

**Investigating the factors that contribute to unstable living
accommodation in adults with a diagnosis of Autistic Spectrum
Disorder**

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A thesis submitted in partial fulfillment of the
Requirements of the University of East London
For the Degree of Professional Doctorate in Clinical Psychology
May 2017

Word Count: 27,655

ACKNOWLEDGEMENTS

I would like to begin by thanking the participants who took part in this study and trusted me to account for their experiences. I share your hopes of a different future.

Thank you to Director of Studies, Dr Matthew Jones-Chesters. Thank you for the time and commitment you gave to this study, and for the support and encouragement you gave to me.

I would also like to thank my field supervisor, whose name I have omitted to protect the anonymity of the participants in this study. Your commitment to improving the lives of those you work it commendable, and I hope that this study goes some way towards strengthening this endeavor.

Finally, I am always indebted to my family. Mum and Dad, thank you for the hours you gave me in editing and proof reading. But mostly thank you for your unfaltering belief in me and this project. Thank you to Krystyna, Nick and Huw for your love and for giving me perspective.

ABSTRACT

There is a paucity of research and theory to account for homelessness as experienced by people with a diagnosis of autism. Historically, the terrain of knowledge regarding both autism and homelessness has neglected to account for the views of those with personal experience. In response, this research shall develop a model of homelessness as experienced by people with a diagnosis of autism that prioritises the views of people with personal experience. This research is intended to inform the work of clinical psychologists when working with this group. A critical realist grounded theory was adopted due to its congruence with the research aims. The grounded theory model “losing and gaining connection” was constructed from interview data provided by people with a diagnosis of autism who have personal experience of homelessness and professionals who offered them support. “Losing connection” was the dominant process that led up to homelessness. This process demonstrated how multiple contexts limited the lives of those with a diagnosis of autism. People with a diagnosis of autism responded to such limiting contexts through disconnecting with them, resulting in homelessness. “Gaining connection” was the dominant process during and following homelessness. This process demonstrates the ways in which people with a diagnosis of autism and their networks acted in flexible ways to respond and transform such contexts during and following homelessness. This study demonstrates the importance of developing and maintaining the connection that people with a diagnosis of autism have with others and makes recommendations for how this can be achieved.

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1. INTRODUCTION

This research will construct a model of homelessness related to those who have received a diagnosis of autism.

The introduction begins by reviewing the ways in which the labels of both “autism” and “homelessness” have been constructed historically. This will lead to the rationale for the terms used within this research.

The current state of knowledge of autism and homelessness is then to be evaluated and used to inform the position of the researcher regarding this study. Processes involved in homelessness are explored along with their relevance to those with a diagnosis of autism. To further inform the exploration of homelessness and autism, a narrative review of relevant literature is provided. A review of applicable law, policy and service guidelines regarding people with a diagnosis of autism and people who have been homeless is then set out, alongside the impact of such on the practice of clinical psychologists. The relevance of this research to clinical psychology is then considered. This section concludes with the aims and questions of the research.

1.1. DEFINITIONS AND TERMS FOR RESEARCH

This section reviews the way in which the terms “autism” and “homelessness” have been constructed historically. This will enable the researcher to select the most appropriate terms to apply to this research.

1.1.1. Historical Construction of Autism

The term “autism” is Greek in origin, derived from autos, meaning self (Onions, Friedrichsen & Burchfield, 1966). The use of the term autism within the psychiatric realm was first introduced by psychiatrist Eugene Bleuler. Bleuler (1911) used the term autistic to describe the socially withdrawn, temporary state of mind he observed in psychotic individuals.

The development of the term to describe a pervasive impairment rather than a temporary state, was the outcome of the work of Leo Kanner. Kanner (1943) used the term ‘infantile autism’ to define his observation of 11 children who

displayed emotional and intellectual impairments alongside a preference for solitude from early life.

Such observations were then formalised into a set of diagnostic criteria by Eisenberg and Kanner (1956). The criteria focused on two dimensions, a profound lack of affective contact and repetitive ritualistic behaviours. At this point, Eisenberg and Kanner speculated that the etiology of their diagnosis would be difficult to prove, due to the “interpenetrating concepts” of genetics and environment (Kanner & Eisenberg, 1957, p.563).

Further formalisation of the diagnostic category of autism was based upon data from a large amount of developmental observational studies. Psychiatrists Lorna Wing and Judith Gould (1979) and Michael Rutter (1978) developed the work of Hans Asperger (1944) and created the expanded concept of ‘Autistic Spectrum Disorders’. This included both children with and without intellectual disability, all of whom shared impairments in social communication. This research diversified the concept of autism into the “triad of impairments”. The triad proposed that autism could be characterised by three impairments (a) impaired social development (b) delayed and deviant language development and (c) insistence on sameness.

The triad was introduced into the DSM III within the distinct diagnostic category of “infantile autism” (DSM) (American Psychiatric Association (APA), 1980). This was later replaced by the more expansive definition of “Autistic Disorder” in the DSM III- Revised (APA, 1987).

The introduction of autism into the DSM III stimulated interest in the psychological basis of autism. This coincided with the development of the concept of Theory of Mind (Baron- Cohen, Leslie & Frith, 1985). The Theory of Mind provided evidence to suggest that the central deficit for those with a diagnosis of autism was the individual’s lack of capacity to understand the intentions, thoughts and beliefs of others. This research suggested a possible biogenetic basis of such impairments.

The DSM IV (APA, 1994) introduced Asperger Disorder. This was defined as the presence of social communication deficits, without intellectual impairment. Both Autistic Disorder and Asperger Disorder were encapsulated under the category of Pervasive Development Disorder.

The publication of the DSM V (APA, 2013) brought further changes in the way autism was understood. The DSM V removed the differentiation between Asperger Disorder and Autistic Disorder and created a unified Autistic Spectrum Disorder diagnosis. This diagnosis reduced the triad of impairments to a dyad of (1) impairments in social interaction and communication and (2) restrictive and repetitive behaviours. This shift also removed language delay from the diagnosis, and incorporated a more inclusive approach to age of onset, noting that symptoms may be present in early childhood but not fully become manifest until a later age.

These recent changes have attracted some criticism. Some have suggested that such changes have the potential to result in a narrowing of the concept, creating impacts to diagnosis and service provision (Volkmar & Reichow, 2013). Others have suggested that the unitary label encompasses a great deal of heterogeneity, which creates confusion in terms of how it is understood and diagnosed (Lai, Lombardo, Chakrabarti & Baron-Cohen, 2013).

The prevalence rates of autism have shown a marked increase over the past four decades (Brugha *et al*, 2009), leading some to question the putative genetic basis of the condition and to suggest possible social and political factors that may contribute to autism (Timimimi, 2016). These will be explored further in the *Terrain of Knowledge* section. However, the way in which the definition of the diagnosis has interacted with academic interests over time should be acknowledged. It therefore seems that although there is evidence to suggest a clinically useful and meaningful constellation of specific behaviours and communications associated with the autism diagnosis, it is acknowledged that academic trends inherently shape current understandings.

1.1.2. Terms For Research and Rationale

The historical development of the terms, as above, has demonstrated the different ways autism has been constructed and understood. This research will therefore use the most contemporary terms as in the DSM-V (APA, 2013) however, it is acknowledged that this definition is culturally and socially determined and may develop further in the future.

The DSM-V Criteria (APA, 2013) characterises Autism Spectrum Disorder (ASD) as a dyad of impairments.

(1) Impairments in social interaction e.g. difficulties in social communication, difficulties in understanding non-verbal communication, difficulties in relating to others.

(2) Repetitive or restrictive behaviours e.g. insistence on sameness, restricted interests, sensory sensitivities.

To gain a diagnosis, these impairments should be present from childhood and limit and impair everyday functioning. Within the United Kingdom (UK), a diagnosis of ASD is usually given by a Psychiatrist or highly specialised Clinical Psychologist.

1.1.3. Historical Construction of Homelessness

Investigating the changing conceptualisation of homelessness can be achieved through tracking the ways in which homelessness is acknowledged and managed within legislation and social care policy. However, many have suggested that due to the links between homelessness and poverty, homelessness has always been a recognized problem within Britain (Slack, 1990; Thompson, 1993; Rose, 1998; Crowther, 1981; Archard, 1979).

The Poor Law of 1530 acknowledged homeless vagrants, and parishes were allocated responsibility to provide occasional subsistence to the poor. The law was punitive towards begging, which was criminalised and discouraged by harsh penal sanctions (Pound, 1971). Such approaches were thought to represent a view that the homeless and poor did not have a stake in society and therefore were not deserving of support from it (Hutson, 1997).

The New Poor Law of 1834 saw a continued punitive approach to supporting the homeless and destitute through the introduction of workhouses. Workhouses required hard menial work from the homeless in exchange for shelter and food (Webb & Webb, 1910).

The ethos of personal responsibility continued throughout the second half of the 19th century. This time saw the development of refuges and night shelters provided by voluntary organisations, which continued to focus on encouraging

individuals to be responsible citizens and to develop strength of character (Neale, 1997).

The post war period saw a changing ethos within Britain regarding the homeless. The creation of the welfare state (1945 -1948) underpinned a basic national standard of living, education, healthcare and employment (Glennister and Le Grand, 1995). The coinciding National Assistance Act (1948) created local authority responsibilities for welfare departments to provide resettlement and temporary housing for the homeless.

The Housing Act (1977) transferred responsibility for the homeless from general social care services to solely housing departments and as such reflected a change in perspective of cause and remedies for homelessness. Homelessness became a housing issue and local authorities were given a duty to provide secure, long term housing for the statutory homeless. This was specified to be those in “priority need”, or families with dependent children, pregnant women, victims of fire and flood and ‘single’ people vulnerable due to mental, physical conditions or old age.

Duties to those in priority need were separated from the duties of advice and assistance required for the single homeless (Fitzpatrick, Kemp & Klinker, 2000). Charities suggested that such rigid definitions of homelessness failed to acknowledge the widening amount of people living in poor physical conditions and whose homelessness is not accounted for official statistics. The term “hidden homeless” has become an acknowledgement of this situation (Fitzpatrick, Pawson, Bramley, Wilcox & Watts, 2016). The view that the homeless are responsible for their own fate has reappeared over the past two decades. Whiteford (2010, p193) described a “responsible citizenship” in which government policies incentivised the disadvantaged, including the homeless, to earn services rather than having the rights to these.

Finally, the international political context should be accounted for within the changing conceptualisation of homelessness. Between December 2012 and December 2016 numbers of people emigrating from countries within the European Union to the UK increased (Office of National Statistics, 2017), as did numbers of people seeking asylum within the European Union (EU) from not EU countries (Eurostat, 2017). The European Observatory on Homelessness (2016) conducted a survey in order to detail the impact of such changes in migration on

EU homelessness services. Homelessness services within the UK reported that there has not been a significant increase in asylum seekers or refugees entering into homelessness services in recent years. Such service also reported that people migrating to the UK from other EU countries for economic purposes has had a more significant impact on service provision.

Currently within the UK, statistics relating to homelessness are separated into rough sleeping, statutory homelessness and hidden homelessness. The most robust estimates in England are provided by The Homelessness Monitor 2016 (Fitzpatrick *et al*, 2016) the latest issue of which demonstrated:

- A long term trend of rising rough sleeping
- A rising trend of acceptances of statutory housing since 2012
- A rising trend of those living in temporary accommodation since 2010

Welfare reforms and resulting benefits cuts were reported as the greatest contributors to these increases.

1.1.4. Terms For Research and Rationale

The broadening and diversification of the term “homelessness” and the ways in which this term interacts with social, political and economic factors demonstrates the complexity of this term. Within this research the definition of homelessness provided by Andersen and Christian (2003) will be used. This definition states that a person is homeless if:

- (1) They have no accommodation that they are entitled to, or that is reasonable for them to occupy *or*
- (2) Rough Sleeping *or*
- (3) Living in temporary or unstable accommodation *or*
- (4) Living in intolerable physical conditions

The definition chosen is intentionally broad, in order to acknowledge and account for the breadth of homelessness experience not always accounted for by legislative terms. It is hoped that such a broad definition will help to acknowledge

the structural factors that influence homelessness, whilst it remains acknowledged that this definition is culturally and socially determined.

1.2. THE TERRAIN OF KNOWLEDGE

As this research attempts to develop a new theory relating to autism and homelessness, the current state of knowledge of autism is to be analysed. This analysis will then inform the position of the researcher regarding this study.

1.2.1. The Terrain of Knowledge Regarding Autism

Theories that attempt to understand the difficulties faced by those with a diagnosis of autism are often framed within cognitive or socio-cultural models. This section will analyse such models before accounting for how these have been understood by those with a diagnosis of autism. The impact of such models and perspectives on the current research shall then be demonstrated.

1.2.1.1 The Cognitive Model

The cognitive model of autism asserts that the difficulties faced by those with a diagnosis of autism are due to some form of deficit in one or more of the following mental faculties:

Impairments in Theory of Mind. Deficits in the Theory of Mind, or the capacity to understand the intentions, thoughts and beliefs of others, are commonly thought of as the pathognomic impairment of autism (Baron-Cohen, 1995). Such understandings are based around classical tests such as the Sally Anne test, (Premack & Woodruff, 1979) which assesses individual capability for third party thought. Baron-Cohen, Leslie & Firth (1985) demonstrated that children with a diagnosis of autism were highly likely to fail such tests and concluded that deficits in the Theory of Mind may account for the central cognitive impairment of autism. However, there has been a great amount of conflicting evidence using such tests. Many studies have failed to show impaired performance in those with a diagnosis

of autism, especially in samples where participants are described as high functioning or older (Rajendran & Mitchell, 2007).

Impairments in Executive Dysfunction. Observations of the correlation between symptoms related to autism and symptoms of those with frontal lobe damage, stimulated research regarding executive functioning deficits in those with a diagnosis of autism. Such overlapping symptoms seem to relate to the non-social elements of autism, such as lacking impulse control, need for sameness and difficulty switching attention (Russel, 1997). There has been a breadth of research that indicates impairment in executive functioning in those with a diagnosis of autism, and the relationship between impairments in cognitive flexibility and restrictive and repetitive symptoms have been particularly strongly made (Hill, 2004).

Weak Central Coherence. The Weak Central Coherence Theory (Frith, 1989, 2003; Frith & Happé, 1994; Happé, 1999) relates to the ability of an individual to derive overall meaning from a mass of details. This theory was proposed after superior performance was observed in those with a diagnosis of autism in tasks that require attention to smaller components rather than a global figure, such as the Block Design Test (Shah and Frith, 1993) and the Embedded Figured Test (Witkin, Oltman, Raskin, & Karp, 1971). This led Frith (1989) to argue that superior performance by those with a diagnosis of autism may suggest a lack of cognitive drive to attend to global form. Such impairments were thought to relate to the social communication difficulties found in autism. Many have suggested that a weak central coherence is needed to understand communicational intention beyond the surface structure of language (Frith & Snowling, 1983; Happé, 1997; Jollive & Baron-Cohen, 1999; López & Leekam, 2003; Snowling & Frith, 1986)

Critiques of the Cognitive Models

Cognitive theories can be critiqued for their domain specific approach that fail to account for the range and variability of cognitive performance in those with a diagnosis of autism. Such approaches can also be criticised for their focus on

cognitive mechanisms implying static cognitive styles that decontextualise human behaviour (Simon, 2016). However there has been some attempt in these research fields to work towards a multiple deficit explanations that account for the heterogeneity in neurological profiles and behavioural phenotypes in those with a diagnosis of autism (Pellicano, Maybery, Durkin, & Maley, 2006).

Postmodern critiques have also been offered in relation to the theory of mind model. Leudar and Costall (2004) suggest that pursuit of knowledge to understand the minds of others arose out of specific historical conditions, such as the rise and influence of the discipline of cognitive psychology. As a result, it is suggested that the ability to infer the mental states of others should not be considered as a timeless and transcultural aspect of the human condition, rather reflective of particular historical contexts. Runswick-Cole (2014) explores the action that follows from constructions of a deficit of theory of mind, suggesting that the pursuit of defining abnormalities in those with a diagnosis of autism creates boundaries between normal (non autistic) and abnormal (autistic). This results in the segregation and subordination of people with a diagnosis of autism.

Perspectives of People with Autism

Despite these academic critiques, some autistic activism movements have celebrated and encouraged attempts to locate autism in the genetic and neural structures of the brain. The neurodiversity movement argues that autism is the result of a naturally occurring brain difference. These movements advocate for the increased understanding of autistic cognitive profiles in order to develop societal acceptance and understanding of autism (Runswick-Cole, 2014). It seems important to note that such movements advocate the acknowledgement of cognitive difference rather than deficit, inviting action for the individual's autistic needs to be adapted to rather than pathologised and cured.

Goodley (2016) drew parallels between these movements and what Rose and Novas (2005) described as biological citizenship, or an emergent form of alternative subjectivation in the field of health and illness. In relation to autism, biological citizenship may oppose the dominant forms of subjectivation where the autistic "patient" is a passive object of medical understanding and intervention.

Instead those with a diagnosis of autism may develop a biological citizenship where they become active co-creators of knowledge and their own health status. The acceptance and acknowledgement of cognitive deficit may therefore be seen as essential by some in the autistic community in order to develop the power to define their own health status and support.

Impact on Research

The cognitive approach of autism is long founded and sustained. Although academic critiques have been provided for such a pursuit, it seems important to acknowledge the attachment that many of those with a diagnosis of autism have made to such understandings and the power this allocates to the autistic community to define their own health status. Criticisms of the cognitive model seem to be centered on their neglect to account for the environmental influences on human behaviour (Simon, 2016).

As some of those with a diagnosis of autism advocate for an increased understanding of the cognitive differences related to autism (Runswick-Cole, 2014), this research will position itself as aware and curious about the narratives related to perceived individual difference and the impact of these on the lives of those with a diagnosis of autism. This research will remain aware of such ideas, whilst also remaining open and responsive to the ability of such ideas to silence social understandings.

1.2.1.2. The Social Model

The social model of disability asserts that the difficulties faced by those with disabilities, such as autism, are not the result of an individual's impairment rather, the inability of society to cope with and adapt to such impairments (Oliver, 1996; Williams, 1999; Shakespeare and Watson 2001). Such ideas have stimulated the development of disability studies that attempt to consider the way in which social, political, cultural and economical factors create disability (Siebers, 2013).

For example, materialist perspectives on autism consider disability as a social consequence of a capitalist economy. Oliver (1996) demonstrated how the social

segregation and isolation of those with disability is rooted within the transition from a feudal to capitalist economy in which workers were required to engage in the rapid, disciplined requirements of factory work. This resulted in the segregation of those unable to participate due to their disabilities. Timimimi (2005) applied such ideas to those with a diagnosis of autism, demonstrating that the more recent shift from manufacturing to service based industries has created a context in which people with a diagnosis of autism become unable to fulfill the occupational roles expected of them.

Materialist perspectives of autism may therefore suggest that the “symptoms” of autism, such as social isolation, may be related to processes such as social segregation, rather than as a result of purely cognitively deficits.

Critiques of the Social Model

Some advocates of social model of disability assert that as the diagnosis of autism lacks scientific validity and may be the product of social attitudes, there is a justification for the diagnosis to be abolished (Timimimi, 2011). Milton & Bracher (2013) warn that such appeals are predominantly suggested by academics and may not represent the views of those with a diagnosis of autism. Others have warned that the emphasis of structural barriers within the social model of disability limits the acknowledgement of the difficulties created by impairment. Shakespeare and Watson (2001) add that as the personal experience and limitations of those with disabilities are unlikely to be completely eliminated by the removal of social barriers, acknowledgement of the difficulties created by impairments should remain.

It therefore seems that accounting for the role of society and context in the creation of difficulties for people with a diagnosis of autism remains important, but such difficulties cannot be reduced to purely societal elements.

Perspectives of People with Autism

Environmental activism movements (Goodley, 2016) attempt to draw awareness to structural factors that act to disable and exclude people with a diagnosis of autism. This leads to action that challenges the inability of society to take account

for and adapt to the needs of those with a diagnosis of autism. Influences of such activism can be seen in law and policy such as the Autism Act (2009) and The Autism Strategy, Fulfilling and Rewarding Lives (Department of Health (DOH), 2011). It should be noted that although such movements suggest the acknowledgment of the structural factors that bring difficulty to the lives of those with a diagnosis of autism, the perception that autism is reducible to such factors is not well accounted for with literature that presents the perspectives of this group.

Impact on Research

Moving through the terrain of knowledge regarding autism, it has been demonstrated that neither explanations relating to social barriers or individual impairment are adequate in providing a fully informed understanding of the difficulties associated with the autism diagnosis.

There also seems a level of discrepancy between the way clinicians and researchers and those with a diagnosis of autism would prefer the difficulties associated with autism to be understood. Academic literature has acted to polarise understandings into impairment or social discourses, which are often in conflict with the more integrative, nuanced approach adopted by the autistic community.

It is therefore the primary concern of the researcher to attempt to oppose the polarisation of theories relating to autism. This research will therefore attempt to understand autism as an interaction between individual disposition and abilities within a particular social context. It also sees that those who have received a diagnosis of autism are best placed to comment on the nuances of interaction between individual and structure. This research will therefore prioritise the views of those with a diagnosis of autism.

1.2.2. The Terrain of Knowledge Regarding Homelessness

Academic arguments relating to the homeless are also segregated into individual versus structural explanations. This section will analyse such theories before demonstrating their impact on the current research project.

1.2.2.1. Individual Agency and Resilience Model

Concepts such as agency and resilience have been applied to the understanding of homelessness. These concepts suggest that homelessness is the result of individual factors.

Prior to the mid 20th century the homeless were considered as responsible and held to blame for their position, often considered as deviants, alcoholics, vagrants and tramps (Ribton and Turner, 1887). Such “victim blaming” narratives were reflected in policy and provision, which took punitive and rationed approaches to service provision for the homeless (Clapham, Kemp & Smith, 1990; Evans, 1991). The “personal inadequacy” narrative gained favor in the mid 20th century, suggesting that homelessness was the result of some form of personal failure, such as mental health issues or drug use (Scott, 1993). Public opinion was mobilised into new forms of response following mainstream television of the “Cathy Come Home” drama in 1966. This led to new forms of humanitarian response from the state, aiming at supporting individuals back to the level of functioning required to sustain housing (Johnson, Murie, Naumann, & Yanetta, 1991).

Ideas relating to agency are still argued within contemporary social policy and theory. McNaughton-Nicholls (2009) suggests that as issues such as substance misuse and mental health issues are common amongst homeless people and require the acknowledgement of agency in their treatment, it is important to account for agency in the understanding homelessness.

Conceptualisations regarding resilience have been made by Fitzpatrick (2005) who suggests that resilience to homelessness can be undermined by issues such as mental health problems. Ideas such as these are well articulated in the psychological literature, which highlights the relationship between homelessness and experiences of complex trauma, suggesting that the homeless may have disrupted attachments to people and place (Cockersell, 2011; Keats, Maguire, Johnson, & Cockersell, 2012).

Critiques of the Individual Agency and Resilience Model

The agency and resilience models are often critiqued for their tendency to attribute blame and pathology to the homeless.

Pleace (2008) argued that such pathologising assumptions leads to attempts by services to “correct” deviant behaviour and “treat” the pathologies of drug addiction or mental health problems. Although results regarding psychologically informed approaches have shown some positive outcomes, others have warned that they can often encourage services to adopt fixed ideas relating to the pathology of the homeless leading to prescribed, rigid and possibly ineffective interventions (Busch, Geertsema, & Sahlin, 2007).

The impact of such conceptualisation on the perpetuation of oppression and silencing of the homeless has also been suggested. Rosenthal (2000) notes that pathologising models construct the homeless as deserving yet incompetent in determining the support they need. Paradis (2000) furthers this critique through observing how inferring the pathology of the homeless justifies the need for professional intervention, thus reinforcing the idea that the homeless are incompetent and unable to articulate the causes, maintenance and solutions to their homelessness.

It may therefore be suggested that individual agency models of homelessness may risk inferring pathology to this group resulting in rigid and possibly ineffective interventions.

1.2.2.2. Structural Theories

Structural theories relating to homelessness place emphasis beyond the individual on wider societal and economic contexts.

Structurally orientated accounts gained popularity within the 1980s when it was commonly thought that homelessness was the result of inequality generated by economic systems and barriers to welfare, health and housing services (Drake, O'Brien, & Beiuyc 1981). A response to which was seen in British social policy where a “housing only” (Pleace, 2016, p 23) approach followed, providing housing for those who were defined as having high priority needs.

Such approaches have gained variable results, and led to criticism from some that providing housing only to the homeless neglected to acknowledge the individual factors that may impact a person's ability to resettle (Pleace, 1995).

Critiques of Structural Theories

Although structural approaches attempt to avoid pathologising narratives regarding the homeless, their neglect of agency of the homeless can be suggested to create a position of the homeless as passive victims of circumstance. This has led to the suggestion that the homeless have been written out of theories regarding them (McNaughton-Nicholls, 2009) resulting in the perpetuation of the silencing and oppression of this group (Jacobs, Kemeny & Manzi, 1999). Such accounts therefore neglect to attend to the ways that individuals are able to resist structural influences (Pleace, 2016), an understanding of such is vital to inform the development of interventions to support them.

It can therefore be suggested that such structural theories relating to homelessness continue to limit in the input of this group into theory regarding them.

1.2.2.3. Interactive Models

Interactive models of homelessness critique the binary and essentialist assumption of pure individual or structural accounts. Fitzpatrick (2005) suggested a "new orthodoxy" that challenges ideas relating to solely individual or structural accounts of homelessness. This model suggested that homelessness results from the interaction of structural and individual factors.

This element of interaction is further articulated through Fitzpatrick's applications of structuration theory (Giddens, 1984). Structuration theory suggests that human agency involves a conscious, reflective processing of the choices available within existing power structures. This results in behaviour that has the ability to reproduce or, on occasion, to transform society. Application of structuration theory to the understanding of homelessness within the 'new orthodoxy' therefore

proposes the importance of understanding the oscillations between individual and structure.

Impact on Research

The complexity of homelessness and inadequacy of solely individual or structural theories to account for this has been demonstrated. Reviewing the theoretical terrain has also suggested that such accounts act to position the homeless as passive or incapable of reflecting on and adding to knowledge regarding homelessness.

This study will therefore adopt Fitzpatrick's (2005) approach to the enquiry of homelessness, through adopting an open, curious approach to the interaction between individual and structural factors in individual's accounts of homelessness. This interaction will come to be known through prioritising the views of those with personal experience of homelessness.

1.2.3. Research Aim 1

Reviewing the terrain of knowledge relating to both autism and homelessness has therefore led to the first research aim:

Research Aim 1: To prioritise the views of those with a diagnosis of autism and experience of homelessness in the construction of knowledge relating to them.

1.3. PARALLELS BETWEEN AUTISM AND HOMELESSNESS

The previous section reviewed the terrain of knowledge relating to autism and homelessness and demonstrated the importance of accounting for both individual and structural factors when developing new forms of knowledge relating to these groups.

This section will attempt to account for some of the structural and individual factors that have previously been associated with homelessness. Each factor will be considered in terms of its relevance to those with a diagnosis of autism. This

section will conclude with a review of the literature that attempts to explore the association between autism and homelessness, before demonstrating the rationale for this research.

1.3.1. Structural Factors

1.3.1.1. Economics

The intimate relationship between economics and homelessness is well documented (Robson & Poustie, 1996). As economic structures have the potential to generate poverty and limit access to resources such as housing, spikes in homelessness are often found within economic recessions (Burt, 1991) making those in lower economic groups particularly vulnerable (Watson & Austerberry, 1986).

Systematic reviews of the economic position of the autistic community is not well documented within academic literature. However, a recent survey of employment possibilities conducted by the National Autistic Society (NAS) (2016) suggested that just one third of the 2080 respondents were in employment, despite over three quarters of respondents noting that they would like to work. This survey highlighted how employment rates in the autistic community are lower than that of the general population and lower than those with physical disabilities (NAS, 2016). In addition, the majority of jobs occupied by those with a diagnosis of autism have been described as unskilled and poorly paid (Howlin, Moss, Savage, & Rutter, 2013).

It may therefore be suggested that people with a diagnosis of autism are more likely to occupy lower economic positions and may therefore be more likely to be vulnerable to poverty and homelessness.

1.3.1.2. Financial Support

Those in lower economic positions are likely to face increased risks to homelessness when their access to welfare is limited (Fitzpatrick, 2005). The impact of welfare reforms is well documented and benefits cuts have been

suggested to be the largest contributor to the recent increase in rough sleeping in the UK (Fitzpatrick *et al*, 2016).

There has been a historical concern that the welfare system does not adequately meet the needs of those with a diagnosis of autism (NAS, 2011a). The recent introduction of the Welfare Reform Act (2012) has added further concern. Many individuals with a diagnosis of autism have reported the lack of knowledge of assessors regarding the unique needs of those with autism as a key barrier to claiming benefits (Campbell, 2015).

It can therefore be suggested that the interaction between restricted employment and welfare is likely further weaken the economic position of those with a diagnosis of autism.

1.3.1.3. Housing Structures

Downward shifts in affordable housing supply are thought to contribute to rising homelessness (Burt, 1991). Those with a diagnosis of autism living in the UK are likely to live in social housing, live alone and live in deprived areas (Brugha *et al*, 2009). Over the past 10 years the number of additional social housing properties has decreased by around 20,000 homes (ONS, 2015). In addition, it is uncertain whether those with a diagnosis of autism are protected by rights to social housing within the Housing Act (2004) and Homelessness Act (2002).

As people with a diagnosis of autism may be reliant on social housing, current climates of reduced social housing provision are likely to increase their risk to homelessness.

1.3.1.4. Summary

It has been demonstrated that those with autism are likely to be in lower economic groups and may struggle to gain protection by welfare and housing structures. The combination of such factors is likely to place those with autism at increased risk of homelessness.

1.3.2. Individual and Interpersonal Factors

1.3.2.1. Interpersonal Factors

Pleace (2016) suggests that homelessness can be effectively resisted should an individual have sufficient support from interpersonal relationships. In this way interpersonal relationships may reduce the impact of structural factors.

There is evidence to suggest that those with a diagnosis of autism may possess a narrower interpersonal networks. The majority of adults with a diagnosis of autism live with their families and are dependent on their families for financial support (NAS, 2012).

Considering social relationships, a survey by the NAS (2016) indicated that those with a diagnosis of autism are likely to have limited social relationships and face risk of physical, sexual and financial abuse within such relationships.

Such frail support networks may create further vulnerabilities to homelessness when these individuals face issues with housing.

1.3.2.2. Individual Attributes

Individual factors such as internal decision-making processes and personal resilience have been suggested to interact with structural factors, increasing an individual's vulnerability to homelessness (McNaughton-Nicholls, 2009).

Fitzpatrick (2005) adds that resilience to homelessness can be undermined by issues such as mental health problems.

Psychiatric diagnosis, particularly depression and anxiety are high in individuals with a diagnosis of autism (Howlin & Moss, 2012; Hofvander *et al*, 2009) and therefore individual reliance on the previously mentioned structural factors may be likely to be undermined.

In addition, psychological models of homelessness have suggested a link between trauma and attachment, suggesting that as the homeless often have experiences of trauma, their attachment to both people and place is likely to be disrupted (Scanlon & Adlam, 2006). These models seem particularly relevant to those with a diagnosis of autism, who report multiple experiences of trauma and abuse (NAS, 2016). It may therefore be suggested that secure attachment and

resilience to homelessness may be undermined in people with a diagnosis of autism, impacting the ability of this group to resist homelessness.

1.3.3. Research Aim 2

An account of the possible association between autism and homelessness has been demonstrated. This leads to the second research aim.

Research Aim 2: To construct a model of homelessness as experienced by those with a diagnosis of autism that accounts for the complexity of this process.

1.4. LITERATURE REVIEW

An account of the possible association between autism and homelessness has been demonstrated. This section reviews existing literature that attempts to account for autism and homelessness.

1.4.1. Narrative Review of Autism and Homelessness

Preliminary review of the academic literature using the search terms “autism” and “homelessness” yielded no relevant articles. Mainstream search engines revealed some preliminary small-scale studies. Prichard (2010) conducted a small study of 14 rough sleepers in Devon and found that 7 of these people reported having a diagnosis of autism. A survey of 415 people with a diagnosis of autism and family members based in Wales noted that around 12% of the respondents reported an experience of homelessness (NAS, 2011b). Although these studies provide evidence for the possible association between autism and homelessness, the small sample size and reliance on self reporting autism question the applicability of these studies to the general population of people with a diagnosis of autism who have experienced homelessness.

Campbell (2015) conducted a thematic analysis of interviews of 12 people with a diagnosis of autism that had experienced homelessness in Wales. This study was the first of its kind to explore the relationships between autism and

homelessness in the UK. This study suggested the following factors may contribute to homelessness in this population:

- Risk factors (gaps in services and exploitation)
- Features of ASD (sensory and communication difficulties)
- Co-occurring conditions (depression and anxiety)
- Housing not matched to need (being placed in temporary accommodation)
- Unemployment and poverty
- Relationship breakdown

This research led to some useful recommendations. The author suggested a need for housing services to become more adapted to the needs of those with a diagnosis of autism. Increased support for people with a diagnosis of autism regarding housing advocacy was also suggested. However, this study can be critiqued for its lacking integration of such factors required for a coherent account of homelessness (Yardley, 2000). The methods used neglected to explore the intricacies of such factors, their relationships to one another and how they interact with personal agency to bring about homelessness. Without a comprehensive picture of homelessness as experienced by those with a diagnosis of autism, services may remain unable to adequately meet the needs of this population.

1.4.2. Narrative Review on Learning Disabilities and Homelessness

1.4.2.1. Rationale for Reviewing Learning Disability Literature

As demonstrated in the previous section, the preliminary review of the academic literature using the search terms “autism” and “homeless” yielded no articles. In order to inform the approach and method of the current research, narrative review of a closely related population was necessary. Narrative review on homelessness and learning disability will therefore be provided based on the following rationale:

1. Autism and learning disability are developmental disorders share a similar set of cognitive difficulties (Lecavalier, Snow and Norris, 2011) and developmental trajectories (Smith, Maenner, & Seltzer,2012).
2. Learning disabilities and autism show high comorbidity (Matson and Shoemaker, 2009) and therefore there may be a proportion of the research studies that include autism within their design.

1.4.2.2. Rationale For Review Strategy

A systematic approach to searching relevant literature was applied and is demonstrated below. As the resulting literature possessed a great amount of heterogeneity in terms of methods and outcomes, a narrative synthesis (Popay *et al*, 2009) of the literature will be provided.

1.4.2.3. Objectives

The review was guided by the following questions.

- Is there evidence to suggest a presence of people with a diagnosis of Learning Disability in the homelessness population?
- What contributes to vulnerability to homelessness in those with a diagnosis of Learning Disability?
- What contributes to maintenance of homelessness in those with a diagnosis of Learning Disability?

1.4.2.4. Methods

Eligibility Criteria

Qualitative and quantitative articles published in the English Language in which the primary focus investigation was homelessness in those with learning disabilities. There were no limits on time frame or study design.

Information Sources

The following data bases were searched: Psychinfo, PsychArticles, CINAHL Plus, Medline and Academic Search Complete with no limits on date or country.

Search Strategy

The following search terminology was used in varied combinations: (homeless OR homelessness) AND (learning disabilities or intellectual disabilities OR developmental disabilities or intellectual development disorder or developmental disabilities disorder).

Data Management and Selection Process

30 papers were provided based on the initial search terms. Further papers were excluded based on:

- Learning Disability or Homelessness were mentioned but not linked
- Children were the primary focus
- Learning Difficulties (Dyslexia, Dyspraxia) were the primary focus.

This is specified in the figure below.

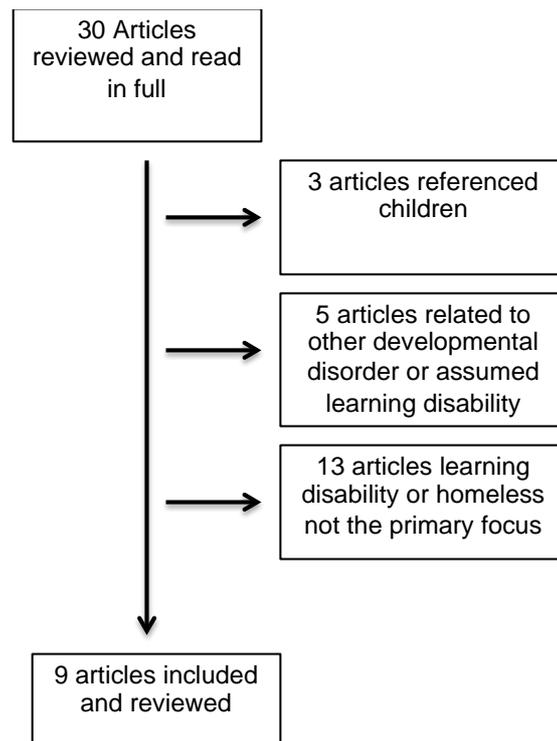


Figure 1: Overview of Search Process

1.4.2.5. Outcomes

9 publications were identified (6 from *PsycInfo*, 3 from *Cinal*). A search on the Cochrane library for systematic reviews using the search terms “homelessness” revealed 8 systematic reviews, none of which referenced learning disability or related terms.

Resulting papers were organised around the themes of

- Prevalence
- Causal and maintenance factors
- Professional opinion

Each theme is reviewed below and a critical evaluation provided.

Prevalence

Prevalence studies attempt to estimate the number of people within the homelessness population who meet criteria for a diagnosis of learning disability. The most stringent approach to measuring learning disability was found in a study conducted in England by Oakes and Davies (2008). The researchers tested for learning disability in 50 homeless people registered at a GP practice in the East of England, using measures in accordance with DSM-IV criteria e.g. a combination cognitive (Wechsler Abbreviated Scale of Intelligence (WASI)) and adaptive functioning (Adaptive Behaviour Assessment Scales (ABAS)) assessment as well as drawing information from historical care notes and interview. This research found that 12% of the sample met criteria for learning disability, leading researchers to propose a possible over-representation of learning disability in the homeless population when compared to the general population means. The small sample size within this study suggests such a comparison with population means should be interpreted with caution. Three studies adopted less formal approaches to identifying those with learning disability in the homeless population. For example, Mercier and Picard (2011) estimated a learning disability prevalence rate of 34% in their study based in

Canada. Learning disability in this study was measured by whether individuals received specialist input from learning disability services.

Nishio *et al* (2015) recruited 18 homeless men from a social welfare centre in Japan and found a prevalence rate of 39% using cognitive measures alone (Wechsler Adults Intelligence Scale 111 (WAIS 111) to define learning disability. Van Straaten, *et al* (2014) used a screening measure (Hayes Ability Screening Index (HASI) to estimate learning disability prevalence rates in the Netherlands. This study found that 29.5% of the 387 homeless people known to social care services across a number of sites met the screening criteria for learning disability. Whilst these three studies indicate a possibility of homelessness within the learning disability population, all of these studies can be critiqued for their lacking rigour in assessing learning disability in accordance with DSM V (APA, 2013) criteria. The lacking specificity and sensitivity of measuring learning disability may increase the chance of false positives in these studies.

Causal and Maintenance Factors

Two studies referenced possible causal factors to homelessness in the learning disability population.

Hebblethwaite, Hames, Donkin, Colam and Forsyth (2007) interviewed 14 people receiving support from local learning disabilities services in the North of England regarding their pathways into and out of homelessness. This study noted breakdown in relationships a key trigger to homelessness. Such a breakdown was usually the result of interpersonal conflict or death of a supportive family member, or through manipulation or harassment from others. This study included a small sample of participants, all of whom were known to learning disabilities services and cannot therefore account for the experiences of those not currently engaged with services.

Mercier and Picard (2011) also attempted to identify factors related to homelessness in the learning disability population through reviewing the case files of 68 homeless people with suspected learning disability known to homeless services in Canada. In line with Hebblethwaite *et al* (2007) relationship breakdown, in addition to substance misuse, were key issues in the loss of an individual's home. The identification of the key role of relationship breakdown led authors in this studies to conclude the need for early intervention with these

groups to support the maintenance of protective supportive relationships. This study was based on retrospective and secondary data and may therefore lack the completeness required to uncover a comprehensive understanding of causal factors.

Two studies investigated maintenance factors relating to homelessness in the learning disability population. Van Stratten *et al* (2014) and Van Stratten *et al* (2017) compared the social, health and psychological profiles of homeless people in contact with services with and without a suspected learning disability (using the HASI screening measure) within the Netherlands. At follow up (Van Stratten *et al*, 2017) those with suspected learning disability reported to have a greater amount of sustained psychosocial problems (psychosocial distress, substance dependency, financial problems) than those without suspected learning disability. This study concluded that the learning disability population is more likely to have enduring care needs requiring long term, sustained support. Again, this study lacked formal measurement of learning disability in line with DSM V (APA, 2013) criteria and it cannot be concluded therefore that findings are specific to those with a diagnosis of learning disability.

Professional Opinion

Four studies investigated professional opinion regarding possible factors that may be related to homelessness in the learning disability population. Professionals ranged across forensic, health, social care and third sector agencies. Two studies considered vulnerability factors to homelessness. Trueland (2009) interviewed GPs, community learning disability nurses, hostel managers and third sector learning disability professionals regarding their work supporting individuals with Learning Disabilities who have experienced homelessness across England and Scotland. Professionals identified a population of individuals with mild learning disabilities being particularly at risk to homelessness due to their narrower protective support networks when compared to more cognitively impaired individuals with learning disability. Professionals also observed inflexibility in housing services adapting to the needs of those with learning disabilities

The limited social support networks of those with a learning disability was also highlighted by Loughheed and Farrell (2013) who used their own professional and clinical experience to speculate on the causes of homelessness in the learning disability population in Canada. They suggested the “challenging personality” possessed by those with a learning disability may make relationships with support networks and healthcare professionals liable to break down. This was considered in combination social stigma towards diagnosis and increased waiting lists barriers in access to healthcare. The authors also considered that challenges in accessing welfare and poor budgeting ability due to limited cognitive skills created factors possible to bring about homelessness.

Two studies investigated maintenance factors. Colman, Hebblewaite, Hames, Forsyth & Donkin (2007) interviewed professionals from across health, probation and homelessness services regarding their experience of supporting individuals with learning disability within the North East of England. This research highlighted the inability of services to meet the complex health, social and personal needs of people with learning disability. Specifically, they highlighted the increased vulnerability that temporary accommodation such as hostels place on this group to victimisation and exploitation.

Loughheed and Farrell (2013) highlighted how homelessness in the learning disability population may be maintained through the coping style of individuals. They suggest that the threatening atmosphere of hostels may result in reactions of assault, anger and defensiveness by those with learning disability. They add that such coping styles may create increased likelihood of exclusions from hostels.

Professional opinion articles highlighted the complex multifactorial nature of homelessness in the learning disability population. However, such articles were mainly speculative, interview pieces and therefore lacking systematic rigor in their analysis. In addition, although useful, professional perspectives seem to have been prioritised in the literature over those with personal experience of homelessness. This may be suggested to maintain the silencing and oppression often experienced by those with a diagnosis of learning disability and the homeless.

1.4.3. Summary and Impact on Current Research

There is a developing interest in evidencing the presence and processes of homelessness within the learning disability and the autistic population. Such studies should be commended for their attempts to stimulate the research field into investigating and supporting people with a diagnosis of learning disability or autism who have also been homeless.

The literature relating to autism and homelessness was sparse and there is a paucity of research that attempts to develop a cohesive and comprehensive model of homelessness that accounts for this process. This may impact the ability of services to adequately meet the needs of this population.

The current research terrain regarding learning disability and homelessness contains studies that often adopt approaches to assessing learning disability that would not meet formal diagnostic guidelines. This limits the ability of these studies to inform accurate and effective interventions for this group. In addition, although useful, professional perspectives seem to be prioritized in this literature over those with a personal experience of homelessness. Such neglect may be suggested to act to maintain the silencing of those with a learning disability in the production of knowledge regarding them.

It seems therefore that further research investigating the factors that contribute to homelessness as experienced by those with a diagnosis of autism is justified. This study shall adopt a rigorous approach to research and analysis in order to construct a model of homelessness that is able to coherently account for the likely complexity of this process. It will also adopt a more formal approach to eligibility, ensuring that the research regards those who meet formal diagnosis of autism. Finally, it shall attempt to prioritise the views of those with a diagnosis of autism in order to appose the historical silencing of this group.

The next section shall consider the impact of this research on the practice of clinical psychologists. This shall be achieved through reviewing relevant law, policy and service provision for people with a diagnosis of autism and people with an experience of homelessness.

1.5. CURRENT LAW, POLICY AND SERVICE PROVISION

1.5.1. Law, Policy and Provision for Autism

1.5.1.1 The Autism Act (2009)

The Autism Act (2009) was the first law covering autism in England. Following wide spread campaign to improve the recognition and support provided to adults with a diagnosis of autism in England, the act placed a duty on the Government to produce a strategy for this group. This led to the production of two autism strategies: Fulfilling and Rewarding Lives (DOH, 2010) and Think Autism (DOH, 2014). The details of such strategies, along with their potential influence on homelessness and on the service provision as offered by clinical psychologists, is explored below.

1.5.1.2. Fulfilling and Rewarding Lives (2010) and Think Autism (2014)

Fulfilling and Rewarding lives (2010) and Think Autism (2014) acknowledged the social and economic exclusion of adults with a diagnosis of autism and proposed methods by which such exclusions could be tackled. One key aim of these strategies was to increase awareness of autism across frontline services. This included providing autism awareness training to all mainstream health professionals in England. Think Autism (2014) also proposed the introduction of Autism Aware Communities. This was achieved through the introduction of pledges and awards to communities able to demonstrate their awareness to the needs of those with autism.

Increasing awareness of autism within health services and across communities is likely to have an impact on the housing stability of those with a diagnosis of autism. It may be suggested that broadening the awareness of autism and its associated difficulties may increase the breadth of protective networks for people with a diagnosis of autism. This may result in increased support for this group if their housing becomes vulnerable.

Another aim of these strategies was to improve accurate and timely diagnosis of autism in the adult population. It was hoped that improved access might result in

a strengthening of the relationships between people with a diagnosis of autism and health and social care services. It may therefore be suggested that the development of such relationships may enable individuals to access protective support systems when facing issues with their housing.

Finally the strategies aimed at improving the access to welfare and employment for those with a diagnosis of autism. One method by which this was intended to be achieved was through the training to Disability Employment Advisors at Job Centres. Such an intervention may increase an individuals access employment or welfare, reducing the likelihood of poverty and homelessness.

As there is no research to account for the prevalence of autism within the homeless population, it is not possible to account for the impact of such policies on homelessness. The impact of such policies on the service provision offered by clinical psychologists is explored below.

1.5.1.3. Application to Clinical Psychology

In terms of frontline clinical work, the Autism Act (2009) resulted in a greater proportion of clinical psychology provision allocated to the assessment, diagnosis and onward support of adults with a suspected diagnosis of autism. As a result, clinical psychologist are now formally involved in the health and social care support of this group. In relation to supporting those with a diagnosis of autism through homelessness, this is likely to be a difficult process for clinical psychologists due to the demonstrated paucity of research or theory to guide practice. Development of a model to account for homelessness within people with a diagnosis of autism is therefore likely to provide evidence needed to stimulate effective intervention by clinical psychologists.

As clinical psychologists are now expected to take a more active role in leadership, service development and policy (Lavender and Hope, 2007) they are well placed to highlight, challenge and intervene within the sociopolitical factors that maintain oppression and distress. The development of a model of homelessness that accounts for the structural and social factors that create homelessness for people with a diagnosis of autism may therefore inform clinical

psychologists of areas for intervention within their service development and policy regarding this issue.

1.5.2. Law, Policy and Provision for Homelessness

1.5.2.1. The Housing Act (2004) the Homelessness Act (2002) the Homelessness Reduction Act (2017)

The Housing Act (2004) and Homelessness Act (2002) gave statutory duties to local authorities to provide housing for specified groups of homeless people. This was restricted to those defined as in priority need. Priority need was defined as the following:

- Pregnant Women
- Families with Children
- People who are vulnerable as a result of old age, mental illness, learning disability or physical disability
- People who are homeless as a result of a disaster
- Young people aged 16 to 17 not owed duty to as a child in care or care leaver
- Young people under 21 formally in care between the ages of 16 and 18
- People who are vulnerable as a result of being in care
- People who are vulnerable as a result of being in the UK armed forces
- Vulnerable people formally in custody
- Vulnerable people fleeing violence

It is unclear as to whether those with an autism diagnosis, without a learning disability, are defined as a vulnerable group according to the act. In addition the discretionary powers given to local authority practitioners to make such decisions have been heavily criticised for lacking standardisation (Dwyer, Bowpitt, Sundin & Weinstein, 2015). This results in an uncertain position for those with a diagnosis of autism as to whether they will be provided housing support when they become homeless.

The recently introduced Homelessness Reduction Act (2017) placed requirements on local authorities to intervene earlier to support individuals at risk of homelessness. This act obligates councils to assess someone at risk of homelessness 56 days before losing their home (replacing the previous 28 day window). The impacts of this new act are yet to be monitored, but this act represents a shift in focus of the government towards preventing homelessness.

1.5.2.2. No Health Without Mental Health (DOH, 2011)

The DOH (2011) highlighted the complex mental health needs of homeless people and recommended the integration of therapeutic interventions and housing solutions within support provisions for the homeless. This created increased attention regarding the incorporation of psychological services into homelessness services. An increased presence of clinical psychology services within homelessness services is now in development (Cockersell, 2016).

1.5.2.3. Application to Clinical Psychology

It is uncertain whether individuals with a diagnosis of autism will meet the criteria for statutory housing when presenting as homeless. A result of this may be that they make up an increasing proportion of those within temporary accommodation and hostels. As clinical psychologists are now having an increasing presence within such services (British Psychological Society (BPS), 2015) the development of clinical psychology theory and practice to meet the needs of this group is required.

Current approaches offered by clinical psychologists involve the conceptualisations of the homeless as likely victims of complex trauma (Cockersell, 2011; Keats *et al*, 2012). This has led to the incorporation of mentalisation-based approaches for the homeless through direct interventions (Williams and Taylor, 2015) and indirect interventions offered by hostel staff (Cockersell, 2016).

Other approaches to supporting the homeless have been reviewed by community psychologists. Community psychologists link the distress within the homeless

population to broader structural issues and processes such as disempowerment (Orford, 2008). Such models adopt social action approaches in order to highlight and oppose the structural factors that contribute to homelessness. Although such approaches may be useful impacts in accounting for both the individual and structural processes involved in homelessness, these approaches lacking an account for the specific factors associated with homelessness in those with a diagnosis of autism.

This current study hopes to add to this growing momentum of clinical psychology within the homeless population. Through the development of a model that aims to account for homelessness as experienced by people with a diagnosis of autism, it is hoped that clinicians can develop the provision of evidence based practice for this group.

1.5.3. Research Aim 3

Current law, policy and service provision related to homelessness and autism has been provided. This review provided justification for involvement of clinical psychologists in supporting those with a diagnosis that have also been homeless. It also highlighted the paucity of research to inform such practice. This leads to the third research aim.

Research Aim 3: To develop theoretical framework to inform the work of clinical psychologists when working with those with a diagnosis of autism who have also been homeless.

1.6. SUMMARY OF RESEARCH AIMS

Theoretical, clinical and ethical justification of researching the processes involved in homelessness as experienced by people with a diagnosis of autism has been demonstrated. The proposed research responds to this call, undertaking a qualitative investigation of this process, prioritising the perspectives of adults with a diagnosis of autism who have been homeless and professionals who have supported them. The research has three aims:

1: To prioritise the views of those with a diagnosis of autism and experience of homelessness in the construction of knowledge relating to them.

2: To construct a model of homelessness as experienced by those with a diagnosis of autism that accounts for the complexity of this process.

3: To develop theoretical framework to inform the work of clinical psychologists when working with those with a diagnosis of autism who have also been homeless.

1. 7. RESEARCH QUESTIONS

Using the perspective of adults with a diagnosis of autism who have been homeless and professionals who support them, this research will address the following questions:

1. What processes contribute to homelessness in those with a diagnosis of autism?
2. What processes maintain homelessness in those with a diagnosis of autism?
3. What processes lead to a solution to homelessness in those with a diagnosis of autism?

The next section will set out the epistemological position and consider appropriate methods to address these research aims and questions.

2. METHODOLOGY

This chapter will outline the epistemological and ontological position of this study and then the methodological approach adopted. The design and ethical stance are then discussed. Procedures of participant recruitment and methods of data collection are described before considering the approach to analysis. The chapter ends with the positioning of the researcher in the context of this study.

2.1. EPISTEMOLOGY, ONTOLOGY, METHODOLOGY

2.1.1 Epistemology

This study is intended to help us better understand homelessness as experienced by people with a diagnosis of autism, giving priority to the perspectives of those with this experience. The study is approached within a critical realist epistemology, negotiating the dualism of realism and relativism. Critical realism questions the realist pursuit of predictable empirical realities for their simplicity. Critical realism instead suggests that the social world is the result of a complex, multi-layered, multi-causal web of interacting forces, otherwise known as 'generative mechanisms' (Bhaskar, 1978). This position therefore suggests that the pursuit of better understanding external reality is legitimate while rejecting that this can be fully known through the experimental paradigm alone.

Additionally, this position agrees with relativist notions regarding the mediating role of language, meaning-making and social context in the acquisition of knowledge; but rejects that language is productive of the social world. Critical realists therefore see a continuous interaction of generative mechanisms, ideation and reality (Hacking, 1999).

From the researchers perspective, attention is therefore focused upon uncovering the complex conditions that bring about homelessness in the autism population whilst accounting for the mediating filters of language, meaning making and social context.

2.1.2 Ontology

Ontological positions are also placed within a realist-relativist spectrum. A realist ontology asserts that there is an external reality which might be objectively and accurately measured. Relativist ontology asserts the impossibility of an objective external reality and sees that people impose their own interpretations on the world to create their own realities (Henwood and Pidgeon, 1992). A critical realist ontology maintains the existence of an external reality but questions the idea that it can ever be objectively known.

Accordingly, I consider homelessness to have an existence beyond the participant's accounts and my interpretations of them. I also acknowledge that we can come to know the reality of homelessness indirectly through our constructs (Raskin, 2008). I therefore aim to explore the accounts of participants of their experience of homelessness in order to develop a theory of the conditions which best accounts for this process, but cannot entirely reflect nor be reduced to these conditions.

2.1.3 Methodology

The version of critical realism adopted in this research is instantiated in a Grounded Theory approach. The following section outlines the rationale for adopting a Grounded Theory methodology, before exploring the central tenets of Grounded Theory. It ends with an exploration of the methodological specifics of a critical realist Grounded Theory.

2.2 GROUNDED THEORY

Grounded Theory (GT) was selected for use within this project due to its alignment with the ethical and theoretical aims of the study.

GT is unique in its attempt to move beyond rich descriptions of phenomena toward the production of theory, grounded in the data obtained by researchers (Charmaz, 2014). In this way, GT is well placed to the support ethical intention of

this research, specifically to rebalance the terrain of knowledge regarding those with an autism diagnosis, whose perspectives have classically been neglected from the production of knowledge regarding them (Milton, 2014).

GT is also seminal in its inductive approach. It aims to generate contextualized theories rather than verify existing theory (Wuest, 2012). In this way GT is well aligned to the research aim to investigate the observed phenomena of autism and homelessness, which as yet, lacks a strong theoretical framework.

2.2.1 Central Tenents of GT

Although the approach has evolved within a number of contrasting epistemological frameworks, some central tenents remain. The overarching aim of GT is to construct theoretical framework from data through processes of induction (Charmaz, 2014). Further exploration of the central tenents of this method is provided below.

2.2.1.1 The Inductive Method

GT was developed in opposition to the dominance of the hypothetico-deductive method of mid-twentieth century science. The inductive approach is based on a data driven, bottom up method, in which the researcher analyses and codes data immediately to develop theoretical analysis (Glaser & Strauss, 1967). Such methods are intended to minimise preconceived ideas about the research problem and encourage the resulting analysis to be grounded in the data (Charmaz, 2005).

2.2.1.2. The Iterative Approach

The iterative approach refers to the researchers method of raising emergent levels of analysis through going back and forth between data collection and analysis (Charmaz, 2008). This also refers to the constant comparisons between and within data, codes categories and concepts (Charmaz, 2014). This ensures that the resulting theory is grounded within participant experience (Mills, Bonner & Francis, 2006) and that the researcher is fully alerted to the convergence and

divergence of the data, allowing the researcher to attend to this within emerging categories (Charmaz, 2014).

2.2.1.3. Developing Theory

GT attempts to develop a coherent theory or model that accounts for the data. This involves a process of increasing abstraction of the data. Initial coding begins the analysis in which the researcher attempts to stay close to the words of the participants. Coding then progresses with increasing levels of abstraction using focused codes and categories that account for large amounts of data. To develop coherence of model, categories are then linked to one another to produce a model that accounts for the data (Charmaz, 2014). This can be achieved through axial coding, in which categories are related to each other and the properties and dimensions that link each category are specified (Strauss, 1987).

2.2.3 Central Tenants of a Critical Realist GT

GT has demonstrated flexibility in its ability to accommodate positions that span epistemological and ontological positions from its inception (Charmaz, 2014).

The epistemological flexibility of GT accords with that of critical realism. Critical realists propose that the central relation of social reality is of the interactions between agency and structure (Danermark, Ekstrom, M & Jakobsen, 2001). Corbin and Strauss (2008) note the importance of contextualizing action and see the consideration of structural factors as an important aspect of analysis within GT. GT is therefore well placed to attend to the interaction of social structure and individual action that are the focus of investigation this study.

Critical realism also states a primacy of ontology, maintaining the existence of an external reality but adding that the ways in which this can be come to be known is reliant on understanding the way in which it is socially constructed (Oliver, 2011). Critical realist grounded theory has its basis in symbolic interactionism, in which understandings of society and reality are understood as constructed from the interactions between communicating individuals. In this way GT methods see that

data is constructed from the interaction between researcher and participant and therefore endeavor to come to understand reality through this interaction.

Finally, a critical realist epistemology would also see all understanding as partial and tentative and therefore require a method that allows for conceptualization and reconceptualization (Pratt, 1995). This is achieved through GT attempts to make researchers more aware of their preconceptions, through methods such as reflexivity, open coding, the constant comparative method and theoretical sampling (Corbin and Strauss, 2008) these are further explored throughout this chapter.

2.3 ETHICAL ISSUES

2.3.1 Ethical stance

The focus on cognitive or social accounts of autism has dominated the terrain of research and knowledge concerning autism. The effect of such polarized academic pursuit has been to remove those with a diagnosis of autism from the process of knowledge production relating to them. Such acts result in the perpetuation of existing inequalities faced by those with a diagnosis of autism. In response, there has been a movement to reorganize the field of research to include and prioritise the views of those with a diagnosis of autism into research regarding them (Milton, 2014). By using the first hand experiences of those with a diagnosis of autism who have been homeless (in order to create a theory regarding their homelessness), this research will give voice to these issues.

2.3.2 Ethical Considerations

Ethical approval was obtained from the University of East London Ethics Committee (Appendix One) and a London based NHS Research Ethics Committee (Appendix Two). The research was also approved by the Central London Community Healthcare NHS Trust, Research & Development Department (Appendix Three). The research was developed and conducted within the BPS Codes of Human Research Ethics (2014). All participants were

fully informed of the nature and aims of the study and issues relating to confidentiality, consent and right to withdraw. Participants were offered both easy-read and standard written documentation relating to this (Appendix Four). The researcher met with all participants prior to the interview date to discuss these documents, such discussions placing particular emphasis on how participation would not impact upon the services they received. A protocol was in place to support participants who experience distress as a result of the interviews. The field supervisor and local support staff agreed to provide support for these participants if necessary in addition to participants being given an information sheet detailing organisations that may be able to offer support and guidance (Appendix Five). A full debrief was provided at the end of the interview and the contact details of the researcher given to allow participants to ask further questions regarding the study after the interview was completed. Records of the participant's names or contact details were stored within a password protected file. All transcripts were stored within a separate password protected data file stored in isolation from the personal details. All identifiable details were anonymised or removed from the transcript. Only the researcher, supervisors and examiners had access to the full data set. The audio-tapes of the interviews will be deleted following the submission of the thesis (July 2017). The completed transcript was achieved within two months of the interview.

2.4 DESIGN

This study will construct a model of homelessness as experienced by adults with a diagnosis of autism. It is acknowledged that many forms of data, both qualitative and quantitative, can be collected for analysis within a critical realist GT. This has intention of affording completeness within theoretical categories. However, as logistical and ethical constraints limited breadth of data collection, the decision was made to conduct semi-structured interviews, following the iterative approach in which data collection and analysis ran concurrently.

2.5. PROCEDURE

2.5.1. Observations Within Services

Professionals in adult autism services and homelessness services within an inner London borough identified service users known to both services. This led to collaborative work between the services to support homeless adults with a diagnosis of autism into stable accommodation. Outcomes of this support have been variable (Homeless Link, 2015). Anecdotally, services have reported this to be a difficult process due to the paucity of evidence and clinical guidance relating to autism and homelessness. The services in question therefore approached the University of East London requesting statement of interests from Professional Doctorate in Clinical Psychology students to undertake this research as part of their research training and experience.

2.5.2. Sampling

GT uses theoretical sampling, where people, events or information are pursued to develop the properties of developing theory. This helps to refine the properties, boundaries and relevance of categories on which theory is based (Charmaz, 2014). Initial sampling was therefore purposive and participants were recruited based upon their position across the homelessness spectrum. This increased the diversity of data and allowed for comparative potential (Barbour, 2008). The initial tranche (n=3) therefore included people with a breadth of homelessness experience namely, temporary accommodation (n=1), sofa surfing (n=1) and long term rough sleeping (n=1).

Following the identification of the initial sample, theoretical sampling was adopted following leads and concepts as they emerged within the data, within the parameters of the inclusion criteria below. This resulted in the recruitment of three more participants with a diagnosis of autism and three professionals that had offered them support (Appendix Six). As the decision to include professionals within the sample was influenced by the emerging themes from the data provided

by those with a diagnosis of autism this sampling was considered as complementary to the emancipatory ethical stance of the project.

2.5.3. Inclusion Criteria

2.5.3.1. Age

As this research will consider homelessness in adults with a diagnosis of autism, adults over the age of 18 were included. There was no upper age limit.

2.5.3.2. Status of Autism Diagnosis

This research is positioned within a critical realist epistemology and therefore asserts that the specific behaviours and communication associated with autism exist independently from the ways in which these are constructed socially. In addition, it sees that diagnostic categories, such as autism are inherently shaped by social forces and are therefore historically and culturally relative. In this way, I see autism as a construct that has developed as useful within this historical and social context and describes the correlation of observable behavioural traits. Accordingly, to ensure that participants had an autism diagnosis, participants were either recruited from services where a qualified professional made a diagnosis or participants were asked to provide documentation relating to their diagnosis. As some participants were unable to provide full assessment reports, documents regarding autism diagnosis from autism services were accepted.

2.5.3.3. Status of Homelessness

As this research aims to develop a theory of homelessness in an under researched population, a broad definition of homelessness is required to develop an initial theory that attempts to cover the breadth of the homelessness condition. Homelessness was therefore defined using Anderson and Christian's (2003) terms, include rough sleeping, living in temporary accommodation and living within intolerable physical conditions. Participants who reported experiencing any of these conditions were included in the study. As the research aimed to explore

factors into and out of homelessness, only participants who were currently housed were included in the study.

2.5.3.4. Learning Disability

In the preliminary meeting and demographic screen none of the participants disclosed having a diagnosis of learning disability. In addition, no evidence or suspicion of learning disability emerged during subsequent interviews.

2.5.4. Recruitment of Participants

Participants were recruited from the following services:

- An Inner London Adult Autism Assessment and Diagnosis Service (within a large NHS Trust in London)
- Third Sector Adult Autism Service (National Autistic Society (NAS))
- Academic Conference on Homelessness

Leads within each service were contacted initially and the project aims and remit was discussed. Professionals were asked to identify potential participants. For each potential participant a nominated professional provided potential participants with information about the study. I then met with each participant and their nominated individual, if they requested this, for a preliminary meeting. This meeting provided more detailed information regarding the rationale for the study and provided a space for participants to ask further questions relating to the study. A time, date and location of interview proper was then negotiated and agreed. All participants were given the option of having someone present during the interview.

2.5.5. Payment

Service user participants were given a £10 voucher for taking part in the interview. This was funded by the University of East London. This payment was

aimed to promote a sense of mutual transaction through acknowledging the expertise provided by each participant (Walmsley, 2001). This was also decided after consultation with professionals within homelessness services who raised concerns relating to the “hard to reach nature” of this group and advised that a £10 voucher would be appropriate.

Potential participants were informed about the payments within the preliminary meeting. Participants were informed at the beginning of the interview that they would receive payment and not be requested to return the money should they wish to terminate the interview.

2.5.6. Profile of Participants

Six people, one female and five males, with a diagnosis of autism and experience of homelessness were interviewed. Three professionals, all male, who had supported somebody with a known diagnosis of autism through their homelessness, were interviewed. The profile of participants is provided in the table below, demographic information relates to the person who experienced homelessness, rather than the professionals that supported them. Unfortunately, S2, was unable to provide this information.

Table 1: Profile of participants

Profile of Participant	Participant Identifier	Description of Homelessness	Gender	Age	Ethnicity
Personal Experience of Homelessness	P1	Unstable Accommodation	Male	31	White British
Personal Experience of Homelessness	P2	Sofa Surfing	Male	51	British Canadian
Personal Experience of Homelessness	P3	Rough Sleeping	Male	60	White British
Personal Experience of Homelessness	P4	Rough Sleeping	Female	56	French
Personal Experience of Homelessness	P5	Hostels	Male/Intersex	63	English
Personal Experience of Homelessness	P6	Hostels, Rough Sleeping, Unstable Accommodation	Male	40	White British
Professional- Autism Project Co-ordinator	S1	Male	Male	56	French
Professional- Homelessness Engagement Worker	S2	Male	Male	-	-
Professional General Practitioner (GP)	S3	Male	Male	55-50	White British

Regarding gender, the sample may be suggested to have an adequate male/female ratio when compared with population means of adults with a diagnosis of autism (Werling & Geschwind, 2013). There is also a varied representation of age. The sample contains participants from European and North American countries and may be suggested to lack representation from other ethnic groups. A survey by the NAS indicated an under representation of people from Black, Asian and Minority Ethnic (BAME) communities within autism services (NAS, 2014). The survey suggested that issues relating to knowledge of the autism diagnosis, stigma and poor accessibility of services for BAME groups may contribute to this under representation. Such issues are likely to have affected the recruitment pool for this research.

2.5.7. Interview

Interviews took between 50 and 130 minutes. Participants were informed about the process of recording prior to the interview. Participants were then asked to sign a consent form (Appendix Seven). Participants with a diagnosis of autism were offered the choice of interview within NHS or NAS offices. Professional participants were interviewed at their place of work. All interviews were held within a confidential space. All participants were reminded of the purpose of the study, the clauses of confidentiality and their right to withdraw. The interview schedule (Appendix Eight) broadly guided the interview addressing the following areas:

- The factors that led to the homelessness experience
- The factors that maintained the homelessness experience
- The factors that led to the person's current living circumstances

Participants with a diagnosis of autism were asked to speak from their own experience. Professional participants were asked to speak from their perspective, referring to one person that they had supported.

As research is a political act and therefore has the potential to further exploit and disempower vulnerable groups (Swain, Heyman & Gillman, 1998) careful consideration was made regarding the inherent power imbalance between researcher and participants through the following adaptations.

All participants with a diagnosis of autism were offered a pre interview meeting to discuss the emancipatory and service development agenda of the research. This attempted to reduce the potential of interviews to recreate familiar contexts in which people with disabilities feel their views are invalid or misunderstood (Lewis and Porter, 2004)

Interview schedules shared and negotiated with the participant prior to the interview and referred across each phase of the interview process. This was intended to increase the predictability of the interview, in order to reduce

participant anxiety and power differential between participant and researcher (MacLeod, Lewis and Robertson, 2014).

All participants were offered time to debrief at the end of the interview and were given time to consider any unexpected emotional response that may have been fostered within the interview. Participants were provided with details of after-care along with contact details of the field supervisor or professional support staff and Head of Psychology, should they wish to discuss any concerns relating to the research.

2.5.8. Analysis

I drew from the GT guidelines of Charmaz (2014) working from a Critical Realist epistemology. The analysis process was iterative in nature, with a constant comparison between data collection and analysis, using methods of transcription, coding, and diagramming.

3.5.9. Transcription

As the focus of analysis was macro-level content rather than micro level organisation of language or discourse, a simple approach to transcription was used (Langdrige & Hagger-Johnson, 2009) following Parker's (2005) transcription scheme. Transcription was performed by the researcher as a way to strengthen the bond between participant perspective and resulting analysis (Langdrige and Hagger-Johnson, 2009). During this process identifiable information was removed. A concurrent approach to data collection and analysis was performed through the progressive nature of transcription, coding, memo writing and amendment of interview schedules (Appendix Six) in attempt to create an inductive theory developed from the data (Glaser and Strauss, 1967).

2.5.10. Coding

Charmaz (2014) GT coding guidelines were selected for their suitability to critical realist enquiry. Coding consisted of four contemporaneous stages as detailed below. Each stage supported abstraction of codes to model, whilst also

maintaining the grounding of the model in the data. Memos supported the articulation of ideas relating to the analytic steps taken to raise codes to categories to model (Appendix Nine).

2.5.10.1. Initial Coding

Initial coding involves the researcher coding each line data with a code that remains as close as possible to the words of the participant. This includes the use of in vivo codes, or codes taken from the exact words of the participant (Charmaz, 2014). Initial coding also involves coding with gerunds, or verb forms which act as a noun (*e.g. being accepted*) this support the development of active code that detail process (Appendix Ten).

2.5.10.2. Focused Coding

Focused coding involves the researcher reviewing initial codes for both frequency, salience and significance through comparing initial codes to the data and other codes. This resulted in the selection and refinement of initial codes that best account for larger segments of data (Appendix Ten).

2.5.10.3. Codes to Categories

Focused codes are then treated as tentative categories and reviewed for their ability to account for themes running throughout the data. This involves the selection of focused codes that account for themes across the data and refining their wording for conceptual reach. Again such categories are compared back to data, codes and other categories to test their salience and significance (Appendix Eleven).

2.5.10.4. Axial Coding

Axial coding was employed to develop coherence within and between categories, reassembling the fragmentation of data from initial coding. This consisted of relating categories to each other and specifying the properties and dimensions that link each category (Appendix Twelve).

2.5.10.5. Diagramming

Diagramming was used throughout the coding process to provide visual representations of the categories, their relationships and connections. Diagramming ran contemporaneously across data collection and coding (Appendix Twelve).

2.6. ENSURING RIGOUR

To ensure rigour of qualitative method, Yardley's (2000) guidelines were followed to inform method. These guidelines consider sensitivity to context; commitment, rigour and coherence; and transparency as necessary methodological processes.

2.6.1. Sensitivity to Context

Yardley (2000) suggests assessing sensitivity to context regards the facets of sensitivity to theory as well as sensitivity to social cultural context. This is achieved in GT through the use of memos to demonstrate their evidence of developing theoretical dimensions (Appendix Nine).

2.6.2. Commitment and Rigour

The concept of commitment regards the extent to which the researcher demonstrates prolonged engagement in the topic and develops skill in method (Yardley, 2000). This will be achieved through a detailed process of initial, focused and axial coding supported through memo writing and reflexive journals (Appendix Nine, Ten, Twelve and Thirteen).

The concept of rigour relates to the completeness of data collection and how the sample is able to supply all the details needed for a comprehensive analysis (Yardley, 2000). This is achieved in GT through triangulation, or the bridging together of data gained from both the perspectives this stimulate further interrogation of emergent contradictions, allowing for a more nuanced understanding of the issues (Olsen, 2004). This was achieved through the recruitment of both participants with a diagnosis of autism and professionals that had supported them.

2.6.3. Transparency and Reflexivity

Theoretical orientations and personal anticipations both in advance and throughout the research should be recognized and the role these play in the developing understanding accounted for and impacts on the developing analysis considered (Yardley, 2000). In GT, this is achieved through the use of a reflexive journal, in which the researcher examines how their researchers interests, positions and assumptions influence their enquiry of the subject (Charmaz, 2014). The stance entering the research is explored below and experts from the reflective journal used throughout data collection and analysis are provided in Appendix Thirteen.

With regards to research interests, I have a strong professional background working within adult learning disabilities services in which the social model of disability (Shakespeare, 2006) has mediated my perception of this group. I therefore challenge the individual deficit view of disability and instead attempt to respond to the social, political cultural and economical factors that perpetuate disability. This enquiry led me to seek a project that would enable the further exploration of the social barriers that influence people with a diagnosis of autism. I therefore approached this project from its conception with the consideration that homelessness may be a further demonstration of a disabling social environment rather than simply the result of impairment associated with and autism diagnosis.

Regarding my positioning to the subject matter, I see both the constructs of autism and homelessness as meaningful and necessary within this historical context whilst acknowledging their temporal boundaries. I also acknowledge their fallibility and the political agendas that such labels serve. Regarding my position on autism, I see neither explanations relating to social barriers or individual impairment as adequate in providing a fully informed understanding of the difficulties associated with the autism diagnosis nor the possible factors relating to their homelessness. I consider such polarized understandings as a product of academic pursuit rather than the result of knowledge produced and accepted by those with a diagnosis of autism. I therefore endeavor to pursue the experiences of those with a diagnosis of autism (and front line professionals as resulting from

theoretical sampling) in order to appose these polarized academic perspectives and to work towards the development of nuanced model of homelessness in this population that is able to account for the interaction between individual and structure.

Regarding my position on homelessness, again I see neither social or individual explanations as adequate in understanding factors related to homelessness and endeavor to explore the complex interaction between them both. As a trainee clinical psychologist and healthcare professional I also see that I have an ethical duty to respect, protect and fulfill the human rights of those I work with (BPS, 2011). As homelessness risks the violation of a number of articles within the Human Rights Act (Lynch & Cole, 2003), I see it as an ethical duty to find a solution to homelessness. I therefore adopt the position that homelessness is a problem for those with a diagnosis of autism and this research will attempt to locate its solution.

These perceptions were considered as “sensitising concepts” (Charmaz, 2014) in the beginning of the analysis, and were held as tentative ideas to pursue and guide rather than command my enquiry.

3. ANALYSIS

This chapter sets out the grounded theory analysis, following the methods described in the previous chapter. The model depicting the core process relating homelessness as experienced by people with a diagnosis of autism shall be presented first, before moving onto a detailed analysis of each section of the model.

3.1 THE GROUNDED THEORY MODEL: LOSING AND GAINING CONNECTION

The “Losing and Gaining Connection Model” constructed from the participant’s data is presented within Figure 2. The model was inducted from the account of participants through a process of initial, focused and axial coding as discussed within the methods section. It is acknowledged that within these forms of coding no one category or model can fully characterize the entirety of participant’s narratives. As such, the “Losing and Gaining Connection Model” was felt to most adequately represent participant’s perspectives.

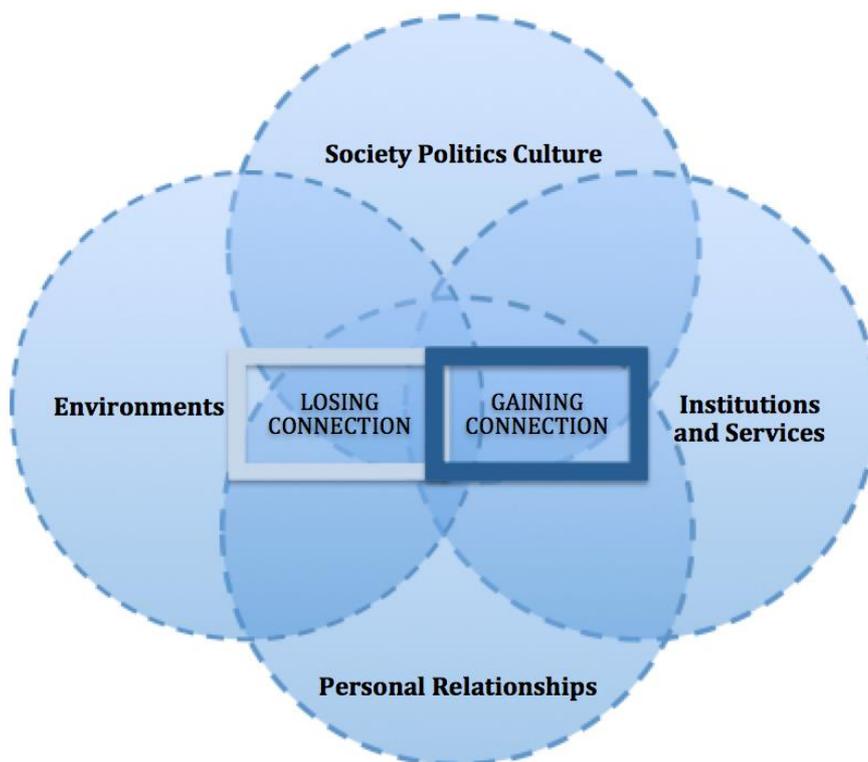


Figure 2: “Losing and Gaining Connection”

The model depicted in Figure 2 is composed of four sets of overlapping contexts. Each set represents a context possible to bring about or end homelessness, with boundaries closest to the center representing the overlap of sets and therefore increased possibility of homelessness. Each set is contained within a perforated boundary representing the changing influence of each context over time. Traversing each context is the core theoretical process of “Losing and Gaining Connection”.

“Losing Connection” was the dominant process described by participants leading to homelessness. “Gaining Connection” was the dominant process described by participants during and following homelessness. However, participants described a constant oscillation between these processes prior to, during and after homelessness. Therefore the borders of “Losing and Gaining Connection” are overlapping within the model to represent this constant oscillation.

“Losing Connection” was developed from data from every interview. It represents the dominant process described by participants that lead up to homelessness. Participants described how four contexts; society politics and culture, institutions and services, personal relationships and environments, limited the lives of those with a diagnosis of autism. People with a diagnosis of autism responded to such limiting contexts through disconnecting with them, resulting in homelessness.

“Gaining Connection” was also developed from narratives across all interviews. This represents the dominant process described by participants during and following homelessness. Participants described how during and following homelessness people with a diagnosis of autism and their networks acted in flexible ways to respond and transform the contexts that previously limited the lives of people with a diagnosis of autism. This resulted in people with a diagnosis of autism gaining connection to such contexts. A detailed analysis of the model is provided below.

3.2 DETAILED ANALYSIS OF THE MODEL

The two core processes “Losing and Gaining Connection” will now be discussed in terms of their interaction with each of the contextual structures outlined in Figure 2. These core processes are detailed through the exploration of categories, codes and quotes that they were inducted from. Double quotation marks are given to in vivo codes, or codes that were inducted from the direct words of the participants.

3.2.1 Society, Politics and Culture

The “Society, Politics and Culture” context relates to how those with a diagnosis of autism lost their connection to society. This loss is defined by a process of understanding the self as different and separate to others within society. This loss of connection is also defined by a loss of protection from the state. Connection to a new form of society is gained by becoming homeless. Those with a diagnosis of autism were integrated into tolerant, understanding and accepting communities. Within homelessness, those with a diagnosis of autism were repositioned as worthy and eligible for support and protection from the state.

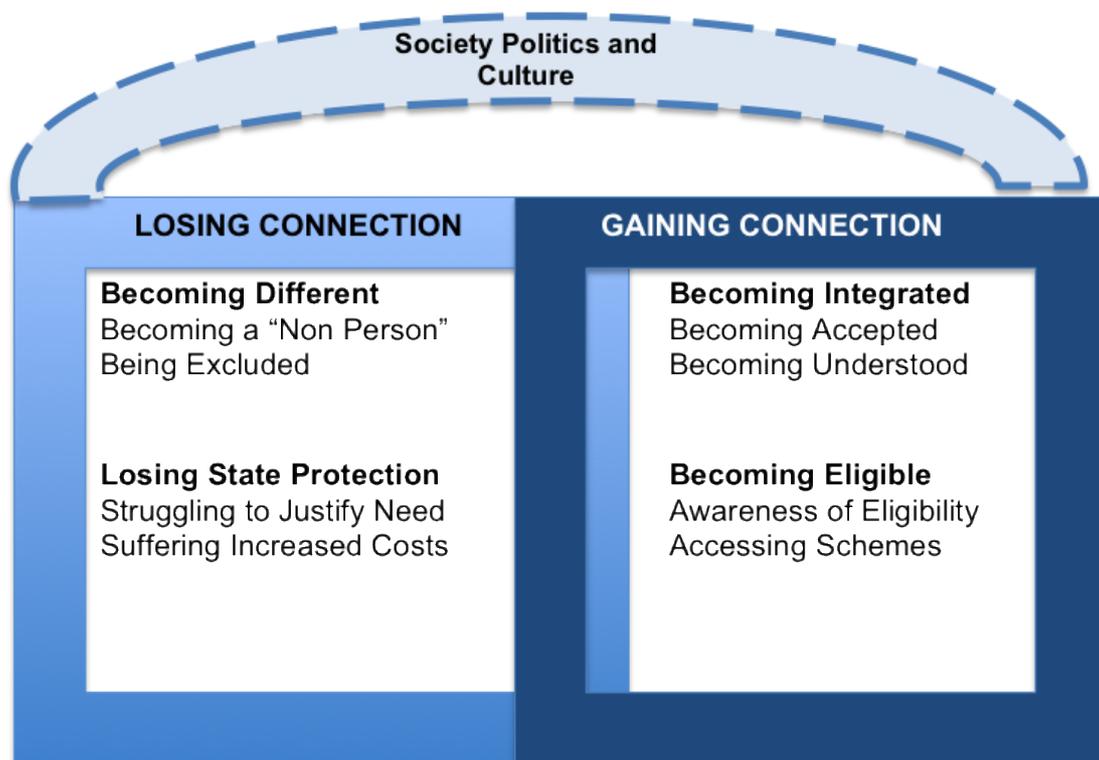


Figure 3: Society, Politics and Culture Context

3.2.1.1. Becoming Different

The “Becoming Different” category includes how people with a diagnosis of autism compared themselves to other members of society. This developing sense of self as different to other members of society punctuated their pathway into homelessness. Processes such as comparison, rejection and exclusion defined this developing sense of self as different.

Becoming a “Non-Person”

Through a process of comparison, participants with a diagnosis of autism developed an identity of difference between self and other members of society. This resulted in a distancing between self and other members of society.

P3 compares themselves to others within society. Through this comparison they conclude that having a diagnosis of autism allows freedom and distance from the

social obligations of society. Homelessness seems to allow further disconnection from such obligations:

“I think perhaps people on the spectrum don’t feel that they are part of society in quite the same way as most other people would. They don’t feel they have some obligation to interact all the time or show interest in other people. So being kind of disconnected, I think is can be quite appealing. I don’t know if that makes much sense but that what I meant by non-person.” (P3, 1111-1117).

In the following quote, P4 observes a lack of integrity in others. His difficulty in making sense of this creates a distancing between self and other:

“In a way you know, how many...how many different personality (sic) do people have in their lives, one at home, one work, one with acquaintance, one with close friends, and each time they swap. I can’t do that. What you see is what you get.” (P4, 480-484).

Being Excluded

The participants with a diagnosis of autism explored the multiple ways in which they felt they were excluded by society. This exclusion became an integral aspect of a person’s disconnection with society throughout their pathway into homelessness.

P4 uses the metaphor of a train to demonstrate their life as a journey. This journey is defined by a sense of hoping for inclusion and being met with exclusion from society.

“...you are part of a train which is life. And most of it you spend it either waiting on the platform, waiting for the next one, but nobody come (sic), or when you get on the train, people said excuse (me) sir, it is not your train, you should go out. And you feel like, why?” (P4, 564-569).

Other participants discussed how abuse resulted in exclusion:

“...minding your own business walking to Colchester station, minding my own business. People taking the right... you’re not offended by swearing? People taking the right piss out of you. One person said “Oh that person wants to hit you”, and all this stuff”.” (P2, 1165-1169).

This exclusion also intersected with other forms of difference causing participants to question their place within society, as described by P4:

“I was gay on top of that and that didn’t go very well. I was considered as a pervert or whatever, so you know there was a lot of rejection on various levels. So anyway you can completely...probably... psychologically squashed you know, feel like, why am I here?” (P4, 151-156).

3.2.1.2. Losing State Protection

The “Losing State Protection” category includes how people with a diagnosis of autism lost state controlled welfare provisions, such as income and housing. This increasing difficulty in obtaining income and maintaining housing was integral in the developing homelessness of people with a diagnosis of autism. These processes were connected to the political and economic contexts of the time, in which those with a diagnosis of autism struggled with increased costs and decreased welfare provisions. Processes such as struggling to justify need for support and suffering increased costs punctuated this loss of state protection.

Struggling to Justify Need

Within this code, both participants with a diagnosis of autism and professional participants explored how they faced pressure to justify need for state protection within restricted economic contexts. Through this process the participants explored their exclusion and disconnection from economy and state.

S1 and S3 describe the constant process of justification when discussing an individual’s receipt of Disability Living Allowance:

“Every couple of years we’ll have to keep having to justifying that to another squeezing system” (S1, 595-596).

“He did get benefits and I think Disability Living Allowance, erm, but then there was a problem. You know, because people have to attend assessments or send back documents, and I think he went through a period when he lost his benefits for a bit because he didn’t do something like attend an appointment.” (S3, 183-189).

P4 also explored how despite clear vulnerabilities in their housing, they remained unable to justify their need for support:

“He was waiting for me to be on the pavement with my belongings to do... actually, he couldn’t do anything” (P4, 1652-1654).

Suffering Increased Costs

Within this code, participants discussed increasing economic costs and reducing benefits. Within this context of reduced state support, people with a diagnosis of autism gradually lose their connection to protection from the state.

S1 and P2 discussed how increased costs were not met by increased benefits:

“Two years ago, the rent was increased on the property and he’s unemployed, has housing benefit and it was looking like that wasn’t going to be able to be covered.” (S1, 54-57).

“And then because, all of my rent, my rent was £750 and housing benefit was £750 and then after the first year, it went up £25. It went to £775 per month. So then I had to then top up that money.” (P2, 315-319).

P4 discussed how these increased costs intersected with cuts to benefits:

'...the bill keep(s) going up, the benefit doesn't go up and you, it means, there has been a review and they give me half of it, of my DLA now.' (P4, 1617-1619).

3.2.1.3. Becoming Integrated

The "Becoming Integrated" category relates to the integration and reconnection of people with a diagnosis of autism into society, which was lost in their transition into homelessness. This reconnection and integration was achieved through communities demonstrating an understanding and acceptance of people with a diagnosis of autism.

Becoming Accepted

"Becoming accepted" by others was a key driver in the reconnection and integration of people with a diagnosis of autism into society. This acceptance seemed to relate to an increased recognition and tolerance towards people with a diagnosis of autism. Acceptance helped participants to build connections and become integrated into communities both during and following homelessness.

P3 explored how the homeless community demonstrated an acceptance of their difficulties in social communication. This allowed P3 to feel more at ease within the homeless community:

[PG: "And you said that they are more accepting is that right?"]

"Yeah I think so. So I think its perhaps part of the reason why some autistic people may not find it difficult being homeless."

[PG: "Can you tell me a bit more about what you meant by that?"]

"Well because in normal life people are expected to behave in a certain way and to be keen on socialising with other people and to talk in a particular way and to understand nuances and emotions and things like that. But the expectation is much less for homeless people, so it may be a bit easier for autistic people." (P3, 951-966)

P2 discussed the importance of living within an accepting community after homelessness:

“...but that’s not my main reason, it’s because of the Asperger’s groups and I feel I’m traveling within the community.” (P2, 1378-1379).

Finally, when discussing their relationship to society, P4 described their hopes for acceptance to allow for their reintegration into society:

“If you, if they feel accepted and not exploited, you’re going to encourage many people. Nobody want to live in bubble all his life and miss the opportunity of life.” (P4, 1524-1527).

However, P5 reveals the temporality of new accepting relationships developed following homelessness:

[PG: “Did you meet some friends there?”]

“Yeah and of course I’ve lost touch with everybody.”

[PG: “Yeah, and how did that happen?”]

“Well the place fizzled out and the hotel closed, er, I did see some people for a while afterwards but then it gradually sort of disappeared.” (P5, 1157-1167).

This example provides evidence for the constant oscillation of losing and gaining connection across the homelessness journey.

Becoming Understood

Becoming understood also related strongly to having a diagnostic term such as autism. This term seemed to provide a framework for society to understand and adapt to the needs of those with a diagnosis of autism.

This was reflected in professional’s accounts. S2 and S3 stated how the framework of autism and its associated traits allowed them to develop a connection with the people they supported:

“It’s a recognition that they have difficulties and a framework for understanding those difficulties and for other people to appreciate them and help them manage them. So the diagnosis is very helpful” (S3, 671-675).

“Erm, it gave us a bit better... a better understanding of what the person was going through and it gave a better understanding of what some of his behaviours were, what the reason of the behaviour were.” (S2, 707-711).

P5 predicted that a diagnosis would have created an understanding of specific difficulty and acted to protect them from job loss and resulting homelessness. However P5 also adds that barriers to gaining employment may remain:

“I suppose if I’d know that I’d had the diagnosis in the first place I’d never had got the job. I wouldn’t have passed the medical, so you can’t win. I don’t know. But I suppose if I’d got the diagnosis after I was working there, I would have been able to not accept the promotion and, and probably not get the sack.” (P5, 701-707).

3.2.1.4. Becoming Eligible

The “Becoming Eligible” category relates to how homelessness repositioned people with a diagnosis of autism as worthy of state support, despite continual contexts of restricted welfare policies. This repositioning as worthy allowed those with a diagnosis of autism to access to financial and housing resources, resulting in their reconnection to homes.

Awareness of Eligibility

Both P4 and P5 discuss how their connection to homelessness services allowed them to become aware of their eligibility for support. This contrasted with previous perceptions of self as ineligible to state support:

“I didn’t know what I was entitled of, it means, you know, everything I have, it means because at some point I have people who open the door and they

said “But Rob, you are entitled to have some help.” Because I never had any in my life, I was just carrying on like that.” (P4, 1444-1446).

“...they had a benefits expert solicitor from the local law center, came in every Monday, and you could see him. And then he would deal with it until it was done. So things like DLA were much less of a problem.”

[PG: “And did you struggle to do that before?”]

“I’d never claimed anything before, I’d lived 12 years with no money, because it never occurred to me to claim.” (P5, 172- 182).

Accessing Schemes

Homelessness also allowed people with a diagnosis of autism to access schemes for council housing.

P3 and P6 noted council housing was accessed as a consequence of their homelessness.

“Um, after a few times of seeing him a woman took over from him and um, she told me that the (an inner city London) Council provide council flats for 6 people every year who have been sleeping rough in (Inner City London borough) for more than three years.” (P3, 1523-1529).

“...yeah it was just twice a year that the council had a quota of a certain amount of flats that they would give to the rough sleeping pathway hostel and homeless projects.” (P6, 1403-1407).

“And it was roughly like an 18 months stay project and from there they had twice a year nominations. So I was one of the nominations within a certain period to go to the local authority and they offered me a flat.” (P6, 1367-1372).

3.2.2 Institutions and Services Context

The institutions and services context relates to how people with a diagnosis of autism interacted with health, social care and voluntary agencies. It demonstrates a gradual disconnection with institutions and services as these become unable to meet the needs of people with a diagnosis of autism. Within and following homelessness people with a diagnosis of autism experience a reconnection with institutions as institutions develop an ability to meet their needs.

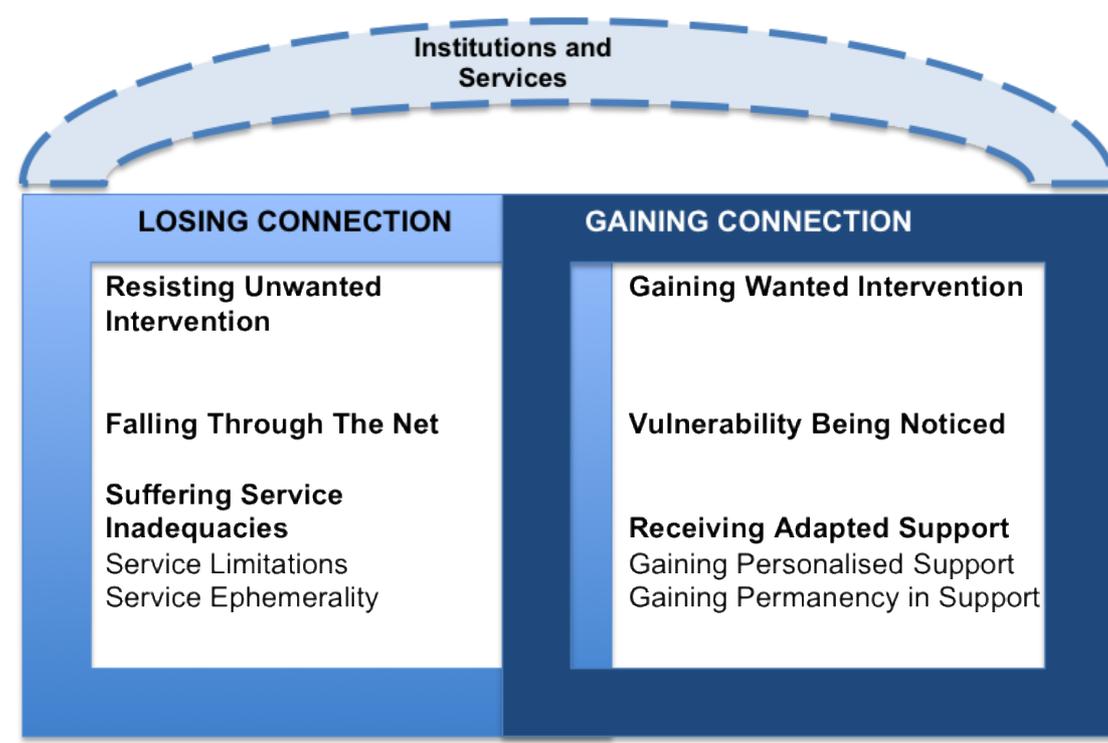


Figure 4: Institutions and Services Context

3.2.2.1. Resisting Unwanted Intervention

This category regards the experiences of people with a diagnosis of autism of services offered to them within their pathway into homelessness. It demonstrates how people with a diagnosis of autism sometimes found interventions forceful and unwanted. Unwanted intervention was coped with through forms of resistance, which included escape and defiance. This resistance created a

developing disconnection between people with a diagnosis of autism and institutions.

P3 suggested an increased inability to cope with interventions by debt collectors. P3 coped with such intervention through escape into homelessness. Homelessness therefore became a way of achieving distance from these institutions:

“...and then got into quite a lot of debt and I couldn’t seem to see a way out of it, so, I was thinking of killing myself. But then, when it actually came to it I couldn’t go through with it and I thought as an alternative I could just walk out of my flat and leave things behind and try sleeping rough”. (P3, 13-19)

Other participants discuss how their resistance to enforced intervention was met with stronger enforcement of intervention by institutions:

“...and when I tried to go back to work, they said I couldn’t go back to work unless I’d been signed off, off the sick. Er, and I said I’m coming back anyway, and they got me sectioned.” (P5, 527-531).

When discussing a possible enforced move out of their community, P2 explores the extent to which they would resist this:

*“And some people move, end up having to move to places like Stoke and Birmingham.
[PG: “Yeah and is that, that one of the reasons...”]
(Interrupting) “I would rather, I would rather sleep on a bed of nails than move up there. Well in fact I’d rather sleep on a bed of nails than move out of Haringey.” (P2, 1209-1217).*

Participants also discussed how they received unwanted intervention regarding employment.

P4 explores the pressures to find employment by the DWP:

“And to have a diagnosis could take a long, long time and I was so anxious, because it means you know, it is all about timing again, if you can’t provide the reason why you are not working or why you are not well, on time, it (is) disastrous.” (P4, 1737-1741).

Professional participants also provided accounts of unwanted interventions. S3 discusses the assessment of needs performed staff within the Department of Work and Pensions and how it pressures those with a diagnosis of autism into employment:

“Yes, they will go for an assessment and they will find them fit to work, because they can walk in and they can lift things up and they can talk, and no one has written autism, so they say “right your fit to work”. And then they’ve got to go and look for work and they can’t to it, they are terrified by it, so they risk losing their benefits” (S3, 725-726).

3.2.2.2. Falling Through the Net

Participants with a diagnosis of autism explored how even when they received a diagnosis, they remained excluded from services. Participants seemed to fall through the net of services, becoming ineligible for mainstream support but lacking access to autism specific services.

P5 explored how gaining a diagnosis of autism created difficulties for them in gaining access to support:

“I thought that once I was diagnosed that I was going to get...that it would be better but it wasn’t. It was the worse thing that ever happened. Because then all the services from mental health or whatever just stopped dead” (P5, 441-445.)

“...although your allowed to have that sort of support for mental illness you’re not allowed to have it for Autism. So it just stops, so in that respect getting a diagnosis doesn’t actually help.” (P5, 782-785).

Professional participants gave similar accounts. S3 discusses how conceptualisations of functioning can miss the nuances of vulnerably presented by those with a diagnosis of autism, leading to ineligibility for support:

“...this is a very long term problem with someone who can sometimes be pretty highly functioning and doesn’t immediately cross the threshold for these services, the bar is too high for them.” (S3, 271-275).

S2 and S3 explore how an autism diagnosis may have allowed services to protect individuals from losing their homes:

“...but if he had had that diagnosis before then there could have been some support available, maybe more awareness from those around him that he would need this support” (S3, 243-247).

“...I don’t know if they were officially diagnosed. Erm, probably yes because it may have been more difficult to make them homeless.” (S2, 60-63).

3.2.2.3. Suffering Service Inadequacies

This category demonstrates an inability of services to meet the needs and wishes of people with a diagnosis of autism. It describes how people with a diagnosis of autism struggled to cope with the limited, rigid and ephemeral nature of services. This acted to maintain the distance between people with a diagnosis of autism and institutions.

Service Limitations

Participants with a diagnosis of autism explored how services and professionals were often unable to provide services that met their needs and requirements.

P2 references dissatisfaction with his support worker and their inability to advocate for his preferences regarding housing:

“I mean it seemed to be, one person says and he’ll agree with what the other person says. He doesn’t seem to...well at one point it seemed as though he was going along with erm... I dunno. He didn’t seem to have an opinion.” (P2, 236-239).

P4 discusses how lacking resources create limitations in service provision offered to those with a diagnosis of autism:

“But between what you want and what’s on offer, you know, as we say the most beautiful girl can’t give you what she doesn’t have.” (P4, 1856-1859).

Professional participants reinforced such accounts. S2 explores how location specific support can create limitations on support offered:

“It depends what area you are in, so if you are in London or Central London, there’s more homelessness services in Central London but if you go to outer areas, if you go to mid Sussex or somewhere like that, there is virtually nothing.” (S3, 76-81).

However, P3 explored how services remained rigid during their homelessness. This acted to maintain the disconnection of P3 from institutions within homelessness:

“...he did then try and get me to stay in a bed and breakfast for a few days and he did give me the list of these phone numbers of B and B’s that took people on housing benefit and they were awful anyway. I’d heard the kind of places that keep ex homeless people are not very nice anyway so, I wasn’t sure I wanted to do that anyway so. I just carried on sleeping in the subways.” (P3, 1469-1479).

The above example provides evidence for the constant oscillation between losing and gaining connection during homelessness.

Service Ephemerality

Professional participants discussed how the temporary nature of services might increase the risk of homelessness in those with a diagnosis of autism. S1 discusses how the “pillar” of support from services is at risk of loss of funding:

“Those three pillars are all very fragile as well, as well as the flat, and they could easily fall away, suddenly our project doesn’t get re tendered, or, we only really live well pretty much year to year.” (S1, 465-470)

S2 discusses the lacking of sustainability in hostel institutions:

“...and the reality is sustainability doesn’t exist anymore. Not in that sense, not forever, you’ve got a maximum amount of time you can keep somebody, erm, once you get to a point that you’ve, you’ve got to a point where they can move somewhere else, then that’s what you’re expected to do so other people can come in.” (S2, 944-951).

S3 discusses staff turnover and the impact this has on consistency of support for people with a diagnosis of autism:

“Erm, and even if they did the person would probably not be around for long periods, people are always moving jobs and so...” (S3, 250-253).

Participants with a diagnosis of autism also discussed the relation between loss of services and homelessness:

“I mean I see people that I used to know, who were doing quite well when I went to MIND and I see them sleeping in a doorway somewhere. I find that very disturbing.” (P5, 797-800).

3.2.2.4. Gaining Wanted Intervention

This category explores how people with a diagnosis of autism used resources to create wanted and needed intervention. This was often achieved through gaining connections to advocates who were able to support, change and adapt institutional support on their behalf. This allowed people with a diagnosis of autism to begin to access housing, maintain housing or prevent eviction from housing.

P2 explores how the advocacy of a support worker (Andrew)¹ and mental health services created flexibility within the council to maintain their housing:

“I think Andrew perhaps, my ex support worker now, I think perhaps he ended up speaking, I dunno. We ended up going to the council a couple of times and all that.”

[PG: “Do you know what he did?”]

“I ended up staying in the place. And also the mental health team didn’t want me to move out either, they wanted me to stay there.” (P2, 1362-1370).

The process of gaining wanted intervention was also described by professionals. S3 describes an awareness of their own power as a GP to support the access to housing of his patients:

“...being able to give authoritative support to applications and so on, that make things happen, er, like vulnerability assessments, housing assessments, benefits assessments that sort of thing.” (S3, 546-550).

S1 describes how the input of a friend with housing experience was useful in challenging their risk of eviction:

“I imagine he’s incredibly wealthy. I don’t know what industry he works in, but there’s something to do with just working with people, it might be

¹ Andrew is a pseudonym

property that he's in. But he weaved some kind of black magic. And the person that I support, I don't think is privy entirely to what's happened" (S1, 349-353).

3.2.2.5. Vulnerability Being Noticed

This category relates to the gradual inclusion of people with a diagnosis of autism into institutions. It relates to how people with a diagnosis of autism become repositioned as vulnerable within homelessness. Such an acknowledgement of vulnerability allowed people with a diagnosis of autism to become included in and connected to, institutions.

P6 explores the link between services noticing their vulnerability and their access to housing. This observed vulnerability was the result of having clear signs of physical abuse:

"...and erm, the housing worker came in the morning, took one look at me and told me to go to the housing office. So I went down there and they interviewed me and they immediately said "you can have the room!" (P6, 1362-1366).

The subtlety of vulnerability was explored in the professional's accounts, where they described detecting a vague rather than obvious vulnerability:

"We knew there was something there. What wasn't known was how to deal with him. So that was more our, our sort of erm, discovery was how to deal with him." (S2, 275-277).

"I guess, you give people a bit more time and perhaps engage a bit more in some personal comment about how they look, whether they look anxious or hungry, just something that indicates that I've, you know, had a look at them and seen something" (S3, 355-358).

3.2.2.6. Receiving Adapted Support

The “Receiving Adapted Support” category includes how homelessness allowed people with a diagnosis of autism to access personalised, long term support. Such support enabled the gradual reconnection of people with a diagnosis of autism with services within and following their homelessness.

Gaining Personalised Support

Participants with a diagnosis of autism considered the use of personalised support in their reconnection with institutions.

P3 and P5 noted how drop-in services allowed them to regain choice and control within their support. For both participants this created a momentum towards returning to housing:

“He just explained where their offices were and I could just drop in any time and set it in motion” (P3, 1343-1344).

“...if the drop in hadn't been there, I wouldn't have seen anybody that would be able to organise this with the council, and, and everything else.” (P5, 257-259).

Professionals spoke about their gradual, graded attempts to connect with the person they supported. This also included supporting the individual to be able to connect with new professionals:

“The therapist person supported him and myself. So we met, all together, we met in a kind of environment where erm, the chap that I support trusted this other person, and so then your sort of being let into someone's sort of trusted space a bit.” (S1, 485-490).

“...with him, there was a lot more going round the houses with it. I wouldn't normally, if somebody moved on I wouldn't normally go and do a shadow shift at the hostel where they move to.” (S2, 1109-1113).

Professionals also spoke about adopting an unorthodox approach to create continued engagement with the people they support:

“So it was almost unorthodox in support, you don’t normally do that in support, yeah, you don’t normally speak like that in support, but in this instance it was the way that got through to him.” (S2, 379-838).

“So we’ve tried to sort of maintain, and some, well quite a lot of weeks would be one session where I would go to the hospital with him for and MRI scan, or a CT scan and this that and the other, but then still try and maintain our appointments. So be like “that wasn’t your appointment that week, you still get to have coffee and a chat”” (S1, 518-524).

The above accounts reference how homelessness often allowed participants to gain personalised support. However, it should be noted that such personalised support was often not provided within the hostel institutions as explored by P1 and P5:

P1 notes how hostels services were unable to meet their needs.

“... but on the other hand a sheer frustration that they staff stubbornly refuse to do anything to meet neuro-atypical needs” (P1, 839-841).

P5 also discussed an increasing disconnection with hostels as a result of feeling unsafe within them.

“...Well it wasn’t very good really. I just used to go there as late as possible at night and leave as early as possible in the morning.” (P5, 1220-1222).

The above examples provided evidence for the constant oscillation between losing and gaining connection during homelessness.

Gaining Permanency in Support

Professionals all explained the importance of allowing time when aiding the person they support to reconnect with institutions:

“It was about me going to his space sort of space where he was at. But it took, took a long time’ (S1, 500-501).

“...but dealing with his type of autism, your gonna need time and your gonna need flexibility, and your gonna need to be able to sort of learn the individual and so, your gonna need a good staff team to be honest” (S2, 1231-1235).

S3: “I’m aware of that, and the importance of engaging with people in the longer term.” (S3, 344-345).

3.2.3 Personal Relationships

This section details how people with a diagnosis of autism lost connection to personal relationships within their pathways into homelessness. As personal relationships are intimately linked to the homes in which people lived, the loss of connection to these relationships ran in parallel to the loss of connection to the home. This separation was defined by people with a diagnosis of autism escaping subjugation in relationships, or by families and acquaintances discarding their connection to people with a diagnosis of autism. Homelessness provides an opportunity for people with a diagnosis of autism to regain equality in relationships and to gradually redevelop bonds with others.

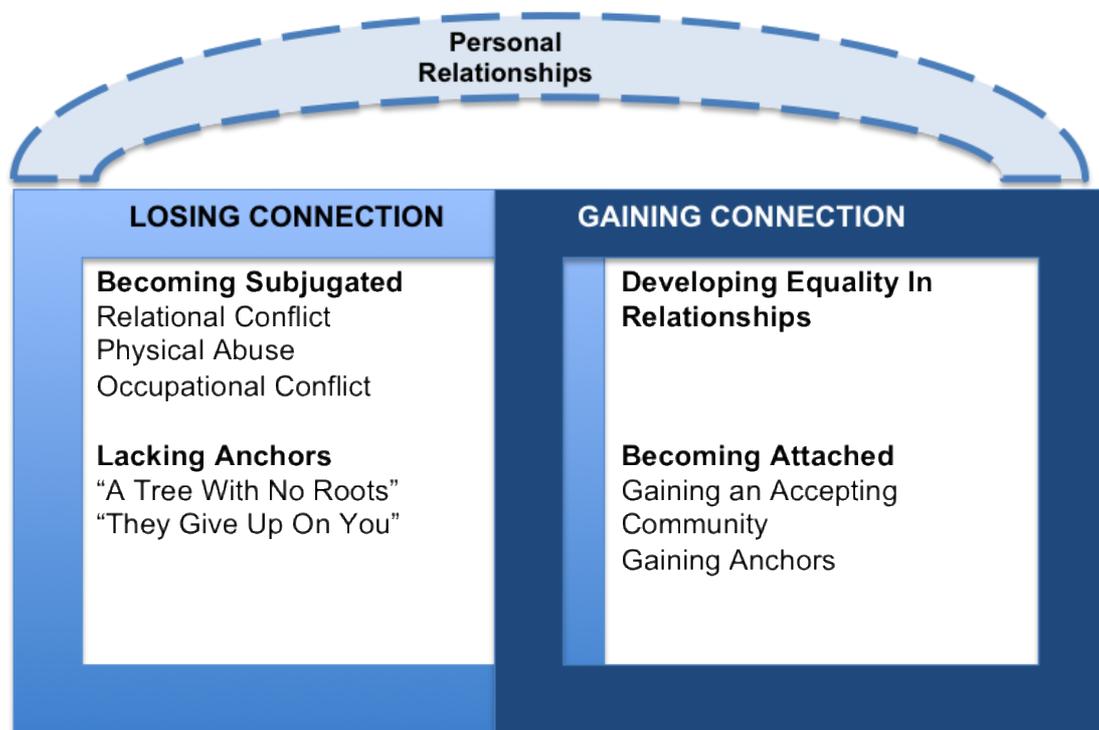


Figure 5: Personal Relationships Context

3.2.3.1. Becoming Subjugated

The “Becoming Subjugated” category relates to the relational difficulty experienced by people with a diagnosis of autism. This relational difficulty regarded relationship with friends, family and colleagues. Relational difficulty seemed to be defined by a loss of power within relationships, where people with a diagnosis of autism become under the domination or control of another. “Becoming subjugated” was coped with through a gradual disconnection from social relationships.

Relational Conflict

The majority of participants with a diagnosis of autism discussed conflict within personal relationships. Across these accounts a sense of powerlessness to such conflicts was described. Relational conflict seemed to pervade across childhood and adulthood and within relationship with neighbors, parents and partners.

P5 discusses their confusion regarding frequent experiences of conflict with neighbours:

“Well none of my neighbours will speak to me and nobody will tell me why, and that sort of thing. But that happens wherever I go really. They start off perfectly pleasant and something just goes wrong.” (P5, 748-752).

P4 gives the example of how his father misunderstood his intentions, resulting in conflict:

“Because I said something was funny he thought, er, I was exposing a lack of respect to him and he built up very fast, very, very fast and he lost his temper.” (P4, 30-33).

Regarding his partner, Chris, P2 discussed the relationship between relational conflict and damage to his rented home:

“Chris pulled the bloody curtains down. That was a bad experience.... And there is no way I would have got my deposit back either”. (P2, 71-75).

Two participants discussed the direct connection between these conflicts and a distancing from familial relationships and their homes.

P6 discusses this in relation to a sibling, P1 in relation to their parents:

“I just didn’t know where to, how, how to fit in to her activities at all. Erm, so I found that quite stressful and I wanted to get out of the house as soon as possible.” (P6, 416-420).

“And then had to spend some time at my parents’ house and there was various disputes there. And they were then kind of retiring somewhat and moving abroad at least temporarily. And I was then made, you know, statutorily, kind of like homeless.” (P1, 160-166).

Physical Abuse

Participants with a diagnosis of autism described experiences of physical abuse within personal relationships. Being the victim of abuse was another example of how these participants lost power within their relationships. Some participants dealt with physical abuse by escaping these relationships. As abusers were often residents of the homes in which participants lived, escaping abuse also resulted in an escape from stable housing.

Two participants explored the direct relationship between homelessness and the escape and distancing from physical abuse:

“I went to my room and he came to me and started to be physically abusive to me so I chose to run away.” (P4, 34-35).

“So, erm, after a couple of er, moments where I was er, physically assaulted I needed to just stop staying there.” (P6, 25-28).

These experiences of abuse also then spanned into expectations that participants had regarding how they may be treated within hostels:

“I think I would prefer to be on the streets than to be in a shelter.

[PG: “And why’s that?”]

“I can’t cope to be with other people environment. I wouldn’t feel safe. I’ve been attacked three times in my life. So it means probably I would feel, I would, I would prefer to be on the pavement.” (P4, 1679-1687).

And when discussing declining the offer of a hostel, P3 also referenced expectations of physical abuse:

“Well I thought I might have to share a bedroom with people who might be aggressive or for some reason I might not be able to get on with.” (P3, 1486-1488).

Occupational Conflict

Conflict with others also included the relationships between people with a diagnosis of autism and their colleagues. Participants with a diagnosis of autism told stories of struggling to develop relationships with colleagues and how this created barriers to performing the roles expected of them. Such conflicts risked job loss, created financial vulnerabilities and difficulties in maintaining housing.

P3 explores how this occupational conflict created barriers to career progression:

“I got these kind of assessment reports that were part complimentary, part rather damning so, saying that, acknowledging that I worked hard and some of my work was good but then I had such poor ability to communicate and get on with people this was a real obstacle to any further advancement.”
(P3, 303-308).

Other participants discussed how their jobs required an element of social interaction. Participants discussed the difficulties they faced within social interaction, and how they coped with such difficulties through avoidance:

“I started to be the manager, that was the worse thing you could do with me because I have to socialise. And I was locked in my office most of the night, just to avoid to talk to people.” (P4, 1208-1212).

“I admit I wasn’t very good at administering a department at doing... I’d rather be actually doing some work. Not interested in dealing with people, but I did not realize of course then that I, I’m a bit, some would say deficient in that department.” (P5, 505-511).

3.2.3.2. Lacking Anchors

This category described how people with a diagnosis of autism were affected by a lack of permanency and stability in their personal relationships. This lack of connection to both people and place created instabilities in the permanency of housing for those with a diagnosis of autism.

“A Tree With No Roots”

Participants with a diagnosis of autism spoke of a lack of permanent connection to relations and the ways in which this increased the risk of losing their home:

“I was like a tree with no roots. So I knew because the family was not there, and, to support me or to anchor me. With what I guess you normally have is unconditional love, so for me I always knew I was very vulnerable from a very early age.” (P4 841-846).

P6 spoke about a personal lack of attachment to place and questions how this interacts with their status of homelessness:

P6: “...so its, it’s a place, it’s a home for my things but I don’t need to be there. I have no sense of needing to be in there. Erm, in my head I’m, I’ve sometimes wondered like and before my diagnosis, am I still homeless? Am I, I was given a flat but have I ever been housed?” (P6, 786-798).

Professional participant, S1, also describes how the person they support lacked a secure bond with their family:

“...and he, you know he has such a small amount of people in his life. I mean he has his, erm, his mother and also his biological mother but they live abroad. He was estranged from his family for a long time.” (S1, 562-565).

“They Give Up On You”

Participants with a diagnosis of autism described the multiple ways in which they lost the support and protection of their personal relationships. This breakdown of protective social relationships appeared to coincide with a breakdown in provision of permanent housing.

P4 explored how the difficulties that friends and family had in understanding their behaviours or idiosyncrasies created a breakdown in support:

“A bit like my parents, because they could not understand what it going on, when people don’t understand, they are not able, or they don’t want to, they give up on you.” (P4, 1481-1484).

P3 explored how they felt that the support and tolerance from others had been exhausted:

*[PG: “And did you, was there anyone around you at that time that could have been supportive to you? Maybe financially, or in different ways?”
“Um...not really because as I’d had as much support as my family were able to do.” (P3, 72-77).*

P6 also explored how friends and relations lost tolerance towards their hobbies and interests:

“...I’ve bought back three bikes and kind of I’ve got some huge Lego pieces there and, so it doesn’t work for them, me doing what I’m doing” (P6, 1152-1155).

3.2.3.3. Developing Equality within Relationships

This category explores how people with a diagnosis of autism developed relationships based on increased equality following their homelessness. Such relationships allowed participants to begin to reconnect with others. Following homelessness relationships became defined by a sense of mutuality, authenticity and equality. In this way the people with a diagnosis of autism were able to begin to gradually reconnect with others.

P3 spoke about a development in power to control the extent to which they became connected to others when rough sleeping:

“If you feel kind of disconnected from the world and people and want to have some limited contact but not much from them it can be quite appealing

being a non-person who's partially connected but not too connected.” (P3, 1090-1094).

S2 describes how the person they supported was accepted into the hostel through a sense of tolerance and space:

“A lot of the residents as well knew that he had issues, so nobody harassed him for money, nobody, if he started shouting at somebody, people just tended to, other residents just tended to ignore him or just leave him alone, or look at him like “ok”. So he was treated quite well by other residents” (S2, 532-359).

S1 described a natural development of connection post homelessness and post autism diagnosis and how such relationships were defined by a sense of choice and acceptance:

“It is just an acquaintance, but it's one, it's someone that has grown, kind of organically and someone that isn't paid to be in your life as well, and that's, I think that's really important.” (S1, 551-553).

“(he) has now made a friend, a person who goes to the support group and, yeah so, they are quite different people but they share a mutual understanding of each other's differences” (S1, 543-546).

3.2.3.4. Becoming Attached

The “Becoming Attached” category relates to how people with a diagnosis of autism reconnected and developed sustainable attachments to others following homelessness. Attachment to others related to a progression towards permanency and stability in relationships and progress towards community acceptance.

Gaining Accepting Personal Relationships

Participants with a diagnosis of autism spoke about how they were able to begin to build and develop communities within their homelessness.

P3 discusses how the culture of understanding and acceptance of diversity allowed them to begin to feel connected to a community of the homeless:

“...but after a few months I did get to talk to some of them and actually it was ok because they generally understand that people come from all kinds of background and all kind of different reasons why they end up on the streets.” (P3, 932-937).

Hotels also provided access to established communities as explored by P5:

“Because there was a dykes meeting every Friday in the bar, so I, I went to that and met some really interesting people.” (P5, 1131-1133).

Finally, P1 explains how living within a community of individuals with similar needs and experiences helps them to maintain connection to place and relationships:

“The best thing about living in Haringey is I’ve got friends. I’ve got like my own special needs community.” (P2, 1098-1099).

Gaining Anchors

Gaining anchors through relationships was vital in maintaining people with a diagnosis of autism in their homes:

“...I’ve spent 17 years of adult life living with partners and when I’ve lived with partners, erm, there’s been a clear thing to go home for, erm, because they are in it.” (P6, 745-758).

Some professionals considered anchoring as the result of professional input. It seemed that through maintaining a consistent residence, people with a diagnosis

of autism were able to access consistent professional support. These professionals acted as the anchors to retaining housing.

“...with the borough comes all of his support. So there’s psychological support team only see him because he’s a resident of the borough, I only see him because the project is funded, er, because we are funded by that borough as well.” (S1, 68-71).

“...he has, the OT, the psychologist and me. I think those, having those anchors in his life there are people that he can go and see and talk to about himself, er, and, and have a receptive response” (S3, 304-308).

However, it should be noted that following homelessness was not always defined by developing such anchors, and participants often remained isolated in their homes. This again demonstrates the constant oscillation of ‘losing and gaining connection’ and how losing connection can regain dominance following homelessness.

S1 notes how the person he supports made failed attempts to gain anchors:

“So he, he was sort of forcing himself to be more social, and they were having parties but he would find it incredibly difficult. Erm, to the point where these friendships were, wouldn’t last very long.” (S1, 194-197).

S3 predicts a continued isolation of the person they support as a result of their lacking anchors following homelessness:

“...so and again there’s no social network that he has built up either, it is only professionals. So it always feels tentative to me and vulnerable to break down.” (S3, 714-716).

3.2.4. Environments

This section details the how the environment of the home conflicted with the needs associated with the autism diagnosis, creating difficulty for people with a diagnosis of autism. It seemed that homelessness provided some form of soothing of such difficulty. This also increased the participants sense of personal resilience.

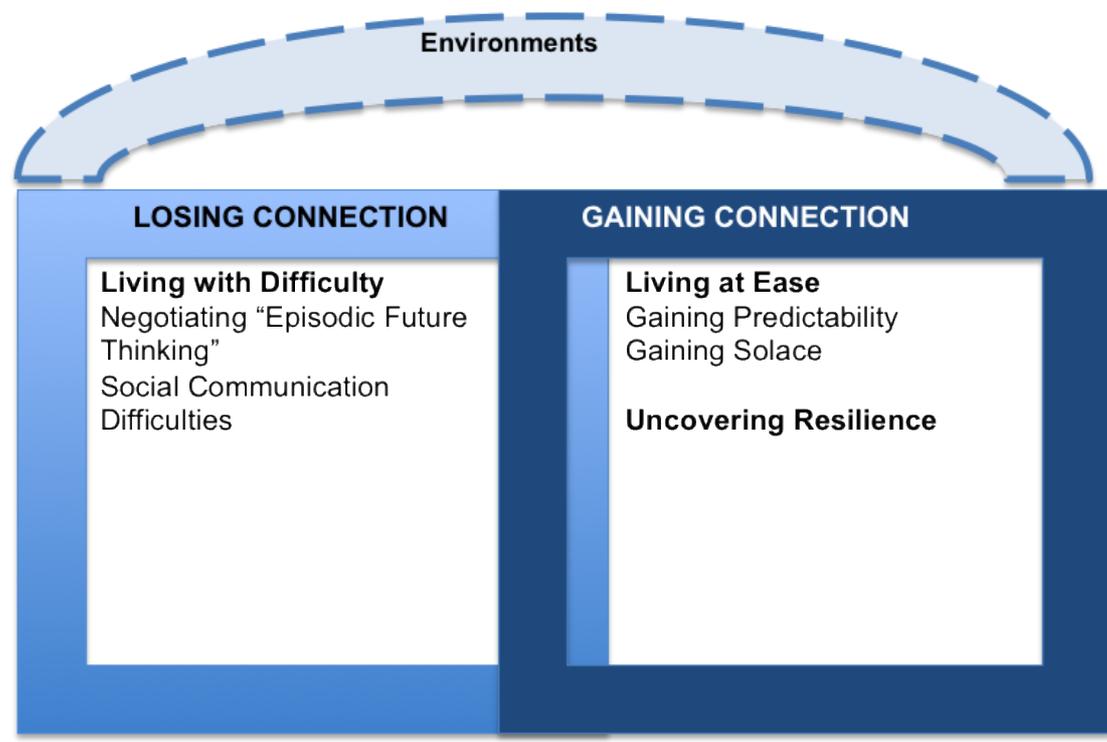


Figure 6: Environments Context

3.2.4.1. Living with Difficulty

The “Living with Difficulty” category relates to the difficulties that people with a diagnosis of autism faced in negotiating requirements of the home environment. Participants with a diagnosis of autism described the home environment as requiring an aptitude in future planning and social communication. This created difficulty for people with a diagnosis of autism, creating complications regarding the management of their housing.

Negotiating “Episodic Future Thinking (EFT)”

P3 introduced their understanding of EFT and their experiences of this:

“...Episodic Future Thinking with autistic people, we have trouble thinking through what, what could happen in the future. If things aren’t definite and laid down, then we can’t learn the rules” (P3, 31-34)

P3 also explores how this difficulty created financial implications, resulting homelessness:

“...making financial speculations without thinking, they were well thought out or whether they were likely to work just on the assumption that um, because um, some of the things I have done before have been successful, it was bound to work again” (P3, 25-30)

Other participants demonstrated difficulties in negotiating future thinking. P5 makes a direct link with this difficulty and increased disarray post moving:

“I’m not very good at making plans. I’ve never, every time I’ve moved, I’ve always finished up in a mess.” (P5, 1384-1385).

P4 discusses how this lack of planning created increased vulnerability after they chose to escape conflict in the family home:

“I had no baggage, no luggage and no paper, nothing. I was completely mortified and stressed so I chose to run but I was almost like a headless chicken.” (P4, 40-43).

Social Communication Difficulties

Prior to homelessness people with a diagnosis of autism faced persistent difficulties in social communication, stimulated by the home environment.

P4 spoke about his attempts to engage with others and the difficulties that this creates:

“...and people playing you know, this kind of game about pretending, trying to impress. I can’t, I can’t, you know and I’m not going to be rude, it means I already find it so difficult, I find it already find it so difficult to focus.” (P4, 464-468).

“...spending time with people you don’t have a lot in common. Pretending to be interested because that’s what... I cant do that.” (P4, 241-243).

A professional participant, S3, also discussed the difficulties that the person they support has regarding social communication with others. This results in an increase distance between the person with a diagnosis of autism and others:

“...he’s quite irritated by other people as well, he, there is a sense of wanting to, to express his irritation and therefore which obviously will push, tend to push people away, he doesn’t have a sense of wanting to invite people in.” (S3, 56-61).

3.2.4.2. Living at Ease

It seemed that elements of the homelessness environment were better suited to the needs of those with a diagnosis of autism. This allowed people with a diagnosis of autism to live with increased ease and uncover a sense of personal strength and resilience.

Gaining Predictability

Homelessness provided much needed predictability that allowed people with a diagnosis of autism to live with increased ease.

P3 explores the appeal of the homelessness environment as a result of the requirements for present focused thinking:

“...living in the present that comes back to the kind of difficulty with Episodic Future thinking and thinking of your life as projecting yourself through time.

So because homelessness people generally think focus on day to day living so I think that's appealing to ASD people.” (P3, 1261-1267),

P6 notes how the stability provided by the homelessness environment created an increased ease and focus to their day:

“And when, when I was then kind of in a very, well both routine and not routine because I had to adapt all the time, but there were certain core things that I had to kind of focus on and to do each day and I, I was just so absorbed in it” (P6, 1509-1515).

A professional participant discussed how the sense of routine and predictability provided an individual with an environment that the person with autism did not want to leave:

“I think partly he wanted to stay because we do a lot of we do, we provide food, you pay £23 a week and we provide you two meals a day. People get, if you go and get Pret they have Pret. We supply with washing materials obviously you know you get... we take care of all of the basic needs of people” (S2, 239-246).

However, P5 offered a conflicting account, suggesting that the homelessness environment often increased exposure to the unpredictabilities of others:

“...I've never met anyone who behaved so peculiarly she was, she'd disappear for three days and then come home and sleep for 2, for 48 hours and then disappear again, you know.” (P5, 1184-1188).

This example provides evidence for the constant oscillation of losing and gaining connection across the homelessness journey.

Gaining Solace

Homelessness provided a relief from pressures to communicate socially, providing people with a diagnosis of autism with a sense of reconnection to their wants and need for independence.

P3 explores how they were able to gain space and solace from pressures to communicate when living on the streets:

“Well they didn’t seem to mind or realize some people are quite quiet and largely want to be left on their own. So they, they didn’t necessarily expect some kind of lengthy conversation with me and were often quite happy with a brief exchange of a few words.” (P3, 971-976).

P6 notes that they were able to reconnect with abilities in self-sufficiency and disconnect from feelings of disability within their homelessness:

[PG: “Why did you feel safer?”]

“Erm, because I, I knew where everything was that I needed and kind of erm, it, it, was that thing of self-sufficiency and independence. I, I just struggled with growing up in a house, sharing a room with two other siblings.” (P6, 325-332).

Professional participants also discussed how solace was regained for those with autism after homelessness:

“...he lives there on his own, again the good side of that is that he can be himself there. Er, he often refers to it as his “bubble”, a place that he goes into and he just, can have the time of his life in there.” (S1, 187-190).

“...I think he, this place is somewhere that he can retire to and lock the door and be quiet.” (S3, 691-693).

3.2.4.3. Uncovering Resilience

Finally, people with a diagnosis of autism were able to reconnect with a feeling of personal ability and self-sufficiency in their homelessness. This was mainly achieved through uncovering their skills in resilience.

Resilience was uncovered in the ability of participants with a diagnosis of autism to sustain the harsh physicality of living on the streets:

“Well, I suppose I proved to myself I could physically cope with it and survive.” (P3, 1035-1036).

“And packets of crisps down my top, but, but erm they were both kind of solutions to both eating and keeping warm.” (P6, 502-505).

Abilities to survive and remain in control were also uncovered:

“It was like a rollercoaster, I mean it was about me trying to survive, if I could.” (P4, 1421-1422).

Finally, abilities in planning and organizing were revealed:

“...I mean I as always busy working out things that I would need to do, where I would stay, how I would sleep” (P6, 539-542).

4. DISCUSSION

This chapter will begin by reviewing and interpreting the research findings. This review will inform recommendations. A critical review and reflexive review of the research is then provided and conclusions drawn.

4.1. REVIEW OF MODEL, INTERPRETATION AND RECOMMENDATIONS

This research aimed to construct a model of homelessness as experienced by people with a diagnosis of autism. This was achieved through addressing the following research questions:

1. What processes contribute to homelessness in those with a diagnosis of autism?
2. What processes maintain homelessness in those with a diagnosis of autism?
3. What processes lead to a solution to homelessness in those with a diagnosis of autism?

The resulting model demonstrated how the core process of “losing connection” across many levels of context resulted in homelessness for people with a diagnosis of autism. “Gaining connection” across the same levels of context both maintained and/or acted as a solution to homelessness (Figure 2). This finding can be understood in relation to Giddens (1984) structuration theory and Fitzpatrick’s (2005) interactive theory of homelessness. These theories propose a duality of agency and structure. They suggest that structures in society enable and constrain human agency and that human agents have the power to reproduce and transform such structures. In relation to “losing connection”, it was demonstrated how four contexts; society politics and culture, institutions and services, personal relationships and environments, limited the lives of those with a diagnosis of autism. People with a diagnosis of autism responded to such limiting contexts through disconnecting with them, resulting in homelessness. This model also drew attention to the ways in which people with a diagnosis of autism and their networks acted flexibly to respond and transform such contexts

during and following homelessness. This resulted in people with a diagnosis of autism gaining connection to such contexts. This study was therefore unique in uncovering the contexts and actions that contributed to homelessness in people with a diagnosis of autism. The next section shall explore the possible structures that may have impacted the contexts and actions highlighted in this study.

4.1.1. Losing Connection

This section considers the core process of losing connection. It will consider how structures and resulting contexts limit the lives of those with a diagnosis of autism. This helps to explain why people with a diagnosis of autism lose connection to a range of contexts prior to homelessness. This will inform recommendations aimed at preventing people with a diagnosis of autism from becoming homeless.

4.1.1.1. Society, Politics and Culture Context

Structural conditions of austerity may help to explain why people with a diagnosis of autism may lose connection with society, politics and cultural contexts prior to homelessness. This study demonstrated how people with a diagnosis of autism may face difficulty in obtaining sufficient income due to an economic context that increases costs and decreases state support (Figure 3). Dunlop & Mletzko (2011) note that the current service based economy favours those who excel in 'people skills' and excludes those less proficient in these skills. It may be suggested that this has relevance to people with a diagnosis of autism, increasing their reliance on obtaining income through state support. In a climate of increased austerity and cuts to state funded benefits, concerns have been raised about how people with a diagnosis of autism may face increasing health and social inequalities (NAS, 2011a). This research further highlights this concern, suggesting that structural conditions of austerity and resulting reductions in welfare provision, create increased risk of homelessness for people with a diagnosis of autism.

This study also highlighted how people with a diagnosis of autism often felt different to, and excluded by, society (Figure 3). This is an interesting finding to reflect upon in relation to the structural conditions of austerity. Goodley (2014)

suggests that contexts of austerity have the ability to increase disabilism, as hostilities within communities are often enacted against those considered unable or unwilling to contribute to the economy. It may be suggested that the feelings of difference and exclusion experienced by the participants within this study may have been influenced by a context that promotes hostility to those reliant on state support.

4.1.1.2. Institutions and Services Context

This study demonstrated how inadequate, limited and unwanted interventions from services promoted the disconnection of people with a diagnosis of autism to institutions and services prior to homelessness (Figure 4).

Again, the structural conditions of austerity can also help to understand this finding. Hastings, Bramley, Gannon, & Watkins (2015) demonstrate how the political context of austerity pressures services to demonstrate effective practices, driving competition between services. Regarding services for people with a diagnosis of autism, this has taken place alongside historical ideologies such as the normalisation agenda (O'Brien, 1981). The normalisation agenda been criticised for prioritising behavioural conformity over the subjective needs of people with a diagnosis of autism (Kapp, Gillespie-Lynch, Sherman, & Hutman, 2013). It may be suggested that the continued impact of these political and ideological structures may have reduced the ability of institutions to work flexibly and responsively to the needs and wants of people with a diagnosis of autism. This may act to reduce the connection between people with a diagnosis of autism and institutions, reducing the capability of institutions to protect this group from homelessness.

4.1.1.3. Personal Relationships Context

This study demonstrated how people with a diagnosis of autism possessed personal relationships prior to homelessness defined by subjugation and abuse (Figure 5).

Although the acknowledgement and inquiry into abuse of those with a diagnosis of autism has gained momentum in recent years, McGurie (2016) suggests such

abuse is often constructed as random, individual tragedies. This acts obscure the structural factors in which such abuse is promoted. Chan & Lam (2016) conducted an ecological analysis on parental maltreatment of children with a diagnosis of autism. They suggested that structures including economic pressure on families and the experience of discrimination towards people with a diagnosis of autism might predict child maltreatment. However, there is little research to understand the structures that may contribute to abuse and conflict between people with a diagnosis of autism and their close personal relationships in adulthood.

It may be suggested that the lacking acknowledgement and understanding of such conflictive and possibly abusive relationships prevents those with a diagnosis of autism and their networks from accessing support. Such a circumstance is likely to further increase the disconnection between individuals with a diagnosis of autism and their personal relationships, resulting in a loss of protective relationships that may prevent homelessness.

4.1.1.4. Environments Context

This study suggests that environments that require proficiency in future planning and social communication are difficult for people with a diagnosis of autism to tolerate. Having become homeless, some people with a diagnosis of autism found that such difficulties were lessened (Figure 6).

The social model of disability has had great success in highlighting and advocating the removal of the physical structures of society that act to exclude those with physical disabilities (Shakespeare, 2013). The application of such a model for those with a diagnosis of autism can be seen with the neurodiversity movement. This movement promotes increased awareness and acceptance within society of behaviours that may conflict with social norms, such as reduced social communication and eye contact (Bagatell, 2010). This research provides further evidence for the necessity of continued attempts to highlight and remove the environmental barriers that prevent those with a diagnosis of autism from engaging within society. Neglect to create more accessible environments for people with a diagnosis of autism is likely to perpetuate the disconnection of this group from society, sustaining their risks to homelessness.

4.1.2 Recommendations for Preventing Homelessness

4.1.2.1. Knowledge Production

It is likely that the structural conditions that contribute to the homelessness as experienced by people with a diagnosis of autism, will continue if such conditions remain hidden from public consciousness.

Sue (2013) suggests that continued and persistent dialogue is required to raise the public consciousness of the ways in which the structures of society cause inequality and harm to marginalised groups. Further research fields aimed at uncovering, scrutinising and challenging the structures that cause harm to those with a diagnosis of autism is therefore suggested. Such research may take the form of participatory action research in which people with a diagnosis of autism take an active role in the co production of knowledge and solutions to the problems affecting them (Wright, Wright, Diener, & Eaton, 2014). It is intended that the dissemination of this research will begin to stimulate the development of such research fields.

4.1.2.2. Policy and Service Level Recommendations

The Autism Act (2009) was explicit in its aim to tackle the social and economic exclusions faced by those with a diagnosis of autism. This research highlighted how those with a diagnosis of autism continue to face barriers to gaining support from employment, welfare and other public services. This research therefore suggests that the aims of The Autism Act (2009) may yet need to be fulfilled. In response, an amendment to The Autism Act (2009) to require local branches of the Department of Work and Pensions to monitor and report on the impact of recent welfare cuts on those with a diagnosis of autism is recommended. A review of the performance of local branches of the Department of Work and Pensions in making reasonable adjustments to the needs of those with a diagnosis of autism is also required. Finally, an amendment to the Homelessness Act (2002) to clearly include those with a diagnosis of autism within its “priority need” criteria is essential.

Such amendments of law alongside increased monitoring and review will provide evidence of the unequal impact of welfare reforms on those with a diagnosis of autism, a situation likely to be in breach of The Equality Act (2010) and the UN Convention on the Rights of Persons with Disabilities (2006).

4.1.2.3. Clinical Practice

This research provides evidence of the multiple ways in which structures within society contribute to the homelessness of people with a diagnosis of autism. Clinical psychologists may therefore have a key role to play in supporting those with a diagnosis of autism to challenge and tackle such structures in order to prevent homelessness.

Patel (2003) advocates the development of clinical psychology practice to draw attention to the ways in which structural inequalities cause distress and harm, and proposes that clinical psychologists promote social action to challenge such inequalities. Moane (2010) adds that as helplessness and powerlessness often accompany inequality, personal and interpersonal development may be required prior to social change.

Regarding personal development, psychologists may wish to consider applying postmodern social constructionist practices with this group, with the aim of using language to reconstruct a sense of self that is able resist the powerlessness and helplessness associated with inequality (Afuape, 2012).

Regarding interpersonal development, psychologists may wish to consider how they can support those with a diagnosis of autism to connect with others and develop social networks. This may be through the development and facilitation of local autism networking groups. Supporting people with a diagnosis of autism to forge alliance and develop social networks may support their ability to begin to oppose the isolation and fragmentation that accompanies inequality (Montero, 2007).

One outcome of bringing individuals with a diagnosis of autism together in this way may be that the shared contexts of both wellbeing and oppression are brought into awareness. This may support those with autism to consider the ways in which they may wish to take collective action to change such conditions (Nelson & Prilleltensky, 2004).

It is hoped that such interventions support reconnection between those with a diagnosis of autism and the societies in which they live. However, it is also noted that the persistent experiences of inequality, combined with possible aversion to group contexts may create barriers for those with a diagnosis of autism to take part in such interventions. Psychologists may therefore wish to use this framework to guide rather than prescribe practice, and consider how to adapt this framework to meet the needs of those they work with.

4.1.3. Gaining Connection

This section considers the core process of gaining connection. It will draw attention to the ways in which people with a diagnosis of autism and those around them acted in flexible ways to transform the contexts that previously limited the lives of people with a diagnosis of autism. Understanding the factors that influenced such flexible responses will inform recommendations for responding to homelessness.

4.1.3.1. Society, Politics and Culture Context

Participants described how homelessness provided a culture that was accepting, tolerant and understanding of them (Figure 3). This draws parallels to Ravenhill's (2008) ethnographic research on the "culture of homelessness" that described the counter culture of rough sleepers. This counter culture opposed social norms of mainstream society, allowing for the integration of previously marginalised individuals.

The current study demonstrated how during their period of homelessness, people with a diagnosis of autism felt more accepted and understood by other homeless people. This study also demonstrated how feeling accepted and understood supported people with a diagnosis of autism to gain connection to society following homelessness. It seems therefore that the consideration of alternative ways in which normality and abnormality are constructed may support the connection of the autistic community with society following homelessness.

4.1.3.2. Institutions and Services Context

Participants in this study described how during and following homelessness, professionals acted in responsive and flexible ways tailored to their needs (Figure 4). This supported participants to reconnect to institutions.

This is an interesting finding, as professionals seemed able to act flexibly, despite working under the rigid restrictions placed on services within structural conditions of austerity. Applying psychodynamic theory to services and institutions, Evans (2015) suggested that rigid, prescribed practice in services, promoted by the restrictions placed on services in times of austerity, can be avoided if professionals are supported to process the anxieties related to their work.

Psychologically informed reflective practice is in development across homelessness services and has demonstrated positive impacts on the ability of services to act flexibly and responsively to the needs of the homeless (Cockersell, 2016). Although it is uncertain as to whether psychological support was provided to the institutions referenced in this study, it seems important to consider how psychologists may promote flexible and responsive practice within homelessness services. This may support the reconnection of those with a diagnosis of autism to institutions following homelessness.

4.1.3.3. Personal Relationships Context

Participants in this study described how relationships defined by increased equality, acceptance and permanency allowed them to connect with others during and following their homelessness (Figure 5). Participants discussed how becoming connected to small, closed knit communities with permanent members allowed them to gradually develop relationships with others.

This finding links to Müller, Schuler & Yates (2008) who demonstrated how people with a diagnosis of autism found the provision of small, highly structured group settings useful in developing social relationships with others. It therefore seems important to consider the unique settings and support required to enable people with a diagnosis of autism to connect with others following homelessness.

4.1.3.4. Environments Context

This study described how gaining predictability and solace from social communication allowed people with a diagnosis of autism to interact with their environments with increased ease (Figure 6). The autism strategy, Think Autism (DOH, 2014) provided funding grants to local authorities to support the development of “autism aware communities”. Examples included training staff in colleges and local charity shops in autism awareness. It is clear that bringing order and predictability to the complex social world may not be realistic, however, this research does indicate that developing environments more suited to the needs of those with a diagnosis of autism may support their reconnection following homelessness.

4.1.4 Recommendations for Responding to Homelessness

4.1.4.1. Knowledge Production

This research project noted how broadening constructions of normality and abnormality supported people with a diagnosis of autism to reconnect with others within homelessness. This finding provides further backing to Greenstein’s “radical inclusive pedagogy of disability” (2013), which advocates further research, report, and exploration of constructions of normality and abnormality within society. Such research is intended to bring the awareness of society to the implausibility of the binary distinctions of normality and abnormality that define disability. A consequence of such may be to reduce the marginalisation and segregation of those with disabilities.

Further research that draws emphasis on the ways in which the binary distinctions of normality and abnormality impact people with a diagnosis of autism is therefore suggested. It is hoped that such research may develop societal acceptance towards people with a diagnosis of autism, thereby supporting their connection to society.

4.1.4.2. Policy and Service Level Interventions

This research suggested that relationships defined by acceptance, tolerance and equality supported those with a diagnosis of autism to connect with others following their homelessness. The importance of supporting those with a diagnosis of autism to develop personal relationships in structured, predictable ways was also discussed. It is therefore suggested that interventions by homelessness services aimed at re-housing those with a diagnosis of autism should be mindful of established personal relationships. Attempts to find housing located in areas in which those with a diagnosis of autism have established social relationships should be made. In addition, services who offer support for adults with a diagnosis of autism should consider the importance of providing regular, frequent, structured social groups. This may support the development of connection between people with a diagnosis of autism and others.

This research suggested that the predictable nature of homelessness and reduced requirements of social interactions provided environments that were suited to the needs of people with a diagnosis of autism. In order to support individuals into stable housing, a review of the environments within homelessness institutions is suggested. It is questioned whether the multiple moves between hostels prior to gaining permanent housing, as common within UK homelessness services, is able to provide the stability and permanency required by those with a diagnosis of autism. Direct access to permanent housing following homelessness as demonstrated in the 'Housing First' model (Bretherton and Pleace, 2015) may provide the stability and permanency needed by this group.

4.1.4.3. Clinical Practice

This research provided evidence that flexible, responsive, long-term support met the needs of people with a diagnosis of autism following homelessness. It was suggested that the provision of psychologically informed support within homelessness services may enable professionals to work flexibly despite rigid service structures. Clinical psychologists working with those with a diagnosis of

autism who have been homeless should therefore focus their clinical practice on systems-based interventions. Such interventions may include the provision of reflective spaces for professionals working with this group. Reflective spaces may focus on supporting professionals to acknowledge and explore anxieties produced by working with this group within restricted systems and encourage the consideration of responsive person centered practice.

4.2. CRITICAL REVIEW

4.2.1. Review of Research Aims

This section will review each of the research aims and the extent to which these were achieved. This will inform recommendations for future research.

4.2.1.1. Research Aim 1

This research aimed to develop a model of homelessness that prioritised the views of those with a diagnosis of autism and an experience of homelessness. The research sample included six individuals with a diagnosis of autism and three staff members that offered them ongoing support. The decision to include professionals was influenced by the emerging themes from the data provided by participants with a diagnosis of autism and was therefore considered as complementary to ethical stance of the project. Sample size was also considered adequate to provide a contextualised exploration of homelessness in this group, although it is acknowledged that a larger sample size may have yielded more saturated theoretical concepts.

The current lack of recording of autism and homelessness within support services limited the recruitment pool for this research. It is therefore recommended that services begin to record this population to increase the recruitment pool required for future research.

4.2.1.2. Research Aim 2

This research also aimed to construct a model of homelessness as experienced by those with a diagnosis autism that accounts for the complexity of this process. The resulting model accounted for the impact of four core contextual factors- society, institutions, personal relations and environments and how people with a diagnosis of autism negotiated these contexts through the process of losing and gaining connection (Figure 1). The discussions also highlighted the possible structures that may have influenced such contexts.

However, the methods used in this study did not allow analysis of the relative impact of each of these contextual factors. Such an understanding may be useful for the development and prioritisation of preventative and responsive social policy. Impact analysis regarding the relative impact of each of the contextual factors suggested in this model, and their broader structural influences, on a larger international sample is therefore recommended.

4.2.1.3. Research Aim 3

This research aimed to develop a theoretical framework to inform the work of clinical psychologists when working with those with a diagnosis of autism who have also been homeless. The model developed within this research is intentionally succinct and cohesive, setting clear direction for intervention and further research inquiry. The intent to develop a model with clinical reach was balanced throughout its development with ensuring that the model was fully grounded in the participant's data.

This research highlighted how multiple contexts were unable to meet the needs of people with a diagnosis of autism, resulting in their homelessness. As such contexts were highly influenced by the structures in society, it is likely that they impact the lives of many individuals with a diagnosis of autism, regardless of whether or not they have experienced homelessness. Considering how to maintain the connection between those with a diagnosis of autism and broader society may therefore be an important consideration of clinical psychological practice when working with the autistic community in general.

4.2.2. Evaluation of Methodology

This research constructed a model of homelessness within a critical realist epistemology using qualitative methodology. Yardley (2000) suggests four flexible criteria on which to assess qualitative methodology:

- Sensitivity to context
- Commitment, rigour and coherence
- Impact and importance
- Transparency.

Each of these is explored below in relation to the critical realist GT methods employed in this study.

4.2.2.1.Sensitivity to Context

Yardley (2000) suggests that when assessing sensitivity to context, clear evidence for theoretical discriminations and conflicting observations must be demonstrated. The coding methods I applied in line with GT methodology provide evidence for my theoretical discriminations and ensured the resulting model remained grounded in the participant's data (Appendix Ten to Twelve). This research was also committed to an account of conflicting observations and contradictions. This was achieved through performing a negative case analysis (Appendix Fourteen). This highlighted how the core processes of losing and gaining connection were in constant oscillation prior to and following homelessness. This analysis informed the final model.

Yardley (2000) also suggests that as language and culture are central to the meaning attributed to data, it is essential to acknowledge the ways in which socio-cultural factors influence data. Regarding this research, it is noted that accounts of isolation, segregation and exclusion are likely to be influenced by the inner London urban context in which this study was based. Further research may wish to consider the process of homelessness across different contexts. This may include considering more hidden forms of homelessness or within international contexts with more flexible social welfare policies.

4.2.2.2. Commitment, Rigour and Coherence

The concept of 'commitment' regards the extent to which the researcher demonstrates prolonged engagement in the topic and develops skill in method (Yardley, 2000). The detailed process of coding, constant comparison (Appendix Ten) and memo writing (Appendix Nine) allowed me to become fully immersed in my data and therefore sensitive to the emerging codes and categories.

The concept of 'rigour' relates to the completeness of data collection and how the data is able to supply the detail needed for a comprehensive analysis (Yardley, 2000). In GT completeness is achieved through methods such as triangulation (Olsen, 2004). This was achieved in this study through the recruitment of both participants with a diagnosis of autism and professional participants. This allowed for the bridging together of different perspectives, stimulating more nuanced understandings of the data.

The concept of 'coherence' relates to the clarity and cogency of analysis (Yardley, 2000). In GT this can involve the participants in the review of model development. Time limits within this project did not allow for the constant review of analysis with all participants throughout the research project, however, review of clarity and cogency of the model was conducted with P3. P3 considered the model as a meaningful, clear and accurate representation of their experience. This participant also suggested the development of the model to more clearly portray the dynamic and oscillating nature of losing and gaining connection following homelessness. This also supported the development of the overlapping depiction of these processes within the final model.

4.2.2.3. Impact and Importance

Impact and importance relates to the extent to which research can influence and change in beliefs across theoretical, practical and socio cultural domains (Yardley, 2000). Regarding theoretical impact, this research was unique in its exploration of homelessness in an under researched population. It was also innovative in its attempt to develop a theory that prioritizes the views of those with a diagnosis of autism. Regarding practical impact, the model developed in this research has led to clear, pragmatic suggestions regarding clinical practice and

action. Dissemination of the research will take multiple forms to increase this impact. The research is to be fed back to participants, services and commissioners within the inner London borough in which this study was based in the coming months. Broader dissemination of this research is intended within an academic journal article, Good Autism Practice and Autism are to be approached initially.

4.2.2.4. Transparency

Transparency requires that researchers reflect on the influence of personal assumptions, values, intentions and actions, and show how these affected the products of their research (Yardley, 2000). Within GT methodology, a reflexive diary is encouraged to support the researcher in understanding how theoretical orientations and personal anticipations shape the data. Entries to a reflexive diary were made throughout the research (Appendix Thirteen), key themes are demonstrated below.

4.3 REFLEXIVE REVIEW

Gentles, Jack, Nicholas, & McKibbin (2014) suggest reflexive observations should take place across levels within GT, including interactions with theory, analysis and write up and the impact of the research on the researcher. Each of these levels is explored below along with its impact upon the research.

4.3.1. Researcher Interactions with Theory

Corbin and Strauss (2008) suggest that theoretical comparison should be made throughout GT. This includes comparing incidents in the data to the researchers personal experience in order to help the researcher see ways the conceptual phenomenon in question can vary. Approaching this research, I reflected upon my professional background working within adult learning disabilities services and acknowledged how the social model of disability mediated my perception of this group. I noticed how this model mediated my perception of the people within this study, and wondered about the barriers in society that may influence the

homeless experienced by people with a diagnosis of autism. However, throughout analysis phase of the research I was alerted to how the action of people with a diagnosis of autism, in addition to the impairments associated with the autism diagnosis also contributed to homelessness. As Corbin and Strauss (2008) maintain the primacy of data, I attempted to stay close to the data and the interaction between structure and agency that it demonstrated. As a consequence, this research has moved me to question the social model of disability. I have begun to explore other models of disability that are able to more adequately account for the interaction between individual and structure, such as the interactional model of disability (Shakespeare and Watson, 2001).

4.3.2. Researcher Influence on the Analysis and Write Up

I was aware across all phases of the research of the importance of balancing the needs of the stakeholders who proposed this research (heads of autism and homelessness services within an inner London borough) with that of research participants and academic audiences. Although I feel the model constructed in this research is clear, acceptable and coherent to all these groups, I am aware that the academic tone required for a doctoral thesis may be not meet the needs of stakeholders and participants. Further development of a clinical research article and accessible summary will therefore be developed with the aim of sharing the findings with a wider group of stakeholders.

4.3.3. Influence of Research on the Researcher

This research has highlighted to me the ways in which personal and professional status can be both complementary and conflicting.

Personally, I question the ethics of promoting those with a diagnosis of autism to return to mainstream society following homelessness, if society is structured in a manner likely to cause this group difficulty. However, professionally, I also see that I have an ethical duty to respect, protect and fulfill the human rights of those I work with (BPS, 2011). I see it as professional ethical duty for me to find a solution to homelessness, as homelessness risks the violation of a number of articles within the Human Rights Act (Lynch and Cole, 2003).

This observation of the conflict between the personal and the professional has moved me to hold ethical boundaries under the same critical eye and scrutiny that I apply across my clinical and academic practice. Going forward, I endeavor to maintain to use ethical guidelines to inform my practice, whilst also remaining interested in, and questioning of, the theoretical and political agendas that influence them.

4.4. CONCLUSION

This study suggested that homelessness as experienced by people with a diagnosis of autism is the result of a complex interaction between contextual and individual factors. Following from this study, two key conclusions are drawn. Firstly, this study drew attention to four key contexts that limit the lives of people with a diagnosis of autism. As it has been suggested that these contexts may have been influenced by broader social structures, it is likely that the findings of this study are relevant to the autism community as a whole, regardless of their homelessness experience. Secondly, due to the complex, multi-layered, multi-causal nature of the social world (Bhaskar, 1978) change at one layer of society is likely to impact others. It is therefore proposed that supporting the development of connections between people with a diagnosis of autism with the contexts highlighted in this study may have transformative effects across structures in society. Considering how to develop and maintain the connection of those with a diagnosis of autism to others should therefore be considered as key intervention to prevent homelessness and to improve the overall health and social outcomes of this group.

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APPENDIX ONE: UNIVERSITY OF EAST LONDON ETHICAL APPROVAL

School of Psychology Research Ethics Committee

NOTICE OF ETHICS REVIEW DECISION

For research involving human participants
BSc/MSc/MA/Professional Doctorates in Clinical, Counselling and Educational
Psychology

REVIEWER: Miles Thomas

SUPERVISOR: Matthew Jones-Chesters

COURSE: Professional Doctorate Clinical Psychology

STUDENT: Paula Grant

TITLE OF PROPOSED STUDY: Investigating the factors that contribute to unstable living accommodation in adults with a diagnosis of Autistic Spectrum Disorder (ASD)

DECISION OPTIONS:

- 1. APPROVED:** Ethics approval for the above named research study has been granted from the date of approval (see end of this notice) to the date it is submitted for assessment/examination.
- 2. APPROVED, BUT MINOR AMENDMENTS ARE REQUIRED BEFORE THE RESEARCH COMMENCES** (see Minor Amendments box below): In this circumstance, re-submission of an ethics application is not required but the student must confirm with their supervisor that all minor amendments have been made before the research commences. Students are to do this by filling in the confirmation box below when all amendments have been attended to and emailing a copy of this decision notice to her/his supervisor for their records. The supervisor will then forward the student's confirmation to the School for its records.
- 3. NOT APPROVED, MAJOR AMENDMENTS AND RE-SUBMISSION REQUIRED** (see Major Amendments box below): In this circumstance, a revised ethics application must be submitted and approved before any research takes place. The revised application will be reviewed by the same reviewer. If in doubt, students should ask their supervisor for support in revising their ethics application.

DECISION ON THE ABOVE-NAMED PROPOSED RESEARCH STUDY
(Please indicate the decision according to one of the 3 options above)

approved

Minor amendments required *(for reviewer):*

Major amendments required *(for reviewer):*

ASSESSMENT OF RISK TO RESEACHER *(for reviewer)*

If the proposed research could expose the researcher to any of kind of emotional, physical or health and safety hazard? Please rate the degree of risk:

MEDIUM

Reviewer comments in relation to researcher risk (if any):

This is a potentially challenging group of participants to interview but the researcher has put into place a number of appropriate systems to manage this. It is important the protocols are followed to manage the risks.

Reviewer *(Typed name to act as signature):* Miles Thomas

Date: 2nd March 2016

This reviewer has assessed the ethics application for the named research study on behalf of the School of Psychology Research Ethics Committee

Confirmation of making the above minor amendments (for students):

I have noted and made all the required minor amendments, as stated above, before starting my research and collecting data.

Student's name (*Typed name to act as signature*):

Student number:

Date:

(Please submit a copy of this decision letter to your supervisor with this box completed, if minor amendments to your ethics application are required)

PLEASE NOTE:

*For the researcher and participants involved in the above named study to be covered by UEL's insurance and indemnity policy, prior ethics approval from the School of Psychology (acting on behalf of the UEL Research Ethics Committee), and confirmation from students where minor amendments were required, must be obtained before any research takes place.

*For the researcher and participants involved in the above named study to be covered by UEL's insurance and indemnity policy, travel approval from UEL (not the School of Psychology) must be gained if a researcher intends to travel overseas to collect data, even if this involves the researcher travelling to his/her home country to conduct the research. Application details can be found here: <http://www.uel.ac.uk/gradschool/ethics/fieldwork/>



1st November 2016

Dear Paula,

Project Title:	Investigating the factors that contribute to unstable living accommodation in adults with a diagnosis of Autistic Spectrum Disorder
Researcher(s):	Paula Grant
Principal Investigator:	Paula Grant

I am writing to confirm that the application for the aforementioned NHS research study reference **16/LO/1280** has received UREC ethical approval and is sponsored by the University of East London.

The lapse date for ethical approval for this study is **1st November 2020**. If you require UREC approval beyond this date you must submit satisfactory evidence from the NHS confirming that your study has current NHS R&D ethical approval and provide a reason why UREC approval should be extended.

Please note as a condition of your sponsorship by the University of East London your research must be conducted in accordance with NHS regulations and any requirements specified as part of your NHS R&D ethical approval.

Please confirm that you will conduct your study in accordance with the consent given by the Trust Research Ethics Committee by emailing researchethics@uel.ac.uk.

Please ensure you retain this approval letter, as in the future you may be asked to provide proof of ethical approval.

With the Committee's best wishes for the success of this project.

Yours sincerely,

Catherine Fieulleateau
Research Integrity and Ethics Manager
For and on behalf of
Dr Lisa Mooney
University Research Ethics Committee (UREC)
Research Ethics
Email: researchethics@uel.ac.uk

SCHOOL OF PSYCHOLOGY

uel.ac.uk/psychology

Acting Dean: Professor Rachel Mulvey, BA MA DCG PhD FICG FHEA



Date: 18/05/2016

Student Number: u1438304

Dear Paula,

Registration as a Candidate for the University's Research Degree

I am pleased to inform you that the Research Degrees Subcommittee on behalf of the University Quality and Standards Committee, has registered you for the degree of Professional Doctorate.

Title of Professional Doctorate: Professional Doctorate in Clinical Psychology

Director of Studies: Dr Matthew Jones Chesters

Supervisor/s: Dr Dora Whittuck

Expected completion: According to your actual date of registration, which is **1st February 2016** the registration period is as follows:

Minimum 18 months maximum 48 months (4 years), according to a full time mode of study.

Your thesis is therefore due to be submitted between:

1st August 2017 - 1st February 2020
--

I wish you all the best with your intended research degree programme. Please contact me if you have any further queries regarding to this matter.

Yours sincerely,

Dr Kenneth Gannon
School Research Degrees Leader
Direct line: 020 8223 4576
Email: k.n.gannon@uel.ac.uk



APPENDIX TWO: NHS ETHICAL APPROVAL



Health Research Authority

London - Brent Research Ethics Committee

60 London Road

Skipton House

London

SE1 6LH

Telephone: 020 7972 2554

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

01 September 2016

Ms Paula Grant
Trainee Clinical Psychologist
Camden and Islington NHS Foundation Trust
4th Floor, East Wing, St Pancras Hospital, 4 St Pancras Way, London
NW1 0PE

Dear Ms Grant

Study title: Investigating the factors that contribute to unstable living accommodation in adults with a diagnosis of Autistic Spectrum Disorder
REC reference: 16/LO/1280
IRAS project ID: 202247

Thank you for your letter of 31st August, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact the REC Manager, Ms Julie Kidd, nrescommittee.london-brent@nhs.net.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

1. If rough sleepers are involved in the study a substantial amendment will need to be sent to the Committee for review.

You should notify the REC once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. Revised documents should be submitted to the REC electronically from IRAS. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which you can make available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk or at <http://www.rforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Covering letter on headed paper [Covering Letterin	1	01 May 2016a
Covering letter on headed paper [Covering Letterin	2	01 August 2016us
Consent of Sponsor insurance or indemnity (non NHS Sponsors	1	01 May 2016a
Consent of Sponsor insurance or indemnity (non NHS Sponsors	1	01 May 2016a
GP/consultant information sheets or letters [Letter to GP Version 2.0	2	01 August 2016us
Interview schedules or topic guides for participants [Interview	2	01 August 2016
Interview schedule Version 2 08.08.16	2	01 August 2016
IRAS Application Form [IRAS_Form_22082016]		01 June 2016
IRAS Checklist XML [Checklist_22082016M		01 August 2016us
IRAS Checklist XML [Checklist_31082016is		01 August 2016
Participant Debrief Sheet (Appendix G and H)]	1	01 May 2016a
Registration Letter	1	01 May 2016a
Email RE UEL Indemnity Process From Head of Research	1	01 May 2016a
UEL Ethical Approval	1	01 May 2016
Risk assessment		01 August 2016
Participant consent form [Participant Consent Forms (Appendix E and F)]	Participant Consent Form Version 3	01 August 2016us

	§.1:08.1 08	
Participant information sheet (PIS) [Participant Information Sheet]	3	01 August 2015
Referee's report or other scientific critique report [Scientific Critique Report]		
Local research protocol or project proposal [Project Proposal]	1	01 May 2014a
Summary CV for Chief Investigator (CI) [Chief Investigator CV]	1	01 May 2014a
Student summary CV for student [CV for Student]	1	01 May 2016
Supervisor summary CV for supervisor (student research) [CV for Supervisor]	1	01 May 2014a
Flowchart, summary, synopsis or diagram (flowchart) of protocol in non-technical language [Summary]	1	01 May 2014a

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document *After ethical review – guidance for researchers* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:

<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at

<http://www.hra.nhs.uk/hra-training/>

16/LO/1280

please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely
PP



Dr Manish Saxena
Chair

Email: nrescommittee.london-brent@nhs.net

Enclosures: "After ethical review – guidance for researchers"

cc copy to:

Bill Professor Neville Punchard 


Ms Paula Grant
Trainee Clinical Psychologist
Camden and Islington NHS Foundation Trust
4th Floor, East Wing, St Pancras Hospital, 4 St Pancras
Way, London
NW1 0PE

Email: hra.approval@nhs.net

07 September 2016

Dear Ms Grant

Letter of HRA Approval

Study title:	Investigating the factors that contribute to unstable living accommodation in adults with a diagnosis of Autistic Spectrum Disorder
IRAS project ID:	202247
REC reference:	16/LO/1280
Sponsor	University of East London

I am pleased to confirm that **HRA Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. Please read *Appendix B* carefully, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

It is critical that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details and further information about working with the research management function for each organisation can be accessed from www.hra.nhs.uk/hra-approval.

Appendices

The HRA Approval letter contains the following appendices:

- A – List of documents reviewed during HRA assessment
- B – Summary of HRA assessment

After HRA Approval

The document *“After Ethical Review – guidance for sponsors and investigators”*, issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

In addition to the guidance in the above, please note the following:

- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the *After Ethical Review* document. Non-substantial amendments should be submitted for review by the HRA using the form provided on the [HRA website](http://www.hra.nhs.uk), and emailed to hra.amendments@nhs.net.
- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the [HRA website](http://www.hra.nhs.uk).

Scope

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found at <http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hsc-rd-review/>.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application

IRAS project ID	202247
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procedure. If you wish to make your views known please email the HRA at hra.approval@nhs.net. Additionally, one of our staff would be happy to call and discuss your experience of HRA Approval.

HRA Training

We are pleased to welcome researchers and research management staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

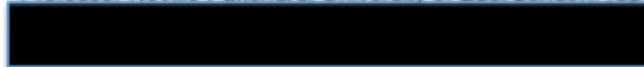
Your IRAS project ID is 202247. Please quote this on all correspondence.

Yours sincerely

Thomas Fairman
HRA Assessor

Email: hra.approval@nhs.net

Copy to: *Professor Neville Punchard, University of East London. (Sponsor Contact)*



Appendix A - List of Documents

The final document set assessed and approved by HRA Approval is listed below. Assessors should be mindful that the document set has been populated from the assessment column in HARP. Assessors should ensure that only those documents which should be listed below are ticked on the assessment column in HARP.

Document	Version	Date
Covering letter on headed paper [Covering Letter]	1	31 May 2016
Evidence of Sponsor Insurance or Indemnity (non NHS Sponsors only) [Registration Letter]	1	31 May 2016
Interview schedules or topic guides for participants [Interview Schedules (Appendix A) Version 1]	1	31 May 2016
IRAS Application Form [IRAS_Form_22062016]		22 June 2016
Other [Participant Debrief Sheet (Appendix G and H)]	1	31 May 2016
Other [Registration Letter]	1	18 May 2016
Other [Email RE UEL Indemnity Process From Head of Research]	1	31 May 2016
Other [UEL Ethical Approval]	1	31 May 2016
Other [UEL Professional Indemnity Certi 2015-16]		03 August 2015
Other [HRA Schedule of Events]	2	14 July 2016
Other [statement of activities]	2	07 September 2016
Participant consent form [Participant Consent Forms (Appendix E and F)]	1	31 May 2016
Participant information sheet (PIS) [Participant Information Sheet]	1	31 May 2016
Referee's report or other scientific critique report [Scientific Critique Report]		
Research protocol or project proposal [Project Proposal]	1	31 May 2016
Summary CV for Chief Investigator (CI) [Chief Investigator CV]	1	31 May 2016
Summary CV for student [CV for Student]	1	31 May 2016
Summary CV for supervisor (student research) [CV for Supervisor]	1	31 May 2016
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Summary]	1	31 May 2016

Appendix B - Summary of HRA Assessment

This appendix provides assurance to you, the sponsor and the NHS in England that the study, as reviewed for HRA Approval, is compliant with relevant standards. It also provides information and clarification, where appropriate, to participating NHS organisations in England to assist in assessing and arranging capacity and capability.

For information on how the sponsor should be working with participating NHS organisations in England, please refer to the, *participating NHS organisations, capacity and capability and Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria) sections in this appendix.*

The following person is the sponsor contact for the purpose of addressing participating organisation questions relating to the study:

Professor Neville Punchard, University of East London, (n.punchard@uel.ac.uk, 020 8223 4532)

HRA assessment criteria

Section	HRA Assessment Criteria	Compliant with Standards	Comments
1.1	IRAS application completed correctly	Yes	No comments
2.1	Participant information/consent documents and consent process	Yes	No comments
3.1	Protocol assessment	Yes	No comments
4.1	Allocation of responsibilities and rights are agreed and documented	Yes	The sponsor has submitted a Statement of Activities and indicated that they intend for this to form the agreement between the sponsor and participating sites. The sponsor is not requesting, and does not require any additional agreements.
4.2	Insurance/indemnity arrangements assessed	Yes	Where applicable, independent contractors (e.g. General Practitioners) should ensure that the professional

Section	HRA Assessment Criteria	Compliant with Standards	Comments
			indemnity provided by their medical defence organisation covers the activities expected of them for this research study
4.3	Financial arrangements assessed	Yes	No application for external funding has been made. The sponsor has indicated, in Schedule 1 of the Statement of Activities that no funding will be provided to sites.
5.1	Compliance with the Data Protection Act and data security issues assessed	Yes	No comments
5.2	CTIMPS – Arrangements for compliance with the Clinical Trials Regulations assessed	Not Applicable	No comments
5.3	Compliance with any applicable laws or regulations	Yes	No comments
6.1	NHS Research Ethics Committee favourable opinion received for applicable studies	Yes	REC favourable opinion was received from the Brent Research Ethics Committee on the 1 st September 2016. Confirmation of compliance with conditions was issued on the 5 th September 2016.
6.2	CTIMPS – Clinical Trials Authorisation (CTA) letter received	Not Applicable	No comments
6.3	Devices – MHRA notice of no objection received	Not Applicable	No comments
6.4	Other regulatory approvals and authorisations received	Not Applicable	No comments

Participating NHS Organisations in England

This provides detail on the types of participating NHS organisations in the study and a statement as to whether the activities at all organisations are the same or different.

All NHS organisations participating in the study will undertake the same study activity. Therefore there is only one site type participating in the research.

Please note that the remit of HRA Approval is limited to the NHS involvement in the study. Research activity undertaken at non-NHS sites is therefore not covered and the research team should make appropriate alternative arrangements with relevant management at these organisations to conduct the research there.

The Chief Investigator or sponsor should share relevant study documents with participating NHS organisations in England in order to put arrangements in place to deliver the study. The documents should be sent to both the local study team, where applicable, and the office providing the research management function at the participating organisation. For NIHR CRN Portfolio studies, the Local LCRN contact should also be copied into this correspondence. For further guidance on working with participating NHS organisations please see the HRA website.

If chief investigators, sponsors or principal investigators are asked to complete site level forms for participating NHS organisations in England which are not provided in IRAS or on the HRA website, the chief investigator, sponsor or principal investigator should notify the HRA immediately at hra.approval@nhs.net. The HRA will work with these organisations to achieve a consistent approach to information provision.

Confirmation of Capacity and Capability

This describes whether formal confirmation of capacity and capability is expected from participating NHS organisations in England.

NHS organisations in England that are participating in the study **will be expected to formally confirm their capacity and capability to host this research.**

- Following issue of this letter, participating NHS organisations in England may now confirm to the sponsor their capacity and capability to host this research, when ready to do so. How capacity and capability will be confirmed is detailed in the Agreement section of this appendix.
- The [Assessing, Arranging, and Confirming](#) document on the HRA website provides further information for the sponsor and NHS organisations on assessing, arranging and confirming capacity and capability.

Principal Investigator Suitability

This confirms whether the sponsor position on whether a PI, LC or neither should be in place is correct for each type of participating NHS organisation in England and the minimum expectations for education, training and experience that PIs should meet (where applicable).

A study Principal Investigator should be appointed at all NHS study sites participating in the research. The sponsor has indicated that they do not require the assistance of study sites in identifying suitable individuals to fulfil this role.

GCP training is not a generic training expectation, in line with the [HRA statement on training expectations](#).

HR Good Practice Resource Pack Expectations

This confirms the HR Good Practice Resource Pack expectations for the study and the pre-engagement checks that should and should not be undertaken

The sponsor has confirmed that, all study activities at participating NHS organisations will be undertaken by local staff who have a contractual relationship with the relevant organisation. Therefore no honorary research contracts or letters of access are expected for this study.

Other Information to Aid Study Set-up

This details any other information that may be helpful to sponsors and participating NHS organisations in England to aid study set-up.

The applicant has indicated that they do not intend to apply for inclusion on the NIHR CRN Portfolio.

**APPENDIX THREE: NHS TRUST RESEARCH AND DEVELOPMENT
DEPARTMENT APPROVAL**

[Redacted] 

[Redacted]

From: [Redacted]

Date: 5 October 2016

To: Paula Grant

Cc: [Redacted]

Subject: Confirmation of Capacity and Capability at [Redacted] Trust

Attachment: agreed statement of activities.

Dear Paula

RE: IRAS 202247 Investigating the Factors that contributes to unstable living accommodation in adults with a diagnosis of Autistic Spectrum Disorder

This email confirms that [Redacted] Trust has the capacity and capability to deliver the above referenced study. Please find attached our agreed Statement of Activities as confirmation.

We agree to start this study on a date to be agreed when you as sponsor give the green light to begin.

If you wish to discuss further, please do not hesitate to contact me.

Kind regards

[Redacted]

[Redacted]

Head of Research and Development

[Redacted]

[Redacted]

APPENDIX FOUR: INFORMATION SHEETS

APPENDIX B-PROFESSIONALS INFORMATION SHEET

The Principal Investigator(s)

Paula Grant

U1438304@uel.ac.uk

Consent to Participate in a Research Study

The purpose of this letter is to provide you with the information that you need to consider in deciding whether to participate a research study. The study is being conducted as part of my Professional Doctorate in Clinical Psychology degree at the University of East London.

Project Title:

Investigating the factors that contribute to unstable living accommodation in adults with a diagnosis of Autistic Spectrum Disorder (ASD)

Project Description

The aim of the research is to develop a model of the processes involved in homelessness in the autistic population. This research defines homelessness or unstable living conditions, as those have no accommodation that they are entitled to, no accommodation that is reasonable for them to occupy, rough sleeping, living in temporary accommodation, or living within intolerable physical conditions. It defines autism as those who self report as being diagnosed with ASD. It is hoped that this model will be used to inform support provided by services homeless adults with a diagnosis of ASD. Through using the perspectives of those with a diagnosis of ASD and have been homeless, the research also aims to more clearly represent the voice of adults with ASD in the development of theories and interventions to support for them.

The research involves interviews with AROUND 12 adults with a diagnosis of ASD who have experienced the above stated unstable living conditions and/or

professionals who have worked with adults with ASD within the following services:

- XXXX Autism Assessment and Diagnosis Service (XX NHS Trust)
- XXXXX Autism Service (Third Sector Organization)
- XXXX City Council commissioned services for the Homeless

The questions are likely to evolve throughout the research in response to the themes that emerge within the interviews, however, it is likely that you are asked questions such as what contributed to the autistic individuals you have worked with to becoming homeless? What factors made it difficult to support these individuals into stable accommodation? What factors helped to support this individual into stable accommodation?

The researcher will also collect the following personal details from you:

Your name, age, gender, ethnicity and contact details (email address or phone), service in which you work.

There are no risks or dangers involved in taking a part, but we may discuss things that you find difficult or distressing. If you do become upset, the researcher can provide you with be details for other organisations that can offer you support

Confidentiality of Data

Each interview will be with the researcher, Paula Grant. The interview should last around an hour. The interview will be conducted face to face and last between 1-2 hours. This may be distressing for you and if so you will be offered the option of holding the interview via email.

Face to Face interviews:

These will be recorded on a digital recorder and then saved onto a password-protected computer. Only Paula Grant will listen to the recordings. The researcher will then type up the interview into a transcript. The transcript will be saved into a password-protected computer. In the transcript, any names, including yours, will be changed. Anything that you say that will mean someone

could identify you will also be changed in the transcript. The transcript will be stored in a separate file to any personal details that you provide the researcher with. This transcript will be read by the researchers supervisor at the University of East London (Matthew Jones-Chesters) and supervisor in the XXXX Adult Autism Service, XXXX and the examiners who assess Paula Grant during thesis examination. No one else will read the transcript.

Email Interviews:

For email interviews, the researcher will agree a time and date for the interview. On this time and date the researcher will provide the participant with a list of questions and a secure nhs.net account to send the responses to. The researcher will give you time to respond and then email with follow up questions. This process will take up to an hour and a half. After the interview is completed the researchers will save the responses onto a word document within a password-protected computer and delete the email thread from the email account. The researcher will advise you also to deleted the email thread or save into a password-protected file if you wish to keep a record of the interview. The email will be saved separately from identifiable information such as the participants name or email address.

After the thesis examination in (estimated July 2017), the researcher will delete the audio recordings and email thread and your personal detail. The written anonymised transcript will be stored separately on a password-protected computer and deleted five years after the research has been submitted (estimated July 2022) and might be used for additional publications based on the research.

The final thesis will include a small number of quotes from the interviews. This thesis will be shared with people that work in the following services

- XXXX Autism Assessment and Diagnosis Service (XXX NHS Trust)
- XXXX Autism Service (Third Sector Organization)
- XXXXX City Council commissioned services for the Homeless

It will also be shared with the adults with ASD that have been homeless that were

interviewed. There may be a chance that someone who was interviewed or who works in these services and knows you may recognize something you said and may be able to identify you. To try and prevent this from happening, identifiable information will be changed within the extracts from the interview.

Location

The interviews can take place at:

- XXXX Adult Autism Assessment and Diagnosis Service (XXX NHS Trust)
- XXXX Autism Service (Third Sector Organization)
- XXXX City Council commissioned services for the Homeless

Disclaimer

You do not have to take part in this study and should not feel coerced or obliged to do so. You are free to withdraw at any time. If you choose to withdraw, you do not have to give any reason and this will not cause you any disadvantage, it will not affect your relationship with:

- XXXX Adult Autism Assessment and Diagnosis Service (XXX Trust)
- XXXX Autism Service (Third Sector Organization)
- XXXX City Council commissioned services for the Homeless

If you withdraw all transcripts and recordings will be deleted. You can withdraw from the study up until January 2017 when analysis of the interviews will begin. Due to the methods of analysis used in this study (Grounded Theory) interview questions are amended according to the themes that emerged in previous interviews. This means that the researcher may refer to themes or issues raised in your interview, in order to justify parts of the analysis, even after you have withdrawn from the study. Your exact words will not be used in this process and themes or issues will be drawn on in a general way. If you would like a break during the interview or to change the time of the interview please discuss with Paula Grant who will be happy to discuss this with you further.

Please ask the researcher, Paula Grant, if you have any further questions regarding this study. If you are happy to participate, you will be asked to sign a



consent for prior to the interview. Please keep hold of this information letter as it may be useful for future reference.

If you have any concerns regarding how the research has been conducted, please contact the study supervisor via Matthew Jones-Chesters , School of Psychology, University of East London, Water Lane, London E15 4LZ. m.h.jones-chesters@uel.ac.uk

Or

Chair of the School of Psychology Research Ethics Sub-committee: Dr. Mark Finn, School of Psychology, University of East London, Water Lane, London E15 4LZ. (Tel: 020 8223 4493. Email: m.finn@uel.ac.uk)

Thank you in anticipation,

Yours sincerely,

Paula Grant

NON EASY READ INFORMATION SHEET



The Principal Investigator(s)

Paula Grant

U1438304@uel.ac.uk

Consent to Participate in a Research Study

The purpose of this letter is to provide you with the information that you need to consider in deciding whether to participate in a research study. The study is being conducted as part of my Professional Doctorate in Clinical Psychology degree at the University of East London. It is hoped that the research will be published in a professional journal in order to inform the support provided to those with a diagnosis of Autistic Spectrum Disorder (ASD) and have been homeless.

Project Title:

Investigating the factors that contribute to unstable living accommodation in adults with a diagnosis of Autistic Spectrum Disorder

Project Description

The aim of the research is to develop a model of the processes involved in homelessness in the autistic population.

This research defines homelessness or unstable living conditions, as those who have:

-no accommodation that they are entitled to (for example living in a squat or having no legal protection to live in a property)

and/or

-rough sleeping (for example sleeping on the streets)

and or

-living in temporary accommodation (for example living in a hostel)

and/or

living within intolerable physical conditions or unreasonable living conditions- (for example conditions that may cause physical health problems).

It defines autism as those who report to have a diagnosis of ASD.

It is hoped that this model will be used to inform support provided by services for homeless adults with a diagnosis of ASD. Through using the perspectives of those with a diagnosis of ASD and have been homeless, the research also aims to more clearly represent the voice of adults with ASD in the development of theories and interventions to support them. The findings of this research may also be used to influence the practice of clinicians and front line staff when working with adults with ASD who have also been homeless.

The research involves interviews with adults with a diagnosis of ASD who have experienced the above stated unstable living conditions and professionals who have worked with adults with ASD within the following services:

- XXXX Adult Autism Assessment and Diagnosis Service (XXX Trust)
- XXXXXXXX Autism Service (Third Sector Organization)
- XXXX City Council commissioned services for the Homeless

The questions are likely to evolve throughout the research in response to the themes that emerge within the interviews, however, it is likely that you are asked questions such as:

-Tell me about how Autism affect you?

-Tell me about your interests?

-Which of the above unstable living conditions have you experienced?

-What happened before this, what lead up to this?

-Tell me about what it was like to experience this?

-Tell me about how this experience could have been improved?

-Where do live now? What is it like? What lead to this happening?

The researcher will also collect the following personal details from you:

Your name, age, gender, ethnicity and contact details (email address or phone) area in which you occupied when homeless, date of ASD diagnosis and names of services that supported you regarding ASD and Homelessness.

It may be difficult for you to answer some of these questions. They may make you feel upset or they may be difficult to understand. To prevent this, the researcher, Paula Grant, will meet with you before the interview to discuss the questions and structure of the interview in order to minimise any confusion or distress. In this meeting we will also discuss what I can do during the interview to help keep worry or distress that you may experience to a minimum. You can bring someone with you to the interview if this will help you to feel more comfortable.

There are no risks or dangers involved in taking a part, but we may discuss things that you find difficult or distressing. If you do become upset, the researcher can provide you with be details for other organisations that can offer you support. If you disclose anything that indicates that you or others are at risk, the researcher will be obliged to inform relevant services.

Confidentiality of Data-

Each interview will be with the researcher, Paula Grant. The interview should last between 1 and 2 hours. You can choose whether to have the interview face to face or via email.

If you choose the interview to be via email, the researcher will provide you with a list of questions and a secure nhs.net account to send the responses to on an agreed time and date. On this date, the researcher will email follow up questions. This process will take up to an hour and a half. After the interview is completed the researcher will save the responses onto a word document within a password-protected computer and delete the email thread from the email account. The email thread will be saved separately from any identifiable information such as

your name and contact details.

If you choose the interview to be face to face it will be recorded on a digital recorder and then saved onto a password-protected computer. Only Paula Grant will listen to the recordings. After the face to face or email interview, the researcher will type up the interview into a transcript. The transcript will be saved into a password-protected computer. In the transcript, any names, including yours, will be changed. Anything that you say that will mean someone could identify you will also be changed in the transcript. The transcript will be stored in a separate file to any personal details that you provide the researcher with. The transcript will be read by the researchers supervisor at the University of East London, Matthew Jones-Chesters and supervisor in XXXX Service, XXXX and the examiners who assess Paula Grant during thesis examination. No one else will read the transcript.

After the thesis examination in (estimated July 2017), the researcher will delete the audio recordings, email thread and personal details. The written transcript with anonymised data will be stored separately on a password-protected computer for three years after the research has been submitted (estimated July 2022) and might be used for additional publications based on the research.

The final thesis will include a small number of quotes from the interviews. This thesis will be shared with people that work in the following services

- XXXXX Adult Autism Assessment and Diagnosis Service (XXX NHS Trust)
- XXXX Autism Service (Third Sector Organization)
- XXXXX Council commissioned services for the Homeless

It will also be shared with the adults with ASD that have been homeless that were interviewed. There may be a chance that someone who was interviewed or who works in these services and knows you may recognize something you said and may be able to identify you. To try and prevent this from happening, identifiable information will be changed within the extracts from the interview.

Location

The interviews can take place at:

- XXXX Adult Autism Assessment and Diagnosis Service (XXX NHS Trust)
- XXXX Autism Service (Third Sector Organization)
- XXXX City Council commissioned services for the Homeless

Remuneration

You will be given £10 gift voucher in appreciation for your participation in this study.

Disclaimer

You do not have to take part in this study and should not feel coerced or obliged to do so. You are free to withdraw at any time. If you choose to withdraw, you do not have to give any reason and this will not cause you any disadvantage, it will not affect your relationship with:

- XXXX Autism Assessment and Diagnosis Service (XXX NHS Trust)
- XXXX Autism Service (Third Sector Organization)
- XXXX Council commissioned services for the Homeless

If you withdraw all transcripts and recordings will be deleted. You can withdraw from the study up until January 2017 when analysis of the interviews will begin. Due to the methods of analysis used in this study (Grounded Theory) interview questions are amended according to the themes that emerged in previous interviews. This means that the researcher may refer to themes or issues raised in your interview, in order to justify parts of the analysis, even after you have withdrawn from the study. However, the transcripts will be deleted and your exact words used will not be used. Only the themes or issues from your interview will be used. If you would like a break during the interview or to change the time of the interview please discuss with Paula Grant who will be happy to discuss this with you further.

Please ask the researcher, Paula Grant if you have any further questions regarding this study. If you are happy to participate, you will be asked to sign a consent form prior to the interview. Please keep hold of this information letter as it

may be useful for future reference.

If you have any concerns regarding how the research has been conducted, please contact the study supervisor via Matthew Jones-Chester's, School of Psychology, University of East London, Water Lane, London E15 4LZ. Email: m.h.jones-chesters@uel.ac.uk

Or

Chair of the School of Psychology Research Ethics Sub-committee: Dr. Mark Finn, School of Psychology, University of East London, Water Lane, London E15 4LZ. (Tel: 020 8223 4493. Email: m.finn@uel.ac.uk)

Thank you in anticipation,

Yours sincerely,

Paula Grant

EASY READ INFORMATION SHEET

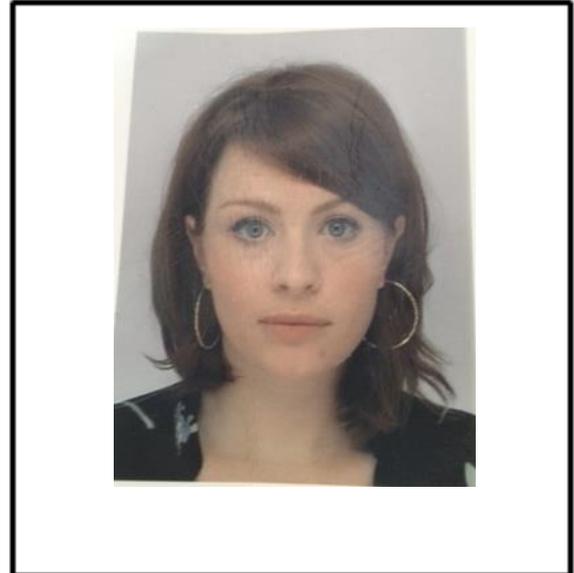
THE RESEARCH

This is a picture of Paula

Paula is reseraching what it is like to have autism and not have a home

Paula wants to talk to you about

1. What led you to not having a home
2. What made it difficult for you to find a home
3. What helped you find a home



AFTER THE INTERVIEW

Paula will save the recording or email thread on a computer with a password.

The recordings will be deleted from the digital recorder within 24 hours from now.

Email threads from the interview will be deleted from the email account within 24 hours from now.

The recordings and email threads wil be deleted from Paula's computer in July 2017.

Paula will type up the interviews. The types interviews will be deleted after five years.

THE REPORT

After the interview Paula will write a report about the things that everyone said.

Paula will not write your name in the report.

Paula's report may be put into a journal so that everyone can read it.

THE REPORT

After the interview Paula will write a report about the things that everyone said.

Paula will not write your name in the report.

Paula's report may be put into a journal so that everyone can read it.

APPENDIX FIVE-DEBRIEF SHEETS



DEBRIEF SHEET

Thank you.

Thank you for participating in the study. Your participation will help us to better understand the processes involved in homelessness in adults with a diagnosis of ASD. We hope to provide recommendations and guidance to health and social care professional who support homeless adults with a diagnosis with ASD. We hope these recommendations will help to improve current practice in support services.

The research will continue until May 2017, if you have any questions regarding the research, please feel free to contact me on: u1438304@uel.ac.uk until this date.

Please remember you free to withdraw your data from the study at any time. If you choose to withdraw, you do not have to give any reason and this will not cause you any disadvantage, it will not affect your relationship with

- XXXX Adult Autism Assessment and Diagnosis Service (XXX NHS Trust)
- XXXX Autism Service (Third Sector Organization)
- XXXX Council commissioned services for the Homeless

If you withdraw all transcripts and recordings will be deleted. You can withdraw from the study up until January 2017 when analysis of the interviews will begin.

What happens to my data?

As a reminder, the data recorded from this interview will be saved onto a password protected computer. Recordings will be deleted from the digital recorded within 24 hours from now. Email threads from the interview will be deleted within 24 hours from now.

The recordings and email threads will be stored separately from any identifiable information that you have provided to the researcher (name, age gender and contact details). The recordings, email threads be deleted after the thesis

examination (July 2017).

The researcher will type up the interview data into a transcript within three months of today. The transcript will be saved into a password-protected computer in a file separate from any identifiable information that you have provided to the researcher. The written transcript and personal details of participants will be stored separately a password-protected computer and deleted after for five years (estimated July 2022).

The transcript will be read by the researchers supervisor at the University of East London, Matthew Jones-Chester's and supervisor in XXXX Adult Autism Service, XXXX and the examiners who assess Paula Grant during thesis examination. No one else will read the transcript.

The final thesis will include a small number of quotes from the interviews. This thesis may be published. To try and prevent people reading this research and identifying you, identifiable information will be changed within the extracts from the interview.

If you feel distressed....

If after this research you feel distressed or concerned please contact the organisations for support:

Mind: 0300 123 3393

Samaritans: 116 123

Or for issues relating to housing:

Shelter: 0808 274 5283

THANKYOU

Thankyou for taking part in my study.

We hope that this research will help people who are homeless and have a diagnosis of ASD.

If you have any questions about the research after today, or change your mind about being in the study please contact me: u1438304@uel.ac.uk. You can change your mind up to December 31st 2016.

WHAT HAPPENS NEXT

Paula Grant will now save the recordings or email thread on a computer with a password.

Recordings will be deleted from the digital recorder within 24 hours from now.

Email threads from the interview will be deleted within 24 hours from now.

The recordings and email threads will be deleted from Paula Grant's computer in July 2017.

Paula Grant will type up the interviews. The typed interviews will be deleted after five years.

IF YOU FEEL UPSET.....

Please tell Paula Grant if you feel upset

If you would like to talk to someone, here are some of the contact details that may be useful:

Mind: 0300 123 3393

Samaritans: 116 123

Or for issues relating to housing:

Shelter: 0808 274 5283

APPENDIX SIX: THEORETICAL SAMPLING/AMMENDMENT TO INTERVIEW SCHEDULE- MEMOS

1: Excerpt from memo after Interview 1:

Key themes that emerged:

- Oppressive/Unequal Structures (Service Access Barriers, Service Lacking Adaptive Support, Lacking Opportunity)
- ASD Needs (Needing Adaptive Environment, Naivety to others intentions)
- Position and Power in Society (Craving Community, Being Abused, Being Silenced)

These lead to a loss of accepting community and resulting homelessness.

- Creating power (Self-Advocacy, Recruiting Advocates of Power, Services Creating Opportunities, Developing Advocacy Networks)

Possible Areas of Enquiry:

- How do homelessness services adapt to the needs of those with ASD
- Do the hostels become a reflection of how society should be a “utopia”?

2: Excerpt from memo after interview 2:

Key themes that emerged:

- ASD Needs (Sensory needs, Naivety to others intentions/behaviours).
- Position in Society (Feeling judged, Wanting Normality, Being Threatened).
- Experiential Needs (Needing Safety and Security, Needing Committed Support).

These lost the power of the participant to maintain housing and

- Creating Power (Receiving Advocates of Power, Gaining Support, Refusing to move)

Acted as a solution.

These themes seemed to combine to create a loss of power to make decisions about the home and maintain tenancy.

Possible Areas for Enquiry:

- *If people with ASD lose their power within homelessness, how can they become more powerful to prevent/respond to homelessness?*
- *How do participants use others to create power?*
- *ASD was again pulled on my participants as a issue that contributed to homelessness, it seems important to further understand this?*

3: Excerpt from memo following interview 3:

Key themes that emerged:

- Self in relation to society (Diminished, Faulty, Being Harassed, Feeling a failure, Being Scrutinized, Being Temporary)
 - ASD Needs (Being impulsive, Being Reckless, Episodic Future Thinking)
- These made coping with mainstream society difficult and homelessness was a preferable option- Element of choice emerges.

- Homeless ended as a result of flexibility in social barriers (Being noticed, Receiving Sympathy)

Possible Areas of Enquiry

- *End of homelessness was triggered by an outreach worker that was able to adopt flexible responsive practices, what was the process of this?*

It seems that professionals play a key role in offering a new form of support for participants, based on giving participants choice and advocating for their needs and wants. As this was a key factor in the solution to homelessness, further enquiry of this process is necessary.

Methodological Decisions:

- 1. Recruit professionals that have supported those with a diagnosis of autism through their homelessness.**
- 2. Remain alert to issues relating to ASD and Position in Society in Future Interviews and further enquire into these**

APPENDIX SEVEN-CONSENT FORMS

NON- EASY READ CONSENT FORM FOR SERVICE USER PARTICIPANTS FACE TO FACE INTERVIEW UNIVERSITY OF EAST LONDON

Consent to participate in a research study:

Investigating the factors that contribute to unstable living accommodation in adults with a diagnosis of Autistic Spectrum Disorder (ASD)

I have read the information sheet relating to the above research study and have been given a copy to keep. The nature and purposes of the research have been explained to me, and I have had the opportunity to discuss the details and ask questions about this information. I understand what is being proposed and the procedures in which I will be involved have been explained to me.

I understand that the interview will be recorded on a digital recorder and saved onto a password-protected computer. I understand that the recordings will be typed into a transcript with all identifiable information changed which may be read by University of East London (Matthew Jones-Chesters) and supervisor in the XXXX Adult Autism Service, XXXX and the examiners who assess Paula Grant during thesis examination. I understand that after the thesis examination in (estimated July 2017), the researcher will delete the audio recordings. The written anonymised transcript will be stored separately on a password-protected computer and deleted three years after the research has been submitted (estimated July 2022) and might be used for additional publications based on the research.

I understand that my involvement in this study, and particular data from this research, will remain strictly confidential. Only the researcher(s) involved in the study will have access to identifying data. It has been explained to me what will happen once the research study has been completed.



I hereby freely and fully consent to participate in the study which has been fully explained to me. Having given this consent I understand that I have the right to withdraw from the study at any time without disadvantage to myself and without being obliged to give any reason. I also understand that should I withdraw, the researcher reserves the right to use my anonymous data in the write-up of the study and in any further analysis that may be conducted by the researcher.

Participant's Name (BLOCK CAPITALS)

.....

Participant's Signature

.....

Researcher's Name (BLOCK CAPITALS)

.....

Researcher's Signature

.....

NON- EASY READ CONSENT FORM FOR SERVICE USER PARTICIPANTS

EMAIL INTERVIEW

UNIVERSITY OF EAST LONDON

Consent to participate in a research study:

Investigating the factors that contribute to unstable living accommodation in adults with a diagnosis of Autistic Spectrum Disorder (ASD)

I have the read the information sheet relating to the above research study and have been given a copy to keep. The nature and purposes of the research have been explained to me, and I have had the opportunity to discuss the details and ask questions about this information. I understand what is being proposed and the procedures in which I will be involved have been explained to me.

I understand that the interview will take place via email on a secure nhs.net account and after the interview the email thread will be saved onto a password-protected computer and deleted from the email account. I understand that the recordings will be typed into a transcript will all identifiable information changed which may be read by University of East London (Matthew Jones-Chesters) and supervisor in the XXXX Adult Autism Service, XXXX and the examiners who assess Paula Grant during thesis examination. I understand that after the thesis examination in (estimated July 2017), the researcher will delete the document containing the email thread. The written anonymised transcript will be stored separately on a password-protected computer and deleted three years after the research has been submitted (estimated July 2022) and might be used for additional publications based on the research.

I understand that my involvement in this study, and particular data from this research, will remain strictly confidential. Only the researcher(s) involved in the study will have access to identifying data. It has been explained to me what will happen once the research study has been completed.

I hereby freely and fully consent to participate in the study which has been fully explained to me. Having given this consent I understand that I have the right to

withdraw from the study at any time without disadvantage to myself and without being obliged to give any reason. I also understand that should I withdraw, the researcher reserves the right to use my anonymous data in the write-up of the study and in any further analysis that may be conducted by the researcher.

Participant's Name (BLOCK CAPITALS)

.....

Participant's Signature

.....

Researcher's Name (BLOCK CAPITALS)

.....

Researcher's Signature

.....

EASY READ CONSENT FORM

I have read the information sheet

It is ok for Paula Grant to talk to me about what it was like to not have a home

Choose Box 1 or Box 2 below:

I would like to talk to Paula Grant over email.

It is ok for Paula Grant to save the emails with a password onto a computer.

I would like to talk to Paula Grant face to face

It is ok for Paula Grant to record what I say and write it down.

It is ok for Paula Grant to write a report this will not have my name in it.

I know the report may be put into a journal so lots of people can read it

I would like to see a copy of the report

Name:

Signature:

Date:

CONSENT FORM FOR PROFESSIONAL PARTICIPANTS
UNIVERSITY OF EAST LONDON



Consent to participate in a research study:

Investigating the factors that contribute to unstable living accommodation in adults with a diagnosis of Autistic Spectrum Disorder (ASD)

I have the read the information sheet relating to the above research study and have been given a copy to keep. The nature and purposes of the research have been explained to me, and I have had the opportunity to discuss the details and ask questions about this information. I understand what is being proposed and the procedures in which I will be involved have been explained to me.

I understand that my involvement in this study, and particular data from this research, will remain strictly confidential. Only the researcher(s) involved in the study will have access to identifying data. It has been explained to me what will happen once the research study has been completed.

I hereby freely and fully consent to participate in the study which has been fully explained to me. Having given this consent I understand that I have the right to withdraw from the study at any time without disadvantage to myself and without being obliged to give any reason. I also understand that should I withdraw, the researcher reserves the right to use my anonymous data in the write-up of the study and in any further analysis that may be conducted by the researcher.

Participant's Name (BLOCK CAPITALS)

.....

Participant's Signature

.....



Researcher's Name (BLOCK CAPITALS)

.....

Researcher's Signature

.....

APPENDIX EIGHT: INTERVIEW SCHEDULE

Interview Schedule

BEFORE HOMELESSNESS

- Tell me about what was happening in your life?
- Tell me about the things that you found difficult to manage?
 - Tell me about the good things about this time?
 - Tell me about the bad things about this time?
 - Looking back, why do you think that you ended up rough sleeping?

DURING HOMELESSNESS

- Tell me about what it was like to be homeless?
- Tell me about the good things?
- Tell me about the bad things?
- Looking back tell me about how this experience could have been improved?

AFTER HOMELESSNESS

- Where do live now?
- What is it like?
- Tell me about the good things about where you live now?
- Tell me about the bad things about where you live now? -What led to you living where you live now?

TIMEFRAMES?

APPENDIX NINE- Excerpt from Memo Following Initial and Focused Coding of P4

Isolation is like a drug- short term gains- serenity, peace but long term difficulty- creates problems in mood- isolation and removes buffer.

Again this person escaped from intolerable social world and finds an alternative world which is manageable (can observe and limit social contact) so that the person is able to gradually develop skill and meet needs for social contact but not struggle with the full responsibilities that living within the social world required (links with P3 possible P2).

Persistence is key- person often refuses an opportunity when it is first offered and then accepts after persistence (and commitment?) is demonstrated.

P4 very eloquently explains the process of developing in job-success leading to increased social expectations- coping with these through avoidance- avoidance being notices losing job- developing turmoil

Masking vulnerability makes it very difficult to be given the support that is required. “. I think at some point, it means I have been very blessed, or lucky, whatever you call it. It to people to believe the level of distress and the risk, because I think I am very good, I think, at masking it.”

The vulnerability that comes alongside homelessness open up advocates and therefore rights (links to p2,3). “And you know, (Charity) said at some point “But you have a social security number?”. And I was Like “No.”.

Lacking choice also a key theme-

-Considering death- Also reaching a point where suicide/death is the only other option.

Trust in others is a key element to change and this can take time- also legitimacy of others is helpful “That was something a bit more risky but, and Martin was someone I knew for a long, long time. Very established professionally and successful.’

-Perhaps due to the strong need and following of rules- P4 shows an awareness of the social rule of reciprocity- he sees that someone has done something for him, so demonstrates his gratitude through appeasement- doing what the other says. This brings up ethical dilemmas, who has the power and right to determine what that person needs and can the person make the decision themselves. Perhaps when it comes to health this should be prioritised and making clear indications of what is required of the person could be helpful- but other more complex expectations- eg showing “engagement” may be more difficult to understand and follow. “but because Dan is there, I feel like, I have to. This is my obligation. He is taking time to go with you, you have to go. So, that the thing is, that give me a kind of structure

of doing things. Not for me. Not directly in the first place is not for me. But because someone takes the time to do it, that's my part is to assist and to go there. "

Being forced- This is a different story- this person seems to benefit from direction, sometimes even order- when a potential is seen. Others need seems to require a much softer, slower, more persistent approach ""Rob, Tim cant make it tonight and we need to open in 30 minutes time. And I was like eh?" "Your going to have to play the music" and I said "No!" and he said "Yes, because we are in trouble nobody can play the music" and I said " I never play" and he said "Yes but we see you, you, you work every night here, you spend some time at the bar, a lot of time with Tim looking at the this table, turning table at what he is doing, so you are going to do it".

-Are people still homeless with a home? If the conditions are there yes- people may have roofs- but they may still be within the context of homelessness and attempt to created a space which helps them to find a home (an accepting community-face book page reference)

-If people still feel isolated, ejected and misunderstood- they are still homeless- we need to stop being distracted by the physical condition of a home and start to see the social and emotional. This needs to be a priority of support otherwise support is likely to fail and a person may find the homes they wish for on the street- creating issues for health and lifespan.

APPENDIX TEN Examples of Initial and Focused Coding
Examples of Constant Comparative Method (Emergent codes that replace earlier codes in italic and articulated in memo under coding tables).

Participant Code: S1

Service Frailty	<p>Gaining support network. Managing social contact.</p> <p>Having fragile support networks. Facing temporary support. Taking time to develop relationships.</p> <p>Struggling with temporal nature of support. Taking time to develop relationships.</p>	<p>P7: Yeah I think those, his support network, which is not big, but is quite profound to him, because it's some of only the people he sees in a week. There's those and then his friend, but his friend is getting on a bit, so those, those three pillars are all very fragile as well, as well as the flat, and they could easily fall away, suddenly our project doesn't get re tendered or, we only really live well pretty much year to year. Erm also it takes him a long time to build up relationships with people as well. And its not to say I am, you know indesposable, but if I was to leave it would be really hard for him to meet somebody new. I've known him for about four years and for the first two, we met twice and never met again. And that took so long to get back into this position.</p> <p>Paula: How did you do it?</p>	<p>463. 464. 465. 466. 467. 468. 469. 470. 471. 472. 473. 474. 475. 476. 477. 478. 479.</p>
Gaining Personalised Support	<p>Showing commitment to therapy. Needing practical support. Being offered further support. Meeting with trusted support. Letting others in</p> <p>Being invited to social group. Finding noise aversive.</p> <p>Preferring quiet.</p>	<p>P7: Erm, he started to, well I think he was continuing with his therapy. And there were some things his therapist couldn't do, more practical, out and about things. Erm, so then, because I work closely with him so he said "well can we just try again?" The therapist person supported him and myself. So we met, all together, we met in a kind of environment where erm, the chap that I support trusted this other person, and so then your sort of being let into someone's sort of trusted space a bit. And erm, and it was also, he came to this building and had, he didn't have a great experience of it. It was very loud, there might have been like er, there was lots of doors banging one day. He came to the social group a few times, again just really noisy and not the sort of quiet, tranquil place that he likes to be. So then I was associated with this building, so from then on, when we did meet again it was either in his flat, or just walking around one of the parks in London. Going to a coffee shop, so we never had any more sessions here. It was about me going to his space sort of space where he was at. But it took, took a long time for that and there was no guarantee that I would stay working with him or that I would be able to keep working with him. So its, yeah. I don't know what it is.</p>	<p>480. 481. 482. 483. 484. 485. 486. 487. 488. 489. 490. 491. 492. 493. 494. 495. 496. 497. 498. 499.</p>
Gaining Permanency In Support			<p>500. 501. 502. 503.</p>

<p>Gaining Personalised Support</p> <p>Gaining flexible support.</p>	<p>Being supported with housing administration. Being supported with health administration.</p> <p>Declining physical health. Gaining flexible support.</p> <p>Maintaining social support. Gaining flexible support.</p> <p>Being authorized to be flexible. Feeling under qualified.</p>	<p>Paula: Yeah and you were saying a bit about supporting him practically, that the therapist couldn't support home practically, what were those practical things that you were doing to help?</p> <p>P7: Erm, I cant remember at the time what they were. It might, it might have been some form filling but over the last couple of years. There's been a lot of hospital appointments, doctors appointments, yeah there's something like 40 this year</p> <p>Paula: God, that's a lot.</p> <p>P7: He's very unwell. So we've tried to sort of maintain, and some, well quite a lot of weeks would be one session where I would go to the hospital with him for and MRI scan, or a CT scan and this that and the other, but then still try and maintain our appointments. So be like "that wasn't your appointment that week, you still get to have coffee and a chat".</p> <p>Paula: So your quite flexible with him?</p> <p>P7: Yeah, um, so that's yeah, that's where sort of the broader remit of our support we can fill gaps where the therapist couldn't do. And then there's obviously lots of things that they can do that I'm not qualified to do.</p> <p>Paula: So is the support, is the therapist part of this support pillar?</p> <p>P7: Yeah</p>	<p>504. 505. 506. 507. 508. 509. 510. 511. 512. 513. 514. 515. 516. 517. 518. 519. 520. 521. 522. 523. 524. 525. 526. 527. 528. 529. 530. 531. 532. 533. 534. 535.</p>
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Participant Code P5:

<p>Resisting unwanted intervention.</p>	<p>Becoming reckless. Losing control. Borrowing money. Trying to keep going. Resisting unwanted intervention Getting into debt. Struggling to see way out. Considering suicide. Failing suicide attempt. Considering alternatives to suicide. Leaving things behind. Sleeping rough.</p>	<p>previously Um, and then I started becoming more reckless and things went wrong. Then started borrowing money from credit cards and various institutions to try and keep it going and then got into quite a lot of debt and I couldn't seem to see a way out of it, so, I was thinking of killing myself. But then, when it actually came to it I couldn't go through with it and I thought as an alternative I could just walk out of my flat and leave things behind and try sleeping rough so that's what I did.</p> <p>Paula: And you said that you, you said that you were reckless at that time, I'm wondering what that meant? What were you doing that was reckless?</p>	<p>10.. 11.. 12.. 13.. 14.. 15.. 16.. 17.. 18.. 19.. 20.. 21.. 22.. 23.. 24.. 25.. 26.. 27.. 28.. 29.. 30.. 31.. 32.. 33.. 34.. 35.. 36.. 37.. 38.. 39.. 40.. 41.. 42.</p>
<p>Being impulsive <i>-Struggling to manage EFT</i></p> <p>Lacking forethought- <i>Struggling to manage Episodic Future Thinking</i></p>	<p>Being impulsive. Making assumptions based on past experience. Feeling certain of success.</p> <p>Attributing recklessness to Episodic Future thinking. Believing that those with ASD have difficulty considering variable probabilities. Needing life to have rules. Struggling with unpredictability of life. Relating difficulties of working through action to ASD. Struggling with unpredictability. Attributing personal problems to ASD. Feeling that difficulties for ASD are common.</p>	<p>P3: Um, well um, making financial speculations without thinking, they were well thought out or whether they were likely to work just on the assumption that um, because um, some of the things I have done before have been successful, it was bound to work again, were as um, the literature shows there is a real problem with Episodic Future Thinking with autistic people, we have trouble thinking through what, what could happen in the future. If things aren't definite and laid down, then we cant learn the rules. If there is a number of different scenarios that could result from an action we have trouble. I think many other autistic people do have trouble working through the action. A could lead to X, Y or Z, we just assume because its been said in the past its going to be said again. It's a problem I think I've lived with all my life. It seems to be quite common, on the spectrum.</p>	<p>10.. 11.. 12.. 13.. 14.. 15.. 16.. 17.. 18.. 19.. 20.. 21.. 22.. 23.. 24.. 25.. 26.. 27.. 28.. 29.. 30.. 31.. 32.. 33.. 34.. 35.. 36.. 37.. 38.. 39.. 40.. 41.. 42.</p>

Memo Excerpt: Constant Comparative Method- “Becoming impulsive with money” to “Struggling with Episodic Future Thinking”.

Becoming impulsive with money was initially coded quickly and close to the data. However, positioning the behaviour and process as “impulsive” made

me feel uncomfortable, as though I was being complicit in the pathologisation of this behaviour. I recalled a code offered by a the earlier in the interview, “Becoming Impulsive” seems to be speaking of what P3 also described as “Episodic Future Thinking”. As this code was offered by the participant, I felt that it had more descriptive power and seemed less blaming and pathologising than my initial interpretation. This code was then applied to other forms of “impulsivity” seen in the data.

Participant Code: P5

<p>Being excluded</p>	<p>ASD diagnosis closing off service.</p>	<p>Paula: Ok and I'm wondering about the diagnosis as well. Having a diagnosis often opens up services, so do you think that could have helped?</p> <p>P5: Well it didn't it closed them all off.</p> <p>Paula: Yeah, when you go the...</p>	<p>771. 772. 773. 774. 775. 776. 777. 778.</p>
<p>Falling through the net.</p>	<p>Remaining third sector support. Losing social worker.</p>	<p>P5: I mean it didn't affect things like XXX as that's a charity but the things like social workers that were attached to the NHS all just stopped dead. Er, because although your allowed to have that sort of support for mental illness your not allowed to have it for Autism. So it just stops, so in that respect getting a diagnosis doesn't actually help.</p>	<p>779. 780. 781. 782. 783.</p>
<p>Not being vulnerable enough</p>	<p>Being allowed support for mental illness. Losing eligibility for support. Not being vulnerable enough.</p>	<p>Paula: Yeah, yeah. So there's more services for mental health, not as many for autism in fact, maybe none.</p> <p>P5: I think so yeah.</p>	<p>784. 785. 786. 787. 788. 789. 790. 791.</p>
<p>Observing reduction in state support</p>	<p>Seeing closure of mental health service.</p>	<p>Paula: And that makes people more vulnerable to losing the homes.</p>	<p>792. 793. 794. 795.</p>
<p>Service Frailty</p>	<p>Seeing impact of closure of service users. Being disturbed.</p>	<p>P5: Although I worry about the services for mental health these days. I mean I see people that I used to know, who were doing quite well when I went to XXX and I see them sleeping in a doorway somewhere. I find that very disturbing.</p>	<p>796. 797. 798. 799. 800.</p>

Memo Excerpt: Constant Comparative Method- “Being Excluded” “Falling Through the Net” “Not Being Vulnerable Enough”

Here the participants is reflecting a similar story to previous participants, regarding how their unique vulnerabilities are not picked up by services. It seems that focused codes from previous interviews have reach here, they are accounting for this process of “Not being Vulnerable Enough” and “Falling Through the Net” that emerged in other interviews.

APPENDIX ELEVEN- Focused Codes to Categories Memos

From initial and focused coding of the I could see how participants would speak about influence to their homelessness from four interacting levels of context- environmental, personal relationships, institutions and society, politic and culture, all contexts having factors that possess the ability to cause or act as a solution to homelessness.

The general story seemed to be a loss of fit with the housed world, this results in two options- gain what is missing in homelessness or go through a process of adaptation or becoming adapted to, to fit in with the housed world.

1. Environmental Contexts

Individuals spoke of the difficulties that they faces as a consequence of their ASD diagnosis and the ways in which these pervaded their lives. It seemed that homelessness provided some relief to these needs. Individuals spoke of a perception of being disabled that was freed in their homelessness where they were enabled and uncovered a self perception of personal ability and strength. Individuals spoke of a form of coping through avoidance and an adaption of self to other in housed world.

The focused codes seemed to fall within the following categories:

ENVIRONMENTAL CONTEXT	
CORE PROCESS: ?	CORE PROCESS ?
<u>Category: Living with Difficulty</u> Focused Codes: Being impulsive Lacking forethought Struggling to understand others Taking financial risks Struggling interpersonally Finding others inconsistent Struggling with homelessness administration Struggling with housing administration Being unable to ask for help Uncertainty regarding social expectation Being reckless Displaying communication difficulties Struggling to communicate needs Struggling to communicate vulnerability Misunderstanding social norms	<u>Category: Living at ease</u> Focused Codes: Gaining routine Gaining predictability Gaining permanency Gaining solace Gaining familiarity Gaining sensory pleasure Gaining freedom Gainign choice Gaining creativity Gaining independence Becoming anonymous Living at ease Seeking diagnosis Loosing interdependence Gaining anonymity Living in present (Gaining present focus) Gaining consistency

<p>/others intentions Breaking social norms Lacking attachment Lacking desire to socialize Niavety to others intention Rejecting social expectations Feeling helpless to others demands Masking Vulnerability Becoming overwhelmed Needing certainty Needing consistency Avoiding interpersonal contact Masking label Avoiding sensory overload Avoiding social interactions (coping through avoidance) Seeking isolation Living in solitary Avoiding social expectation Separating self Bargaining physical safety Isolating self Avoiding interpersonal expectation Avoiding public space Coping through isolation Becoming Vigilant Becoming irritated Coping through aggression Refusing to pretend</p> <p><u>Other</u> Lacking resilience Losing ability to cope Avoiding oppressors Insensitivity to physical needs</p>	<p><u>Uncovering Resilience</u> Uncovering trust Uncovering skills Uncovering resilience Uncovering persistence Wanting to survice Valuing uniqueness Uncovering self sufficiency Uncovering tolerance Becoming Self determined Developing communication Applying experience Rejecting disability Pushing boundaries Developing social acuity Becoming ready to develop Becoming successful Self advocating Cherishing potential Holding onto ambition</p> <p><u>Meeting others needs</u> Appeasing others Practicing social interaction Exposing vulnerability Demonstrating engagement Tying to live within rules Presenting socialy desirable behaviour Adapting to expectations Proving legitimacy Demonstrating normality Justifying credibility Avoiding avoidance</p> <p><u>Other</u> Realizing vulnerability Becoming attached to homelessness</p>
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Personal Relationships Context

Participants went through a process of losing and gaining power in social relationships and becoming automotons and becoming attached to social relationships in their homelessness or post homelessness.

In the social-relational context, it seemed that participants went through a process of loss of power in social relationships; this was through the experience of abuse (physical or emotional). It seemed that through homelessness some control or power was regained through the individuals ability to gain control over social connection or contact, usually the extent to which they were connected to others became easier to manage themselves as others were less reliant on them and the relationships become more transient. This can also be achieved in the housed world, the participants needing a sort of accommodation which would allow a level of anonymity and management of social interaction.

There was also a process of becoming autonomous and therefore losing the necessity of social connections. This included reducing breadth of social connections, becoming an unwanted connection (becoming a burden, exhausting tolerance) or being excluded from interpersonal connections (being forced to leave, being forced from acceptance). In homelessness a gradual attachment occurs where individuals are notices and appreciated, or become a part of an accepting community. In the housed world, gaining a dependent on them can also fulfill this attachment process (p6).

The focused codes seemed to fall within the following categories:

PERSONAL RELATIONSHIPS CONTEXT	
CORE PROCESS?	CORE PROCESS?
<p><u>Becoming Subjugated</u> Being deceived Having information withheld Escaping abuse Experiencing trauma Being assaulted Lacking social protection Being assaulted Being forced from acceptance Being forced to leave Being interrogated</p> <p><u>Lacking Anchors</u> Losing protective relationships Exhausting tolerance</p>	<p><u>Becoming Attached</u> Gaining interpersonal connections Developing support networks Gradually developing relationships Gaining control over social connections Gaining control over interpersonal contact Gaining partial social connection</p> <p><u>Developing Equality in Relationships</u> Escaping Harassment Escaping abuse Avoiding Oppressors Gaining Community</p>

<p>Lacking anchor Struggling to develop alliance Becoming a burden</p> <p><u>Other</u> Lacking stability Consequences of oppression Needing safety Escaping relational difficulty Minimizing social dependency Craving community Lacking breadth in social connections Feeling disconnected</p>	<p><u>Becoming Necessary/Depended on</u> Becoming reliant Gaining positive appraisal Gaining community Needing a dependent Gaining anchor Living with support</p>
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Institutional Context

Participants go through a process of rejecting or being rejected from institutions based upon their lack of ability to adapt to the needs of ASD and then regaining support in homelessness as the institutions recognize vulnerability and adapt to meet their needs. (however some rigidities remain that make accommodation tentative)

Participants spoke of rejecting unwanted interventions from institutions, mainly regarding their housing or their health care. People seemed to reject this seemed to be rejected through the separating from contact with services. Homelessness therefore provides a loss of reliance on interaction with institutions. People gained a connection with services when the services supported them to challenge this unwanted intervention through using powerful tools such as advocacy and legislation.

Participants also spoke of being rejected from institutions that possessed rigidities that were not in line with the needs of those with ASD (rigid, boundaries having certain conceptions of vulnerability). Interaction with institutions was regained in homeless world that were able to provide unorthodox support (namely flexibility, authoritative, persistence (Dan). This was facilitated through the awareness of ASD in some instances but the support was person centered. . Or this is continued to be a risk of living within a home (coping seems to shut off services)

Participants lost contact with services also due to their fragility- in homelessness a sense of permanency was obtained- peoples vulnerability was demonstrated through their loss of home and services responded by trying to commit to that person Participants spoke of rejecting unwanted interventions from institutions, mainly regarding their housing or their health care. People seemed to reject this seemed to be rejected through the separating from contact with services. Homelessness therefore provides a loss of reliance on interaction with institutions. People gained a connection with services when the services supported them to challenge this unwanted intervention through using powerful tools such as advocacy and legislation.

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Participants lost contact with services also due to their fragility- in homelessness a sense of permanency was obtained- peoples vulnerability was demonstrated through their loss of home and services responded by trying to commit to that person

The focused codes seemed to fall within the following categories:

INSTITUTIONAL CONTEXT	
CORE PROCESS?	CORE PROCESS?
<p><u>Category: Suffering service inadequacies</u> Focused Codes: Being commodified Facing rigidities in services Not fitting in with support Facing barriers to support Facing barriers to services Support failing to meet needs Suffering effects of boundaried support Receiving boundaried support</p> <p><u>Category: Falling through net</u> Focused Codes: Increasing fragility of support Losing support Exhausting support Losing eligibility Reducing support</p> <p><u>Category: Resisting Unwanted intervention</u> Focused Codes: Forced separation from networks Losing control over space Preferring street to hostel Avoiding hostilities of hostel Being colluded against Unwanted intervention Forced dependency</p> <p>Needing committed support Being commodified</p>	<p><u>Category: Receiving Adapted support</u> Focused Codes: Gaining unorthodox support Gaining comprehensive support Gaining support Gaining flexible support Gaining permanency in support Gaining authoritative direction</p> <p><u>Category: Gaining Wanted interventions</u> Focused Codes: Recruiting powerful advocates Gaining powerful advocates Gaining benefits support Using scheme Using professional Using legislation</p> <p><u>Category: Vulnerability Being noticed</u></p>

Society, Politics, Culture

Participants spoke of a process of losing rights to be in society, this being demonstrated through how they were treated and understood in broader society. This pervaded even into political agendas and political protection of citizens. Opposition to this rejection is found in homelessness where peoples difference becomes tolerated and accepted.

Participants spoke of becoming rejected from society – this can be from public space, through unfair and unjust treatment (Being subordinated, facing pride) or through being made to feel difference and separate from society (being different, excluded, temporary). This is opposed in the homeless society where there is a tolerance of difference, people are accepted and understood- all difference is accepted and tolerated.

This societal rejection also pervaded into rights as a citizen- participants spoke of how they lost rights to political protection regarding finances, they lost eligibility for support and protection and “fell through the net.” They also lost the right to freedom to behave in a manner comfortable to them and again this was gained in homelessness. Homelessness again shows a kind of vulnerability which triggers an renewal of rights to support, protection and the person becomes legitimized and recognized in need for help.

The focused codes seemed to fall within the following categories:

Society, Politics, Culture CONTEXT	
CORE PROCESS?	CORE PROCESS ?
<u>Category: Being different</u> Focused Codes: Being misunderstood Being harassed Losing identity Being silences Feeling judged Being judged Being misunderstood Being scrutinized Being rejected from public space Being persecuted Facing judgment Being excluded Feeling inspected Being faulty Facing prejudice Being pushed Being mocked Facing victimization	<u>Category: Becoming Eligible</u> Focused Codes: Learning rights Gaining legitimacy <u>Becoming integrated</u> Focused Codes: Gaining solace Gaining understanding Becoming accepted Becoming notices Becoming accepted Being given opportunity Gaining acceptance Being understood <u>Gaining rights</u> Focused Codes: Gaining equality in relationships

<p>Facing prejudice Experiencing inequality Being silenced Being infantilized Facing skepticism Facing scrutiny Being temporary Being subordinated</p> <p><u>Lacking state protection</u> Focused Codes: Fearing exposure Having benefits cut Losing rights Success being socially determined Becoming an economic burden Not being vulnerable enough Being victim to political change Falling through the net</p> <p><u>Consequences of rejection</u> Focused Codes: Feeling unsafe Expecting barriers Feeling a failure Fearing persecution Avoiding scrutiny Lacking opportunity Lacking awareness of rights Becoming worthless Becoming vulnerable Regaining disability</p> <p>Needing anonymity</p>	<p>Gaining freedom Potential being acknowledged Being liberated</p>
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APPENDIX TWELVE: MODEL DEVELOPMENT/EXAMPLE OF AXIAL CODING

MODEL 1- Following initial and focused coding, the initial categories emerged. Selective Coding allowed for the selection of codes with the greatest reach across data.

Losing State Protection
 Falling Through the Net
 Losing ability to manage autism
 Becoming Different
 Suffering Service Inadequacies
 Becoming Subjugated
 Lacking Anchors

Not Fitting In? Losing Accommodation? Trying to Fit in? Being Rejected? Losing Membership? Facing Rigidities? Losing Citizenship? Losing Integration? Becoming Marginalised? Becoming Peripheral?

Fitting In? Gaining Accommodation? Being Accepted? Gaining Membership? Finding Flexibility? Gaining Citizenship? Losing Integration? Becoming Included?

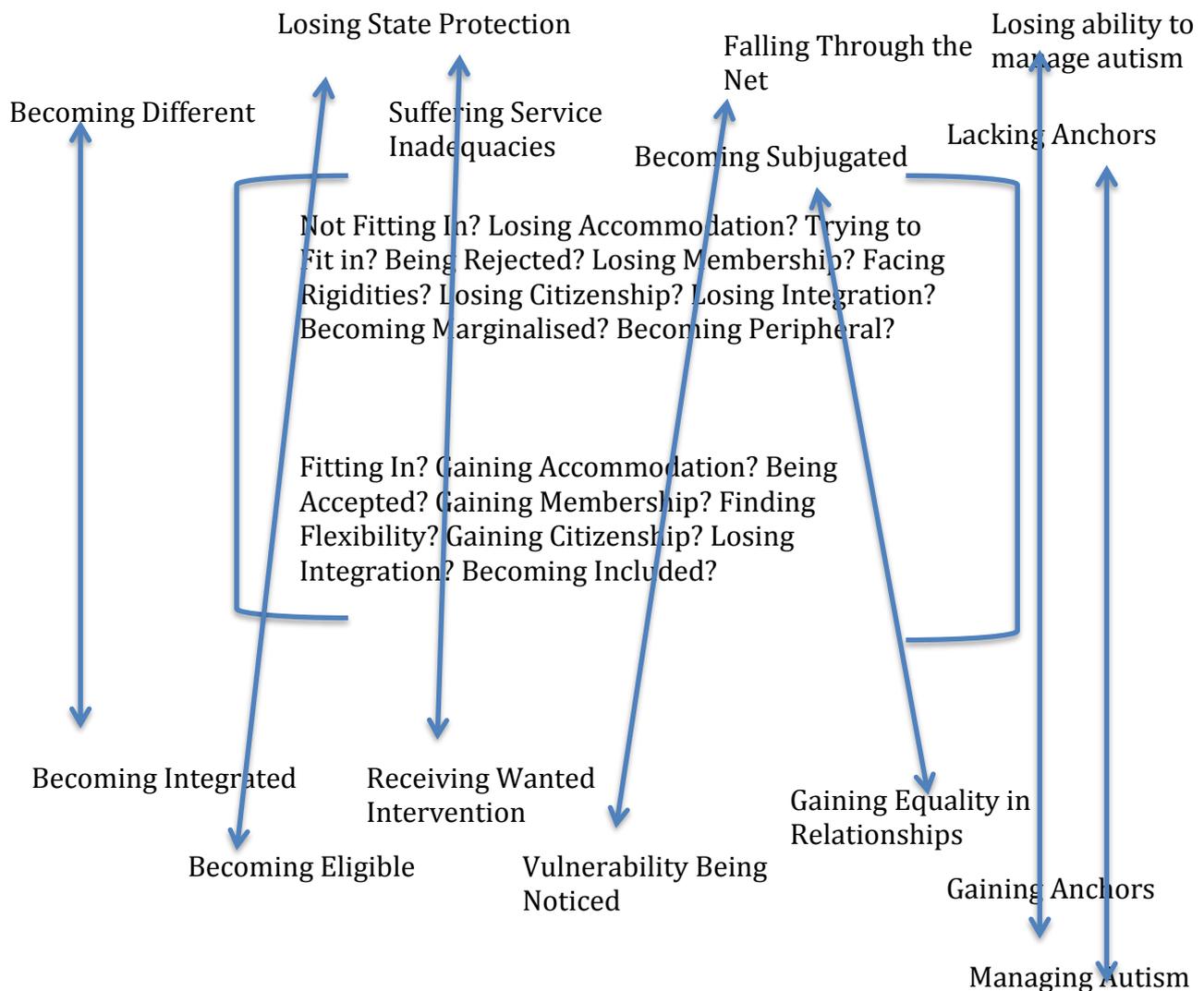
Becoming Integrated
 Becoming Different
 Receiving Wanted Intervention
 Gaining Equality in Relationships
 Becoming Eligible
 Vulnerability Being Noticed
 Gaining Anchors
 Managing Autism

Many of the categories seem to be along axis of losing or gaining?

Methodological Decision: Consider where axis emerge

MODEL 2- Many of the categories can be seen along an axis. It seems that the in the process of homelessness something is lost, which is then gained during or following homelessness.

Axial coding specifies the properties and dimensions of a category (Strauss and Corbin, 1998). Although Strauss and Corbin suggest a scheme for coding (conditions, actions, consequences) I wanted to ensure that the axis emerged from the data (Charmaz, 2014) and therefore the following losing and gaining categories seemed to fit.

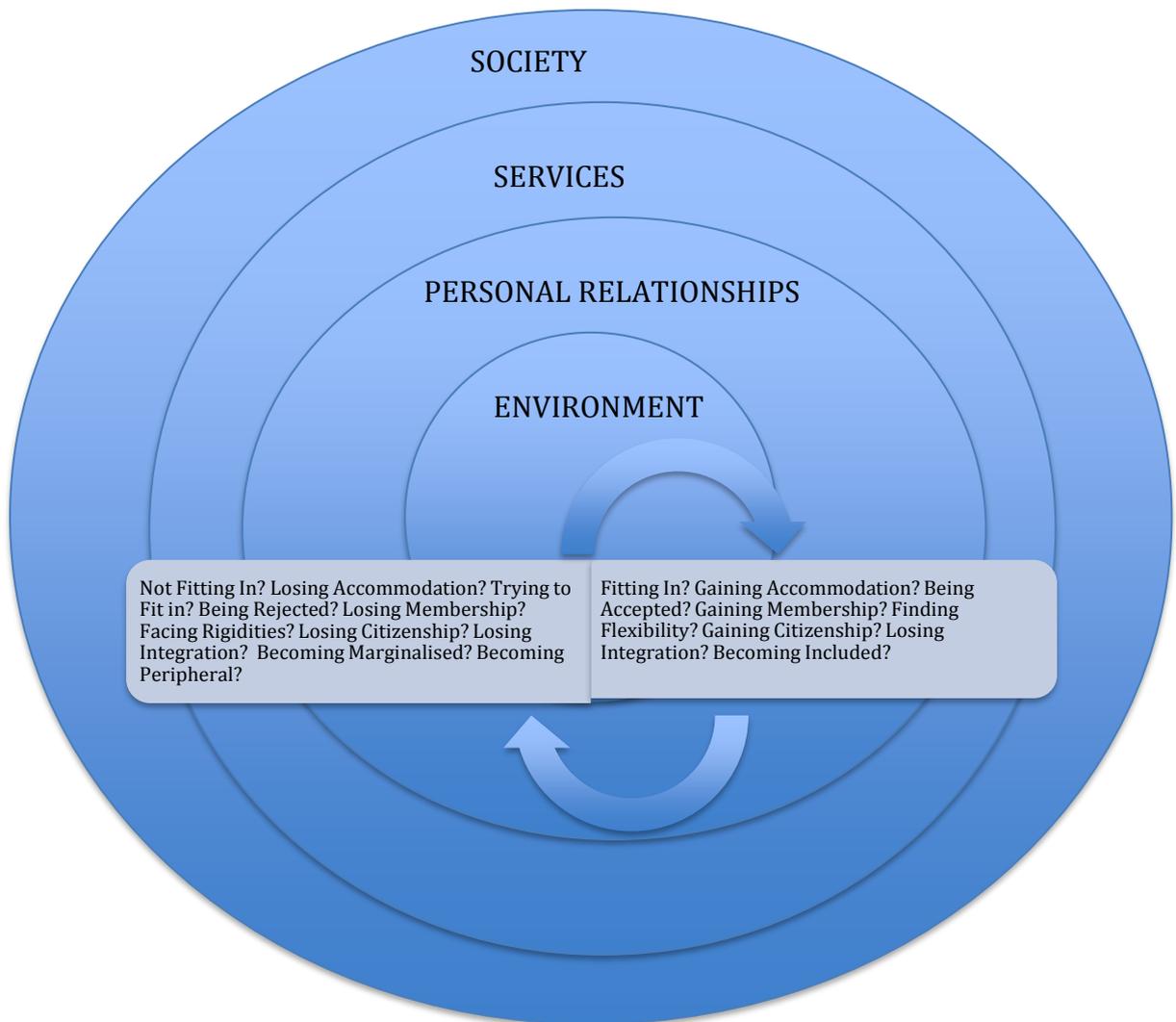


Memo Excerpt: I can see the various levels that are considering a process on various levels of society. These may be being a member of society, interactions with institutions and service, personal relationships and self management of autism.

Methodological Decision- See if Strauss and Corbin's (1998)

'conditional/consequential matrix' fits the data.

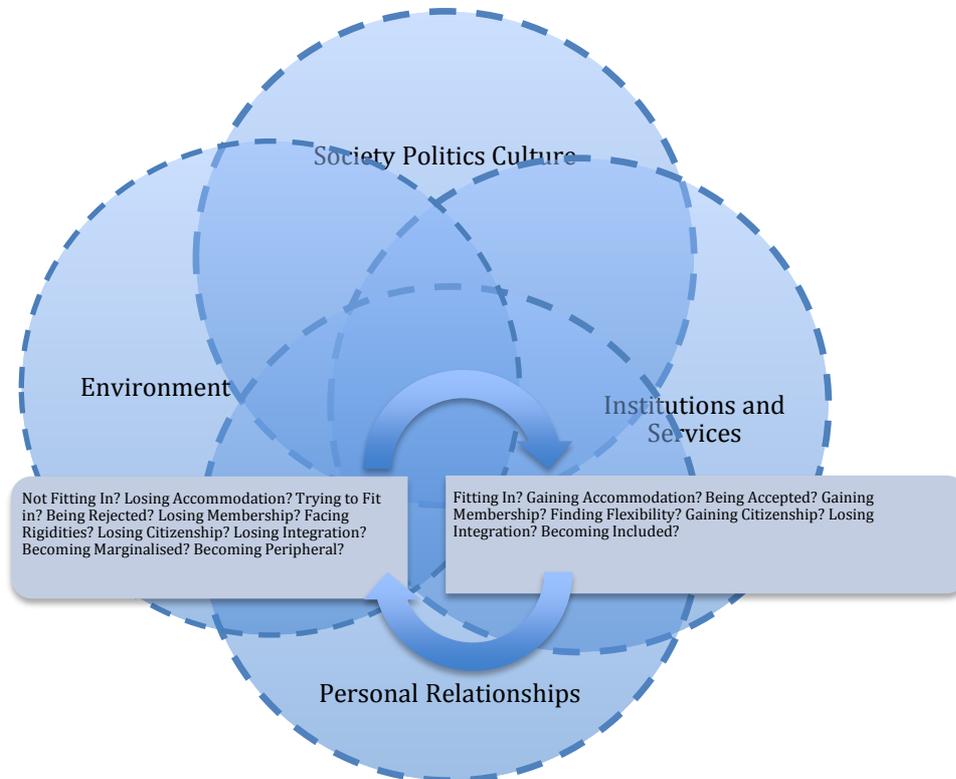
MODEL 3- Exploring Strauss and Corbin (1998) 'conditional/consequential matrix and how this fits the data



This model is inspired from Strauss and Corbin's (1998) 'conditional/consequential matrix' or a set of concentric circles, with each level corresponding to a different unit of influence (context). The inner rings represent individual influences on actions and interactions, with further rings representing more distal influences.

The model represents the contextual influences offered by participants in their data, however, the model seems to suggest that further circles have lesser influence. This was not a case in my data, societal issues (rejection and inequality) have as larger impact as those closer to participants on individual's homelessness and this should be more equally accounted for.

METHODOLOGICAL DECISION: Re diagram to more accurate represent level of influence.
MODEL 4- Re diagramming to represent levels of influence



Locating core process

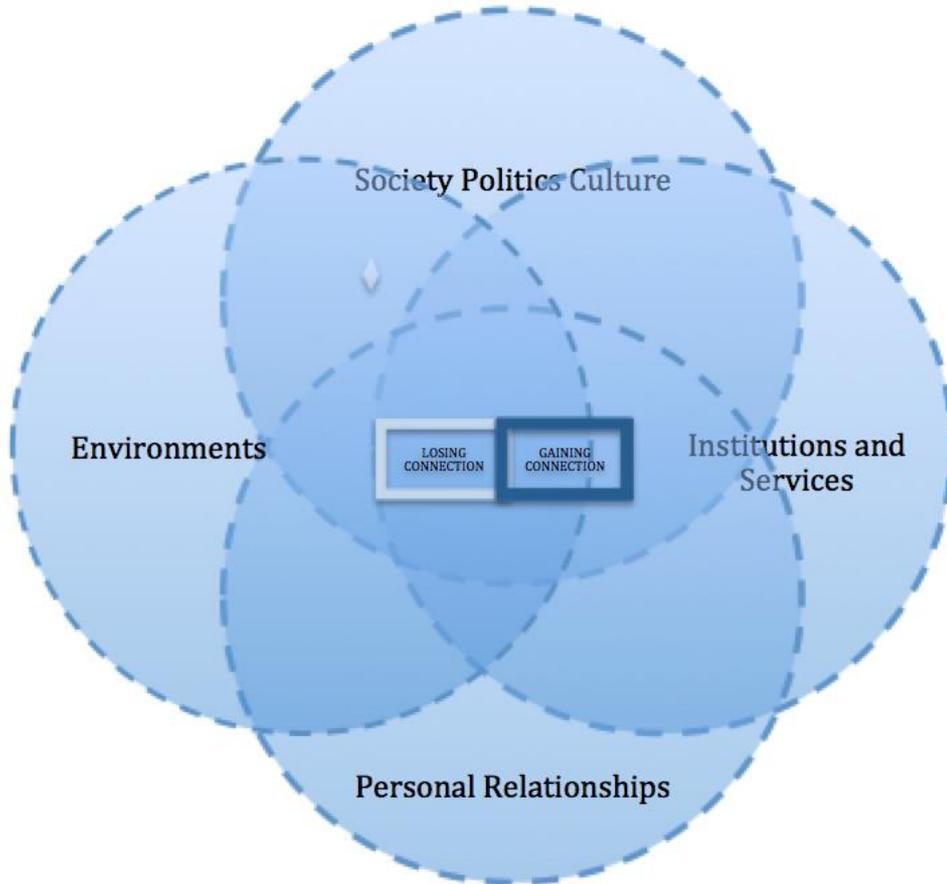
- Losing Citizenship? Losing Integration? Becoming Marginalised? Becoming Peripheral?

I am aware of how these terms are politicised and loaded terms –oppression, citizenship, marginalisation are all commonly used in sociology and politics and have often very contested definitions. I am therefore conscious that I may be pulled towards these popular terms and away from what my data is actually saying. I need to search for a term more neutral and locate the process that the data is telling me.

- Not fitting in? Being Rejected/Excluded/Marginalised/Segregated

These terms account for some of the data. However, these terms do not consider the sometimes active process that participants has in their homelessness, that it was occasionally a preferable choice to meet their needs rather than purely a simple exclusion. Something that is less related to being forced away and softer, accounting for both the push into homelessness and the pull into homelessness

Losing and Gaining Connection- this seems to best account for the data.
MODEL 5- Final model with core process of “Losing and Gaining Connection”



APPENDIX THIRTEEN: EXCERPTS FROM REFLEXIVE DIARY

Reflexive Journal Following Interviews

I noticed feeling anxious after completing interviews. The participants offered rich honest accounts of their feelings of segregation and marginalisation. Not being understood by others was also a key theme and I have noticed how this makes me feel concerned about my abilities as a researcher to create an account for the vast array of stories that I have heard that is acceptable to the participants. I have also noticed that I felt aligned with the participants with a diagnosis of autism, possibly to counter their experience of isolation and rejection.

Its seems important to remain alert to this feeling of alignment, and to attempt to remain open and responsive to the accounts offered by professionals as well as those with a diagnosis of autism. I also feel that developing a coherent model is important, to ensure that it is understood and accepted by the participants, in order to create efforts to resist becoming another agent in their segregation.

Reflexive Journal Entry Following Focused coding:

Theoretical orientations and personal anticipations both in advance and throughout the research should be recognized and the role in which these play in the developing understanding accounted for and impact on the developing analysis considered (Elliot, Fischer and Rennee, 1999).

After focused coding a story seemed to be emerging of and interaction between ASD and an uncompromising society, leaving the person feeling as though they were isolated or separate from. This idea of a jigsaw society came to mind, as though the person possess certain characteristics and idiosyncrasies that do not fit into the shape of society. It doesn't seem like this is always a rejection as such, more that there is a lack of cohesion between the two. What results is a person feels alone and perhaps seeks somewhere where their idiosyncrasies (behaviours, views, communication) cause less friction. The homeless society does not provide a new jigsaw, more that the idiosyncrasies are more varied across the population and therefore peoples differences are less obvious and more merged with a realm of difference.

I can see how this understanding is in line with my previous leanings towards the social model of disability. I am intending to this lightly so that I can see its influences and potentials beyond this influence. I intend to consider this model and where it helps and hinders my understanding of my data. The idea of fit links with the social model, however, the ideas of barriers or exclusions doesn't seem to be what my data is telling me, it is more about the lack of harmony between the two relating difficulty for both, rather than a refusal of

society to adapt to the need of ASD, as there are examples when both society and ASD try to adapt, but this still does not create a harmonious fit.

It is questionable as to whether the harmony is ever achieved, people become housed and safe and to some extent content, but there are often continued difficulties, where either has to adapt, with some difficult consequences.

I was also surprised about the use of the diagnostic term to provide help and understanding for the participants. I came to the research considering the ASD label as useful for professionals to understand and work with this group of people, but questioned its ownership by the ASD population and the consequences of attracting such a label, however despite this, there were many examples of how the label was owned by the participants and provided them with a frame in which to view their difficulties.

In terms of the support for the homeless, I began to notice how my perception of support for the homeless was upheld within the data, that the systems often met the needs of a majority, but a majority who were able to adapt to the requirements of the services and tolerate the feelings of danger and fear.

Reflexive Journal after Model Development

The overall story of the model seems to construct a picture of individuals gradually losing a fit and connection with society. The idea of a jigsaw comes to mind and the cantors of which seem to solidify in adulthood. The person becomes unable to fit in with society and therefore loses citizenship across levels. The homeless world seems to be more of a melting pot, which complexities but also more rounded edges that the person with ASD is able to mix and integrate within. For the person to be housed, the housed world and the person need to loosen their edged, both needs to adapt to the other. This may be at an individual level, where the person meets the needs of society, or their needs become met by society, relational, institutional and sociopolitical level.

Regarding the process of homelessness, my initial perceptions of protecting those with ASD from homelessness were challenged within the data. Many spoke of the gaining of acceptance, skill, acknowledgement, tolerance within the streets and a preference for staying there. I was forced to challenge the idea that everyone should have a home and that we should support those without a home back into a marginalising and segregating society. Whilst I believe that everyone should have safety and health, shelter seems to be less of a priority for those with ASD, and this is often bargained for acceptance and self fulfillment. It makes me reconsider Maslow's hierarchy of needs and how this does not account for the uniqueness and difference within the human condition and autism. The hierarchy of needs seems reestablished for ASD, physiological needs remains a priority, but safety is less of a concern- participants will put themselves in unsafe environments and priorities a need for self sufficiency and achievement as this isn't gained within everyday social

conversation perhaps. Safety comes third and belonging final- this is less necessary but still required.

I am also aware of the model cohesion with my personal leanings towards the social model of disability. Holding this in awareness helped me to scrutinize my data for difference from this leaning. It seemed that the data was talking of a lack of fit, rather than a feeling of facing exclusions or barriers. There was variance in the accounts people gave regarding the fit, some noting less of an exclusion, and more of a preference from their perspective to exclude others. In addition, some felt empowered by this difference and wanted it maintained. Whilst the data justified some of my predetermined notions of the consequences of oppression and segregation that come with a disabling label such as ASD, I was challenged to see the individuals accounts of a level of choice, choosing an alternative lifestyle of the streets rather than being a powerless subject to numerous barriers and inequalities.

APPENDIX FOURTEEN: NEGATIVE CASE ANALYSIS

Category: Becoming Integrated. Code: Being Accepted: P5 notes how following homelessness, being accepted is not a permanent state of affairs.

Paula: "Did you meet some friends there?"

P5: "Yeah and of course I've lost touch with everybody."

Paula: "Yeah, and how did that happen? Because they've shut them down or...?"

P5: "Well the place fizzled out and the hotel closed er I did see some people for a while afterwards but then it gradually sort of disappeared."

Category: Receiving Adapted Support. Code: Gaining Personalised Support. P1 and P5 noted how personalised support is not always provided in hostels.

P1: "... but on the other hand a sheer frustration that they staff stubbornly refuse to do anything to meet neuro-atypical needs"

P5: "...Well it wasn't very good really. I just used to go there as late as possible at night and leave as early as possible in the morning."

Category: Becoming Attached. Code: Gaining Anchors. S1 and S3 note that following homelessness was not always accompanied by gaining anchors.

S1: "So he, he was sort of forcing himself to be more social, and they were having parties but he would find it incredibly difficult. Erm, to the point where these friendships were, wouldn't last very long."

S3: "...so and again there's no social network that he has built up either, it is only professionals. So it always feels tentative to me and vulnerable to break down."

Category: Regaining Ability to Manage Autism: Gaining Predictability.

P5 suggests that homelessness led to increased exposure to unpredictabilities

P5: "I've never met anyone who behaved so peculiarly she was, she'd disappear for three days and then come home and sleep for 2, for 48 hours and then disappear again, you know."

Methodological Decision

It seems that losing and gaining connection are not distinct process during and following homelessness, although losing connection seems to gain dominance prior to homelessness and gaining connection seems to develop dominance following homelessness, this negative case analysis provides information of how they are in constant oscillation and can be depicted below.



Appendix 15: Transcription Conventions (adapted from Parker, 2005).

P: Indicates Participant

PG: Indicates Interviewer

(): Indicates Pause

(inaudible): Indicates unclear speech

(interruption): Indicates interruption

/: Indicates overlapping speech

-: Indicates unfinished word