed.). London: Routledge.

Burr, V. (2015). Social Constructionism. London, Routledge.

Butler, M. P., Begley, M., Parahoo, K., & Finn, S., (2014). "Getting psychosocial interventions into mental health nursing practice: a survey of skill use and perceived benefits to service users." Journal of Advanced Nursing 70(4): 866-877.

Cage, E., Di Monaco, J., & Newell, V. (2018). Experiences of Autism Acceptance and Mental Health in Autistic Adults. Journal of Autism and Developmental Disorders, 48(2), 473-484. doi:10.1007/s10803-017-3342-7

Cambers, W. (2016). Exploring the merits of the recovery model for mental health nursing in Scotland. Mental Health Practice, 20(1), 27-31. doi:10.7748/mhp.2016.e1103

Cassidy, S., Bradley, L., Shaw, R., & Baron-Cohen, S. (2018). Risk markers for suicidality in autistic adults. Molecular Autism, 9(1), 42. doi:10.1186/s13229-018-0226-4

Care Quality Commission (2017). The state of care in mental health services 2014 to 2017. Retrieved from NHS England. https://www.england.nhs.uk/ourwork/part-rel/cqc/.

Carleton, R., (2012). The intolerance of uncertainty construct in the context of anxiety disorders: Theoretical and practical perspectives. Expert Review of Neurotherapeutics, 12(8), 937–947. doi:10.1586/ern.12.82.

Carrington, S., & Graham, L. (2001). Perceptions of school by two teenage boys with Asperger's and their mothers: a qualitative study. Autism, 5(1), 37 - 48.

Carrington, S., Templeton, E., & Papinczak, T. (2003). Adolescents with Asperger Syndrome and Perceptions of Friendship. Focus Autism Other Dev Disabl, 18, 211.

Cassidy, S., Bradley, L., Shaw, R., & Baron-Cohen, S. (2018). Risk markers for suicidality in autistic adults. Molecular Autism, 9(1), 42. doi:10.1186/s13229-018-0226-4

Catty, J., Cowan, N., Poole, Z., Ellis, G., Geyer, C., Lissouba, P., & Burns, T. (2012). Attachment to the clinical team and its association with therapeutic relationships, social networks, and clinical well-being. Psychology and Psychotherapy: Theory, Research and Practice, 85(1), 17-35. doi:10.1111/j.2044-8341.2010. 02011.x

Chaplin E, McCarthy J, & Underwood L. (2013). Autism spectrum conditions and offending: an introduction to the special edition. Journal of intellectual disabilities and offending behaviour, 4(1/2), 5-8. doi:10.1108/JIDOB-05-2013-0012

Chaplin, R. (2004). General psychiatric services for adults with intellectual disability and mental illness. Journal of Intellectual Disability Research, 1(48), 1-10.

Cheely, C., Carpenter, L., Letourneau, E., Nicholas, J., Charles, J., & King, L. (2012). The Prevalence of Youth with Autism Spectrum Disorders in the Criminal Justice System. Journal of Autism & Developmental Disorders, 42(9), 1856-1862. doi:10.1007/s10803-011-1427-2

Chin, W., Chao, K., Chang, H., Li, H., & Chen, S. (2017). Coping strategies of Taiwanese children with autism spectrum disorders. Journal of Clinical Nursing, 26(21-22), 3408–3421.

Clark, A., Browne, S., Boardman, L., Hewitt, L., & Light, S. (2016). Implementing UK Autism policy & National Institute for Health and Care Excellence guidance - assessing the impact of Autism training for frontline staff

in community learning disabilities teams. British Journal of Learning Disabilities, 44(2), 103-110. doi:10.1111/bld.12116

Clarkson R., Murphy, G. H., Coldwell J. B., & Dawson, D. L. (2009). What characteristics do service users with intellectual disability value in direct support staff within residential forensic services? Journal of Intellectual and Developmental Disability, 34(4), 283-289.

Clifton, A., Hemingway, S., Felton, A., & Stacey, G. (2017). Fundamentals of Mental Health Nursing : An Essential Guide for Nursing and Healthcare Students. Newark, UNITED KINGDOM: John Wiley & Sons, Incorporated.

Connors, C. (2003). Conner's third edition. Toronto: MHS.

Cooper, K., Smith, L. G. E., & Russell, A. (2017). Social identity, self-esteem, and mental health in autism. European Journal of Social Psychology, 47(7), 844-854. doi:10.1002/ejsp.2297

Creswell, J. W. (2013). Research Design: Qualitative, Quantitative and Mixed Methods (3rd ed.). London: Sage.

Crist, J., & Tanner, C. (2003). Interpretation/Analysis Methods in Hermeneutic Interpretive Phenomenology. Nursing Research, 52(3).

Crotty, M. (2013). The Foundations of Social Research. London: Sage.

Crowe, L, Butterworth, P. (2016) The role of financial hardship, mastery and social support in the association between employment status and depression: Results from an Australian longitudinal cohort study. BMJ Open. 6: e009834.

D'Andrea, W., Sharma, R., Zelechoski, A. D, & Spinazzola, J. (2011). Physical health problems after single trauma exposure: when stress takes root in the body. Journal of American Psychiatric Nurses Association, 17(6), 378-392.

Dean M., Harwood R.& Kasari C. (2017). The art of camouflage: gender differences in the social behaviours of girls and boys with autism spectrum disorder. Autism 21(6), 678-689

De Benedictis, L., Dumais, A., Sieu, N., Maihot, M. (2011). Staff Perceptions and Organizational Factors as Predictors of Seclusion and Restraint on Psychiatric Wards. Psychiatric Services, 62(5), 484-491. doi:10.1176/ps.62.5.pss6205_0484

De Giacomo, A., Craig, F., Terenzio, V., Coppola, A., Campa, M. G., & Passeri, G. (2016). Aggressive Behaviours and Verbal Communication Skills in Autism Spectrum Disorders. Global paediatric health, 3, 2333794X16644360. doi:10.1177/2333794X16644360

Delaney, K. R., Shattell, M., & Johnson, M. E. (2017). Capturing the Interpersonal Process of Psychiatric Nurses: A Model for Engagement. *Archives of Psychiatric Nursing, 31*(6), 634-640. doi:https://doi.org/10.1016/j.apnu.2017.08.003

Dellapiazza, F., Vernhet, C., Blanc, N., Miot, S., Schmidt, R., & Baghdadli, A., (2018). "Links between sensory processing, adaptive behaviours, and attention in children with autism spectrum disorder: A systematic review." Psychiatry Research 270: 78-88.

Denscombe, M. (2004). The Good Research Guide for small scale social research projects. London: Sage.

Department of Health (1983). The Mental Health Act.

Department of Health (2008). High Quality Care for All. Retrieved from London: www.nhshistory.net/High_Quality_Care_for_All.

Department of Health (2009) The Autism Act. Retrieved from: https://www.legislation.gov.uk/ukpga/2009/15/pdfs/ukpga_20090015_en.pdf.

Department of Health (2010). The Autism Strategy. Retrieved from: https://www.legislation.gov.uk.

Department of Health (2010). The Equality Act.

Department of Health (2012). National Framework to Improve Mental Health and Wellbeing

Department of Health (2014). The Care Act. London: Department of Health.

Department of Health (2014). Think Autism Fulfilling and Rewarding Lives, the strategy for adults with autism in England: an update. London.

Department of Health (2016). New investment in mental health services. Retrieved from https://www.gov.uk/government/news/new-investment-in-mental-health-services

Department of Health (2016). Progress Report on Think Autism: the updated strategy for adults with autism in England. London.

Department of Health (2017). Restraint and restrictive intervention. Retrieved from London: https://www.gov.uk/government/organisations/department-of-health-and-social-care

Detrie, P., & Lease, S. (2007). The relation of social support, connectedness, and collective self-esteem to the psychological well-being of lesbian, gay and bisexual youth. Journal of homosexuality, 53(4), 173-199.

Dewinter, J., Van Prarys, H., Vermeiren, R., & Van Nieuwenhuizen, C., (2017). "Adolescent boys with an autistic spectrum disorder and the experience of sexuality: an interpretive phenomenological analysis." Autism 21: 75-82.

Dillenburger, K., Jordan, J. A., McKerr, L., Devine, P., & Keenan, M. (2013). Awareness and knowledge of autism and autism interventions: A general population survey. Research in Autism Spectrum Disorders, 7(12), 1558-1567. doi:https://doi.org/10.1016/j.rasd.2013.09.004

Donner, B., Mutter, R. & Scior, K. (2010). Mainstream in-patient mental health care for people with intellectual disabilities: Service user, carer and provider experiences. Journal of Applied Research in Intellectual Disabilities, 23(3), 214-225.

Dunn, E. L. (2012). An Assessment of Mental Health Service Provision for High Functioning Autistic Adults in East Lancashire. East Lancashire Primary Care Trust Mental Health Commissioning.

Elias, N., & Dunning, E. G. (1986). Quest for excitement: sport and leisure in the civilizing process. Oxford: Blackwell.

Ellis, R. (2017). Heritage and Stigma. Co-producing and communicating the histories of mental health and learning disability. Medical Humanities, 43(2), 92-98. doi:10.1136/medhum-2016-011083

Elsabbagh, M., Divan, G., Koh, K., Kim, Y., Kauchali, S., Marcín, C., and Fombonne, E. (2012). Global prevalence of autism and other pervasive developmental disorders. Autism Research, 5(3), 160-179.

Elwin, M., Ek, L., Schröder, A., & Kjellin, L. (2012). Autobiographical accounts of sensing in Asperger syndrome and high-functioning autism. Archives of Psychiatric Nursing, 26(5), 420-429.

Emerson, E. (1995). Challenging Behaviour: Analysis and Intervention in People with Learning Disabilities. Cambridge: Cambridge University Press.

England, N. (2017). Care and treatment reviews. Retrieved from www.England.NHS.UK

Eisenberg, P.F. & Lazarsfeld, P (1938) The psychological effects of unemployment. Psychological Bulletin, 35, pp. 358-390.

Fakhoury, W., & Priebe, S. (2007). Deinstitutionalization and reinstitutionalization: Major changes in the provision of mental healthcare. Psychiatry, 6, 313-316.

Faulkner, S., & Bee, P. (2017). Experiences, perspectives and priorities of people with schizophrenia spectrum disorders regarding sleep disturbance and its treatment: a qualitative study. BMC Psychiatry, 17(1), 158. doi:10.1186/s12888-017-1329-8.

Feldman, J. I., Kuang, W., Conrad, J., Tu, A., Santapuram, P., Simon, D., Foss-Feig, J., Kwakye, Leslie D., Stevenson, R., Wallace, M., & Woynaroski, T., (2018). "Brief Report: Differences in Multisensory Integration Covary with Sensory Responsiveness in Children with and without Autism Spectrum Disorder." Journal of Autism and Developmental Disorders.

Fergusson, DM, Horwood, LJ, Woodward, LJ. (2001) Unemployment and psychosocial adjustment in young adults: Causation or selection? Social Sci Med; 53: 305–320.

Forbes, P. A. G., Wang, Y., & de C., Hamilton, A. F. (2017). My Interactions: Gaze and the Modulation of Mimicry in Adults on the Autism Spectrum. Psychonomic Bulletin & Review, 24(2), 529-535. doi:10.3758/s13423-016-1136-0

Foucault, M. (1961). Madness and civilization. London: Routledge.

Foucault, M. (1972). The archaeology of knowledge. London: Tavistock Publications Ltd.

Gates, B. (2007). Learning Disabilities: Toward Inclusion (5 ed.). London: Elsevier.

Ghaziuddin, E., Weidmer-Mikhail, E., & Ghaziuddin, N. (1998). Comorbidity of Asperger syndrome: a preliminary report. Journal of Intellectual Disability Research, 42(4), 279-283.

Gibbs, S. M., Brown, M. J. & Mule, W.J. (2008). The experiences of adults with intellectual disabilities and their carers in general hospitals: a focus group study. Journal of Intellectual Disability Research, 52(12), 1061-1077.

Giddens, A. (1991). Modernity and self-identity: self and society in the late modern age. Cambridge: Polity.

Gilburt, H., Rose, D., & Slade, M. (2008). The importance of relationships in mental health care: a qualitative study of service users' experiences of psychiatric hospital admission in the UK. BMC health services research, 8, 92. doi:10.1186/1472-6963-8-92.

Gillingham, G. (1995). Autism: handle with care!: understanding and managing behaviour of children and adults with autism. New York: Future Education Inc.

Goffman, E. (1961). Asylums. New York: Anchor.

Goffman, E. (1963). Stigma: The Management of Spoiled Identity. Harmondsworth: Penguin.

Gooding, P. (2016). From deinstitutionalisation to consumer empowerment: mental health policy, neoliberal restructuring and the closure of the 'Big bins' in Victoria. Health Sociology Review, 25(1), 33-47. doi:10.1080/14461242.2015.1134261

Gordon, K., Murin, M., Baykaner, O., Roughan, L., Livermore-Hardy, V., Skuse, D., & Mandy, W. (2015). A randomised control trial of PEGASUS, a psychoeducational programme for young people with high functioning autism spectrum disorder. *Journal of Child Psychology and Psychiatry,* 56 (4), 468-476.

Grimes, J. O., Cheek, J. M., & Norem, J. K. (2011). Four Meanings of Introversion. Paper presented at the Society for Personality and Social Psychology, San Antonio.

Gunasekaran, S. and Chaplin, E. (2012). Autism spectrum disorders and offending. Advances in Mental Health and Intellectual Disabilities, Vol. 6 No. 6, pp. 308-13.

Hall, I., Parkes, C., Samuels, S., & Hassiotis, A. (2006). Working across boundaries: Clinical outcomes for an integrated mental health service for people with intellectual disabilities. Journal of Intellectual Disability Research, 50(8), 598-607.

Hall, J. E. (2004). Restriction and control: The perceptions of mental health nurses in a UK acute inpatient setting. Issues in Mental Health Nursing, 25, 539-552. doi:10.1080/01612840490443473

Hall, L. W., Moore, S. M., & Barnsteiner, J. H. (2008). Quality and nursing: Moving from a concept to a core competency. Urologic Nursing, 28(6), 417-425.

Hamilton, J., Ingham, B., McKinnon, I., Parr, J. R., Tam, L. Y.-C., & Le Couteur, A. (2017). Mental capacity to consent to research? Experiences of consenting adults with intellectual disabilities and/or autism to research. British Journal of Learning Disabilities, 45(4), 230-237. doi:10.1111/bld.12198

Hanna, J. (2009). CBT on the wards: standards and aspirations. In C. A. H. Wilson (Ed.), Cognitive Behaviour for Acute Inpatient Mental Health Units. (pp. 11-21). Hove: Routledge.

Hannant, P., Cassidy, S., Van de Weyer, R., & Mooncey, S. (2018). Sensory and motor differences in Autism Spectrum Conditions and developmental coordination disorder in children: A cross-syndrome study. Human Movement Science, 58, 108-118. doi: 10.1016/j.humov.2018.01.010

Hare, D., Gould, J., & Mills, R. (1999). A Preliminary Study of Individuals with Autistic Spectrum Disorders in Three Special Hospitals in England. London. National Autistic Society.

Harris, B. and Panozzo, G. (2019), Barriers to recovery-focused care within therapeutic relationships in nursing: Attitudes and perceptions. Int J Mental Health Nurs, 28: 1220-1227. doi:10.1111/inm.12611

Hayward, S. M., McVilly, K. R., & Stokes, M. A. (2019). Autism and employment: What works. Research in Autism Spectrum Disorders, 60, 48-58. doi:https://doi.org/10.1016/j.rasd.2019.01.006

Hedley, D., Uljarević, M., Foley, K.-R., Richdale, A., & Trollor, J. (2018). Risk and protective factors underlying depression and suicidal ideation in Autism Spectrum Disorder. Depression and Anxiety, 35(7), 648-657. doi:10.1002/da.22759

Hedley, D., Wilmot, M., Spoor, J., & Dissanayake, C. (2017). Benefits of Employing People with Autism: The Dandelion Employment Program.

Herbig, B, Dragano, N, Angerer, P. (2013) Health in the long-term unemployed. Deutsches Arzteblatt Int; 110: 413–419.

Hertfordshire County Council (2017). Asperger's Team - Hertfordshire Outreach. Retrieved from: https://autism-connect.org.uk/provider/Asperger-Team---Hertfordshire

Hertfordshire Partnership NHS University Foundation Trust. (2016). Young Carers Mental Health Booklet.

Hirvikoski, T., Mittendorfer-Rutz, E., & Boman, M. (2016). Premature mortality in autism spectrum disorder. British Journal of Psychiatry, 208(3), 232-238.

Hochschild, A., (2012). The Managed Heart: Commercialization of Human Feeling. Berkerley, United States: University of California Press.

Hoole, L. & Morgan, S. (2011). 'It's only right that we get involved': Service-user perspectives on involvement in learning disability services. British Journal of Learning Disabilities, 39(1), 5-10.

Hopkins, J. E., Loeb, S. J., & Fick, D. M. (2009). Beyond satisfaction, what service users expect of inpatient mental health care: a literature review. Journal of Psychiatric and Mental Health Nursing, 16(10), 927-937. doi:10.1111/j.1365-2850.2009. 01501.x

Howard, K., Katsos, N., & Gibson, J. (2019). Using interpretive phenomenological analysis in autism research. Autism. doi:10.1177/1362361318823902

Howlin, P. (2005). Autism and Asperger Syndrome - Preparing for adulthood (2nd ed.). London: Routledge.

Hsiao, Y. J. (2016). Pathways to mental health-related quality of life for parents of children with autism spectrum disorder: roles of parental stress, children's performance, medical support, and neighbour support. Research in Autism Spectrum Disorders, 23, 122-130. doi.org/10.1016/j.rasd.2015.10.008

Husserl, E. and D. Welton (1999). The Essential Husserl: basic writings in transcendental phenomenology. Indiana, Indiana University press.

Hurlbutt, K., & Chalmers, L. (2002). Adults With Autism Speak Out:Perceptions of Their Life Experiences. Focus on Autism and Other Developmental Disabilities, 17(2), 103-111. doi:10.1177/10883576020170020501

Idring, S., Lundberg, M., Sturm, H., Dalman, C., Gumpert, C., Rai, D., & Magnusson, C. (2015). Changes in Prevalence of Autism Spectrum Disorders in 2001–2011: Findings from the Stockholm Youth Cohort. Journal of Autism and Developmental Disorders, 45(6), 1766-1773. doi:10.1007/s10803-014-2336-y.

Im, D. (2016). Template to perpetrate: an update on violence in autism spectrum disorder. Harvard Review of Psychiatry, 24, 14-35.

Jackson, L. (2016). Asperger syndrome and bipolar disorder: a personal understanding. Paper presented at the Autism and Mental Health Conference, Manchester.

Johnson, S., Wood, S., Paul, M., Osborn, D. P., Wearn, E., Loyd-Evans, Killaspy, H., Totman, B, Araya, R., Burton, E., Sheehan, B., Hundt, G., Wellman, N. and Nolan, F., (2011). Inpatient mental health staff morale: a national investigation. Retrieved from: http://www.nets.nihr.ac.uk/__data/assets/pdf_file/0020/64532/FR-08-1604

Jones, R. S. P., & Meldal, T. O. (2001). Social Relationships and Asperger's Syndrome: A Qualitative Analysis of First-Hand Accounts. Journal of Intellectual Disabilities, 5(1), 35-41.

Joshi, G., Wozniak, J., & Petty C. (2013). Psychiatric comorbidity and functioning in a clinically referred population of adults with autism spectrum disorders: a comparative study. Journal of Autism and Developmental Disorders, 43, 1314–1325.

Jury, A., Lai, J., Tuason, C., Koning, A., Smith, M., Boyd, L., Gruar, A. (2019). People who experience seclusion in adult mental health inpatient services: An examination of health of the nation outcome scales scores. International Journal of Mental Health Nursing, 28(1), 199-208. doi:10.1111/inm.12521

Kahng, S., Iwata, B. A., & Lewin, A. B. (2002). Behavioural Treatment of Self-Injury, 1964 to 2000. American Journal on Mental Retardation, 107(3), 212-221. doi:10.1352/0895-8017(2002)10

Kanner, L. (1943) Autistic disturbances of affective contact. The Nervous child. 2, 217-250.

Kanner, L. (1973). Childhood psychosis: Initial studies and new insights. New York: John Wiley and Sons.

keller, T., Ramisch, J., & Carolan, M. (2014). Relationships of Children with Autism spectrum disorders and their fathers. The Qualitative Report, 19(66), 1-15.

Kelly, A., & Barnes-Holmes, D. (2013). Implicit attitudes towards children with autism versus normally developing children as predictors of professional burnout and psychopathology. Research in Developmental Disabilities, 34(1), 17-28. doi:https://doi.org/10.1016/j.ridd.2012.07.018

Kennedy, M. (2015). Changes to the Mental Health Act 1983 and what this means for services. Paper presented at the Autism and Mental Health Conference, London.

Kiernan, J. (2017). Commentary on "A family's battle to understand 'challenging behaviour'. Tizard Learning Disability Review, 22(2).

King, C., & Murphy, G. (2014). A Systematic Review of People with Autism Spectrum Disorder and the Criminal Justice System. Journal of Autism & Developmental Disorders, 44(11), 2717-2733. doi:10.1007/s10803-014-2046-5

Kochenderfer-Ladd. B. and Skinner, K. (2002) Children's Coping Strategies: Moderators of the Effects of Peer Victimization. Developmental Psychology, 38, 267-278. http://dx.doi.org/10.1037/0012-1649.38.2.267

Kumagami, T., & Matsuura, N. (2009). Prevalence of pervasive developmental disorder in juvenile court cases in Japan. Journal of Forensic Psychiatry, 20(6), 974-987. Laing, R.D. (1965). The Divided Self. Harmondsworth: Penguin Books.

Lai, M., & Baron-Cohen, S. (2015). Identifying the lost generation of adults with autism spectrum condition. The Lancet Psychiatry, 2(11), 1013-1027. doi:https://doi.org/10.1016/S2215-0366(15)00277-1

Lakin, J. L., Chartrand, T. L., & Arkin, R. M. (2008). I Am Too Just Like You: Nonconscious Mimicry as an Automatic Behavioural Response to Social Exclusion Psychological Science, 19(8), 816-822. doi-org.ezproxy.herts.ac.uk/10.1111/j.1467-9280.2008. 02162.x

Längle, G., Baum, W., Wollinger, A., Renner, G., U'ren, R., Schwarzler, F., & Eschweiler, G. W. (2003). Indicators of quality of in-patient psychiatric treatment: the patients' view. International Journal for Quality in Health Care, 15, 213-221.

Langstrom, N., Grann, M., Ruchkin, V., Sjostedt, G. and Fazel, S. (2009). Risk factors for violent offending in autism spectrum disorder: a national study of hospitalized individuals. Journal of Interpersonal Violence, Vol. 24 No. 8, pp. 1358-70.

Lerner, M., Haque, O., Northrup, E., Lawer, L., & Bursztajn, H. (2012). Emerging perspectives on adolescence and young adults with high functioning autism spectrum disorders, violence and criminal law. The Journal of the American Academy of Psychiatry and the Law, 40, 177-190.

Lever, A. G., & Geurts, H. M. (2016). Psychiatric co-occurring symptoms and disorders in young, middle-aged, and older adults with autism spectrum disorder. Journal of Autism and developmental disorders and Developmental Disorders, 46(6), 1916-1930. doi: https://doi-org.ezproxy.herts.ac.uk/10.1007/s10803-016-2722-8

Lidstone, J., Uljarevic, M., Sullivan, J., Rodgers, J., McConachie, H., Freeston, M., Le Couteur, A, Prior, M & Leekam, S. (2014). Relations among restricted and repetitive behaviours, anxiety and sensory features in children with autism spectrum disorders. Research in Autism Spectrum Disorders, 8, 82–92.

Lincoln, Y, & Guba, E. (1985). Naturalist Inquiry. California: Sage.

Lobar, S. L. (2016). DSM-V Changes for Autism Spectrum Disorder (ASD): Implications for Diagnosis, Management, and Care Coordination for Children with ASDs. Journal of Paediatric Health Care, 30(4), 359-365. doi.org/10.1016/j.pedhc.2015.09.005

Luciano, C., Keller, R., & Politi, P. (2014). Misdiagnosis of high function autism spectrum disorders in adults: an Italian case series. Autism, 4, 131.

MacLeod, A., et al. (2017). "'Here I come again': the cost of success for higher education student diagnosed with autism." International Journal of inclusive education.

MacLeod, A., Lewis, A., & Robertson, C. (2013). 'Why should I be like bloody Rain Man?!' Navigating the autistic identity. British Journal of Special Education, 40(1), 41-49. doi:10.1111/1467-8578.12015

Maisel, K. G. Stephenson, M. South, J. Rodgers, M. H. Freeston, & S. B. Gaigg, (2016). Modelling the Cognitive Mechanisms Linking Autism Symptoms and Anxiety in Adults. Journal of Abnormal Psychology, 125(5), 692–703.

Magiati, I., Ong, C., Xin Yi Lim, Wen-Li Tan, J., Yi Lin Ong, A., Patrycia, F., Shuen Sheng Fung, D, Min Sung, Poon, K & Howlin, P. (2016, Vol. 20(3)). Anxiety symptoms in young people with autism spectrum disorder attending special schools: Associations with gender, adaptive functioning and autism symptomatology. Autism, 20 (3), 306–320.

Malfait, S., Vandewalle, J., Eeckloo, K., Colman, R., & Van Hecke, A. (2017). The Development and Validation of the Patient Participation Culture Tool for Inpatient Psychiatric Wards (PaCT-PSY). Archives of Psychiatric Nursing, 31(5), 463-469. doi:10.1016/j.apnu.2017.06.010

Maloret, P., & Scott, T. (2017). Don't ask me what's the matter, ask me what matters: Acute mental health facility experiences of people living with autism spectrum conditions. Journal of Psychiatric and Mental Health Nursing, n/a-n/a. doi:10.1111/jpm.12438

Mandell, D. S. (2008). Psychiatric Hospitalization Among Children with Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders, 38*(6), 1059-1065. doi:10.1007/s10803-007-0481-2.

Mannion, A., & Leader, G. (2013). Comorbidity in Autism Spectrum Disorder: A Literature Review. Research in Autism Spectrum Disorders (7), 1595-1616.

Matson, J., & Williams, L. (2013). Differential diagnosis and comorbidity: distinguishing autism from other mental health issues. Neuropsychiatry, 3(2), 233-243.

Maras, K. and Bowler, D. (2010). The cognitive interview for eyewitnesses with autism spectrum disorder. Journal of Autism and Developmental Disorders, 40, 1350-1360.

Markowitz, F.E. (2005). Sociological models of recovery. In R. Ralph & P. Corrigan (Ed.), Recovery in mental illness: Broadening our understanding of wellness (pp. 85–100). Washington DC: American Psychological Association.

Markowitz, F. E., Angell, B., & Greenberg, J. S. (2011). Stigma, Reflected Appraisals, and Recovery Outcomes in Mental Illness. Social Psychology Quarterly, 74(2), 144-165. doi:10.1177/0190272511407620

Marriage, G. M., Miles, T., Stokes, D., & Davey, M. (1993). Clinical research implications of the cooccurrence of Asperger's and Tourette syndromes. Australian and New Zealand Journal of Psychiatry, 27, 666-672.

Marston, G. M., & Clarke, D. J. (1999). Making contact with bereavement and Asperger's syndrome. Irish Journal of Psychological Medicine, 16(One), 29 to 31.

Martins, Y., Young, R. L., & Robson, D. C. (2008). Feeding and Eating Behaviours in Children with Autism and Typically Developing Children. Journal of Autism and Developmental Disorders, 38(10), 1878-1887. doi:10.1007/s10803-008-0583-5

Marvel, M. K., Epstein R. M., Flowers, K., Beckman, H. B. (1999). Soliciting the patient agenda: have we improved? The Journal of the American Medical Association, 281, 283–287.

Mason, J. (2014). Qualitative Researching (2nd ed.). London: Sage.

May, T., Cornish. K., Conduit. R., Rajaratnum. S. & Rinehart. N., (2015). Sleep in high functioning children with autism: longitudinal developmental change and associations with behaviour problems. Behavioural sleep medicine, 13(1), 2-18.

Mazurek, M. O. (2014). Loneliness, friendship, and well-being in adults with autism spectrum disorders. Autism, 18(3), 223-232. doi:10.1177/1362361312474121

McCrae, N. (2014). Protected engagement time in mental health inpatient units. Nurse Manage, 21(1).

McSkimming, S., Hodges, M., Super, A., Driever, M., Schoessler, M., Franey, S. G. and Lee, M. (1999). The Experience of Life-Threatening Illness: Patients' and Their Loved Ones' Perspectives. Journal of Palliative Medicine, 2(2), 173-184.

McWilliams, N. (1994). Psychoanalytic diagnosis. New York: The Guilford Press.

Mengoni, S. E., Gates, B., Parkes, G., Wellsted, D., Barton, G., Ring, H., Khoo, M., Monji-Patel, D., Friedli, K,. Zia, A,. Irvine, L., & Durand, M.-A. (2016). Wordless intervention for people with epilepsy and learning disabilities (WIELD): a randomised controlled feasibility trial. BMJ Open, 6(11). doi:10.1136/bmjopen-2016-012993

Menzies, L. (1959). The functions of social systems as a defence against anxiety: a report on the study of the nursing service of a general hospital. Human relations, 13, 95-121.

Microsoft. (2017). About our autism hiring program. Retrieved from https://www.microsoft.com/en-us/diversity/inside-microsoft/cross-disability/hiring.aspx

Milton, D., & Sims, T. (2016). How is a sense of well-being and belonging constructed in the accounts of autistic adults? Disability & Society, 31(4), 520-534. doi:10.1080/09687599.2016.1186529

MIND (2006). Ward Watch: Mind's Campaign to Improve Hospital Conditions for Mental Health Patients. Retrieved from: London: https://www.bl.uk/.../ward-watch-minds-campaign-to-improve-hospital-conditions-for.

MIND (2013). Mental health crisis care: physical restraint in crisis - A report on physical restraint in hospital settings in England. Retrieved from London: https://www.mind.org.uk/media/197120/physical_restraint_final_web_version.

MIND (2018). Coping with the loneliness. Retrieved from: https://www.mind.org.uk/information-support/tips-for-everyday-living/loneliness.

McKee, H., & Porter M., (2009). Playing a good game: ethical issues in researching MMOGs and Virtual Worlds. International Journal of Internet Research Ethics, 2(1), 5.

Moor, J. (2008). Playing, Laughing and Learning with children on the Autism Spectrum (2nd ed.). London: Jessica Kingsley.

Moher D., Liberati A., Tetzlaff J & Altman D.(2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. *journal.pmed, 6*(7). doi:doi:10.1371/1000097

Mouridsen, S., Rich, B., Isager, T., & Nedergaard N. (2008). Pervasive developmental disorders and criminal behaviour: a case control study. International Journal of Offender Therapy and Comparative Criminology, 52, 196-205.

Murphy, D., & Mullens, H. (2017). Examining the experiences and quality of life of patients with an autism spectrum disorder detained in high secure psychiatric care. Advances in Autism, 3(1), 3-14. doi:10.1108/AIA-02-2016-0006.

Narendorf, S., Shattuck, P., & Sterzing, P. (2011). Mental health service use among adolescents with an autism spectrum disorder. Psychiatric Services, 62(8), 975-978.

National Development Team for Inclusion. (2012). Reasonably Adjusted? Mental Health Services for People with Autism and People with Learning Disabilities. Retrieved from: https://www.ndti.org.uk/uploads/.../NHS

National Institute for Health and Care Excellence (2014) Autism; Quality standard [QS51] London: DOH.

National Institute for Health and Care Excellence. (2017). Violence and aggression overview. London: DOH Retrieved from: http://pathways.nice.org.uk/pathways/violence-and-aggression.

National Research Authority. (2017). Planning and improving research. Retrieved from: https://www.hra.nhs.uk/planning-and-improving-research/.

Network Autism. (2015). Police interviewing of autistic witnesses and defendants: what is best practice?

NHS. (1990). NHS and Community Care Act. Retrieved from London: https://www.legislation.gov.uk/id/ukpga/

NHS Digital. (2017). Mental Health Services Monthly Statistics: Final September 2017. Retrieved from http://digital.nhs.uk/catalogue/PUB30177

NHS England. (2015). Transforming Care for People with Learning Disabilities - Next Steps. Retrieved from London: https://www.england.nhs.uk/wp-content/uploads/2015/.../transform-care-nxt-

NHS England. (2018). The 6C's. Retrieved from: https://www.england.nhs.uk/leadingchange/about/the-6cs/

NHS Health Research Authority. (2017). Questions and Answers – Mental Capacity Act 2005, Core principles of the Act. from NHS: https://www.hra.nhs.uk/planning-and-improving-research/.../mental-capacity-act

Nissen, J. M., & Haveman, M. J. (1997). Mortality and avoidable death in people with severe self-injurious behaviour: Results of a Dutch Study. Journal of Intellectual and Disability Research, 41, 252–257.

Northcote, M. (2012). Selecting Criteria to Evaluate Qualitative Research. Education Papers and Journal Articles (8).

O'Brien, J. (2010). Improving mental health services for people with intellectual disabilities: Service users' views. Advances in Mental Health and Intellectual Disabilities, 4(4), 40-47.

Ohl, A., Grice Sheff, M., Small, S., Nguyen, J., Paskor, K., & Zanjirian, A. (2017). Predictors of employment status among adults with Autism Spectrum Disorder. Work, 56(2), 345-355.

Orth, U. (2017). The Family Environment in Early Childhood Has a Long-Term Effect on Self Esteem: A Longitudinal Study from Birth to Age 27 Years. Journal of Personality and Social Psychology.

Palucka, A., & Lunsky, Y. (2007). Review of Inpatient Admissions of Individuals with Autism Spectrum Disorders to a Specialized Dual Diagnosis Program. JOURNAL ON DEVELOPMENTAL DISABILITIES, 13(1), 205-210.

Parkes, C., Samuels S., Hassiotis A., Lynggaard, H. & Hall, I. (2007). Incorporating the views of service users in the development of an integrated psychiatric service for people with learning disabilities. British Journal of Learning Disabilities, 35(1), 23-29.

Passwerk. (2017). Passwerk Qualities. Retrieved from http://www.passwerk.be/en/qualities

Pellicano, L. (2016). Involving autistic people in research: an interview with Prof Liz Pellicano. Paper presented at the XI Autism-Europe International Congress, Edinburgh.

Pelton, M. K., & Cassidy, S. A. (2017). Are autistic traits associated with suicidality? A test of the interpersonal-psychological theory of suicide in a non-clinical young adult sample. Autism Research, 10(11), 1891-1904. doi:10.1002/aur.1828

Pescosolido, B. A. (2013). The Public Stigma of Mental Illness: What do we think; What do we know; What can we prove? Journal of Health and Social Behaviour, 1.

Petales, M., et al. (2015). "Typicality and subtle difference in sibling relationships: experiences of adolescents with autism." Journal of Child and Family Studies 24: 38-49.

Powell, E. (1961). The Water Towers speech. Paper presented at the National Association for Mental Health, Brighton.

Power, E, Clarke, M, Kelleher, I. (2015) The association between economic inactivity and mental health among young people: A longitudinal study of young adults who are not in employment, education or training. Irish J Psycholog Med. 32: 155–160

Puddicombe, J., & Lunsky, Y. (2007). Aggression and dual diagnosis: Implications for Ontario's developmental services. Journal on Developmental Disabilities, 13, 191-196.

Prior, A., Fenger-Grøn, M., Larsen, K. K., Larsen, F. B., Robinson, K. M., Nielsen, M. G., Christensen, K., Mercer, S. & Vestergaard, M. (2016). The Association Between Perceived Stress and Mortality Among People with Multimorbidity: A Prospective Population-Based Cohort Study. American Journal of Epidemiology, 184(3), 199-210. doi:10.1093/aje/kwv324

Public Health England. (2016). Autism Self-Assessment Exercise – 2016 - Detailed report and thematic analyses. London.

QSR International (Producer). (2017, 2017). NVivo 11. [Data Analyse]

Radcliffe, M. (2006). Meanwhile, over in the corner: Reclaiming care. Psychiatric and Mental Health Nursing, 13, 453-455.

Randell, E., McNamara, R., Delport, S., Busse, M., Hastings, R. P., Gillespie, D., Warren, G. (2019). "Sensory integration therapy versus usual care for sensory processing difficulties in autism spectrum disorder in children: study protocol for a pragmatic randomised controlled trial." Trials U6 - Journal Article 20(1): 113.

Ree, J. (1998). Heidegger: history and truth in being and time. New York, Phoenix Press.

Reeve, J., Lloyd-Williams, M., Payne, S., and Dowrick, C. (2009). Insights into the impact of clinical encounters gained from personal accounts of living with advanced cancer. Primary Health Care Research & Development, 10, 357-367.

Rey, J. H. (1994). Universals of psychoanalysis in the treatment of psychotic and borderline states. London: Free Association Books.

Ricoeur, P., & Embree, L. E. (1967). Husserl: An Analysis of His Phenomenology. Evanston: Illinois.: Northwestern University Press.

Rieffe, C., Oosterveld, P., Terwogt, M. M., Mootz, S., Leeuwen, E. V., & Stockmann, L. (2011). Emotion regulation and internalizing symptoms in children with autism spectrum disorders. Autism, 15(6), 655-670. doi:10.1177/1362361310366571

Righi, G., Benevides, J., Mazefsky, C., Siegel, M., Sheinkopf, S. J., Morrow, E. M. (2018) Developmental Disabilities Inpatient Research, C. (2018). Predictors of Inpatient Psychiatric Hospitalization for Children and Adolescents with Autism Spectrum Disorder. *Journal of Autism & Developmental Disorders, 48*(11), 3647-3657. doi:10.1007/s10803-017-3154-9

Robertson, A. E., Stanfield, A. C., Watt, J., Barry, F., Day, M., Cormack, M., & Melville, C. (2018). The experience and impact of anxiety in autistic adults: A thematic analysis. *Research in Autism Spectrum Disorders, 46*, 8-18. doi:10.1016/j.rasd.2017.11.006

Rodgers, J., Glod, M., Connolly, B., & McConachie, H. (2012). The Relationship Between Anxiety and Repetitive Behaviours in Autism Spectrum Disorder. Journal of Autism and Developmental Disorders, 42: 2404–2409. doi:10.1007/s10803-012-1531-y

Rogers, A., & Pilgrim, D. (2014). Sociology of Mental Health and Illness. Maidenhead, McGraw-Hill Education.

Rosenfield, S. (2012). Triple Jeopardy? Mental Health at the intersection of gender, race and class. Social Science & Medicine, 74(1), 1791-1796.

Rosenfield, S., & Wenzel, S. (1997). Social Networks and Chronic Mental Illness: A Test of Four Perspectives. Social Problems, 44(2), 200-216. doi:10.2307/3096942

Ross, T. (2009). Constructing a Virtual World as a Research Tool

Ross, T. Lessons Learned from the First Iteration in the Development of Greenland. Paper presented at the 2009 International Conference on Computational Science and Engineering.

SAP. (2017). SAP Company information. Retrieved from https://www.sap.com/corporate/en/company.html

Sasson, N. J., Faso, D. J., Nugent, J., Lovell, S., Kennedy, D. P., & Grossman, R. B. (2017). Neurotypical Peers are Less Willing to Interact with Those with Autism based on Thin Slice Judgments. Scientific Reports, 7, 40700. doi:10.1038/srep40700

Scambler, G. (2009). Health-related stigma. Sociology of Health & Illness, 31(3), 441-455. doi:10.1111/j.1467-9566.2009.01161. x.

Schalkwyk, G., Peluso, F., Qayyum, Z., McPartland, J., & Volkmar, F. (2015). Varieties of Misdiagnosis in ASD: An Illustrative Case Series. Journal of Autism & Developmental Disorders, 45(4), 911-918. doi:10.1007/s10803-014-2239-y

Schleiermacher, F. (1998). Hermeneutics: the handwritten manuscripts. Atlanta: Scholars Press.

Schleiermacher, F., & Kimmerle, H. (1977). Hermeneutics: The Handwritten Manuscripts (J. Duke and J. Forstman, trans.). Atlanta: Scholars Press.

Schröder, A., Ahlström, G.; Larsson, B. W. (2006). Patients' perceptions of the concept of the quality of care in the psychiatric setting: a phenomenographic study. Journal of Clinical Nursing, 15, 93–102.

Second Life (2019) Retrieved from: http://go.secondlife.com/landing.

Shaw, R. (2010). Interpretive phenomenological analysis. In A. Forrester (Ed.), Doing qualitative research in psychology: a practical guide. London Sage: Sage.

Sherwood, G. (2015). Perspectives: Nurses' expanding role in developing safety culture: Quality and Safety Education for Nurses – competencies in action. Journal of Research in Nursing, 20(8), 734-740. doi:10.1177/1744987115621142

Shinebourne, P., & Smith, J. (2010). The communicative power of metaphors: an analysis and interpretation of metaphors in accounts of the experience of addiction. Psychology and Psychotherapy, 83, 59-73.

Siegal, M., & Gabriels, R. (2014). Psychiatric hospital treatment of children with autism and serious behavioural disturbance. *Child and adolescent psychiatric clinics, 23*, 125-142. doi:doi.org/10.1016/j.chc.2013.07.004.

Silverman. (2014). Interpreting Qualitative Data (5th ed.). London: Sage.

Simonoff, E., Jones, C. R. G., Baird, G., Pickles, A., Happé, F., & Charman, T. (2013). The persistence and stability of psychiatric problems in adolescents with autism spectrum disorders. Journal of Child Psychology and Psychiatry, 54(2), 186-194. doi:10.1111/j.1469-7610.2012. 02606.x

Slemon, A., Jenkins, E., & Bungay, V. (2017). Safety in psychiatric inpatient care: The impact of risk management culture on mental health nursing practice. Nursing Inquiry, 24(4), e12199-n/a. doi:10.1111/nin.12199

Slevin, E., McConkey, R., Truesdale-Kennedy, M. & Taggart, L. (2008). People with learning disabilities admitted to an assessment and treatment unit: impact on challenging behaviours and mental health problems. Journal of Psychiatric and Mental Health Nursing, 7(15), 537-546.

Smith, J., & Osborn, M. (2008). Interpretative phenomenological analysis. In J. A. Smith (Ed.), Qualitative Psychology: A Practical Guide to Methods. London: Sage.

Smith, J. A. (2016). Sensory Processing as a Predictor of Feeding/Eating Behaviours in Children with Autism Spectrum Disorder. The Open Journal of Occupational Therapy, 4(2).

Smith, J. A., Flowers, P., & Larkin, M. (2013). Interpretative Phenomenological Analysis - Theory, Method and Research. London: Sage.

Spencer, L., Ritchie, J., Lewis, J., & Dillon, L. (2003). Quality in qualitative evaluation: A framework for assessing research evidence. London: Cabinet Office.

Spencer, S., Stone, T., Kable, A., & McMillan, M. (2019). Adolescents' experiences of distress on an acute mental health inpatient unit: A qualitative study. International Journal of Mental Health Nursing, 28(3), 712-720. doi:10.1111/inm.12573

Starks, H. and H. Trinidad (2007). "Choose your method: a comparison of phenomenology, discourse analysis, and grounded theory." Qualitative health research 17(10): 1372-1380.

Stenhouse, R. C. (2011). 'They all said you could come and speak to us': patients' expectations and experiences of help on an acute psychiatric inpatient ward. Journal of Psychiatric and Mental Health Nursing, 18(1), 74-80. doi:10.1111/j.1365-2850.2010.01645. x.

Stephensen, J. and C. Adams (2016). "The social communication experience of children with autism in mainstream school." Good Autism Practice 17(To): 43-54.

Stewart, M., (2006). Presentation of depression in autism and Asperger syndrome: a review. Autism, 10, 103-160.

Stoddart, K., Burke, L., & King, R. (2012). Asperger Syndrome in Adulthood - A Comprehensive Guide for Clinicians. London: Norton.

Suglia, S. F., Sapra, K. J., & Koenen, K. C. (2015). Violence and Cardiovascular Health. American Journal of Preventive Medicine, 48(2), 205-212. doi: 10.1016/j.amepre.2014.09.013

Summers, J., Shahrami, A., Cali, S., D'Mello, C., Kako, M., Palikucin-Reljin, A., Savage, M,. Shaw, O. & Lunsky, Y. (2017). Self-Injury in Autism Spectrum Disorder and Intellectual Disability: Exploring the Role of Reactivity to Pain and Sensory Input. Brain Sciences, 7(11), 140.

Strandh, M, Winefield, A, Nilsson, K. (2014) Unemployment and mental health scarring during the life course. Eur J Public Health. 24: 440–445.

Strauss, A. L. and Glaser, B. G. (1975) Chronic Illness and the Quality of Life, Saint Louis, G. V. Mosby and Co.

Symons, F. J. (2011). Self-injurious behaviour in neurodevelopmental disorders: Relevance of nociceptive and immune mechanisms. Neuroscience & Biobehavioural Reviews, 35(5), 1266-1274. doi.org/10.1016/j.neubiorev.2011.01.002

The American Psychiatric Association. (2013). Diagnostic and Statistical Manual 5. Washington: The American Psychiatric Association

The American Psychologist Association. (2018). Anxiety. Retrieved from: http://www.apa.org/topics/anxiety/

The National Autistic Society. (2012). What Is Asperger's. Retrieved from: http://www.autism.org.uk/About-autism/Autism-and-Asperger-syndrome-an-introduction/What-is-Asperger-syndrome.aspx

The National Autistic Society. (2015). Gender and autism. Retrieved from: http://www.autism.org.uk/About-autism.

The National Autistic Society. (2017). About Autism. Retrieved from: http://www.autism.org.uk/about.aspx.

The National Autistic Society (2018). Little facts about autism. Retrieved from: http://www.autism.org.uk/About-autism

The National Autistic Society. (2018). Sensory Differences. Retrieved from: http://www.autism.org.uk/sensory

The National Institute for Health and Care Excellence. (2015). Violence and Aggression: Short Term Management in Mental Health, Health and Community Settings. Department of Health.

The World Health Organisation. (2010). MH GAP Intervention Guide for mental, neurological and substance use disorders in non-specialized health settings. Retrieved from Geneva:

The World Health Organisation. (2017). ATLAS - Global Resources for Persons with Intellectual Disabilities. Retrieved from Switzerland:

The World Health Organisation. (2017). Autistic Spectrum Disorders. Retrieved from: http://www.who.int/mediacentre/factsheets/autism-spectrum-disorders/en/

Tuffour, I. (2017). A Critical Overview of Interpretative Phenomenological Analysis: A Contemporary Qualitative Research Approach. Journal of Healthcare Communications, 2(52). doi:10.4172/2472-1654.100093.

Tullis, C. A. and A. N. Zangrillo (2013). Sexuality education for adolescents and adults with autism spectrum disorders. Psychology in the Schools 50(9): 866-875.

University of Hertfordshire. (2017). Data Management Policy (Vol. UPR IM12). Hatfield.

Van Steensel, F. J. A., Bögels, S. M., & Dirksen, C. D. (2012). Anxiety and quality of life: Clinically anxious children with and without autism spectrum disorders compared. Journal of Clinical Child & Adolescent Psychology, 53(41), 731–738. doi.org/10.1080/15374416.2012

Virtanen, P, Hammarstrom, A, Janlert, U. (2016) Children of boom and recession and the scars to the mental health: A comparative study on the long-term effects of youth unemployment. Int J Equity Health. 15.

Vos, A., Markar, N., & Bartlett, L. (2007). A survey on the learning disability service user's view of admission to an acute psychiatric ward. British Journal of Developmental Disabilities, 53(1), 71-76.

Wang, Y., & Hamilton, A. (2012). Social top-down response modulation (STORM): a model of the control of mimicry in social interaction. Front Hum Neurosci, 6(153). doi:10.3389/fnhum.2012.00153

Williams, E. (2004). "Who really needs a 'theory 'of mind? An interpretive phenomenological analysis of the autobiographical writings of ten high-functioning individuals with an autism spectrum disorder." Theory and psychology 40: 704-724.

Whetzel, M. (2014). Interviewing tips for applicants with autism spectrum disorder. Journal of Vocational Rehabilitation, 40(To), 155-159.

Weiss, J. A., Cappadocia, M. C., MacMullin, J. A., Viecili, M., & Lunsky, Y. (2012). The impact of child problem behaviors of children with ASD on parent mental health: The mediating role of acceptance and empowerment. Autism, 16(3), 261-274. doi:10.1177/1362361311422708

Weiss, M., Ramakrishna, J., & Somma, D. (2006). Health-related stigma: rethinking concepts and interventions. Psychology, Health and Medicine, 11, 277–287.

Whittaker, A., & Williamson, R. (2011). Research project plans and literature reviews for Nursing Students. Exeter: Learning Matters.

Wigham, S., Rodgers, J., South, M., McConachie, H., & Freeston, M. (2015). The Interplay Between Sensory Processing Abnormalities, Intolerance of Uncertainty, Anxiety and Restricted and Repetitive Behaviours in Autism Spectrum Disorder. Journal of Autism and Developmental Disorders, 45, 943–952. doi:10.1007/s10803-014-2248-x

Williams, J. G., Higgins, J. P. T., & Brayne, C. E. G. (2006). Systematic review of prevalence studies of autism spectrum disorders. Archives of Disease in Childhood, 91(1), 8-15. doi:10.1136/adc.2004.062083

Willig, C. (2008). Introducing qualitative research in psychology: adventures in theory and methods. Berkshire: Open University Press.

Willis Towers Watson (2016). Global. Retrieved from https://www.willistowerswatson.com/en-GB

Wing, L., & Gould, J. (1978). Systematic recording of behaviours and skills of retarded and psychotic children. Journal of autism and childhood schizophrenia, Eight, 79-97.

Wolfensberger, W. (1972). The Principle of Normalisation in Human Management Services. Toronto: National Institute of Mental Retardation.

Wood, D. and Pistrang, N. (2004). A safe place? Service users" experiences of an acute mental health ward. Journal of Community and Applied Social Psychology, 14(1).

Woodbury-Smith, MR, Clare, IC & Holland, AJ. (2006) High functioning autistic spectrum disorders, offending and other law-breaking: findings from a community sample. The Journal of Forensic Psychiatry & Psychology 17: 108–120.

World Health Organisation (2013) Autism spectrum disorders & other developmental disorders - From raising awareness to building capacity. Retrieved from: https://www.who.int/mental_health/maternal-child/autism_report/en/.

World Health Organisation. (2017). International Classification of Diseases (ICD-11). Retrieved from: www.who.int/classifications/icd/

World Health Organisation. (2017) Mental Health ATLAS 2017. Retrieved from: https://www.who.int/mental_health/evidence/atlas/mental_health_atlas_2017/en/.

Wyder, M. E. C., Crompton, D.. McArthur, L., Delaforce, C., Dziopa, F., Ramon, S., Powell, E. (2017). Nurses' experiences of delivering care in acute inpatient mental health settings: A narrative synthesis of the literature. International Journal of Mental Health Nursing. doi:10.1111/inm.12315

Yi-Shin Chang, Owen, J., Desai, S., Hill, S., Arnett, A., Harris, J., & Mukherjee, P. (Producer). (2014, 2018). Autism and Sensory Processing Disorders: Shared White Matter Disruption in Sensory Pathways but Divergent Connectivity in Social-Emotional Pathways. Retrieved from https://doi.org/10.1371/journal.pone.0103038

Young, D. K. W., Ng, P. Y. N., Cheng, D., & Leung, C. H. (2018). A Vocational Recovery Model for Young People with Mental Illness: A Pretest–Posttest. Research on Social Work Practice. doi:10.1177/1049731518757031

Zablotsky, B., Black, L. I., Maenner, M. J., Schieve, L. A., & Blumberg, S. J. (2015). Estimated Prevalence of Autism and Other Developmental Disabilities Following Questionnaire Changes in the 2014 National Health Interview Survey. Natl Health Stat Report (87), 1-20.

Zimmerman, D., Ownsworth, T., O'Donovan, A., Roberts, J., & Gullo, M. J. (2017). Associations between executive functions and mental health outcomes for adults with autism spectrum disorder. Psychiatry Research, 253, 360-363. doi:10.1016/j.psychres.2017.04.023

Zwanenburg, W. (2016). Why interviews exclude people with autism. www.evenbreak.co.uk.

Appendices

Appendix 1 - Literature review characteristics table

Reference	Aim	Type of service	Number of participants	Participant demographics	Methodologies	Format of findings	Limitations	Key Findings
Acker (2018)	The lived experience of male adolescents with ASC who suffer from anxiety.	Not hospital based	14 participants all with an ASC diagnosis.	Ages from 13-18, all male, participants were excluded if they '*lacked verbal the or cognitive ability to take part*'.	Semi-structured interviews	Interpretive Phenomenological analysis, focusing on personal and sense making of a context.	The author indicates that anxiety is more *common* in adolescents with higher functioning ASC, thus justifying excluding those with lower intellectual abilities. It could be challenged that the evidence for this claim (one paper from 2008) is questionable.	This paper offers further insights into the relationship between ASC and anxiety. Additionally, the ability or strategies employed to cope.

Bunyan et al, (2017)	To explore the patient's experience in mental health hospitals and more specifically on rehabilitation wards.	Three rehabilitation wards (one locked and two open)	22 inpatients from the three wards participated.	The participants mean age was 39 and ranged between 19-62. 59% were men. The majority have been diagnosed with schizophrenia and 73% had a secondary diagnosis, such as substance misuse, personality disorder or mild learning disabilities	Qualitative data was derived from focus group meetings led by service user researchers.	Themes	The data drive from the focus groups could have been followed up by semi-structured interviews to gain more insight and understanding into the identified themes	The prominent themes emerged were rules and routine, uncertainty and fear about the future, rigid structures, coercion by nurses including restrictions over patient leave or taking showers, and occasional aggression and here bullying by staff when applying the rules.

Reference	Aim	Type of service	Number of participants	Participant demographics	Methodologies	Format of findings	Limitations	Key Findings
Chaplin, et al (2006)	To explore prevalence and experience of violence on inpatient units. An audit approach	47 UK wide specialist learning disability and autism inpatient units (limited description)	585 practitioners 157 service users	Unknown	Mixed methods approach, questionnaires and semi-structured interviews. Descriptive statistical analysis and thematic analysis	Descriptive statistics Themes	Specific focus on prevalence and experience of violence. Limited demographic information known. Data did not provide meaningful understanding of experience.	The physical environments are frequently unsuitable, there is often poor communication between staff and service users. Low staff moral impacted by the culture of accepting violence and offending behaviour as part of the role.
Donner, et al (2010)	To explore service user, practitioner and service provider views of mainstream service provision Qualitative	Five different mainstream mental health inpatient units into locality areas.	Nine service users, nine family carers, for community nurses, seven service providers interviewed	Recruited up to two years post discharge. Inclusion of service users with ASC, no level of learning disability specified.	Semi structured interviews. Focus group with service providers. Interpretive phenomenological analysis-case-by-case analysis. Father description and evidence of credibility checking.	Themes presented with quotes to support.	Residential service not acute facility.	Positive aspects included the provision of respite, particularly for carers, and good basic care. These were outweighed by a perception of the admission as disempowering and lacking in flexible treatment provision. Accessing help emerged as a major problem, as well as the prospect of staff neglecting the specific needs of people with ID.

Reference	Aim	Type of service	Number of participants	Participant demographics	Methodologies	Format of findings	Limitations	Key Findings
Dunn, (2012)	To explore mental health provision for high functioning autistic adults in East Lancashire (UK)	Number unspecified, a range of mental health inpatient, community teams and specialist Asperger's teams	Questionnaires returned by 19 adults with ASC and 14 parents/ carers. Seven were interviewed and two kept diaries	All participants have an existing diagnosis or moving towards a diagnosis of ASC, over 18 years old, live in East Lancashire, or a parent or carer of an adult who has ASC.	Mixed methods, questionnaires, semi structured interviews and diaries	Descriptive statistics themes	Related to patient journeys through mental health systems and pathways to diagnosis, unspecified information regarding mental health inpatients services.	A training needs assessment found that most staff (70%) had little or no knowledge about autism and 77% felt that they would benefit from autism awareness training. Responses from people with autism who were able to access mainstream mental health support services appeared to indicate that a widespread lack of training and expertise in autism amongst mental health staff led to respondents receiving services which were felt to be ineffective, inappropriate and potentially harmful for this service user group.

Hall et al, (2006)	To explore the effectiveness of an integrated health and learning disability inpatient service	Integrated mental health and learning disability inpatient services	37	Unknown	By using a range of assessment tools/instruments the inpatient group were assessed at admission, discharge and 6 months post admission. The community group were assessed at the point of mental health crisis, after 9 weeks (the median admission time), and six months after the crisis point.	Descriptive statistics teams	Unspecific information regarding the credibility of the assessment tools being used and those assessing.	Inpatients and community groups had similar mental health problems, but inpatients had higher unmet needs and those lower functioning were at greater risk. Working with mainstream mental health services and across health and social service boundaries delivers effective mental health care for people with intellectual disabilities.

Reference	Aim	Type of service	Number of participants	Participant demographics	Methodologies	Format of findings	Limitations	Key Findings
Murphy and Mullens (2017).	An examination of how individuals with an ASC are represented in records of key risk management actions within high secure psychiatric care (i.e. seclusions and incompatibilities with other patients).	Mainstream mental health, high security.	127	121 non-ASC patients compared to 6 ASC diagnosed patients.	An observation of hospital data examining two key risk management actions for a group of individuals with an ASD is detained in one HSPC hospital. These include the number of formal incompatibilities with other patients and the number of, and hours in, seclusion. Both actions require extra staff and security provisions and can decelerate the rehabilitation and recovery process.	Descriptive statistics and thematic analysis.	Disproportionate number of non-ASC patients compared to a small number of ASC patients made comparisons difficult.	In addition to suggesting an overall increase in the general prevalence of ASC within the high security hospital compared to previous estimates, individuals with an ASC appear to have a disproportionately higher number of incompatibilities with other patients compared to those patients without an ASD and experience more and longer periods of seclusions.
Parkes et al, (2007)	To obtain views of service users of mainstream inpatient service, admission and integrated service provision.	Mainstream mental health and integrated inpatient service	All service users admitted to unit during a given period were considered eligible Phase 1 of the study: 15 service	Recruitment up to 3 years post discharge. Level of learning disability not specified Phase 1-six women, six men	Semi-structured interviews thematic approach to analysis. Evidence of multiple coding and credibility checking.	Themes reported with supporting quotes given.	Approach to thematic analysis not specified. Level of learning disability not stated.	People with learning disabilities reported what it was like to be looked after in general psychiatric wards and in a local psychiatric ward where four of the beds are for people

			users eligible, 12 interviewed Phase 2 of the study: 23 service users eligible, 19 interviewed	26 to 54 years of age (41 mean). Admitted 1 to 78 weeks (mean 15). Seven voluntary, five detained Phase 2 -12 women, seven men. 22-68 years of age (mean 39). Admitted 1 to 24 weeks (mean nine). 11 voluntary, 8 detained.				with learning disabilities. They found it frightening and things were not always explained very well. Most people said that they got on well with the other people in both types of ward and they felt that social contact with others was one of the most positive things about their admission.
Slevin et al, (2008)	This study describes the evaluation of an assessment and treatment unit for people with learning disabilities and ASC.	Specialist learning disability inpatient service	48	All had a clinical diagnosis of a learning disability, unspecified as to how many had a comorbidity of an ASC.	Behavioural and mental health assessment tools/instruments we used to measure behaviours are mental health problems across three-time periods.	Descriptive statistics and themes	Number of participants with associated mental health problems and ASC unspecified.	The analysis found significant reductions in challenging behaviours and mental health problems following admission to the unit. A number of issues of concern included: access to mental health services for people with learning disabilities, the need for robust community services and areas that require further research. The study found evidence supporting the value of the inpatient unit and how it may lessen distress in learning disabled people who are behaviourally disturbed. Nurses

								played a key role in the unit, but they need to make the support and caring they provide more visible. Nurses need to harness and make explicit the caring they provide for people with learning disabilities.
Spencer et al (2019)	An exploration of adolescent experiences of distress in an acute mental health inpatient units.	Adolescent inpatient mental health unit.	18 nurses and 7 adolescent inpatients	The inpatient participants were all over the age of 13, six of the seven were female	Non-participants observations were recorded using a critical incident technique framework. An interpretive descriptive method was used to analyse the observational data.	Three separate coding systems are described, and emergent themes are explained.	Low representation of inpatients especially male. Consensual issues appear to be the reason for this.	This study provides insight into how these young people attempt to cope with their distress, provides assistance to other adolescents that could help resolve their distress and enable them to develop coping strategies.
Robertson et al (2018)	An exploration of the experience and impact of anxiety in autistic adults.	Not hospital based	17 participants with an ASC diagnosis or the supporters of those with ASC.	Age range 19-60, mixed male/female. 10 participants with ASC and 7 supporters.	Semi-structured interviews	Thematic analysis	Relatively low representation of participants with ASC.	Provides a comparative view of participants with ASC and their supporters, although similarity of perceptions exist, differences are also evident, confirming the need to listen the lived experience and further research in this area.

Appendix 2 – Research Consent Form

Version Number 4, 22 August 2015

RESEARCH CONSENT FORM

Research aims:

This study aims to explore the lived experience of a person with an autistic spectrum condition (ASC) when being admitted to a mental health unit and to understand how this particular experiential phenomenon is understood from the perspective of people with ASC.

Principal researcher:

Paul Maloret (Principal Lecturer in Learning Disability Studies)

Address: University of Hertfordshire, Centre for Learning Disability Studies, College Lane Campus, University of Hertfordshire, Hatfield, Hertfordshire

Email:

Phone:

Participant consent:

Please initial each of the 6 points below

1.	I agree to participate in this research.	
2.	I have had the opportunity to ask any questions about the study.	
3.	I realise that I may withdraw from the study at any time, without giving a reason.	
4.	I have been given full information regarding the aims of the research and have been given information with the researcher's names on and a contact number and address if I require further information	
5.	All personal information provided by myself will remain confidential and no information that identifies me will be made publicly available. The exception to this confidentiality agreement is in the event of disclosure of poor/illegal practice in which case the Nursing and Midwifery Council - professional code of conduct will be adhered to.	
6.	I agree that my interview can be audio recorded and understand that this recording will be kept in a secure place.	

Print name: .....

Signed: .....

Date: .....

Statement by Investigator

I have explained this project and the implications of participation in it to this participant without bias and I believe that the consent is informed and that he/she understands the implications of participation.

Investigator's name: .....

Investigator's signature: ….....

Date: ….....

Appendix 3 – Participation Information Sheet

Version 4, 22 August 2015

PARTICIPATION INFORMATION SHEET

Study Title

Being a mental health inpatient: The experiences of adults with Autism Spectrum Conditions. A phenomenological study.

Invitation and brief summary

This study aims to explore the lived experience of a person with an autistic spectrum condition (ASC) whilst being admitted to a mental health unit and to understand how this particular experiential phenomenon is understood from the perspective of people with ASC. Additionally, it aims to explore how the former-patient perceived their role, whether they make sense of it as being treated, cared for or incarcerated or something completely different.

What is involved?

The researcher has for many years witnessed cases first-hand of the struggles incurred by people with Autism whilst they are away from their homes, friends and families and in acute mental health or learning disability settings. This study aims to gain the views and knowledge of what that experience is really like and the outcomes of the study will join a body of evidence which aims to support and improve practice within these mental health settings.

What would taking part involve?

This research involves an interview, lasting approximately 1hr, in which we will discuss your experiences of being patient within a mental health inpatient unit. Although there are some standard questions, it is more important to hear about your thoughts, feelings and experiences. The interview will either be conducted using a face to face interviewing in an environment that suits you. The interview will be one to one and will be completely confidential. However, if you feel necessary, you may request for another person to be present.

What are the possible benefits of taking part?

The benefits include helping health care professionals improve upon the patient experience and helping them to comprehend the nature of this experience from those who have the best understanding, i.e. those who have lived it. i.e. this information will be used to: (1) better understand the experience of those with ASC in mental health units (2) allow a more systemic and holistic understanding of how to care for those with ASC, (3) provide information to guide practitioners in training programs, and (4) lead to the better care of people with ASC whilst in mental health care. You will be notified of the final results and told how they will be disseminated.

What are the possible disadvantages and risks of taking part?

It is plausible that discussing your experiences of suffering from a mental illness could cause some distress. Therefore, great care will be taken to ensure that any potential distress is minimised. This will be addressed by providing information to you regarding the types of questions that will be asked and the areas of exploration prior to interviewing, thus allowing you to make an informed choice regarding your decision to take part. You

can break at any time, terminate the interview and refuse to answer any questions that you did not desire to and of course there is no obligation to take part in this study. It is unlikely that your participation in this study will cause you any distress, but just in case the following steps will take place. A debrief will follow each of the interviews, in which a review will take place to see how you found the process, and a debrief sheet detailing sources of support will be provided should you be interested.

What will happen after the interview?

The principles of the Helsinki Declaration (World Medical Association 2008) apply to research, which aim to protect the well-being of research participants, maintain the confidentiality of participants' personal data and ensure informed consent was gained. The interview recording will be stored on a password protected and encrypted USB drive and backed up on a password protected and secure computer. With this transcription common themes and ideas within yours and other former patient's experiences will be analysed to try to make sense of this phenomenon. You may be asked to meet for a second time to ensure that the researcher has interpreted your given information correctly. The data will be used as part of a Doctoral Thesis.

What if something goes wrong?

In the situation whereby, you wish to make a complaint about any aspect of the research, the first point of contact will be myself and the contact details below can be used. If however you wish a more formal complaint and a contact independent of the study is more suitable, please contact The Asperger's Social care Team @ asperger.team@hertfordshire.gov.uk or call 01442 453535, stating the nature of your compliant. All complaints will be given an immediate response and necessary action will be taken.

Contact details of Researcher:

Paul Maloret (Principal Lecturer in Learning Disability Studies)

Address: University of Hertfordshire, Centre for Learning Disability Studies, College Lane Campus, University of Hertfordshire, Hatfield, Hertfordshire, AL10, 9AB.

Email

Telephone:

Ethical approval:

The project has received approval from the Health and Human Sciences Ethics Committee at the University of Hertfordshire and NHS National Research Ethics Service.

Appendix 4 – Debriefing Guidance Sheet

Version 1, 01 August 2015

Debriefing guidance sheet

This sheet of information is offered to participants of a research study that via a debriefing discussion with the interviewer has indicated that they have found the elements, or all the process distressing and would welcome the opportunity be supported further. It is plausible that when discussing your experiences whilst suffering from a mental illness in an inpatient service, it could cause some distress.

The Asperger Social Care Team in Health and Community Services, in Hertfordshire has offered to support any participants in this situation. It has been agreed the Chief Investigator, Paul Maloret will refer participants to the team who will meet with them as soon as they are able to and offer the required level of support which will be discussed. If the team decide that another agency would be best place to offer longer term support, they will discuss this with the participant.

The Asperger team has been developed in response to feedback from people with Asperger's and high-functioning autism, and their carers, who have been saying consistently they do not fit into traditional learning disability and mental health services and they want to be supported in a different way. Further information on the team will be given upon request or available online @ http://www.communitycare.co.uk.adults-with-aspergers or 01442 453535.

Additional services that could be useful are listed below:

Adult Care Services Client Services - www.hertsdirect.org Tel: 01438 737511

Hertfordshire Partnership NHS Foundation Trust -www.hertspartsft.nhs.uk

National Autistic Society -www.nas.org.uk Tel: 0845 979 4004

St Albans Asperger Support Group -ASG@hertscc.gov.uk

Ware Asperger Support Group -ASG@hertspartsft.nhs.uk

Work Solutions -www.hertsdirect.org/work solutions

Carers in Herts -www.carersinherts.org.uk 01992 586969

Harc – the Hertfordshire branch of the National Autistic Society -www.harc-online.org.uk

Stop Gap -stopgap@hcs.co.uk 01923 630408

Appendix 5 – Interview Schedule

Version 1, 18 June 2015

INTERVIEW SCHEDULE

The research seeks to find out how former patients with ASC coped with, understood and made sense of their experiences in a mental health inpatient unit. Including their social interactions with other patients and staff, reactions to staff interventions, being in a different environment, hypersensitivities and the emotional experience. Each participant will be given the option to meet face to face at an environment of their choice or complete the interview using an online communication forum.

1) *INTRODUCTION*

2) *UNDERSTANDING WHY THE ADMISSION HAPPENED*
   a. What was you understanding of why the decision to admit you had taken place?
   b. What were your initial thoughts/feelings towards to the admission?
   c. What emotions/feelings arose for you during this time?

3) *EXPERIENCE OF THE INITIAL DAYS OF YOUR ADMISSION*
   a. What did you do on a day to day basis?
   b. What were your thoughts during this initial period?
   c. What was your emotional response to being in the unit?

4) *EXPERIENCE OF THE INTERVENTIONS FROM THE CARE TEAM*
   a. Did you understand what the treatment care plan was for you?
   b. Where you involved in the development of any care plans?
   c. How did you experience any care interventions?
   d. Did you feel understood by the care team?

5) *EXPERIENCE OF THE PHYSICAL ENVIRONMENT*
   a. What were your experiences of the being in this environment?
   b. What emotions did you experience towards the physical environment?

6) *EXPERIENCE OF THE SOCIAL ENVIRONMENT*
   a. Do you feel you established any relationships with other patients?
   b. Do you feel you established any relationships with any of the care team?
   c. What emotions/feelings arose for you about these relationships or lack of them?
   d. How were difficult emotions managed/supported by the care team?

7) *CONCLUSION*
   a. Is there anything else you would to tell me regarding your admission experience?

8) *DEBRIEF*