

Portfolio Volume 1: Major Research Project

# How People With Intellectual Disabilities Experience Transitions through the Transforming Care Programme: a Grounded Theory Study

Volume 1

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## Abstract

Following the exposure of abuse of people with Intellectual Disabilities (ID) at Winterbourne View, the Government launched the Transforming Care programme, to support people to transition out of hospital into their own home. A literature review revealed limited research into people with ID's experiences of transitioning. The study aimed to explore how transitions through Transforming Care were experienced. Eleven people with ID were interviewed about their experiences, with ten nominating a Key Support Person to be interviewed alongside them on a second occasion. Interviews were analysed using a Social Constructionist Grounded Theory methodology. The model demonstrated that participants experienced transitioning as a highly complex process of managing change. In hospital, how participants were seen by significant others and how they saw themselves resulted in a 'restricted story.' In moving to the community, participants and those around them were able to shift ideas about who they were, allowing for a 'widening out' of their story. Participants discussed seeking a sense of safety in new relationships, managing loss, and going through uncertainty as part of the process of transitioning. The findings of this study demonstrate that transitioning is not a single event, but an ongoing process over time. Clinical implications include ensuring that people with ID feel prepared about their move and the importance of staff understanding peoples' behaviours within a wider context.



# 1. Introduction and Literature Review

“Whilst others might move house, get a job or find a partner, as a powerless one, all you get to decide is whether it is better to dance, fight, withdraw or hurt yourself. If you choose to fight – as surely many of us would – something has to give and soon comes your first move. You learn quickly that you don’t move like everyone else; your placement breaks down. A different local service is now supporting you; you have grown fully into your role in life. The more you struggle for power, the more powerless you become”

*(Oakes, 2012, p.157, a clinical psychologist writing about some of the potential typical life experiences of someone with ID, after the events at Winterbourne View<sup>1</sup>).*

## 1.1 Chapter Overview

This research focuses on people with Intellectual Disabilities (ID) experiences of moving out of hospital into their own homes as part of the Transforming Care<sup>2</sup> programme, and uses a Grounded Theory approach to analysis. In this first chapter, I will define the terms that will be used throughout the report, followed by stating both my personal and epistemological positions to the topic. I will

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<sup>1</sup> In 2011 the BBC Panorama programme exposed the abuse of residents at Winterbourne View, a privately run mental health hospital for people with ID. This will be described in more detail in section 1.5.3 of this report.

<sup>2</sup> Following Winterbourne View, an in-depth review of inpatient services for people with ID and the resulting report, *Transforming Care: A National Response to Winterbourne View*, set out plans to move people out of inappropriate hospital settings into community placements (Department of Health, 2012). This will be described in more detail in section 1.5.3 of this report.

then explore the broad historical, social and political contexts in which people with intellectual disabilities have made transitions from a hospital into the community. Peoples' experiences of these transitions will then be the focus of the systematic literature review, which will illustrate and critically evaluate what is understood already from the existing literature. Finally, I will conclude the chapter with the rationale for the present study. I value the use of self-reflection in qualitative research (Ortlipp, 2008), and therefore aim to demonstrate this transparently through the use of reflections on the project throughout the thesis, which will be italicised. Furthermore, a reflective research diary was kept during the process, and excerpts are found in Appendix A.

## **1.2 Introduction to and Definition of Key Concepts**

### **1.2.1 Intellectual Disabilities**

The British Psychological Society (BPS; 2010) define 'Learning Disability' as having a "significant impairment of intellectual functioning; significant impairment of adaptive/social functioning; and age of onset before adulthood" (p.4). The terms Learning Disability and Intellectual Disability are often used interchangeably. I will use the term Intellectual Disabilities (ID) throughout this report, reflecting the change of terminology used by the BPS (BPS, 2017). Consultation with a group of people with ID prior to the study commencing found that they preferred the word 'people' rather than, for example, service users. The phrase 'people with ID' is therefore used throughout the report.

### **1.2.2 Hospitals and Institutions**

People with ID may spend time in specialist mental health inpatient services. A number of terms exist in the literature and in clinical practice: Assessment and Treatment Units (ATU), secure 'units' (Oakes, 2012), psychiatric inpatient care (Glover, Brown & Hatton, 2014), inpatient units, or specialist mental health hospitals. These services are run by the National Health Service (NHS) or

by private companies (Glover et al, 2014). There are also a number of specialist forensic units for people with ID who often have concurrent mental health difficulties (Lindsay et al, 2010). Discharge from such units has been a focus of the Transforming Care programme (Royal College of Psychiatry, 2014). The term 'hospital' will be used throughout to refer to all of these settings (except where a different word is used in direct quotations by participants). The term 'institution' is used in this report to signify a more historic concept, that of large-scale and typically more restrictive hospitals (Mansell & Beadle-Brown, 2010) which were largely shut down in the deinstitutionalisation schemes of the 1980s and 1990s in the UK.

### **1.2.3 Transitions**

This report focuses on people moving from a hospital setting into their own home in the community. A 'transition', which can be conceptualised as a change in one's life, can be a time of challenge and of opportunity (Schlossberg, 1981). Although the word 'transition' is often used in ID literature to refer to people progressing from youth to adult services (e.g. Floyd, Costigan & Piazza, 2009) within the current report, I will use the word 'transition' to refer to the process of moving home, from living in one setting to living in another.

*It is interesting that the words 'to live' refer not only to where one resides, but have a much wider meaning about being alive. In this respect, where one 'lives' means so much more than the physical parameters of the building, but indicate this is where one is able to live life. A simple statement like "I live in/at ....." implies initially a geographical location, but actually has much a deeper meaning – it links to the importance of one's home as the place where one can try to live the kind of life that one wants. The dual-meaning of the word is surely not coincidental. These reflections highlighted for me how central ideas about 'home' are in our language, society and*

*culture. For participants in the study, therefore, I tried to keep in mind the significant implications of home.*

### **1.3 My Relationship to the Topic**

My journey towards this project stemmed from experiences of transitions in my own family. My oldest sister has an Intellectual Disability, and has moved from the family home into one supported living setting, and then another. The challenges she has faced at times have made me reflect on the assumptions I have made, from my non-disabled position, about the ease of moving into one's own home. When the incidents at Winterbourne View came to light, I was truly saddened by the things that people went through there, though also heartened by the strength and resilience shown by residents, which reminded me of my sister. On choosing an area for the thesis, I was driven to conducting research with people with ID, who I believe are too often overlooked in clinical psychology and in research; I really wanted to do a project which could allow people to share their own experiences. I was therefore drawn to developing a project that explored how transitions were experienced by people who had moved under Transforming Care.

### **1.4 Epistemological Position**

My journey through clinical training has opened my eyes to social constructionist ways of thinking. Social constructionism argues that our perceived 'reality' is a construction, created between people, based on the values of the culture in which we find ourselves (Burr, 1995). Our understanding of the world is created and maintained through language (Dallos & Draper, 2015; Gergen, 2001). From this epistemological position, it is important to recognise that 'knowledge' is not representative of a phenomenon as it 'objectively exists' but rather will be time- and culture-bound. This research has been informed by a social constructionist position, in particular the work of Burrell and Trip (2011) who explore how, historically, knowledge about people with ID has been

created, and how at times it has been used for social control. Taking a social constructionist framework allows one to move from seeing ID as some internalised 'deficit' to something which is influenced by the environment in which the person is situated (Webb, 2014). A social constructionist view also unveils how powerful the language around ID is in implying that it is a "self-evident truth" (p.14, Dallos & Draper, 2000) rather than a construct of our social and cultural expectations (Burrell & Trip, 2011). The word 'dis-ability' focuses solely on what the person is unable to do, setting them within a powerful discourse of being 'unable.' Therefore they, and those around them, may find it more difficult to shift the narrative onto what people can do (Webb-Peploe & Fredman, 2012).

Fisher, Sonn and Evans (2007) note that power is enacted through the "discourses that mediate between people and social systems" (p.260), such that certain constructs can become "taken for granted and experienced as a given" (p.260). In terms of the construct of ID, this indicates that the language and social structures around ID can maintain its position as a 'given' and therefore keep people with this diagnosis in a relatively powerless position. For example, a Western society in which education and employment are reified means that differences in peoples' cognitive abilities come to the fore. As Clements (1999) notes, in a normal distribution of IQ scores, why is it that our society pathologises those at the lower end of the bell curve by labelling them with ID, but does not pathologise the 'gifted', at the upper end of the distribution? Taking a social constructionist frame has allowed me to keep a critical and questioning eye on the powerful influences that play a part in the lives of people with ID.

However, social constructionism could be criticised from some angles as involving a denial of the reality of a disability, and the real impact on people's lives (Webb, 2014). Sinason (2010) also discusses the impact of the *reality* of a disability on the person, and those around them. She

describes a 'primary disability' which could be defined as neurological or biological in origin; as well as a 'secondary disability'. The idea of a secondary disability is formulated from a psychoanalytic perspective to be a defensive protection from the reality of the pain of being disabled. I therefore wanted to approach the study keeping these ideas in mind, and chose to take a critical realist social constructionist position (Harper, 2011). Critical realists assume there is some reality that exists, but that research does not constitute an exact reflection of this reality (Willig, 2013). I therefore took a viewpoint that the experiences shared with me by participants were socially constructed, through language; but I also kept a recognition that some people have cognitive and developmental difficulties, which will have an impact on the reality of their lives. This could be argued to be in line with current ideas within critical disabilities studies, which acknowledge that both social and individual factors can contribute to disability, and therefore critique the polarisation of the two factors (Meekosha & Shuttleworth, 2009).

Within this position, I aim to acknowledge my own relative power as a researcher who is non-disabled. There is discussion in the literature of the differences between 'emancipatory' versus 'inclusive' research (Caldwell, 2013). I could not define my research as emancipatory; as although I am acting from the best of intentions to enable the voices of those with ID to be heard, neither the ideas nor methodology have been fully formulated and led by people with intellectual disabilities themselves. Nevertheless, given my views on how knowledge about people with intellectual disabilities has traditionally been constructed, it is my hope that this project goes some way towards allowing peoples' own voices to contribute to the wider 'knowledge' that is held about them.

## **1.5 The Context of Transitions for People with ID**

Before considering the individual experiences of people with ID who transition, I believe it is important to understand more about the contexts in which these transitions take place. These include the historical context of where people with ID have lived, as well as the political and economic context in which both Winterbourne View and subsequently Transforming Care have taken place in the UK. A brief account of these contexts is explored below, before I then go on to systematically and critically review the literature on people with ID's experiences of transitioning.

### **1.5.1 The Historical and Cultural Context**

**1.5.1.1 Moves towards institutionalisation of people with ID.** In the UK, prior to the nineteenth century, people who may in the future have received a diagnosis of 'intellectual disability' would have lived in the community in which they grew up, supported by the family and wider social network (Jarrett, 2015). The development of ID as a concept emerged alongside the development of post-industrial social constructs such as education and employment. Ideas around the 'existence' of ID fitted into the tenets of a scientific theory, which lent it increased legitimacy; it was then further sustained by, and enshrined in, legal procedures (Holland, Clare & Mukhopadhyay, 2002). With the Poor Laws of the 1830s, people were seen - and valued - more and more solely through the prism of whether they could work (Gleeson, 2010) meaning that "eventually, often unwillingly, the emergent state had to accept responsibility for care of the 'unproductive'" (Gleeson, 2010, p.6).

As such, people were moved to large communal living asylums, or latterly 'institutions.' Ostensibly, this was to protect and care for the more vulnerable members of society. However alongside this ran an additional discourse about the necessary 'management' of people with ID (Johnson, 1998; Philo & Metzel, 2005): "given that they were almost invariably economically and socially disadvantaged, these men and women were ideally placed to embody widely held anxieties about

social breakdown, moral degeneration and rising crime” (p. 7, Stedman-Jones, 1971; cited in Holland et al, 2002). Philo and Metzger (2005) have formulated this as a splitting and projection of the ills of society onto some of its more powerless members, leading to people with ID being regarded as so inherently ‘other’ that they were physically kept apart from other members of society (Smith, 2005).

**1.5.1.2 Moves towards deinstitutionalisation.** By the latter half of the twentieth century, perspectives on ID were slowly changing. Through increasingly viewing ID as a social construct, there was a dawning awareness that environmental contexts could increase disability. Critique stemming from the 1970s drew attention to the idea that “institutions reinforced the devalued role [of people with ID]” (p.178, Burrell & Trip, 2011). This therefore led to initiatives to change environments, namely deinstitutionalisation (Barron, Hassiotis & Paschos, 2011). The 1971 White Paper, *Better Services for the Mentally Handicapped*, crystallised these ideas into UK government policy, with an increased focus on community rather than institutional residences (Department of Health, 1971). The promotion of deinstitutionalisation and ‘community living’ became a national social agenda in the 1980s and beyond. This was underpinned by theories of normalisation (Burrell & Trip, 2011) alongside “neo-liberal economic policies” (p.182, Simpson & Price, 2009), whereby the state coordinated the market for welfare, rather than providing welfare. Policies promoting community living were further reinforced in the Government white papers *Valuing People* (Department of Health, 2001) and *Valuing People Now* (Department of Health, 2009) in the UK; and internationally, by the United Nations treaty, *Convention on the rights of persons with disabilities* (United Nations, 2006, cited in Mansell & Beadle-Brown, 2010). The number of inpatient beds used by people with ID has dropped significantly since deinstitutionalisation, from over 30,000 in the late 1980s to under 3000 in most recent figures (NHS England, 2015a).



## **1.5.2 The Political and Economic Context**

**1.5.2.1 Issues with housing options in the community.** As institutions closed, the prevailing model initially was on group homes, typically with three to eight residents (Mansell & Beadle-Brown, 2010). These are still common but have also been supplemented by 'supported living' schemes (Mansell, 2006) whereby individuals have more choice over their accommodation and staffing. Nevertheless, when trying to find community living arrangements, there is sometimes a lack of appropriate local provision (Mansell, 2006). This section will explore some of the reasons for these difficulties.

Due to anxieties about how to manage cases in the community, people with ID with more complex needs (such as people with behaviours which challenged) were generally the last people to move out of institutions in the first round of deinstitutionalisation (Beadle-Brown, Mansell & Kozma, 2007; Hubert & Hollins, 2010). This meant community services were often set up only to support people with ID with less complex difficulties. As such by the time the institutions eventually all closed, local services were not sufficient for people with more complex needs (Martin & Ashworth, 2010). A lack of local provision therefore meant that those with more complex needs were more likely to be 're-institutionalised' through readmission to hospital (Beadle-Brown, Mansell & Kozma, 2007) and/or placed in out-of-area placements (Mansell, Beadle-Brown, Skidmore, Whelton & Hutchinson, 2006). The increased reliance on out-of-area placements led to a drain of resources from the local area in order to pay for these out-of-area services (Barron, Hassiotis & Paschos, 2011). This created a negative cycle whereby there were not enough financial resources to create services locally (Barron et al, 2011). When placed out-of-area, people remained the responsibility of the social services team where they came from, yet received care from the local services they had moved to. This created a significant risk of lack of communication and understanding about the person's needs (Mansell, 2006).

Private providers of accommodation for people with ID often bought cheaper properties in non-urban areas (Mansell, 2006), leading to a larger number of beds further away from peoples' homes and a widening disparity between options available in different parts of the country (Mansell, 2006). This was more marked in typically expensive areas; for example, in 2008 72% of people with learning disabilities from Inner London were placed out of area, and 35% from the South East (Whelton, 2009). This progression to a market-driven approach to the provision of social care housing, with the need to cut costs and maximise profits, in some cases led to a focus on increasing the number of available places, rather than on optimising the quality of life for residents (Mansell, 2006).

There have been further criticisms in how dominant discourses about 'independence' could potentially exacerbate problems for people with ID in relation to their living arrangements. 'Independence' is one of the key values in *Valuing People* (Department of Health, 2001), and is often embedded as a goal within local service provision (Clegg & King, 2006). However, *Valuing People* has been criticised by Simpson and Price (2009) for having only an idealistic vision of community living and independence. They argue that this has led to cases where the real difficulties and risks associated with independent living have not been fully assessed, leading to increased disability. They give an example of someone who was not fully assessed for his ability to understand financial issues and not given adequate support, and who therefore became hugely indebted to unscrupulous money lenders. (Simpson and Price, 2009). They therefore critique the "romanticism" (p.38) inherent in some *Valuing People* policies. In a similar vein, Clegg and King (2006) reported that they often found a general consensus in supported homes in the community that everyone with ID could be independent 'if only the service and staff tried hard enough'. They reported that by promoting solely the discourse of 'independence', the person, staff and service may have too high expectations placed upon them. This runs the risk of 'setting people up to fail'

by expecting autonomy. The discourse of 'independence' potentially ignores the *interdependence* that people without ID use all the time, through friends, partners, or colleagues. Taking a systemic perspective, Clegg & King (2006) therefore discuss "side-stepping autonomy" (p.124); they used this term to mean valuing interdependence, rather than reifying independence in ID services.

In summary, although since the 1980s onwards there has been a policy level drive for people to live in the community, the economic context has sometimes meant that people with complex needs may not have been given adequate support for these community placements to succeed. This has contributed to circumstances in which they are re-hospitalised or, in when there are also forensic issues, re-admitted to prison (Simpson & Price, 2009; Slevin, McConkey, Truesdale-Kennedy & Taggart, 2008).

**1.5.2.2 Where people with ID live.** Most people with ID will live in the community and never require inpatient mental health services (NHS England, 2015a). However, a significant minority may be supported in inpatient settings, in forensic and/or mental health hospitals.

Regarding forensic services, the closure of institutions has had a knock-on effect on the criminal justice system (Hutchinson, 2013; Lindsay et al, 2010; Smith, 2005) with higher referrals of offenders with intellectual disabilities to prison settings. A study found that people with ID who engaged in criminal or antisocial behaviour were more likely to be young men, and come from backgrounds with social disadvantage. A high proportion of them had behavioural problems dating back to childhood; and many also had mental health problems (Holland, Clare & Mukhopadhyay, 2002).

Aside from forensic settings, people with ID may be admitted to mental health hospitals, for reasons of assessing behaviour which challenges, and/or mental health difficulties (Slevin et al,

2008). Psychiatric crises are the primary reason for hospitalisation (Lake, Palucka, Desarkar, Hassiotis, & Lunsky, 2014) and those who are admitted to inpatient settings tend to have complex needs, e.g. psychosis, behaviours which challenge (Bakken & Martinsen, 2013). Sometimes admissions are not appropriate, and could be better treated in the community (Purandare & Wijeratne, 2015). Figures indicate that a significant number of people with ID are still residing in inpatient settings: 2595 recorded on 30<sup>th</sup> September 2016, and 2550 on 31<sup>st</sup> October 2016 (NHS England 2015b; NHS England 2016). In the 2015 figure, more than 75% of people had been there for a year or more (NHS England, 2015b).

### **1.5.3 Winterbourne View and Transforming Care**

Several years prior to the events at Winterbourne View, in 2007, the Royal College of Psychiatrists, the British Psychological Society and the Royal College of Speech and Language Therapists (SaLTs) commissioned a joint report, *Challenging Behaviour: A Unified Approach*. They noted that more and more people whose behaviour was deemed to be challenging were being placed in 'long-stay residential' accommodation, when they should be supported in community based settings (Banks et al., 2007). Nevertheless in 2011, following a whistle-blowing tip-off from a former nurse, a BBC Panorama journalist posed undercover to work at Winterbourne View, a privately-run hospital for the assessment, treatment and rehabilitation of adults with ID (BBC, 2011). This undercover filming exposed the abuse, mistreatment and neglect of patients, as well as excessive use of restraint, often used by staff as punishment rather than for the safety of residents or staff (Department of Health, 2012). A number of clients were in out-of-area placements (Department of Health, 2012).

As part of the Government response to the events of Winterbourne, Care Quality Commission (CQC) inspections of all similar hospitals were subsequently commissioned (Department of Health, 2012). Although instances of abuse on the scale of Winterbourne View were not found in other

hospitals, the incident was thought to unveil problems with hospital care for people with ID across the country. The results of inspections reported that “only 14% of people residing in inspected units were in places that fully complied with the standards inspected” (p. 12, Mencap, 2012). The CQC also reported that too many people were being moved to inpatient services without enough or adequate assessment or treatment, and people often remained in hospital for longer than necessary before being discharged (Bubb, 2014). A joint report was produced by NHS Commissioning Board, Adult Social Services, and Local Government Authority, proposing the Transforming Care agenda (Department of Health, 2012). The report set out the Government intentions, that the norm for people with ID should be to live supported in their own homes based within communities, with individualised personalised packages of support. When hospital treatment was deemed necessary this should be for short periods of time, with a focus on rehabilitation, and be as close to home as possible (Department of Health, 2012). NHS England has reaffirmed commitment to the programme in supporting people to move from hospital settings into their own or supported homes in the community (Department of Health, 2015) and the National Institute for Health and Care Excellence has recently published guidelines on supporting transitions between hospital and community settings (NICE, 2016). Nevertheless, progress under Transforming Care has not always met targets, and a substantial number of people remain in hospital (Leaning & Adderley, 2015). It has been argued that this lack in progress is due to people with ID and key stakeholders around them not having enough power for significant changes to take place (Bubb, 2014).

As Flynn and Citarella (2013) disdainfully note, “inadvertently, Winterbourne View Hospital illuminated a misplaced faith in ‘hospitals’ as places of healing” (p. 177). A change in environment does not necessarily lead to better treatment if the beliefs and practices that existed in older institutions are carried onto the new buildings (Bigby & Fyffe, 2006). This explains why the term

'transinstitutionalisation' has been used when people move nominally to the community, but to similarly restrictive settings, rather than a real progression to community living (Talbot, 1975, cited in Burrell & Trip, 2011; Drake, 2014). Despite the values of *Rights, Independence, Choice, Inclusion* that are pledged in the *Valuing People* white paper (Department of Health, 2001), the situation for people with ID (often those with the most complex needs) in the beginning of the 21<sup>st</sup> century was such that the events of Winterbourne View could take place. The Transforming Care programme offers a significantly different approach to supporting people in the community. The *Building the Right Support Plan* (NHS England, 2015a) sets out how service pathways should be made clearer, better and more personalised support should be available in the community, and support at home (or if necessary in hospital) should be better planned and coordinated.

In the next section, I will present a systematic review of the literature to further consider how transitions are experienced by people with ID.

### **1.6 Systematic Literature Review**

In this section I will briefly overview some of the relevant research on deinstitutionalisation, before presenting a systematic review of the literature on people with ID's experiences of transitioning.

A significant number of studies were undertaken internationally during earlier periods of deinstitutionalisation, which often focussed on quantitative measures, such as whether there was a reduction of behaviour that challenges, or increase in quality of life (QoL), pre- and post-transition. Chowdhury and Benson (2011) completed an international review of 15 QoL studies post-deinstitutionalisation, comprising over 1200 people with ID. They reported that overall people

had higher indicators of QoL in the community, including more choice and more opportunities for activities. However, they noted that for many of the studies, following the initial improvement period of up to one year, QoL results plateaued (or declined slightly in a few studies). Similarly, in a systematic review of 68 studies between 1997 and 2007, Kozma, Mansell and Beadle-Brown (2009) reported that for the majority of outcomes (including 'objective' QoL measures), things had improved for people who had moved from large institutions to smaller community based residences. They noted some important exceptions however: people with behaviours which challenged, and/or very complex needs often did not have as positive results as other participants; furthermore, there were mixed results for whether community settings were better able to support those with behaviour which challenged. Hubert and Hollins (2010), writing before *Transforming Care*, noted that the complex needs of this client group were not consistently met in community provision.

Although these studies have been very valuable in exploring some of the consequences of moving, they do not fully answer questions around *how* transitions are experienced. Questionnaire studies on deinstitutionalisation have been "criticised for omitting the voice of people with intellectual disabilities" (p.568, Bigby & Fyffe, 2006).

Therefore, a literature review was undertaken in search of papers which explored how transitions are experienced by adults with a diagnosis of ID. To keep the search as comprehensive as possible, studies which looked at transition from mental health hospitals, forensic settings, and other residences (e.g. the family home) were included. The time period covered was from 1970 (to capture research from the first period of deinstitutionalisation) to present day. This large time period was covered as there has been very little research since *Transforming Care* was launched. Further details of the search can be found in Appendix B.

The review included studies which sought to understand how people found life now, after having been in hospital, as these were considered to capture some element of how peoples' experiences had changed over time. The inclusion and exclusion criteria for the literature search are displayed in table 1. Several studies were identified which explored peoples' experiences of life in hospital, or more general life story work with people with ID. Although these were of interest to the general topic area, they did not meet the criteria for the present search, and were therefore excluded. A summary of these papers is included in Appendix C.

Inclusion criteria	Exclusion criteria
<p>Adults with ID.</p> <p>An attempt to gather information about the <i>experience</i> from the transitioning person's own perspective.</p> <p>Something that captures <i>either</i> the experiences of moving (during the process) <i>and/or</i> a change in living arrangements, from a hospital-like setting to something more independent; life before and after a move – i.e. a change over time.</p>	<p>A non-residential transition – e.g. from college to work.</p> <p>Research only on physical health during transition.</p> <p>Research solely on psychiatric medication over time.</p> <p>Research on children not adults.</p> <p>Research solely from a behavioural perspective (e.g. demographic information about self-injurious behaviours; evaluation of a behavioural support programme).</p> <p>Research solely on clinical outcomes of inpatient admissions (e.g. comparisons of pre- and post-inpatient treatment measures of clinical symptoms) with no reference to how transition out of hospital / ATU was experienced by the person.</p> <p>Paper on transitions of people not with ID.</p> <p>Paper on experiences not relevant to present study (e.g. experiences of motherhood for people with ID).</p>

Table 1: Literature review inclusion and exclusion criteria

### 1.6.1 Summary of Findings from the Literature Review

Sixteen studies were included in the literature review. All of the studies used a qualitative design. Seven studies were conducted in the UK (Bond & Hurst, 2009; Brown, Dodd and Vetere, 2010; Forrester-Jones et al , 2002; Holland & Meddis, 1997; Hubert & Hollins, 2010; Jahoda & Markova,



2004; Owen, Hubert & Hollins, 2007), and eight outside of the UK (Republic of Ireland and Australia; Bramston & Cummings, 1998; Ellem, 2012; Ellem et al, 2012; Hamilton & Atkinson, 2009; Isaacson et al, 2014; Johnson, 1998; Sheerin et al, 2015; van Dooren et al, 2017). Only one paper was identified which explored a transition that took place in the context of the Transforming Care agenda (Leaning & Adderley, 2015). Two studies appear to be using the same participant group and possibly data set (Ellem, 2012; Ellem, Wilson & Chui, 2012). However, as the papers have a slightly different focus, both were included in the review.

Elliot, Fischer and Rennie (1999) and Mays and Pope (2000) argue that qualitative research should meet quality standards in a number of different domains, such as whether the report is written reflexively, and whether the findings of the study are grounded in sufficient examples that the reader can clearly see the analytic process. These criteria were therefore used in the evaluation of all papers used in the review. A summary table is displayed in Table 2. A more in-depth summary table for all papers' strengths and limitations can be found in Appendix D, with two examples of the more in-depth analysis completed for all papers in Appendix E.

In the following sections I will discuss the findings of the research; this has been divided according to the types of transitions which took place.

**1.6.1.1 Transitions from institutions and hospitals.** Seven studies looked into the experiences of people who had moved from large-scale hospitals as a result of deinstitutionalisation. Of these, three studies explicitly focussed on the experiences of people with ID during the transition of moving (Hubert & Hollins, 2010; Johnson, 1998; Owen, Hubert & Hollins, 2007). Johnson (1998) completed a 20 month ethnographic study, following the experiences of 22 women on a locked ward in Australia, all denoted to have ID and behaviours which challenged.

She completed intense observations of the participants, as well as interviews with key stakeholders and analysis of their case files, over the course of the hospital closing down and their move into accommodation in the community. She reported that there were mixed emotions when women in an institution found out it was closing – some were excited but for others it was a great source of anxiety. Johnson (1998) reported that when decisions were made about where they should move to next, the women were generally assessed as to whether they would 'fit in' to existing alternative services, rather than this process happening the other way round for a truly person-centred approach. In the new community homes, she noted that staff working with the women often failed to take into account the context from which people came, e.g. their backgrounds, past experiences of loss, or how the current move might be impacting on them (Johnson, 1998).

Owen et al (2007) completed a similarly in-depth ethnographic study of 11 women with "severe" ID and behaviour which challenged, as they went through the process of moving out of a UK institution which was closing down. The women were not involved in choices about their move or prepared for the transition, which they reportedly found stressful. Eight of the participants moved to a home on the hospital grounds, where many restrictions of the ward remained. These participants, who had also moved to a temporary home before settling into their permanent home, seemed to find the move the most difficult. Owen et al (2007) postulated that this was likely linked to the increased uncertainty and insecurity they felt with multiple changes in staff, and lack of communication about what was happening. Three women moved to houses in the community, and on the whole these women experienced more choice and improvement of day to day life. Similarly to the study by Johnson (1998), Owen et al (2007) reported that staff often found it hard to understand the impact a transition would have for the women.





<p>X = Criteria not met</p> <p>? = Criteria partly included / met / unclear</p> <p>✓ = Criteria met</p> <p>✓✓ = High standard</p>	Worth / relevance	Clarity of research question	Appropriated design	Content well described	Sampling is clear	Data & analysis	Relevancy of report	Explicit purpose of study	Appropriate method	Respect for participants	Methods specified	Appropriate discussion	Clear presentation	Contributes to knowledge	Own perspective acknowledged	Sample situated	Grounded in examples	Credibility checks	Coherence	Task specificity	Resonance
	Mays & Pope, 2000.							Elliot, Fischer & Rennie (1998)													
Bond & Hurst (2009).	✓	✓	✓	✓	X	?	✓	✓	✓	✓✓	?	✓	✓	✓✓	X	✓	✓✓	✓	?	✓	✓
Bramston & Cummings (1998).	?	?	?	✓	X	X	X	X	?	?	?	✓	✓	X	X	X	✓	✓	✓	?	?
Brown, Dodd & Vetere (2010).	✓	✓✓	✓✓	?	✓	✓✓	✓	✓✓	✓✓	✓✓	✓✓	✓✓	✓	✓	?	✓	✓	✓	✓	?	✓
Ellem (2012).	✓	✓	✓	✓✓	?	?	X	✓	✓✓	✓	✓✓	✓	✓	✓	X	✓	✓	✓✓	✓	✓	?
Ellem, Wilson & Chui (2012).	✓	?	?	X	✓	X	X	✓✓	✓	X	X	✓✓	✓	✓✓	X	✓✓	✓	✓	✓	?	✓
Forrester-Jones et al (2002).	✓	✓✓	✓	✓✓	✓	✓	X	✓✓	✓✓	✓✓	✓	✓	?	✓	X	✓	✓	✓	✓	?	✓
Hamilton & Atkinson (2009).	✓	?	✓	✓	X	X	X	✓	?	✓✓	?	✓	✓	✓	X	✓	✓	✓	✓	✓	✓

Holland, A., & Meddis, R. (1997).	✓	✓✓	✓	✓	✓	✓	X	✓	✓✓	?	✓	?	✓	✓	X	?	X	X	?	✓	✓
Hubert & Hollins (2010).	✓✓	✓	✓	✓✓	✓✓	✓✓	?	✓✓	✓✓	✓✓	✓✓	✓✓	✓	✓✓	X	✓	✓✓	?	✓✓	✓	✓
Isaacson, Cocks, & Netto (2014).	✓	✓	✓	✓✓	?	✓	✓✓	✓	✓✓	✓	✓	✓✓	✓	✓	✓	✓✓	✓✓	✓✓	✓✓	✓✓	✓
X = Criteria not met ? = Criteria partly included / met / unclear ✓ = Criteria met ✓✓ = High standard	Worth / relevance	Clear research question	Appropriate design	Context well described	Sampling is clear	Data & analysis	Reflexivity of report	Explicit purpose of study	Appropriate method	Respect for participants	Methods specified	Appropriate discussion	Clear presentation	Contributes to knowledge	Own perspective acknowledged	Sample situated	Grounded in examples	Credibility checks	Coherence	Task specificity	Relevance
	Mays & Pope, 2000.							Elliot, Fischer & Rennie (1998)													
Jahoda & Markova (2004).	✓	✓✓	✓	✓	X	?	X	✓	✓	✓✓	✓	✓	✓	✓	X	✓✓	?	X	✓	?	✓
Johnson (1998).	✓	?	✓	✓	✓✓	✓✓	?	✓	✓✓	?	✓	✓✓	✓	✓✓	?	✓	?	✓	✓	?	✓
Leaning & Adderley (2015).	✓	?	?	✓✓	?	?	?	✓	?	✓✓	✓	✓	✓	✓	?	✓	✓	X	✓	✓	✓
Owen, Hubert & Hollins (2007).	✓	✓	✓✓	✓✓	✓✓	✓✓	X	✓✓	✓✓	✓	✓	✓✓	✓✓	✓✓	X	✓✓	✓✓	?	✓✓	?	✓
Sheerin, Griffiths, de Vries & Keenan (2015).	✓	✓✓	✓	✓	?	✓	X	✓	✓	?	?	✓	✓	✓	X	✓	✓✓	✓	✓	?	✓
van Dooren et al (2017).	✓✓	✓	✓	✓	✓✓	X	X	✓	✓	✓	?	✓✓	✓	✓✓	X	✓	✓	?	✓	✓	✓

*Table 2: A summary of qualitative research evaluation.*

Hubert and Hollins (2010) completed a similar ethnographic study in the UK, following 17 men with “severe” ID and behaviour which challenged, over their transition from a long-stay hospital which was closing down, and then over a six year period in their new community accommodation. There were mixed experiences among the men. Some had a stable management team in their new campus accommodation, which the authors reasoned was instrumental in their improved quality of life after the move. However, other participants endured a two-year wait in temporary accommodation before they were resettled permanently, during which time “many of the men showed signs of severe disturbance and distress” (p.192, Hubert & Hollins, 2010). Together, these three studies significantly add to the understanding of how transitions were experienced by people with very complex needs, who may have struggled to understand and process what was happening when their well-known ‘homes’ closed and they moved out. The studies also make clear how the attitudes, language and understanding of staff could have a very important role in how such transitions were experienced.

Four further studies investigated the experiences of moving for people who had previously lived in institutions, although less directly than the above-mentioned research. Brown, Dodd and Vetere (2010) undertook a narrative analysis of how six older adults with Down’s Syndrome made sense of their own identities, and their relationships with others. Although their study did not set out to explicitly explore transitions, this key theme came up for all participants, who had all experienced moving and living in different places. The authors noted that “the majority of participants preferred their current way of life as opposed to living in the institution” (p. 4, Brown et al, 2010). In another study with older adults, Hamilton and Atkinson (2009) shared excerpts from some life story work undertaken with eleven older adults in the Republic of Ireland, all of whom had previously lived in institutions prior to living in community settings. The participants in this study discussed times of struggle while they were in hospital, but also times where they experienced kindness from others.



The paper does not include a systematic analysis of the data gathered from life story work, and it can therefore only make a limited contribution to understanding of *how* people make sense of transitions. However, of note, one participant explained their frequent residential moves occurred “because I was always complaining” (p.319) which seems to indicate an internalised and ‘at-fault’ position.

Jahoda and Markova’s (2004) Scottish study explored how people made sense of their new identities when they faced a move into the community, and how they managed stigma towards themselves. They interviewed 18 people who were making a move out of an institution into the community. The authors noted that these participants made sense of their identities in the context of being hospital residents, and felt disconnected from the “outsiders;” anyone who lived outside of the institution (Jahoda & Markova, 2004, p.722). A number of people felt that moving out of hospital was a chance “to become a different kind of person” (p.725). Participants at times talked about how different they were from other people with ID, as a way of making sense of the fact they were transitioning while others were not. The authors reported that this appeared to be in a way “to counteract their stigmatised status” (p.726) through distancing themselves from other people, which may have helped them to “reject a stigmatised identity” (p.728). They noted, however, a tension in participants also wanting to align themselves with others with ID, in an effort to form a sense of community with people who had been through similar experiences. The research therefore suggests that a time of transition is likely to be one in which people with ID may struggle with their identity and status relative to others. Finally, a large-scale study by Forrester-Jones et al (2002) consisted of a long-term follow-up of people who had moved out of institutions as part of a Care in the Community programme in the 1980s. The authors conducted interviews with 196 people with ID and 128 people with mental health difficulties, 12 years after their transition. Overall, participants reported that they enjoyed their new home environment, the relationships they had

with other residents and staff, and the levels of independence they experienced. However, participants also reported that sometimes their homes were still restrictive (e.g. many people had set bedtimes), and they did not always get on with other tenants (Forrester-Jones et al, 2002). The authors reported that a main factor in satisfaction with living arrangements after being in hospital was having “a warm comfortable home, shared with people you like” (Forrester-Jones et al, 2002, p.754).

**1.6.1.2. Transitions from forensic settings.** Three studies reported on people with ID’s experiences of moving out of forensic settings into the community; all these studies were conducted in Australia (Ellem, 2012; Ellem et al, 2012; van Dooren, 2017). As noted above, the same sample of 10 participants were reported in two separate papers (Ellem, 2012; Ellem et al, 2012). These studies found that six out of the 10 participants moved to a secure mental health unit after discharge from prison, and half of the group eventually became homeless, as they were not able to find appropriate accommodation. It was reported that transitions from prison could often happen with little planning or preparation for the move (Ellem, et al, 2012), and sometimes with no warning, with prisoners being told on the very day that they were being released (Ellem, 2012). The authors discuss how this lack of preparation for life in a new setting could have contributed to the placement break downs described above. van Dooren et al (2017) interviewed six people with ID who left prison. Similarly to Ellem (2012) and Ellem et al (2012), the authors found that participants reported that leaving prison could be an ‘overwhelming’ experience, and they often were not supported in the move. The authors concluded that “practical support... from trusted people was crucial” for people with ID when they transitioned out of prison (van Dooren et al, 2017, p.41).

**1.6.1.3. Transitions from the family home.** Three studies explored the experiences of people with ID moving out of the family home for the first time (Bramston & Cummings, 1998; Isaacson, Cocks & Netto, 2014; Jahoda & Markova, 2004). In the study by Jahoda and Markova (2004), which has been partially described above in section 1.6.2.1, the authors also interviewed 10 people with ID who moved from their family home into supported living in the community. Some participants in this group described how important it was for them that significant others, such as parents, saw them as ready to live more independently; however others noted that their family members still did not recognise their abilities in this way, which they found painful. These issues were not discussed by the participants moving from hospital. However, there were similarities across both participant groups, as both at times described themselves as different or ‘superior’ to other people who they saw as having ID. This indicates that moving from the family home or from hospital can make subtle differences in how people make sense of their identities, but all participants were at times acutely aware of the stigma attached to ‘being someone with ID’. Isaacson et al (2014) analysed the experiences of two young people (aged 21 and 25) leaving the family home for the first time in Australia. They conducted a thematic analysis of interviews and observations with the whole families over the course of seven months, commencing four / six months after the participants had moved. One participant discussed being initially worried about the move, but both ultimately reported enjoying living in their new homes. The authors findings suggested there is a re-negotiation of relationships and roles in families when a young person moves out, affecting all family members, including siblings (Isaacson et al, 2014). For the young person, this meant taking on a new role as someone now in a more “adult” position, with all the implications for independent living that came with this status such as having more choice. Alongside this, parents needed to adapt to a different position as a carer. This meant losing the role of main caregiver, but still playing some part in their sons’ lives, such as managing finances (Isaacson et al, 2014). The role of other sources of care, including siblings and services outside

of the family, were all noted to be important in supporting transitions (Isaacson et al, 2014). In the final study, Bramston and Cummings (1998) followed four participants over five months before, during and after transitioning in Australia; three of whom moved out from their parents. Contrastingly to other studies which highlighted the worries that people transitioning could experience (e.g. Hubert & Hollins, 2010; Johnson, 1998), Bramston and Cummings (1998) reported that participants in their study did not report any changes in “stress level because of the transition” (p.305). These participants had made the choice to move when it suited their plans for their lives. Bramston and Cummings (1998) speculated that if the person’s transition was a much hoped for event, this could support them to find the move enjoyable rather than stressful. The authors drew on Reich and Zautra’s (1988; cited in Bramston & Cummings, 1998) stress model to explain the findings, reporting that perhaps participants had a sense of mastery and control over the move, which lessened feelings of stress.

**1.6.1.4. Transitions from other settings.** Four studies explored peoples’ experiences of moving from other settings (Bond & Hurst, 2009; Bramston & Cummins, 1998; Holland & Meddis, 1997; Sheerin , Griffiths, de Vries & Keenan, 2015). Bramston and Cummins (1998) interviewed one participant who moved out of supported living accommodation to live with her boyfriend. As described above in 1.6.2.3, the participants in this study did not report elevated stress levels during the transition. In the study by Bond and Hurst (2009), six of their nine participants moved from other, less independent, residential care settings to living on their own, and three moved from living with partners. Participants reported that overall living independently was better than in residential settings. However, they discussed that there were challenges, and participants could feel isolated or vulnerable at times, even though they received support from staff to maintain living on their own. A study by Holland and Meddis (1997) also identified that relationships with other people played a key role in how people with ID found it to live in the community. Their study explored how six

people with ID viewed their current residences after moving from other settings. The findings indicated that relationships with staff, with other tenants, and with people outside of the service all shaped participants' experiences of their home (Holland & Meddis, 1997). Overall participants in this study reported being happier with their lives now (Holland & Meddis, 1997). Similar sentiments were expressed by participants in a final study by Sheerin et al (2015). The researchers interviewed five people with ID who moved into the community from a congregated setting<sup>3</sup> in the Republic of Ireland, as well as relatives of two of the participants. Participants reported a sense of pride in having their own home, and enjoyed the new independence they felt. However, they also reported feeling less secure, and had little social integration into the community. The authors' analysis indicated that overall the transition from congregated setting to new home was well-managed and most participants reported being involved with making choices and decisions (Sheerin et al, 2015).

**1.6.1.5. Transitions as part of Transforming Care.** One paper was identified which explored someone's experience of moving as part of the Transforming Care programme (Leaning and Adderley, 2015). The authors describe a narrative case study of Raymond, who had been diagnosed with "severe and profound ID, autism spectrum disorder and severe challenging behaviour" (p.2). Raymond has been in hospital for 46 years, and was deemed 'too challenging' to live in the community. However, he was identified as someone who could and should be discharged from hospital under the new Transforming Care agenda. As a local Clinical Psychologist, the first author visited Raymond in the hospital, noting that "Raymond was playing out the generic villain story just the way he had been depicted in his file.... [he] had somehow

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<sup>3</sup> Congregated setting is a term used in the Republic of Ireland for group homes of more than 10 people with ID, often quite isolated from the community (Health Service Executive, 2017).

bought into this story of himself and was the embodiment of the long-held dominant views of others” (Leaning & Adderley, p. 3). The author spent time at the hospital building a relationship with Raymond, to begin to explore alternative stories about him. He shared these with the staff team, and they developed support plans, particularly focusing on “what were the triggers for Raymond’s happiness” (p.4). By the time the transition took place, “we [staff team] all bought into an alternative optimistic narrative of Raymond (and it seemed like he did too) and by the time he was ready to get out of the ambulance and walk through the front door of his new home, he was smiling confidently at the staff he had come to know. He opened his door with his own key and went into his kitchen to put his kettle on and made his own cup of tea for the first time in over four decades” (p.4, Leaning & Adderley, 2015). This case study was a powerful description of how Raymond’s story was able to shift, through those around him hearing and believing a richer array of stories about him.

*Although trying to take a critical research perspective to the studies in the review, I found myself overwhelmed with sadness while reading some of them, particularly the study by Hubert and Hollins (2010). They noted the change in one participant, from someone who would “sit happily, and smile, and come up and hug you and kiss you on the cheek” from their field notes in 1999; but by the follow-up study he was on strong medication and “no longer danced or teased, but shuffled slowly around the house looking at the floor, or sat on his bed for hours, immobile, without giving eye contact. He died in 2005 of a respiratory infection” (p.192). It drew into sharp focus that stories of a move to the community are not always happy endings. Also, in some ways, I wondered whether I found it easier reading about institutions from the time of deinstitutionalisation – this was so long ago, professionals didn’t know any better, I could tell myself. But to read this case made me really emotional. It should not happen ever, but to think it has happened so recently made me*

*wonder how many cases like this are happening now; I found myself feeling similarly when reading the case study written by Leaning and Adderley (2015).*

### **1.6.2 Synthesis of Findings**

Research into transitions when a hospital closed down and people were relocated suggested that this could be a very challenging time, and very distressing for people with ID. This seemed to be more so when there was uncertainty, and a lack of consistency in staff teams (Hubert & Hollins, 2010; Johnson, 1998; Owen et al, 2007). The importance of relationships in how transitions were experienced was further highlighted in research into people with ID moving from forensic units (van Dooren, 2017), as well as from other settings (Bond & Hurst, 2009; Holland & Meddis, 1998). Findings from research into moving out of the family home indicate that these transitions could be experienced as worrying, or could bring challenges to family dynamics. However, they indicate that with support and if people have a sense of control over their move, these transitions can mark a point of significant personal growth and development for people with ID (Isaacson et al; Bramston & Cummins, 1998).

The literature suggested the need for detailed planning before, during and after discharge (Ellem, 2012; Ellem et al, 2012). The study by Bramston and Cummings (1998), in which participants indicated no change in stress levels when they had actively chosen to move, further implicates the role of choice and preparation in how transitions are experienced.

The majority of studies were conducted outside of the context of Transforming Care. The studies were also not intended to be generalised, limiting the applicability of findings to today's context. The evaluation of literature section below will outline the studies strengths and limitations in more detail.

### 1.6.3 Evaluating the literature

The literature review identified a number of studies with very small sample sizes, which limits the generalisability of the findings. There was one single case report (Leaning & Adderley, 2015) and one study comprised of only two participants (Isaacson et al, 2014); six further studies included fewer than 10 participants with ID (Bond & Hurst, 2009; Bramston & Cummins, 1998; Brown et al, 2010; Holland & Meddis, 1997; Sheerin et al, 2015; van Dooren, 2017). There was one very large study with nearly 200 respondents (Forrester- Jones et al, 2002) but in this study participants had transitioned during the 1980s, when the social climate was very different to transitions under Transforming Care. This indicates that the results may not be fully relevant today. Furthermore, a significant limitation of the study is that results from all participants (those with ID and those with mental health difficulties) have been reported on together as one group, without consideration of the idiosyncratic differences in community living that may affect those with ID and those with mental health difficulties. It is therefore difficult to understand clearly how these transitions were experienced by people with ID.

Five studies did not provide a clear description of how the analysis was conducted (Bramston & Cummings, 1998; Ellem, 2012; Hamilton & Atkinson, 2009; Holland & Meddis, 1997; van Dooren et al, 2017). These studies also did not reflect on their own relationship to the research, which makes it difficult to know how data was chosen systematically to support the conclusions drawn, or whether the presented data was representative of all participants' experiences. Without clearly reflecting on their own positions, the lenses through which data was analysed were unclear. A fifth study (Ellem et al, 2012) identifies using narrative and thematic analyses, however the process of analysis was not clearly described in the paper. Four studies used thematic analysis (Bond & Hurst, 2009; Forrester-Jones et al, 2002; Isaacson et al, 2014; Sheerin et al, 2015), and a fifth



used both thematic and content analyses. Willig (2013) notes that a thematic analysis that is not positioned epistemologically may not contribute an in-depth enough analysis of the data, rather represent only the researchers' opinions. Both Bond and Hurst's (2009) and Sheerin et al's (2015) papers do not make their epistemological approaches clear, though Sheerin et al (2009) imply more of a positivist position through writing about "discovering" the experiences of their participants through the research process. Although both have provided some interesting and illustrative themes, they have not fully analysed the meaning of peoples' experiences.

Eight of the studies were conducted outside of the UK: six in Australia (Bramston & Cummings, 1998; Ellem, 2012; Ellem et al, 2012; Isaacson et al, 2014; Johnson, 1998; van Dooren et al, 2017) and two in the Republic of Ireland (Hamilton & Atkinson, 2009; Sheerin et al, 2015). Although some processes that people go through when they transition could be universal, the local context of the transition is also likely to contribute to the experience. For example, what the policies are around how much and what type of support is available, what is provided by social care or charities in the local community, and what the discourses are around ID in that culture are all likely to impact on someone's personal experience of moving.

### **1.7 Rationale for the current research project**

Three papers explicitly researched peoples' experiences of moving out of hospital, by analysing their experiences before, during and after the transition (Hubert & Hollins, 2010; Johnson, 1998; Owen et al, 2007). However, the literature review revealed that as yet there has been no study which has attempted to specifically understand the process of transition. Clegg and King (2006) note that "although transition is frequently described as a problem for people with intellectual disabilities, there is virtually no theoretical analysis of why transitions should provoke distress" (p.126). The proposed study, using a GT methodology, intends to address this gap in the literature. Furthermore, only one paper found by the literature review explored transitions as part of

Transforming Care which was a single case study rather than a research paper.. As argued above in section 1.5.3, the context in which transitions happen under Transforming Care agenda are likely to be markedly different from transitions which happened in previous rounds of deinstitutionalisation. Those deemed 'too complex' to move previously are now being considered for moves; more in-depth planning is taking place around the transition, with additional support available in the community (Department of Health, 2015a). Fink (2004, cited in Simpson & Price, 2009, p.182) noted that "policy should be understood through the hidden lives of the people who experience it;" it therefore seems timely for an exploration of how transitions as part of Transforming Care are experienced.

Therefore, the present study aimed to investigate the following research question:

How do people with ID experience transitioning as part of the Transforming Care programme?

## 2. Methodology

This chapter aims to provide an overview of the methodology used to address the research question. The design and rationale for qualitative methods will be discussed, followed by explanation of the methodology used in order to address some of the power issues in ID research. The chapter will also focus on recruitment, participant information, consultation with service users, ethical considerations, and finally the procedures and analysis used.

### 2.1 Design

#### 2.1.1 Qualitative approach

Qualitative research is invaluable in attempting to explore understanding and meaning-making of individuals' experiences, whereas quantitative research may be more suitable for exploring cause and effect relationships (Willig, 2013). As such, a qualitative research methodology was chosen. It was hoped that this would allow for analysis of the complexity of people's experiences.

The study used in-depth interviews with participants who had transitioned as part of Transforming Care. Participants were invited to have someone else who knew them well also interviewed with them, a Key Support Person (KSP; see section 2.3.2.1 below). Participants were recruited through purposive sampling.

**2.1.1.1 Assessing quality of the research.** As described in the literature review, qualitative research should uphold certain standards to assess its quality. As above, ideas from two research evaluation guidelines (Elliot, Fischer & Rennie, 1999; Mays & Pope, 2000) were

applied to the present study throughout the process of data collection and writing of the thesis. A table with more details of how this study met the quality criteria can be found in Appendix F.

### **2.1.2 Grounded Theory**

Glaser and Strauss (1967, in Willig, 2013) founded Grounded Theory (GT) techniques as a way of generating new theory from data, in a bottom-up rather than top-down approach to research. GT researchers aim to use participants' data to construct a theoretical understanding which remains 'grounded' in the data. It can be of particular value in fields of research where little is currently known about the phenomena under investigation. This seemed particularly relevant to the present study, as the literature review exposed a current lack of understanding of how transitions are experienced by people with ID. It was also hoped that the development of a theoretical model could be useful for staff who work with people with ID who are transitioning, as it could allow them to have a greater understanding of the processes that the participants in this study went through during their transition.

Initial incarnations of GT took a critical realist stance in which new theory was thought to 'emerge' from data, implying a discovery of something 'real' (Willig, 2013). However, Charmaz's book, *Constructing Grounded Theory* (2014) explores the methodology from a social constructionist framework, and acknowledges the relationship which exists between researcher and data (Charmaz, 2008). Further information on the process of analysis in GT research can be found in the section on data analysis (2.5.3) below.

**2.1.2.1 Consideration of other methodologies – why GT?** Other qualitative methodologies were considered, namely Interpretative Phenomenological Analysis (IPA) and Narrative Analysis (NA). The considerations for both these methods are explored below.

Phenomenological research aims to study how participants view and understand the world, through making explicit the underlying assumptions in the person's explanation of their experiences (Willig, 2013). An IPA approach was considered for the present study, as it could have been useful to explore and interpret how people made sense of what they went through. However, Willig (2013) critiques this methodology for the demands it places on participants to provide a rich, verbal account of their experiences, which could be more difficult for some people. This therefore could have excluded less verbally-able people from the present study. The method also does not focus on the processes within an experience, so may have been less useful clinically than a GT approach.

NA is derived from ideas from narrative psychology, and is concerned with the stories people tell about their lives, and what societal discourses they draw from to tell them (Squire, Andrews & Tamboukou, 2013). This method would have been valuable in the present study in analysing how people make sense of their stories of transitioning; furthermore how they construct them, and to what effect (Willig, 2013). To this end, participants were asked whether they consented to the data they provided being used for future research, as a narrative inquiry could be used in the future by the research team to further explore their experiences. Nevertheless, it was felt that a GT analysis would be most pertinent for the purposes of the present study, as a means of exploring a sparsely-researched area, and generating a theoretical understanding of peoples' experiences.

### **2.1.3 Altering the Methodology – Issues of Power**

Research with people with ID may need adaptations to the research methodology to make it as accessible as possible (Nind, 2009). Adaptations to the present study will be explored in this

section, namely changes to the interview method to address issues of power, and other considerations to make research accessible and relevant to this population.

Issues of power may be particularly pertinent in research concerned with people with ID who may have less power than their non-disabled counterparts. Chappell (2001) asked: “how do we prevent non-disabled researchers, even ones who are sympathetic to the struggles of people with ID, from assuming a dominant role in the research process?” (p. 41). This and similar questions significantly informed my thinking around the methodological design.

**2.1.3.1 Dyadic interview technique.** Dyadic interviewing is a qualitative research method which values interdependence, and that which is created relationally when a participant pair is interviewed, rather than one person on their own. As Caldwell states (p.5, 2013), “[it] is an interdependent methodology because instead of ignoring, attempting to control for, or otherwise creating an illusory division between people, it recognizes the value of interconnected relationships.” Its use has been growing in health research, where it has been used to explore, for example, how a serious health diagnosis impacts couples (e.g.: Morris, 2001, cited in Caldwell, 2013). An appreciation of the value of interdependence, rather than independence, can be particularly important in working with people with ID (Clegg & King, 2006; Fredman, 2006).

When using the method with a pair consisting of a person with ID and a non-disabled person (or Key Support Person; KSP), there is a risk of an uneven power balance, meaning the KSP may inadvertently overshadow the main participant. Caldwell (2013) therefore suggests the following stages to the interview process:

1. Meet the person with ID for a preliminary interview
2. Interview the KSP to gather further data

### 3. Interview person with ID again to check and enrich the previous data

In this way, there is an attempt to triangulate and cross-reference the data while adding layers of meaning and understanding.

**2.1.3.2 Keeping the person with ID's voice central.** Although the dyadic interview technique aimed to favourably redistribute some of the power towards the person with ID, I had concerns that the KSP's experience of the transition could dominate the experience of the person themselves (for example, a mother might – understandably – begin describing her own distress while waiting for the move to take place; this could be seen as de-centring the experience of the person with ID). Therefore I chose to adapt Caldwell's (2013) original interview plan by borrowing the systemic ideas of interviewing an "internalised other" from Karl Tomm (cited in Mudry et al, 2016). This technique is used in family therapy to invite people to step into another's shoes, explore issues from multiple perspectives, and generate differing understandings regarding the positions others may take (Vasconcelos & Neto, 2014). Within the ID field, it has been proposed as a tool in family session to bring all voices into the room, for example when working with someone who is non-verbal (Baum, 2006; Baum, 2007). It has been documented to be a very powerful tool in opening up different perspectives (Haydon-Laurelut & Wilson, 2011), for example, among staff teams when working with people whose behaviour challenges. The technique aims to bring a possibly marginalised perspective into the centre of the discussion. The method was therefore adapted so that when the KSP was interviewed, they were asked to answer 'as if' they were the person with ID, in the first person. A further adaption to the method suggested by Caldwell (2013) was to have the person with ID present at both interviews. This then gave them the chance to listen to their KSP, and agree or correct as appropriate. This is the first time a method like this has been used in the published literature to my awareness. The adapted methodology took the following format:

1. Initial meeting with participant to give more information about the study
2. First interview: with the participant on their own
3. Second interview: with participant and KSP. In this interview, the KSP was interviewed, answering as the participant. The participant was asked to comment on whether they agreed with the KSP.

This will be described in more detail below in the Procedure section (2.5.2).

#### **2.1.4 Other Adaptations for Research in ID Field.**

There are a number of procedural techniques specific to research with this client group which were used in the design and implementation of the present study. An effort was made to personalise the research process to each participant depending on their specific needs. Where appropriate, pictures and photos were used to supplement verbal data collection (see appendix G for an example); furthermore questions were kept simpler to facilitate understanding (Finlay & Lyons, 2001; Rodgers, 1999). Questions that put too much emphasis on placing events in the correct time or sequence were also avoided, as these can be difficult for people with ID (Ramcharan & Grant, 2001) and could lead to disengagement if the participant felt they were getting things 'wrong'. Although not often a key feature in qualitative research, closed questions were used at times to generate more data than typical open-ended questions, which people with ID can find harder to answer (Booth & Booth, 1996). However, these were not used exclusively, due to the noted tendency for acquiescence in people with ID in research (Gilbert, 2004). For one participant, Talking Mats were used (Murphy, Cameron, Markova & Watson, 2004) to support communication on topics related to moving house (see appendix H for example).

**2.1.4.1 Issues of understanding.** Gilbert (2004) discussed the importance of ensuring people understand what is meant by 'research'. This was done here by establishing participants'



understanding of what the project aimed to do, during the initial information-sharing and consent-seeking stages (Burke, McMillan, & Cummins et al, 2003). Rodgers (1999) advises meeting with the person for an informal discussion, to build rapport. Therefore, before any data was collected, I met with each participant to tell them more about the project. In addition, particular care was taken with the language used from the very outset. For example, in William's (1999) study people with ID defined 'research' as "finding things out;" this phrasing was used throughout the present project. It was also hoped that by framing the project as "finding things out" the researcher and participants would be positioned as co-detectives, or co-constructors of the research outcomes, and in this way establish more of a balanced power dynamic.

## **2.2 Participants**

### **2.2.1 Inclusion and Exclusion Criteria**

The participants were people with ID who had transitioned, or were transitioning, as part of the Transforming Care programme. They were recruited from one county in the South East of England which had been granted Fast Track status by NHS England (NHS England, 2015a), and had used this to create a specialist Transforming Care team, embedded within social services. Although a number of potential participants were identified who were waiting to transition, it was felt by those around them that it was not appropriate for them to be contacted (for example, it was felt to be too distressing). However, one participant (Darling) had transitioned under the scheme, but had been re-admitted to hospital and was awaiting a new transition at the time of interview.

*This was a difficult recruitment issue to navigate. On the one hand, there are fundamental ethical implications of approaching someone to take part in a project which they could find traumatising or seriously distressing. I wanted to err on the side of caution, and respect the opinions of the people around the participant, who knew them well and were better able to make a judgement*

*about how the person may react. On the other hand, however, during the course of some interviews, I saw times when staff / family members wanted to veer conversations away from anything upsetting; for example they might list all the positives of the move when someone talked about missing their old friends from hospital. I wondered whose distress was really being pushed away – the person with ID or the person who was listening? It also made me think about how much space people with ID felt they had to bring up these more negative narratives or emotions. As such, I wondered whether there were people who could have contributed to the research, but were kept apart through an understandable, but not always helpful, wish to ‘protect’ them.*

Participants were required to be able to take part in some form of interview. The use of a KSP and the adaptations described above (e.g. use of pictures) aimed to open up participation to a wider range of people, rather than only those verbally able enough to complete a one-hour in-depth interview on their own. However, inevitably this criteria meant the exclusion of some candidates who were not verbally able enough to understand the consent procedure. Although there is informative advice in the literature on conducting research with non-verbally able people (Booth & Booth, 1996) as along with successful examples (e.g. Hubert & Hollins, 2010), it was felt that this exclusion criterion was appropriate within the scope of the present project.

### **2.2.2 Participant Recruitment**

Potential participants were identified by members of the Transforming Care team. All participants were linked to the local NHS community mental health team. The team member gave people a brief initial information sheet (in Easy Read format) which invited them to contact the researcher if they would like to find out more (see Appendix I). Contact was made to the researcher via telephone or email, by the potential participant themselves, the member of the Transforming Care team, or someone who was known to the person with intellectual disabilities (for example, the

manager of their new home, a support worker, or a family member). Participants were then given the full information guide (Appendix J) and information on choosing a KSP (Appendix K). KSPs were given an information sheet (Appendix L). One participant, Oliver, had previously made a video about his transition experience for training in the Transforming Care team. He consented to this being used for the study, but did not want to take part in any further interviews with me.

Following initial recruitment to the study, theoretical sampling was used to identify additional participants who could further enrich the developing model (Charmaz, 2014). Further details of theoretical sampling and how it informed the data analysis can be found in section 2.5.3. below.

### **2.2.3 Participant Information**

11 people with ID took part in the study, alongside nine individual KSPs (one Social Worker, Patsy, acted as a KSP for three participants). See table 3 for details. All identifying details have been modified. All participants were white British. Age ranges rather than specific ages are given to aid anonymity. As described above, I tried to be mindful throughout of the power that people held as participants of this study. To support them to feel more ownership and an increased sense of control over the project, I invited participants to choose their own pseudonyms for this write-up. This was discussed when explaining the confidentiality section to them at the initial meeting. I explained that no one would know it was them because they could choose a pretend name to have instead. I found participants enjoyed choosing a name that they liked for their pseudonym, and many chose someone that they were a fan of – as such the participants included Elvis Presley, Jason Donovan and Dave the Minion. Names of KSPs have also been changed.

This number of participants reflects the amount of data used for the project to reach data saturation sufficient to develop an explanatory model. One participant, Darling, was also identified as someone whose transition into the community had recently broken down, resulting in her

admission to a specialist ID inpatient unit. It was hoped that as someone with a different story to other participants, she would provide data that tested out the model's applicability to a wide range of experiences, as suggested in Charmaz (2014). Furthermore, Dave and his Dad Peter were asked to feed back on the developing model in addition to providing information about MD's transition.

<b>Name of participant</b>	<b>Name of and relationship to KSP)</b>	<b>Age</b>	<b>Time scales</b>	<b>Brief history of institutional / inpatient experiences prior to Transforming Care transition</b>
Pamela	Rachel, Home Manager	50-55	Approximately nine months waiting to transition; moved two years before interview.	Diagnosis of ID, with forensic history and history of behaviour which challenges. Lived in a variety of hospitals for nearly 40 years. Now lives in own flat with 24 hour support.
Jason	Ayo, Support Worker in new home	40-45	Four months waiting to transition; moved one year before interview.	Diagnosis of Autism, ID and forensic history and history of behaviour which challenges. Admitted to NHS secure setting approximately 23 years, during which time he moved between different but related units (medium and low secure). Longest admission was nine years. Moved to a private hospital two years before he then left through Transforming Care. Now lives in own flat with 24 hour support.
TJ	Patsy, Social Worker	20-25	14 months waiting to transition; moved four months before interview.	Diagnosis of Autism, ID and forensic history. Admitted to private forensic (medium secure) unit in late teens for 2 years. Moved to NHS medium secure unit for three years. Lived in NHS low secure unit for two years before Transforming Care transition. Now lives in own flat with 24 hour support.

Larry	Fran, Home Manager	50-55	Approximately eight months waiting to transition; moved one year before interview.	Diagnosis of ID, with forensic history. Had lived independently in the past, though had then been in hospitals for over 15 years. Now lives in shared accommodation with three other tenants, 24 hour support.
Benny	Patsy, Social worker	50-55	Approximately 12 months waiting to transition; moved approx. 18 months before interview.	Diagnosis of ID. Psychiatric diagnosis of "schizoaffective disorder." History of behaviour which challenges and self-injurious behaviours. Long history of inpatient stays, including under the Mental Health Act. Now lives in own flat as part of a shared accommodation facility (shared dining and lounge area with other tenants). 24 hour support.
Clive	Patsy, Social Worker		Initial transition was delayed by building work. Total waiting time for transition around 18 - 20months. Moved around six months before interview.	Diagnosis of ID as well as physical disability. History of behaviour which challenges. Had lived in a number of hospital settings for several years prior to discharge. Now lives in own flat as part of a shared accommodation facility (shared dining and lounge area with other tenants). 24 hour support.
Oliver	Chose not to consent to KSP being contacted.		Time waiting for transition unknown. Moved approximately nine months before interview.	Diagnosis of ID, with forensic history and history of behaviour which challenges. Psychiatric diagnoses of "schizophrenia" and "personality disorder;" history of alcohol misuse. Around 10 different hospital placements over approximately 40 years. Now lives in own flat with 24 hour support.
Elvis	Betty, mother and Gerry, father	30-35	Approximately two years waiting for transition. Moved around 18 months before interview.	Diagnosis of Autism and ID and psychiatric diagnosis of "Generalised Anxiety Disorder." History of behaviour which challenges and self-injurious behaviours.

				10+ years in NHS and private inpatient hospitals. Now lives in own house with 24 hour support.
Fred	Harriet, mother.		Approximately six months waiting for transition. Living in present accommodation for around nine months at time of interview.	Diagnosis of autism and ID. Forensic history. Now lives in own house with 24 hour support.
Darling	Wendy, nurse on inpatient unit		Had transitioned last year, returned to hospital two months before interview.	Diagnosis of ID and psychiatric diagnosis of depression. Previous history of posing risks to staff, and self-harm. Currently in hospital at the time of interview waiting for a new placement to be found.
“Minion” Dave	Peter, father	30-35	Approximately 18 months waiting for transition. In present accommodation for over two years.	Diagnosis of ID and behaviour which challenged. Had been two different hospitals, one for approx. one year, and the second for eight years which was out of area.

*Table 3. Participant information.*

## **2.3 Service User Consultation**

A number of steps were taken to allow for people who use ID services to consult on the design and development of the study. This can be particularly important for people with ID, to support them to feel like active participants in the research process (Rodgers, 1999).

### **2.3.1 During the Project Design**

An Expert-by-Experience, employed by the team, was consulted on the appropriateness of the questions and the language used, and adaptations were made accordingly.

A number of information sheets were created for the project, in an Easy-Read format. I arranged a consultation with members of a social club, based at an ID charity which I had worked in prior to training. Feedback from eight people on the wording and visual presentation of information sheets was sought, and a number of amendments were made to make the information clearer and more understandable.

### **2.3.2 Dissemination**

The dissemination of results is particularly important in ID research, for participants to gain a sense of ownership over the work to which they have contributed (Gilbert, 2004). To this end, all participants were asked if they would like to be contacted in the autumn 2017; all agreed. I am creating an easy-read report of the results to share with those who inform me they would like to meet after the project ends. The local Trust ID services would like to present the findings of the study at a mini-conference for local care providers, commissioners, service users and other key stakeholders. Where possible, and with consent, I would like to invite participants to support the presentation of the study findings at this conference.

I am currently working with my supervisors and other local clinicians to feedback the results to the local Transforming Care team; to NHS England; to the local community ID mental health team. I am liaising with staff at the University as to whether there could be some relevant teaching for the BSc Learning Disability Nursing programme. Results from the study were shared as a poster presentation for a NHS research showcase at the University in April 2017 (see Appendix M).

## **2.4 Ethical Considerations**

### **2.4.1 Ethical Approval**

The research projected was granted ethical approval by the NHS Research Ethics Committee on 6<sup>th</sup> June 2016, and the NHS Health Research Authority on 12<sup>th</sup> August 2016 (IRAS no: 200695, REC reference: 16/LO/0816). See Appendix N for NRec confirmation letter and Appendix O for full sponsorship letter from the University. It was subsequently granted approval from the University of Hertfordshire (protocol number: LMS/PGR/NHS/02316). As interviews took place in people's homes, local Trust lone working policies were adhered to throughout.

### **2.4.2 Issues of Consent**

Ensuring that participants are fully informed of what it means to take part in the research process and that they are able to consent may be a more complex process in research with people with ID; as such a number of strategies to assess consent were introduced. A Record of Assessing Consent sheet was created, based on suggestions from a paper by Cameron & Murphy (2007), with permission (see Appendix P). This assessed verbal and non-verbal indications of consent (e.g. eye contact, positive comments about participation) as well as non-consent (e.g. turning away, acquiescence without obvious understanding). Feedback was sought from anyone else present at this meeting (e.g. a support worker) regarding whether they felt the person understood the information well enough to consent (Cameron & Murphy, 2007). Participants and KSPs were invited to sign one of two consent forms (Appendix Q and R).

The information about the study was presented a week before the first interview, to allow participants time to think about whether to consent, and to discuss their participation with others if they wished. Assessment of consent was undertaken at the first initial meeting, and again at the time of the first interview. All participants gave informed consent to take part.



*Though I felt reassured by these measures, I reflected on the power I held in my role as researcher, especially as a white, middle class professional. I could not ignore who I possibly represented for the participants, who had undoubtedly had people in influential positions like me make significant decisions over the ways that they could live their lives. At times I noted how easily I (as 'professional') and some of the participants fell into a familiar and well-worn power dynamic. Despite the assertions in my opening spiel, how much did people really feel in a position to say no?*

### **2.4.3 Maintaining Confidentiality**

An encrypted audio recorder and laptop were used, so that data could not be stored outside of these two devices. All transcription documents were password protected, and identifiable information was altered or anonymised. All data was kept confidential, and used in line with the Data Protection Act (UK Government, 1998).

### **2.4.4 Participant Wellbeing**

One main risk was identified: that participants could become distressed in being asked about difficult past experiences, while in hospital or during the move. To manage this risk, a personalised plan was developed ahead of each interview (Cambridge & Forrester-Jones 2003). This included signs that the person was becoming distressed and the best ways to manage this (see appendix S for example). For one participant, this involved adapting the interview schedule to only ask about how things were at present, as it was felt by their care team that asking questions about hospital could be perceived by the person as an attempt to re-hospitalise them. For another, this meant finishing an interview early when there were various indications of unease such as fidgeting.

Participants were invited to choose the location of the interview in which they would feel most comfortable. They were informed that they could have someone present outside the interview room (for first interview) if they wished. At the initial meeting, participants were offered more detailed information about the types of questions that would be asked, so that they would feel less anxious on the day.

## **2.5 Procedure**

### **2.5.1 Development of Interviews**

The initial questions formed a loose guideline, inspired by examples from Charmaz (2014) on ways to clarify people's personal experiences of transitions (see appendix T). In line with GT methodology, for later participants, the interview schedule was honed to explore areas of the evolving model which were less clear.

### **2.5.2 Interview Procedure**

For the purposes of the present study, the methodology was altered slightly from the original dyadic interview technique proposed by Caldwell (2013; see section 2.1.3.1). In this adaptation, the person with ID and KSP were interviewed as a pair, so the participant had the chance to respond and enrich the interview at the time.

Stage 1: Potential participants were contacted as described above (see 2.2.2).

Stage 2: I arranged to meet with the person with ID for an initial meeting (between 30 - 60 minutes), to allow time for questions, as well as to build up a rapport with the participant (Kirkevold & Bergland, 2007). At this meeting, they were shown the comprehensive information booklet (see appendix J) and invited to ask questions. This was the first opportunity to use the Evaluation of

Consent checklist (see 2.4.2 above). If the person agreed they would like to take part, a date was set for the first interview. At this meeting, and/or through other contact with people who knew the participant well, a personalised interview design was developed – for example, photographs of the hospital were printed and kept ready for the interview, to aid memory. The participant identified someone who could be a KSP, with the aim of allowing people with ID to feel more empowered within the research process (Caldwell, 2013). They were given information to support them in making this decision (see appendix K).

Stage 3: First interview. This was the second opportunity for assessing consent. If the person was deemed able to consent to the project, they were asked to sign a consent form (see appendix Q). They were then interviewed, using adapted approaches as required.

Stage 4: Second interview. This took place with the participant and the KSP, around one week after the first (this ranged from five days to 12 days, though for two participants they happened on the same day due to a specific request). The participant was first invited to add anything that they felt they had missed out in the previous interview. The initial methodology was for the KSP to be interviewed fully (for around 45 minutes) while the participant listened; the participant was then invited at the end to comment on what they had heard, agreeing or making amendments, to add further layers of richness to the data. However, after two interviews conducted in this way (Pamela and Jason) I felt that not being able to speak for a long period of time about their story seemed to be difficult for participants. This was both in terms of the cognitive demands of keeping so much information in mind for their reflection at the end, as well as feeling that I had silenced them through allowing only the KSP to talk. As such, in subsequent interviews, participants' views on the KSP's responses were sought much more frequently, throughout the KSP's interview and again at the

end. The KSP was asked similar questions to those asked of the participant, with an effort to clarify or develop key points.

*During the interview process, I reflected constantly on how this methodological device was being used by the participating Key Support People. It was used in different ways by different people. For a few people, it was necessary initially to prompt and remind them to use the first person. I wondered whether this indicated that they were mainly responding from their own memories of the transition, and were in fact using the first person to placate my request, rather than because they had truly 'stepped into the participants' shoes' as I had hoped.. There was the odd moment when it seemed to be a struggle for the KSP to connect with the participant's experience, For example, one support worker described the participant's hopes for the future as 'I want to get a job.' I wondered whether this came more from a discourse within society, or the service expectations, of 'typical' goals, rather than something the participant may be able to do, or even wanted! It felt perhaps he was responding how he thought the participant 'should' feel, rather than really trying to feel how the participant felt.*

*Nevertheless, I was struck by how the majority of KSPs seemed to manage to use it successfully, in a way that added richness to participants' stories. Some found it easier than others – a mother replied that it was easy "as I have been speaking for him his whole life" as an advocate. Another KSP, a participant's father, reflected at the end "I see why you asked me to answer like that, as answering as him made me think more about how he saw things, not how I did." One KSP reflected at the end that she had found it an emotional experience, to discuss the participant's distress 'as if' it was her own. For others it seemed more difficult at times; during a different interview, a Social Worker looked at the (relatively less verbally-able) participant, as if trying to see into his mind, and say thoughtfully "I don't know what you felt" in answer to my question. The time and space she*

*allowed to think through the eventual response she gave indicated to me that she was truly trying to tap into her internalised version of the participant, to really think through what he had experienced during the move.*

### **2.5.3 Data Analysis**

The data was analysed using a constructivist framework to GT (Charmaz, 2014). The computer software QSR NVivo 11 for Windows was used to store and process interview data.

Interviews for the first three participants were analysed using initial coding; namely, coding the data line by line to explore the underlying processes in the experiences being described. In this way, “implicit meanings and actions grow visible” (p. p.116, Charmaz, 2014) as the researcher tries “to understand participants’ views and actions from their perspectives” (p. 115, Charmaz, 2014). Codes were chosen that seemed to explain the experience from the person’s point of view. Initial coding was a challenging and lengthy process, of selecting codes which seemed to ‘fit closely’ with the data, yet also added an analytic eye to understanding and conceptualising the underlying processes. Over time and with supervision, I honed my skills at this – for example, one piece of text that had been initially coded as ‘doors being locked’ did not quite encapsulate how this was experienced, and was therefore changed to ‘being locked in’. This felt like it was an inherently constructionist process. I came to the data from an epistemological position where I felt multiple realities, constructed by language, co-exist. I could therefore not assume that a chosen code objectively described someone’s experience, but was rather a co-construction through the lenses which I also saw the world.

*The use of a constructionist GT fitted very well with my epistemological position. For me, I could not see myself as separate from my data. The process of coding, sifting and analysing the data*

*reminded me how much my experiences became a lens through which I saw what was being said. I paid attention to Elliot's (2007) advice on "stomach coding: When you read your data, pay attention to how it feels in your gut... when you make a new category or code a piece of data into a new category, make sure your stomach agrees with it." In this way, the analysis was inevitably shaped by me, and my gut!*

Following initial coding, focussed codes were used to analyse subsequent interviews. Focussed codes were generated by grouping initial codes which seemed to be most frequent or salient within the data sources. Similar (or contrasting) experiences which seemed to be speaking about a larger concept were grouped together. This accelerated the analytic process. However, I took care not to hold these nascent focussed codes too tightly; initial codes were shifted around to fit somewhere more appropriate, and initial focussed codes were honed to make sense of conflicting information which seemed not to fit under the original conceptualisation. For example, one participant spoke of eating curry for the first time in her new home, given the initial code of 'trying new things now'. This was initially grouped under a fledging focussed code of 'moving on'. However, as analysis went on, the idea of 'moving on' did not seem to fit the data. There was no point at which the transition was 'finished' to then allow someone to move on from it! Therefore the code, and data from where it came, were revisited. 'Trying new things' was therefore moved alongside other bits of data which were coded things like 'doing what I want' and 'gaining sense of ownership'; these eventually were grouped under the category 'adapting to a new life' (see Results for more details). Appendix U contains examples of other focussed codes and their subsidiary initial codes.

The data from participants and from KSPs were both used in the analysis. Supervision and the reflective diary were used throughout the process of analysis to ensure that participants with ID's voices were weighted accordingly so that their own stories made up the majority of the model. To this end, wherever possible direct accounts from participants was given precedence in the analytic

procedure, as this was thought to more directly reflect the experiences of people with ID. Where KSP accounts were used, these were cross-referenced with what participants had said, as well as whether the participant had agreed during the interview with the narrative given by the KSP.

During this part of the analysis, earlier data sources were revisited to ensure that the newly constructed codes made sense of all experiences, the process of 'constant comparison' described by Charmaz (2014). Memoing was also used to help me make sense of how I thought the data and codes were fitting together (Charmaz, 2014; see Appendix V for an example of memoing that supported the development of concepts around changes in identity, and an attempt to synthesise the participants' data into a first person account, to move the analysis forward).

At this stage, nVivo was used to sort the codes; furthermore many pen and paper drawings of different formulations of the process were also mapped out, to begin to understand the relationships between concepts, as well as to try and find mappings which 'best fit' the data (Charmaz, 2014; see examples of early mapping in Appendix W). Of note, the first full model developed partway through analysis was significantly different to the final model; this is presented in Appendix X alongside a critique.

Theoretical sampling is a further GT technique for use when a model is starting to be constructed from the data, to support the development of categories which are not yet fully understood (Charmaz, 2014). At this stage of the analysis, I was beginning to develop categories and see how they could fit into concepts. However, some ideas remained somewhat 'thin' (Charmaz, 2014), indicating there was still more to be understood about them. Specifically, the experiences of waiting to transition had been spoken about by a number of participants, and coded accordingly, but I felt the model would benefit more from gathering further data specifically on this transition phase.

Therefore, theoretical sampling was used to identify a further participant who was currently in hospital, waiting for the transition to take place, Darling. Darling had previously had a transition under Transforming Care, but this had not been successful, and she had been re-admitted to hospital at the time of our interview. She was therefore well placed to contribute data which helped me to fill out some of the under-developed categories in the evolving model.

Throughout the analysis, I met with three other trainee Clinical Psychologists using the method GT data for a number of workshops. We met before data had been collected, through analysis, to the stage of constructing and refining models. This was invaluable in talking through the data and themes, and checking whether codes and categories seemed to make sense. The 'emerging' model was also talked through with my supervisors on a number of occasions. These discussions allowed me to shift and develop the model to be as representative as possible of the data.

As the model developed towards the form presented in this report, I arranged an interview with Dave and his father Peter. Prior to this interview, I emailed the model and a summary to Peter for him to read through. He agreed that the model broadly seemed to fit Dave's experience. We used the interview to discuss the model in line with Dave's own transition journey.

The subsequent chapter will explore the results of the GT analysis.



### 3. Results

This chapter aims to present the GT analysis. Figure 1 depicts the model constructed from the data.

The model is proposed to be an 'adaptation to transition' model (c.f. Schlossberg, 1981; see Discussion chapter for further details). It demonstrates the participants' journey through the notable changes that accompany transitioning out of hospital.

The model depicts first a circular loop, representing the concept 'A Restricted Story'. This captures the time the person was in hospital, and how they made sense of themselves in that setting. Breaking out of this loop is the second concept, 'Going through the Transition'. This encapsulates how people had the opportunity to move to the community through the Transforming Care programme, and the processes that they went through while the transition took place. The final concept is 'A Widening Story'; this is another looped process but one which widens out - to allow for new ways of the person seeing themselves, new skills to be learned, and new ways to be treated by others. These concepts will be explained in more detail below, with illustrative quotations.

*While writing this results section, I tried to keep in mind the words of one participant, TJ: "I think, I think it's so hard for people to judge or to explain, what it is like in hospital, without experiencing it. You need to experience it, to then know what it's like." By bringing together peoples' voices and experiences in the analysis, I acknowledge the power that I hold as a non-disabled researcher. In my lifetime and potential future career, I am much more likely to be the professional in peoples' stories than ever have to go through something like the participants here did. I bring my lens of a*

*white, middle-class female trainee clinical psychologist to the understanding of the data. I hope to do justice to the words that have been generously shared with me to co-construct something with the participants to make sense of their experiences.*

Figure 1: Grounded Theory 'adapti  
model of participants' experience o  
hospital.

### **3.1 A Restricted Story**

Oliver: Because I've been stuck in hospital a very, very long time.

The concept 'a restricted story' captures the person's experiences while in hospital. It contains a circular process: how the treatment from others ('feeling unsafe and controlled') impacted on how the person made sense of their own identity ('internalising a restricted identity'). The name of the concept aims to emphasise that the person's story was sometimes limited by the environment in which they found themselves. People sometimes expressed their feelings about being in hospital in ways that were then seen as a reason to justify the restricted environment, in a loop that was hard to interrupt. Some participants also discussed a continued sense of threat that they could be readmitted to hospital in the future. Importantly, the concept also covers exceptions to this stuck story. This section will explore this concept in more detail, and then go on to say how it links to the following concept of 'going through the transition.'

#### **3.1.1 Feeling Unsafe and Controlled by Others**

This category covers how participants felt in relation to other key people in the hospital system. It is comprised of two sub-categories: 'feeling unsafe' and 'feeling controlled' which will both be explored in more detail below.

**3.1.1.1 Feeling unsafe.** People described instances of being abused, threatened or vulnerable, in hospital environments which could be scary or chaotic. This was from both other patients, and at times from staff.

Fred, describing an incident with another patient:

My glasses were broken, my head was smashed. All my face was smashed up. I was all punched and my face was all kicked in. I was bleeding to death and... so every time he comes nearer, I had to run to my bedroom. And stay in there. I was so frightened then.

Pamela, describing running away while on holiday many years ago:

And they found me. And they gave me an injection to make me sleep. And I couldn't go out the next day. And the sister who did it got into trouble. Because she shouldn't have done it because I wasn't written up for it. I wasn't written up for the injection.

When restrictive behaviours had been used by staff members, people were left worried that this could happen again, even a long time after the event. This implied to me the damaging nature of such behaviour when enacted by people in a 'caring' role; and furthermore the amount of power that staff held relative to the people with ID.

Interviewer: Do the staff here treat you differently to the staff in hospital?

Oliver: (Nodding emphatically) Yeah they do. They don't, they don't shout at you. And they don't push you about. And they don't threaten you or anything like that.

Interviewer: And you've previously had experience of that?

Oliver: Yeah. And I don't want that to happen again.

People could also become unsafe through modelling adaptive behaviours from others in hospital, which then left them vulnerable to being treated in more restrictive ways. For example:

Elvis' Dad: He also learnt a lot of bad stuff while he was in there. Not because he wanted to, but because he had to compete with the people in there. He had to become like them to

survive. Things that he never did before. Be more aggressive towards staff. Shout. Fight. Throw things about. All stuff what the other ones did. But because he was in that environment for so long it became normal.

Elvis' Mum indicated how much this seemed to be a change to who Elvis was as a person, which indicates how 'feeling unsafe' links to ideas about how identities could change depending on the environment:

Elvis; Mum, Betty: He thought if he copied them, he'd be alright. If he was himself, he wouldn't be.

**3.1.1.2 Feeling controlled.** Participants described often having less control over their daily lives in hospital, from having to adhere to strict routines, to not being allowed to make decisions about meals or trips out. As Jason said, in hospital there were "certain rules that you can't do there." Several people talked about how it felt being 'locked up' or 'locked in':

Oliver: You can get claustrophobic, being locked up, in one certain place at the same time. And it can, it can make you very anxious, and upset. When you're stuck in, 24 hours a day, in a hospital.

Darling further described how feeling controlled by staff impacted on her mood:

Darling: [In previous hospital placement] I just weren't coping. I just crying, depressed, sleeping. And, just weren't coping.

Interviewer: What was making you cry there?

Darling: I just didn't like it, the staff were rude. The staff weren't very nice to me.

Interviewer: What did the staff do that made you feel you weren't getting on with them?

Darling: They used to hurt me when they were showering me. They wouldn't let me shower on my own. And I told them I could do it myself, since I've come here they've let me do it all myself.

Patsy, during the interview with TJ, described the circular pattern of behaviours and consequences which could lead to a restricted story:

I think there's a lot of people who are not able to articulate [their frustration with being in hospital]. And then they do something that they-, their behaviours become challenging, they jeopardise that, and then the doctor says "oh, they can't go, cos look what they did last week".

Darling's KSP, a nurse on the unit, discussed understanding how Darling felt on the ward:

I do get the frustration Darling has with the whole situation. It's not easy for her. It's just sort of a day to day, sort of a waiting game. I know that's frustrating. Because she's so able. But, you know, these are the rules and we all have to abide by them, while we're here really. [To Darling] We don't make the rules Darling, we just have to-, we're told these are the rules. That's why we try and be a bit flexible where we know it's an ok thing for you to control.

These descriptions of life in hospital at the time of interview indicated staff members could be very understanding of the restrictions that are put on people, and aware these could feel controlling. However, in this example the rules are described as something integral to 'the system' rather than

something that people could influence. It may be that at times staff also felt relatively powerless when working in these settings.

Being in a hospital environment could be physically restrictive, when people were not allowed to leave, and were restrained if they tried. The use of medication was noted by some participants as something that was 'controlling'.

Peter, Dave's Dad, describing the first hospital Dave had been admitted to hospital:

It was horrible. I couldn't..... It was probably about the most upsetting part of Dave's whole life really. He'd been sectioned. And you just have no control over anything. And they filled him with all these drugs. So he was all dopey, his siblings came to see him and they were in tears. They couldn't believe that he was in such a state. Cos he was all sort of dopey, you know. At that point he wasn't, he was completely...You know, it was dreadful, I just can't imagine how, how.... Cos he'd been perfectly alright, you know, he was perfectly alright before he went in. and he came out-, it was just terrible.

Pamela: Yeah. Like if you do anything wrong . Like try and get out. ... they'd used to press the alarm, and then you'd get the staff from all over the ward coming in. And then they used to pin you down, and then they used to give you an injection to keep you quiet.

Within this description, I noted a narrative of behaving in ways that were 'wrong', which spoke of dominant discourses in hospital of ways that you should, and should not, behave. The subsequent sub-category goes on to explore instances when this sense of 'wrongness' seemed to have been taken a step further, and internalised by some of the participants.



### 3.1.2. “You’ll get out. If you’re good. If you’re bad – forget it”: Internalising a Restricted Identity

Some participants seemed to have conflated how they acted with who they were as a person. It seemed to me that, at times, people built an identity from both how they perceived themselves, and from the stories they heard about themselves from others:

Interviewer: What sort of person were you when you lived in the unit?

Larry: Terrible (laughing)

Interviewer: Why was that?

Larry: Naughty man.

Interviewer: What did you do? (pause) What happened?

Larry: Things wrong.

Interviewer: What advice would you give another person if they were going into hospital, like you?

Oliver: Behave yourself. And do the treatment. And you’ll get out. If you’re good. If you’re bad – forget it.

The way that Oliver talked about ‘being’ bad, rather than ‘doing bad things’, indicated to me the ways that he had internalised a sense of self from the behaviours that he used.

*This is a difficult area to think about- as on the one hand I feel so sad for these people, who believe things about themselves in such a labelled way. However, when people have transgressed the law (e.g. sex offenses, arson) like some of these participants, the labelling happens at a wider societal level (not just from a staff team), and importantly exists for reasons of safety of themselves and*

*others. But no matter what people have done, I can't help but reflect on how infantilising the words 'naughty' or 'bad' are for grown men to use about themselves. As Burr (1995) writes, "if language is indeed the place where identities are built, maintained and challenged, then this also means that language is the crucible of change, both personal and social" (p. 43). It made me think about how important language is for people to begin building and maintaining alternative identities.*

For some, the 'problem focused story' they had in hospital seemed to limit a sense of who they were beyond the difficulties that had been through in the past:

Interviewer: And how did [new staff when you transitioned] get to know you, did they ask you questions about you and your life? Did they hang out with you?

Fred: They have to check all the paperwork, and make sure any risks and things. They have to check all the paperwork you see.

This suggested to me that Fred saw himself first and foremost as a 'risk case,' behind which his sense of himself as a person had diminished. Larry's manager, speaking as him, gave a further striking example of an identity lost behind behaviour:

In the meetings that I had, over the years, it was always: Larry, why did you do this? Larry, why did you do that? What made you do this Larry? Nobody sort of said: how are you Larry? Who are you Larry? ... I think who I was as a person got forgotten, it was this behaviour that was the main factor that, that drove everything that happened in my life.

There was a sense from some people that showing your real emotions might not be tolerated, and you had to put on a front for those around you. This could have been learnt from past experiences

of showing a distressed emotion that was then reacted to negatively by others. The description below from Benny's social worker Patsy, speaking as him, gave a vivid picture of the 'handicapped smile' that Sinason (2010)<sup>4</sup> formulated in her work:

Patsy: I've also lost-, I used to have this smile that was [mimes big grin baring all teeth]. And I don't do that as much anymore. It used to-, it's like a "yeah I'm fine, everything's fine." Like a fake, wasn't it. Erm, and that's gone now.

Interviewer: Why do you think you had that smile?

Patsy: People would ask me if I'm ok, so I'd smile. Because, that's a yes.... It was a communication 'yeah I'm fine,' but really...

Interviewer: Was there a feeling that if you were honest and said, 'no I'm not ok', that wouldn't have been acceptable?

Patsy: Yeah.... I think there were times that I was not ok, and everyone would know it. But there were other times that I wasn't ok but I was managing it the best I could. And that's when you'd see the smiling.

### **3.1.3 "If you step out of line, you're probably going back to prison and they throw the key away": Living with a Sense of Threat**

This category represents the possible loop that links back from a widening story to a restricted story. Although not discussed by all participants, for some there seemed to be a very strong theme of a continued sense of threat that they could be sent back to hospital. Noticeably, those who described 'being let down' or who had transitions which were unplanned seemed to report more

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<sup>4</sup> Sinason (2010) postulated that non-disabled others find it distressing to face the truth of disability, and therefore need to see the disabled person as 'happy' to defend against this. Terming this the 'handicapped smile', she explained "someone with mental or physical pain has less reason to smile or feel happy than the rest of the population, yet there is a tremendous pressure to insist on signs of pleasure precisely because of that" (p.119, Sinason 2010).

worries about readmission. These participants described having to behave 'well' otherwise there could be serious repercussions about their placement. Fred described: "say for instance I go off somewhere, if I be a bit naughty, then they have to call the on-call person, or the old bill." Again, use of the term 'naughty' highlighted the way that behaviour seems to have been polarised into 'good' or 'bad' for some participants. He later went on to say:

If anything goes wrong, if you step out of line, you're probably going back to prison and they throw the key away.

In a similar vein, Elvis' Mum, described the sense of fragility of the placement in his mind, even with reassurances to the contrary:

Betty speaking as Elvis: I'd try and be as good as possible. When I first moved in. I thought 'if I'm on my best behaviour they won't drag me out of here and put me back in the clinic'. And nobody said to me "you're going back". They kept reassuring me that 'this is my house'. But I still have my doubts. If I get angry or upset.... Because at any time it could be snatched away from me.

The emotive language used in the two quotes above, such as 'throw away the key' and 'drag me out of here' indicated to me the strength of peoples' fears about things going wrong in the present placement. A jokey interaction between Jason and his support worker also hinted at Jason's worries about possible outcomes in the community.

Jason: Well, you're fired. (laughter)

Ayo: Ah you'll be supporting yourself!

Jason: I don't mind!

Ayo: Oh! (several seconds of laughter)

Jason: Well, I do mind really. I don't like the – you-know-who. Look, if I fired Ayo, right, the police might come. The you-know-who might come.

For some, if not all, participants the 'threat' of going back to hospital was a real one. Specialist hospitals have a place in the assessment and treatment of mental health and behavioural difficulties that cannot be managed in the community, and the Transforming Care programme is clear about the use of such hospitals when needed and appropriate (Department of Health, 2012a). It is therefore not unreasonable for people to have these concerns. However, at times it seemed that this sense of threat could be (perhaps unwittingly) used by those in more powerful positions as a way of controlling behaviour, as this excerpt from Fred indicates:

Interviewer: What advice would you give someone else who was going to move out of hospital, like you did?

Fred: Be nice, I been told, be nice to the staff.

Interviewer: Why is that?

Fred: Cos if you be nasty to them, you'll be kicked out. So I been told by [social worker] and Mum to be nice to 'em.....If I do anything wrong. That's what [social worker]'s saying as well, maybe I'll go back to prison.

Interviewer: And how does that make you feel?

Fred: Quite sad. I been in prison before.

Additionally, it seemed that many participants discussed how they felt very used to getting let down. As well as the reality of a re-admission, experiences of being let down in the past also

seemed to be linked to how they managed this sense of threat. There were a number of stories of people feeling let down in past, both on smaller day-to-day levels, and also on a more major scale:

Patsy, speaking as Benny: [Now in the community] When I'm told I'm going out, nine times out of ten I do. Whereas in the hospital, something would happen, I would put my coat on then we wouldn't be able to go out because somebody else was upset.

TJ: It took a long time [to move on from first hospital placement]. A lot longer than what I was told. I was told I'd be in [secure unit] for three months.

Interviewer: How long were you there?

TJ: Two and a half years.

In summary, many participants discussed instances in the past where they had felt let down by the people who were looking after them, those in more powerful positions. Combined with the reality that people could be re-admitted to hospital, there seemed to be a clear sense of threat that many participants lived with.

#### **3.1.4 “Staff were amazing”: Other stories of life in hospital**

Notably, participants also talked about the positive care they received from staff. For some, despite the restrictive setting, they found that other people were universally supportive; for example, TJ described that in one hospital he was in:

Staff were amazing. You know, they, they're easy to approach. They're really talkative, you can, have a joke with them. Have a laugh with 'em.

Other participants noted a mixture of supportive and less supportive relationships with the staff teams. For example, Larry spoke about not getting on with certain members of staff, for example one nurse who he stated used to say to him “you’re going to get yourself into trouble, Larry. If you keep going on like that”. However, he described a different type of relationship with another nurse:

He was a very good bloke. When we didn’t go out, he came in my room and whispered, he said ‘it’s not right for you lot not to go out’. He said, ‘it’s not right, to do that to people’. I used to get on with him very well.

I wondered whether it was important for participants to hear stories such as these, which were alternatives to focusing on their problems. If there were, at times, dominant discourses about ‘getting into trouble’, the fact that there were also staff who had different perspectives may have supported people in moving on from ‘a restricted story’. This is represented in the model by a dashed line, from ‘exceptions and alternatives’ to ‘being given a chance.’ The next section will build on this idea further, by examining how it was that people were ‘given a chance’ and beyond.

*This category was added into the model slightly later on. Initially, the time the person spent in hospital was captured only by the circular stuck loop between themselves and others. As I began writing about this, I began to get a growing sense of unease about the narrowness of this explanation. I had been acutely attuned to stories of abusive or overpowering behaviour at the hands of the staff, and wanted to make sure these narratives were heard. However, it slowly dawned on me that by reifying these stories above others, I was actually doing my participants a significant disservice. By demonstrating how powerful others were in their stories in hospital, I realised I might be positioning those with ID as powerless victims. I went back to the data and found codes which related to alternative non-victim positions, and realised these had not been*

accounted for in the model. I hope that the amended model now does more justice to a broader range of perspectives; the experience has again made me truly mindful of just how powerful I can also be as a researcher.

### 3.2. Going through Transition

The concept of 'going through transition' captures how it was that participants moved from a 'restricted story', in hospital, to a place where a wider story could begin developing for them. To begin making the moving process, participants had to first be 'given a chance' at exploring life outside of hospital.

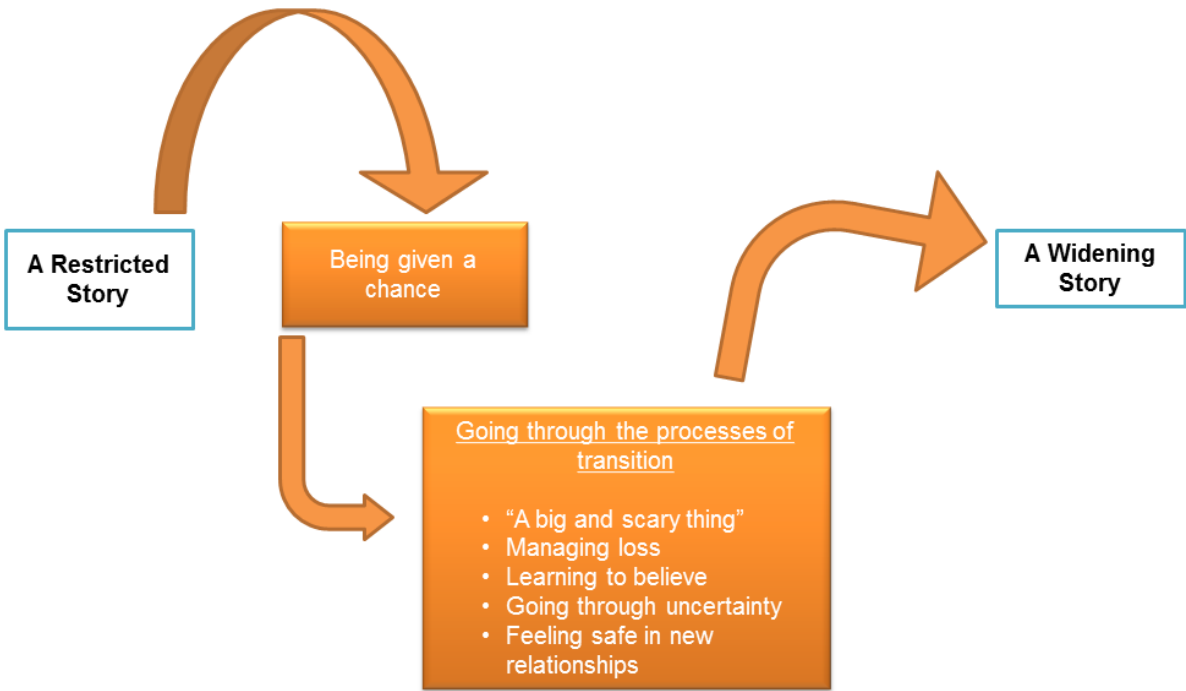


Figure 2: A close-up of the 'going through transitions' concept.



### 3.2.1. Being Given a Chance

People spoke of there being progress through the systems they found themselves in, from more to less restrictive settings. For some people, perhaps progress may have happened anyway:

Fred: “Then I went into the hospital into I think it was (lists different wards moved to within hospital complex). Then upstairs to X Ward. Downstairs, you have a kitchen, They cook the food for you. But upstairs you cook your own meals, for everyone.”

However, for others, Transforming Care seemed to be the key and only factor in being given an opportunity to break out from the cycle in hospital:

Patsy, speaking as Benny: I don't think, until [Transforming Care social worker] came along, that a move was ever talked about... So before that was just staying there. It was where I was living, and that was that.

Oliver: I've been given a chance. To prove myself. And I've proved it. So... That means I stay here. And get on with my life (laughs).

*The way Oliver described his experience spoke to me of having to 'earn' one's place in the community, by proving oneself. This made me think about how it could perhaps feel like a privilege, rather than a right. For him, this seemed to have worked out and he was doing well in the community; but it also reminded me of the powerless position which this category puts people into, always being the passive recipients of 'a chance'.*

There were instances when some participants were acknowledged by others to be ready to move, or they thought themselves ready for discharge. However, they could have difficulties in moving when there was not sufficient community placements locally, or there were complications due to the complex needs of the client. These could result in the person remaining 'stuck' in hospital. Fred's mother, speaking as Fred, explained:

But it took a long time, and I got very frustrated. Cos I was keen to move. But the forensic psychiatrist in [town] thought I was too big a risk. And was not keen to take me on.

Darling described that while in hospital at the moment:

I get very irritable. Cos I know that I shouldn't be in hospital. I'm not unwell, you know. I know when I'm unwell. But, I told the doctor that, I'm not unwell. I'm fine.

Once given a chance, participants could then begin the process of going through the move, and learning what would happen outside of hospital. These ideas will be explored in the subsequent section.

### **3.2.2. Going through the Processes of Transition**

When a move out of hospital had been proposed, and decided on, this allowed for people to begin going through a number of processes which made up the transition. This category comprises five sub-categories: 'learning to believe'; 'a big and scary thing'; 'managing loss'; 'going through uncertainty' and 'feeling safe in new relationships.'

**3.2.2.1. Learning to believe.** All participants mentioned that at points through the process, they found it hard to believe or imagine living in the community. Some participants talked about previously never thinking that they would live anywhere but in a hospital setting:

Interviewer: When did you believe that you would get out of hospital?

Oliver: Never.

For others, when it was first discussed with them, they did not believe it at all:

Ayo, speaking as Jason: I was thinking that maybe – it's a... it's joke. You see?

Interviewer: You didn't believe it?

Ayo: No, no I did not believe it, I was taking it as a joke.

Interviewer [to Jason]: So you didn't believe that you were going to move out?

[Jason shakes head].

When participants had to wait a long time for the move to happen, this often made them begin to have doubts about whether it would ever really go ahead:

Interviewer: What was it like waiting for over a year to move?

Patsy, speaking as Clive: Er, I think I thought it was never going to happen. People kept talking about it but nothing was gonna happen.

For some participants, it was very complex to understand what was going to happen in the future. Speaking as Benny, his social worker Patsy described being "confused" by the wait. She expanded to explain, as Benny, what helped:

Talking to people, going through my pictures. And having regular contact with somebody. Going over what we did. So saying, “do you remember going to see that place?” And I had photos of some of the staff.

This indicated that having tangible evidence of the move was helpful in reminding people that the move was going ahead. Building on this, other participants needed solid proof that it was real for example seeing the house, or having some other form of concrete evidence. For others, the reality only really became clear after they had properly moved in:

Interviewer: And when they told you you were going to move, did you believe them?

Larry: No, not really! Not until I got the letter. And I was off my section.

Interviewer: Did you believe it before you came to see the flat, or once you'd seen the flat?

Oliver: Once I'd seen the flat.

TJ, describing his first morning in the new flat: And then the next day it was- sunk in more, you know. I had a lovely new bed and everything like that. Woke up and it was lovely and quiet. No noise or anything! Got up, and I was just like - I can't believe it.

For some participants, a sense of disbelief remained beyond the transition itself. This then links back to people struggling with a sense that things could go wrong again:

Elvis' Dad Gerry, speaking as Elvis: But first of all, when I first came out the clinic, everything was great. For about 6 months, 8 months. It was great. I'm in me own house. But then after the 6 month period you start to think of: 'is this really mine?' 'It seems too good to be true'.

The lack of belief about moving was quite poignant for some participants. It seemed that for some people, the 'restricted story' had grown large enough to block out the perceived existence of other opportunities that could be available to them.

**3.2.2.2. A big and scary thing.** Although moving out into the community often seemed to be packaged up by staff as a positive move, participants spoke of, at times, feeling a mixture of emotions about the move. Some spoke of their joy at finding out about the move, whereas others had the initial reaction of not wanting to move when it was first suggested:

Fred: I was happy. I was over the moon, and I couldn't put it into words.

Pamela: I didn't want to move any more. Cos I moved so many times.

Participants described holding conflicting views at the same time, or being uncertain. For example, Clive spoke about enjoying things on the ward he was on before moving out, but also being happy to move on:

Interviewer: What was it like [on X ward]?

Clive: Me like it there

Interviewer: Do you remember what it was like when you were told you were moving out?

Clive: Me happy about that.

Interviewer: What was it like when people talked to you about moving out of [hospital]?

Dave's Dad, Peter: (to Dave) Weren't very sure were you?

Dave: Not very sure

Peter: you weren't very sure. You knew where you were at [hospital]. You weren't very sure. You weren't against the idea, you just weren't very sure.

Some people spoke of a sense of guilt about the fact that they were going to transition whereas others were staying in hospital:

Interviewer: Was it tough, telling your friends that you were moving?

Pamela: It was tough yeah. Because some of them have been there a little longer than I have. And it made it feel hard and tough, to tell them that I was leaving

Although the hospital environment may have been restrictive, it may have contributed to beliefs about how much one needed others to rely on, and concerns about one's ability to manage in a different setting:

Fred's Mum Harriet, speaking as Fred: [When I found I was moving] it was mainly exciting. I was really pleased. But I was a bit worried as well. Cos having been to boarding school, and then having been locked up in institutions, then having my own places was a little bit worrying. But I was more excited than worried.

Interviewer: And do you remember what some of those worries were about?

Harriet: Er, how I would cope on my own.

Other people discussed that the prospect of moving was scary or frightening. People did not always know what to expect of life in the new residence, and were particularly concerned about building new relationships.

Oliver: it's hard, but... it's very hard but...you've just got to do it. Coming out of hospital into a flat is a very big, scary thing.

This indicated that a move from hospital could be viewed as the loss of something known and familiar, which was daunting, even scary, for participants to consider. Other aspects of loss are explored in the following sub-category below.

### **3.2.2.3. "I'd like to hear from him one of these days but I don't think I ever will":**

**Managing loss.** A number of losses were mentioned by participants. Some discussed losing touch with old friends from hospital:

Larry: My friend Jerry... he lives in Ireland, I don't, I don't know what part. I haven't heard from him since I left. And, you know. I'd like to hear from him one of these days but I don't think I ever will.

Pamela: When I first moved here, I missed my friends. And I got used to it cos I used to phone them any time, but now they don't bother so I don't bother ringing them and I'm quite happy without them.

I wondered whether Pamela here put up an unconscious front against the sadness of her loss by telling herself how little she missed the old friends. With the number of out-of-area placements in

hospitals, sometimes the reality would be that people would return to distant areas from each other after discharge, adding extra barriers to keeping in touch. When Larry spoke of wanting to hear from his old friend Jerry, it made me mindful of the important role that other key people played in keeping connections going, or not.

Several participants spoke about missing the staff from hospital, having often built up significant relationships. Jason talked about being sad during the transition because “well. I miss all the staff.”

TJ talked about the loss of relationships:

When you live somewhere like in hospital and that, I lived there for three and a half years. You kind of make, them kind of, professional relationships.

People also spoke about missing the hospital in general; or missing a way of life that they had grown accustomed to, often one that was significantly different to living on your own in the community.

Benny: I miss [institution which closed 20 years ago]. I miss it.

Patsy: Oh. Yeah. Do you know what, that was when you were younger, like remembering your childhood, isn't it.

Benny: I miss it!

Patsy: Yeah. It's not there anymore!

Benny: Not there. All gone.



Patsy, speaking as Clive: Even though I couldn't handle the busy environment [on the ward], because I'd get physically tired, I liked that environment. I like lots of things happening, I like engaging and being sociable with people. It's slightly quieter here.

**3.2.2.4. "It's frustrating and upsetting. Cos I want to move": Going through uncertainty.** Having to wait in hospital while the new placement was being sorted was a key factor in many participants' discussions. This was sometimes associated with feelings of stress and anxiety. TJ described waiting to find out if there was a Responsible Clinician (psychiatrist) willing to take over his care in the community as "a bit of a heart miss moment"; and Pamela stated:

I had to wait for quite a while so I got upset a bit and a bit moody.

Dave's Dad Peter, speaking as Dave, described what it was like to have plans to move change at the last moment:

Peter: Well, exceedingly upsetting. I did a lot of shouting. I did a lot of, er, getting very angry. And er, I packed my bags, and marched out. Er, and I had to put them back again. So exceedingly upsetting. I would say that was by far the most upsetting thing.

Darling was in hospital at the time of the interview, hoping her social worker would find her a community placement. When asked how it felt to wait, she stated:

Oh, it's so frustrating! I just, [social worker], she's not telling me anything, and it's just frustrating, [social worker] isn't, and it's frustrating and upsetting. Cos I want to move, I'm ready to be discharged. But six places have turned me down. She keeps saying, 'someone's

coming, someone's coming.' But. They haven't been yet. But I don't hold too much hope.

Some people spoke about how others played a role in supporting them through the times of uncertainty:

Elvis' Mum Betty, speaking as Elvis about waiting to transition from hospital: I had one or two special friends in the clinic, staff. And when they were on [shift], they would take me out for a walk. Or they would sit and talk to me. Or we'd sing and-, we were good friends. So, if it wasn't for them I wouldn't have coped.

The transition process often included going to lots of meetings, with the aim of keeping them involved in the transition planning. For some people this level of involvement was key in them feeling in control of some aspects of the move; whereas others found the meetings difficult.

TJ: I said, the only thing that bothers me, is I wanna be kept in the loop of what's happening.

Ayo, speaking as Jason: I was so tired, I wanted to tell them that I don't want to go there because the meetings is too much. So all the time we're meeting, meeting every Tuesday, meeting every Thursday, they come and they give me a cup of tea – and I don't like it!

Darling: I do [go to the meetings], but I try and, they don't like me to go to them because I get very upset. And I start getting my hopes up, and things don't always happen. It might break, it might break through or summat or. Might, might not go ahead. So, I try not to go to em', if I can, cos it's, they're very upsetting. I know I'd rather wait til [social worker] actually tells me.

The move (and therefore the amount of time waiting) could be held up by factors out of the control of the Transforming Care team; for example housing regulations and landlord restrictions, things going wrong at the new property, or difficulties finding a suitable placement and team that would be suitable for the needs of the person.

Patsy, speaking as Clive: I was due to move, and everybody was talking about the move, then it was delayed. It was delayed because we had some bad floods in the area. I needed a flat with a lift, cos I can't do stairs. So we found a flat with a lift, then the flood damaged the lift. And I then couldn't move. And it then took over a year to get the lift fixed. So lots of talk, and nothing happened for a very very long time.

Where there were challenges, the remit of Transforming Care seemed to mean that extra efforts were made for the transition to take place; when perhaps in the past the circumstances might have been deemed too complex to continue (see Appendix Y for further example).

The lack of local provision to meet participant's choices was a concern for Darling, who was waiting to move at the time of the interview:

They've asked me where I wanna go, I've said [town] or [town], to me social worker. She said if she can't get me there, she'll have to get me further afield again. But I didn't want that, cos that's why the placement in [location out of area] broke down. Because I, I was missing my family, I weren't seeing my family. I got very depressed at times, and very upset. Because, I weren't seeing my family enough

While waiting for the move to happen, for some participants it helped when people could see that those involved were working hard:

TJ: [Social worker] was trying her hardest to try and get everything sorted out. Trying to get people motivated, trying to keep people moving

However, at times it was really hard for people to understand these factors:

Darling, while still in hospital waiting to hear about a new placement: I think [social worker]'s given up on me she has.

In summary, there were a wide range of factors which could influence the move going ahead, and this inevitably involved some element of waiting or not-knowing for participants. Although some people found that staff were able to reassure them about the progress being made, for others the wait was a real challenge and time of stress.

**3.2.2.5. “But once I got to know them I was alright”:** Learning to feel safe in new **relationships**. Being able to have a sense of trust in the new team and their ability to support participants seemed to be key to successful transitions, and had not always happened in previous placements which had broken down.

Elvis' Dad Gerry, as Elvis, describing a previous transition which had not worked out: Yeah that was a last-minute thing. And it would have been better for me if [the new staff team] had kind of like, taken me out a few times to introduce me. But there was none of that cos it was all rush rush. Bish bash done.

Interviewer: What was it like moving that often?

Patsy, speaking as Clive: I hated it.

Clive: Why?

Patsy: Cos I was scared. Because I was worried people wouldn't know how to take care of me? I was worried they wouldn't put my thickener in my food. And I would become ill.

Clive: [to interviewer] Do you know me take thickener in my drink?

Building trust with a new team did not happen immediately, as Elvis's parents stated: "[Trust] has to be earned. It takes a long time to earn it."

Pamela: [When I first moved] I was sort of quiet because I didn't know anybody. But once I got to know them [staff] I was alright.

A key factor for most people in developing their relationships with new staff was how, during the transition process, staff from the new placement would come to spend time with them in hospital. This meant that when they moved, they had already begun forming relationships with their new team.

Fred: "They came down and took me out. They got to know me, with- One staff came from here, but one staff came with me for the time being. To, to, to get used to them first. Then, then second time they, the doctor said it was ok to go with the staff from, the staff from the transition place."

In summary, participants were able to break out of the restrictive story by making progress through the hospital system, and/or being given a chance to move as part of the Transforming Care programme. After a transition had been agreed, people went through a process of believing that the move would really happen, which was helped by concrete evidence and consistency from staff; though the experience of waiting and uncertainty was challenging for them. Participants experienced a range of emotions about the move, with fear and guilt appearing alongside happiness. People also went through managing the loss of familiar people or ways of life from the hospital setting; and they also went through having to build new trusting relationships with new teams. The final part of the model will be explored further below.

### **3.4. A Widening Story**

The concept 'a Widening Story' describes peoples' lives since Transforming Care became involved in their lives, and since transitioning out of hospital. The process of 'a widening story' began for some participants as soon as they knew they would be moving out; this awareness that others thought they should no longer be in hospital allowed their stories to start to shift. The widening story then continued once the move had taken place.

There are three categories which make up the concept: 'being considered differently by others'; 'changing ideas about who I am'; and 'adapting to a new life'. A close-up of this section of the model is displayed in figure 3. The circular nature of this process indicates how important relationships are in the development of new ideas about the self, and new ways of being. It indicates that 'how others see and treat me' impacts on the development of 'a different sense of self'; identity appears to be socially and internally constructed from the things people are told and the beliefs that they then come to hold about themselves. This changing self-image in turn impacts on the treatment received by others in a recursive pattern. Furthermore, the model indicates that

being seen in a new light can facilitate the processes needed to ‘adapt to a new life’ outside of hospital; this in turn again impacts on how they are seen and treated by others. This section of the report will describe this concept in more detail.

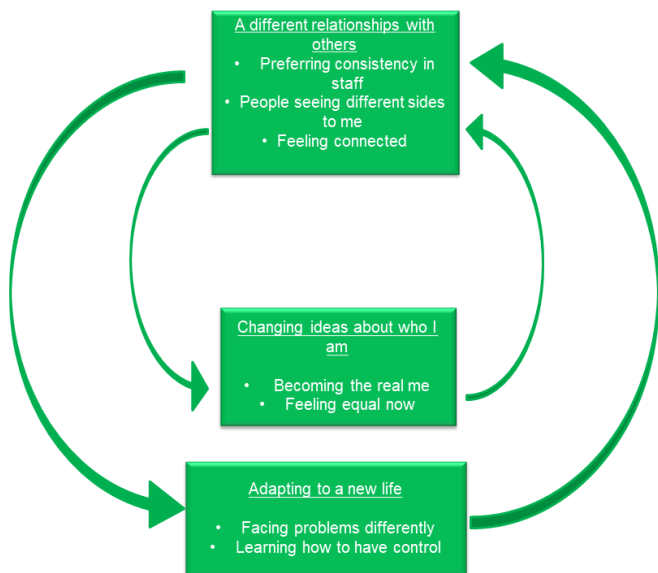


Figure 3. A close-up of ‘a widening story’ concept.

### 3.4.1 Being Considered Differently by Others

This category sums up the role that other people play in how participants managed after moving out of hospital. Within the idea of a ‘widening story’, for many participants there appeared to be a shift in how they were seen and treated now, with a different understanding to their behaviours and a wider understanding of them as a person. It also encompasses what people need from their relationships to allow for this growth; namely a sense of security and safety. It consists of two subcategories: ‘how others see me’ and ‘needing others to be reliable’ which will be explored below.

**3.4.1.1 “But they all keep coming and going you see. I wasn’t very happy”:** Preferring consistency in staff team. This sub-category captures how important is was for people to feel

that they could rely on a new staff team. Participants expressed a clear preference for staff they knew well, and who they felt knew them well.

Pamela: [Staff members] might go into another house [managed by the care company to support a different client]. But I told 'em they couldn't have [name] and [name]. Cos they were my own staff. Because it upsets me if they move. And I get somebody else. Who I don't really know much.

Times where there had been inconsistencies in staff teams had been challenging for people.

Fred: We've had so many managers come and go you see, come and go. We had Chris. The manager. We had somebody else. Dave and somebody else. But they all keep coming and going you see.

I: How's that when people keep coming and going, how does that make you feel?

F: Errrrm it wasn't very, I wasn't very happy. I bought him a card, I gave it to him, I said I'm going to miss you like a hole in the head! (laughs) I said I'm going to miss you Dave, I said you're a nice bloke to work with Dave.

However being known to a stable staff team seemed to make people feel safer. This allowed for not only consistency of the staff around them, but also a consistency in the approaches used.

Patsy, speaking as Benny: [Here, in the community] Staff know me, they know how to work with me, they know what to say to me, they know when to leave me alone, they know.... Er what my triggers are, what upsets me. And how, when I'm upset, how to pull me out of it.



And I think that on X ward, although it was written down, people tried to do ad hoc type of things really. Which made me feel unsafe. And they were new all the time, high turnover of staff.

When people felt less secure in their relationships, they could sometimes test the boundaries of the relationship:

Elvis' Dad Gerry, speaking as Elvis: And also, I do tend to test people. I do tend to test people to see what I can get away with.

Jason's support worker, speaking as Jason: Sometimes (laughs) I'll be trying to kick off, but they still stay with me. So I'll be thinking that 'oh, this is the kind of people I'm going to work with, this is the kind of people I'm going to live with.'

People seemed to want to know that they would receive support irrespective of their behaviour; perhaps trying out whether they could trust others to provide the unconditional support required for a sense of safety in their relationships. Participants spoke of wanting an understanding that they would have times that were more challenging, but to know that people would stay with them through these times, rather than reject them:

Elvis' Dad Gerry, speaking as Elvis: Obviously I have my bad days. And they're always gonna stay with me. But when people understand my bad days. And they compensate. And they know how to treat me well when I'm having a bad day. I find it much easier to come out of that bad place. Than if I'm just ignored, or shut in a room, or-, there's nobody there to guide me or talk to me.

There were times since the move where new staff changed quickly, which was challenging for participants. TJ described it as “my team fell apart.” This dramatic description indicated to me how significant it felt to him when staff left and needed to be replaced. He later went on to talk about how he felt about his social worker in the Transforming Care team soon to be handing over to a social worker in the local team:

TJ: To be honest with you, sometimes I don't like change. So over the years, I've had a lot of nurses change, a lot of social workers. A lot of managers change and things like that. I suppose that [small laugh] sometimes I just haven't got any choice really. I'd rather have Patsy for the rest of my time. But that's not going to happen. It's just one of those things really. But it is difficult, and it is kind of hard to swallow.

**3.4.1.2. “They don't treat me like a little kid”:** People seeing different sides to me. This sub-category pertains to how people felt they were seen in the eyes of those important to them, including family members and staff. At the time of moving out of hospital, it seemed to be important to be seen by others as ready to move. When asked “what did it mean to you, that other people thought you were ready to move,” speaking as Pamela, her support worker stated:

Just feel that they had confidence in me, you know, that I was able to do it. [Pause] And it was nice to be thought of that I... that I was obviously...was at a time of my life that I could do that.”

And to the same question, Elvis' Mum answered: "the world." These responses indicated just how important it felt for participants to have their readiness to move noticed by others, which seemed to then provide an opening to another way of understanding themselves.

Having moved, the appreciation that people felt from others about their progress seemed to also support them in believing a more positive self-image. Larry described his family's views on him in his new home:

Interviewer: What do [your siblings] say about you, now you live here?

Larry: They're pleased with me.

Interviewer: So if your brother was here now, what would he say about you?

Larry: Be happy with me.

TJ describes in more detail how seeing himself as 'doing well' through the eyes of others could be an incentive to spur him on:

TJ: Every time we was in a meeting [Mum] goes "oh I'm so proud of you TJ."

Interviewer: How did that feel, her saying she was proud of you?

TJ: Oh! You know, I was a bit embarrassed. But no, it was really nice to hear, and made me want to carry on doing what I'm doing so. Really, you know, really commit to it.

Participants discussed how their behaviour was treated differently in the community. Patsy, Benny's social worker, talked about how staff in the new home reacted to him breaking items that he didn't like:

Patsy: And I think also that I'm not told off for my behaviour. Whereas I think in hospital I think I was stopped from acting in certain ways. Here, it's more a case of 'ok, let's clear that up, throw it away, job done, don't worry that it's broken.' And that'll be the end of it. So it's better.

Benny: Better Patsy.

These changes in reaction to behaviours that could be labelled as 'challenging' seemed to allow for other ways of understanding when incidents happened, rather than being 'told off' or otherwise responded to in a way that implied some level of 'naughtiness'.

Being treated differently seemed to also play a significant role in the new ways that people saw themselves, as indicated in the model by the recursive nature between identity and action. Pamela talked about what it felt like in her new home, not being a 'patient':

Pamela: We were treated like patients.

Interviewer: What does that mean to you, to be a patient?

Pamela: Horrible... it made me feel that I couldn't do anything for myself.

Interviewer: What do you feel like now?

Pamela: Really good, I can do things myself now. They don't treat me like a little kid.

In the second interview, she expanded on how not being treated 'like a little kid' was linked to how she saw herself in hospital, compared to how she saw herself in the community:

Her support worker, speaking as Pamela: Well, I ... I got an identity now. I'm not a number or something I'm... just a name...you know I'm called by my name. You know, and that's how people see me. As an individual.

Pamela: I used have a bow in my hair. When I first came here.

Interviewer: And why don't you wear it anymore?

Pamela: Because I don't want to I'm not a girl. I'm not a child.

Interviewer: And... did you wear it before because you felt more like a child?

Pamela: Yeah. Yeah.

In summary, participants spoke of the importance of relationships with others, particularly staff, in allowing them to feel safe and secure in the new setting. There was a preference for feeling known by, and knowing, the team; but people also still faced difficult staff transitions in the community. Furthermore, there seemed to be a narrative of how being seen and treated differently by others allowed for different ideas about participants to come into view, and to then influence how they saw themselves. This concept will be elaborated further in the following discussion about the next sub-category.

### **3.4.2. Changing Ideas about Who I am**

Adding to the previous sub-category, 'changing ideas about who I am' explored how much being in the community seemed to influence how people saw themselves. Having transitioned, participants spoke of being seen and being treated differently by significant others, which seemed to influence how they saw themselves, in a cyclical process. This section of the model mirrors the circular process in the 'a restricted story' concept; however, whereas that first process often became stuck in a negative loop, 'a widening story' is opening up in a circular process which broadens out, opening participants up to new opportunities for identity development. This category

consists of three subcategories: 'becoming the real me'; 'feeling connected'; and 'feeling equal now.'

**3.4.2.1. Becoming the real me.** There seemed to be a strong theme which was constructed from the data about how people felt some intrinsic sense of their *self* changed as part of the transition process. As described above Pamela's discussion of no longer feeling like a child indicated to me that she now saw herself as an adult woman; for others the identity transformation seemed to be to becoming a 'good person':

Interviewer: So what sort of person would you say you are now?

Ayo, speaking as Jason: I'm a new person.

Interviewer: A new person?

Ayo: yes, yes, a new person, a new different person now. I'm talking about a good person.

With good character.

Interviewer: [to Jason] Ayo said you feel like a different person now.

Jason: Yeah

Interviewer: So What's different about Jason now?

Jason: Errrrm. Very well. Very good. With myself.

Patsy, speaking as Benny: I was always told that I've got to be good to move out. That was an expression people used to use. So I suppose... maybe I think I'm.... good? Now?

To me, this indicated how influential the stories told about people could be in shaping their self-perception. Linked to the sub-category above of internalising a restricted 'identity' which explored how people viewed themselves in hospital, stories of 'being good' or 'being bad' seemed to have

a powerful effect, which could then alter how people saw themselves now in the community in comparison to in hospital.

Interviewer : What sort of person were you when you lived in the unit?

Larry: Terrible (laughing)

Interviewer: And what sort of person are you now?

Larry: A normal man

Interviewer: What does that mean?

Larry: I'm a good man.

For some participants, if it felt like hospital had changed them in a negative way, the identity transformation was back to the 'old' self, before life in hospital:

Elvis' Mum, Betty: How do you feel, in yourself? Since you've got your own house now?

Has it made you...

Elvis: Yeah, happy. Make me proud I s'pose.

Betty: And how did you feel before, when you weren't here?

Elvis: Bit sad. Bit, er, down in the dumps.

Betty: But you're a different person now, aren't you.

Elvis: Yeah.

Interviewer: How is it that moving here has made you a different person?

Betty: It's made you back to your more caring self. That you used to be, before. The big teddy bear we all know and love.

Elvis: Yeah.

Betty: Cos when you weren't here, what was you like? Not a big teddy bear was it, it was like a big...

Elvis: Bear with a sore head! [laughter] I was like I was bear with a sore head all the time! I was a bit snappy.

Dave's Dad, Peter, speaking as Dave: I'm back to the person I used to be. I think I've discovered how to be mischievous again. In a way that I was never mischievous at [hospital]. The opportunity to be mischievous wasn't there. But here [new home], I managed to jump on the bus all on my own when staff weren't looking! Mischievous. I let out my housemate's canaries when he wasn't looking!

The sub-category was named to imply a difference over time, but also to capture that for some people this was not a transition to someone new, but to someone they had been before. It also encapsulated how people felt being an individual now, a person, rather than a case or patient.

Elvis' Mum Betty, speaking as Elvis: [In hospital] it was more like, a number. I felt like a number rather than a human, human being. Rather than a real person. Here, I feel like I'm a real person. And I'm treated like a friend. Rather than just a number.

**3.4.2.2 “I don't call the staff ‘staff’, I call them family. They're my family”:** **Feeling connected.** Throughout the data, there seemed to be discussions of how important it felt for participants to feel connected to others socially. Those with families talked of missing them while in hospital, especially when it was a long distance from them.



Ayo, speaking as Jason: [When I was in hospital, my parents] drive to see me, maybe every two weeks. So now, I miss them and I want to see them. So now, I'm moving to XXXshire. Which means that my Mum and Dad will be seeing me regularly, all the time.

Having moved out of hospital, I noted strong themes of people seeking connections to a number of different contexts. Some people's accounts alluded to wanting a sense of community, for example feeling that they were known locally, or belonging to a church for example. Pamela seemed very touched when "one of the ladies [next door], bought me some flowers to welcome me come in as a neighbour." This suggested how important it felt for her to be accepted into the community. For Clive, being known in the local area sounded very important to him.

Patsy, speaking as Clive: My favourite thing to do here is going to collect the papers every day. And say hello to my friends at the newsagents.

Clive: Yeah

Dave's Dad explained that now in the community: Well, he's just more confident. More confident when out and about. Same as anybody else. Just likes to be known. If you're not known, you don't feel you belong, you know.

For others, it seemed important that the staff team that now surrounded them should feel like being part of a friendship group, or a family. TJ described trying to employ staff who were similar to him: "I'm looking for somebody who's the same age as me, got similar interests, wanna do active stuff and so on." This implies that it was important for him to feel that staff around him were more like a peer group. For Elvis, he called his support team his 'friends', which designated something distinctly different to a relationship with staff:

Elvis' Mum, speaking as Elvis: Now I can talk to my friends. And they are like friends and I can, am learning to trust and feel safe with them.

Pamela summed this sub-category up by saying: "I don't call the staff 'staff', I call them family. They're my family."

**3.4.2.3 Feeling equal now.** This sub-category covers ideas about people feeling now more on an equal footing to the staff or other people, rather than historically taking a less powerful position. This seemed to be intrinsically linked with the concept of identity, as participants could see themselves as more similar in identity to others around them. Uniform seemed to play a significant role, although notably uniforms were only mentioned by KSPs rather than participants themselves:

Patsy speaking as Benny: [staff here] are not nurses in uniform. Green shirts, so they all look the same.

Interviewer: How does that make a difference?

Patsy: It humanises people I suppose. It makes us look more on par. Rather than, if you've got a nurse whose outfit on... it's a divide. It's them and me. It's definitely, the people in power had keys, the people in the green shirts had power and keys, and made all the decisions. Whereas here I can make some of the decisions and people aren't wearing shirts.

Ayo, speaking as Jason: [In hospital] they wear uniform, just like erm, I've been under care, if you try to understand what I'm saying, But. The reason I'm saying this is that, these new people, new company, they don't wear uniform. We feel the same yeah. They wear mufti.

But those people there, they wear uniform. But the new company, they don't wear uniforms.  
[Unclear] they are the brothers and sisters.

When people felt more equal, this was played out through how they felt they were treated:

Interviewer: How do [staff] treat you differently, now, to, maybe experiences you had before?

Elvis' Mum Betty: [To Elvis] They treat you like you, don't they. Like an equal. Like you are like them.

Elvis: Yeah

Betty: They treat you like a true friend, not a...

Elvis: Like a rubbish friend (laughs). Not a rubbish friend.

As part of this, there were times that participants hinted at being 'different' to other patients in hospital. After admission to hospital, Elvis' Dad said "his words were 'why am I here, I'm not like them'"; and Pamela described hospital as "with clients what couldn't talk, was undressing themselves. And I was the only decent one there."

*I wondered whether this may have been a way for participants to make sense of how they had managed to move out while others had not. It also made me reflect on power in a more general sense: to take back some power, move up the power scale, is it always necessary to push others down below you? To feel more equal to non-disabled people, like staff, did participants have to see themselves as superior to others with ID?*

In summary, participants spoke about feeling different since their transition into the community, and this transformation seemed to be made up of a number of factors. These included feeling like a new person and/or the person they were before hospital; feeling more equal to people without a disability; and feeling connected in valued relationships. These aspects of identity change seemed to happen in the contexts of the relationships they held with others. Linked to this was how people then learnt more practical aspects of living in the community; this category will be explored below.

### **3.4.3 Adapting to a New Life**

The category 'adapting to a new life' encapsulates some of the more practical aspects of moving into the community that participants faced. The two subcategories will be explained in further detail below: 'learning how to have control'; and 'facing problems differently'.

**3.4.3.1 . "I have more freedom than what I used to have": Learning how to have control.** As encapsulated in the 'restricted story' concept, many people had experienced hospital as a place where they had limited control over some or many aspects of their lives; and for some there was a big shift when they moved into the community. People spoke about learning new things, like money management or choosing their own meals, even looking after pets. They described new freedoms to be less restricted in how they wanted to live their lives:

Fred: But here... I can sit in the bath now for three hours in the bath, and be nice and wrinkled! I'll be like a prune!

Larry: I'll tell you something. I have more freedom than what I used to have.

Adapting to having more control was described as difficult for some people; having been so used to others having the power, it was a learning process to get used to a new way of behaving:

Pamela: I'm very used to getting told what to do, in hospital. It felt a bit hard that, you know, I could... because my money, right, my bank card, I always used to say to [staff members in new home] can I buy this, and they'd said it's not my money it's your money, as long as you've got your money in the bank for your bills and that, that's fine with us.

Participants described that getting used to these new levels of control was a process of learning, of practising and of trial and error. This quote from Elvis's Dad indicates how important others are in this learning process:

Gerry, speaking as Elvis: So it's very-, I find it very hard. Because of, when I was in the clinic you were told: "can't do that at the moment. Wait a little while and I'll sort you out shortly". It was, like, always being put off? But now that everything's here, I find it very hard to adjust from: "wait a minute, we'll do it shortly" to - it's there when I want it? And like I find it um, difficult to adjust.

Interviewer: How it is that you're able to get used those changes? And make those adjustments?

Gerry: That's down to the staff. My friends. To guide me. And if I get confused, they talk to me a lot. Because it takes a long time for me to take anything on board.

There did seem to be a limit to having more choice, in that some people also seemed to find it containing to have rules, and to know what was expected of them:

Interviewer: Who was the most helpful person while you were moving?

Larry: [manager of current house]

Interviewer: How was she helpful?

Larry: Cos she told me the rules. Told me the rules about the house.

**3.4.3.2 Facing problems differently.** Participants discussed that they were adapting to face problems in new and more constructive ways. Oliver described buying a drum kit, which had not been permitted in hospital, which he hoped would be “therapeutic for me.” For others, talking to their staff team was a key way that they now approached times of difficulty. For example, Pamela explains:

Interviewer: So do you face any problems now?

Pamela: No. I talk about them now.

Interviewer: Is that different?

Pamela: Yeah, because I used to keep them in me.

Interviewer: And what happened then?

Pamela: I got depressed, I got upset. I started hurting myself. But now I haven't done it for ages.

This seemed to be clearly linked to how safe they felt in the relationships, as people mentioned only opening up to staff in this way if they felt they could trust them. As such, this seems to link recursively with the sub-category of ‘needing others to be reliable’ described above. A sense of safety, through a predictable and containing relationship, allowed for people to use talking to communicate problems, rather than communicating this through, for example, behaviours that

challenged. Furthermore, being seen as someone who could cope with problems better could support the construction of an identity as someone who is managing to live independently.

## 4. Discussion

### 4.1 Revisiting the Research Question

This research project set out to answer the question 'how do people with ID experience transitioning as part of the Transforming Care programme?'

The GT model constructed from the data represents an 'adaptation to transition' model (Schlossberg, 1981). The model indicates that participants went through a significant change process when transitioning from hospital to the community, whereby they needed to adapt to a different kind of life after their move. They navigated shifting beliefs about who they were as a person, which were also shaped by how other people around them perceived them. This allowed them to shift their identities from 'a stuck story' to 'a widening story'. This widening story in the community supported people to adapt to their new lives out of hospital, to learn new skills and to explore being a different kind of person. People also coped with a number of complex processes associated with moving home, including managing loss, experiencing powerful emotions about their move, and going through uncertainty. They reported it was vital to feel safe in new relationships, and these relationships were instrumental in supporting 'a widening story'. However, even after the move to the community, a number of participants reported the sense of impermanence of their new home, and a sense of threat that they could return to hospital.

Therefore, people with ID in the present study experienced their transition as a complex process of adapting to momentous changes in their lives. The model shows that these changes encompass far more than a change of physical environment or location, and indicate a broad range of processes which are part of transitioning as part of Transforming Care.



Overall, the model presented in this report aligns with Schlossberg's "model for analysing human adaptation to transition" (p.2; 1981). Schlossberg presented a theoretical framework to explain how adults experience and adapt to changes in their lives, based on a wide range of empirical studies across a range of transitions. She proposed that at a time of 'transition' people move to a place of 'adapting' to the change. This process is mediated by three components which influence how well people adapt to the transition: (1) the type of transition, as perceived by the person going through it; (2) the nature of the environments both before and after transitioning; and (3) the characteristics of the person who is transitioning (Schlossberg, 1981). Each of these components will be looked at in turn, to explore how they fit with the model in this study, as well as link to previous literature on transitions for people with ID.

#### **4.4.1 The Type of Transition**

Schlossberg argued that various aspects of the transition itself would play a part in how it was experienced, and how people adapted (Schlossberg, 1981). Schlossberg's model included factors such as whether the transition was conceptualised as "on-time or off-time; positive or negative", if the change was "gradual or sudden", or "permanent, temporary or uncertain" (p.5, Schlossberg, 1981).

The presenting GT model is proposed to expand the evidence base for this element in Schlossberg's (1981) model. For example, in the present study it was reported that unplanned transitions in the past had often not worked out and had been a source of stress. Furthermore, the category 'living with a sense of threat' indicated that a sense of uncertainty about the permanence of the participants' new lives could impact on how they experienced their transition. The challenges of coping with uncertainty about a new residence had also been found in previous research in the field (Hubert & Hollins, 2010).

Furthermore, elements of participants feeling in control of, and prepared for, their move were noted to be influential in how they experienced transitioning, which further links the GT model to the model produced by Schlossberg (1981). Participants spoke about the importance of working with new staff before the transition, or making visits to the new accommodation. These experiences were discussed as important in helping people feel ready for the move. As described in the literature review in the first chapter, a number of previous studies found that transitions were experienced as more challenging and disruptive when people were not adequately prepared for the move (Ellem, 2012; Ellem et al, 2012; Owen et al, 2007). For participants in the present study, choices about when to move were made by professionals in more powerful position, who decided whether they were ready yet to be 'given a chance.' This context is in contrast to findings by Bramston and Cummings (1998) who reported that people found moving less stressful when they had actively made the choice to move out. The GT model suggested that adapting to having more control was a challenging process for some people, not something they could get used to overnight.

In summary, the GT model suggests that idiosyncratic differences in how moving as part of Transforming Care were managed (e.g. whether the move was well-planned and how much control participants had over their move) impacted on how the transitions were experienced. This is has provided further evidence for Schlossberg's (1981) model of transitions.

*A further aspect suggested by Schlossberg (1981) was whether there were positive or negative feelings associated with the transition. The present study indicated that there were challenges as well as gains associated with transitioning. These included going through the loss of familiar ways of life and valued relationships, and dealing with a mixture of sometimes conflicting emotions about*

*the move. Through the course of interviews there were times when 'progress' was spoken about, in the ways that participants, KSPs and those around them talked about how 'well' things were often going since the move. While ideas about progress may be beneficial or aspirational to people with ID and those around them, it can also be viewed as a particularly Western capitalist concept. I was reminded of the critique of 'recovery' by user-led group Recovery in the Bin (RITB, n.d.), who argue that ideas about recovery can be moulded by the structures within neo-liberal societies to maintain inequalities which keep mental health problems going. I wondered if ideas about 'progress' could be subjected to similar arguments: I was reminded again of Simpson and Price's (2009) critique of the "romantic" ideologies of ID policies, which can lead to a denial of the realities of life with a disability. From this perspective, it can be questioned whether dominant discourses about progress could mask opportunities for discussions about the difficulties that come with moving. I was reminded of the research by Johnson (1998) and Owen et al (2008) who reported that no counselling was offered to participants in their studies, despite the traumatic way that the hospitals closed down.*

#### **4.1.2 The Nature of Environments**

In her "model for analysing human adaptation to transition" (p.2), Schlossberg argued that the environment pre- and post- transition would impact on how it was experienced. She proposed that three key features of the environment played a part in how well people adapt: "interpersonal support; institutional support; and physical settings" (p.10, Schlossberg, 1981).

The GT 'adaptation to transition' model is proposed to add further weight to Schlossberg's (1981) model, as the importance of "interpersonal support" (p.10) was found to be a key factor in how transitions were experienced in the present study. Participants described building new relationships with staff, and the importance of feeling connected to others. In this section I will

explore further a theoretical understanding of the importance of relationships, and how this aligns with previous literature.

A number of participants in the present study described moving to hospitals far from their families, moving placements multiple times, or experiencing frequent changes to their staff team, both in the past and in their present home in the community. These findings are replicated in the literature: Horn and Moss (2014) reported that a “pattern of continued disrupted attachments with people and places” (p. 180) is often a common theme in the lives of people with ID; they often have to manage when there is instability in their staff teams (Isaacson et al, 2014). The value of relationships which were supportive, safe and fostered a sense of belonging has been found from research when people moved out of prison (Ellem et al, 2012) and out of hospitals (Hamilton & Atkinson, 2009; Holland & Meddis, 1997; Hubert & Hollins, 2010; Owen et al, 2007).

Clegg and Lansdall-Welfare (1995) discussed how attachment theory can be used to understand the attachments that people with ID develop with staff, noting relationship difficulties may be more prevalent in this client group than the general population. John Bowlby and later Mary Ainsworth (cited in Dallos & Draper, 2015) developed attachment theory based on observations of young children and their caregivers. They argued that for optimum development, infants require a safe base from their caregiver, from which they feel secure enough to go and explore the world, and to which they know they can return for comfort and protection. In the present study, a number of participants referred to ‘testing’ the new relationships with staff, or needing time to feel they could trust in these relationships. From an attachment perspective, this behaviour in new relationships could be seen as testing out whether boundaries with new staff would be maintained in ways that provided a sense of containment and security, what Clarkson (2003) termed a ‘reparative’ or ‘developmentally needed’ therapeutic relationship.

Staff in mental health services (Adshead, 1998) and ID services (De Schipper & Schuengel, 2010) have been shown to act as attachment figures for service users, and can function to modulate stress and anxiety (Adshead, 1998, De Schipper & Schuengel, 2010). Many participants in the present study reported that a sense of consistency with their staff teams was important to them, both in the past and now, in the community. For example, Pamela explained: “[Staff members] might go into another house. But I told ‘em they couldn’t have [name] and [name]. Cos they were my own staff. Because it upsets me if they move. And I get somebody else. Who I don’t really know much.” ID services can therefore be seen as playing an important role in providing a secure base to people so as to minimise anxiety and promote therapeutic attachment relationships (Watt & Brittle, 2008).

In summary, the GT model therefore demonstrates that elements of the social environment (particularly the quality of relationships in which people with ID can feel safe and secure) are hugely influential on how transitions are experienced. This is comparable to Schlossberg’s (1981) model of transitions.

#### **4.1.3 The Characteristics of the Person Transitioning**

The final modulating factor suggested by Schlossberg’s (1981) transition model refers to the traits of the person who is transitioning. She argues that demographics such as gender, health and socioeconomic status will impact on how the transition is experienced. A further suggestion by Schlossberg (1981) is that “self-attitudes... [including] ‘the capacity to maintain a coherent and consistent self-image’” (Liebermann, 1975, cited in Schlossberg, 1981, p.12) play a part in the successful adaptation to a transition. However, the GT ‘adaptation to transition’ developed in this study does not support this suggestion. Conversely to the model proposed by Schlossberg (1981),

the concepts of 'a stuck story' and 'a widening story' indicate that the ability to alter one's identity story is an important feature of going through a transition as part of Transforming Care. In this section I will now explore an explanation for why this could be the case.

From a social constructionist perspective, Burr (p.51, 1995) notes that "our identity is constructed out of the discourses culturally available to us, and which we draw upon in our communications with other people." This perspective indicates that "our sense of self is... fragmented, complex and multiple. At any given moment and in different contexts, one aspect of our identity may dominate another" (p.97, Dallos & Draper, 2010). The findings from the present research project demonstrated that, at times, one aspect of a person's identity (namely, aspects which were seen as challenging) could override others. This then could lead to an internalised sense of 'being bad'. This was highlighted succinctly by Larry's KSP (speaking as Larry) when she said "I think who I was as a person got forgotten, it was this behaviour that was the main factor that, that drove everything that happened in my life." Discourses around behaviours which challenge are generally pervasive in hospital settings, as hospitals are often commissioned with the key purpose of assessment and treatment of such behaviours (NHS England, 2015c). The present study indicated that this focus in hospital could contribute to problem-focused identities that obscured other aspects of the participants. Gillman, Swaine and Heyman (1997) reflected on the "tyranny of professional discourse" (p.675), stating that problems can arise when 'life' stories become solely 'case' stories. They reported that when working in this way, the identity of the person can be lost, whereas the only information that gets retained is that which is useful for professionals (e.g. risk, medical). This seems to reflect the process reported by participants in the present study. Conversely, on moving out of hospital, the model demonstrated a broadening out of available narratives which participants could align themselves with.

The GT 'adaptation to transition' model indicated that how participants were seen by others could become internalised over time, shaping their beliefs about the type of person they were. As Oliver noted, "[in hospital you should] behave yourself. And do the treatment. And you'll get out. If you're good. If you're bad – forget it." This resonates with the case-study by Leaning and Adderley (2015) of Raymond, who the authors note "had... bought into this [negative] story of himself" while in hospital for 46 years (p.3). The study by Jahoda and Markova (2004) attempted to explain this. They noted that the "participants' sense of self was not merely a 'reflection' of how they were treated or perceived by significant others" (p.728) as suggested by Cooley (1956, cited in Jahoda & Markova, 2004). Instead, it can be understood as a complex interaction of treatment by others and self-awareness, in comparing oneself to an internalised version of a 'typical' person (Jahoda & Markova, 2004). This is supported by the present study, whereby participants described feeling like a 'different person' since leaving hospital, such as being 'more adult' or 'a more caring person'. In doing so participants aligned themselves with identities that seemed more 'typical' given their modern Western context, where there are expectations for adults to live 'independently' in the community.

Social identity theory (Tajfel & Turner, 1979) proposes that people want to find themselves a member of a group, and will tend to exaggerate the difference between themselves and others in the 'out-group'. The theory indicates that a sense of 'fitting in' is important for knowing one's place in society, and for enhancing a sense of self-esteem (Tajfel & Turner, 1979). This theory can be useful in understanding how people with ID make sense of their identities (Brown et al, 2009). Stets and Burke (2005) argue that "people act to verify their conceptions of who they are" (p.129), and these actions, at the individual level, take place within a context at the level of social structures, such that there is a "reciprocal relationship between the self and society" (p.128). As such, in the present study it may be that within the social context of 'living in the community', participants were

able to conceptualise themselves as people who fitted into this social grouping, and internalise these new understandings about their 'selves'. As TJ said: "Every time we was in a meeting [Mum] goes 'oh I'm so proud of you TJ' .... it was really nice to hear, and made me want to carry on doing what I'm doing. Really, you know, really commit to it."

The GT model indicated that behaviours in the community were seen as just one part of participants' identity, not their whole identity. This seemed to fit with a social constructionist narrative perspective (White & Epston, 1990) which values seeing people as comprising multiple stories, rather than just one dominant 'problem-saturated' story. This also resonated with the single case study of Raymond (Leaning & Adderley, 2015), who, through moving out of hospital, had a richer array of stories available to make up his identity. Coles, Caird and Smyly (2012) undertook narrative work with people with ID, and found that staff might need support in hearing people with ID's preferred stories following a narrative intervention. In the context of dominant discourses of disability rather than ability, they noted that alternative stories of strengths may sometimes still be dominated by the overpowering, more negative stories attached to people. Sharing and celebrating more positive stories could help all members of the system appreciate that the person with ID can be *both* 'in need of support' *and* 'able' (Coles, Caird & Smyly, 2012). These clinical observations fit with the findings of the present study, as the model implied that both the participant and those around them are implicated in the identity changes that allow for a 'widening story'. Modern Western societies sometimes have a "tendency to define problems in personal rather than interpersonal terms" (p.95, Dallos & Draper, 2015). Viewing problems as interpersonal, as suggested from both the results of this study, and from a social constructionist perspective, allows for opening up new ways of seeing and understanding difficulties. The findings indicate how important everyone in the system is in creating and maintaining identities.



Therefore, changes to ideas about identity were central to the processes of transitioning as part of Transforming Care. The GT 'adaptation to transition' model illustrates that fluid processes of identity development influenced how transitions were experienced, in contrast to Schlossberg's (1981) model of transitions. These processes of identity change can be better understood from ideas related to a social constructionist perspective on identity (e.g. Burr, 1995) and from social identity theory (Tajfel & Turner, 1979).

*Engaging in this research project has had a profound influence on how I view the power of the systems which purport to provide mental health support. Although I have faith that most mental health services have been set up with the will to help and support others, I continue to reflect on how they can, and do, harm the most vulnerable people in society. This has been of particular poignancy on the clinical placement that coincided with the majority of my work on this research project. On placement in a complex mental health service, I was struck, again and again, by the power that a number of helping professions such as Clinical Psychology have in peoples' lives. This is not intended to be critical of the intentions or motivations of individual staff members, who endeavour to make small shifts for service-users. But that the 'modern power' (White, 2002) which exerts itself through language in well-established ways of working such as the Mental Health Act (Department of Health, 1983) and the diagnostic system (Division of Clinical Psychology, 2013) can be incredibly powerful, and need to be used with great care and thought.*

## **4.2 Clinical Implications**

In an effort to meet Elliot et al's (1999) criteria for demonstrating respect for participants, I feel it would be unethical not to use the data to offer some tentative ideas for clinical implications. Furthermore, efforts were made to reach data saturation through interviewing a diverse range of participants, and it is therefore hoped that the model could be viewed as somewhat representative of others' experiences. Nevertheless, Elliot et al (1999) caution qualitative researchers against

overgeneralising their findings beyond the scope of their study. I am therefore mindful that the model presented in this report is representative only of the data from the 11 people with ID and their KSPs. With this in mind, below I will consider some of the implications of the model as a whole, before suggesting some more specific clinical implications.

#### **4.2.1 Overall Implications**

The theoretical 'adaptation to transition' model emphasises the complex processes that people went through when transitioning out of hospital. The study indicates that people should be given a significant amount of support and time to manage transitions. The findings on the 'restricted story' indicate that stories about the person and the behaviour they present with can begin in, or perhaps even before, they enter hospital. There are subtle differences in the language used around behaviour, from 'doing' inappropriate things to 'being' inappropriate, or even bad; the study has shown how language used in services can have long-lasting implications. Services which are designed to be accepting of difference may be invaluable in this client group. The GT model demonstrates that a transition is not a singular event, but a process which begins long before moving day, and will continue long afterwards.

The results also highlight the considerable resources that people with ID drew on to successfully navigate the challenges of moving out of hospital. These abilities should not be underestimated by those involved in their care. The study indicated that sustaining communities of support can be developed around the person who transitions, which can be used to mediate the process of transition, and forward into their new lives. Importantly, the research demonstrates the value in seeking the views of people with ID, and how much they can contribute to the body of knowledge in this field.

## **4.2.2 Specific Clinical Implications**

**4.4.4.1. Supporting staff to understand peoples' experiences of moving.** The present study suggested that transitions could at times be difficult for participants, with unanticipated delays and uncertainty. While many of the people in the system around the transitioning person may endeavour to empathise with their experience, it has been well documented that the emotional worlds of people with ID have long been overlooked (Arthur, 2003; O'Driscoll, 2009). The present study provides evidence that internalised other interviewing techniques can support non-disabled people to step into the shoes of people with ID to get closer to understanding their emotional journey. As documented in section 2.5.2 above, at times for KSPs this was an emotional experience which helped them to see what moving might really have been like for those they supported. This technique could therefore be used clinically, for example when working with a staff team during or just after transition. By inviting staff to think through what the person transitioning may be feeling and thinking from a first person perspective, a broader awareness of the challenges of the move could be appreciated by staff. This could then allow them to be more cognisant of how and why someone might be reacting in certain ways to their experience and different stages of the process.

**4.2.2.2 Preparing to move.** The results indicated that participants found it valuable to spend time with their new staff teams getting to know them before they moved. This allowed them to build relationships and feel more prepared, making for a smoother transition. Conversely, it was reported that transitions which felt 'rushed', with less opportunity to get to know staff, were more likely to be unsettling for participants. This could lead to people feeling less safe in their relationships, which could heighten anxiety about the move (and in turn increase the risk of behaviours which challenge). This suggests that transitions be planned to involve a handover of

staff where possible, with new staff working with the person in the hospital environment before the move. The importance of stability in staff teams was also powerfully highlighted by this study, suggesting that wherever possible, efforts should be made to recruit teams who are stable, without high turnover of staff.

**4.2.2.3 Clearer pathways** Noticeably, participants who had a clearer idea of all aspects of their admission and treatment seemed to be less affected by the overarching threat of re-admission. In line with NICE guidance on transitioning out of hospital (NICE, 2016) it seems important that people with ID and those in their immediate system take an active role in hospital admissions and discharges. This study does not however indicate all participants should be involved in every aspect of the process, as some participants found attending all meetings helpful, and others found this anxiety-provoking. Waiting for - and uncertainty about - discharge from hospital was reported to be challenging, and at times led participants to doubt if the discharge would ever happen. Therefore it may be beneficial for services to consider a “whole-systems approach” (Devapriam, Gangadharan, Pither & Critchfield, 2014, p.211) whereby housing, social support, funding and NHS services work in unison to expedite discharge from hospital.

**4.2.2.4 Increased local services.** Alongside the suggestion above, this study indicates a need for funding for more suitable placements available locally, so that spaces are available when needed, rather than placements having to be developed from scratch each time someone transitions from hospital (Department of Health, 2012; Mansell et al, 2006).

**4.2.2.5 Wider understanding of behaviours which challenge.** The results suggested that for many of the participants who were now living in the community, there was a wider

understanding of the factors which could be influencing their behaviour, rather than sometimes a sense of inherent 'naughtiness' which was described historically in hospitals. This seems in line with current guidance on the use of Positive Behavioural Support (PBS) to work with behaviours which challenge (NICE, 2015), through making improvements to the person's environment and daily life (NICE, 2015). The joint paper *Challenging Behaviour: A Unified Approach* written by psychiatrists, psychologists and SaLTs was also clear on the need for teams to move on from an internalised explanation of behaviours which challenge, to situating them within environmental contexts (Banks et al, 2007). Therefore it may be that the emphasis on PBS approaches in the Transforming Care agenda has provided opportunities for people to have their behaviours viewed differently since their move to the community. It is important that Clinical Psychologists play a role in the continued training and supervision of staff teams around these ideas (Carr et al, 2002; Learning Disability Professional Senate, 2015). This could allow for a continued move away from "the individualisation of the social" (Jamrozik, 2009, p312; cited in Ellem et al, 2012, p.405). The model suggests there is still the need for thoughtfulness over language use, as identities seem to be constructed in conversations (Hedges, 2005). Staff should therefore be mindful of emphasising strengths and abilities to move away from problem-focussed narratives.

### **4.3 Methodological Considerations**

In the ensuing section I will consider in turn a number of the strengths and limitations of the present project (see also section 2.1.1.1 and Appendix F).

#### **4.3.1 Strengths of the Current Project**

One of my key motivating factors from the project's inception was the urge to keep the person's voice central. This stemmed from my epistemological position of how knowledge is generated and used, as well as from the ethical standpoint of being aware of my relative power as a researcher.

The use of an 'internalised other' interviewing device enabled additional data to be gathered about the participants' experiences, but while not allowing their story to be overshadowed by that of their non-disabled counterpart (Caldwell, 2013).

A further strength of the present study was the robust consideration of an ethical methodology. This involved systematic evaluation of the participants' ability and willingness to consent, time taken to build rapport with a participants, and personalised adaptations to the interview methods.

A final significant strength of the study is that it captured and made sense of the experiences of people who transitioned under very different circumstances. One participant, TJ, was already on a path to move out of forensic services, but Transforming Care was there as extra leverage to secure a placement more quickly and with full support in place. Others, such as Oliver and Pamela, had lived in hospitals for a very long time, and this placement was the first in the community for many years. For others, such as Clive, there had been a number of moves into and back out of community then hospital settings, until an appropriately supportive setting could be found. And for Darling, a recent placement had broken down, and she was back in hospital at the time of the study.

#### **4.3.2 Limitations of the Current Project**

A notable limitation is that all participants were white British. People with ID who are from minority ethnic backgrounds may experience difficulties with accessing services which are appropriate to their cultural needs (Caton, Starling, Burton, Azmi & Chapman, 2007; Department of Health, 2001). People from different cultural backgrounds may have significantly different experiences to the participants in this study. The participant demographics represented the main demographics of the geographical research area, but further research with other groups would be welcome.

Although the dyadic interview technique aimed to redress some of the power imbalances within the pair, a number of shortcomings of the technique could be noted. Patsy, the Social Worker in the Transforming Care team, was the KSP for three of the participants due to her involvement with each person through their transition. Although she and I spent time reflecting on how best she could 'step into the shoes' of three different people, this may have limited the range of perspectives on peoples' experiences. Furthermore, seven participants used staff as their KSP. This may have reflected the nature of some relationships in this field; for example Darling's family had moved to a different county. However, it has been queried whether in ID research, the presence of staff could influence interviewees to answer in a way to please them, therefore biasing the results (Young & Chesson, 2006). Furthermore, participants may be reluctant to speak critically of services, for fear that these could be withdrawn (Beail & Merriman, 2009, cited in Beail & Williams, 2014). These factors could therefore have influenced the results of the present study. Nevertheless, each participant was interviewed on their own before the KSP interview (apart from Elvis and Dave, who were interviewed with a parent present) which, it is hoped, limited this potential influence.

Deciding to interview the KSP's 'internalised participant' could be further criticised for not truly tapping in to the participant's 'real' experience, and therefore lessening the validity of this contribution. However, the use of 'internalised other' techniques is always, inevitably, a construction of the other (Haydon-Laurelut & Wilson, 2011); and within the social constructionist frame of this project the 'real' experience does not 'exist' to be studied. As indicated by some of the quotations in Chapter 3, the technique was not used ubiquitously – KSPs often drew on their experiences to answer questions from their own viewpoint, as well as stepping into the shoes of the participant. However, this could be argued to be a strength – data for the study therefore

consisted of direct data from participants, of the direct experiences of the KSP, and of something constructed between KSP and the participant using the internalised other technique. These different perspectives enriched the data and subsequent analysis.

#### **4.4 Areas for future research**

In this section I will suggest several areas which could be valuable for future research.

##### **4.4.1 Longitudinal Study**

Transforming Care is a relatively new programme of work. People who have transitioned could be interviewed in a longitudinal study, to investigate how their lives in the community develop over time. This could be valuable for investigating factors which support and maintain successful transitions; as well as potentially identifying triggers for readmission to hospital. The model suggested that some participants were left with a sense of threat, whereas for others this was not such a prevalent issue. A longitudinal study could also explore what factors diminish, maintain or worsen this sense of threat over time.

##### **4.4.2 Young Adults / People who are Non-Verbal**

Transforming Care also incorporates young adults, i.e. those currently under 18 years old, so that their transitions into adult care adhere to the ideas within the programme (NHS England, 2015a). Further research into young people transitioning under Transforming Care would therefore be very valuable. The fit of the model could be tested with this client group. A further extension of the present study could be a larger scale ethnographic research project, similar to Owen et al (2007) and Johnson (1998). This could potentially capture the views of non-verbal people who were excluded from this study.



#### **4.4.3 Significant Others' Views on Transitions**

Although gathering service-user views on transitions is important, Murphy et al (1996) state “it may be unwise to argue that service-user views are the *only* important measure of service quality, as others' views are likely to be important if community-based placements are going to remain viable” (p. 258, italics in original). As such, it would be useful to research families' and staff's views of what makes transitions under Transforming Care successful, as well as the barriers to constructive transitions.

#### **4.5 Concluding Comments**

The project presented in this report aimed to develop a theoretical model to understand how people with ID experienced transitioning out of hospital as part of Transforming Care. Analysis of interviews with 11 participants, and 10 KSP and participant pairs, demonstrated that people with ID experienced moving as a complex process, associated with considerable changes to their lives. Transitions were not experienced in a bubble; those around the person transitioning played an important role in shaping their experiences, and supporting them to explore new ideas about who they were in their new lives in the community.

*Speaking to so many people who have had a successful transition as part of this project has been truly touching and inspirational. I have had the pleasure of meeting very resilient people, both the service users and the people around them, who have all worked incredibly hard to make the improvements that have been seen in people's 'widening stories'. However, I wondered at times whether surrounding myself with such positive stories also served to shield me from the stories of the thousands of people still in hospital. Watching a recent Dispatches episode (Under Lock and Key, Channel 4, 2017); or reading the Royal College of Nursing document Connect for Change (2016) also reminded me that there is still so much work to be done in this field. Will the money*

*dry up before it does? After all, this feels an uncomfortably familiar position to be in. I have had conversations with my Mum, a retired ID social worker, who spent much of the 90s moving people out of institutions. We should not think that Transforming Care is so revolutionary an idea. It still requires a huge amount of work. But I have not been left feeling overwhelmed by this, as I have had the honour to meet people for whom it has worked in a truly transformational way.*

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## **Appendix A: Research Diary**

### **January 2016**

We had our MRP presentations last week, and mine went pretty well I think. I made my powerpoint Easy Read, as an example of how I hope to create most of my materials for the project. I got some nice feedback, including that I was clearly trying to be inclusive, and that I seem like the right person to do this project. I hope I live up to expectations....

I spoke to Mum and Dad today about the project. Mum reflected on her experiences as a ID social worker of moving people from hospitals in the 80s and 90s. She spoke about how, for some people, a hospital setting was actually beneficial as it provided some containment and security – she talked about someone she had worked with, who had been able to have more independence in an institution, as they were able to wander between buildings on a secure hospital site, and had taken on small jobs; how they lost this independence in the community as they couldn't go out alone / without supervision. This has reminded me of the importance of entering research without preconceived ideas about the findings – had I already been thinking 'hospital= bad, community = good'? It reminds me that it will be important to truly listen to what people tell me, and build the analysis from the data upwards.

### **June 2016**

I'm currently feeling pretty frustrated with ethics – despite starting in December, I had quite a lot of back and forth and discussions about the methodology, so it didn't get submitted til April. I had hoped to get it in asap so that I could start recruiting over the summer, but that is looking less likely now. I guess I did find the process of all the discussions helpful overall. It really helped me to focus on what it was I hoped to achieve with the project, and then really think through the process of how to get there. It made me realise how passionate I felt about keeping the person with ID's voice central to the research - I wanted to make an epistemological stand about who creates knowledge in the ID field. So it was worth the time it took to think through the best ways to do this. I'm pleased with the method that has been submitted to ethics, and I think it will be a really valuable approach.

### **August 2016**

Finally ethics has come back, and I have just had a phone conversation about the first potential participant. I literally had butterflies during the call. It seems strange, somehow, that I will finally be getting started. After such a long wait, and so much planning, it feels strange that the hypothetical situations in my head will come to fruition. I've been a bit jealous of my colleagues also doing grounded theory, who have started gathering data and analysis. I have felt a bit panicked recently about the scale of my project, the lengthy methodology and analysis I have given myself.

## **October 2016**

We had grounded theory study group today at uni, which was both really daunting and really helpful. I suddenly find myself with quite a bit of data – a few transcribed, and another recorded. I coded the first interview, and tried to stick really close to the data. However, sharing this with and speaking to others, and going back to the chapter in Charmaz, I now realise that I was not nearly analytic enough. There is scope in the method to really try to read between the words people say, perhaps even more so with people with ID who may find it more difficult to say these things for themselves. By holding back too much from being analytic, it could be that I'm actually not doing justice to the participants. What if people with ID don't have the words to say it, and then researchers / professionals hold back for fear of getting it wrong and not giving words for them? Then things will just not be said.... I will start again with this interview, scrap the coding I've done and start again.

## **December 2016**

I found the interview with Elvis and his parents an emotional experience. His story, of being let down, just wanting to fit, and now living in fear that everything could be pulled from under him, was particularly poignant when crossed with the fairly jolly guy I met, who wanted to talk about his dog and sing Christmas songs. His Dad appeared to get tearful at one point, speaking as Elvis and discussing how he just wants to be accepted for who he is.

His parents discussed their understandable bitterness about psychiatrists and psychologists, "the so-called experts", making decisions about what would be best for Elvis, based on theory and knowledge that, for them, had no connection to Elvis' real life. In being positioned, as a psychologist, in this way, I found myself wanting to align myself back on the side of people with ID, and ended up mentioning my sister as my inspiration for my research project. Even before I said it, I wondered if I shouldn't, as this would be 'unprofessional'. But this discourse seemed to exemplify exactly what his parents had found difficult in the past – people hiding behind professional boundaries and screens, rather than connecting with the humanness that puts us all back onto a level playing field.

I feel the emotional engagement I felt with their stories will draw me into potentially reifying it. I also don't want to become another professional who doesn't listen to them. I'm really looking forward to our next GT workshop this afternoon to see where to go next with the coding.

## **March 2017**

I went to meet Darling in hospital two weeks ago for our initial meeting. She was very keen to meet and talk with me, and tell me about what things have been like for her. We arranged that I would go back last week, to re-check consent and do the first interview. However, when I arrived she wasn't in a good place, and did not want to see me. I felt really bad, she's clearly so upset and frustrated with her lack of progress in moving

out. I made sure she knew that it wasn't compulsory to take part; but said that I could come back this week if she wanted. I spoke to her on the phone in the week, and she said she was feeling better, so I went today to meet for our first interview. It was hard hearing how frustrated she has been on the ward, waiting for a team to support her. I think the interview will be really useful in adding to the model, but I left feeling like I had taken from her without being able to give anything back. Once again, it really made me think about the power I take for granted as someone without a disability.

### **April 2017**

So that's it, all data has now been collected. The last few interviews all seemed to be generating further support for the model, maybe the odd tweak here or there. I am glad to have it all gathered and have begun writing the method. I have really enjoyed the interview process – it has been really wonderful to meet some of the people who have gone through this, who have generously invited me to hear their stories. I have been touched and also had quite a few laughs with participants, it has been great.

## Appendix B: Literature Review Process

### Part One

Three searches were undertaken using SCOPUS (see searches 1-3 in table B1 below) between June and September 2016. A number of trial search terms were used to get a clearer idea of which terms would generate the most comprehensive searches. The search terms were used so as to cover broad and narrower regions of the literature. The search outcomes were combined and abstracts screened for papers which were relevant to the topic. Inclusion and exclusion criteria, as displayed in table X, were applied. Email alerts were set up to ensure more recent publications from these search term were also included. This search identified 13 papers.

### Part Two

CINAHL and PUBMED were also searched (see searches 4 and 5 in table X below) between January and March 2017. Again, a number of trial searches were completed to get a clearer idea of which terms would generate the most comprehensive searches. As the Scopus search had already been completed, the list of papers was compared with the previous search, and duplicates were deleted. This identified 2 new papers.

### Part Three

All papers which were relevant were checked to see if there were additional papers in their reference lists; in addition, Google Scholar was used to whether each paper had been 'cited by' any other relevant paper published more recently. Also searched were: relevant NICE guidelines to the topic area, relevant book chapter's reference lists; publication pages of the websites of key authors in the field. This identified 2 further papers.

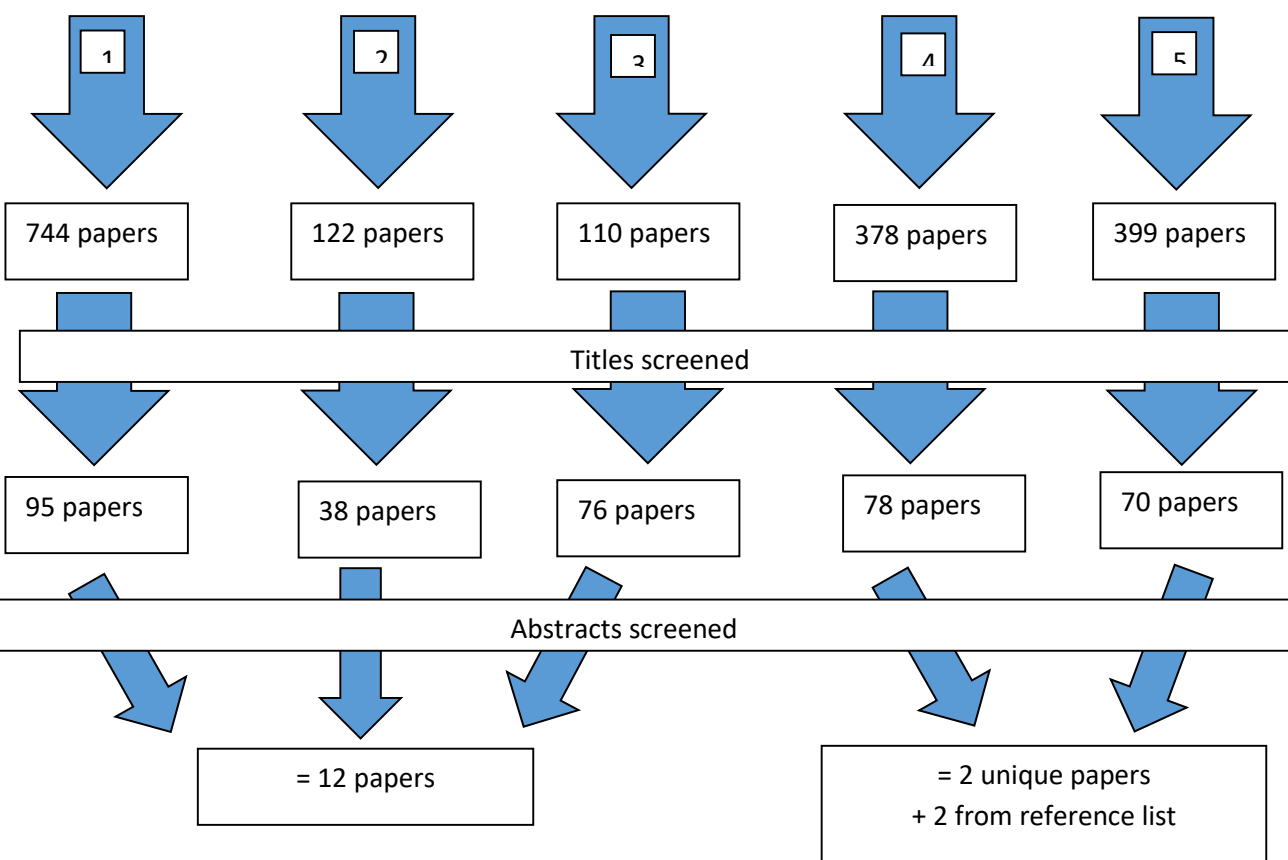
A flow chart of the literature review is displayed in figure B1.

	Search terms
Search 1 Scopus.	intellectual disability OR intellectual disabilities OR developmental disabilities OR developmental disability OR learning disabilities OR learning disability  AND transition OR moving OR move OR deinstitutionalisation OR deinstitutionalise
Search 2 Scopus.	intellectual disability OR intellectual disabilities OR developmental disabilities OR developmental disability OR learning disabilities OR learning disability  AND  transition OR moving OR move OR deinstitutionalisation OR deinstitutionalise OR hospital OR unit OR assessment and treatment unit
Search 3 Scopus.	[in TITLE] intellectual disability OR intellectual disabilities OR developmental disabilities OR developmental disability OR learning disabilities OR learning disability  AND  transition OR transitioning OR moving OR move OR deinstitutionalisation OR deinstitutionalise OR discharge OR rehabilitate  AND

	hospital OR unit OR {assessment and treatment unit} OR institution OR {residential service} OR inpatient OR clinic
Search 4 Pub Med	[in TITLE] intellectual disability OR intellectual disabilities OR developmental disabilities OR developmental disability OR learning disabilities OR learning disability  AND  transition OR transitioning OR moving OR move OR deinstitutionalisation OR deinstitutionalise OR discharge OR rehabilitate OR deinstitutionalization OR deinstitutionalize OR leave OR leaving
5 CIANHL	intellectual disability OR intellectual disabilities OR developmental disabilities OR developmental disability OR learning disabilities OR learning disability  AND  transition OR transitioning OR moving OR move OR deinstitutionalisation OR deinstitutionalise OR discharge OR rehabilitate OR deinstitutionalization OR deinstitutionalize OR leave OR leaving  [Searched parameters – Academic Journals, Adults]

Table B1. Search terms for literature review.

Figure B1. Flow chart for literature review search.



## Appendix C: Significant Studies Excluded from the Review

Fourteen studies were found in the literature review which were relevant to the overall topic area, but did not meet the inclusion criteria for the review. They will be briefly referred to in this section.

Three notable studies were excluded which used a life stories approach. In Stefánsdóttir and Traustadóttir's (2015) research four women with ID in Iceland share their life stories which represent an attempt to offer alternatives to other dominant discourses which were available at the time. For example, one woman talks about her experience wanting to leave an institution to live with her family, which is presented alongside a newspaper clipping from the same time (mid 1930s) where people with ID are described in a derogatory manner. However, although the women used to live in institutions and had since moved to group homes / the community, their experiences of moving, or life now compared with life in hospital, was not explored. Similarly, in the discourse analysis by Moya (2009) information about how people experienced the transition is not explored. Nevertheless, this was an interesting study, looking at how staff make use of life-story books for people with complex ID who have moved from a long-stay institution to the community to construct and/or 'reveal' the person's identity. The study can be commended for how the author endeavoured to contribute to knowledge about people who are non-verbal and therefore may otherwise not be included in research. Horn and Moss (2015) presented a case study of one woman with 'mild ID', aged 34, recruited from a Community Learning Disability Team. The participant described her life, which was marked by a number of adverse circumstances and challenging relationships (with others and also with herself). She described moving house a number of times, and her story was marked by "a pattern of continued disrupted attachments with significant people and places" (Horn & Moss, 2015, p. 180). However she had never been resident in a hospital or institution. The narrative analysis indicated that having a 'place of safety' was vitally important as a protection against traumatic experiences.

Four studies were also excluded which gathered participants' experiences of life in an institution / hospital, but did not explore people's experiences of transitioning from one place of living to another. Murphy, Estien and Clare's (1996) study asked people retrospectively on their evaluation of a specialist inpatient treatment service, but this did not capture how people have found the change in their living environment. There were a number of notable studies of people's experiences in inpatient units which were informative, but did not explore how a transition was experienced, either into hospital or back out (Hubert & Hollins, 2006; Lloyd, Hemming & Tracy, 2013). Nonetheless, Chinn, Hall, Ali, Hassell and Patkas (2011) reported people talked about missing their families now they were in hospital, which indicated some change in experience for participants.

A further seven studies were identified that gathered family viewpoints on transitions. Two papers explored the views of parents considering a transition for their adult child (Hubert, 2011; Unwin, LeMesurier, Bathia

& Deb, 2008). Parents were reported to be wary of residential settings, and uncertain about how professionals would support them through the move. Two further studies investigated families' experiences of a completed transition from the family home (Grey, Griffith, Totsika & Hastings, 2015; Mirfin-Veitch, Bray & Ross, 2003), and reported that it could be a time of stress and uncertainty for them. Three studies looked at perspectives of families when someone moved out of a long-stay hospital (Barton, 1998; Doody, 2011, O'Doherty et al, 2016). There were mixed views on the transition, with some discussion of positive changes to peoples' lives, but alongside that wariness about the process and concerns about the future.

Although the studies described above contributed significantly to the field of transitions, these excluded papers do not explore how transitions were experienced from the point of view of the person with ID.

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Doody, O. (2012). Families' views on their relatives with intellectual disability moving from a long-stay psychiatric institution to a community-based intellectual disability service: an Irish context. *British Journal of Learning Disabilities*, 40(1), 46-54.

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Horn, J. H., & Moss, D. (2015). A search for meaning: telling your life with learning disabilities. *British Journal of Learning Disabilities*, 43(3), 178-185.

Hubert, J. (2011). 'My heart is always where he is'. Perspectives of mothers of young people with severe intellectual disabilities and challenging behaviour living at home. *British Journal of Learning Disabilities*

Hubert, J., & Hollins, S. (2006). Men with severe learning disabilities and challenging behaviour in long-stay hospital care. *The British Journal of Psychiatry*, 188(1), 70-74.

Lloyd L.C., Hemming C., Tracy D.K. (2013). Service users' experiences, understanding and hopes about care in an inpatient intellectual disability unit: A qualitative study. *Advances in Mental Health and Intellectual Disabilities*, 7(4), 201-210.

Moya, H. (2009). Identities on paper: Constructing lives for people with intellectual disabilities in life story books. *Narrative Inquiry*, 19(1), 135-153.

Mirfin-Veitch, B., Bray, A., & Ross, N. (2003). "It was the hardest and most painful decision of my life!": Seeking permanent out-of-home placement for sons and daughters with intellectual disabilities. *Journal of Intellectual and Developmental Disability*, 28(2), 99-111.

Murphy, G. H., Estien, D., & Clare, I. C. (1996). Services for people with mild intellectual disabilities and challenging behaviour: service-user views. *Journal of Applied Research in Intellectual Disabilities*, 9(3), 256-283.

O'Doherty, S., Linehan, C., Tatlow-Golden, M., Craig, S., Kerr, M., Lynch, C., & Staines, A. (2016). Perspectives of family members of people with an intellectual disability to a major reconfiguration of living arrangements for people with intellectual disability in Ireland. *Journal of Intellectual Disabilities*, 20(2), 137-151.

Stefánsdóttir, G. V., & Traustadóttir, R. (2015). Life histories as counter-narratives against dominant and negative stereotypes about people with intellectual disabilities. *Disability & Society*, 30(3), 368-380.

Unwin, G., LeMesurier, N., Bathia, N., & Deb, S. (2008). Transition for adolescents and young adults with learning disabilities and mental health problems/challenging behaviours: the parent carers' views. *Advances in Mental Health and Learning Disabilities*, 2(1), 22-28.





## Appendix D: Summary and Evaluation of Studies in the Systematic Literature Review.

Title; Location	Participants	Research methodology	Summary of study and key findings	Strengths and Limitations
Bond & Hurst (2009). How adults with ID view living independently.  England, UK.	9 people with “mild ID” who lived on their own, 6 who had moved from other, less independent, residential care settings.	Qualitative study. Participants were interviewed with questions from an Occupational Therapy perspective. Thematic analysis.	Exploratory study of how people view living independently. People reported that overall living independently was better than residential settings. However, it was not without its challenges, for example feeling isolated or vulnerable at times.	The authors appeared to be very thoughtful about service-user involvement in the study, and there was a clear effort to make information about the project accessible.  However, the paper discusses independence as something that people with ID should “achieve” (p.287); there is not a critical analysis of the discourse of independence for this group of people. In addition, it would have been useful to see some examples of the questions posed in the interviews.
Bramston & Cummings (1998). Stress and the move into the community.  Australia.	4 people, 3 moving out of family home for first time, 1 moving from “supervised hostel.”	Mixed methods. 1:1 brief interview (5 minutes), and the Lifestress Inventory (Bramston & Bostock, 1994, cited in Bramston & Cummings, 1998). Met fortnightly for 5 months.	Each individual case is presented separately, highlighting not only the transition but a stressful life event which occurred for each person over the study period (for example illness of a parent). The authors conclude that participants did not feel stress due to the transition. They point to a number of protective factors which could have influenced them including: a sense of ownership over the move; high levels of support and advice; higher sense of control over the situation.	There was a good attempt to situate their findings in an existing theoretical model of stress; and to triangulate questionnaire measures with verbal data.  However, the study does not explain why the research design was chosen; furthermore there was no explanation of how the qualitative data was analysed or selected for the report; there is no explanation of any ethical issues or whether consent was sought from participants.
Brown, Dodd & Vetere (2010). ‘I am a normal man’: a narrative analysis of the accounts of older people with Down’s syndrome	6 older adults (aged 50 – 56) with Downs Syndrome.	Qualitative study. Semi-structured interviews with participants, over three occasions. Analysed using several different narrative approaches.	A narrative analysis was conducted with older people with Down’s Syndrome, to explore how people saw themselves, both in terms of their own identity, and in relation to others.  Participants discussed their lives, and described main themes including loss, the transitions they had experienced, and how	The paper makes explicit use of Elliot et al (1998)’s quality checks; the write-up is of a very high standard. The explanation of the rationale for the choice of a narrative approach is a particular strength of this study, as well as the clear research questions.

<p>who lived in institutionalised settings.</p> <p>England, UK</p>			<p>they made sense of their identities. The authors noted a number of different narrative styles were used by participants in the telling of their stories, although some people were able to provide more coherent life accounts than others.</p>	<p>However, it was not fully clear where participants were recruited from – the author states from a local NHS Trust, but it is not clear whether this was from mental health services.</p>
<p>Ellem (2012). Experiences of leaving prison for people with intellectual disability.</p> <p>Australia.</p>	<p>10 ex-prisoners diagnosed with an Intellectual Disability, who had spent time in non-specialist prisons.</p> <p>Also six “practitioners” in related areas.</p>	<p>Qualitative study. Analysed by “identifying themes” that were “of interest”.</p>	<p>Ex-prisoners described transitions which had been arranged with very little notice, and/or very little planning to support the person after release, both in the short and long term. Within the Queensland system, they were expected to make their own arrangements for living / employment after release. This proved to be very challenging for them – people found themselves without anywhere to live, and/or socially isolated. 8/10 were later re-admitted to forensic services.</p>	<p>A key strength was how data was member-checked by participants, and then further interviews were undertaken with practitioners to triangulate the data. (Though it would have been beneficial to have further details on the professions of these practitioners, and their relationships to the main participants.)</p> <p>Furthermore, it is not clear how the data was analysed. The author does not discuss using a systematic approach. She describes identifying “themes of interest” which, without a statement of her own position to the work, do not make it clear how themes were developed.</p>
<p>Ellem, Wilson &amp; Chui (2012). Effective responses to offenders with ID: generalist and specialist services working together.</p> <p>Australia</p>	<p>10 people, 7 men 3 women. Interviewed on average 4 times over 12 months on transition from prison in Queensland, Australia</p>	<p>Qualitative study. Interviews with participants plus with staff. Analysed narratively then thematically.</p>	<p>The paper explores reasons why people with ID may find themselves in forensic services. Also what life is like in prison for them - they may be more vulnerable to exploitation or abuse, may struggle with mental health difficulties and may find it hard to engage with rehabilitation programmes which have not been adapted to their needs. People also described their lives after prison. They encountered a lack of coherence in the services they received, as well as stigma and fewer opportunities. The paper concludes with recommendations for balancing specialist</p>	<p>The paper attempted to situate the sample by clearly stating throughout how many participants had contributed to each theme from the analysis. The authors also have drawn sound and critical conclusions from their findings, including excellent suggestions for service delivery.</p> <p>However, the analysis used is unclear – the paper reports that data was analysed “initially using a narrative approach and then analysed thematically” but it would be beneficial for the reader for further explanation of the steps used.</p>

			and generic services in Australia, emphasising the importance of relationships and clear goals for support.	The authors do not make explicit their own positions, or how these might impact on the analysis.
Forrester-Jones et al (2002). The quality of life of people 12 years after resettlement from long stay hospitals: Users' views on their living environment, daily activities and future aspirations.  England, UK	196 people with ID contributed to interviews about their lives now, 12 years following resettlement as part of the ' <i>care in the community</i> ' project in England in the 1980s. (also interviewed 128 people with mental health problems who also moved).	Qualitative study. Open interview questions with the participants. Thematic analysis.	This large scale study reported on aspects of life enjoyed and not enjoyed by people with ID and people with long term MH problems who had been deinstitutionalised. People reported enjoying the new home environment, the relationships they had with other residents and staff, and new levels of independence. However, people reported that sometimes their home was still restrictive (e.g. set bedtimes), and they did not always get on with other tenants.	One of the strengths of the study is that rather than use questions pre-set by the researchers, the authors organised focus-groups to determine what questions would be valuable to ask participants. The very large sample size is also noteworthy.  However, it is not clear from the paper how participants were recruited, or whether (and how) consent was sought from participants. Furthermore, participants with mental health difficulties and those with ID have been reported on together, without consideration of the idiosyncratic differences in community living that may affect these groups. It is also unclear whether some participants had both ID and mental health difficulties. Although it was useful to see demographics on where people are living now, other demographics such as age and gender were not reported.
Hamilton & Atkinson (2009). 'A story to tell': learning from the life stories of older people with ID in Ireland.  Republic of Ireland.	11 people aged 54 and over, interviewed about their experiences in care.	Interviews.  Life story work – data not analysed systematically.	The authors share excerpts from some life story work undertaken to gain further understanding of people with ID's lives in Ireland during the 20 <sup>th</sup> century. Quotations are used to illustrate people's experiences of being controlled, and of experiencing kindness from others.	The authors have clearly demonstrated respect for participants, through a thorough explanation of their ethics process, and through checking data credibility with participants.  However, it is not clear from the paper how the data was analysed – it does not appear to have been done systematically. The authors have not acknowledged their own positions and how these could have impacted on the conclusions drawn.

<p>Holland, A., &amp; Meddis, R. (1997). People living in community homes: their views. <i>British Journal of Learning Disabilities</i>, 25(2), 68-72.</p> <p>England, UK.</p>	<p>Six people with ID, aged between 21 – 42 years. All participants were living in the community, having moved from a family home, hospital or other care setting.</p>	<p>Qualitative research. Researchers used an adapted version of the structured Service User Interview (Conroy &amp; Bradley, 1985, cited in Holland &amp; Meddis, 1997); there were also opportunities for more open discussion on topics the participant and/or researcher felt were relevant. Participants were interviewed on at least 6 occasions. Unclear what analysis was used.</p>	<p>The paper reports that there were four main themes that came up when people described their feelings about their present living arrangements: one was to do with knowing about alternatives to their present setting, the other three were concerned with the quality of relationships – with staff, with other tenants, and with people outside of the service. The paper reported three case studies to illustrate three people with positive, mixed and negative feelings about where they lived currently.</p>	<p>The researchers have made explicit attempts to account for the validity of the data; for example, in the use of question types, in using reversed closed questions to check for acquiescence, and in discussing topics at least twice to check for consistency over time.</p> <p>However, the method of analysis is unclear. The use of coding statements as positive, negative or neutral may have over-simplified people's complex meaning making around their experiences. Furthermore, the presentation of case studies limits how many voices contribute to the paper, and there is sparse use of direct quotations.</p>
<p>Hubert &amp; Hollins (2010). A Study of Post-Institutionalized Men With Severe Intellectual Disabilities and Challenging Behaviour.</p> <p>England, UK.</p>	<p>17 men with “profound to severe ID”, alongside behaviour which challenges, mental health problems and/or autism. All had been in hospital since childhood; age range 29-46. Family members of 11 men were interviewed as well.</p>	<p>Ethnographic study. The researchers spent significant time with the men in hospital before it closed. They were then visited over a six year period in their new residences. Their medical files were also used as data.</p>	<p>For the men who moved into a campus residence, which has only had one manager since the transition, their quality of life appears to have increased, and they appear relatively settled, with their individual strengths built on. Ten men moved into 2x 5-bed houses in the community, but also endured a two year wait in temporary accommodation.</p>	<p>A real strength of this study is the respect and value afforded to the participants. Information from the first part of the study, in the hospital, was used reflexively to inform their transitions, in developing care plans and sharing knowledge with the new staff teams around the men.</p>
<p>Isaacson, Cocks, &amp; Netto (2014). Launching: The experiences of</p>	<p>2 young people (aged 21 and 25) who were leaving home for the first</p>	<p>Qualitative study. Data gathered through “interviews, participant</p>	<p>The analysis constructed 5 main themes: “transitioning to adult roles; parent involvement; sibling involvement; use of</p>	<p>The paper describes a very clear methodology, including an ‘audit trail’ of data collection, and section on “methodological rigour” (p.273).</p>

<p>two young adults with intellectual disability and their families in transition to individual supported living.</p> <p>Australia.</p>	<p>time, and their families (both sets of parents; one young person's sister).</p>	<p>observation and documentation" (p.272). Thematic analysis.</p>	<p>supports outside the immediate family; planning and the future" (p. 274).</p> <p>Findings suggested there is a re-negotiation of relationships in families when a young person moves out – parents may face the loss of a caregiver role, and the young person has to take on the role of being more independent.</p>	<p>Discussion of the researchers' own reflexivity was a particular strength of the study.</p> <p>The study was limited by the small sample size; however the authors noted that the findings related to previous research in the area and could therefore potentially be generaliseable.</p>
<p>Jahoda &amp; Markova (2004). Coping with social stigma: people with ID moving from institutions and family home.</p> <p>Scotland, UK.</p>	<p>28, of which 18 were moving to the community from long-stay hospital accommodation; 10 moved from the family home to a group home.</p>	<p>Qualitative study. Semi-structured interviews. Analysed using content analysis, followed by a 'participant-observer approach' used by Edgerton (1984, 1967, cited in Jahoda &amp; Markova, 2004)</p>	<p>The study explored how people make sense of their new identities in the community, and manage stigma towards them. Some people did this by emphasising the distance and differences between themselves and other people with ID; whereas others found it helpful to describe a sense of community with other people with ID who had similar experiences. People who had lived in hospital described a sense of being 'cut off' from the outside world. A number of people felt that moving out of hospital was a chance "to become a different kind of person."</p>	<p>The paper sets up a clear rationale for the research, and has a good sample size. The findings appear to make a valuable contribution to the field, and some clear theoretical links are made to understand the findings of the study.</p> <p>However, although it was noted that 11/18 hospital participants had lived there for "the majority of their lives" (p721) it was not clear how long this was, or the range in length of stays. Furthermore, it may have been interesting to separate the findings from those with long and shorter hospital placements, to see whether this influenced their reports of managing stigma.</p>
<p>Johnson (1998). Deinstitutionalisation: the management of rights.</p> <p>Australia.</p>	<p>22 women on a locked ward denoted to have "ID and challenging behaviours."</p>	<p>Qualitative study. 20 month ethnographic study – observations, discussions and examination of patient files. Content and thematic analyses were used.</p>	<p>The author discusses the conflict during deinstitutionalisation of getting a balance between the discourses of 'management' of people, and their 'rights'. People were consulted on decisions but this appeared to often be superficial. People were assessed as to whether they would 'fit in' with existing alternative services, rather than this process happening the other way round for a truly person-centred approach. Staff</p>	<p>Very robust and comprehensive study, which has made clear efforts to include all the women on the ward in the study. The author makes strong and logical theory links to make sense of the findings, and has suggested practical applications for staff and service providers.</p> <p>However, it is not clear from the paper how participant consent was sought or assessed.</p>

			working with the women often failed to take into account the context from which people came, e.g. their background, past experiences of loss, how the current move might be impacting on them.	
Leaning & Adderley (2015). From long-stay hospitals to community care: reconstructing the narratives of people with learning disabilities.  England, UK.	1 man with “severe and profound ID, autism spectrum disorder and severe challenging behaviour” who has moved as part of Transforming Care.	Narrative case study.	The primary author discusses his involvement in supporting someone leave hospital after 46 years, as part of Transforming Care. He discusses the challenges	This paper is not a research paper, but was included in the literature review as the only paper in the literature regarding a transition under Transforming Care.
Owen, Hubert & Hollins (2007). Moving home: the experiences of women with severe ID in transition from a locked ward.  England, UK.	11 women, “most with severe ID.” Many women had MH difficulties and “all were said to have had ‘challenging behaviour’.”	Qualitative study. 18 month ethnographic study – in depth participant observation; and interviews with some participants. Grounded theory analysis.	The women had to move out when a hospital was shut down. 8 moved to a home on the hospital grounds, where many restrictions of the ward remained. 3 moved to houses in the community, and on the whole experienced more choice and improvement of day to day life. Overall the women were not involved in choices about their move or prepared for the transition, which they found stressful. Staff often found it hard to understand the impact a transition would have for the women.	A strong study with a clear rationale, and well-explained and thought-through research methodology. The authors also generate some very thoughtful practical implications from the research outcomes.  However, it may have been beneficial to have a visual representation of the grounded theory model to illustrate how the constructs fitted together.
Sheerin, Griffiths, de Vries & Keenan (2015).	5 “middle to older age individuals (3F, 2M) with mild to	Qualitative study. Semi-structured interviews with participants.	Residents moved from a “service-based congregated setting into a community-based home.” Overall the transition was	The authors provide a clear data collection trail which could be replicated. Additionally, the

<p>An evaluation of community living in Ireland.</p> <p>Republic of Ireland.</p>	<p>moderate ID.” Ireland.“ Relatives of 2 of these people also participated.</p>	<p>Thematic analysis.</p>	<p>well-managed and most people reported being involved with making choices and decisions. Participants reported a sense of pride in having their own home, and enjoyed the new independence they felt. However, they also reported feeling less secure, and had little social integration into the community.</p>	<p>research findings are well grounded in examples, with a range of illustrative quotations.</p> <p>However, the authors do not reflect on their own positions in relation to the data or analysis. From the write-up it could be assumed they take a positivist position, but this could have been more explicitly stated. A further critique is the level of depth of analysis undertaken: they do not explore in much detail people’s possible meaning making behind moving into the community, rather it focuses on more practical issues (which are nonetheless very useful to hear about).</p>
<p>van Dooren, Young, Claudio, Cumming, Lennox (2017). Understanding the transition out of prison for people with intellectual disability.</p> <p>Australia.</p>	<p>17 stakeholders and 6 people with ID were interviewed about experiences of leaving mainstream prison services.</p>	<p>Qualitative study. Semi structured interviews. Stakeholder data was analysed by thematic analysis. However the data from people with ID was not analysed systematically.</p>	<p>Key stakeholders identified a number of specific needs of people with ID who are discharged from prison. This included managing the complexity of multiple difficulties such as social disadvantages and health problems. They identified a number of systemic problems in community support which can be barriers to addressing these needs.</p> <p>People with ID reported that leaving prison could be an ‘overwhelming’ experience, and people reported that they often were not supported in the move.</p>	<p>The report sets out clear intentions, and is a worth addition to the field, which has been under-researched in seeking information about the experiences of this client group. There was a valuable discussion of the barriers to recruitment which could be useful for other researchers in the field.</p> <p>However, in this report, the data was not analysed, but rather is grouped in general themes. A more systematic analysis (thematic analysis) was used in an associated published article but this did not include the data from people with ID. Although six people were interviewed, quotations are only included from four participants, and the rationale for this is not clear.</p>

Table D1: displaying summaries and evaluation of the literature review.



**Appendix E: In-depth evaluation of two sample papers from the systematic literature review.**

Bond, R. J., & Hurst, J. (2010). How adults with learning disabilities view living independently. *British Journal of Learning Disabilities*, 38(4), 286-292.

<b>Criteria (Mays &amp; Pope, 2000).</b>	<b>Evidence for meeting criteria</b>
Worth or relevance—Was this piece of work worth doing at all? Has it contributed usefully to knowledge?	Yes – the paper adds to the current (sparse) understanding of independent living for people with ID
Clarity of research question—If not at the outset of the study, by the end of the research process was the research question clear? Was the researcher able to set aside his or her research preconceptions?	This was clearly stated
Appropriateness of the design to the question—Would a different method have been more appropriate? For example, if a causal hypothesis was being tested, was a qualitative approach really appropriate?	The method was appropriate to answer an exploratory question
Context—Is the context or setting adequately described so that the reader could relate the findings to other settings?	The context of the study was described in adequate detail.
Sampling—Did the sample include the full range of possible cases or settings so that conceptual rather than statistical generalisations could be made (that is, more than convenience sampling)? If appropriate, were efforts made to obtain data that might contradict or modify the analysis by extending the sample (for example, to a different type of area)?	Not fully met – the project used convenience sampling. The participants did seem to represent a range of view however (e.g. there were mixed views about living independently).
Data collection and analysis—Were the data collection and analysis procedures systematic? Was an “audit trail” provided such that someone else could repeat each stage, including the analysis? How well did the analysis succeed in incorporating all the observations? To what extent did the analysis develop concepts and categories capable of explaining key processes or respondents’ accounts or observations? Was it possible to follow the iteration between data and the explanations for the data (theory)? Did the researcher search for disconfirming cases?	The details on data collection were somewhat lacking for this report. It would have been beneficial to see some examples of interview questions, for example. Also the interview process was not described – i.e. length of interview, how many times they met, where they took place etc.
Reflexivity of the account—Did the researcher self-consciously assess the likely impact of the methods used on the data obtained? Were sufficient data included in the reports of the study to provide sufficient evidence for readers to assess whether analytical criteria had been met?	The researchers do not explicitly state their position to the research. They discuss ‘achievement’ of independence, without critical analysis of this dominant discourse.
<b>Criteria (Elliot, Fischer &amp; Rennie (1998)</b>	<b>Evidence for meeting criteria</b>
<i>Explicit scientific context and purpose.</i> The manuscript specifies where the study fits within relevant literature and states the intended purposes or questions of the study.	Yes- the report fits into an Occupational Therapy framework for supporting independent living.
<i>Appropriate methods.</i> The methods and procedures used are appropriate or responsive to the intended purposes or questions of the study.	Yes appropriate and justified.
<i>Respect for participants.</i> Informed consent, confidentiality, welfare of the participants, social responsibility, and other ethical principles are fulfilled. Researchers creatively adapt	Very good – the researchers were clearly thoughtful about service user involvement. They describe in detail the consent

their procedures and reports to respect both their participants' lives, and the complexity and ambiguity of the subject matter.	process, as well as the options they gave of offering accessible information to participants.
<i>Specification of methods.</i> Authors report all procedures for gathering data, including specific questions posed to participants. Ways of organizing the data and methods of analysis are also specified. This allows readers to see how to conduct a similar study themselves, and to judge for themselves how well the reported study was carried out.	Specific questions were not presented; however these were based on a pre-existing Occupational Therapy questionnaire, which is referenced so the reader could refer to this if needed.
<i>Appropriate discussion.</i> The research data and the understandings derived from them are discussed in terms of their contribution to theory, content, method, and} or practical domains, and are presented in appropriately tentative and contextualized terms, with limitations acknowledged.	Good – the researchers discuss appropriate limitations to their study, as well as some useful clinical implications.
<i>Clarity of presentation.</i> The manuscript is well-organized and clearly written, with technical terms defined.	The authors have combined the results and discussion sections; in this context it made sense to do this and reads coherently.
<i>Contribution to knowledge.</i> The manuscript contributes to an elaboration of a discipline's body of description and understanding.	The research generates useful insights into how health and mental health can link into independent living; there are also important discussions about the impact of stigma in people's lives.
1. <i>Owning one's perspective.</i> Authors specify their theoretical orientations and personal anticipations, both as known in advance and as they became apparent during the research. In developing and communicating their understanding of the phenomenon under study, authors attempt to recognize their values, interests and assumptions and the role these play in the understanding. This disclosure of values and assumptions helps readers to interpret the researchers' data and understanding of them, and to consider possible alternatives.	The author discusses keeping a research diary though the process, which indicates a reflection of their own perspective. However, it could have been useful to have a few sentences on <i>how</i> this influenced the process. There is no clear explanation of the researchers' assumptions or values, and how these might have influenced their findings.
<i>Situating the sample.</i> Authors describe the research participants and their life circumstances to aid the reader in judging the range of people and situations to which the findings might be relevant.	The participants were well described. However, it may have also been useful to know why people had moved from more supported living, and how long ago.
3. <i>Grounding in examples.</i> Authors provide examples of the data to illustrate both the analytic procedures used in the study and the understanding developed in the light of them. The examples allow appraisal of the fit between the data and the authors' understanding of them; they also allow readers to conceptualize possible alternative meanings and understandings.	The quotations are illustrative of the analytic interpretations and themes.
<i>Providing credibility checks.</i> Researchers may use any one of several methods for checking the credibility of their categories, themes or accounts. Where relevant, these may include (a) checking these understandings with the original informants or others similar to them; (b) using multiple qualitative analysts, an additional analytic 'auditor', or the original analyst for a 'verification step' of reviewing the data for discrepancies, overstatements or errors; (c) comparing two or more varied qualitative perspectives, or (d) where appropriate, 'triangulation' with external factors (e.g. outcome or recovery) or quantitative data.	The authors acknowledge they would have liked to check their data with participants but did not have sufficient time. The first author described using supervision and their mentor for advice.
<i>Coherence.</i> The understanding is represented in a way that achieves coherence and integration while preserving nuances in the data. The understanding fits together to form a data-based story} narrative, 'map', framework, or underlying structure for the phenomenon or domain.	The results were presented coherently, under seven themes. It might have been interesting to have explored how some of the themes linked together. For example one participant discussed both 'loneliness' and stigma associated with 'the impact of having a learning disability'; it could have been useful to draw links between these two phenomena.
<i>Accomplishing general vs. specific research tasks.</i> Where a general understanding of a phenomenon is intended, it is	The researchers acknowledged that it was a relatively small sample, which limits its generalisability.

<p>based on an appropriate range of instances (informants or situations). Limitations of extending the findings to other contexts and informants are specified. Where understanding a <i>specific</i> instance or case is the goal, it has been studied and described systematically and comprehensively enough to provide the reader a basis for attaining that understanding. Such case studies also address limitations of extending the findings to other instances</p>	
<p><i>Resonating with readers.</i> The manuscript stimulates resonance in readers} reviewers, meaning that the material is presented in such a way that readers} reviewers, taking all other guidelines into account, judge it to have represented accurately the subject matter or to have clarified or expanded their appreciation and understanding of it.</p>	<p>A well thought through and interesting paper, with findings relevant to community Occupational Therapy work. It would have resonated with me somewhat more if some of the psychological aspects of moving had been explored further (e.g. as suggested above) but I am aware this was not within the remit of the paper.</p>

Table E1: Evaluation of the study by Bond & Hurst (2009)

Jahoda, A., & Markova, I. (2004). Coping with social stigma: People with intellectual disabilities moving from institutions and family home. *Journal of intellectual disability research*, 48(8), 719-729.

Criteria (Mays & Pope, 2000).	Evidence for meeting criteria
Worth or relevance—Was this piece of work worth doing at all? Has it contributed usefully to knowledge?	A relevant research project, into stigma which is an under-known area.
Clarity of research question—If not at the outset of the study, by the end of the research process was the research question clear? Was the researcher able to set aside his or her research preconceptions?	Very clearly stated
Appropriateness of the design to the question—Would a different method have been more appropriate? For example, if a causal hypothesis was being tested, was a qualitative approach really appropriate?	The method was appropriate to the question.
Context—Is the context or setting adequately described so that the reader could relate the findings to other settings?	The context was very well described.
Sampling—Did the sample include the full range of possible cases or settings so that conceptual rather than statistical generalisations could be made (that is, more than convenience sampling)? If appropriate, were efforts made to obtain data that might contradict or modify the analysis by extending the sample (for example, to a different type of area)?	This study had a very good sample size of 28. There was a robust approach to participant selection described.
Data collection and analysis—Were the data collection and analysis procedures systematic? Was an “audit trail” provided such that someone else could repeat each stage, including the analysis? How well did the analysis succeed in incorporating all the observations? To what extent did the analysis develop concepts and categories capable of explaining key processes or respondents’ accounts or observations? Was it possible to follow the iteration between data and the explanations for the	The authors describe in great detail how data was collected. However, it would have been useful to have more information on how the content analysis was conducted.

data (theory)? Did the researcher search for disconfirming cases?	
Reflexivity of the account—Did the researcher self-consciously assess the likely impact of the methods used on the data obtained? Were sufficient data included in the reports of the study to provide sufficient evidence for readers to assess whether analytical criteria had been met?	This was not present in the report.
<b>Criteria (Elliot, Fischer &amp; Rennie, 1998)</b>	<b>Evidence for meeting criteria</b>
<i>Explicit scientific context and purpose.</i> The manuscript specifies where the study fits within relevant literature and states the intended purposes or questions of the study.	This was very clear.
<i>Appropriate methods.</i> The methods and procedures used are appropriate or responsive to the intended purposes or questions of the study.	These were very appropriate to the research question.
<i>Respect for participants.</i> Informed consent, confidentiality, welfare of the participants, social responsibility, and other ethical principles are fulfilled. Researchers creatively adapt their procedures and reports to respect both their participants' lives, and the complexity and ambiguity of the subject matter.	Very good – the authors described spending significant periods of time with participants to help them to feel comfortable in the research process.
<i>Specification of methods.</i> Authors report all procedures for gathering data, including specific questions posed to participants. Ways of organizing the data and methods of analysis are also specified. This allows readers to see how to conduct a similar study themselves, and to judge for themselves how well the reported study was carried out.	The authors describe in great detail how data was collected. However, it would have been useful to have more information on how the content analysis was conducted.
<i>Appropriate discussion .</i> The research data and the understandings derived from them are discussed in terms of their contribution to theory, content, method, and) or practical domains, and are presented in appropriately tentative and contextualized terms, with limitations acknowledged.	Good – there were thoughtful and critical links to the existing literature to make sense of the results.
<i>Clarity of presentation.</i> The manuscript is well-organized and clearly written, with technical terms defined.	The report was well structured.
<i>Contribution to knowledge.</i> The manuscript contributes to an elaboration of a discipline's body of description and understanding.	Clearly added to the body of existing research.
<i>Owning one's perspective.</i> Authors specify their theoretical orientations and personal anticipations, both as known in advance and as they became apparent during the research. In developing and communicating their understanding of the phenomenon under study, authors attempt to recognize their values, interests and assumptions and the role these play in the understanding. This disclosure of values and assumptions helps readers to interpret the researchers' data and understanding of them, and to consider possible alternatives.	This was not clearly done.
<i>Situating the sample.</i> Authors describe the research participants and their life circumstances to aid the reader in	Yes very good

judging the range of people and situations to which the findings might be relevant.	
<i>Grounding in examples.</i> Authors provide examples of the data to illustrate both the analytic procedures used in the study and the understanding developed in the light of them. The examples allow appraisal of the fit between the data and the authors' understanding of them; they also allow readers to conceptualize possible alternative meanings and understandings.	The examples given were very useful in illustrating the researchers' findings. However, examples were not given for every theme.
<i>Providing credibility checks.</i> Researchers may use any one of several methods for checking the credibility of their categories, themes or accounts. Where relevant, these may include (a) checking these understandings with the original informants or others similar to them; (b) using multiple qualitative analysts, an additional analytic 'auditor', or the original analyst for a 'verification step' of reviewing the data for discrepancies, overstatements or errors; (c) comparing two or more varied qualitative perspectives, or (d) where appropriate, 'triangulation' with external factors (e.g. outcome or recovery) or quantitative data.	This was not mentioned in the report.
<i>Coherence.</i> The understanding is represented in a way that achieves coherence and integration while preserving nuances in the data. The understanding fits together to form a data-based story} narrative, 'map', framework, or underlying structure for the phenomenon or domain.	The report is well written and clear.
<i>Accomplishing general vs. specific research tasks.</i> Where a <i>general</i> understanding of a phenomenon is intended, it is based on an appropriate range of instances (informants or situations). Limitations of extending the findings to other contexts and informants are specified. Where understanding a <i>specific</i> instance or case is the goal, it has been studied and described systematically and comprehensively enough to provide the reader a basis for attaining that understanding. Such case studies also address limitations of extending the findings to other instances	In the discussion, the writers talk about the participants' experiences, rather than implying the results are about all people with ID. However, there is no clear statement of how / whether this could be generalised.
<i>Resonating with readers.</i> The manuscript stimulates resonance in readers} reviewers, meaning that the material is presented in such a way that readers} reviewers, taking all other guidelines into account, judge it to have represented accurately the subject matter or to have clarified or expanded their appreciation and understanding of it.	This was an interesting and thought provoking paper.

Table E2: Evaluation of the study by Jahoda and Markova (2004).

## Appendix F: Evaluation of the Present Study

As noted in the section 2.1.1.1, the criteria suggested by Elliot, Fischer and Rennie (1999) and Mays and Pope (2000) were used throughout the research procedure and writing of the present report to evaluate the quality of this thesis. A summary is below in table F1.

<b>Criteria (Mays &amp; Pope, 2000).</b>	<b>Evidence for meeting criteria</b>
Worth or relevance—Was this piece of work worth doing at all? Has it contributed usefully to knowledge?	The literature review revealed that there has so far been little research into this field, therefore the research was worthwhile and timely.
Clarity of research question—If not at the outset of the study, by the end of the research process was the research question clear? Was the researcher able to set aside his or her research preconceptions?	The research question was clearly stated at the end of the first chapter. The broad questions used during interviews (in appendix T) demonstrate that I came to the topic with an open mind and not pre-fixed agenda.
Appropriateness of the design to the question—Would a different method have been more appropriate? For example, if a causal hypothesis was being tested, was a qualitative approach really appropriate?	The rationale for Grounded Theory was clearly stated in the Methods chapter. I also clearly considered other methodologies before deciding on GT.
Context—Is the context or setting adequately described so that the reader could relate the findings to other settings?	The context of all participants is clearly described in the Method chapter, with sufficient information about client backgrounds and settings so as to make the findings relatable.
Sampling—Did the sample include the full range of possible cases or settings so that conceptual rather than statistical generalisations could be made (that is, more than convenience sampling)? If appropriate, were efforts made to obtain data that might contradict or modify the analysis by extending the sample (for example, to a different type of area)?	The sample demonstrates cases from a variety of different backgrounds, as recommended by GT methodology. Efforts were made to find participants who might contradict the model – ie Darling, whose placement had broken down.
Data collection and analysis—Were the data collection and analysis procedures systematic? Was an “audit trail” provided such that someone else could repeat each stage, including the analysis? How well did the analysis succeed in incorporating all the observations? To what extent did the analysis develop concepts and categories capable of explaining key processes or respondents’ accounts or observations? Was it possible to follow the iteration between data and the explanations for the data (theory)? Did the researcher search for disconfirming cases?	The Method chapter describes a clear process of how the data was collected, with a step-by-step description. Furthermore, the analysis of the data was also described in adequate detail to illuminate how I went through the GT process, with examples both in the main body of the report, with additional references in the appendices (e.g. Appendix U).
Reflexivity of the account—Did the researcher self consciously assess the likely impact of the methods used on the data obtained? Were sufficient data included in the reports of the study to provide sufficient evidence for readers to assess whether analytical criteria had been met?	My epistemological position was clearly stated at the beginning of the report. How this position influenced the process of research was also reflected on throughout the report at appropriate points. The quotations used in the Results chapter covered all the participants, and demonstrated the breadth of data that contributed to the resulting model.
<b>Criteria (Elliot, Fischer &amp; Rennie (1998)</b>	<b>Evidence for meeting criteria</b>
<i>Explicit scientific context and purpose.</i> The manuscript specifies where the study fits within relevant literature and states the intended purposes or questions of the study.	The literature review demonstrated that there was currently a paucity of research in this field, therefore the rationale for the present study was clearly identified.

<p><i>Appropriate methods.</i> The methods and procedures used are appropriate or responsive to the intended purposes or questions of the study.</p>	<p>The research set out to explore peoples' experiences, hence the method was appropriate for this purpose. This rationale is clearly explained in the Method chapter</p>
<p><i>Respect for participants.</i> Informed consent, confidentiality, welfare of the participants, social responsibility, and other ethical principles are fulfilled. Researchers creatively adapt their procedures and reports to respect both their participants' lives, and the complexity and ambiguity of the subject matter.</p>	<p>The consent procedures were thoroughly thought through, and clearly described in the Method chapter. There is a clear explanation that adaptations were made to suit participants, and an example plan is presented in appendix S. In addition I reflected on their own position of relative power throughout the report, which further demonstrates respect for the participants. Respect for the ambiguity and complexity of the subject matter is demonstrated through the use of memoing while data was being analysed, as shown in appendix V.</p>
<p><i>Specification of methods.</i> Authors report all procedures for gathering data, including specific questions posed to participants. Ways of organizing the data and methods of analysis are also specified. This allows readers to see how to conduct a similar study themselves, and to judge for themselves how well the reported study was carried out.</p>	<p>The example question guide is shown in appendix T Furthermore, examples of how codes were sorted is given in the Method section, as well as in appendix U.</p>
<p><i>Appropriate discussion .</i> The research data and the understandings derived from them are discussed in terms of their contribution to theory, content, method, and} or practical domains, and are presented in appropriately tentative and contextualized terms, with limitations acknowledged.</p>	<p>The Discussion chapter focuses on how the findings fit with psychological theory, and with previous similar research. Clinical implications are tentatively suggested, and the limitations of the project are discussed.</p>
<p><i>Clarity of presentation.</i> The manuscript is well-organized and clearly written, with technical terms defined.</p>	<p>The terms used throughout the report are defined at the start of the first chapter. Efforts have clearly been made to organise the report in a logical and sequential manner.</p>
<p><i>Contribution to knowledge.</i> The manuscript contributes to an elaboration of a discipline's body of description and understanding.</p>	<p>The study is unique within the literature and the findings can be seen as contributing to the relatively new are of work under the Transforming Care agenda.</p>
<p><i>Owning one's perspective.</i> Authors specify their theoretical orientations and personal anticipations, both as known in advance and as they became apparent during the research. In developing and communicating their understanding of the phenomenon under study, authors attempt to recognize their values, interests and assumptions and the role these play in the understanding. This disclosure of values and assumptions helps readers to interpret the researchers' data and understanding of them, and to consider possible alternatives.</p>	<p>My personal perspective on the project is described at the beginning, which sets the scene for the rest of the project, Further reflections on the process and my expectations are also at appropriate points during the project.</p>
<p><i>Situating the sample.</i> Authors describe the research participants and their life circumstances to aid the reader in judging the range of people and situations to which the findings might be relevant.</p>	<p>Adequate information about the participants is given in the Method chapter.</p>
<p><i>Grounding in examples.</i> Authors provide examples of the data to illustrate both the analytic procedures used in the study and the understanding developed in the light of them. The examples allow appraisal of the fit between the data and the authors' understanding of them; they also allow readers to conceptualize possible alternative meanings and understandings.</p>	<p>A wide range of example quotations are used throughout the Results chapter to illustrate the model.</p>
<p><i>Providing credibility checks.</i> Researchers may use any one of several methods for checking the credibility of their categories, themes or accounts. Where relevant, these may include (a) checking these understandings with the original informants or others similar to them; (b) using multiple qualitative analysts, an additional analytic 'auditor ', or the original analyst for a 'verification step ' of reviewing the data for discrepancies, overstatements or errors; (c) comparing two or more varied qualitative perspectives, or (d)</p>	<p>A number of methods were used assure the analysis had credibility:</p> <ul style="list-style-type: none"> <li>● In the Method chapter, I described attending regular GT workshops with fellow trainees, where I regularly shared the stages of my analysis and adapted to feedback.</li> <li>● I also met regularly with my supervisors to talk through the analysis.</li> <li>● The methodology in itself could be seen as a way of triangulating the data, as the KSPs added an extra layer to the stories given by participants.</li> </ul>

<p>where appropriate, 'triangulation' with external factors (e.g. outcome or recovery) or quantitative data.</p>	<ul style="list-style-type: none"> <li>• The final participant and KSP were invited to review the model ahead of our interview, and discussed how well this fit with their experiences.</li> </ul>
<p><i>Coherence.</i> The understanding is represented in a way that achieves coherence and integration while preserving nuances in the data. The understanding fits together to form a data-based story} narrative, 'map', framework, or underlying structure for the phenomenon or domain.</p>	<p>The GT model displayed in the Results chapter provides a coherent model which is easily understandable in pictorial form. The chapter then goes on to expand the model with illustrative quotations, so nuances to the results are not lost.</p>
<p><i>Accomplishing general vs. specific research tasks.</i> Where a <i>general</i> understanding of a phenomenon is intended, it is based on an appropriate range of instances (informants or situations). Limitations of extending the findings to other contexts and informants are specified. Where understanding a <i>specific</i> instance or case is the goal, it has been studied and described systematically and comprehensively enough to provide the reader a basis for attaining that understanding. Such case studies also address limitations of extending the findings to other instances</p>	<p>In the Discussion chapter I discuss the limitations of the project which could limit its generalisation to other people. The Method chapter clearly states why the number of participants was chosen.</p>
<p><i>Resonating with readers.</i> The manuscript stimulates resonance in readers} reviewers, meaning that the material is presented in such a way that readers} reviewers, taking all other guidelines into account, judge it to have represented accurately the subject matter or to have clarified or expanded their appreciation and understanding of it.</p>	<p>I hope that the report has been thought provoking to read, and has expanded the readers' appreciation and understanding of the subject matter.</p>

Table F1: Summary of how the present study meets quality evaluation criteria.



## Appendix G: Examples of Prompts Used in the Research

The Photosymbols website was used to find pictures of things that could generate conversation about people's lives in hospital, during the move, and in their new home. Some examples are provided here.

Figure G1: Examples of pictures used during interviews.

## Appendix H: An Example of Talking Mats

As noted in section 2.1.4 in the main body, Talking Mats were used for one participant (Murphy, Cameron, Markova & Watson, 2004). Talking Mats comprises of simple pictures and symbols, which can be used by people with communication difficulties. In the present study, the symbols were used to prompt discussion on topics relevant to the research. Examples are displayed in image H1 below.

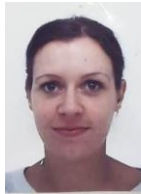


Image H1 – Example of Talking Mat created by one participant on topics to do with their new home.

## Appendix I: Initial Information Sheet for Participants



# Would you like to help find things out about moving out of hospital?



My name is Annabel. I am training to be a Clinical Psychologist at the University of Hertfordshire.



I want to find things out about people who have moved out of hospital into their own home.



I would like to listen to their stories.



If you think you might be interested, I can come to talk to you.

If there is anything else you want to know you can contact me:



**Annabel Head**

Trainee Clinical Psychologist

Telephone number: xxxx

Email: xxxx

## Appendix J: Full Information Sheet

# Would you like to help find things out about moving out of hospital?



My name is Annabel. I am training to be a Clinical Psychologist. I am doing my training at the University of Hertfordshire.



I want us to find things out about people who have moved out of hospital.



This sheet has information for you if you think you might want to take part. It is important you read this to help you think about what you would like to do.

### Contents

1. What do we want to find out?
2. How will we find things out?
3. Saying 'yes' or 'no'.
4. More details if you want to say 'yes'

5. What happens after taking part?

6. Who can I contact?

If there is anything else you want to know you can contact me. My contact details are at the end.



## 1. What do we want to find out?

Transforming Care is a plan by the government to help people move out of hospital. It helps them to live in their own home.



I would like to hear the stories of people who have moved out of hospital.



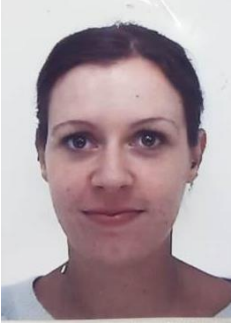
An Ethics Committee has said it is OK to find things out about this.



We will start finding things out now. We will finish next summer, in 2017.



## 2. How will we find things out?



If you want to take part, I will come and visit you two times. This is so that I can talk to you more about taking part.



I will ask you if it is ok for me to speak to someone who knows you well. This might be a family member or a carer. I would like to talk to them about the best ways we can work together.



You can ask me questions.



We will make a plan together about how we will find things out.



We will have our first meeting on our own. This will be an "interview".



I might ask you questions about what happened when you went to hospital and what happened afterwards.



We will have a second interview. You can choose if you want someone who knows you well to come to our second meeting. I will ask them questions too.



Or we will have our second interview on our own. It is up to you.



The information you talk to me about is private. In the reports I will not use your name so no one will be able to know it is about you. This means it is 'confidential.'



### 3. Saying 'yes' or 'no'.

You do not have to take part. It is your choice. It is up to you to decide.



You can talk to other people to help you choose.



If you want to take part I will ask you to sign a consent form. This means saying "yes, I agree."



If you do not want to take part you can say "no."



Even if you have already said "yes", you can say "no" later on.





You do not have to give a reason for saying “no”.  
Saying “no” will not change how people treat you.



If you chose to say “no” at any time you can contact me to tell me.



We can talk about what we will do if you have already talked to me about moving out of hospital.

## 4. More details if you want to say 'yes'



So that I can hear your story, it is important we meet on our own for the first interview.



But it is ok for someone you know to be around, maybe outside the door or in the next room.



I will interview you by asking you questions.



We might also use pictures and questionnaires together to help you answer the questions.



We might talk for up to one hour.



I will record the interview on a recorder.



I will check if it is ok to come back another time so we can talk more.

We will make a date to meet again.



You can choose if you want someone with you for your second interview.

If you choose 'yes' you would like someone with you, I will ask them about things that have happened.

I will then ask you to talk about what they said.



If you choose 'no' to having someone with you, I will ask you questions on your own again.

We might meet for one or two hours.



The information you talk to me about is private. No one will be able to know it is about you in the reports. This means it is 'confidential.'



But if I am worried about something you tell me I might need to talk to someone else. For example, I might be worried that you are in danger, or that someone else is in danger.

I will try to talk to you about this before I speak to anyone else.



### **What could happen if you take part?**

I will ask you questions about moving out of hospital. You might think about difficult things that have happened to you

Sometimes this is hard and you might feel upset, sad or angry.



If you feel upset you can chose not to answer my questions.



You can choose to have a break.



Remember, you can choose to say “no” to taking part.



If you feel very upset, we can talk about where else you can find support.

## 5. What happens after taking part?



I will type up the interviews on a computer. I will then delete the recordings. This means they will be gone forever.



I will change information, like your name. The information will be 'anonymous' – this means no-one will know it is you.



The information on the computer will be kept locked with a password. This means it is 'confidential.'



I will write a report about what we have found out. I will talk about what we have found out at a meeting with the Transforming Care Team.



I might write things that you have said into these reports. But I will not use anyone's names.



Transforming Care is a plan to help people move into their own homes. People all over the country will move out of hospital.



So lots of people might want to read the report. They might want to learn what went well for your move. They might also want to learn about what could be better.



People who want to learn more might be:

People like you who are moving house  
Their families and their carers  
Social workers  
Psychologists  
Doctors



If you would like to know more about what we have found out, I will arrange to let you know. I could meet with you or I could write to you.



I will write the reports in Spring 2017.

Before April next year (2017) you can ask me not to write about the things you told me.

After April next year (2017) it will be too late for the things you told me to be taken out of the reports.

But remember, I will not use your name. So people who read the reports will not know they are about you.



## 6. Who can I contact?

If you have any questions you can contact me. I will do my best to answer your questions. Or I will help you find someone else who can help you.

### Who to contact

Two Clinical Psychologists, named Helen and Louisa, are helping me find things out. Our contact details are here:



#### **Annabel Head**

Trainee Clinical Psychologist

Tel: xxx

Email: xxx



#### **Dr Helen Ellis-Caird**

Clinical Psychologist

Academic Supervisor, University of Hertfordshire

Email: xxx



#### **Dr Louisa Rhodes**

Clinical Psychologist

Email: xxx



## Appendix K: Choosing a Key Support Person Information Sheet

### Finding out about moving house - Choosing someone to support me



You have agreed to help Annabel to find out about what it is like to move out of hospital.



If you want, you can have your second interview with someone who knows you well.



It can be someone in your family, an advocate, a friend, a carer or someone else.



It is your choice if you would like someone else with you. You can choose 'Yes' or 'No'.



If you want to have an interview with someone else, you can choose who this is.

If you can't find someone who wants to take part, you can still take part on your own. Or you can say no to taking part.

It is important you pick someone who knew you while you were moving out of hospital.



Annabel will ask them about what it was like for you to move out of hospital.

## **Appendix L: Information Sheet for Key Support Person**

### **Transitioning under the Transforming Care programme**

#### **Information sheet for participating as a Key Support Person**

#### **What is this information sheet for?**

We are inviting the person you care for to take part in some research. They have asked you to also take part in the research. This sheet gives you more information about the project to help you to make a decision about whether or not to participate. Please take your time to carefully read the information about why this research is being conducted, and what taking part involves.

If there is anything else you want to know or you have any questions, please feel free to contact me. My contact details are below.

#### **Background to the research**

Following reports of abuse at long-stay hospitals and treatment units, NHS England introduced the Transforming Care programme in 2011. This programme hopes to support people to move out of inappropriate hospital placements, and to find them accommodation and support in the community. Currently there is no published research into how people who have moved under the Transforming Care programme have found their experiences.

#### **What is the purpose of the research?**

For this research project I hope to interview people with Intellectual Disabilities who have moved, or are in the process of moving, as part of the Transforming Care programme. In this way, I hope to increase clinician's understanding of what it is like to move house as part of this scheme, and to develop ideas about best practice to support future transitions. On the whole there is very little research which focuses solely on the stories of people with intellectual disabilities, rather than for example their carers or professionals. As such this research hopes to allow people with intellectual disabilities to contribute more to the evidence base of intellectual disability research. This research is part of my doctoral training at the University of Hertfordshire to become a Clinical Psychologist.

This study has been approved by the Hertfordshire NHS Research Ethics Committee (Protocol Number: 200695). It has also been approved by the Hertfordshire Partnership NHS Foundation Trust Research and Development Department and Hertfordshire County Council.

#### **Is it compulsory to take part?**

Participation in the study is completely voluntary. You are completely free to choose to say no to participation. Furthermore, participants are able to withdraw from the study at any time, even if they have already agreed to take part. If you choose not to take part this will not affect the person you care for in any way.

#### **Being a Key Support Person**

The person you support agreed to take part in the research, and is able to consent fully to participation in the project. They will take part / have taken part by being interviewed about their experience of moving house. As part of this process, they have nominated you as a Key Support Person to add to their voice about their experience of moving.

If you have any questions about the project, you can contact me using the details below. The choice whether to participate is completely up to you, and you would be able to withdraw from the study at any time. Furthermore, there are no expectations that you should take part if nominated; whether or not you participate will not affect the person's data in any way. If you choose to participate, I will ask you to read and sign a consent form.

For the interview, I will meet with you and the participant. I will ask you broad questions about the person's experience of transitioning under the Transforming Care programme; these questions will ask you to 'step into the

shoes' of the person and try to answer from their perspective. They will then be interviewed as well to respond to what you have said about their experiences.

An interview will typically last between 1-2 hours. The interviews will be audio taped, and I will then write a transcript from the tapes. I will make the transcripts anonymous by changing any identifiable information, such as names. The recordings will be destroyed as soon as the transcripts have been typed. I will ask you if you would like me to come back to tell you more about my findings at the end of the project.

### **What happens next?**

I will use the transcripts of the interview data to help me to understand how people experience transitions, using a Grounded Theory approach to data analysis. These will be saved on a laptop as password protected documents.

As part of the doctoral training, I will write a research report from the findings of the study. This will be submitted to the examination board. My supervisors (details at the bottom) will also have access to the report to support me while I am writing it. To enable the findings from this research project can be used to inform other clinicians about best practice or recommendations for transition work, I will write up the research for publication in a peer-reviewed academic journal.

I may use direct quotations from the interview you provide in either or both of these reports. All information that could be used to identify yourself, the person you support or others involved will be fully anonymised throughout.

I will make arrangements to come to speak to the person with Intellectual Disabilities, and /or you about the results of the study if this is something you would be interested in.

### **Will your information be kept confidential?**

All information which is collected about you and/or the person you support during the course of the research will be kept strictly confidential.

However, there are limits to this confidentiality – for example, if I am concerned that you or someone else is at risk of harm due to something you have told me, I will break our confidentiality agreement and I would need to speak to someone else about my concerns. However, I will always try to speak to you before I do this.

### **What will happen if you chose to withdraw?**

If you would like to withdraw from the study at any time, please contact me or one of my supervisors using the contact details below. If you have already completed the interview at the time you would like to withdraw, I will ask you whether you would like the data you have already contributed to be part of the study – it will be your choice whether it will be included or withdrawn completely.

I will be writing the report for submission in the spring of 2017. Unfortunately beyond April 2017 I would not be able to withdraw the data you have contributed from the reports I will write for submission to the University of Hertfordshire and for publication in an academic journal.

### **Who to contact**

Annabel Head  
Trainee Clinical Psychologist

# Appendix M: Poster for NHS Research Conference

## How do people with Intellectual Disabilities experience moving as part of Transforming Care? A Grounded Theory Study

Annabel Head<sup>1</sup>, Dr Helen Ellis-Caird<sup>1</sup>, Dr Louisa Rhodes<sup>2</sup> & Kathie Parkinson<sup>3</sup>



### Background

In 2011 a BBC Panorama documentary exposed the abuse of residents in Winterbourne View, a privately run care home for people with Intellectual Disabilities (ID). Following this, NHS England announced the Transforming Care programme to support people to move out of hospital into community placements with personalised packages of support. They reported that too many people with ID were living in hospitals too far from home, for too long, without adequate assessment or treatment. (DoH, 2012).

This study explores peoples' experiences of moving into their own homes as part of the Transforming Care programme.

### Method

11 people with ID were interviewed about their experiences of moving out of hospital. Of these participants, 10 people also selected a 'Key Support Person' (KSP) to be interviewed with them on a second occasion (Caldwell, 2013). This was someone who knew them well during the transition, for example a social worker or parent. The KSP answered the questions 'as if' they were the person with ID, so as to keep this person's voice and story central to the research. This methodology was inspired by 'internalised other' interviewing from systemic theory (Karl Tomm, cited in Mudry et al, 2016).

A social constructionist grounded theory method was used to analyse the data (Charmaz, 2014).



### Results

A grounded theory model was constructed from the data, consisting of three concepts, made up of a number of categories and sub-categories. The grounded theory model is shown left.

**A Restricted Story**  
When participants were in hospital, they seemed to get stuck with a restricted story. This is shown in the model by a circular loop. Sometimes participants felt unsafe or controlled by others. This seemed to impact on how they made sense of their own identity; for example sometimes seeing themselves as a 'bad person'.

Interviewer: What sort of person were you when you lived in the unit?  
Larry: Terrible (laughing)  
Interviewer: Why was that?  
Larry: Naughty man.

The data showed the role that relationships with others played in developing these identities. There were exceptions however, where participants heard and understood alternative stories about themselves.

As part of Transforming Care, people were given a chance to move out into the community. They then went through a number of processes as part of the transition. These included learning to believe that the move was really happening; managing the losses associated with the change; feeling mixed emotions about moving; and learning to feel safe in new relationships.

Oliver: It's hard, but... it's very hard but... you've just got to do it. Coming out of hospital into a flat is a very big, scary thing.

Benny: I miss [institution which-closed 20 years ago]. I miss it.  
Patsy [social worker]: Yeah. It's not there anymore!  
Benny: Not there. All gone.

### A Widening Story

When people moved into the community, this opened up opportunities for new ways for the participants to see themselves. Participants reported being seen and treated differently now they were out of hospital.

Pamela: [In hospital] we were treated like patients... it made me feel that I couldn't do anything for myself. [In the community] I can do things myself now. They don't treat me like a little kid.

Elvis' Mum, speaking as Elvis: [In hospital] it was more like, a number. I felt like a number rather than a human, human being. Rather than a real person. Here, I feel like I'm a real person. And I'm treated like a friend. Rather than just a number.

Being seen and treated differently allowed participants to start shifting ideas about the kind of person they were. This then linked back in a reciprocal way to how they were seen by others. This is represented in the model by a second circular loop; however, rather than the stuck loop in hospital, this was a 'widening story'. Participants sense of identity again seemed to take place in the context of relationships.

### Living With a Sense of Threat

For some participants, they now had some strong worries that they could be re-admitted to hospital from the community.

Fred: If anything goes wrong, if you step out of line, you're probably going back to prison and they throw the key away.

### Conclusions

Participants in the present study moved out of hospital placements into the community as part of the NHS England Transforming Care agenda. The data suggested that both intra- and interpersonal factors allowed participants to 'widen out' their identity story after moving out of hospital. Participants discussed the important roles that other people played in changing their sense of self, and in helping them feel safe. They also discussed the challenges associated with moving out.

The findings indicate the importance of (1) Helping people to prepare both practically and emotionally for the move; (2) Allocating sufficient time and resources for the person to become familiar with their new team before moving and being supported by them; (3) Offering people the opportunity to talk about positive and negative emotions associated with the move; (4) Ensuring the service user is actively involved in decisions.

<sup>1</sup> Doctorate in Clinical Psychologyxxx

<sup>2</sup> Community Assessment and Treatment Team, xxx NHS Trust

<sup>3</sup> Transforming Care Team, xxxxx

This project is awaiting completion to meet requirements for the Doctorate in Clinical Psychology for the first author.

#### References

- Caldwell, K. (2013). Dyadic interviewing: a technique valuing interdependence in interviews with individuals with intellectual disabilities. *Qualitative Research*, 14 (4), 488-507.
- Charmaz, K. (2014). *Constructing grounded theory: A practical guide through qualitative analysis* (2nd Ed.). London: Sage Publications.
- Department of Health (2012). *Transforming care: A national response to Winterbourne View Hospital*. London: HMSO
- Mudry, T. E., Strong, T., Sametband, I., Rogers-de Jong, M., Gaete, J., Merritt, S. & Ross, K. H. (2016). Internalized other interviewing in relational therapy: Three discursive approaches to understanding its use and outcomes. *Journal of marital and family therapy*, 42(1), 168.

Image M1: Poster for NHS Research Conference.

## Appendix N: Confirmation Letter from NRec



### Health Research Authority

Dr Helen Ellis-Caird  
DClinPsy, Health Research Building  
University of Hertfordshire  
Hatfield  
AL10 9AB  
[h.ellis-caird@herts.ac.uk](mailto:h.ellis-caird@herts.ac.uk)

Email: [hra.approval@nhs.net](mailto:hra.approval@nhs.net)

11 August 2016

Dear Dr Ellis-

Caird

Letter of HRA Approval

<b>Study title:</b>	<b>How people with Intellectual Disabilities experience transitions under the Transforming Care Programme: a grounded theory study.</b>
<b>IRAS project ID:</b>	<b>200695</b>
<b>Protocol number:</b>	<b>LMS/PGR/NHS/02316</b>
<b>REC reference:</b>	<b>16/LO/0816</b>
<b>Sponsor</b>	<b>University of Hertfordshire.</b>

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](http://www.hra.nhs.uk/hra-approval).

Your IRAS project ID is **200695**. Please quote this on all

correspondence. Yours sincerely

Beverley  
Mashegede  
Assessor

Email: [hra.approval@nhs.net](mailto:hra.approval@nhs.net)

Copy to: Professor John Senior (University of Hertfordshire), [j.m.senior@herts.ac.uk](mailto:j.m.senior@herts.ac.uk),  
Sponsor Contact

[REDACTED]

[REDACTED] Lead NHS R&D Contact

Annabel Head (University of Hertfordshire), [a.head2@herts.ac.uk](mailto:a.head2@herts.ac.uk), Student

## Appendix O: Full Sponsorship from the University of Hertfordshire

University of Hertfordshire Higher Education Corporation  
Hatfield  
Hertfordshire  
AL10 9AB  
Telephone +44 (0) 1707 284000  
Fax +44 (0) 1707 284115  
Website [www.herts.ac.uk](http://www.herts.ac.uk)

# UH

## University of Hertfordshire

16 August 2016

Dear Dr Ellis-Caird and Ms Head

Re: UNIVERSITY OF HERTFORDSHIRE SPONSORSHIP IN FULL for the following:

RESEARCH STUDY TITLE: How people with Intellectual Disabilities experience transitions under the Transforming Care Programme: a grounded theory study

NAME OF CHIEF INVESTIGATOR (Supervisor): Dr Helen Ellis-Caird

NAME OF INVESTIGATOR (Student): Ms Annabel Head

UNIVERSITY OF HERTFORDSHIRE ETHICS PROTOCOL NUMBER: LMS/PGR/NHS/02316

This letter is to confirm your research study detailed above has been reviewed and accepted and I agree to give full University of Hertfordshire sponsorship, so you may now commence your research.

As a condition of receiving full sponsorship, please note that it is the responsibility of the Chief Investigator to inform the Sponsor at any time of any changes to the duration or funding of the project, changes of investigators, changes to the protocol and any future amendments, or deviations from the protocol, which may require re-evaluation of the sponsorship arrangements. It is also essential that evidence of NHS Trust Management Permissions (formerly known as R&D Approval) is sent as soon as they are received.

Permission to seek changes as outlined above should be requested from myself before submission to a HRA (NHS) Research Ethics Committee (REC) and notification to the relevant University of Hertfordshire Ethics Committee with Delegated Authority (ECDA), and I must also be notified of the outcome. It is also essential that evidence of any further relevant NHS management permissions (formerly known as R&D approval) is provided as it is received. Please do this via email to [research-sponsorship@herts.ac.uk](mailto:research-sponsorship@herts.ac.uk)

Please note that University Sponsorship of your study is invalidated if this process is not followed.

In the meantime, I wish you well in pursuing this interesting research study. Yours sincerely

Professor J M Senior

Pro Vice-Chancellor (Research and Enterprise)

## Appendix P: Assessing Consent (with example)

Participant ID: ...xxxx.....Record for assessing consent

Date: xxxx First information meeting

What are the signs that the person has understood information?

Signs that the person is listening / has understood	Was this happening (please tick)	Details
Does the person seem engaged? Does their body language / eye contact suggest they are interested?	✓	Appeared engaged and interested
Is the person elaborating verbally – for example, comments that they would be interested in taking part?	✓	Asked me about the project Clearly stated interest
Any non verbal signs they are interested – for example, nodding?	✓	

What are the signs that the person has not understood the information?

Signs that the person is not listening / has not understood	Was this happening (please tick)	Details
Is the person unengaged with the researcher or conversation? Are they avoiding eye contact? Do they seem indifferent?	X	Seemed very engaged with me
Are there concerns that the person is acquiescing with the researcher?  Do they agree to things without clearly understanding?	X	Participant seemed to understand the project and the role they would take in it  Use of mixed questions indicated they are not acquiescing
Do they appear to be ambivalent or disinterested?  Any negative non verbal signs, such as facial expressions?	X	Engaged with me throughout our meeting



Date: xxxxx Second information meeting

How much can the person remember about the project?

- Researcher's name
- Meeting the researcher previously
- Seeing the information sheet before
- The overall aims of the project
- What their part will be in the project
- What will happen after the interviews
- Information about 'what is consent'
- Information about 'confidentiality'

What are the signs that the person has understood information?

Signs that the person is listening / has understood	Was this happening (please tick)	Details
Does the person seem engaged? Does their body language / eye contact suggest they are interested?	✓	Again, appeared well engaged and pleased to see me
Is the person elaborating verbally – for example, comments that they would be interested in taking part?	✓	Yes – remembered meeting me and what we had spoken about
Any non verbal signs they are interested – for example, nodding?	✓	Yes- nodding

What are the signs that the person has not understood the information?













Signs that the person is not listening / has not understood	Was this happening (please tick)	Details
Is the person unengaged with the researcher or conversation? Are they avoiding eye contact? Do they seem indifferent?	X	No, appeared engaged
Are there concerns that the person is acquiescing with the researcher? Do they agree to things without clearly understanding?	X	No – remembered me and the project, seemed keen to get started!
Do they appear to be ambivalent or disinterested? Any negative nonverbal signs, such as facial expressions?	X	None














## Appendix Q: Consent Form for Participants



### Finding out about moving out to the community

My name is .....

Please circle		
 <b>YES</b>	 <b>NO</b>	I have seen the information sheet.
 <b>YES</b>	 <b>NO</b>	I have met with Annabel to talk about the project.
 <b>YES</b>	 <b>NO</b>	I have been able to ask questions about the project. I know what I will be asked to do to help find things out.
 <b>YES</b>	 <b>NO</b>	I know that I can say “no” to taking part at any time in the project.
 <b>YES</b>	 <b>NO</b>	I know that this means I can stop at any time in the interview. I can also call Annabel at any time to tell her I don’t want to take part any more.
 <b>YES</b>	 <b>NO</b>	I know that information about me will be “confidential” – this means private. However, I know that if Annabel is worried about me or someone else she might need to talk to someone else.

 <b>YES</b>	 <b>NO</b>	<p>I know that Annabel will use a voice recorder to record my interview.</p>
 <b>YES</b>	 <b>NO</b>	<p>I know that Annabel will type up things up. This might be things that I say, or questionnaires that I answer. I know that Annabel will not use my real name. I know that no one will be able to know it is about me.</p>
 <b>YES</b>	 <b>NO</b>	<p>I know that Annabel will use the interviews to write a report and this might be published.</p>
 <b>YES</b>	 <b>NO</b>	<p>I know that before April next year (2017) I can ask Annabel not to write about the things I have shared.</p>
 <b>YES</b>	 <b>NO</b>	<p>I know how to contact Annabel, Helen or Louisa.</p>
 <b>YES</b>	 <b>NO</b>	<p>I know that Annabel will ask me if I would like her to get in touch to explain more about what we have found out.</p>
 <b>YES</b>	 <b>NO</b>	<p>I say “yes” to taking part in the project.</p>

Signed here (participant):.....

Signed by researcher: .....

Other people might want to use my interviews for a new project in the future. It is ok for this to happen?



Yes



No

## Appendix R: Consent form for Key Support Person

### Consent form

#### Research Project:

Transitioning under the Transforming Care programme: a grounded theory study

- I have seen and read the information sheet, and had the chance to have my questions answered.
- I have been given contact information of the research lead and other researchers involved in the project.
- I understand the aims of the project, and what my involvement will be.
- I understand that the project will run until July 2017 and I am able to withdraw from the study at any time before April 2017.
- I understand that the information I discuss will be confidential. The limits of this confidentiality have been fully explained to me.
- I understand that the interviews will be recorded using audio recorders. These recordings will be stored password protected on encrypted computer and will be permanently deleted at the end of the project.
- I understand that typed information about the person I care for, myself and others will be fully anonymised.
- I understand that information from the interviews, including direct quotations, may be used in a report for submission as part of the Doctoral in Clinical Psychology training programme.
- I agree that information I provide as part of the project (including anonymised direct quotations) may be published in an academic journal.
- I give my consent to taking part in the present research study.**

Signed (participant):.....

Signed (researcher):.....

#### Additional consent:

Do you give consent for the data you provide to be used for future research projects which are an extension of, or are closely related to, the present study?

- YES, I give consent to the data I provide to being used in this way.
- NO, I give consent for the data I provide to be used for this study only.

## **Appendix S: Personalised Plan**

I had a phone conversation with the participant's social worker and then mother, who were initially unsure about whether discussing hospital would be distressing. They were understandably concerned that I would be seen as 'a professional' and by asking him questions about hospital I was somehow linked with wanting to send him back to hospital. We therefore came up with a plan which would still allow him to participate and give his voice to the project, but without being threatening in any way.

Plan:

- I will call on the day ahead of the arranged interview to double-check with his Mum that he seems in a positive and calm mood, and is still happy for me to come and meet him. If not, to rearrange for another day, or remind him that he can say no to taking part without giving a reason.
- If I attend for interview – to meet with him with one of his parents, as this will help him to feel calmer.
- I will ask questions about life now, and not ask questions directly about his time in hospital.
- His parents will know signs that he might be getting upset, or beginning to worry about why I am asking these questions. They will therefore end the interview at this stage by thanking me for coming.
- Depending on stage of interview, we may rearrange to meet with him another time, or to decide not to.
- I will then interview his Mum and Dad without him present. This is because they think it would be valuable to share his story with me for the project, but they feel hearing it would be very distressing for him.
- All other issues re consent, withdrawing data etc to remain as in the Participant Information Sheet.

## **Appendix T: Interview Questions Guide**

### **Time in hospital**

Tell me about where you lived before you lived here.

What were things like there?

Can you describe what sort of person you were there?

Could you tell me about what led up to you leaving there?

### **The process of moving**

What did you know about moving out?

Did other people know about the move before you?

How did it feel to be told/ not told?

When someone told you you would be moving, can you remember what you thought? Can you remember how you felt?

What did it mean to you that other people thought you were ready to move out?

Was anyone else involved?

Who supported you? How?

What happened next?

Did you make any choices about your move?

Were there any things that you did not get to choose?

What were the good things about when you moved?

What were the more difficult things?

What sort of person were you when you were going through the move?

Was it clear, or confusing, or something else?

How did that make you feel?

Did you feel prepared for the move? What did people do / not do that made you feel / not feel prepared? How did it help?

What did you learn when you were moving?

Did it happen at the right time for you? How long did it take?

What problems did you face when you were moving?

How did these problems happen?

What helped you to manage these problems?

Who was the most helpful person while you were moving? How was he/she helpful?

Has anyone else been helpful?

Did people know and understand you while you were moving? Was there trust and did you get on

What did that feel like?

Has anything else been helpful? (E.G. another organisation, service etc)

What was a typical day like when you were waiting to move?

When you look back on moving, are there any things that stand out? (prompt: were there any meetings that you had, any visits that you did, any people that came to talk to you that you remember?) Can you tell me about these? How did this affect your move?

### **The present and the future**

What is a typical day like now?

Who is helpful for you now? How are they helpful?

If you have new staff – what did they do to get to know you?

Do new staff ask what things were like for you before you moved here?

Do you have the chance to meet / get to know people who aren't staff?

What sort of problems do you face now? What if anything helps you manage these problems?

What other problems might you face in the future?

What are the good things that have changed in your life since you moved?

What are the negative things?

Have your views on being in hospital changed since you moved out?

Did you see yourself as a 'patient' before you moved?

What do you see yourself as now you have moved?

What sort of person are you now?

Have you changed as a person since you moved?

Tell me about the strengths you have developed through moving.

What do you value about yourself now? What do other people value in you?

When you think about the sort of person you are now you're not in hospital, how do you feel?

What are your hopes? Worries?

Where do you see yourself in (two, five, ten) years' time? What sort of person do you hope to be then? Is that different or the same as how you are now?

What advice would you give to someone else who was facing moving out of hospital?

Is there anything else you think I should know to understand better what it is like to move out of hospital?

Is there anything you would like to ask me?



## **Appendix U: Data Analysis.**

### **nVivo Coding Examples**

Two examples of coding, screenshots from the nVivo computer programme for sorting and managing data. In the programme, codes are named 'nodes'. Pieces of data can be highlighted in the programme and given names; these are the codes. Subsidiary initial codes can be grouped underneath a focussed codes / categories. The sources column indicates how many interviews (or sources) contain the code. The reference column indicates how many pieces of data have been coded under the node.

The first example illustrates the sub-category 'Adapting to a new life'. Earlier initial codes can be seen when this node is expanded on nVivo, as seen listed below this node. These were pieces of data which were given initial codes, and as the theme developed, dragged 'into' the node which I named 'adpating to a new life'.

Image U1: Screenshot of coding from nVivo - Adapting to a new life.

The second example below illustrates the nodes which eventually made up the sub-category 'coming out of hospital is a big, scary thing.'

Image U2: Screenshot of coding from nVivo.- Coming out of hospital is a big and scary thing.

NB not all data sources were coded using nVivo. As the model took shape during analysis, later interviews were coded and sorted into the model straight from the Microsoft Word document, as data saturation was being reached for the 'emerging' model. Therefore the figures above for number of sources does not fully reflect how many data sources made up the categories in the final model.





**Part 2: Extract from two interviews with coding.**

## **Appendix V – Examples of Memos**

This section has three parts, to illustrate to the reader how the process of memoing supported the construction of the grounded theory model. My memoing took different forms, and I found it to be a flexible and creative way to explore the data and aid analysis.

The first part aims to demonstrate the evolution of once concept (namely ideas about identity) evolved over time. The second part shows a large memo, part-way into the analytic process, which was an attempt to explore the links and understanding I had made from the data to that point. The third part was an attempt at a later synthesis of peoples' reports so far. Through writing a first-person perspective, I aimed to step into the shoes of my participants, and capture the processes they had been describing to me, to help me in developing the analysis and model.

### **Part One: Memos around Changing Identity**

#### **27<sup>th</sup> October 2016**

Through some of the interviews, there is a sense of the old normalisation approach. That being in hospital makes you 'other' - either a patient, a child... For example, Jason's KSP discussed how he saw himself as patient in hospital, but not now.

But now, after transition, the person has moved to more of what they see as a 'normal' position. They own their own furniture. They make choices about their lives in ways they couldn't in hospital. This links to being like other people - all wearing the same clothes (Jason), my staff are my family (Pamela), my carers are my own age and are my friends (TJ), now I'm a normal man (Larry). This is a real process of change - perhaps moving some steps towards the ideals of a 'normal life' which have been fed to us all by society?

But even though these describe their experiences, I still hold onto thoughts about how different these lives are. But is that then me putting a value on what a life should be like? Just like society does. We have a 'normal' view of people leaving home in their late teens, early twenties, to eventually one day settle into a new home, with a partner. But this is a very modern, westernised view of 'normal'! Maybe the lives of people with ID represent more closely those of people of other times / cultures, but just feel alien in comparison to the modern western ideals?? Though they will still be affected by these powerful discourses of normality, and potentially feel sad when this doesn't happen.

#### **19<sup>th</sup> November 2016**

Jason's KSP: But now I don't see myself as patient. I feel like (0.5) we're all the same, we're all equal.

I find this quote really poignant, and others that go with it. There's something about it being a significant transition for Jason, moving from feeling more like... a thing, object, nuisance, patient? To now being like others, with own home, less controlled by others. But tinged with that, is how much is this an ideological hope? Held on to by support staff to motivate them to keep going? Or to hark back to days of normalisation? He's still not really the same as Ayo who is doing the talking for him

### **8<sup>th</sup> December 2016**

Obviously, change was always going to be part of the process in the data; but I'm struck by what seems to be coming up about becoming a new / different person. Some people talk about change from 'naughty to good' (Larry) or from child-like to adult (Pamela) ; (TJ also talks about the development and maturation he goes through, though this is more linked to age). From old me to a new me= (a different person - TJ). Or, for Elvis, it's about returning to the 'real' me that got lost when in hospital.

Everyone has a different experience of it; these different descriptions are all related, but not the same process. How do they link? Yes, they are about change, but at a more analytic level.... could be a change to a more 'socially accepted' version of themselves? So not the one who is naughty or who acts out; but the one who is normal, grown up and is playful / fun, who gives back to society and understands their internal motivations and behaviour. *A change to self which is less distressing for me and for those around me.*

### **6th January 2017**

There seems a shift, through Transforming Care, from 'being' to 'doing'. So rather than 'being' bad and therefore deserving and staying in hospital, there may a shift to how the behaviours are seen by those around me. So I can be a more integrated person, who sometimes 'does' things that are challenging; but that this is not indicative of some central part of who I am.

## **Part Two: Reflecting on Where I am with the Data So Far....**

### **Early October 2016**

Where am I with my data so far – having completed 7 interviews, with 4 people, coded 3.5.

I'm thinking about how Transforming Care was different – a team of people who consistently broke or bent the old rules, such that these ways of thinking or being treated became the new normal. The one off occasions of this happening in the past may have given people small nuggets of hope to hold on to, small exceptions to 'the system' and tiny opportunities to see that things were not always going to have to be the restrictive way they were.

I'm also thinking about the shift from not believing the move would happen, to believing. Sometimes this only came about after a physical move, and concrete proof that things had changed. The doubt (often extremely strong) that people would let you down again, based on probably many past experiences of having hopes raised and dashed. A learning process of 'don't hope anymore'? And I think wider, of being let down by the promises that society told you your life would look like, and how far these are from the reality you have kept coming up against. Is this linked to a category / concept around trust?

Relationships and how important they are – to have a sense of safety in hospital, how important not to lose this before being secure/ less wobbly on the new base. And the vital importance of building those new relationships before the move, while the move is happening. I think this has been key to all the experiences I have heard so far.

And trust, believing and relationships are linked, somehow. That trust and new relationships have to develop alongside each other? (Or do 'new people learning me' and 'me learning new people' become part of 'trust')? These new relationships lead to the development of a new sense of security. Also the idea of containment, that the new staff will 'hold' you, no matter what. You can push but they won't reject you. Like the rejections you've had before. And this might be a distressing process for all involved! How much can they hold? How much can you trust them to keep holding firm? What training and other support do *they* have to be able to be that buffer for you, to stay strong as a team?

Trust could also be made up of the shift from not believing to believing. You need to develop trust, over time, to be able to start believing what these new people are telling you.

Is trust also feeling safer? From being somewhere where you could be targeted and vulnerable – someone could find out your forensic hx, abuse you. To somewhere you now feel safe and can keep your door open.

Participants have also spoken about a learning process, in learning how to be a new person in the community. To make choices and decisions for yourself – e.g. not having to ask how you spent your money, what time you needed to go to bed. Having more freedom. The word freedom has come up a few times. Liberty, freedom, how different that is! How do you go through adjusting to that? Not having to have your door locked!

Also learning new ways of being in relationships – this links to the trust and containment – but is also about how you use others to get you through difficult times. How do you use relationships more like you would use a family relationships – them being people you can turn to for support rather than being someone who controls you and has power over you. A more level playing field? I think there is something in a change in a relationship from one of powerless and powerful, to a more family like relationship.



Interdependence – a process of acceptance? For the people with intellectual disabilities, maybe this acceptance is realising they will have a different life from the typical family life that is sold to them. But perhaps there is an hidden process going on in staff as well, which they pick up on – that needing staff support (and therefore not being typically 'independent') is ok, and even good. That this is a different kind of family life. Is this a process of adjustment that TC makes happen, by changing staff perspectives on what is ok to expect from this person. That it is ok for us to accept that this person will need care (maybe 24/7) rather than this being a failure of that person launching successfully. Can I infer this from my data? Or does this really need another research project and different questions and perspectives? IE is one of the key things about TC that it has changed staff, as a whole's perspectives that the person may need lifelong support and that is fine? Changing *staff's* ideas about what life should look like.

Holding on to old relationships – there is a process of loss, but maybe this isn't as key as I thought? People seem to take these new relationships with them

Seeing the move as a positive change. Making meaning from time in hospital as a way of moving on – TJ, Pamela. Have to have gained some benefit from it to assimilate it into a new life story

How does TJ's account fit?? Is his description was of what he gained from hospital, how it all helped him to develop as a person – maybe this fits best with above – how people have to make sense of their experiences, assimilate their past into how this has helped them to develop to where they are today. Making meaning of past events.

Identity changes- from a child to a person, from a naughty to a normal man, from a patient to a person. *Finding* an identity for the first time even. Knowing oneself as a person, not a passive object to be moved about, or be done to, but to be a real person. Does this link to learning, above? Learning how to be a person outside of hospital, who can meet own needs through choice and control in ways that you couldn't before??

### **Part Three: Stepping into my Participants' Shoes – December 2016**

What is it like for *me* to transition, if I am to step in the shoes of my participants?

I'm in hospital. Maybe I have a clear pathway out – there's still uncertainty and disappointment on the way but I never lose hope that I'll get out and lead my life. MY life is out there; the hospital is a treatment interim.

But maybe I don't have any hope. Maybe I used to, but over the years I have got so used to disappointments, that I never really hope or believe I will live anywhere else now. I can't really think about the future being any different. The lives that other people live aren't for me. I'm treated as 'naughty' and a problem. I don't really see any way out, or any alternatives. I'm frustrated, sometimes feel lonely and isolated. Sometimes all I want is a cuddle. Or to see my family. Or to spend time with my favourite staff. Or I'll stay in my room because being on my own is less scary and threatening. There's no uncertainty then. And I find uncertainty really stressful. I get snappy, upset, angry, "challenging."

I'm told I'll move – but I find it hard to believe it. Maybe I think it's a joke. I have to go to lots of meetings – sometimes this is confusing and stressful. I still can't believe it – I half expect to be let down and disappointed. I'm not sure about moving – I'll miss this way of life, my friends, the staff. Moving is upsetting and challenging. Part of me wants to stay here, though everyone keeps telling me it will be better there.

It takes so much time and effort to build new relationships with new staff – it's hard work. Many of them are nice. They show me that they're there for me, that they won't tell me off. These are new kinds of relationships. I still get let down though – sometimes new members of the team have left before I've even left hospital.

The move happens. Sometimes I don't really believe it until I'm really there. Even then, it feels fragile. There's so much change. Having met new members of staff before I moved definitely helps – but I still feel scared sometimes. Will they be able to cope with me? Will they know what support I need? Will they support me, no matter what?

In hospital, sometimes I felt small, child-like, naughty. But I could also think of times staff treated me differently, or I felt superior to the other patients. Maybe I was meant to move on, because I was better than them? I felt bad that others were staying.

Now, I get more choice. Sometimes I don't want choice. It can be challenging having more control – it's a real learning process. It's hard taking back a bit of power, when I have been so powerless for so long.

Now I've transitioned, I'm starting to see other sides to myself. I'm more mature, more adult, I'm back to who I was before, I'm "good", I'm confident, I'm happy. Important in this is how others see me. I often get positive feedback about how 'good' I am, and it encourages me to keep going. Others are proud of me, and I'm proud of myself. These days, when I do act out, it's seen in a wider context. I wonder if now it's ok, rather than a sign I'm bad.

Though sometimes I still think I am bad, and *I must be good* so that things don't fall apart. Sometimes I have a sense of fear that if I act out of line, it will all be taken away from me. This is really scary. However much people reassure me, maybe I can't really believe it. I find it hard to think about the future.

I always just wanted to be part of something – friendships, family, love, acceptance. Acceptance for who I am. I've often felt rejected by society, for my behaviours, for who I am. I've now got a new kind of social group around me. Maybe I see my family a bit more, maybe I don't. but the group I'm now in feels like friends or family. I feel like they accept me. I feel warmth and comfort from them. I've found a group where I can fit.

## Appendix W: Examples of Earlier Mapping out Data

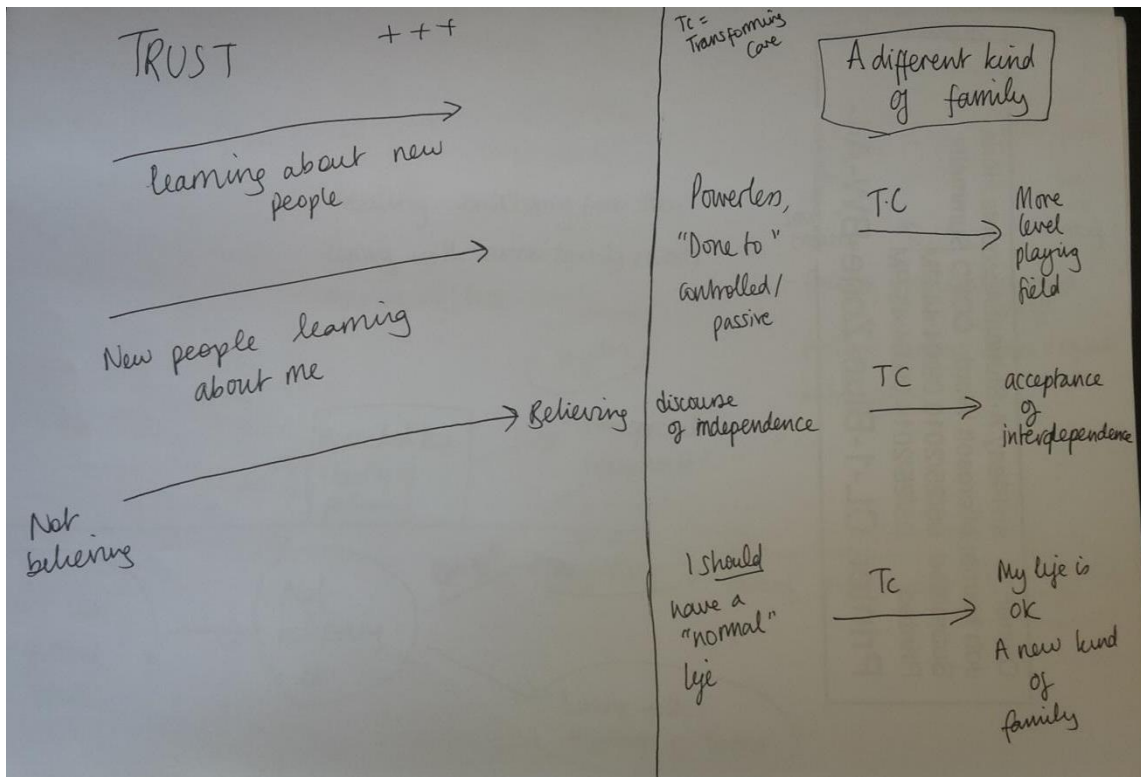


Image W1: Mapping out data in October 2016.

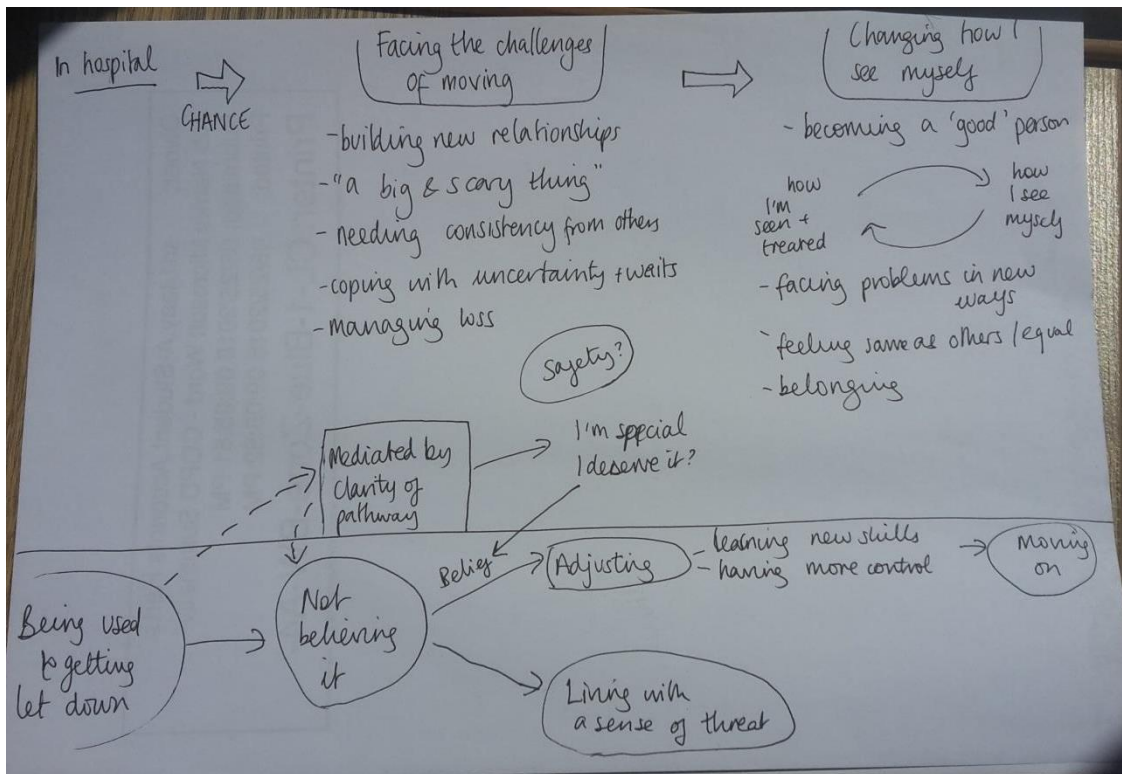


Image W2: Mapping out data in January 2017.



## Appendix X – An Early Version of the Model

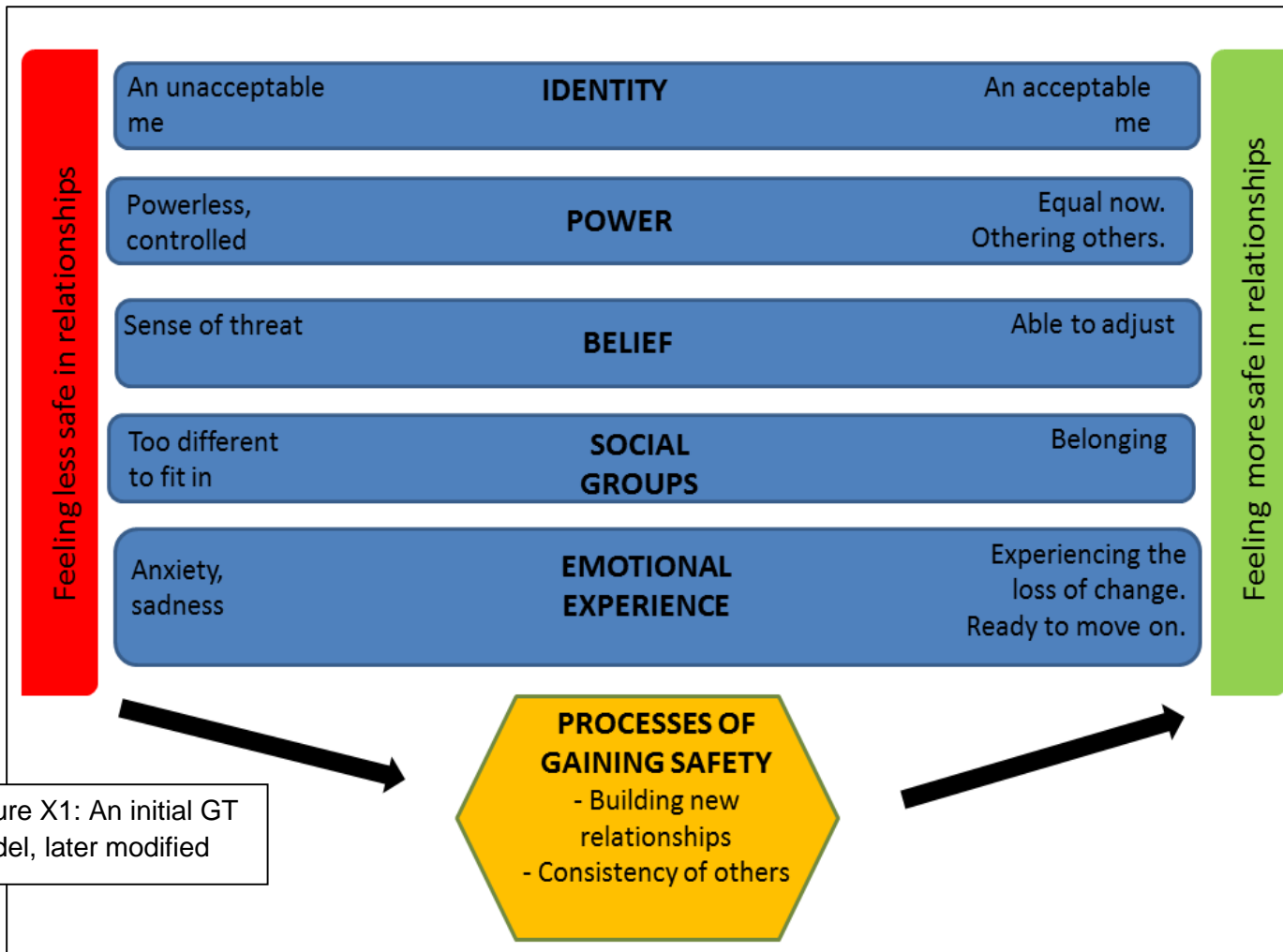


Figure X1: An initial GT model, later modified

As noted in section 2.5.3 of the main report, the first model that I constructed from the data was significantly different to the final model presented. Having memoed extensively, and sorted the data around, I noticed I was finding certain themes, which seemed to have two poles (e.g. being powerless/ controlled, versus feeling equal now).

I found instances of data which suggested that being safe in new relationships was important, and wondered if 'safety' could modulate where people were along these themes.

Initially I was pleased that this model seemed to account for the data I had. However, as I went on with analysis, I saw a flaw in this version. If someone felt a certain level of safe in relationships, (e.g. very close to the green 'feeling safe' end), this model would imply that they would feel towards the end of the poles of all the bars – they would feel 'equal now' and 'able to adjust' and 'a sense of belonging'. This didn't quite work! I realised participants were at different positions along each of the bars. Clearly, 'safety in relationships' could not account for this positioning.

I felt somewhat frustrated, having thought I had cracked it! But I felt nearly there with many of the ideas, so went back to the drawing board not entirely despondent. It can be seen that many of the ideas made it onto the final model presented in the main body of the report; however the final version is also preferable for including an element of the process happening over time.

## Appendix Y: Additional Quotations

For example, Dave's Dad Peter described what happened when the hospital Dave was leaving closed down before his new house was ready:

Peter: [to Dave] The hospital was going to close, do you remember that? They hadn't got all the care provision set up, that was the problem. Do you remember, they said they might put you in some temporary accommodation? And do you remember how really upset we all were about that?

Dave: Yep

Peter: We were really upset about that weren't we. Do you remember what happened next

Dave: erm

Peter: We agreed that I would look after you in [where Peter lives, over 500 miles away] for four weeks. And that you could move in [to new home] in four weeks. The people at [new home] were quite erm sorry that you weren't able to move in when you were supposed to move in. In the last week before you were due to come back down again. Do you remember, two guys came. Who had never been to that part of the country before. And there were two of your, what would become your carers in [new home]. They came to [where Peter lives], and I think they thought they'd come to the very end of the planet! It was February, and it was completely dark for half their journey. They were there, and you showed them all the things that you did [described the jobs helping out at Dad's business]. In fact, you were showing them all sorts of things that you did. And at the end of it, they took you back to [new home]. Brought you back to your new house, didn't you. They took you on the train. And that was it!

Interviewer: What might have happened otherwise?

Peter: [now speaking as Dave] Oh the whole thing would have, the whole thing would have gone completely pear shaped. Erm, this temporary accommodation, nobody knew me; er, I didn't know anybody. Well, the thing was, was so upsetting to go to somewhere temporary, I mean, it would have been a catastrophe.