EXPERIENCES OF PEOPLE WITH LEARNING DISABILITIES ON DISCHARGE FROM HOSPITAL INTO THE COMMUNITY: A NARRATIVE ANALYSIS

Max Tupper

A thesis submitted in partial fulfilment of the requirements of the University of East London for the Doctoral Degree in Clinical Psychology

May 2024

ABSTRACT

Many people with learning disabilities currently live in hospital settings in the UK. The Transforming Care programme has aimed to support their move to community living, but its success has been limited, particularly in ensuring effective discharge processes. A review of the existing literature in this area found this often focuses on the challenges and support needs of people with learning disabilities during discharge, neglecting the strengths, skills, and resources they actively employ. In relation to this, the use of a narrative approach as a methodology has largely been overlooked. Therefore, this study aims to analyse how people with learning disabilities story their discharge experiences from hospital to the community, using a narrative approach.

A qualitative approach was adopted, drawing on the accounts of five participants discharged from various inpatient settings to the community. Interviews were analysed using narrative analysis, which involved the transcripts being reviewed several times in order to construct individual narrative accounts. Emerging themes (storylines) and secondary narratives (sub-stories) were also identified by examining for similarities and differences across these accounts.

The findings demonstrate how people with learning disabilities construct rich, multi-layered narratives that enhance understanding of their discharge experiences. Three main storylines emerged across the participants. These were (1) challenges in navigating the discharge process, (2) drawing on strengths, supports, and resources, and (3) the realities of community life. These findings are considered within the broader socio-political context for people with learning disabilities.

This study illuminates participants' stories of discharge from hospital to the community. Suggestions about possibilities for future research and implications for clinical practice are also made.

TABLE OF CONTENTS

ACKNOWLEDGEMENTS

Firstly, I would like to thank greatly the participants in this study. Your openness and willingness to share your time and stories with me were very generous, and I consider it a real privilege to have had the chance to meet together for this project.

I am also thankful to the support services that helped facilitate the project, and to the University of East London for enabling me to complete this research.

I want to give a special thanks to my research supervisor, Dr Maria Qureshi. Your ideas, support, and guidance from the study's inception through its completion have been invaluable. Thank you so much for your time, encouragement, and feedback throughout the process.

I am also grateful to my colleagues in learning disability services over the years, particularly those at the tri-borough learning disability team. I have greatly valued the chance to work together, and your thoughtfulness and knowledge have been instrumental in shaping my approach as a psychologist.

A big thank you to my family for all their support and encouragement over the years!

And finally, I wish to thank my amazing wife, Jana, for putting up with me during the process, for all her patience, and for keeping me going!

1. INTRODUCTION

1.1. Overview

In this introductory chapter, the key concepts used throughout this report will be defined before situating myself in relation to the research. The historical and social context for people with learning disabilities will be explored, along with the processes of institutionalisation and deinstitutionalisation. The current terrain regarding hospital discharge and community integration for people with learning disabilities will be reviewed to consider the aspirations and realities of the Transforming Care (TC) Programme, which provides an important context to the research. A systematic literature review is presented, focussing on the experiences of people with learning disabilities on their discharge from hospitals into the community. This review aims to critique and synthesise the existing literature in this area, providing relevant background to the current research. The chapter will close by providing a rationale justifying the current study and the importance of research that centres the voices, stories, and perspectives of people with learning disabilities on their discharge from hospitals to the community.

1.2. Introduction and Definition of Key Concepts

1.2.1. Learning Disability

The British Psychological Society (BPS) (BPS, 2010) defines a 'learning disability' as a significant impairment of intellectual functioning, adaptive/social functioning, and an onset before adulthood. The terms 'intellectual disability' and 'learning disability' are frequently used interchangeably. However, this report will consistently use learning disability because in the UK, learning disability is currently the preferred term used in clinical practice, social policy and by advocacy groups (such as People First and Mencap). The historical context and construction of the term 'learning disability' provides insight into its current usage and will be explored further in section 1.4. Currently, it is estimated that there are 1.5 million people with learning disabilities living in the UK (2.16% of the population) (Office for National Statistics, 2020).

It is noteworthy that in both research and clinical services discourse, there is a prevalent trend to abbreviate 'people with learning disabilities' to 'PWLD' or similar acronyms. While such abbreviations offer convenience in writing, this research consciously opts against their use, choosing to write out the term in its entirety. This decision is underpinned by a commitment to respect these people's experiences, challenges, and stories. It is aligned with the broader ethical stance of the research, which aims to foreground the voices and narratives of people with learning disabilities in a manner that affirms their humanity. This decision also aligns with the social constructionist epistemological lens, which values the considerate use of language to reflect the humanity of individuals.

1.2.2. Hospitals

People with learning disabilities are recognised to access a variety of specialist mental health inpatient hospital services. The terminology for these services varies across literature and clinical practice (Oakes, 2012; Glover, Brown, & Hatton, 2014) and includes assessment and treatment units, inpatient units, psychiatric inpatient care, 'long-stay' hospitals and specialist mental health hospitals. Specialist forensic hospitals also cater to people with learning disabilities who face concurrent mental health challenges and have committed offences (Lindsay et al., 2010). These hospital services are provided by either the National Health Service (NHS) or private companies (Glover et al., 2014). On admission to hospitals, most people with learning disabilities will be detained under the Mental Health Act (1983) (NHS Digital, 2024), with some detained via the Deprivation of Liberty Safeguards (DoLS) under the Mental Capacity Act (MCA) 2005.

For clarity and consistency throughout this thesis, 'hospital' will be the term used to collectively describe all such aforementioned mental health or specialist learning disability inpatient settings for people with learning disabilities.

1.2.3. Discharge

'Discharge' will be interpreted as the process and journey through which people with learning disabilities transition from hospitals to community-based settings. Hennan and Birrell (2019) highlight that hospital discharge is not a singular specific event but a complex succession of connected steps that can involve various services and networks. This indicates that the discharge process can vary across contexts (i.e., different hospitals, locations, and community-based accommodations), outlining a diversity in discharge experiences and processes. The discharge phase of someone's care is highlighted in the TC programme as signifying the end of inpatient care and the shift to community, or home-based care environments (NHS England, 2017).

1.3. My Position in the Research

In embarking on this research, I bring the perspective of someone who has had the privilege of working with people with learning disabilities throughout my career. This work has not only allowed me to form valuable connections together with people and hear important stories but also deepened my awareness of the societal inequalities to which people with learning disabilities are exposed. Further, a significant focus of my roles has been facilitating hospital discharges and preventing admissions for people with learning disabilities, offering me a close look at the difficulties and intricacies of these processes.

These experiences have underscored, for me, the importance of prioritising the voices and stories of people with learning disabilities within systems that are not constructed to support or enable their expression. Motivated by a commitment to listening and valuing these narratives, I was able to chose a thesis topic that seeks to explore the discharge experiences of individuals with learning disabilities from a narrative perspective. While I approach this research from the perspective of someone without a learning disability, I have sought to do so with sensitivity and to attempt to remain critically aware of my assumptions and biases. Through this work, I aim to contribute to a more inclusive and respectful understanding of this process in the lives of people with learning disabilities.

1.4. Historical and Social Context

1.4.1. Historical Construction of Learning Disability

Before the late 1800s, the conceptualisation of learning disabilities, as we understand it today, was virtually non-existent (Goodley, 2013). During this period, individuals who may have later been identified as having a ‘learning disability’ worked and lived within the neighbourhoods they grew up in (Smith, 2005). The historical emergence of learning disabilities (or similar) as a category was largely absent before the late 19th Century (Jarrett, 2015).

The conception of learning disability has been noted to be influenced by the urban and industrial transformations of the Victorian era (Goodley, 2013). The values of this era placed importance on paid employment and, as part of this, fast-paced labour and ‘productivity’ (Gleeson, 2010). This period was further marked by dense population centres and the expansion of industrial labour, which served to underscore the visibility of individuals with learning disabilities (Oliver, 1990).

1.4.2. Institutionalisation of People with Learning Disabilities

During this period, the geographical placement of 'idiot asylums' occurred on the outskirts of towns and cities (Scull, 1979). These asylums were supported by legislation such as the County Asylum Act of 1808, which, while initially voluntary, became mandatory by 1845, leading to the development of a network of institutions (Philo, 1987). Further, as a result of the Poor Laws of the 1830s, for those considered 'unproductive', in the sense of being 'unable to work', their care became the responsibility of the state, leading to this group of people being further confined to asylums, poorhouses and workhouses (Gleeson, 2010). Taken together, this meant that over time, this grouping of individuals with 'learning disabilities' became less tolerated by the state and broader communities and increasingly marginalised, with an increasing number of people sent to asylums or similar (Wright, 2001). The increase in asylums in the UK meant that it progressively became the standard for people with learning disabilities to be 'institutionalised' within these settings (Jarrett, 2015).

In the 20th Century, the Mental Deficiency Act (1913) further contributed to the segregation of individuals with learning disabilities in large-scale institutions (Holland et al. 2002). These institutions were characterised as restrictive and unwelcoming environments, notorious for their overcrowding and the minimal rights afforded to those who resided there (Walmsley, 2005). Institutional practices meant individuals' lives were markedly different from those of broader society. The practices in these institutions included a clear and marked hierarchy between residents and staff, no personal belongings allowed, strict and rigid procedures, and few opportunities for privacy (Mansell & Beadle-Brown, 2010). As the proliferation of such institutions increased, partly due to economic challenges, the allocation of financial resources diminished, resulting in inadequate care and support for people within these settings (Bilir, 2018). Moreover, due to state policies and the absence of alternative support systems, individuals with learning disabilities found it very challenging to exit these institutions once they were detained there (Mansell & Beadle-Brown, 2010).

1.4.3. Relevant Cultural Ideologies

1.4.3.1. 'Science' and Eugenics

The late 19th and early 20th centuries witnessed a pursuit of measuring and categorising 'human intelligence'. The development and application of Intelligence Quotient (IQ) tests in the early 20th Century were heavily influenced by eugenic ideologies that sought to classify and rank individuals according to perceived genetic worth (Trent, 1994). This ideology was based on a racialised conception of 'intelligence', creating a hierarchy where white individuals, who were presumed to possess superior cognitive abilities, were at the apex (Trent, 1994). Jenkins (1998) highlights how the advent of these statistical measures of intelligence further marginalised those perceived as 'below average', casting them as potential 'detractors' of societal health and progress. During this period, through the lens of a eugenic ideology, 'mental deficiency' was conceptualised and constructed as a medical problem that threatened the survival of society (Jackson, 2000). Despite criticisms, the IQ test remains a standard tool, reflecting an enduring belief in a biologically based 'general intelligence' (Holland et al., 2002).

This period also marked the establishment and solidification of the 'psy' professions, which became increasingly influential in shaping societal 'norms' and behaviours (Foucault, 1977). By gaining authority over concepts like ‘intelligence’ and ‘mental health’, these ‘psy’ professions created frameworks that classified individuals, using this to justify various forms of control (Gould, 1996). For example, research initiated by American psychologists was used to make assertions regarding the heritability of learning disabilities and to advocate for harmful 'solutions' for this group of people, who were conceptualised as 'problems' (Carlson, 2005).

Rising anxiety around the hereditary nature of 'feeble-mindedness' and its perceived threat to societal integrity further fuelled the expansion of asylums and institutionalisation for people with learning disabilities (Jackson, 2000). Measures such as segregation and sterilisation of people with learning disabilities were consequently advocated for using 'scientific' justifications (Smith & Wehmeyer, 2012). The segregation of this group of people can be seen to be predicated on emphasising the need to control and manage the reproductive capabilities of those institutionalised to prevent the perceived degradation of societal genetic quality (Chinn, 2021). As such, psychological 'science' can be seen to have facilitated the segregation and dehumanisation of individuals with learning disabilities through this process.

However, in recent decades, there has been a shift towards using assessments like IQ and aptitude tests in more constructive and nuanced ways. Rather than solely focusing on deficits, these assessments can be employed to provide a comprehensive cognitive profile of an individual's strengths and areas of need (Hessl et al., 2009). This approach can allow for a better understanding of a person’s unique competencies and could contribute towards more personalised support (Fletcher & Miciak, 2017). It could, therefore, be perceived that evolution in the use of intelligence assessments may reflect a broader cultural shift towards recognising and valuing diversity in cognitive abilities, to some extent.

1.4.3.2. Capitalism and Productivism

This conceptualisation of people with learning disabilities during this period also reflected national efficiency concerns amid rapid industrialisation (Thompson, 1998). The value of an individual was seen to be based on their capacity for 'productive contribution' rather than other attributes, which echoed the industrial capitalist ethos that differentiated between the 'able' and 'unable' in terms of societal advancement (Philo, 1987). Such perspectives inherently problematised people with learning disabilities, overshadowing broader societal contributions of this group of people. This deficit-based perception of people with learning disabilities continues to align with Western capitalist ideologies that prioritise specific abilities and 'productivity' over other competencies (Gleeson, 2010).

This practice of institutionalisation, along with the ideologies that supported this, has contributed to an ongoing legacy of intergenerational trauma among people with learning disabilities and their families (Zuber, 2018). These historical ideologies and practices continue to shape current perceptions and treatment of people with learning disabilities.

1.5. Move Towards Deinstitutionalisation

In the latter half of the 20th Century, a movement for more community-based support for people with learning disabilities contributed to the 'deinstitutionalisation' process (Barron et al., 2011). This shift aimed to reduce hospital admissions of people with learning disabilities and replace this with accessible community care. This facilitated a transition from large-scale institutional settings to more integrated, community-based environments (Bachrach & Lamb, 1989). This was supported by developing smaller, localised mental health centres that provided services within the community (Fakhoury & Priebe, 2007). This transition also aligned with the principles of the United Nations Convention on the Rights of Persons with Disabilities, which advocates for the rights and inclusion of all individuals with disabilities (United Nations, 2007).

This shift was initiated by the Mental Health Acts of 1959 in England, marking the beginning of a period aimed at 'integrating' individuals with learning disabilities into community settings (Kugel & Wolfensberger, 1969). This process gained further momentum with the publication of 'Better Services for the Mentally Handicapped' (Department of Health, 1971), which reinforced the principles of the deinstitutionalisation movement (Barron et al., 2011). Consequently, the 1970s emerged as a critical phase in the transition away from institutional care, with continued efforts to integrate people with learning disabilities into the community (Mansell & Erickson, 1996). However, while intended to empower people with learning disabilities, this transition often resulted in new forms of segregation and control, creating 'asylums without walls' that often failed to foster genuine ‘integration’ into the wider community (Hall & Kearns, 2001*).*

More recently, UK policies such as 'Valuing People' (Department of Health, 2001) and 'Valuing People Now' (Department of Health, 2009) further focused on supporting community living for people with learning disabilities, substantially reducing the number of people with learning disabilities in hospitals.

1.6. Current Terrain of Hospital Discharge and Community Integration

1.6.1. Context Around Detention of People with Learning Disabilities

In the present day, people with learning disabilities may be admitted to hospital for various reasons, including both managing behaviours that challenge and treating severe mental health conditions.

Research indicates that behaviours that challenge often stem from unaddressed needs or difficulties in communication (McGill, 1993). Critics of the current application of the Mental Health Act (2007) argue it inappropriately medicalises such ‘behaviours that challenge’ without exploring their root causes, such as communication barriers, reactions to adverse treatment, or responses to adverse or traumatic environments (Hollins et al., 2019). As a result, this means people with learning disabilities who express their distress through behaviours that challenge can find themselves detained in hospital for prolonged periods. In response, the UK government's Mental Health Bill draft (Department of Health and Social Care, 2022) had proposed substantial reforms to address these concerns, proposing that individuals with learning disabilities should not be detained following an assessment if no mental health condition is diagnosed. This would have represented a significant policy shift.

However, despite this proposal, the omission of the Mental Health Bill from the recent King's Speech implies it will not be enacted before the next general election in 2024, delaying important reform (Mind, 2023). Mencap (2023) have labelled this exclusion as a significant 'lost opportunity' in preventing the inappropriate detention of individuals with learning disabilities and autism in hospital settings.

1.6.2. Transforming Care Programme: Aspirations & Realities

The TC programme was initiated in response to the distressing exposure of abuse at Winterbourne View by a BBC Panorama investigation in 2011. This widely reported scandal uncovered severe cases of abuse by staff to residents in a hospital for adults with learning disabilities (Chapman, 2011). Consequently, TC again aimed to 'transform' the care landscape for people with learning disabilities and autism in the UK (Department of Health, 2012). TC advocated for a shift from hospital-based to community-based living and support.

However, despite the closure of long-stay hospitals and fewer learning disability hospital placements available, there are ongoing difficulties in securing effective transitions for people with learning disabilities on discharge (Chester et al., 2017). As of March 2024, there were still 2,045 individuals with learning disabilities in hospitals (NHS Digital, 2024). Moreover, reports continue to highlight restrictive practices within these hospital settings, such as physical restraint and seclusion (Duffy, 2019). Instances of abusive care, such as those at Whorlton Hall, which led to criminal convictions for the ill-treatment of people with learning disabilities under their care (Durham Police, 2023), continue to underscore the dire need for change and improved care standards (Plomin, 2019). Consequently, there have been calls for better inpatient care and discharge planning for people with learning disabilities (Sheehan et al., 2016).

After missing the initial 2019 TC target, an additional target was set to achieve a 50% reduction in bed numbers by 2024 (Mencap, 2021). This pledge was again missed in 2024, with 71% of local areas failing to meet the target reduction in inpatient numbers (Mencap, 2024). It has been projected that at the current rate of change, this goal may not be achieved until 2030 (Mencap, 2024). To further compound matters, research by Gibson et al. (2023) has highlighted that the challenges in securing timely discharges are exacerbating the situation through adversely affecting the quality of care for people with learning disabilities.

Despite the government's expression of long-term intentions to enhance community care and reduce hospitalisation (Ince et al., 2022), several official reviews have highlighted concerns. The Parliamentary Joint Committee for Human Rights (2019) criticised the excessive use of detention and the conditions of facilities for those with learning disabilities and autism, emphasising the need for substantial legal reform and enhanced community support. Similarly, the Care Quality Commission (CQC, 2020) identified a prevalent misuse of restrictive practices and called for urgent improvements in care standards and the development of less restrictive alternatives. There has also been criticism from Mencap (2021) regarding the government's lack of commitment to addressing delayed discharges. Further, in 2020, the Equality and Human Rights Commission launched a legal challenge against the Secretary of State for Health and Social Care, citing what it deemed a breach of the European Convention of Human Rights, given the 'repeated failure to move people with learning disabilities and autism into appropriate accommodation' (Equality and Human Rights Commission, 2020). Campaigning organisations have also continued highlighting care issues in inpatient settings, such as a lack of meaningful activity and the inappropriate use of seclusion (Duffy, 2019; Mencap, 2021).

Against the backdrop of the TC programme's slow progress, the aspirations to 'transform' care for people with learning disabilities appear to contrast starkly with reality. Having highlighted the gap between the TC programme's aspirations and outcomes, the following sections will detail some challenges that have impeded its implementation and the successful discharge of people with learning disabilities into the community.

1.6.3. Housing Challenges and Community Support

It has been highlighted that a significant reason for discharge delays of people with learning disabilities is linked to a lack of housing options and community support (Mansell & Beadle-Brown, 2010). Supported living schemes, though beneficial, have not fully addressed the gap, particularly for individuals with complex needs. This can lead to instances of inappropriate out-of-area placements far from the local area of people with learning disabilities (Kosma et al., 2007).

Further, the absence of suitable accommodation has been a primary factor in discharge delays historically. This indicates an issue that has persisted for decades and predates initiatives like the TC programme (Watts et al., 2000). Recent studies continue to outline this challenge, with a literature review by Ince et al. (2022) indicating that the unavailability of community placements, or the lack of appropriate placements tailored to individual needs, significantly contributes to the prevalence of 'delayed discharges'.

1.6.4. Economic Implications and Market Driven Care

The financial underpinnings of care provision for people with learning disabilities are complex. On the one hand, the push towards market-driven approaches for 'care' has seen an increase in private care providers, expanding the choice and accessibility of such providers. However, this shift can also be seen to have led to a 'commodification' of people with learning disabilities, where financial imperatives are of importance (Mansell, 2006) and may be centred ahead of care quality and patient rights. Further, the emphasis on cost-efficiency of care provisions appears not to have necessarily translated into high-quality care. Instead, this can result in people with learning disabilities being placed in high-cost, restrictive settings that do little to foster independence or self-determination in the community (Department of Health and Social Care, 2022).

1.6.5. Cultural Challenges

The discharge process involves thorough planning and coordination to establish appropriate support services and care arrangements to address the patient's ongoing needs. Traditional paradigms of care for people with learning disabilities, can prioritise supervision over independence and are deeply entrenched and difficult to change (Bigby & Fyffe, 2006). It should be acknowledged that these paradigms are likely to influence the discharge process of people with learning disabilities, particularly given this process represents an intersect with the ‘harder’ end of mental health services. These cultural challenges could impede the implementation of the TC programme and supporting people with learning disabilities with discharge into the community.

1.6.6. Inequalities and Intersectionality

These needs and difficulties of people with learning disabilities, from admission to discharge into the community, should be situated within a broader context of health and social inequalities experienced by this group.

For example, research has highlighted several health inequalities experienced by people with learning disabilities (Emerson & Baines, 2010), including shorter life expectancies than the general population. Further, people with learning disabilities also face barriers in accessing healthcare services (Northway & Dix, 2019). These disparities are further exacerbated by social determinants of health, such as poverty, poor housing, and exclusion from community participation, which contribute to these health inequalities (Wiseman & Watson, 2021).

In relation to these identified inequalities, Kimberle Crenshaw's intersectionality framework illustrates how diverse aspects of identity interact to create unique experiences of oppression (Crenshaw, 1989). This is particularly relevant when considering the compounded challenges faced by racialised individuals with learning disabilities. For instance, research by Holmes et al. (2023) highlighted a higher likelihood of racialised individuals with learning disabilities being prescribed psychotropic medication, a practice that may reflect systemic and individual racism within healthcare settings.

These intersections can also lead to discriminatory misconceptions among service providers, such as that those from racialised communities are self-sufficient or 'hard to reach' instead of recognising the systemic discriminatory barriers perpetuated by services themselves (Heer et al., 2016; Mir et al., 2001). Notably, the TC programme does not specifically address the needs of racialised communities, nor does it consider how services should be tailored to meet their needs (Chinn, 2021). This omission indicates that, despite widespread discussions around discrimination and health and social inequalities, the particular needs of people with learning disabilities who also belong to minoritised groups are not treated as a priority by health and social care policymakers. These needs are important to consider in the context of discharge planning and interactions with healthcare services for people with learning disabilities. Overcoming cultural and systemic barriers is essential for constructing an equitable and inclusive healthcare system for all, irrespective of people's backgrounds.

1.7. Discharge of People with Learning Disabilities

In summary, the discharge process for people with learning disabilities is integral to the objectives of the TC programme. Still, as outlined above, challenges remain in effective discharges of individuals from hospitals to community settings.

1.7.1. Importance of Voices of People with Learning Disabilities

Historical practices in health and social care research have previously sidelined the perspectives of people with learning disabilities, leading to services that do not fully meet their needs (Nind, 2008). This pattern of exclusion has its roots in eugenic ideologies (as explored in section 1.4.3.1), which stigmatised individuals with learning disabilities as unfit for societal 'participation' and thereby influenced research agendas. Further, societal approaches that are 'protective', while intended to safeguard, can diminish the autonomy of people with learning disabilities, portraying them as incapable of contributing meaningfully towards research participation (Jenkins, 1998).

There is a growing expectation that research concerning people with disabilities should actively include their voices (Oliver, 1990). Adopting inclusive research methods is considered best practice (Nind & Vinha, 2013), marking a significant shift from earlier perceptions that viewed individuals with learning disabilities as unreliable narrators (Sigelman et al., 1981).

Therefore, hearing these perspectives offers an opportunity to understand further how people with learning disabilities navigate their discharge from hospital to community settings. Understanding the discharge experiences is crucial, as these voices can offer invaluable guidance to understanding this process for those placed centrally within it.

1.8. Discharge Experiences of People with Learning Disabilities: A Review of the Literature

1.8.1. Introduction to Literature Review

A systematic literature review was conducted to explore the existing body of literature surrounding this discharge journey. This review aimed to draw together, synthesise, and critique the existing literature (Siddaway et al., 2019) and explore the experiences of people with learning disabilities on discharge from hospital to the community.

Three databases were searched for relevant literature: PubMed, CINAHL Plus, and Scopus. The selection of these databases aligned with the review question and the subject matter, as they host an extensive range of literature appropriate to the research field. Among these databases are Scopus, recognised as an extensive citation source for peer-reviewed articles, and Cinahl Plus, a comprehensive full-text repository for journals in allied health and nursing (Head et al., 2018). These databases were searched together with grey literature using Google Scholar. A total of 10 papers were identified as addressing the experience of discharge of people with learning disabilities of discharge from hospital to the community.

1.8.2. Search Strategy

1.8.2.1. Search Terms

Scoping searches were conducted, and the terms were refined based on the results. The databases were then searched using the terms listed in Table 1. These terms needed to appear in the article's title, abstract, or keywords to ensure relevance.

Table 1. *Search Terms for Literature Review*

Search Topic	Terms Used
Learning Disabilities	Learning Disabilit* OR Intellectual Disabilit* OR Developmental Disabilit* OR Special Needs OR Learning Difficult*
Discharge	Discharge OR Transition OR Leaving OR Leave OR Transfer OR Process OR Moving OR Move
Hospital	Inpatient OR Hospital OR Assessment & Treatment Unit OR ATU OR Secure OR Forensic Ward OR Ward OR Institution
Community	Community OR Residential OR Supported Living OR Family Home OR Home

1.8.2.2. Inclusion and Exclusion Criteria

The review aimed to include only data collected directly from people with learning disabilities, excluding second-hand accounts or proxy data. The review focused on research that addressed the experiences of discharge or transition from hospital to the community for people with learning disabilities. No starting date limit was set for the literature search to encompass a broad historical context, including the initial phase of deinstitutionalisation. The review was concluded in March 2024, marking the upper time boundary for included studies. Detailed inclusion and exclusion criteria are outlined in Table 2.

Table 2. *Literature Review Inclusion and Exclusion Criteria*

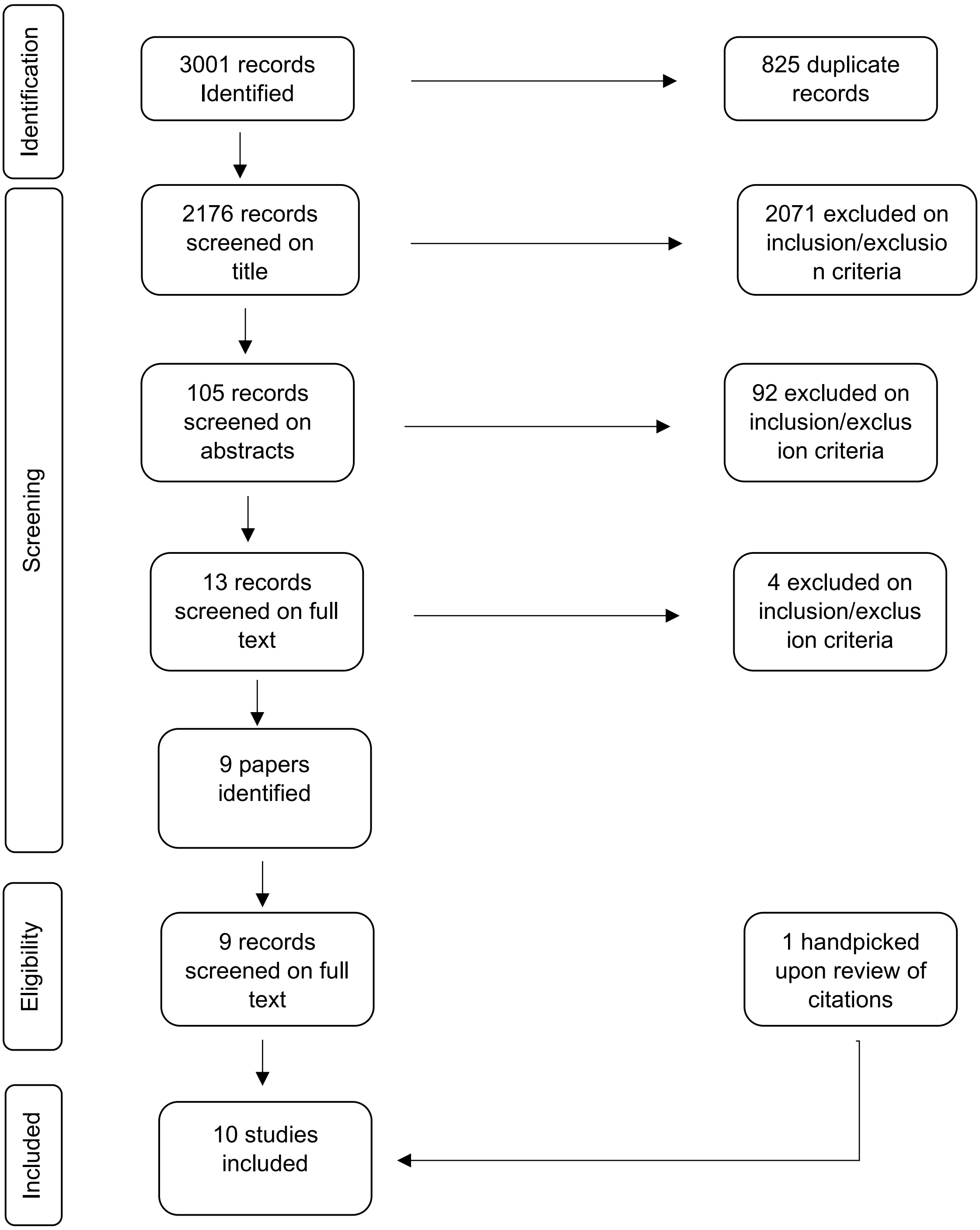
Inclusion Criteria	Exclusion Criteria
• Research based on people with learning disabilities. • The research includes information about the experience of people with learning disabilities on their discharge from hospital to the community. • Where other stakeholders' views are included in the research (i.e., staff	• Research on people without learning disabilities. • Research on children, not adults. • Research that does not explore how transition out of hospital was experienced by people with learning disabilities (i.e., only explores other outcomes concerning discharge, such as

team/family), the perspective of people with learning disabilities is adequately included. • (No lower restriction applied to date).	reduction in behaviours that challenge). • Research that attempts to elicit the view of people with learning disabilities by proxy (i.e. research that does not include direct interviews or input of people with learning disabilities). • Research on experiences of people with learning disabilities that are not relevant to the present study (i.e., not related to discharge from hospital). • Research on people with learning disabilities who share their perspective on discharge but where they have not yet been discharged (I.e., they are admitted to hospital and none of the sample have yet been discharged). • Research on people with learning disabilities who have been discharged from prison. (Prisons are noted to be different from forensic units).

1.8.3. Selection Process

An initial search of the three databases yielded 3001 papers. These papers were exported to Rayaan (a software designed to facilitate the screening process for researchers). Initially, duplicates were removed (n=825). The inclusion criteria were applied to screen the papers at various levels, including titles, abstracts, and full text. Additionally, the reference sections of the papers were reviewed, and searches on Google Scholar were conducted to determine where these papers had been cited. These methods retrieved one further paper. Through examining the papers applying the inclusion and exclusion criteria and reviewing papers that had cited these studies, 10 papers were identified as providing research on the experiences of people with learning disabilities of their discharge from hospital to the community. This process is displayed in the Prisma flow diagram in Figure 1.

Figure 1. *Prisma Flow Diagram for Study Selection Procedure*



1.8.4. Overview of Studies

The studies were published between 1997 and 2022. The majority (n=8) were based in England, with one in Scotland and one in Northern Ireland. All studies used a qualitative methodology (n=10). Please refer to Appendix A for a summary of the studies included.

1.8.5. Quality Appraisal

Mays and Pope (2000) argue that qualitative research should meet quality standards in several domains. They have developed questions that could be used by researchers at various times during the life of a particular research project to improve its quality. Their criteria for assessing the quality of qualitative research emphasise the importance of clear research questions, appropriate design and methodology, comprehensive context description, rigorous sampling, systematic data collection and analysis, and reflexivity in research reporting. Therefore, these criteria were used to evaluate all papers used in the review. A summary table of these criteria applied to the identified studies is displayed in Appendix B. Based on the quality appraisal results, no papers were excluded from the review. However, the results of this appraisal were used to guide the critical evaluation of the conclusions and findings.

1.8.6. Data Collection Methods

Given the inclusion criteria, there was an emphasis on qualitative approaches in understanding the complex and individualised experiences of people with learning disabilities. The collection of studies outlined in the review employed various methodologies.

Several studies predominantly utilised semi-structured interviews (i.e. Mitchell, 2022; McConkey et al., 2003; Jahoda & Markova, 2004; Hollomotz, 2021) to explore the experiences of people with learning disabilities. Another study used dyadic semi-structured interviews involving people with learning disabilities alongside their key support persons (KSP) (Head et al., 2018). Further, Tearle et al. (2020) used semi-structured interviews with open-ended questions to capture a participant's experiences with a learning disability in a collaborative case report.

Holland & Meddis (1997) used an adapted structured interview format, combining structured questions with opportunities for open-ended discussion. They also interviewed participants on multiple occasions to capture the depth of their experiences. Meanwhile, Forrester-Jones et al. (2002) also conducted interviews with open-ended questions to facilitate detailed discussions on participants' experiences. Turner (2019) captured an individual's discharge experience through a story, offering a personal and detailed view of transitioning from hospital to community living. Finally, Owen et al. (2007) conducted an extensive ethnographic study, combining participant observation and interviews.

1.8.7. Samples

The sample sizes from the papers ranged from one to 196 participants, with the median number of participants within the papers being 11. Most papers recruited between 6 – 11 participants (Holland & Meddis, 1997; Hollomotz, 2021; Head et al., 2018; Owen et al., 2007; Mitchell, 2022). Jahoda & Markova (2004) had 28, and McConkey et al. (2003) had 39, whilst Forrester-Jones et al. (2002) had by far the largest number of participants with 196. Two papers focussed on a single case study (Turner, 2019; Tearle et al., 2020).

While the review focused on research with people with learning disabilities, notably, two papers (Hollomotz, 2021; Turner, 2019) also integrated views from both health professionals and service users. Similarly, Head et al. (2018) included KSPs, nominated by participants, to provide additional insights during interviews. Forrester-Jones et al. (2002) also interviewed 102 people with mental health difficulties (and no learning disability), with the results section consequently being split into both groups (learning disabilities and mental health).

The total number of participants of people with learning disabilities in the papers was 314. The age range brackets of participants ranged from 20 – 72, although the age of participants was not stated in all papers (i.e., Turner, 2019). Participants' ethnicity was also not stated in most papers (n=8), and where it was, all participants were white British (Heard et al., 2018; Mitchell, 2022). The ‘severity’ of learning disability was not always stated. However, there was a reference to 'mild learning disability' in

Tearle et al. (2020) and Jahoda & Markova (2004), as well as 'severe' learning disability in Owen et al. (2007). Forrester-Jones et al. (2002) also noted that some participants had not taken part in the interviews due to 'severe communication problems'. Participants were also often noted to have additional diagnoses of autism or further 'psychiatric disorders' throughout the papers.

1.8.8. Settings

While all studies involved discharge from hospital to community-based settings, there were nuances among these within the papers.

Participants were discharged from a range of inpatient settings. Head et al. (2018) and Mitchell (2022) focussed on the process of moving from various hospital environments (i.e., mental health and forensic hospitals), whilst two studies focused solely on people discharged from forensic hospitals (Hollomotz, 2021; Tearle et al., 2020). Notably, the Hollomotz (2021) study took place in a hospital recognised as a flagship site for the TC programme. Another paper focused on discharge from an assessment and treatment unit into a supported living provision (Turner, 2019).

Several studies addressed the movement of people with learning disabilities from long-stay hospitals (n=5) to various forms of community living. This included residential or nursing homes, shared housing, supported living, or, in a few cases, return to family homes (McConkey et al., 2003; Jahoda & Markova, 2004; Forrester-Jones et al., 2002; Holland & Meddis, 1997; Owen et al., 2007).

Most studies were carried out with participants across multiple community settings, with people who had been discharged (n=9). One paper included the perspectives of participants who were both currently residing in hospital and those who had been discharged (Hollomotz, 2021).

1.8.9. Data Analysis Method

The data analysis strategies included thematic analysis (n=3) (Forrester-Jones et al., 2002; Mitchell, 2022; Hollomotz, 2021), grounded theory (n=2) (Head et al., 2018; Owen et al., 2007) and content analysis n=1 (Jahoda & Markova, 2004).

Four papers did not specify a clear data analysis method. Holland & Meddis's (1997) approach involved categorising statements as positive, negative, or neutral, attempting to simplify potentially complex experiences into these groupings. McConkey et al. (2003) quantified views using percentages from interviews to highlight participants' preferences and satisfaction levels post-discharge without a detailed explanation of the methodology used. Turner (2019) did not specify a clear data analysis method but included direct quotes from the participant to support the findings.

Tearle et al. (2020) utilised a participatory action research (PAR) framework but did not specify a traditional data analysis method. Instead, this approach involved collaborative and reflective discussions between the researchers and the service user, focusing on co-creating knowledge and understanding through active participation.

1.8.10. Synthesis of Findings

Given that most of the findings were qualitative, themes were identified from the reviewed literature through a thorough process of reading and re-reading each study. The data were coded while noting similarities and differences, which were then organised into a thematic structure to facilitate analysis. This approach led to the generation of themes, with five key themes emerging from the collective findings of the studies.

1.8.10.1. Identity and Self-Perception

The transition process noted the transformation of identity and self-perception as a theme. For example, Head et al. (2018) illustrated how transitions were not just about physical relocation but also entailed significant shifts in the 'identity and self-perception' of participants. Individuals who moved from institutional settings to the community were noted to experience a 'widening out' of their narratives, transitioning from a 'restricted story' defined by institutional confines to a broader narrative encompassing new roles, relationships, and possibilities within the community. A further illustration of this was in Jahoda & Markova (2004), which explored coping with stigma and the crafting of new identities once participants had been discharged from the community, emphasising the role of transitions in enabling individuals to reconceptualise their sense of self. Hollomotz (2021) also found that upholding and continuing to work on 'pro-social' identity formation was important. This change in self-identity underscores the transition's impact on people moving from hospital, beyond physical relocation.

1.8.10.2. Supportive Relationships

The importance of supportive relationships in facilitating a successful transition was also a recurrent theme across studies. Hollomotz (2021) identified the value of gradually building trust and developing meaningful relationships as easing the transition process into the community. The necessity of a structured yet flexible support network of people accommodating individual’s needs and preferences was highlighted by Tearle et al. (2020). Holland & Meddis (1997) identified the importance of carers in participant’s lives as influencing their overall view of the placement. Concerning how everyday life is experienced, Mitchell (2002) found that connections and relationships with others were meaningful to participants, particularly relationships with staff members. The individual discharged within the Turner (2019) case study valued their staff team, describing that they 'loved' their staff.

However, studies also indicated challenges concerning the lack of supportive relationships. Owen et al. (2007) found this an area of difficulty, with the participants reporting few opportunities for relationships beyond the staff team. Similarly, Forrester-Jones et al. (2002) found that many of those living in the community also spoke of a wish for more personal and sexual relationships.

1.8.10.3. Challenges and Anxieties

Transitioning to community living presented challenges and anxieties, notably around the fear of the unknown and adapting to life outside the hospital. Tearle et al. (2020) highlighted the increased anxiety about changes in the community, reflecting concerns about the uncertainties about support in a new and unfamiliar community environment. This is further reinforced by Owen et al. (2007), who observed that the lack of involvement in decision-making and preparation for transition led to increased stress and difficulty adjusting to new community settings.

Individuals with a forensic history could also face additional challenges due to court-ordered restrictions, impacting these participants' ability to engage in some community activities (Hollomotz, 2021). Furthermore, research by Forrester-Jones et al. (2002) and Mitchell (2022) sheds light on further challenges faced in community settings, including restrictive aspects of new living arrangements and the ongoing impact of hospital experiences on everyday life.

1.8.10.4. Aspirations for Independence

Despite the challenges, the desire for greater independence and community integration remained significant for people transitioning from hospital to community settings. The aspiration to create a sense of 'home' and pursue personal goals was reflected in the studies by Hollomotz (2021), Turner (2019), and McConkey et al. (2003). Forrester-Jones et al. (2002) highlight the overall satisfaction with new living situations compared to hospital settings and emphasise a value placed on independence in community activities. These aspirations underscore the need for community provisions that facilitate independence and support individuals' goals and ambitions.

1.8.10.5. Living Arrangements and Community Integration Experiences

The literature also provides insights into the experiences of people with learning disabilities in their community living arrangements and their efforts towards community integration. Holland & Meddis (1997) emphasised the importance of relationships with the broader community in shaping the living experiences of people post-discharge. Forrester-Jones et al. (2002) also explored the long-term satisfaction with living arrangements in the community, highlighting, for example, the value of a 'warm, comfortable home, shared with people you like'.

1.8.11. Evaluating the Literature

A noteworthy strength of this body of literature is its emphasis on qualitative methodologies, which provide nuanced understandings of the lived experiences, challenges, aspirations, and outcomes of individuals navigating this transition. However, several studies did not clearly describe their data analysis processes, complicating the task of assessing the systematic rigour with which conclusions were derived.

Further, the absence of reflexivity in some studies complicates the interpretation of findings, as it obscures the researchers' potential biases and influences on the data collected (Mays & Pope, 2000). This lack of reflexivity also makes it challenging to assess whether the data was systematically selected to support the conclusions described, or if it accurately represents all participants' experiences.

A further limitation across the literature is the lack of ethnic diversity among study participants. Ethnicity was often not mentioned in the samples, and where it was, all participants identified as white British (Head et al., 2018; Mitchell, 2022). This homogeneity is important as individuals from racialised backgrounds may face distinct challenges, including systemic barriers, which could impact their discharge experiences and outcomes. Expanding research to include ethnically diverse samples would provide a more inclusive understanding of discharge experiences and potential disparities in this process.

Several studies focussed on discharge from a single hospital setting. Whilst providing specific valuable insights, this focus may limit the generalisability of findings to broader populations and different care environments. Further, the relevance of studies conducted under different socio-historical climates, such as those from the 1980s (Forrester-Jones et al., 2002), may not accurately reflect current practices or the contemporary experiences of individuals undergoing discharge.

The literature often mapped out discourses linked to the challenges and support needs of people with learning disabilities during discharge. This focus can neglect the strengths, skills, and resources individuals with learning disabilities actively employ. Moreover, while some research touches upon identity and self-perception changes during this transition phase (e.g., Head et al., 2018; Jahoda & Markova, 2004), the role of personal and social narratives in shaping these experiences appear to remain largely underexplored.

These observations highlight gaps in the existing literature, including the lack of consideration of ethnicity in people with learning disabilities and a lack of focus on the skills, strengths, and knowledge of people with learning disabilities. Addressing these areas would enrich the current understanding of discharge experiences. This thesis aims to contribute towards these gaps by focusing on the transparent stories of individuals with learning disabilities, emphasising their strengths and skills during their discharge experiences into the community.

1.9. Rationale For Current Study

Existing research on the discharge experiences of individuals with learning disabilities has largely overlooked the potential of narrative analysis. Narrative approaches are beneficial for understanding how individuals interpret their experiences, draw upon their strengths, and face challenges. They can also provide people with the opportunity to tell their own stories, demonstrating resistance against forces of oppression (Goodley, 2000).

The current study, therefore, uses a narrative approach to examine the discharge experiences of people with learning disabilities. It will focus on how people with learning disabilities construct their stories, the strengths they rely on, and the skills they use during the transition from hospital to community living. Through prompts (see interview schedule, Appendix H) such as ‘What were the key events or moments that were important for you?’ and ‘What kind of support did you receive?’, the study aims to identify the strengths and skills participants utilised during their transition. The research also aimed to examine the challenges participants faced and the support they received, through questions like ‘Did you face any problems when you left the hospital?’ and ‘Did you receive any help/support when you left the hospital?’

Thus, overall these aims contribute towards the study's research question:

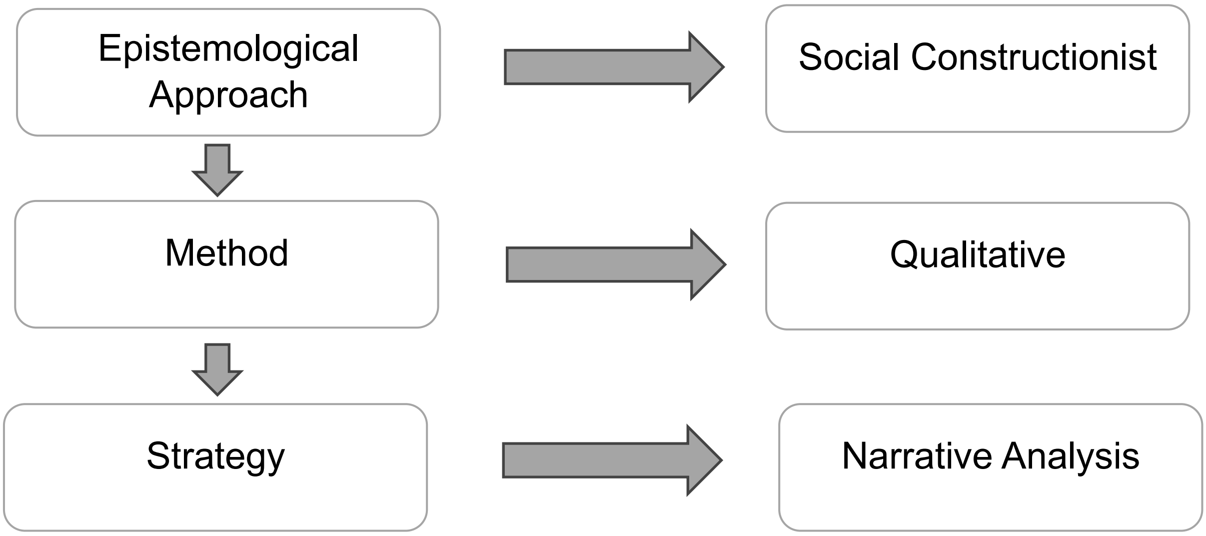
How do people with learning disabilities narrate their journey from hospital to the community?

2. METHODOLOGY

2.1. Overview

This chapter will outline the research epistemology and methodology and provide a rationale for the data collection and analysis. Procedural and ethical considerations will be discussed. Figure 2 provides a diagrammatic representation of the conceptual framework of the research.

Figure 2. *Conceptual Framework of Research*



2.2. Epistemology

Within research, epistemology concerns the connection between theories of knowledge and the concept of 'truth' (Nicolson, 2013). The focus of this research, centring the experiences of people with learning disabilities during hospital discharge, aligns with a social constructionist epistemological position.

Social constructionism concerns the ways individuals communicate their experiences to interpret, portray, and make sense of their world and self (Burr, 2003). It is fundamentally concerned with the idea that knowledge is not a fixed entity but a product of socially mediated processes (Willig, 2013). Within the framework of social constructionism, comprehension of the world is linked with our perceptions, which generates multiple paths through which experiences are constructed. This position asserts that knowledge production is a process shaped by our subjective, constructed frameworks (Burr, 1995).

Social constructionism differs from a positivist viewpoint, which seeks objective 'truths' as being unearthed through research. Social constructionism posits that reality is inherently unique and subjective, influenced by broader cultural, historical, and social contexts, shaping individual constructions of reality (Harper, 2011). This methodological stance is particularly valuable in research areas characterised by relatively limited existing knowledge, such as the experiences of people with learning disabilities on hospital discharge and transition to the community.

Social constructionism further underscores the dynamic nature of knowledge creation and understanding, urging an exploration of culture and language from the participant's perspective (Willig, 2013). In the context of this research, the process of sharing experiences related to hospital discharge is perceived as a construct intricately linked to cultural systems and values.

Social constructionism supports the idea that individuals interpret the world around them through the subjective meanings embedded in their experiences, resulting in a variety of constructions (Cresswell & Poth, 2018). In adopting a social constructionist epistemology, this research aimed to acknowledge and value the diversity of meanings derived from the experiences of people with learning disabilities and their journeys from hospital to community.

This epistemological position also maps onto the chosen narrative approach for the research. Through using a narrative approach, the study draws attention to the importance of understanding how people with learning disabilities share and interlink their experiences into stories, shedding light on dominant narratives and those that are more subjugated. This aligns with the aims of the overarching research question, seeking to explore the depth and diversity inherent in the stories of people with learning disabilities on their journey through discharge.

2.3. Qualitative Approach

Given the capacity of qualitative research to explore understanding and meaning-making in personal experiences (Willig, 2013), a qualitative approach was considered the most suitable method for researching the experiences of people with learning disabilities on discharge. Qualitative methodology seeks to generate contextualised meaning and avoid reductive tendencies that can risk oversimplifying complex phenomena. This was seen as highly significant in addressing the research question. In the context of this research, it was felt that a qualitative design would be an effective tool for exploring this area.

Acknowledging the power dynamics inherent in research, a qualitative approach was also used to facilitate central placement of the individual's stories (Del Busso, 2004) and go some way towards recognising this differential. It was felt that this was particularly important when working with people with learning disabilities, whose voices, perspectives, and stories have historically been suppressed in societal discourse and research (Jarrett & Tilley, 2022). The qualitative design adopted, therefore, aimed to facilitate the centring of the multifaceted and rich stories of people with learning disabilities and avoid oversight of valuable perspectives from those who have often been excluded from the broader narrative.

Further, Harper and Thompson (2012) have emphasised the strength of qualitative approaches in providing comprehension of complex experiences, which aligns strongly with the research question. A qualitative approach, therefore, emerged as the most suitable method for hearing the journey of discharges of people with learning disabilities. It enables exploration of the richness and diversity of these perspectives and ensures these stories are positioned at the forefront of the research.

2.4. The Utility and Power of Case Studies

A distinctive strength of case studies is their ability to detail the complexity of situations (Yazan, 2015), offering a nuanced understanding of the economic, cultural, and political contexts from an individual’s case (Maxwell, 2012). These strengths were seen to be particularly relevant to the current research question.

Critiques of case studies have often focused on their descriptiveness (VanWynsberghe & Khan, 2007). However, a detailed exploration of individual cases can help us grasp an understanding of how the world operates, by contextualising influences on individuals' experiences (Erickson, 1977).

Further, despite critique regarding the challenge of generalising findings from case studies, Stake (1995) contends that the knowledge derived from case studies possesses vividness, concreteness, and richness in comparison to broader qualitative methods. Similarly, VanWynsberghe and Khan (2007) reason that case studies can provide the audience with a sensation of being 'present'. Concerning research involving marginalised groups, such as people with learning disabilities, the use of case studies takes on a political dimension, offering readers the opportunity to bear witness to the existence of individuals whose reality, perspectives and stories are often obscured from the broader public (Rodriguez-Dorans & Jacobs, 2020).

Case studies can, therefore, serve to provide a nuanced and comprehensive account of an individual's journey. This richness of detail, context, and depth, therefore, makes case studies a valuable methodological choice for exploring the experiences of people with learning disabilities during hospital discharge to the community.

2.5. Narrative Approach

Utilising a narrative approach also seems the most fitting way to explore the research question, providing a nuanced exploration of the perspectives of people with learning disabilities and their journeys through discharge. Narrative methodology delves into storytelling, offering freedom and flexibility with no predefined rules (Andrews, Squire & Tamboukou, 2013).

A narrative approach explores how individuals make sense of their experiences (Riessman, 2008), which is especially relevant to this research. Narratives, viewed as a powerful medium for communication (Gottschall & Wilson, 2005), are examined by remaining near to participants' words and constructing personal accounts from these (Seidman, 2006). Participants can develop a sense of understanding of their experiences through narrative, and researchers and audiences engage in a similar process.

While a narrative approach is beneficial in centring participants' experiences, it also introduces ethical considerations related to authorship. Researchers must be transparent about their role in crafting accounts (Seidman, 2006). This further relates to the social constructionist epistemological position of the study, requiring the researcher to acknowledge their relationship with the data to foster an awareness of potential biases in interpreting and reporting (Charmaz, 2008), as will be further considered in Section 2.13.

The data for this study will use a narrative approach and be collected through interviews, aligning with the social constructionist epistemological stance and the research question that seeks a narrative account for people with learning disabilities and their discharge into the community.

2.6. Narrative Case Studies

Narrative case studies uniquely blend the analytical depth of case studies with the personal focus of a narrative approach, making this methodology particularly well suited for investigating complex individual experiences within broader socio-political contexts. By focusing on a smaller number of cases, narrative case studies allow for an in-depth exploration of the stories of people with learning disabilities. This method portrays participants as active narrators of their lives and empowers them as 'expert witnesses', challenging prevalent societal narratives (Bjornsdottir & Svensdottir, 2008).

2.7. Participants

2.7.1. Number of Participants

Using narrative case studies meant that recruiting a limited number of participants was a deliberate choice. Narrative analysis studies often adopt single-case study designs (Frosh & Emerson, 2005) or encompass sample sizes ranging from two cases onwards (Creswell, 2013). Further, as has been outlined, the foundational premise of narrative analysis lies in the in-depth exploration of a small cohort of participants, where the richness of their narratives and meaning-making processes is deemed valuable (Frosh & Emerson, 2005), rather than the research serving as a basis for broad generalisations.

Therefore, the intentional pursuit of a small participant pool, in the range of 3 to 5 individuals, aligns with the overarching goal of exploring meaningful insights within the chosen sample (Riessman, 2008).

2.7.2. Inclusion and Exclusion Criteria

Participants were people with learning disabilities discharged from inpatient hospital settings (i.e., assessment and treatment unit, forensic unit, mental health hospital) within the last five years. Participants were all 18 years or older. The research also focused on people with learning disabilities who communicated verbally and could participate in an interview. Whilst this inevitably deemed the research inaccessible for many people with learning disabilities, it was felt this criterion was applicable and relevant to the scope of the current research project.

2.7.3. Recruitment

Many people with learning disabilities receive direct support from private residential care or supported living providers within the community following discharge (Barnoux, 2019). Therefore, the study aimed to recruit participants via private, non-NHS, supported living and residential settings in England, particularly in or around London, given that this was where the researcher's University was based.

Participants were recruited with the support of the service managers of these residential or supported living settings. Service managers were approached with information about the study and asked if they knew participants who would fit the criteria and would be interested in participating. To support this process, the managers were provided with a parent/carer information sheet (Appendix C) and an accessible information sheet (Appendix D) to share and review with potential participants. A snowball sampling method was used, as contact with these service provider managers often led to signposting to other services/potential participants. The preceding process was then followed again. As part of this process, I attended different service providers and spoke broadly to staff and potential participants to provide information about the research project.

Once potential participants had been identified and had expressed an interest in participating in the research, I arranged initial in-person meetings with them. These meetings were all completed at the participant's place of living, and they were offered to be joined by a preferred person (i.e., parent or carer). During this meeting, the accessible information about the study document was reviewed together. Participants were given opportunities to clarify or ask any questions about the research. For example, some participants asked what 'exactly' we would be talking about or, if they were happy to take part, practicalities about when we could meet together.

Several situations arose during recruitment that influenced the sample of participants. In one situation, a participant expressed a strong interest in participating in the study during the initial in-person meeting. However, after this initial meeting, the service manager contacted the researcher, stating that the participant's social worker had raised concerns over the potential distress taking part may cause to the participant. It was subsequently agreed that the participant would not participate in the research. The researcher noted to the service manager that the participant had expressed an interest in the project and in having a space to talk about their discharge, and this perhaps indicated a need for further support. It was agreed that whilst the researcher was perhaps not the most suitable person for this, given the short-term nature of the research project, the team would consider a referral for more long-term support and a space for the person to talk about their discharge to the community (i.e., a psychology referral). In another case, a participant expressed interest in participating in the study. However, this client was re-admitted to the hospital before the arranged interview date and did not participate in the study. In a further case, the researcher met with a potential participant; however, it was decided that the participant did not demonstrate the capacity to consent to participate in the project, nor did they have a full understanding of the research. These situations and dilemmas around recruitment and accessibility of the research will be reviewed further in Section 4.5.3.

2.7.3.1. Participant Information

Five people participated in the study; see Table 3 for details. All identifying details have been altered. Age ranges, rather than specific ages, are provided to ensure anonymity.

Table 3. *Participant Information*

Name of Participant	**Age**	**Ethnicity and Gender**	**Time since discharge**	**Participated with parent/carer?**
Noah	20 - 25	Black British Caribbean male	2-3 years	No
Owen	60 - 65	White British male	2-3 years	No
Tara	25 - 30	Black British female	1-2 years	No
Phil	25 – 30	White British male	6-18 months	Yes, three support staff members were present (given the support service requirement)
Zach	20 - 25	White British male	1-2 years	Yes, one support staff member was present (given the support service requirement)

2.8. Service User Consultation

Initially, the research plan included a consultation with a learning disability service user forum to enrich the study's design and implementation. The consultation was intended to review the semi-structured interview format sheet in collaboration with service users. Such involvement would have ensured that the interview tool was appropriately tailored to the specific needs of the participants, potentially increasing the accessibility of the interview. However, due to practical constraints, this consultation could not be arranged before the commencement of data collection. Looking ahead, however, there are plans to discuss opportunities for engaging with service user groups during the dissemination phase of the research, as will be outlined in Section 4.4.

2.9. Ethics

2.9.1. Ethical Approval

The research project underwent ethical registration at the University of East London, as documented in Appendix E.

2.9.2. Ethical Standards

Adhering to ethical standards is fundamental in research, and therefore, the study adheres to the guidelines outlined in the BPS's Code of Human Research Ethics (BPS, 2014). This emphasises the significance of optimising the advantages of research participation while minimising potential harm to participants. Willig (2013) also outlines five ethical considerations that must be considered within qualitative research: no deception, confidentiality, informed consent, right to withdraw, and debriefing. Within this study, the methods and aims and were transparent and there was no deception. Each of these, as well as other additional relevant areas, will be addressed below.

2.9.2.1. Issues of Understanding

Ensuring participants understood the nature of the research was paramount. This process was supported by gauging participants' understanding of the project's aims during the initial information-sharing and consent stages. The initial meeting also enabled rapport-building and for participants to familiarise themselves with the project more broadly. This first meeting with each participant provided an in-depth overview of the project and space for clarifications, queries, or questions. During this first meeting, the accessible information sheet was reviewed with participants to support a comprehensive understanding of the research.

A speech and language therapist working with people with learning disabilities was consulted regarding the development of this document and the consent form

(Appendix F). This consultation aimed to support their accessibility in research with people with learning disabilities.

2.9.2.2. Acquiescence

Previous research has highlighted the importance of considering acquiescence in studies with people with learning disabilities. For example, McVilly and Dalton (2006) discuss the challenges of obtaining accurate responses from participants with learning disabilities and emphasise the need for careful consideration of response biases. Research has suggested that it is essential for the researcher to pay close attention to the communication preferences of the participants (Hollomotz, 2018). Therefore, ensuring a responsive approach to each participant's communication style and avoiding inaccessible question formats was essential.

Navigating potential acquiescence was aided by ensuring the participant was in a comfortable and familiar environment. While all interviews were conducted at the participants' places of living, participants (and those who knew them well) discussed where they may feel most comfortable with the meeting (i.e., which room). The format of the meetings were also adapted to the needs of the individual following the discussion (i.e., the length of the interview, frequency of breaks, time of day).

2.9.2.3. Capacity

Ensuring ethical research with people with learning disabilities involves acknowledging the importance of capacity around decision-making to participate in the research. Capacity, defined by the Department of Health (2005), involves understanding, retaining, weighing, and communicating decisions. The Mental Capacity Act (Department of Health, 2005) emphasises the 'presumption of capacity,' necessitating the assumption that individuals can make decisions unless proven otherwise. The research did not include participants who were deemed not to have capacity to take part in the study.

An attentive approach was adopted during the research, ensuring that participants comprehended the research more broadly and their involvement as participants in the project. Indicators of potential capacity issues, such as ambivalence or lack of understanding, were monitored. If concerns arose, recruitment or interviews did not progress.

2.9.2.4. Informed Consent

Ensuring informed consent of people with learning disabilities in research is highly important (McVilly & Dalton, 2006), particularly given the recognised concern of exclusion and involuntary inclusion in research with this population (Cambridge & Forrester-Jones, 2003). The research, therefore, required that participants fully comprehended and voluntarily agreed to their involvement in the research.

This process involved communicating the research's purpose, methodology, potential impacts, and data handling. The accessible information sheet was provided and discussed with participants to support this understanding. This information sheet was presented to potential participants for at least one week before meeting with them again to allow them appropriate time to consider if they would like to consent to participate.

Consent is viewed as a dynamic, ongoing process rather than a singular event (Hughes & Castro Romero, 2015). Therefore, after verbal agreement to participate, participants signed a consent form (Appendix F), their consent was continuously monitored by re-checking with them at different meetings. Feedback was also sought from those who know the person well regarding whether they felt the participant had understood the information sufficiently to provide consent. Cameron & Murphy (2007) identified non-verbal indicators related to consent (i.e., positive non-verbal responses) and doubtful indicators of consent (i.e., ambivalent non-verbal responses), for which further consideration was made on an individual basis. For all participants who provided consent and took part in the research, it was felt that they did so with comprehension of the project and consent to participate.

2.9.2.5. Right to Withdraw

Respecting participant autonomy and ensuring the right to withdraw is also fundamental to ethical research practices (McVilly & Dalton, 2006). The information sheet outlined this right, emphasising participants' freedom to discontinue their involvement at any stage. The ability and right to withdraw was communicated to participants on several occasions throughout the research, assuring them that opting out would have no adverse effects on them.

Participants were explicitly informed that they could refrain from answering specific questions and offered breaks during the interview, reinforcing their control over the process. Notably, during interviews, three participants opted for short breaks, demonstrating a practical exercise of awareness that they could take and request breaks at any point.

2.9.2.6. Confidentiality and Anonymity

The information sheets thoroughly explained confidentiality and its boundaries. Acknowledging this concept's potential complexity, discussions around this were also held during meetings. For example, the researcher asked participants, 'Have you heard of the word 'confidential' before?' Further, those supporting the participant (when this occurred) were also briefed comprehensively on confidentiality. Following procedural practice from Head et al. (2018), participants were invited to choose pseudonyms for the research. The conversation around pseudonyms was discussed when talking about confidentiality, and it was an activity that several participants appeared to enjoy.

Regarding information and data storage, participants were assured that consent forms and any personally identifiable information would be securely stored. Further measures are documented in the research's data management plan (Appendix G).

2.9.2.7. Participant Wellbeing and Minimising Potential Distress

It was acknowledged that given the sensitivity of the topic, the research may evoke psychological distress or risk re-traumatisation for participants who have experienced hospitalisation. The research also acknowledged the context of intergenerational trauma on people with learning disabilities, who, as a group, have suffered recurrent discrimination and harm at the hands of society, often through the process of institutionalisation (Zuber, 2018).

Given this acknowledgement, a trauma-informed approach was adopted to minimise the risk of re-traumatisation. Trauma-informed research is characterised by an awareness of the potential impact of past traumatic experiences and aims to minimise the risk of re-traumatisation during the research process (Hopper et al., 2010). Implementing trauma-informed principles involves creating a safe and supportive environment for participants. In this case, this included providing clear information about the research, offering choice in participation, being attentive to potential triggers or distressing topics during interviews, and providing avenues for ongoing support or debriefing if required. Additional pre-emptive measures involved developing a plan to support potential distress, identifying specific support persons, and discussing coping strategies. Participants were encouraged to contact the researcher for additional support after meetings, and debrief sessions were offered to reiterate the research purpose and provide contact details for any additional concerns. The trauma-informed lens of the research aimed to safeguard participants and align with broader ethical considerations in learning disability research (McVilly & Dalton, 2006).

The chosen narrative methodology also aimed to mitigate this risk by focusing on strengths, resources, and empowering stories, such as those that enabled people with learning disabilities to navigate and survive the discharge process. This allowed participants to articulate and emphasise moments of resilience and agency in navigating and surviving the discharge process.

2.10. Equipment and Materials

The study required encrypted audio-recording and transcribing equipment, an encrypted device to take photographs (for visual materials created during the session), a password-protected computer, and a lockable filing cabinet.

2.11. Procedure

2.11.1. Interview Procedure

Before the interview, the information sheet and consent form were reviewed with participants, ensuring a comprehensive understanding of the research and ethical considerations.

Each participant was initiated into the interview with the question: ‘Can you tell me your story of discharge from the hospital into the community?’ This approach aimed for interviews to be crafted as platforms for participants to narrate their stories authentically (Reissman, 2008). Subsequent inquiries were derived from narrative practice (Denborough, 2012) and utilised to guide participants back to recounting stories embedded in their experiences of strengths and challenges.

A semi-structured interview schedule, outlined in Appendix H, was developed in part to offer supportive scaffolding for the participants. This interview schedule also used as a flexible framework tailored to accommodate each participant's unique communication needs and preferences. Whilst these questions were available, the interview's trajectory was primarily guided by the participant's responses to the initial question. Participants were offered to engage in two separate interviews to enrich and refine their narratives, allowing them to re-author and add depth to their stories. (Two participants chose only to participate in one interview, sharing that they felt there was nothing more they wanted to share). Following the interview(s), debriefing time was ensured to address any concerns raised during participation and respond to questions.

Further, acknowledging diverse communication styles, participants were offered to incorporate paper, pens, and pictures during their interviews to enable them to articulate their journeys and highlight significant chapters in the most comfortable format.

Participants were also given the option of individual or accompanied interviews (i.e., with a parent/carer). In two cases, the researcher was informed beforehand that this 'choice' for participants was not possible, given that the service requirements were for the participants to be always accompanied by support staff (i.e., 24/7). Therefore, these two participants were accompanied by staff, without the choice of meeting individually.

At the end of the interview(s), participants were offered the opportunity to arrange a session to go through their stories with essential people in their lives ('Is there anyone else you would like to share your story with?’) In two cases, participants named the staff members as people they would like to share their stories with, so a final session was arranged to review the participants' stories together. This session aimed to follow the principles of 'outside witnessing' in narrative therapeutic work (White & Epston, 1990), with participants narrating their experiences (i.e., related to discharge from the hospital to the community) back to important people in their lives. The 'outsider witnesses' then provide empathetic validation and 'witnessing' of the participant's story to support the participant in feeling heard and acknowledged. This practice aims to empower individuals by acknowledging the significance of their stories within a supportive social network.

2.12. Narrative Analysis

Narrative analysis (NA) was the chosen method for data analysis, aligning with the narrative framework guiding data collection and reflecting the social constructionist epistemology. NA allows for an analysis of meaning, emphasising dominant narratives shaping individual and collective struggles and acts of resistance. This method acknowledges the dynamic nature of storytelling, the constant revisions, spontaneous elaborations, and the context-driven flow, allowing for a nuanced exploration of conceptions of self, others, and the world (Butina, 2015). NA focuses on moment-by-moment storytelling and re-storying, recognising the interpersonal process with the researcher. This becomes particularly crucial for people with learning disabilities, a group whose narratives are susceptible to being overshadowed by broader oppressive societal narratives (Washington, Bull & Woodrow, 2019).

Adhering to Reissman's (1993) perspective of the research being a learning process for the researcher, I was open to acknowledging that I would be influenced by the interactions with participants and the stories. NA emphasises how stories are significant in making sense of our experiences (McAdams, 1997), with key narratives noted to be shaped by events and processes deemed necessary by the individual, which can manifest in both 'big' and 'small' stories (Boenisch-Brednich, 2002). 'Big stories' may reveal significant life narratives, whereas 'small stories' might be brief or lack a clear structure but story the everyday essence of life's moments (Phoenix, 2008). It has been suggested that both types of stories are important in narrative research as they provide a holistic view of the narrative landscape (Phoenix & Sparkes, 2009).

2.12.1. Framework for Guiding Analysis

There are various frameworks for NA. Riessman (2005) proposes four NA methods: thematic analysis, which focuses on content; structural analysis, which includes thematic elements but also analyses storytelling methods; interactional analysis, examining narratives within conversational interactions; and performative analysis, viewing storytelling as an act of performance.

In this research, to achieve a nuanced understanding of the narrative expression of people with learning disabilities, I chose to combine these different NA analytical strategies, as recommended by Mishler (1995). As part of exploring the narratives of participants, the four approaches, as outlined above, were drawn upon to represent how people with learning disabilities story their journey of discharge into the community. The use of NA allowed for an exploration of these stories within various contexts, including broader social and political contexts (Stephens & Breheny, 2013).

2.12.2. Analytic Process

The participants' narratives and my conversational contributions were transcribed using the same guidelines (transcription convention outlined in Appendix I). After transcribing, each transcript was reviewed several times while listening to the recordings to fully immerse in the narrative accounts. Key messages and emerging stories were highlighted, and the researcher’s role in the storytelling process was acknowledged (Murray, 2014). Notable plots and the construction of narratives were also observed (Riessman, 2008). Special attention was given to the content of the stories (Riessman, 2008) and how narrators used or contested societal discourses (Wells, 2011).

To support the facilitation of this analytic process, I developed a set of guiding questions based upon Riessman's NA methods (2005) and as adapted from previous research utilising similar narrative analysis on case study designs (Cole, 2019; O'Connor, 2023). These questions are provided in Appendix J. See Appendix K for an example excerpt of the data analysis process at this stage.

2.12.3. Reading for Storylines and Subplots

Upon completing the NA for each participant, a summary account was composed for each participant. The final phase of the analysis involved a collective review of all the accounts to identify and compare themes and variations in the stories of participants. By examining the accounts for similarities and differences, it was possible to identify emerging themes (storylines) and secondary narratives (sub-stories) (Cole, 2019). After these themes were identified, the transcripts were revisited to verify the presence and consistency of these identified themes within the narratives. Refer to Appendix L for an example excerpt from a transcript verifying the collective storylines in a participant's account.

2.13. Researcher Reflexivity

Reflexivity plays a pivotal role in ensuring the validity and credibility of narrative research. Therefore, in alignment with a social constructionist epistemological stance (Charmaz, 2008), I implemented a reflexive approach throughout the study. This aimed to assess and consider my influence on the interviews and analysis while reflecting on my perspectives relevant to the research area. This involved maintaining a reflective journal from the start of the research through to its completion. Extracts from the journal are detailed in Appendix M. This journal allowed me to examine my emotional responses, recognise how I contributed to the co-construction of narratives, and consider the influence of my multiple identities, such as being a researcher, male, trainee clinical psychologist, of white British ethnicity, on the co-constructed storytelling process.

3. RESULTS

3.1. Overview

This chapter provides an overview of the interpretation and analysis of the accounts of people with learning disabilities on their discharge from hospital to the community. This aims to reflect the study's research question:

How do people with learning disabilities story their journey from hospital to the community?

I will first present a summary of the dominant narrative themes within each participant's account. Each account highlights important aspects of the person's journey, incorporating their own words. Following the guidance of Chase (2003), I attempt to implement a thoughtful approach to prevent overinterpretation and the risk of drawing unwarranted conclusions or judgments. This approach also aligns with Riessman's (1993) emphasis on evidence-backed interpretations, which I will do by grounding interpretations in direct quotes from the conversations. I have also included short excerpts of our interview, including my own responses, outlining the co-constructed nature of the narratives. This practice aims to ensure transparency and allow readers to evaluate the credibility and relevance of the findings themselves (Riessman, 1993).

Riessman (2008) emphasises that a single story can be interpreted differently. I therefore encourage the readers to reflect on how their experiences and narratives intersect with those presented here and to consider how these shape their interpretations of the stories.

3.2. Dominant Narrative Themes

3.2.1. Owen

Upon first meeting Owen, he said he was pleased to meet and had been looking forward to participating in the research and talking together. He often smiled as we spoke and rocked back and forth while we met. On one occasion, when we met, he waited for me in the lounge, listening to Christmas music. He told me he had helped put up the Christmas decorations with a staff member earlier that week, asking what I thought of them ('very festive!')

Owen began his story by sharing that he had not encountered '*any problems*' with his move from the hospital to the community. He described a gradual adaptation process, emphasising that he grew accustomed to his new environment. '*They just took me here in the car and I got used to it*', he explained. He expressed a preference for his new living situation, stating that '*I thought it was better to come here anyway*.'

Owen consistently spoke of a sense of improved wellbeing at his community placement throughout his story, highlighting a sense of happiness and contentment. '*I feel a lot happier here*', he shared. His story emphasised the importance of accessing the community and building social connections. He alluded to the value of daily outings and a growing sense of familiarity with his surroundings and the people within them. When asked about his experiences in the community, Owen responded positively:

> Owen: *It's good now it's getting better. Yes. Yes. There's more people around here that I'm getting familiar with. Yeah. You know what I mean?*
>
> Max: Is it? Can you tell me more? Yeah
>
> Owen: *And it's good to go out everyday. That's one thing*

Owen further acknowledged the opportunities to meet new people in the community but also spoke of the influence of his behaviour on these opportunities, stating, '*So long as I'm not shouting, I meet friends everywhere.'*

Reflecting on his time in hospital, Owen narrated a sense of '*relief*' at his transition to the community, often referring to his new place of living, in the community, as '*home.'* In comparison, he storied the hospital environment as confining, noting that he rarely had the opportunity to go outside. '*Umm (.) not really, only sometimes*,' he replied when asked if he could go out while in the hospital. Owen further spoke of a contrast between the restrictions of hospital and the freedoms he now enjoyed. '*It's difficult in hospital because you're locked up, but here it's possible (…) you're not locked up*', he explained, perhaps capturing a sense of his liberty in the community. Owen also spoke of a sense of escape from being *'stuck in hospital*.' '*Like at least you're here now*', he shared, conveying a further sense of reprieve. He explained that he now takes '*each day as it comes'*.

In contrast to his generally problem-free narrative, Owen did touch upon moments of difficulty, sharing that he felt '*low'* during his time in hospital. After sharing this, he quickly apologised for being a '*nuisance*.'

Owen went on to emphasise the importance of remaining calm as a key lesson from his journey.

> Max: Yeah. What about? Is there anything you learned along the way, Owen, in your discharge from hospital?
>
> Owen: *Yes there is!*
>
> Max: Oh really! (.) what did you learn?
>
> Owen: *Yes, be calm. Always be calm (…) I've relaxed more now*
>
> Max: Ahh okay. How does that help things?
>
> Owen: *It helps everything unwind a bit*
>
> Max: Really, okay
>
> Owen: *But I am very good and very calm now*

Owen also highlighted the importance of having time to '*settle*' into his new living place. He linked this need for this time to aspects of his identity and character, stating it was '*the way I am*.' He also further identified that '*going out every day'* and '*getting the exercise I need'* were important in helping him acclimate to his new environment.

Despite his initial fears and low expectations, Owen storied being pleasantly surprised by how well his discharge and transition went. '*I expected it not to go well! Sometimes that's how it goes (…) I started at the bottom and didn't want to go downwards*,' he recounted, acknowledging initial apprehensions about the move. However, he explained that the reality of his transition defied his expectations. '*Sometimes it can go the other way*!' he shared, indicating a sense of surprise. Owen concluded his story by identifying his ability to '*keep going*' as a key strength he had embodied during the process.

3.2.2. Phil

My meetings with Phil were held together with three of his support staff in his lounge area, as the support manager had informed me before the interviews that this was a service requirement. When we met, I perceived that Phil spoke very slowly and quietly. He immediately informed me was due to a significant injury he had sustained when younger through experiencing physical violence perpetrated by another person. I spoke with Phil in our first session about the use of additional visual resources to potentially supplement and support our communication together, but Phil explained that he did not like using these and preferred for us to talk verbally. His story was shared over two sessions, with each of our meetings lasting under ten minutes.

Phil began his narrative by sharing that he found the move from hospital '*a bit difficult*.' He explained that his previous community placement had *'broken down'* and that he had several moves in his life, perhaps outlining a difficulty in finding stability in the community.

> Max: Okay then (…) It sounds like you've had a difficult journey up to this point (.) Can I ask (.) how was the move out of hospital to the community?
>
> Phil: *Yeah I was in hospital (.) when I left hospital I lived at [location] (.) But it was a bit small (.) and I had issues with the neighbours (…) I've had loads of moves*

Following a brief hesitation, Phil further narrated a preference for his previous place of living in the community, despite the challenges there, compared to his current placement.

> Max: Hmhmm (…) how does this place compare with your last place in the community?
>
> *Phil: (…) I really prefer the last place*

> Max: Ahh okay (.) what was good about [location]?
>
> *Phil: (.) It was a nice place (.) it had a big garden at the house (…) it was closer to getting into town (.) and had a good bus route*

Phil went on to explain the importance of engagement with familiar routines and social interactions in the community. '*I shop at the local Tesco (…) I see my friends there (…) I see people who know me,'* he said, illustrating the value he placed on being recognised and known in his local area. His support staff echoed this narrative, explaining that Phil was '*very well-known at the local Tesco'* and that he had '*friends at the nearby car wash,'* which Phil agreed with.

Despite his storied engagement with the community, Phil expressed a strong desire to return to his hometown. '*I'd love to go back to [location] (…) it's quite far from here',* he stated, outlining a sense of connection to his previous local community. He further explained to me that he had lived away from his hometown for '*a really long time'*, and that whilst he did enjoy some things about living where he was, he would '*like to be living back there, in [location]*.'

On both occasions when meeting, Phil was explicit about when he wanted to finish the session and requested this clearly, which I appreciated. After finishing the sessions, Phil explained to me what he would do later that day (*'go to the shops'*).

3.2.3. Tara

I meet with Tara on one occasion. Before our interview, Tara outlined that she had much she wanted to share about her time in hospital specifically, as well as the journey to the community. Tara shared that her current living place was her second placement in the community, following a move from the first one that '*didn't go well*.'

Tara commenced her narrative by highlighting the challenges she faced during her discharge. '*Getting discharged is very hard*', she stated, before going on to emphasise the impact on herself, sharing that '*it was stressful.'* Notably, as part of this difficulty, she described the difference in her perspective from the hospital staff, stating that, '*The staff wanted me just to stay there! I was lucky to leave in the end.'* Tara also narrated that she found several of the '*staff in hospital'* to be '*horrible and* *rude'* and felt they did not '*enjoy their job.'* She then shared that she now thought it was '*so important to be kind!'*

Tara placed an emphasis throughout our meeting on the restrictive environment of the hospital. For example, she explained that '*I wasn't even allowed CDs*' when in hospital before going on to narrate that *'I love music'*, particularly '*listening to Beyoncé and Rihanna*.' The inability to access music felt like a notable loss for Tara, outlining the impact on her of the hospital restrictions.

Tara also spoke of the challenges of isolation measures during the pandemic. '*People were getting sick in rooms (…) not allowed to leave their rooms!*', she recounted, before sharing that the impact on patients was '*really difficult.'*

Reflecting on her hospital experience, Tara also spoke of her discomfort with medication on religious grounds as she explained that the medication '*tasted of alcohol.'* She went on to illustrate the coercive measures implemented in hospitals in response by narrating that, '*I didn't wanna take it (…) if you don't take medication, they might inject you (…) sometimes they put something in my arm*.'

Tara was keen to acknowledge how her parents played an important role in her discharge process. She explained that their visits and involvement in conversations with the hospital staff were helpful. '*My mum always helped me (…) she would take me out and say she was helping talk to people*', emphasising both a sense of emotional and logistical support she received from her family. She also spoke about a supportive psychiatrist who helped her find her current placement. '*The psychiatrist was helpful… they looked for places for me to live*,' she noted, appreciating the assistance in searching for accommodation options in the community, whilst still in hospital.

Despite this support, Tara also described a broad sense of unpreparedness for the community. She attributed this to the perceived inadequacy of support and input provided by the hospital (with the exception of support with cooking skills).

> Max: Okay, and Tara, did you feel like you had support to move to the community?

> Tara: *At [hospital name] they were not good, they didn't help me be ready for the community (…) apart from cooking (.) I know how to cook some foods now*

Tara went on to describe community navigation challenges upon moving from hospital. She spoke of difficulties in navigating public transport, sharing that '*I'm not used to taking the bus on my own (…) I'm scared taking the bus*', revealing complications in adjusting to the community.

Tara also highlighted the contrast between hospital life and her current community placement, appreciating the increased personal freedom she now enjoyed. '*Even being here (…) hospital is horrible (…) the main difference is being free*,' she stated. Tara further narrated appreciating the ability to go out '*whenever I want,'* a contrast to the controlled hospital environment, where she stated, '*they control everything.'*

Tara spoke about her experiences of staff teams in her first and second community placements. She noted a sense of connection with the staff team in her current placement and difficulties with agency staff in her first placement. '*They had a lot of agency staff (…) I don't like that because I don't bond with them*', she explained about her first placement, expressing further a '*wish'* for '*politeness'* from the staff team. Alternatively, she stated that the staff in her current placement '*know me well,'* as she laughed.

Faith and family support were also fundamental factors in Tara's story. She spoke of the support of prayer and her mother's encouragement. '*I prayed with my mum (…) my mum says that praying helps*,' she explained, highlighting the significance of her faith in supporting her navigation of the discharge process. Tara also narrated that her family helped her maintain '*determination*', '*patience*', and '*kindness.'* These were qualities she recognised in herself and likewise felt would be recognised in her by others.

Tara concluded our conversation by reflecting on her journey and offering advice to others, which was to '*Keep on going… my mum also helped a lot.*' This appeared to emphasise both the importance of perseverance and a sense of familial support. Tara also explained that she felt she had shared all that she wanted to in our first session.

3.2.4. Noah

I met with Noah on two occasions. He spoke quickly relative to me and often seemed inquisitive of myself. He had a warm and apparent sense of humour and laughed at times, but he often expressed a desire not to be in his current living place throughout our meetings.

Noah began his story by talking of his reluctance to leave hospital, attributing this to the disparity in treatment he received there compared to at his current place of living. '*I was in [hospital name] (...) it was better than here, far better*', he stated, emphasising his preference for the hospital environment over his current community placement. Noah further spoke of the superior treatment he received in the hospital. '*They treated me better in hospital than here*', he explained, narrating a difference in the quality of his care.

Noah chose to employ drawing as a medium during our meeting to support the expression of his story further. He marked a tick next to the hospital part of his journey and a cross next to a drawing of the community placement part (refer to Image 1). '*That's [hospital name], this is the journey, and that's [location]*', he explained. His visual representation underscored his preference for the hospital and his feelings of being misplaced in his current setting. '*There's a cross by [location] because I shouldn't be here',* he further confirmed. Noah's narrative throughout outlined the importance and centrality of being in the wrong place following his discharge.

> Max: That feels like an important part for you to tell me, right? That this isn't the right place
>
> Noah: *Yeah, that's definitely the main thing*

Noah explained that he was in hospital '*because I had a placement breakdown*,' which he clarified '*means that the placement wasn't going well for me.*' Reflecting on his time in the hospital, Noah shared his enjoyment of certain aspects of hospital life, such as the meals and social interactions. '*You got the right treatment (…) nice meals (…) it was a good time there',* he explained, contrasting these positive experiences with his dissatisfaction in the community.

Noah narrated a sense of '*regret'* at having moved to his current placement. He explained the staff '*don't care about me',* as they did in the hospital. '*They keep me here for money and things like that (…) it's not good, is it?'* he asked me rhetorically, outlining an understanding that financial motivations played a role in his community placement. '*I wasn't ready for a place like this',* he narrated, indicating a desire for a living arrangement that better suited his needs. Noah went on to express that, '*I want my own flat (…) anywhere but here*.'

Noah's narrative also touched on his family's role in the decision-making process around his discharge. He explained that his family's opinions influenced the decision to move him out of the hospital. '*My dad, my stepdad, he thought that hospital wasn't good for me (…) and he spoke to them*', he shared, indicating a potential conflict between his own preferences and his family's perspectives. Noah also expressed feelings of not being '*heard'* by those making decisions about his care. '*People just moved me here for no reason',* he stated, perhaps reflecting a broader felt sentiment of disempowerment in the process.

Noah also spoke of the speed of his discharge process. '*It all happened in a jiffy*', he explained, indicating potential inadequate communication in the process and readiness to move. He further discussed the friendships he formed in hospital and the difficulty of maintaining these relationships after his move. *'There's a guy called [name] who was my friend (…) I can't get in contact with them now,'* he lamented, highlighting the social disruptions experienced as part of his transition.

Noah also recounted distressing aspects of his hospital experience, such as the presence of violence on the wards, which contributed to a sense of fear. '*Some hospitals are like prisons (…) you can get beaten up in there*,' he shared, outlining the complexity of his feelings towards hospital life, whilst also having spoken of preferring to remain in hospital. Noah further storied a potential discrepancy, as he explained that, regarding a preparatory visit to the community placement, he '*just faked it that I liked it here, but I didn't like it here.'* Noah further explained his faked approval of the community placement because he thought, '*it might be rude to say I don't like the place because it was my first time here*.' He also emphasised that he did this as he needed to '*get out of hospital.'*

Noah went on to speak of his disapproval of his prescribed medication whilst living in the community. He stated that '*I shouldn't even be on medication*' and would advise others in his position to be cautious about the '*side effects.*' '*The medication makes you dozy and tired*,' he warned, indicating a broader concern about the impact of medication on his wellbeing.

When asked if there was anything he appreciated about his current community placement, Noah mentioned the food, stating that '*the food's really nice (…) jerk chicken (.) I like Jamaican food and African food sometimes*'. When asked about his love of this food, he explained that this came '*from my parents! They used to make it for me quite a lot in [location]*' he shared, connecting his enjoyment of the food to his cultural background.

Noah narrated a vision for his community life that encompassed several goals. These included personal relationships, education, and social activities. As part of this, he also acknowledged the contrast between his past experiences and current environment, emphasising that aspects of community living supported his aspirations:

> Noah: *… I'd like to have a girlfriend in the future (.) that's a good thing about living here, get married, go to college and cinemas and things like that*
>
> Max: Is that a difference from living in hospital and in the community?
>
> Noah: *Yeah that's a good thing*
>
> Max: What other goals do you have?
>
> Noah: *(laughs) I'd like to do a lot of things! Take my girlfriend out on a date. We'd do different things, go to McDonalds, cinema and stuff*

Noah rounded up his story by sharing a final comment regarding his community goals, stating that 'a*nother goal is I want to stay young and handsome forever! And live in the right place would be where I'm happy, settled.'*

Noah asked that we spend some time listening to music together at the end of our time together, which we did very briefly before he said we had now finished. Furthermore, upon talking together, Noah asked that we share his story with the manager of his supported living provision. Noah asked that I speak through areas of his story that he identified as most important (notably parts linked with not wanting to be here), with him adding further narration if he felt necessary. The manager reported it had been helpful to hear Noah's story. This process also prompted a further conversation between Noah and the manager about the processes required to remain at the placement and to move. Noah also reported that he found this a helpful process, given he was aware of the following steps required to move on.

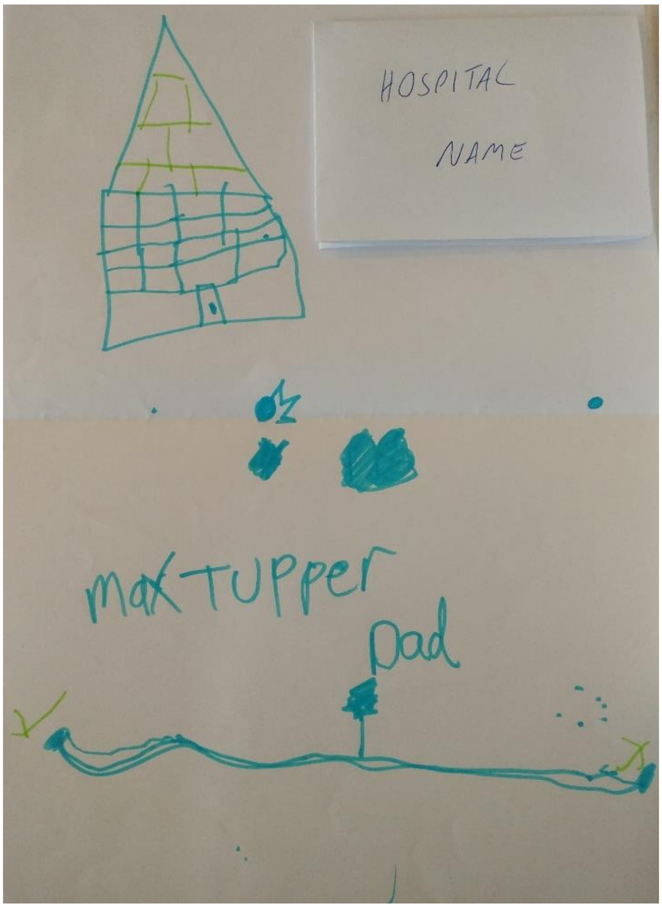


Image 1. *Drawing by Noah*

3.2.5. Zach

Zach and I met three times at his bespoke community accommodation. We met with one staff member present, as this was a service requirement.

Zach’s narrative began with reflecting on his challenges during his transition from the hospital to the community. He highlighted the difficulty he encountered with the change in ‘*new staff’* at his current accommodation. ‘*The new staff were quite tricky because they didn’t understand me,’* he explained. This point was reinforced by the staff member present, who noted, ‘*You like to have a bit of time to establish relationships with people, don't you*?’ Zach agreed, perhaps indicating an importance of stable and familiar staffing relationships.

Despite this, Zach also narrated positive aspects of his transition, such as enjoying the move into a new home. ‘*Yeah, but I was happy to be at the property with the nice new house,'* he shared, indicating a sense of satisfaction with his physical surroundings. He spoke of his family playing a role in his discharge, particularly in furnishing his new home. ‘*Well, my dad got the furniture from [location],’* Zach shared, with the staff member further elaborating that Zach, too, had participated in choosing the items.

Zach’s engagement in the community was another focal point of his story. He spoke about using public transport to ‘*get out and about*’ sometimes for ‘*food’* or ‘*going for walks.’* Zach reflected positively on community life compared to hospital, sharing that ‘*it’s going well (.) I feel more free in here than in hospital*.’ However, he expanded on this, noting that ‘*I still don’t feel quite free, but I feel more free*.’ He also shared that it was ‘*good to be out of there’* referring to hospital.

Zach went on to speak of a sense of interpersonal isolation within his current community. ‘*I still don’t really know many people around here (…) it’s not like [location]’* he said, contrasting his current environment with his previous local community. This lack of social connection contributed to his feeling of being ‘*stranded*’ in an unfamiliar place. ‘*I would like to go back to [location]*,’ Zach stated, expressing a longing to return to his local community. The staff member also acknowledged this desire, noting that it was ‘*a process that is being dealt with, but it’s going to take time*.’

A critical reflection in Zach’s narrative was the emphasis he noticed on building daily living skills in hospital. He felt that this did not fully prepare him for community life.

‘*They try and get you doing things for yourself (.) like cleaning your toilet and stuff*’, he explained, suggesting that these activities, while useful, did not entirely equip him for the broader challenges of independent living. Regarding this concept of ‘*doing some more things for yourself*,’ he stated, ‘*that’s what they say, but I mean (.) you don’t really need to.’* Zach also spoke about the challenges of medication in the community, sharing that he did not currently ‘*have the same energy because of the medication,’* indicating an impact on his daily life.

Additionally, Zach mentioned finding it helpful to have access to porn magazines, though this was a topic he was seemingly steered away from by the support staff during the conversation.

> Max: Yeah, yeah. Like you said, it's been tricky. How have you? How have you managed to get through it?
>
> Zach: *Ummm (…) Fortunately, I've got some porn magazines*
>
> Support Staff: That (.) isn’t appropriate for this discussion. I think what we're looking at really is the fact that you utilise the staff. You know you speak to me. Yeah, yeah.
>
> Zach: *Okay (.) yes that’s it (.) yeah*

Zach's narrative also touched on his aspirations for a romantic relationship. He explained that he would like to *‘go out now and get a girlfriend’* but was unsure ‘*whether or not that’s possible...,’* seemingly referring to broader procedures or restrictions. He expanded upon this as he spoke of wanting to ‘*take my girlfriend out on a date*’, illustrating his hopes for a fulfilling social and romantic life in which he accessed the community together with someone. Again, the staff member responded to this being a ‘*process’* that was ‘*taking place.’*

Zach drew his story to a close by explaining that it was ‘*good’* to be ‘*out of hospital.’* He compared hospital environments to his perception of prisons, noting he would have preferred a prison to a hospital, given its potential for more social interaction.

> Zach*: I’d rather have been in prison than in hospital (.) at least you feel more normal there (.) not like in hospital (.) do you work in prisons?*

> Max: No I don’t, and I haven’t /
>
> Zach: *Because there’s more people there too, so it’s more normal*
>
> Max: Uhh okay yeah I see, was that not what it was like at [hospital name]?
>
> Zach: *No it was quite small, there weren’t many people*
>
> Max: Right (.) Just to check, you’d have rather have been somewhere there were more people?
>
> Zach: *Yes because it’d be easier to make friends and you’d feel normal, more normal (.) in a prison*

After our time together, Zach explained that he would like to share his story with a particular staff member. We spoke together and agreed in this meeting that I would share key headlines of Zach’s story (that I had confirmed with Zach), with Zach narrating further aspects of his story. We consequently facilitated the session together. Zach spoke of sharing his story as being helpful for the staff member to get to ‘*know me.’* The staff member also shared that it was helpful to hear Zach’s story and reported that they appreciated how he had so far, and was continuing to, navigate challenges that arose in the community.

3.3. Storylines

The individual narratives of the participants were then analysed collectively, identifying commonalities and differences among the stories. Three main storylines emerged: (1) Challenges in Navigating the Discharge Process, (2) Drawing on Strengths, Support, and Resources, and (3) Realities of 'Community' Life. Each of these narratives included sub-stories, as detailed in Table 4.

Table 4. *Storylines and Sub-stories*

Storyline	**Sub-stories**
Challenges in Navigating the Discharge Process	Uncertainty and Complexities
	Involvement in the Process: Voice and Choice

Drawing on Strengths, Support and Resources	Learnings and Advice
	Supportive Relationships
Realities of ‘Community’ Life	Sense of 'Community' and 'Integration'
	Freedoms and Restrictions
	Expectations Against Reality

3.3.1. Challenges in Navigating the Discharge Process

The narratives revealed significant and varying challenges faced during discharge from hospital to community living. These challenges were often characterised by uncertainty, complexities, and issues related to the degree of involvement and agency participants felt they had in the process.

3.3.1.1. Uncertainty and Complexities

Participants often spoke of the discharge process as involving uncertainty and logistical challenges, potentially leading to distress on their behalf. The unpredictability and abruptness of the transitions, coupled with unclear timelines, appeared to contribute to difficulties experienced by people through the process.

Tara described the discharge process as ‘*very hard*’ and ‘*stressful,’* noting that hospital staff seemed to ‘*prefer’* her staying in the hospital. This contributed to feelings of frustration and distress. She summarised this by narrating, ‘*It was stressful (…) the staff wanted me just to stay there*!’ She went on to emphasise the unpredictability of the process by advising that it ‘*would be helpful to know when you can leave (.) I never knew when I could leave.’*

Noah's story also illustrated a sense of uncertainty, as he explained that the transition was abrupt and happened ‘*all in a jiffy.’* He also narrated feelings of ‘*regret’* and a broader sense of dissatisfaction with his placement in the community. Owen also stated that the move ‘*just happened,’* sharing that he ‘*did know about it’*, but ‘*not that long before it’*. He summarised that it was ‘*okay for me (.) but I could have known a bit earlier.*’

Phil's narrative emphasised the complexities of the discharge journey, as he spoke of experiencing several transitions in his living place. He narrated that he had '*loads of moves*,' and despite these, he actually preferred '*the last place'* that he had lived in the community, indicating a lack of improvement from his perspective. Tara also shared that she did not '*want to move again, it's alright here.'* She explained that '*I didn't like the first place I was, this place is a bit nicer.'* Noah, too, spoke of an awareness of others moving from his placement, sharing that another person was '*in hospital now for misbehaving, he kept kicking stuff and throwing the TV and things like that*.' These stories around relocation may also underscore the complexity of the discharge process and the sense of instability that remains in the participants' lives upon moving to a placement in the community.

3.3.1.2. Involvement in the Process: Voice and Choice

A recurring sub-story across the narratives was the degree of involvement and agency participants felt they had in their discharge process. Many stories described a sense of being passive recipients of decisions made by others rather than active participants in their own transitions. This lack of involvement appeared to lead to feelings of frustration. However, there were also moments when participants spoke of being involved.

Phil and Zach both spoke of being placed far from their local communities, indicating that their preferences for living arrangements were not considered, or followed. Zach explained, '*Basically I'm feeling stranded and I want to go back to [location] as soon as possible*.' Phil, too, shared that he did not like his current community placement and would '*love to go back to [location]... it's quite far from here*.' These accounts highlight a potential lack of voice and/or choice in participants' discharge process.

Tara's experience echoed this sentiment, as she felt that her perspective on the process was overlooked by hospital staff. She narrated a struggle to have her voice heard, particularly regarding her desire to leave the hospital. She shared that, '*I wanted to leave (.) I was lucky to leave in the end*!' However, Tara also provided an example of feeling involved in the process when '*they told me about supported* *accommodation (.) so they tried to find me a place (…) that's how we got [service provider name] (…) I was so happy.'*

Noah narrated that '*I don't feel like I've been heard',* highlighting injustice in this by sharing that '*it's not been fair on me because I've not been heard.'* Noah also shared that '*my dad, my stepdad, he thought that hospital wasn't good for me and he told that to the nurses.'* This contrasted with Noah's preference, which was to remain in the hospital until '*they found me a better place.'* Noah explained that the whole process made him feel '*a bit upset about moving out'* from hospital. When asked if he would have liked to have known more about the placement prior to moving, Noah responded '*Of course! That's the whole reason I'm complaining about it right now. I'd want more information*.' Noah's narrative here broadly appears to underscore a lack of being centred in the discharge process and outline the emotional impact of this.

Owen's narrative illustrated a potential feeling of powerlessness about decisions around his discharge. He frequently used the words '*they*' and '*I*' to distinguish between actions taken by others and his own areas of responsibility in the process. For example, he stated, '*they just took me here in the car here and I got used to it*.' This language in Owen's story perhaps illustrates a more passive role concerning where he was taken (i.e. community placement) but a more active role in his psychological adjustment (i.e., '*I got used to it'*). Noah also used the term '*people'* to broadly describe the decision-makers in his discharge process, stating that '*people just moved me here for no reason.'*

3.3.2. Drawing on Strengths, Supports and Resources

The second storyline focused on how participants drew on various strengths, supports, and resources while transitioning from hospital to community living. This included supportive relationships, personal learnings, faith, and adaptability and featured advice participants would give to others.

3.3.2.1. Learnings and Advice

Participants drew on personal learnings gained from their experiences. These insights helped them cope with the transition and provided valuable lessons for others in similar situations.

Owen shared that one of the key lessons he learned during his transition was the importance of staying calm. He explained, ‘Y*es, be calm. Always be calm (…) I’ve relaxed more now.*’ Owen noted this ability to remain calm helped him manage the discharge process from hospital and ‘*settle down’* in the community. He consequently advised others to *‘just be happy, yeah, and keep it up and go forwards*.’ He explained that this advice came from his own experiences, saying, ‘*You’ve got to keep moving forwards until you reach the right destination, that’s what happened with me.’* He further shared that in his journey, he had said to himself, ‘*Just keep it up and keep trying.’*

Tara shared insights into how she managed to cope with the emotional aspects of her transition. She emphasised the importance of perseverance and keeping a positive attitude. Tara advised, ‘*Keep on going (…) keep on going’,* as a message that emphasised a sense of determination, similar to that of Owen. Tara further reflected on the personal strengths that helped her during the transition. During her story, she recognised her ‘*determination’*, ‘*patience’*, and ‘*kindness’* as key attributes that aided her journey. By acknowledging these strengths, Tara narrated how these internal qualities supported her ability to navigate the broadly challenging process.

Tara also highlighted the importance of practical skills learned during her time in the hospital, such as cooking. She acknowledged the hospital ‘*didn’t help me be ready for the community (…) apart from cooking (.) I know how to cook some foods now.’* These practical skills appeared to contribute to her sense of capability in her new environment, providing her with a tangible way to manage daily life outside the hospital.

Zach’s narrative also included practical advice for others making the transition. He emphasised the importance of having the necessary resources to set up a new home, such as furniture. Zach shared that others going through the same transition ‘*need to make sure they’ve got furniture for their place (.) you’re gonna need lots of furniture in your new place*.’ This practical advice highlighted the need for adequate preparation and resources to ensure a smoother transition to community living.

Noah offered specific advice regarding the impact of medication, highlighting to others the importance of understanding its side effects. He stated, '*I'd tell them the medication makes you dozy and tired*.' His guidance aims to prepare others for the potential side effects of medication. Noah further shared that he had learnt that '*I'm very friendly and that means that I shouldn't be here in the first place'*.

3.3.2.2. Supportive Relationships

Supportive relationships were narrated as an important resource for participants during their transition from hospital to community living. These relationships provided emotional support, practical assistance, and a sense of belonging, helping participants navigate the challenges of moving to community living. Importantly, participants also spoke of challenges to themselves when these supportive relationships were not felt to be present.

Tara's story underscored the critical role of her family in her discharge process. She narrated how her parents' involvement was supportive in her transition, both emotionally and practically. Tara shared, '*My parents would take me out in hospital (.) they would come to see me*.' She further narrated that '*my mum always helped me (…) she would take me out and say she was helping talk to people.'* Tara's mother talking with '*people'* indicates a potential advocacy role, outlining the multifaceted support she spoke of being provided by her family in helping her navigate the discharge process.

Tara also described how prayer and her mother's encouragement to maintain faith helped her discharge journey. Tara shared, ' *I prayed with my mum (…) my mum says that praying helps (.) so I prayed lots*.' She stated that prayer provided her with strength and a sense of hope during the transition, which she outlined through sharing that '*god gave me a chance.'* This support from her faith, facilitated by her mother's encouragement, and the importance of faith itself, was narrated as providing an important role in helping Tara manage her discharge process.

Zach also spoke of family support during his transition. He shared that his family played a role in setting up his new home, which helped him feel more '*settled.'* Zach narrated that '*my dad got the furniture from [location]'* for his property*,* and this active participation from his father supported his transition by contributing towards creating Zach’s new living space.

Phil emphasised the importance of supportive social relationships in the community too, by narrating that he liked to ‘*shop at the local Tesco*’ because ‘*I see my friends there.’* Owen also explained that ‘*it's good now it's getting better. Yes. Yes. There's more people around here that I’m getting familiar with*.’ This growing familiarity and ability to build new relationships appeared to important to both Owen and Phil in perhaps feeling more involved in the community.

Alternatively, some participants spoke of supportive friendships that were lost during the transition. Noah mentioned difficulties maintaining friendships after discharge, stating that he ‘*can’t get in contact with them now*.’ Similarly, Tara shared that ‘*I lost my friends in hospital*,’ with Owen, too, explaining that ‘*I do miss my friends a bit, but I still prefer it here*.’ In addition, Zach also noted *'I’m not really happy (.) you know I want my friends back and all that.*’ These stories highlight the challenges in maintaining supportive relationships and friendships as part of transitioning from hospital to the community.

There were mixed stories about the support provided through relationships with staff. Owen noted that the staff ‘*in the hospital where I was, they helped me’* and explained that *‘[service manager name], [name] and a guy called [name]’* were important people who helped in his move to the community. Noah also shared that the staff team at his community placement ‘*do know me well here, honestly*’. However, he also expressed feelings of dissatisfaction, stating that ‘*they treated me better in hospital than here*.’ He went on to share that he felt the staff ‘*didn’t care’* for him, which he described as being ‘*not good’* and that the staff in the hospital ‘*didn’t frustrate me like they do here.’*

Tara also spoke of difficulties with the support staff in her first community placement, noting issues with agency staff, who she felt did not understand her needs. She explained that this lack of consistent, empathetic staff support contributed to her initial transition from hospital being more challenging, given the relationships with staff at the first placement. She explained, '*I feel like staff judge me sometimes (.)*

they had a lot of agency staff (.) I don't like that because I don't bond with them.' Zach also explained that he had difficulties in his relationships with agency staff, stating that they did not *'understand me'*.

3.3.3. Realities of 'Community Life'

The third storyline from participants' accounts concerned the realities faced by people with learning disabilities as they transition from hospital to community living. This includes their experiences of community integration, the balance between newfound freedoms and continuing restrictions, and how their expectations matched the reality of their new lives.

3.3.3.1. Sense of 'Community' and 'Integration'

Participants narrated that their experiences of community integration varied, with some narrating a sense of belonging and others feeling isolated or disconnected. The ability to feel integrated into the local community appeared to influence their overall discharge experience.

Owen's story highlighted a positive experience of community integration, emphasising the importance of social connections. He expressed that it was '*good to go out every day'* and that '*I go everywhere, it depends on what's happening outside in the real world.*' This sense of engagement in the community appeared to contribute to his sense of belonging. Noah also spoke of engaging in different aspects of community activities, sharing that '*sometimes I go disco here (.) I do quite a lot here.'*

Phil also spoke of appreciating the routine interactions and the stability of knowing people in his local community. Despite feeling a strong pull to move to his local area, he also spoke of the social aspects of his daily activities, saying, '*I shop at the local Tesco (…) I see my friends there (.) I see people who know me*.'

Tara's story reflected a mixed experience with community integration. She appreciated living with people her age, stating that '*you should be able to live with people your age*' and this was '*good'*. However, Tara also faced challenges in the community, such as her fear of using public transport. She shared that she was ‘*scared taking the bus*’ because she was not ‘*used to it’*, highlighting the ongoing difficulties in fully integrating into the community and achieving independence.

In contrast, Zach’s narrative outlined significant challenges in achieving community integration. Despite his efforts to engage with his new environment, he spoke of struggling to meet people in his neighbourhood and felt isolated. Zach shared, ‘*I still don’t really know many people around here (.) I think that house is empty (.) and that house is empty (.) it’s not like [location]*.’ His sense of isolation was compounded by nervousness about interacting with new people. Zach shared that ‘*actually I don't really talk to people in the community as such (.) Because I get a bit* <u>*nervous*</u> *about it.*’ These difficulties highlighted stories of difficulties with a sense of community and integration.

3.3.3.2. Freedoms and Restrictions

The transition to community living was storied as bringing a mix of newfound freedoms and continuing restrictions, significantly impacting participants' experiences and perceptions of their community life. While some appreciated the increased autonomy, others still felt constrained by various factors.

Tara highlighted the increased personal freedom she enjoyed in the community compared to the hospital. She emphasised that ‘*the main difference is being free… I go out when I want now (.) but in hospital they control everything*.’ She further gave an example of this by sharing that in hospital ‘*I couldn’t have takeaways, but here I can!*’ This newfound autonomy seemed to offer her greater control over her daily activities. Tara also reflected on the restrictive nature of hospital life, particularly during the COVID-19 pandemic. She noted, ‘*I wasn’t even allowed CD’s*’ but that she ‘*listens to my music loudly now!*’ The inability to access personal preferences such as music underscored the restrictive environment of the hospital, which contrasted sharply with her experience in the community.

Owen similarly spoke of appreciating the ability to engage with the community and build social connections. He noted the contrast between the freedom he experienced in the community and the confinement of the hospital, stating, ‘*It’s difficult in hospital because you’re locked up but here it’s possible (.) you’re not locked up*.’ This seemed to highlight a sense of relief and enhanced well-being for Owen, as he described the positive impact of not experiencing the hospital's restrictions and gaining the ability to move about more freely.

However, not all participants spoke of feeling liberated by their new living arrangements. Noah described his community placement as feeling *'like a prison, being trapped in'*. He further pointed to the presence of '*alarm systems,'* which he identified on the wall in his placement, as an example of a measure that made the environment feel controlled. He compared his placement unfavourably to his time in the hospital, saying, '*Here feels more like a prison. Because they've all got the alarms like they've got in prison and things like that*.' Noah's narrative seemed to underscore the paradox of feeling confined within a community setting, assumed to offer more freedom.

Zach's experience also reflected a mix of freedoms and restrictions. While he, too, appreciated the greater freedom compared to the hospital, he still narrated some limitations in his new environment. He shared that *'I feel more free in here than in hospital (.) I still don't feel quite free but I feel more free*.' Zach's cautious optimism seemed to illustrate the complexities of adjusting to a new living situation where some elements of control and restriction remained.

Medication, which could be conceptualised as a chemical form of restriction or restraint, was another significant factor that influenced participants' perceptions of freedom and restriction.' Noah shared his dissatisfaction with medication, noting its negative effects. Zach spoke of feeling '*drowsy'* as a side effect and further explained that he was '*still on the worst medication in the world (.) it's called Nicotine*.' These experiences with medication and prescribed substances appeared to add another layer of complexity to participants' transitions, affecting how free and in control they felt in managing their health and, consequently, their daily lives.

3.3.3.3. Expectations against Reality

Participants narrated that the process of settling into a new community after being discharged from the hospital often involved reconciling expectations with reality. Participants had varied experiences, some finding the transition smoother than expected, while others faced unexpected challenges that complicated their discharge story.

Owen shared that his discharge '*went better than expected*' despite '*expecting the worst*' in preparation. He noted, '*I started at the bottom and didn't want to go downwards... but sometimes it can go the other way!'* Owen's experience suggests that his new placement met and exceeded his expectations as he gradually grew accustomed to his new environment and built social connections.

Tara noted, '*It was a big change moving here (.) I wanted to leave hospital*.' She also spoke of how it '*feels like home now'* as she can '*eat my own food and go out all the time*.' This mixture of expected difficulties and positive aspects highlighted the complex reality of her transition story, seemingly combining fear and anxiety with moments of independence and accomplishment.

In contrast, other participants narrated a mismatch between their expectations and reality in transitioning to community life. Zach described finding it '*tricky* to adapt to the new environment. He also spoke of feeling '*stranded*' due to the distance from his original community. Zach's community goals to '*get a girlfriend'* and '*move back to [location]*' were also hindered by processes controlled by his professional support network, which were '*going to take time'* and were '*waiting for a signature'*.

Similarly, Noah expressed dissatisfaction with his current living situation, feeling it did not meet his expectations of increased freedom and support. He remarked, '*I regret coming here. You know I regret coming here*.' He questioned, '*How come when you move in they seem nice to you, but then after a few days they're a bit on off?'* He broadly summarised that it '*feels bad being here*.' This suggested a sense of disappointment and frustration as he navigated the complexities of his new community environment.

Participants also storied a range of emotions throughout their journey, including happiness, sadness, and frustration. For example, Owen outlined feelings of happiness and contentment as he settled into the community. He shared, '*I felt a lot happier here about living in the community compared to the hospital*.' Conversely, Noah’s narrative included feelings of ‘*sadness’* and ‘*regret’* as he struggled with the reality of his new living situation.

4. DISCUSSION

4.1. Overview

This study set out to understand how people with learning disabilities story their experiences of discharge from hospital to the community. NA was used to explore the stories of five people with learning disabilities and their respective discharge journeys.

This chapter summarises the research findings and considers these in relation to the relevant literature and broader contexts for people with learning disabilities. I will then critically evaluate the strengths and weaknesses of the research, consider the clinical relevance and implications, and recommend avenues for future research.

4.2. Summary and Discussion of Findings

The research project aimed to answer how people with learning disabilities story their journey from hospital to the community.

The narratives shared by participants produced a large amount of data reflecting the rich stories of each participant. Participants described difficulties in navigating a tricky discharge landscape whilst holding on to the importance of strengths, support, and resources to navigate this. From the accounts of participants, three broad storylines were observed. These were storylines of (1) challenges in navigating the discharge process, (2) drawing upon strengths, supports and resources and (3) realities of 'community' life. These stories contribute towards a broader understanding of the experiences and journeys of people with learning disability from hospital to the community.

I will now discuss the identified storylines from the study in relation to relevant literature and the broader context for people with learning disabilities.

4.2.1. Challenges in Navigating the Discharge Process

The participant's stories outlined that whilst current policy emphasises the importance of 'person-centred care' (NHS England, 2017), the terrain of discharge processes remains problematic.

Participants experienced unpredictability and uncertainty in the discharge process due to unclear expectations or timelines. These findings align with previous research (Head et al., 2018), which shows that people with learning disabilities frequently face uncertainties around their discharge processes.

Historically, people with learning disabilities have been excluded from decision-making related to their care (Nind, 2008). This links to the present study, as an issue identified in the participants’ stories outlined a potential lack of meaningful involvement of people with learning disabilities in their discharge planning. NHS England highlights that despite efforts to involve individuals in their discharge process, there remains significant room for improvement, particularly ensuring that individuals, their families, and advocates are fully engaged in decision-making and planning for life post-discharge (NHS England, 2024). Research has shown that this exclusion often stems from organisational and attitudinal barriers, as opposed to limitations associated with individuals’ 'disabilities' (Ferguson et al., 2011).

This sentiment was perhaps further reflected in some participants' stories, where they reported feeling 'unheard' through their discharge process. Participants often used the plural pronoun ‘they’ (e.g., ‘they took me’) in their stories to refer to seeming decision makers and power holders in the discharge process, perhaps highlighting where they felt agency for decisions was located. Such practices can be seen to echo institutional cultures for people with learning disabilities, where important life decisions were made *for* them *by* those in positions of power, further reinforcing their marginalisation (Nind, 2008). Moreover, various studies (e.g., Jingree et al. 2006; Antaki et al. 2002;) have underscored the unequal power dynamics between people with learning disabilities and staff members. In relation to this, Tearle et al. (2020) outlined the need for a structured yet flexible support network that facilitates individuals' involvement in this process and accommodates their specific needs and preferences, a finding this study supports.

Tensions and complexities in 'decision-making' for and with people with learning disabilities are well-documented (Altermark, 2016). Conflicts often arise between professionals aiming to promote what they believe will support an individual's well-being and the preferences expressed by individuals. In this research, participants also storied discrepancies between their views and those of staff regarding the timing and location of their discharge, labelling this tension ‘difficult.’ This can be seen to relate to Owen et al. (2007), who identified that a lack of preparation and involvement in transition planning then significantly contributed to stress and difficulty adjusting to new environments. Dennis (2002) emphasises that respectful relationships and a commitment to listening can help navigate these power imbalances inherent in the lives of people with learning disabilities. It may be that through taking a relational view with people with learning disabilities and seeing them as active agents, encourages those close to them to further facilitate their involvement through listening (Jacobs, 2021).

However, some participants in the research did describe a sense of involvement in the discharge process, for example, through meeting with staff or having help finding accommodation. This aligns with Turner's (2018) findings, which found that supporting the individual’s involvement through the process contributed to a smoother transition.

Participants also spoke of having lived at ‘loads of places’ and wanting to return to their local area. This outlines that frequent moves and placement mismatches remain significant challenges in the discharge process. These stories can also relate to previous research findings that multiple relocations disrupt individuals’ ability to build social networks, leading to feelings of isolation and loneliness (Forrester-Jones et al., 2002). These stories may also illustrate the consequences of inadequate housing options in the community for people with learning disabilities (Mansell & Beadle-Brown, 2010), and therefore contribute towards decisions to move people into unsuitable and unfavourable environments.

It is also important to recognise that hospital re-admission remains a reality for people discharged from hospital. The TC programme emphasises that hospital treatment should still be considered if necessary, and Community Treatment Orders (CTOs) make immediate hospital recall possible (Department of Health and Social Care, 2022). Concerns about moving again were also present in the stories told by participants in this study. This supports previous research findings that people transitioning out of hospitals through the TC programme often face challenges related to the lingering threat of re-admission (Head et al., 2018). The potential of hospital re-admission has also been found to be used by some staff teams as a form of behaviour management (Mitchell, 2022), highlighting the ethical challenges involved in the care of people with learning disabilities in the community.

Furhter, a notable aspect of the narratives was the employment of defensive processes by participants, reflecting the performative nature of storytelling. For instance, one participant stated, ‘It was no problem,’ referring to their discharge experience, yet went on to describe experiences that appeared problematic. This discrepancy highlights the tension between what individuals feel is acceptable to express and what they experience. The statement ‘It was no problem’ could be seen as a performative act, aligning with societal expectations of resilience and compliance, even when ‘reality’ appears to contradict this narrative (McAdams, 1996). Such statements may serve to protect the individual from potential judgement or conflict, illustrating the defensive mechanisms participants may understandably employ in storytelling.

4.2.2. Drawing on Strengths, Supports and Resources

The narrative methodology of the research supported participants in sharing their stories in the context of their strengths and resources (Goodley, 2000). In the face of a challenging and complex process, participants shared resources they used to adapt and navigate this journey. This included drawing on their skills and knowledge, adaptability, supportive networks, faith, and practical learnings. Through telling their stories, participants narrated their resilience and agency in the face of the hospital discharge process.

The insights and advice shared by participants offer valuable guidance for navigating the transition from hospital to community life. These experiences highlight the extensive knowledge that people with learning disabilities, individually and collectively, hold concerning the discharge process. Participants spoke of advice across various domains, including the importance of 'remaining calm', 'keeping on going', being cautious about medication due to its side effects, and looking for necessities before transitioning to a new residence. Their advice can also reflect a desire to empower and support others facing similar challenges. Such knowledge-sharing can enable individuals to learn from each other's experiences.

Faith served as a crucial support for one participant, who explained that their mother encouraged them to pray and maintain their faith. Previous research has found that religion can form an important part of life for people with learning disabilities (LeRoy et al., 2004). This aligns with broader research on spirituality for individuals with learning disabilities, showing that faith-based environments can foster a sense of acceptance and self-worth (Swinton, 2002). Spiritual beliefs and practices have also been found to help individuals with learning disabilities cope with low self-esteem, social stigma, and social isolation (Stiemke, 1994). These findings suggest that spirituality and religious activities can provide significant psychological and social support (McNair & Leguti, 2000).

Family, friendships, and broader social connections were also storied to be important in facilitating transitions from hospital to community. Participants narrated that these relationships could offer emotional support in navigating the discharge process and advocacy in some cases. This aligns with research by McConkey et al. (2003), who found that positive relationships can significantly enhance the well-being of people with learning disabilities transitioning from institutional settings. Further, research has highlighted that families can advocate effectively for their loved ones during this process, offering important support (Emerson & Hatton, 2008). However, family narratives may sometimes not fully align with the individual's needs. For instance, one participant described a potential misalignment between his family's perspective and his desires regarding his placement and leaving hospital, outlining complexities regarding this relationship.

Peer networks were also spoke of among participants in this study. This included a difficulty in maintaining friendships which is important to acknowledge, given the significance of peer groups highlighted in the literature. Previous research has shown that peer groups can provide emotional reassurance and shared experiences that help individuals build confidence to engage with the community (Brackenridge & McKenzie, 2005). Further, difficulties with friendships and social connections are understandably associated with loneliness for people with learning disabilities

(Gilmore & Cuskelly, 2014). Turner (2018) also emphasises that peer networks should be encouraged through activities and social groups to prevent isolation. Challenges in maintaining friendships from hospital may underscore a broader issue in how care systems handle the social and emotional aspects of the transition for people with learning disabilities. Therefore, the stories told by participants appear to indicate care transitions should recognise the value of friendships and provide strategies to help people sustain these relationships.

Participants narrated that they valued supportive staff who 'knew' them well and found it more difficult when they felt this was not the case. Hollomotz (2021) also highlighted the importance of building trust and developing meaningful relationships to facilitate a smoother transition into the community. These stories further align with research on ‘relational safety’, emphasising the role of consistent and predictable relationships (Clarkson, 2003). Relational safety has been identified as key to people's well-being, particularly in the context of support for people who have experienced substantial disruptions in relationships (Clarkson, 2003). Traumatic interpersonal early life experiences were narrated by one participant in the study.

Relational safety is particularly relevant to people with learning disabilities given research indicates reduced levels of attachment security, in comparison to the broader population (Al-Yagon & Mikulincer, 2004; De Schipper & Scheugel, 2010). Rayner, Wood & Beail (2014) also found that people with learning disabilities in secure settings can experience a ‘double bind of dependency,’ where they feel a strong need for relationships but have encountered unhelpful or harmful interactions previously. This further underscores the importance of establishing a sense of relational safety, which Head et al. (2018) noted was important in enabling individuals to express their distress through communication rather than behaviour that challenges.

One participant wished for greater ‘kindness’ from staff, sensing they did not ‘enjoy their job.’ Another participant felt that staff at their residence did not ‘care’ about them, which contrasted with the fundamental ethos of ‘care’ expected in care-based settings. These assertions may address a gap between service intentions and practical implementation. Concerning this, commonly identified challenges for staff in the care sector include low income (Conradie et al., 2017), insufficient training (Hussein, 2017), a perceived low status of the staff (Vassos & Nankervis, 2012), and long contracted hours (Judd et al., 2017). These challenges can be seen to reflect systemic issues within community care and support Bigby and Fyffe's (2006) assertion that improving work conditions in this field is crucial to supporting staff to deliver consistent and compassionate care.

4.2.3. Realities of 'Community' Life

The transition to community living presented participants with new challenges and opportunities. Participants' stories revealed how adjusting to community life was a multifaceted journey that required balancing expectations and reality.

The participants' stories of community life outlined differences in their sense of belonging and inclusion, challenging the dichotomous language often used to describe institutional versus community living. Community living is often conceptualised as a supportive environment in which people live outside of institutions; however, stories told by participants invite further critical evaluation. While some participants found a sense of belonging in the community, others narrated isolation and difficulties' integrating' into their new environments.

One participant, for example, narrated how he enjoyed the familiarity of daily outings and appreciated getting to know people in their local area. This sense of connection with others in the community is particularly important, especially given, as Wolfensberger (1983) points out, the ‘wounds’ and burdens borne by people who have experienced differential treatment and segregation from the rest of society, will not simply vanish upon discharge. For example, this may relate to one participant who spoke of experiencing a nervousness when talking with people in the community. This perhaps also aligns with previous research highlighting the significance of relationships with the broader community in influencing the living experiences of individuals after discharge (Holland & Meddis, 1997).

The participants' narratives within this research suggested that community living, in the manner they were experiencing it, was not always a favourable experience compared to hospital. This gap between the perception of 'community' living and the stories told by people with learning disabilities raises critical questions about how we understand and conceptualise 'community' living for people with learning disabilities.

The participants' stories of challenges with 'integrating' into the communities they were living in can be understood within a broader context in which people with learning disabilities often encounter stigma and discrimination in the community (Jahoda, Wilson & Stalker, 2010). These societal barriers construct challenges that can make it difficult for people with learning disabilities to participate fully in the community. This exclusion reinforce feelings of otherness and prevents individuals from developing meaningful social connections.

Hall (2004) consequently argues that the idea of simply 'integrating' people with learning disabilities into 'mainstream' society overlooks the discriminatory and structural practices they encounter while trying to navigate broader community spaces. This discrimination further relates to the meaning of the word 'community' within these contexts. Whilst ‘community’ is generally viewed positively within services and policy spaces, it implies receiving social structures that will *ensure well-being*; however, this is not a lived reality for people with learning disabilities (Skelly et al., 2022).

Therefore, it is important to acknowledge where responsibility and agency for community 'integration' of people with learning disabilities lies. Whilst services often focus upon the individual and their 'ability' to 'integrate' within the community, Bigby and Fyffe (2006) emphasise that this relies initially on reducing community stigmatisation and discrimination of people with learning disabilities. In support of this concept, Simplican et al. (2015) propose an ecological model of social inclusion for individuals with learning disabilities, emphasising the significance of reducing social barriers to enhance social inclusion.

Further, a broader sense of the term 'community' may not be fully understood or accounted for within the TC programme. While TC's intention is positive, relocating people to the 'community' (often defined simply as placements outside of institutions) may be an idealised and reductionist perspective that fails to consider how people with learning disabilities perceive and value their sense of 'community.' This raises important questions about who holds the power to define 'community' within the context of TC and how broader ideological frameworks, such as capitalism and productivism, may influence this. How 'community' living is conceptualised is consequently very important, as this understanding informs how the TC programme is implemented for people with learning disabilities.

As Sarason (1974) defined, a psychological sense of community is the feeling that emerges as a function of the interaction between the individual and their context. Therefore, a sense of community is not solely about the physical or geographical environment (i.e., living outside of institutions) but also encompasses the individual's and broader communities' interactions with their context. Sarason characterises this sense of community as a perception of interdependence and similarity with others, maintained by doing or giving to other community members. McMillan & Chavis (1986) have also identified membership, influence, integration, and shared emotional connection as dimensions that contribute to a sense of community. A positive example of this from the study was a participant explaining that living with people their own age appeared to provide a sense of shared identity. This story could illustrate how shared identity can foster membership and emotional connection (Sarason, 1974), thus supporting a smoother integration into the community.

Acknowledging the multidimensional nature of the sense of 'community,' it becomes clear that simply placing people with learning disabilities in geographical ‘community’ settings is insufficient. A true sense of community and belonging, as outlined by Sarason (1974) and McMillan & Chavis (1986), requires a supportive structure that enables meaningful interactions and emotional connections within the broader community.

The transition from hospital to community life also represents a shift expected to grant people with learning disabilities more freedom and independence. However, the participants' stories outlined that many continue to feel restricted due to systemic limitations and lingering institutional practices, which complicated the expected sense of liberation.

For example, participants narrated concerns and disapproval concerning their prescribed psychiatric medication. This can be seen to reflect broader issues around the overmedication of people with learning disabilities, particularly among racialised communities (Holmes et al., 2023). Projects like STOMP aim to reduce this reliance on medication by aligning treatments with individuals' long-term well-being and integration goals (NHS, 2017). However, this project was not perceptible based on the storied experiences of discharge from participants in the research.

Mansell and Beadle-Brown (2010) further emphasise that institutional or residential care settings often prioritise safety over personal preferences, which can reinforce feelings of powerlessness for people with learning disabilities. In line with this, the storied journeys of participants in the study often outlined systemic restrictions in the community, mirroring institutional approaches used in hospitals. These stories invite critical reflection on the often dichotomous framing of the culture of care in ‘institutions’ versus ‘the community’ in service and policy-level language, given participants' complex experiences of restrictions in the community. These participants’ stories can be seen to align with the literature related to the persistent institutional shadows that shape community care practices (Jahoda & Markova, 2004).

There were also diverse stories regarding how participants found living in the community compared to their expectations. One participant said discharge ‘went better than expected’ despite ‘expecting the worst’ in preparation. For others, they narrated a mismatch between expectations and reality in transitioning to community life. Participants also storied a range of emotions throughout their journey, including happiness, sadness, and frustration. The emotional complexities in participants' stories are further supported by Mitchell (2022), who also found that participants experienced conflicting emotions during their transitions.

Two participants stated that living in the community was difficult because they were so far away from their local areas. Another participant regretted the move to the community, wishing they had stayed in hospital. These stories may underscore a broader systemic issue regarding the availability of appropriate and preferred community living places. For example, difficulties sourcing housing options are a significant reason for discharge delay (Mansell & Beadle-Brown, 2010), which has led to people deemed 'complex' being placed in communities far from their local areas (Shankar et al., 2015). The limited availability of appropriate bespoke housing is also a common factor leading to delays in people's hospital discharge (Gibson et al., 2023). The result is that people with learning disabilities are often placed in geographically isolated settings, reinforcing a sense of dislocation and marginalisation despite living in the 'community', as was reflected in the participants' stories in the study.

Given these concerns, it is conceivable that without change, the pressure to reduce the number of people in hospital beds could further accentuate this problem. This is particularly relevant in the recent context of the government having failed to meet its pledge to reduce the number of people with a learning disability and/or autism in mental health hospitals by 50% (Mencap, 2024). As outlined through the stories of participants, inappropriate or poorly suited placements in the community can mean that the supposed liberation involved in not being detained under the Mental Health Act can be a disappointment to people.

Participants stories also spoke to the complexities of adjusting to the community. For example, one participant narrated that previously unencountered tasks, such as navigating the bus, presented significant challenges that they had not faced in hospital. Alternatively, another participant explained that having daily outings helped them get used to the new community environment. These stories appear to align with previous research asserting that gradual support is essential for people with learning disabilities to develop the confidence and practical skills that supports community based living and a sense of independence (Bigby & Fyffe, 2006).

4.3. Clinical Relevance and Implications

The research indicates relevant implications at several levels that relate to improving the discharge journey for people with learning disabilities. To review the implications of this research, Bronfenbrenner's (1979) ecological systems theory will be used as a tool to structure this. The implications will, therefore, be considered at the individual level, microsystem (service level), and exosystemic (policy level) through to the macrosystem (societal level).

4.3.1. Individual Level Implications

These implications are focused on supporting people with learning disabilities and their immediate support networks about their discharge from hospital to the community:

4.3.1.1. Development of a Therapeutic Tool

The current research holds promise for developing a therapeutic tool to facilitate discharge discussions. This tool could compile various narratives from individuals who have experienced hospital discharge, detailing their challenges and insights. Like storybooks that address grief, relationships, and sex, this tool would focus on stories of transitioning from hospital to community living. It would explore the complexities of both settings, acknowledging that some individuals may find community living difficult and have specific needs met even within hospital environments.

The narratives could highlight the positive and negative aspects of these experiences and could aim to help facilitate open conversations about moving to the community.

The initial step in this development would be to present the idea at a service user forum. This would allow for a collaborative review of the tool's potential and discuss practical steps forward, ensuring it is both helpful and reflective of the needs of those it aims to support.

4.3.2. Service Level Implications

These implications are intended for relevant learning disability services involved in the discharge process from hospitals to the community for people with learning disabilities. These may include hospitals, community learning disability teams, intensive support teams, and community support providers.

Participants' accounts provided a range of helpful advice and guidance through their stories, which are relevant to these services. These implications have been separated into 'general' implications, 'discharge specific' implications (centred specifically on the discharge process), and 'training' implications.

4.3.2.1. General Implications

2.3.2.1.1. Adoption of Narrative Principles in Services

This research employed a narrative approach in hearing individuals with learning disabilities share their discharge stories. A narrative methodology aims to enable participants to re-author their life narratives, emphasising previously repressed or silenced aspects (White, 1993). This approach could be effectively integrated into learning disability services to promote the principles of narrative approach in working with people with learning disabilities. This is because staff in these services are uniquely placed to promote and support the principles of this approach, enabling people with learning disabilities to develop and share their stories, given the time spent with people with learning disabilities.

By reshaping their narratives, people with learning disabilities can challenge limiting identities imposed on them by societal norms, thereby amplifying marginalised voices and promoting greater representation (Goodley, 2000). It is important to note that these narratives contrast to professionally held 'case notes' or 'case histories,' which often hold power in learning disability services, as they are told from the perspective of the people most centrally involved.

Whilst the success of narrative approaches in influencing practice in learning disability settings remains to be seen (Grant, Ramcharan, & Flynn, 2010), adopting narrative principles within services could, at best, contribute to genuinely person-centred planning. Areas where this approach could be implemented include person-centred reviews, transition planning and integration into staff training. Moreover, the adoption of this approach could humanise processes within learning disability services, which have been dehumanising both historically and in contemporary practices. By focusing on individual stories and experiences, narrative principles can change service delivery, making it more empathetic, responsive, and respectful of the lived experiences of people with learning disabilities.

4.3.2.2. Discharge Specific Implications

Given there are several 'discharge specific' implications that arise from the research, these will be listed below:

- The voices of people with learning disabilities must be centrally considered throughout the discharge process, including the pre-planning, discharge, and post-discharge stages. Practically, the implementation of this aligns with the principles of the co-production ladder. This emphasises the importance of involving service users at all levels of decision-making to achieve genuine co-production (Arnstein, 1969), ranging from minimal consultation to full partnership. This could be used as a resource during discharge to consider different ways people can be involved in the decision-making about their transition.
- Accessible resources should be available to individuals to explain the various stages of the discharge process (Mitchell, 2022). This information might include what to expect when finding a placement with straightforward, transparent details about the timeline for each stage, if possible.
- Community-based staff should become acquainted with the individual before discharge. This could involve staff visiting them in the hospital and offering support with activities on the ward. This process will help build relationships and ensure the staff team feels confident providing care. For the individual, it is also beneficial to visit the placement beforehand.
- Given time in hospital, people with learning disabilities may not have had the opportunities to develop, or maintain, skills relevant to their daily living (i.e., use of public transport). Therefore, it may be that people would benefit from gradual support in these areas. This skill development would benefit from consideration whilst the individual is still in hospital, to enable them with the opportunity to begin to learning skills that are felt to be supportive of their community living. It is important that through this process, the person with learning disabilities is included in considering which skills they would choose to work upon, specific to their community living needs.
- Together with the person and relevant community stakeholders, consideration should also be made to foster and support a sense of community upon their

move. This could be scaffolded by considering how to ensure the following elements for the community and the person with learning disabilities: membership, influence, integration, fulfilment of needs, and shared emotional connection (Sarason, 1974; McMillan & Chavis, 1986).

- The study underscored how connections and relationships with others supported individuals during their discharge journey and facilitated their inclusion in the community after being in hospital. Therefore, services should consider how to assist people in building new relationships and connecting with existing networks according to their preferences.
- Participants spoke of the importance of relationships and the difficulties in sustaining these through discharge. Consideration should be made about maintaining friendships formed in hospital for people when in the community, as these relationships are important for well-being. Peer support groups and spaces for transitioning out of hospital could also be beneficial.
- It is important that there is transparency with the person about restrictions imposed on the person in the community, at least those initially in place. These should be reviewed in line with Positive and Proactive Care (Department of Health, 2014).
- Consideration should be made around how people's stories can be documented in the ways they want them told and how this can be shared with staff supporting them in ensuring continuity of care. This aims to support staff to ‘know’ the person they are working with.

4.3.2.3. Importance of Preparation for Transition

The findings suggested that preparation for the transition from hospital to community living was often inadequate, or to some extent avoided. This lack of preparation could be understood through the lens of attachment theory, which emphasises the importance of a secure base during times of transition (Bowlby, 1988). A secure base, typically provided by a caregiver or trusted figure, allows individuals to explore new environments with the confidence that they can return to safety if needed. In the context of transitioning from hospital to community, healthcare professionals and support staff are most adequately placed to fulfil this role, ensuring that individuals feel supported and prepared for the changes ahead.

However, healthcare professionals, influenced by their own attachment styles, and therefore may understandably struggle with this emotional engagement within these situations, leading to challenges in discussing difficult topics such as transitions, endings, and the associated emotions (Holmes, 2004). For example, an ‘avoidant’ attachment style could understandably result in professionals avoiding in-depth preparation for discharge (Meyer & Pilkonis, 2001). By recognising the potential impact of their own attachment styles, and those potentially reflected in systemic discharge processes, healthcare professionals can work towards creating a more secure and supportive environment, which is likely important for successful transitions.

4.3.2.4. Staff Training

The participants' stories demonstrate the valuable contributions that people with learning disabilities, who have moved from hospital, can make towards improving care and support. I therefore suggest that training workshops could be developed that incorporate the findings of this study. This training could encourage and support staff to think more broadly about aspects that foster a true sense of community for people with learning disabilities. Additionally, the training should focus on how to adopt a genuinely individualised and person-centred approach within the context of broader restrictive frameworks.

This training could be directed towards teams or relevant supporting people with learning disabilities who have moved out of hospital.

4.3.3. Policy Level Implications

Current NHS policy indicates that co-production with service users and carers should be a ‘default’ for improving experiences of care (NHS England, 2022). However, despite efforts to involve people with learning disabilities in policy-level decision-making, they remain one of the most excluded, least independent, and least 'in control' groups in society (Hoole & Morgan, 2010). Consultation and collaboration with people with learning disabilities at a policy level is therefore essential, particularly concerning hospital discharge and community living.

The TC programme, which aims to facilitate discharges into the community, currently risks oversimplifying the experience into a dichotomy where hospital is perceived as unfavourable, and community placement is automatically seen as an achievement. This loss of perspective at a policy level is further highlighted through assessments of TC, noting that the programme is ‘not working and is putting people with intellectual disabilities and autism at risk’ (Taylor, 2021). This can lead to the placement of people with learning disabilities in communities which are not suited to their physical, mental, or emotional needs, being conceptualised broadly as a 'success'. This binary perspective loses the nuance of the individual's voice and specific needs.

I suggest a broader and more comprehensive understanding of community is woven into the TC programme to ensure placements align with personal needs and preferences. Now, perhaps represents a timely point to re-assess and re-conceptualise the concept of 'community' in the TC programme, given that the government has just missed their 2024 pledge related to hospital discharges (Mencap, 2024). It is important to note that this recommendation does *not* minimise or reduce the *urgency* of moving people from hospitals but advocates for a TC policy framework that demands more significant consideration about what is conceptualised as 'successful' placements for people with learning disabilities in the 'community.'

As a part of enabling improvement of this process, it is important to evaluate the success of the TC programme *beyond* just the geographic location of people towards an understanding that 'community' living should be understood to reflect a true sense of community and belonging for people with learning disabilities. Holding these ideas centrally in the TC policy would contribute towards humanising people with learning disabilities after centuries of dehumanisation.

4.3.4. Societal Level Implications

Beyond the policy level, the stories shared by participants also highlight broader marginalising ideologies at a societal level linked to learning disabilities. Historically, institutionalisation and the control of people with learning disabilities were rooted in cultural ideologies focused on productivity and normality, with eugenics, ableism, and a medical model of disability contributing to these practices.

Research by Scior (2011) and Jahoda, Wilson, Stalker & Cairney (2010) has shown that stigma towards people with learning disabilities is a longstanding problem. This research highlights how societal attitudes and stereotypes continue to marginalise individuals with learning disabilities, creating barriers to full inclusion and participation in the community.

Disseminating the findings of this study can challenge these marginalising ideologies at a broader level, contributing to the ongoing effort to address stigma and promote inclusion. However, it is important to acknowledge that tackling stigma and fostering inclusion remains an extensive and ongoing challenge that requires sustained commitment and action.

4.4. Dissemination Strategy

I will share an accessible summary with those who participated. Sharing the study's findings and the stories of people with learning disabilities from a narrative approach could have the potential to influence opinions and shape attitudes. Therefore, I will coordinate with learning disability services to arrange a presentation of the research and its findings.

Additionally, I will aim to share the research with a service user group to help review the findings and consider possible next steps for dissemination. This process could also help identify other opportunities to share the research, including potential presentations to commissioners and other key stakeholders.

It is hoped that sharing the findings can illustrate the real-world implications of policy decisions, such as those related to the TC programme, and highlight the broader importance of involving people with learning disabilities centrally in these conversations.

4.5. Critical Review

4.5.1. Validity

Riessman's (1993) framework for research employing a narrative approach suggests than an evaluation of the data should be based upon the following domains: persuasiveness, correspondence, coherence, as well as its pragmatic utility. The pragmatic use was of this study has already been addressed by discussing the clinical implications of the research (see Section 4.3).

Persuasiveness: This criterion involves an assessment of the 'credibility' of the understandings and interpretations presented in this research, in relation to the data from the research. The study utilised exact quotes and summaries from the interview were employed, including interactions between the participants and myself. This aimed to support the persuasiveness of the research. Interpretations were also transparently linked to broader socio-political contexts (e.g. relevant policy), and research contexts (e.g. relationship with previous literature), and how these contexts then interacted with participant narratives. In relation to persuasiveness, it is also important to hold in mind that this criteria depends on the reactions and responses of the audience receiving the research (Riessman, 1993).

Correspondence: This criterion refers to the extent to which the accounts I developed in the NA, genuinely represented the participants' narratives. In order to support this, I often checked with participants that I had understood them during our meetings, asking clarifying questions to confirm what they were sharing with me. Further, in two cases, participants chose to further share their accounts with identified important people. This consequently involved the participant having a role in confirming that the account developed represented their story, before and during these sessions when their accounts were shared. It has also been suggested that aligning the analyses with existing knowledge (e.g. previous literature), enables broader interpretations of key concepts (Riessman, 2008). This is also something that I sought to achieve in the discussion (Section 4).

Coherence: Coherence refers to connecting meanings across various levels (Riessman, 1993) and how this is supported through NA at stages. This involves considering the experience and interactional context between participant and researcher, as well as consideration of how the story fits within broader narratives. Concerning coherence, this study aimed to maintained transparency in relation to the analysis process and has therefore included example excerpts Appendices K and L. Direct quotes of participants, and interactional excerpts including exchanges between participant and myself, were also included in results (Section 3). This aimed to allow readers to observe the processes of narration, NA, and the interpretations drawn from this.

4.5.2. Methodological Considerations

In this section, I will consider strengths and limitations of the current study and reflect on ethical considerations in the study.

4.5.2.1. Strengths of the Study

This study possessed several notable strengths that contributed to its value and impact within the field of learning disability research. (Also see Appendix N, a quality evaluation of the current thesis, utilising Mays & Pope criteria [2000]).

Using a narrative methodology provided rich, in-depth insights into participants' experiences. By allowing individuals to share their stories in their own words, this approach provided accounts that offered a nuanced understanding of their challenges, strengths, and experiences. This methodology was particularly supportive in resisting marginalised identities and highlighting the authentic voices of participants (Ewick & Sibley, 1995).

The in-depth case study approach highlighted participants' diversity of experiences during discharge. By focusing on detailed, personal narratives, the study captured a range of experiences and perspectives, providing a richer and more comprehensive understanding of participants’ experiences of the discharge process.

The study's small sample size included a relatively diverse range of ages, ethnicities, and localities. This diversity enhanced the generalisability of the findings. Given the sample size, it ensured that the study reflected a relative spectrum of experiences within the population of people with learning disabilities.

Throughout the study, ethical methodology was thoroughly considered and applied. This included a systematic assessment of participants' ability and willingness to provide consent, allowing for informed and voluntary participation. Additionally, sufficient time was provided to establish rapport with participants, ensuring they felt comfortable and supported throughout the research process. Personalised adaptations to the interview methods were also made, reflecting a commitment to keeping the participant's voice at the centre of the study.

The use of adaptive methods, such as drawing, underscored the value of alternative communication methods in capturing the experiences of people with learning disabilities. This approach prompted reflection for myself on the significance of integrating visual tools and resources in therapeutic and support settings, enabling individuals to express their perspectives more fully.

The project undertook a thoughtful and sensitive approach to interviewing participants. Recognising that the transition from hospital to community life can be particularly challenging, the interviews were conducted in a manner that aimed to minimise the risk of re-traumatising participants through the retelling of their stories. This careful consideration ensured that participants felt safe and respected throughout the research process.

A key concept underpinning this approach was the notion of the ‘absent but implicit,’ as discussed by Michael White (2003, 2006) and Jill Freedman (2012). White (2003, 2006) emphasises that what is ‘absent but implicit’ can be important in understanding how people cope with and overcome adversity. This concept posits that individuals possess beliefs, values, strengths, and qualities that may not be explicitly named but are evident in their ability to navigate and endure difficult experiences. Freedman (2012) further elaborates on this by suggesting that these implicit elements are vital for constructing narratives of strength and hope. By acknowledging and exploring these implicit strengths, the interviews aimed to highlight the resilience and resourcefulness of participants without re-traumatising.

By integrating these theoretical frameworks into the interview process, the research aimed to avoid potential harm and provided a richer, more nuanced understanding of participants experiences. This approach allowed the identification of ways in which people with learning disabilities manage their discharge, even in the face of systemic challenges.

The methodology used in this research could provide a starting point for future studies. By demonstrating the potential effectiveness of a narrative and ethically grounded approach, this study could potentially lay the groundwork for further research aimed at hearing the stories of people with learning disabilities and improving relevant learning disability services.

Importantly, this research gave a voice to people with learning disabilities who had experienced the transition from hospital to community life. The study aimed to ensure their insights and experiences were heard and valued by centring their stories.

4.5.2.2. Limitations of the Study

While this study offers valuable insights into the experiences of people with learning disabilities transitioning from hospital to community life, several limitations should be acknowledged.

The relatively small sample size means the findings are not necessarily generalisable to the broader population of people with learning disabilities. While the in-depth, narrative approach provided rich, detailed insights, it is essential to recognise that these findings reflect the specific experiences of the participants in this study and may not apply ‘universally’.

Participants were recruited through specific non-NHS community-based services via service managers. This recruitment method may introduce sampling bias, as service managers may identify particular participants. Although this theme did not necessarily emerge in the research, it raises the question of how different the findings might have been if a more diverse sampling method had been implemented. It also underscores the importance of exploring ways to reach a broader range of participants in future research to ensure a more inclusive representation of experiences.

A further limitation is that the research was conducted at a single point in time. This approach may limit understanding of how discharge experiences and community integration for people with learning disabilities evolve. People's experiences and perspectives may change as they progress through different stages of their discharge journey, and capturing these would help provide a more comprehensive understanding.

Additionally, the study did not include individuals with severe learning disabilities or those who are non-verbal. This exclusion highlights a significant subset of people whose experiences and perspectives were not captured by the methodology used. This will be further considered in Section 4.7.

4.5.3. Reflection on Ethical Considerations

Given the nature of the research, it was important to reflect on various ethical considerations. Below, I will discuss key ethical issues that arose.

One key consideration was the potential reluctance of participants to criticise the support they received. Research has noted that people with learning disabilities may fear losing access to help if they voice criticisms, which is linked to a lack of social capital (Merriman & Beail, 2009). This reluctance can lead to a form of self-policing during interviews, where participants may withhold specific stories or present themselves in certain ways (Rapley & Antaki, 1996) that suggest they are not liable for hospital readmission (Mitchell, 2022). This dynamic underscores the influence of power on the narratives shared and highlights the potential for untold stories in these contexts. In this study, given the service requirement for some participants to have staff present, it is acknowledged that staff presence may have influenced their stories. This highlights the challenge and complexity of conducting research and truly hearing the voices of people with learning disabilities discharged from hospital, within the broader context of power dynamics and systemic issues affecting this population.

A further ethical challenge arose when a participant who had initially given consent and expressed a desire to participate was withdrawn by their support team. I consequently liaised with the support team, suggesting that the participant's desire to engage in the project indicated a need to discuss their discharge experience. This situation highlighted the ethical obligation of the researcher to safeguard participants while also respecting their autonomy and desire to share their stories. This instance also underscored the broader research challenges in this area and the need for careful ethical consideration.

Further, concerning the narrative methodology, the researcher’s reflexivity and self-awareness were important in facilitating rather than ‘taking over’ the participants' stories. This involved working reflection and discussion with the research supervisor in attempting to maintain this approach throughout the study (Goodley, 2000), aiming to ensure that the participants’ voices were at the forefront of the research.

4.6. Areas for Future Research

This section proposes several areas that could provide valuable avenues for future research.

Historically, people living with learning disabilities have rarely been active contributors to research, with their stories often relayed through proxy informants or observational studies. Acknowledging our current position within this broader historical context, it is important that future research should continue to prioritise the direct involvement of people with learning disabilities, ensuring their voices are heard and valued.

Further research is needed to understand and represent the experiences of individuals with severe learning disabilities and those who are non-verbal (Mitchell, 2022). This population has continued to be underrepresented in broader research, and was also in this study, and their perspectives must be included moving forward. As suggested by Mietola et al. (2017), ethnographic methodologies can facilitate the involvement of people with severe learning disabilities in future studies. Further, methods such as photovoice, which enable individuals to share their perspectives through photographs and narratives, could also be particularly effective (Cluley, 2016; Krisson et al., 2021).

Additionally, there is an important need to address the intersectionality of people with learning disabilities and racialised communities. People with learning disabilities from these communities face institutional racism and inequitable treatment in healthcare settings, particularly in the more restrictive and intensive areas of health services (Nazroo, Bhui, & Rhodes, 2020; Chinn, 2018). Future research should focus on uncovering and tackling this institutional discrimination within learning disability services, especially concerning admissions and discharges from hospitals.

Co-working with people with learning disabilities in participatory action research (PAR) can enable this group to shape research that reflects their self-identified needs. Future research on this topic would benefit from adopting this framework, ensuring that the research is not only about people with learning disabilities but also driven by their insights and priorities.

4.7. Conclusion

This study sought to understand the experiences of five people with learning disabilities on their discharge from hospital to the community. From the accounts of the participants, there were three key storylines that emerged. These were stories of (1) challenges in navigating the discharge process, (2) drawing on strengths, supports, and resources, and (3) the realities of community life. These storylines appeared to hold key narratives of how people with learning disability navigate and experience their discharge process.

The study underscores the importance of recognising the tangible, lived experiences of people with learning disabilities and their stories of transitioning from hospital to the community. The research aimed to illuminate participants' stories of this journey and consequently offers valuable insights for clinical practice and future research, as have been discussed. These implications aim to help narrow the gap between policy intentions and the realities of those most centrally placed.

REFERENCES

Altermark, N. (2016). *After Inclusion. Intellectual Disability as Biopolitics.* Accessed on 10th March 2024 from: https://lucris.lub.lu.se/ws/portalfiles/portal/7545822/Altermark_Dissertation.pdf

Al-Yagon, M., & Mikulincer, M. (2004). Socioemotional and academic adjustment among children with learning disorders: The mediational role of attachment-based factors. *The Journal of Special Education*, *38*(2), 111-123.

Andrews, M., Squire, C. & Tamboukou, M. (2013). *Doing Narrative Research (2nd ed).* US: Sage.

Antaki, C., Young, N., & Finlay, W. M. L. (2002). Shaping clients' answers: Departures from neutrality in care-staff interviews with people with a learning disability. D*isability and Society, 17*(4), 435–455.

Arnstein, S. (1969). A ladder of citizen participation. *Journal of the American Institute of Planners, 35*(4), 216-224.

Bachrach L. L. & Lamb H. R. (1989). What Have We Learned From Deinstitutionalisation? Psychiatric Annals. *Health & Medical Collection 19*(1), 12.

Barnoux, M. (2019). Community services and transforming care: Reflections and considerations. *Tizard Learning Disability Review*. *24*(1), 33-37.

Barron, D. A., Hassiotis, A., & Paschos, D. (2011). Out-of-area provision for adults with intellectual disabilities and challenging behaviour in England: policy perspectives and clinical reality. *Journal of Intellectual Disability Research, 55*(9), 832-843.

Bigby, C., & Fyffe, C. (2006). Tensions between institutional closure and deinstitutionalisation: what can be learned from Victoria's institutional redevelopment? *Disability & Society*, *21*(6), 567-581.

Bilir, M. K. (2018). Deinstitutionalisation in mental health policy: from institutional-based to community-based mental healthcare services. *Hacettepe Sağlık İdaresi Dergisi, 21*(3), 563- 576.

Björnsdóttir, K., & Svensdóttir, A. S. (2008). Gambling for capital: learning disability, inclusive research and collaborative life histories. *British Journal of Learning Disabilities*, *36*(4), 263.

Bowlby, J. (1988). *A Secure Base: Parent-Child Attachment and Healthy Human Development.* UK: Routledge.

Brackenridge, R., & McKenzie, K. (2005). The friendships of people with a learning disability. *Learning Disability Practice*, *8*(5), 12-17.

British Psychological Society. (2010). *Learning Disability: Definitions and Contexts*. UK: British Psychological Society.

British Psychological Society. (2014). *Code of Human Research Ethics*. Accessed on 10th March 2024 from: https://www.bps.org.uk/news-and-policy/bpscode-human-research-ethics-2nd-edition-2014

Bronfenbrenner, U. (1979). *The Ecology of Human Development*. US: Harvard University Press.

Burr, V. (1995). *An Introduction to Social Constructionism*. UK: Routledge.

Burr, V. (2003). *Social constructionism (2nd ed.)*. UK: Routledge.

Butin, B. (2015). A narrative approach to qualitative inquiry. *American Society for Clinical Laboratory Science, 28*(3)*,* 190-196.

Cambridge, P., & Forrester-Jones, R. (2003). Using individualised communication for interviewing people with intellectual disability: a case study of user-centred research. *Journal of Intellectual and Developmental Disability, 28*(1), 5-23.

Cameron, L., & Murphy, J. (2007). Obtaining consent to participate in research: the issues involved in including people with a range of learning and communication disabilities. *British Journal of Learning Disabilities, 35*(2), 113-120.

Care Quality Commission (CQC). (2020). *Out of sight: Who cares? A review of restraint, seclusion and segregation for autistic people, and people with a learning disability and/or mental health condition*. Accessed on 10th March 2024 from: https://www.cqc.org.uk/publications/themed-work/rssreview

Carlson, L. (2005). Docile Bodies, Docile Minds: Foucauldian Reflections on Mental Retardation. *In Tremain, Foucault and the Government of Disability.* US: University of Michigan Press.

Caton, S., Starling, S., Burton, M., Azmi, S., & Chapman, M. (2007). Responsive services for people with learning disabilities from minority ethnic communities. *British Journal of Learning Disabilities, 35*(4), 229.

Chapman, M. (Producer). (2011, May 31). *Panorama: Undercover care—The abuse exposed* [television broadcast]. BBC.

Charmaz, K. (2008). Constructionism and the Grounded Theory Method. In J. A. Holstein & J. F. Gubrium (Eds.), *Handbook of Constructionist Research* (pp.397-412). US: The Guildford Press.

Chase, S. E. (2003). Learning to listen: Narrative principles in a qualitative research methods course. In R. Josselson, A. Lieblich, & D. P. McAdams (Eds.) *Up close and personal: The teaching and learning of narrative research* (pp. 79– 99). US: American Psychological Association.

Chester, V., Völlm, B., Tromans, S., Kapugama, C., & Alexander, R. T. (2018). Long-stay patients with and without intellectual disability in forensic psychiatric settings: comparison of characteristics and needs. *BJPsych Open, 4*(4), 226-234.

Chinn, D. (2018). Race, Learning Disabilities and Us. *Clinical Psychology Forum, 309*, 1-6.

Chinn, D. (2021). Racism and Learning Disabilities. In *Racism in Psychology*. UK: Routledge.

Clarkson, P. (2003). *The Therapeutic Relationship*. US: Wiley.

Cluley, V. (2017). Using photovoice to include people with profound and multiple learning disabilities in inclusive research. *British journal of learning disabilities*, *45*(1), 39-46.

Cole, L. (2019). Young people's narrative accounts of participation in the design and delivery of NHS mental health services. Doctoral thesis, University of Hertfordshire. Accessed on 10th March 2024 from: https://uhra.herts.ac.uk/handle/2299/22722

Conradie, M., Erwee, D., Serfontein, I., Visser, M., Calitz, F., & Joubert, G. (2017). A profile of perceived stress factors among nursing staff working with intellectually disabled in-patients at the Free State Psychiatric Complex, South Africa. *Curationis*, *40*(1), 1–8.

Crenshaw, K. (1989). Demarginalising the intersection of race and sex: A black feminist critique of antidiscrimination doctrine, feminist theory, and antiracist politics. U*niversity of Chicago Legal Forum, 1989*(1), 139-167.

Cresswell, J., & Poth, C. (2018) *Qualitative Inquiry and Research and Design: Choosing Among Five Approaches*. US: Sage Publications.

Creswell, J. (2013). *Qualitative Inquiry & Research Design: Choosing Among Five Approaches (3rd ed.).* US: SAGE.

De Schipper J., & Scheugel, C. (2010). Attachment behaviour towards support staff in young people with intellectual disabilities: associations with challenging behaviour. *Journal of Intellectual Disability Research*, *54*(7), 584–96.

Del Busso, L. (2004). Sharing power in the research process: Interviewing young people in the Looked After system. *Clinical Psychology, 44*, 7-9.

Denborough, D. (2012). A storyline of collective narrative practice: A history of ideas, social projects and partnerships. *International Journal of Narrative Therapy & Community Work, 1*, 40-65.

Dennis, R. (2002). Nonverbal narratives: Listening to people with severe intellectual disability. *Research and Practice for Persons with Severe Disabilities*, 27(4), 239-249.

Department of Health. (2014). *Positive and Proactive Care: Reducing the Need for Restrictive Interventions:* Accessed on 10th March 2024 from: https://assets.publishing.service.gov.uk/media/5a7ee560e5274a2e8ab48e2a/JRA_DoH_Guidance_on_RP_web_accessible.pdf

Department of Health and Social Care (DHSC). (2022). *Building the Right Support for People with a Learning Disability and Autistic People Action Plan*. UK: Department of Health and Social Care.

Department of Health and Social Care (DHSC). (2022). *Draft Mental Health Bill*. UK: Department of Health and Social Care.

Department of Health. (1971). *Better services for the mentally handicapped*. UK: HMSO.

Department of Health. (1983) *Mental Health Act*., UK: HMSO.

Department of Health. (2001). *Valuing people: A new strategy for learning disability for the 21st Century.* UK: HMSO.

Department of Health. (2005). *Mental Capacity Act*. UK: HMSO

Department of Health. (2009). *Valuing people now*. UK: HMSO.

Department of Health. (2012). *Transforming care: A national response to Winterbourne View Hospita*l. UK: Department of Health.

Duffy, S. (2019). *Close down the ATUs: Submission to the joint committee on human rights by the Centre for Welfare Reform. Centre for Welfare Reform*. Accessed on 6th November 2022 from: https://www.centreforwelfarereform.org/uploads/attachment/642/close-down-the-atus.pdf

Durham Police. (2023). *Four convicted of ill treatment in Whorlton Hall case.* Accessed on 10th March 2024 from: https://www.durham.police.uk/News/News-Articles/2023/April/Four-convicted-of-ill-treatment-in-Whorlton-Hall-case.aspx

Emerson, E., & Hatton, C. (2008). *People with learning disabilities in England*. UK: Centre for Disability Research.

Emerson, E., Baines, S. (2010). *Health Inequalities & People with Learning Disabilities in the UK: 2010*. Accessed on 10th March 2024 from: https://strathprints.strath.ac.uk/34862/1/vid_7479_IHaL2010_3HealthInequality2010.pdf

Equality and Human Rights Commission. (2020). *Health secretary faces legal challenge for failing patients with learning disabilities and autism*. Accessed on 10th March 2024 from: https://www.equalityhumanrights.com/health-secretary-faces-legal-challenge-failing-patients-learning-disabilities-and-autism#:~:text=Health%20Secretary%20faces%20legal%20challenge%20for%20failing%20patients%20with%20learning%20disabilities%20and%20autism,-Published%3A%2012%20February&text=Today%20we%20have%20launched%20a,and%20autism%20into%20appropriate%20accommodation.

Erickson, F. (1977). Some approaches to inquiry in school-community ethnography. *Anthropology & Education Quarterly, 8*(2), 58–69.

Ewick, P., & Silbey, S. (1995). Subversive stories and hegemonic Tales: Toward a sociology of narrative. *Law & Society Review, 29*(2), 197–226.

Fakhoury, W. & Priebe S. (2007). Deinstitutionalisation and Reinstitutionalisation: Major Changes in the Provision of Mental Healthcare. *Psychiatry 6*(8), 313-316.

Ferguson, M., Jarrett, D., & Terras, M. (2011). Inclusion and healthcare choices: the experiences of adults with learning disabilities. *British Journal of Learning Disabilities, 39*(1), 73-83.

Fletcher, J., & Miciak, J. (2017). Comprehensive Cognitive Assessments are not Necessary for the Identification and Treatment of Learning Disabilities. *Archives of Clinical Neuropsychology, 32*, 2-7.

Forrester-Jones, R., Carpenter, J., Cambridge, P., Tate, A., Hallam, A., Knapp, M., & Beecham, J. (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. *Disability & Society*, *17*(7), 741-758.

Foucault, M. (1977). *Discipline and punish: The birth of prison*. US: Pantheon Books.

Freedman, J. (2012). Narrative therapy: Making meaning, making lives. *Family Process*, *51*(2), 269-284.

Frosh, S. & Emerson, P. (2005). Interpretation and over-interpretation: Disputing the meaning of texts. *Qualitative Research, 5*(3), 307-324.

Gibson, D. A., Eick, H., Meddings, S., & Woodrow, C. (2023). Why am I still in hospital? Evaluation of delayed discharges from two learning disability assessment and treatment units in England. *Tizard Learning Disability Review*, *28*(1/2), 46-53.

Gilbert, T. (2004) Involving people with learning disabilities in research: issues and possibilities. *Health and Social Care in the Community,12*(4), 298-308.

Gilmore, L. & Cuskelly, M. (2014). Vulnerability to loneliness in people with intellectual disability: an explanatory model. *Journal of Policy and Practice in Intellectual Disabilities, 11*(3), 192-199.

Gleeson, B. (2010). Counterpoints of care: two moments of struggle. *Journal of Intellectual Disability Research, 54*(1), 5-15.

Glover, G., Brown, I., & Hatton, C. (2014). How psychiatric inpatient care for people with learning disabilities is transforming after Winterbourne View. *Tizard Learning Disability Review, 19*(3), 146- 149.

Goodley, D. (2000). *Self-advocacy in the lives of people with learning difficulties*. UK: Open University Press.

Goodley, D. (2013). Dis/entangling Critical Disability Studies. *Disability & Society, 28*(5), 631-644.

Gottschall, J., & Wilson, D. (2005). *The literary animal: Evolution and the nature of narrative.* US: Northwestern University Press.

Gould, S. J. (1996). *The Mismeasure of Man (Revised Edition)*. US: Norton

Grant, G., Ramcharan, P., & Flynn, M. (2010). *Learning disability: A life cycle approach*. UK: McGraw-Hill Education.

Hall, E. (2004). Social geographies of learning disability: narratives of exclusion and inclusion. *Area*, *36*(3), 298-306.

Hall, E., & Kearns, R. (2001) Making space for the 'intellectual' in geographies of disability. *Health and Place, 7*(3). 237-246.

Harper, D. (2011). 'Choosing a qualitative research method', in *Qualitative research methods in mental health and psychotherapy*: UK: Wiley-Blackwell.

Harper, D., & Thompson, A.R. (2012). *Qualitative research methods in mental health and psychotherapy: A guide for students and practitioners*. UK: John Wiley & Sons Ltd.

Head, A., Ellis-Caird, H., Rhodes, L., & Parkinson, K. (2018). Transforming identities through Transforming Care: How people with learning disabilities experience moving out of hospital. *British Journal of Learning Disabilities*, *46*(1), 64-70.

Heenan, D., & Birrell, D. (2019). Hospital-Based Social Work: Challenges at the interface between health and social care. *The British Journal of Social Work*, *49*(7), 1741-1758.

Heer, K., Rose, J., & Larkin, M. (2016). The challenges of providing culturally competent care within a disability focused team: A phenomenological exploration of staff experiences. *Journal of Transcultural Nursing, 27*(2), 109– 116.

Hessl, D., Nguyen, D., Green, C., Chavez, A., Tassone, F., Hagerman, R., Senturk, D., Schneider, A., Lightbody, A., Reiss, A., & Hall, S. (2009). A solution to limitations of cognitive testing in children with intellectual disabilities: the case of fragile X syndrome. *Journal of Neurodevelopmental Disorders, 1*, 33-45.

Holland, A., & Meddis, R. (1997). People living in community homes: their views. *British Journal of Learning Disabilities*, *25*(2), 68-72.

Holland, T., Clare, I. C. H., & Mukhopadhyay, T. (2002). Prevalence of 'criminal offending' by men and women with intellectual disability and the characteristics of 'offenders': implications for research and service development. *Journal of Intellectual Disability Research, 46*(1), 6-20.

Hollins, S., Lodge, K. M., & Lomax, P. (2019). The case for removing intellectual disability and autism from the Mental Health Act. *The British Journal of Psychiatry, 215*(5), 633-635.

Hollomotz, A. (2018). Successful interviews with people with intellectual disability. *Qualitative Research*, *18*(2), 153-170.

Hollomotz, A. (2021). Successful community resettlement of men with learning disabilities who have completed a hospital-based treatment for sexual offending. *The British Journal of Social Work*, *51*(1), 150-169.

Holmes, J. (2004). *The search for the secure base: Attachment theory and psychotherapy*. UK: Routledge.

Holmes, R., Kearney, L., Gopal, S., & Daddi, I. (2024). 'Lots of Black people are on meds because they're seen as aggressive': STOMP, COVID-19 and anti-racism in community learning disability services. *British Journal of Learning Disabilities*, *52*(1), 1-10.

Hoole, L., & Morgan, S. (2011). ‘It’s only right that we get involved’: service-user perspectives on involvement in learning disability services. *British Journal of Learning Disabilities*, *39*(1), 5-10.

Hopper, E., Bassuk, E., & Olivet, J. (2010). Shelter from the storm: Trauma-informed care in homelessness services settings. *The Open Health Services and Policy Journal*, *3*(1), 80-100.

Hughes, T., & Castro Romero, M. (2015). A processural consent methodology with people diagnosed with dementia. *Quality in Ageing and Older Adults, 16*(4)*,* 222–234.

Hussein, S. (2017). *The English social care workforce: the vexed question of low wages and stress.* Accessed on 10th March 2024 from: https://kar.kent.ac.uk/68295/1/Routledge-17-AcceptedChapter.pdf

Ince, R., Glasby, J., Miller, R., & Glasby, A. M. (2022). 'Why are we stuck in hospital?' Understanding delayed hospital discharges for people with learning disabilities and/or autistic people in long-stay hospitals in the UK. *Health & Social Care in the Community, 30*(6), 1-16.

Jackson, M. (2000). *The borderland of imbecility: Medicine, society and the fabrication of the feeble mind in late-Victorian and Edwardian England.* UK: Manchester University Press.

Jacobs, P. (2021). Transitions in the lives of Adults with Severe Intellectual Disability: An Ecological Life Course Perspective. Doctoral Thesis, The University of Edinburgh. Accessed on 10th March 2024 from: https://era.ed.ac.uk/handle/1842/38224

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.

Jahoda, A., Wilson, A., Stalker, K., & Cairney, A. (2010). Living with stigma and the self-perceptions of people with mild intellectual disabilities. *Journal of Social Issues*, *66*(3), 521-534.

Jahoda, A., Wilson, A., Stalker, K., & Cairney, A. (2010). Living with stigma and the self-perceptions of people with mild intellectual disabilities. *Journal of Social Issues, 66*(3), 521-534.

Jarrett, S. (2015). The meaning of 'community' in the lives of people with intellectual disabilities: an historical perspective. *International Journal of Developmental Disabilities, 61*(2), 107-112.

Jarrett, S., & Tilley, E. (2022). The history of the history of learning disability. *British Journal of Learning Disabilities*, *50*(2), 132-142.

Jenkins, R. (1998) *Questions of competence: Culture, classification and intellectual disability*. UK: Cambridge University Press.

Jingree, T., Finlay, W., & Antaki, C. (2006). Empowering words, disempowering actions. *Journal of Intellectual Disability Research, 50*(3), 212–226.

Joint Committee for Human Rights. (2019). *Human rights of many people with a learning disability and/or autism are being breached in mental health hospitals. House of Commons.* Accessed on 10th March 2024 from: https://committees.parliament.uk/committee/93/human-rights-joint-committee/ news/91540/human-rights-of-many-people-with-a-learningdisability-andor-autism-are-being-breached-in-mental-healthhospitals/

Judd, M., Dorozenko, K., & Breen, L. (2017). Workplace stress, burnout and coping: a qualitative study of the experiences of Australian disability support workers. *Health & social care in the community*, *25*(3), 1109–1117.

Kozma, A., Mansell, J., & Beadle-Brown, J. (2009). Outcomes in different residential settings for people with intellectual disability: A systematic review. *American journal on intellectual and developmental disabilities*, *114*(3), 193-222.

Krisson, E., Qureshi, M., & Head, A. (2022). Adapting photovoice to explore identity expression amongst people with intellectual disabilities who have limited or no verbal communication. *British Journal of Learning Disabilities*, *50*(1), 41-51.

Kugel, R. B., & Wolfensberger, W. (1969). *Changing Patterns in Residential Services for the Mentally Retarded. Washington*. US: President's Committee on Mental Retardation.

LeRoy, B. W., Walsh, P. N., Kulik, N., & Rooney, M. (2004). Retreat and resilience: Life experiences of older women with intellectual disabilities. *American Journal on Mental Retardation*, *109*(5), 429-441.

Lindsay, W., Carson, D., O'Brien, G., Holland, A. J., Johnston, S., Taylor, J. L. Young, S., Steptoe, L. Wheeler, J. R., Middleton, C. & Price, K. (2010). The Relationship Between Assessed Risk and Service Security Level for Offenders with Intellectual Disability. *The Journal of Forensic Psychiatry & Psychology, 21*(4), 537-548.

Mansell & K. Ericsson (1996). *Deinstitutionalisation and community living: Intellectual disability services in Britain, Scandinavia and the USA*. UK: Chapman & Hall.

Mansell, J. (2006). Deinstitutionalisation and community living: progress, problems and priorities. *Journal of Intellectual and Developmental Disability, 31*(2), 65-76.

Mansell, J., & Beadle-Brown, J. (2010). Deinstitutionalisation and community living: Position statement of the comparative policy and practice special interest research group of the international association for the scientific study of intellectual disabilities. *Journal of Intellectual Disability Research, 54*(2), 104-112.

Maxwell, J. (2012). *A Realist Approach for Qualitative Research*. US: Sage.

Mays, N., & Pope, C. (2000). Assessing quality in qualitative research. *British Medical Journal, 320*(7226), 50-52.

McAdams, D. (1996). *The Stories We Live By: Personal Myths and the Making of the Self*. US: Guilford Press.

McConkey, R., McConaghie, J., Mezza, F., & Wilson, J. (2003). Moving from long-stay hospitals: the views of Northern Irish patients and relatives. *Journal of Learning Disabilities*, *7*(1), 78-93.

McGill, P. (1993). Challenging behaviour, challenging environments, and challenging needs. In *Clinical Psychology Forum, 56*, 14-18.

McMillan, D, & Chavis, D. (1986). Sense of community: A definition and theory. *Journal of Community Psychology*, *14*(1), 6-23.

McNair, J. & Leguti, G. (2000). The Local Church as an Agent of Natural Supports to Individuals with Development Disabilities. *Issues in Transition,* (2), 11-6.

McVilly, K., & Dalton, A. (2006). Commentary on Iacono (2006): Ethical challenges and complexities of including people with intellectual disability as participants in research. *Journal of Intellectual and Developmental Disability, 31*(3), 186–188.

Mencap. (2021). *Tea, Smiles and Empty Promises.* Assessed on 10th March 2024 from: https://www.mencap.org.uk/sites/default/files/2021-05/Tea%2C%20smiles%20and%20empty%20promises%20-%20family%20stories.pdf

Mencap. (2023). *Mencap's response to the King's Speech*. Accessed on March 10th from: https://www.mencap.org.uk/press-release/mencaps-response-kings-speech

Merriman, C., & Beail, N. (2009). Service user views of long-term individual psychodynamic psychotherapy. *Advances in Mental Health and Learning Disabilities*, *3*(2), 42-47.

Meyer, B., & Pilkonis, P. (2001). Attachment Style. *Psychotherapy Theory Research Practice Training, 38*(4), 466-472.

Mietola, R., Miettinen, S., & Vehmas, S. (2017). Voiceless subjects? Research ethics and persons with profound intellectual disabilities. *International Journal of Social Research Methodology, 20*9(3), 263-274.

Mind. (2023). *UK government shelves the Mental Health Bill.* Accessed on March 10th from: https://www.mind.org.uk/news-campaigns/news/uk-government-shelves-the-mental-health-bill/

Mir, G., Nocon, A., Ahmad, W., & Jones, L. (2001). *Learning disabilities and ethnicity*. UK: Department of Health.

Mishler, E. (1995). Models of Narrative Analysis: A Typology. *Journal of Narrative and Life History, 5*(2), 87–123.

Mitchell, O. (2022). *The Everyday Lives of Adults with Learning Disabilities who have Moved Out of Hospital through Transforming Care.* Doctoral thesis, University of Hertfordshire. Accessed on 10th March 2024 from: https://uhra.herts.ac.uk/handle/2299/26550

Murray, P. (2018). *Pathways to inclusion: Building a new narrative on transitioning from hospital to community*. UK: Inclusion Press.

Nazroo, J., Bhui, K., & Rhodes, J. (2020). Where next for understanding race/ethnic inequalities in severe mental illness? Structural, interpersonal and institutional racism. *Sociology of Health & Illness, 42*(2), 262-276.

NHS Digital. (2024). Learning disability services monthly statistics from Assuring Transformation. Accessed on 10th May 2024 from: https://digital.nhs.uk/data-and-information/publications/statistical/learning-disability-services-statistics/at-march-2024-mhsds-february-2024#

NHS England. (2017). *Involving People in Their Own Health and Care: Statutory Guidance for Clinical Commissioning Groups and NHS England.* Accessed on 10th March 2024 from: https://www.england.nhs.uk/wp-content/uploads/2017/04/ppp-involving-people-health-care-guidance.pdf

NHS England. (2017). *Transforming Care. Model Service Specifications*. Accessed on 6th November 2022 from: https://www.england.nhs.uk/wp-content/uploads/2017/02/model-service-spec-2017.pdf

NHS England. (2022). *Improving experience of care: A shared commitment for those working in health and care systems.* Accessed on 10th March 2024 from: https://www.england.nhs.uk/long-read/improving-experience-of-care-a-shared-commitment-for-those-working-in-health-and-care-systems/

NHS England. (2024). *Key Elements for Discharge Supporting People with a Learning Disability and Autistic People to Leave Hospital*. Accessed on 10th March 2024 from: https://www.england.nhs.uk/long-read/five-key-elements-for-discharge-supporting-people-with-a-learning-disability-and-autistic-people-to-leave-hospital/

Nicolson, D. (2013). Taking epistemology seriously: 'truth, reason and justice' revisited. *The International Journal of Evidence & Proof*, *17*(1), 1-46.

Nind, M. (2008) *Conducting qualitative research with people with learning, communication and other disabilities: Methodological challenges.* Accessed on 10th March 2024 from: https://eprints.ncrm.ac.uk/id/eprint/491/1/MethodsReviewPaperNCRM-012.pdf

Nind, M., & Vinha, H. (2013). *Practical considerations in doing research inclusively and doing it well: Lessons for inclusive researchers*. Accessed on 10th March 2024 from: https://eprints.ncrm.ac.uk/id/eprint/3187/1/Nind_practical_considerations_in_doing_research_inclusively.pdf

Northway, R. & Dix, A. (2019). Improving equality of healthcare for people with learning disabilities. *Nursing Times,115*(4), 27–31.

Oakes, P. (2012). Crash: What Went Wrong at Winterbourne View? *Journal of Intellectual Disabilities, 16*(3), 155-162.

O'Connor, K. (2023). Stories of people with dementia who experience word-finding difficulties. Doctoral thesis, University of East London. Accessed on 10th March 2024 from: https://repository.uel.ac.uk/item/8x12x

Office for National Statistics. (2020). *Estimates of the population for the UK, England and Wales, Scotland and Northern Ireland*. Accessed on 10th March 2024 from: https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/datasets/populationestimatesforukenglandandwalesscotlandandnorthernireland

Oliver, M. (1990). *The Politics of Disablement*. UK: Macmillan.

Philo, C. (1987). "Fit localities for an asylum": the historical geography of the nineteenth-century "mad-business" in England as viewed through the pages of the Asylum Journal. *Journal of Historical Geography, 13(*4), 398-415.

Plomin, J. (Producer). (2019, May 22). Panorama: Undercover abuse scandal [television broadcast]. BBC.

Rapley, M., & Antaki, C. (1996). A conversation analysis of the 'acquiescence' of people with learning disabilities. *Journal of community & applied social psychology*, *6*(3), 207-227.

Rayner, K., Wood, H., & Beail, N. (2015). The 'double-bind of dependency': early relationships in men with learning disabilities in secure settings. *British Journal of Learning Disabilities*, *43*(3), 186-193.

Riessman, C. (2008). *Narrative methods for the human sciences*. US: Sage Publications.

Riessman, C. K. (1993). *Narrative analysis*. UK: Sage Publications.

Riessman, C. K. (2008). *Narrative methods for the human sciences*. US: Sage Publications.

Rodríguez-Dorans, E., & Jacobs, P. (2020) 'Making narrative portraits: a methodological approach to analysing qualitative data'. *International Journal of Social Research Methodology, 23(*6), 611-623.

Sarason, S. B. (1974). *The Psychological Sense of Community: Prospects for a Community Psychology*. US: Jossey-Bass.

Scior, K. (2011). Public awareness, attitudes and beliefs regarding intellectual disability: A systematic review. *Research in Developmental Disabilities*, 32(6), 2164-2182.

Scull, A. (1979). *Museums of Madness: The Social Organisation of Insanity in Nineteenth Century England.* UK: Penguin.

Seidman, I. (2006). *Interviewing as qualitative research: A guide for researchers in education and the social sciences*. US: Teachers College Press

Shankar, R., Olotu, V., Axby, S., Hargreaves, C., & Devapriam, J. (2015). Managing clients placed far away from their communities. *Learning Disability Practice, 18*(1), 29-34.

Sheehan, R., Gandesha, A., Hassiotis, A., Gallagher, P., Burnell, M., Jones, G., & Crawford, M. J. (2016). An audit of the quality of inpatient care for adults with learning disability in the UK. *BMJ Open*, *6*(4), e010480.

Siddaway, A. P., Wood, A. M., & Hedges, L. V. (2019). How to do a systematic review: a best practice guide for conducting and reporting narrative reviews, meta-analyses, and meta-syntheses. *Annual Review of Psychology, 70*, 747- 770.

Sigelman, C. K., Budd, E. C., Spanhel, C. L., & Schoenrock, C. J. (1981). When in doubt, say yes: Acquiescence in interviews with mentally retarded persons. *Mental retardation*, *19*(2), 53.

Simplican, S., Leader, G., Kosciulek, J., & Leahy, M. (2015). Defining social inclusion of people with intellectual and developmental disabilities: an ecological model of social networks and community participation. *Research in Developmental Disabilities, 38*, 18-29.

Skelly, A., Shimmens, V., Corner, A. (2022). Transforming nothing: The failure of the Transforming Care Learning Disability Policy framed by the criticisms of Orwell's Politics and the English Language. *Clinical Psychology Forum, 350,* 26-33.

Smith, D. (1990). *The Conceptual Practices of Power: A Feminist Sociology of Knowledge*. US: Northeastern University Press.

Smith, J. D., & Wehmeyer, M. L. (2012). Who Was Deborah Kallikak? *Intellectual and Developmental Disabilities, 50*(2), 169-178.

Smith, P. (2005). Off the map: a critical geography of intellectual disabilities. *Health & Place, 11*(2), 87-92.

Stake, R. (1995). *The Art of Case Study Research.* UK, SAGE.

Steans, J., & Duff, S. (2020). Perceptions of sex offenders with intellectual disability: A comparison of forensic staff and the general public. *Journal of Applied Research in Intellectual Disabilities*, *33*(4), 711-719.

Stiemke, F. (1994). Church-Synagogue-Temple-Mosque Advocacy: An Avenue for Integration in Religious and Secular Communities. *Journal of Religion in Disability and Rehabilitation, 1*(4), 1-11.

Swinton, J. (2002). Spirituality and the Lives of People with Learning Disabilities. *Tizard Learning Disability Review, 7*(4), 29-35.

Taylor, J. (2021) Comment: Transforming care for people with intellectual disabilities and autism in England. *Lancet Psychiatry, 8*(11), 942–944.

Tearle, S., S, S., & Holt, R. R. (2020). Collaborative case report: participatory action research into using EQUIP to support community discharge. *Journal of Intellectual Disabilities and Offending Behaviour*, *11*(1), 23-34.

Thompson, M. (1998). *The problem of mental deficiency: Eugenics, democracy and social policy in Britain, c. 1870-1959*. UK: Oxford University Press.

Trent, J.W. (1993) To cut and control: Institutional preservation and the sterilisation of mentally retarded people in the United States, 1892– 1947. *Journal of Historical Sociology, 6*(1), 56-73.

Turner, U. (2019). North Cumbria and North East Transforming Care, Transforming Lives Case Study. *Advances in Mental Health and Intellectual Disabilities*, *13*(1), 25-30.

United Nations. (2007). Convention on the Rights of Persons with Disabilities. *European Journal of Health Law, 14*(3), 281-298.

VanWynsberghe, R. & Khan, S. (2007). Redefining case study. *International Journal of Qualitative Methods, 6*(2), 80-94.

Vassos, M., & Nankervis, K. (2012). Investigating the importance of various individual, interpersonal, organisational and demographic variables when predicting job burnout in disability support workers. *Research in Developmental Disabilities*, *33*(6), 1780–1791.

Walmsley, J. (2005). *Institutionalisation: A Historical Perspective.* Accessed on 10th March 2024 from: https://www5.open.ac.uk/health-and-social-care/research/shld/sites/www.open.ac.uk.health-and-social-care.research.shld/files/files/ecms/web-content/shld-web-content/education-resources-home-a-history-of-institutions-jan-walmsley.pdf

Washington, F., Bull, S., & Woodrow, C. (2019). The transforming care agenda: Admissions and discharges in two English learning disability assessment and treatment units. *Tizard Learning Disability Review*, *24*(1), 24-32.

Watts, R., Richold, P., & Berney, T. (2000). Delay in the discharge of psychiatric inpatients with learning disabilities. *The Psychiatric Bulletin, 24*(5), 179–181.

White, M. (1993) Deconstruction and Therapy, in S. Gilligan and R. Price (eds) *Therapeutic Conversations*. US: Norton.

White, M. (2003). Narrative practice and community assignments. *International Journal of Narrative Therapy and Community Work*, *2003*(2), 17-55.

White, M. (2006). *Maps of narrative practice*. US: W.W. Norton & Company.

White, M., & Epston, D. (1990). *Narrative Means to Therapeutic Ends*. US: Norton

Willig, C. (2013). *Introducing Qualitative Research in Psychology (3rd ed.).* UK: Open University Press.

Wiseman, P., Watson, N. (2021). "because i've got a learning disability, they don't take me seriously:" violence, wellbeing, and devaluing people with learning disabilities. *Journal of Interpersonal Violence, 37*(13-14).

Wolfensberger, W. (1983). Social role Valorization: A proposed new term for the principle of normalization. *Mental retardation*, *21*(6), 234-239.

Wright, D. (2001). *Mental Disability in Victorian England: The Earlswood Asylum 1847-1901*. UK: Clarendon Press.

Yazan, B. (2015). Three approaches to case study methods in education: Yin, Merriam, and Stake. *The Qualitative Report*, *20*(2), 134-152.

Zuber, A. (2018). *Implications for Healing, Transformation and Prosperity: Historical and Cultural Trauma and People with Intellectual and Developmental Disabilities.* Accessed on 10th March 2024 from: https://conservancy.umn.edu/bitstream/handle/11299/201570/Zuber%20MLS%20Final%20Project.pdf?sequence=1

APPENDICES

Appendix A: Summary of Studies in the Literature Review

Authors, Date, Location	**Title**	**Research Methodology**	**Participant Information**	**Summary of Study and Key Findings**
Mitchell, O. (2022) England	The Everyday Lives of Adults with Learning Disabilities Who Have Moved Out of Hospital through Transforming Care.	Semi-structured interviews analysed using thematic analysis.	10 individuals with learning disabilities who transitioned from hospital settings through the Transforming Care initiative participated in this study. All of them were white British, and their ages ranged from 31 to 70 years. Four of the participants had been in forensic mental health hospitals, while the other six came from general mental health hospitals. Of these individuals, nine resided in either supported housing or residential care facilities, and one person lived independently without the assistance of a support provider.	Explored the everyday lives and experiences of adults with learning disabilities who have transitioned from hospital to community settings. Key findings include four main themes related to daily activities which were: 'Connecting with Others', 'Leisure,' 'Personal Development,' 'Work' and six themes related to the depth of their experiences, such as 'The Importance of Giving to Others,' 'The Value of Autonomy,' 'The Value of Supportive Relationships,' 'The Continued Impact of Hospital,' 'Being Included,' 'Safety through Support.'
Hollomotz, A. (2021).	Successful Community	Semi-structured interviews and thematic analysis.	The study included eleven men who had been inpatients	The hospital where this research took place had

England	Resettlement of Men with Learning Disabilities Who Have Completed a Hospital Based Treatment for Sexual Offending.		at a hospital. Among them, four had already been discharged, three were in the process of being discharged, and four had no current discharge plans. Additionally, interviews were conducted with twenty-two professionals involved in the care of these men. The duration of the participants' hospital stays ranged from 4½ years to 40 years.	medium, low secure and step-down services for people with learning disabilities. Study evaluates the community resettlement process for men with learning disabilities who have completed hospital-based treatment for sexual offending. Findings highlight the important role of discharge readiness and local resources in facilitating successful community resettlement. Also underscores the importance of ongoing support and the adaptation of treatment strategies in community settings, stressing the need for a coordinated approach among healthcare, social care, and criminal justice systems to manage ongoing risks and support the men's transition to community living.
Tearle, S., Sam, S., & Holt, R. (2020).	Collaborative Case Report: Participatory	Semi-structured interview with themes and quotes drawn from the interview.	One 29 year old person with 'mild' learning disability was supported to share their	The study was based at a specialist NHS community forensic service (specifically

England	Action Research (PAR) into using EQUIP to support a community discharge.	Unclear on the analysis methodology.	treatment experiences using PAR. The participant resided in a supported living community placement following discharge and had previously been detained in a medium secure unit.	the Offending Behaviour Intervention Service [OBIS]). The study evaluated the adapted Equipping Youth to Help One Another (EQUIP) program for people with learning disabilities and forensic needs transitioning into the community. Details the participants' engagement with EQUIP as part of their community reintegration process. Findings highlight that while EQUIP supports skills acquisition and aids in discharge and reintegration, a person-centred approach is essential, considering participants' complex emotional journeys. Underscores the importance of developing evidence-based interventions for this population in community settings, contributing unique insights from a service user's perspective on the program's adaptability and efficacy.

Head, A., Ellis, C. H., Rhodes, L., & Parkinson, K. (2018). England	Transforming identities through Transforming Care: How people with learning disabilities experience moving out of hospital.	Qualitative semi-structured interviews, analysed using Grounded Theory.	11 people with learning disabilities who had moved to the community following a hospital admission. All had diagnosis of learning disability, some also had additional 'psychiatric diagnoses' or autism. Age ranges from 20 – 55. Mixed histories of admissions and length of time in hospital. All participants noted to be white British.	Examined the transition process for people with learning disabilities from hospital to community living. Highlighted the emotional and identity adjustments required beyond just physical relocation. It emphasised the evolution from a 'restricted' to a 'wider' personal narrative as individuals navigate new relationships, manage the loss of familiar settings, and confront uncertainties. Importance of thorough preparation and robust support systems is outlined. Advocates for person-centred approaches in both clinical practices and policymaking to facilitate a smoother transition.
Turner, U. (2019). England	North Cumbria and Northeast Transforming Care, transforming lives case study.	Narrative accounts of experiences, direct quotes included but unclear about the analysis methodology.	The individual themselves (participant was someone with learning disabilities and autism, no further information provided) and also the support team involved in	A case study focussed on discharge process from an ATU into the community (supported living provision). Details the impact of the "Building the Right Support" (BRS) initiative, focusing on

			supporting the individual to move out of hospital and	the narrative of the participant and transitioning from long-term hospital care to independent living in a community setting. Emphasises the significance of community-based services, proactive planning, and the importance of listening to the needs and desires of people with learning disabilities and autism to enhance their quality of life and independence.
Owen, Hubert & Hollins. (2007) England	People Living in Community Homes: Their Views.	Qualitative study that involved an 18 month ethnographic study. This included in depth participant observation; and interviews with *some* of the participants. Grounded theory analysis was implemented.	11 women aged between 29-72 with learning disabilities, 'most with severe learning disabilities', several with autism and some also had additional mental health problems. 'All were said to have displayed 'challenging behaviour'.	Context to this study was that the ward was planned to close the following year. Eight of the women, who were deemed to need continuing NHS care, moved to a purpose built 'campus' home in the grounds of the old hospital site. The other three women moved into separate residential care homes in the community. The transition was found to be highly stressful due to lack of communication,

				involvement in the decision-making process, and inadequate support. Those who moved to a campus home experienced little change in their quality of life, restricted by rigid routines and limited opportunities for personal development. In contrast, the three women who moved to community homes shared some improvement, with one significantly benefiting from increased autonomy and the ability to make choices.

Jahoda, A., & Markova, I. (2004) Scotland	Coping with Social Stigma: People with Intellectual Disabilities Moving from Institutions and Family Home.	Semi-structured interviews, with content analysis used as analytic method.	28 participants with a learning disability in total. 10 people making the transition from their family home to live more independently, 18 people moving from a long-stay hospital to live in community housing.	Investigated how people with learning disabilities cope with social stigma during transitions from institutional care or family homes to more independent living. The findings indicated that all participants recognised the stigmatised treatment associated with learning disability and adopted various coping strategies. These included distancing themselves from stigmatising services and individuals with learning disabilities, emphasising personal achievements, and seeking to develop positive identities.
McConkey, R., McConaghie, J., Mezza, F., & Wilson, J. (2003) Northern Ireland	Moving from Long-Stay Hospitals: The views of Northern Irish Patients and Relatives	Information gathered through interviews with both residents and relatives. There were also self-completion questionnaires.	Thirty-nine people with learning disabilities and 34 relatives. They had been 'resettled' from a long-stay hospital over a five year period. They had moved to residential or nursing homes, shared housing or supported living. One person went to live with their family.	Evaluates the outcomes of resettling participants from long-stay hospitals to primarily residential and nursing homes in Northern Ireland. Outcomes were that the majority were happier in their new accommodation compared to the hospital, citing improvements in their

				living environment, greater independence, and an increase in social activities. However, challenges such as restricted social networks and a lack of movement towards more independent living options were noted.
Forrester-Jones et al. (2002). England	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.	Qualitative study with open interview questions. Thematic analysis implemented.	196 individuals with learning disabilities were interviewed about their current lives, 12 years after being resettled as part of the 'Care in the Community' initiative in England during the 1980s. Additionally, 128 individuals with mental health problems who also transitioned as part of this project were interviewed.	Participants views after 'resettlement' from long-stay hospitals. The community settings included residential nursing homes, hostels, staffed group homes or supported accommodation. The most frequently mentioned problems included the social regime, bullying, the physical aspects of the accommodation, and the personal feelings of boredom and loneliness. The most preferred activities were outings, education and work, relaxation, and leisure. The activities that were not liked included ‘nothing to do’ and chores around the home. Those who spoke of

				their future detailed a desire for personal and sexual relationships, more outings and greater independence.
Holland, A., & Meddis, R. (1997). England	People Living in Community Homes: Their Views.	Qualitative research employed a modified version of the structured Service User Interview. Additionally, participants had the chance to engage in more open-ended discussions on subjects deemed relevant by either the participant or the researcher. Each participant was interviewed a minimum of six times. The specific analysis method used remains unclear.	Six individuals with learning disabilities, aged between 21 and 42, participated in the study. They were all living in community settings, having previously moved from family homes, hospitals (in the case of two participants), or other care facilities. Each participant had spent more than 10 years in a hospital. Now, they reside in various community accommodations such as staffed houses, extended homes, or community units.	Investigated the views of people with learning disabilities on their community-based residential services. Study found that four out of six participants wanted to leave their current residential services, citing reasons such as knowledge of alternative living arrangements, preference for certain companions, dissatisfaction with the behaviour of other residents, and issues with staff members. The research highlights the importance of considering interpersonal dynamics and individual preferences in managing and improving community residential services for people with learning disabilities.

Appendix B: Quality Appraisal of Papers (Utilising Mays and Pope [2000])

✓ = Criteria Met ? = Criteria partially met or unclear X = Criteria not met	Worth/Relevance	Clear Research Question	Appropriate design	Context Well Described	Sampling is Clear (and more than convenience sampling)	Data & Analysis	Reflexivity of the account
Mitchell, O. (2022).	✓	✓	✓	✓	✓	✓	✓
Hollomotz, A. (2021).	✓	✓	✓	✓	✓	✓	✓
Tearle, S., Sam, S., & Holt, R. R. (2020).	✓	✓	✓	✓	✓	?	✓
Head, A., Ellis, C. H., Rhodes, L., & Parkinson, K. (2018).	✓	✓	✓	✓	✓	✓	✓
Turner, U. (2019).	✓	✓	✓	✓	?	✓	x

Owen, Hubert & Hollins (2007).	✓	✓	✓	✓	✓	✓	X
Jahoda, A., & Markova, I. (2004)	✓	✓	✓	✓	X	?	X
McConkey, R., McConaghie, J., Mezza, F., & Wilson, J. (2003)	✓	✓	✓	✓	✓	?	?
Forrester-Jones et al. (2002).	✓	✓	✓	✓	✓	✓	X
Holland, A., & Meddis, R. (1997).	✓	✓	✓	✓	✓	✓	X

Appendix C: Parent/Carer Research Information Sheet

PARENT/CARER INFORMATION SHEET

Project Title:

Experiences of People with Learning Disabilities on Discharge from Hospital into the Community: A Narrative Analysis

Contacts Details:

Max Tupper (Trainee Clinical Psychologist). Email – u2195634@uel.ac.uk

Supervised by: Dr Maria Qureshi (Clinical Psychologist). Email – m.qureshi2@uel.ac.uk

Purpose of this Information Sheet

The purpose of this document is to provide you with information about the research study that the adult with learning disabilities you support might choose to take part in. If anything is unclear, or you have any questions, please do not hesitate to contact me on the above email.

Who am I?

My name is Max. I am a postgraduate student in the School of Psychology at the University of East London (UEL) and am studying for a Doctorate in Clinical Psychology. As part of my studies, I am conducting research with people with learning disabilities.

What is the purpose of the research?

The research aims to explore the journey of people with learning disabilities being discharged from hospital into the community. It is hoped that the research will provide further knowledge into the discharge experience for people with learning disabilities and highlight the strengths, skills and resources people have drawn upon to navigate this process. The findings may also be used to help improve practice around discharge.

Participants who wish to participate in the study will be asked to meet with the lead researcher, Max Tupper, for two sessions. The sessions will depend on the participant's needs but could last for around 1 hour on both occasions. During this time, the researcher and participant will discuss their journey from hospital and into the community. This discussion will be guided by semi-structured interviews and the support of visual resources.

Who will be invited to take part?

To address the study aims, I am inviting people with learning disabilities who have been discharged from mental and learning disabilities inpatient hospitals to take part in the research. If people have been discharged into the community within the last 5 years, they will be eligible to participate in the study. The study aims to recruit 3-5 participants.

It is entirely **up to the person** whether they choose to take part or not. Participation is voluntary.

Participants can also change their minds at any time and withdraw from the research without explanation, disadvantage or consequence. Separately, participants can request to withdraw their data from being used even after participating in the study (provided this request is made within three weeks of meeting with the researcher to discuss their discharge).

How will the information provided be kept secure and confidential?

For the purposes of data protection, the University of East London is the Data Controller for the personal information processed as part of this research project. The University processes this information under the 'public task' condition contained in the General Data Protection Regulation (GDPR). Where the University processes particularly sensitive data (known as 'special category data' in the GDPR), it does so because the processing is necessary for archiving purposes in the public interest, or scientific and historical research purposes or statistical purposes. The University will ensure that the personal data it processes is held securely and processed in accordance with the GDPR and the Data Protection Act 2018. For more information about how the University processes personal data please see: www.uel.ac.uk/about/about-uel/governance/information-assurance/data-protection

What will happen to the results of the research?

The research will be written up as a thesis and submitted for assessment. The thesis will be publicly available on UEL's online Repository. Findings may be disseminated to a range of audiences, such as learning disability services and hospitals or learning disability special interest groups.

In all material produced, the **identity of participants will remain anonymous**, in that, it will not be possible to identify them personally. Any personally identifying information will be removed or replaced. Anonymised research data will be securely stored by Dr Maria Qureshi (researcher's supervisor) for a maximum of 3 years, following which all data will be deleted.

Who has reviewed the research?

My research has been approved by the School of Psychology Ethics Committee. This means that the Committee's evaluation of this ethics application has been guided by the standards of research ethics set by the British Psychological Society.

Who can I contact if I have any concerns?

If you have any questions or concerns about how the research has been conducted, please get in touch with my research supervisor Dr Maria Qureshi (contact details at the top of the first page).

or

Chair of School Ethics Committee: Dr Trishna Patel, School of Psychology, University of East London, Water Lane, London E15 4LZ.

Email: t.patel@uel.ac.uk

Thank you for taking the time to read this information sheet

Appendix D: Participant Research Information Sheet

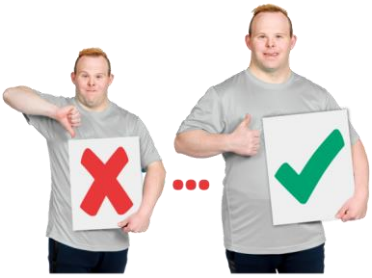
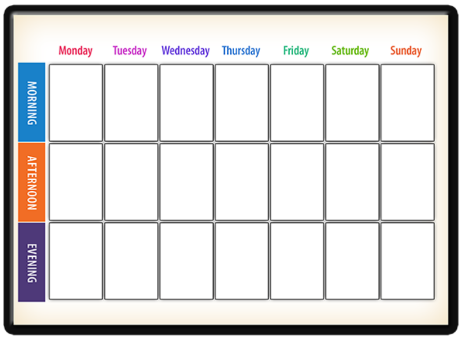
Information Sheet

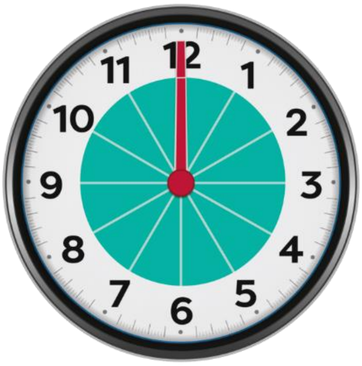
Research on experiences of people with learning disabilities discharge from hospital into the community

Picture of Max	My name is Max
	At university I am doing some research
	This document is to give you information about this research

	After reading this document you can decide if you would like to take part in the research
	I am interested in hearing from people with learning disabilities
	Lots of people with learning disabilities have been discharged from hospital to the community

	I am meeting with people who have been discharged from hospital to the community
	I hope to hear the stories of these people and their journey from hospital to the community
	I hope to hear about what discharge was like? How did people get through it? What strengths and skills did they use?

	I also hope to improve the discharge process for people with learning disabilities in the future through this research
	It is your choice if you would like to take part in the research
	If you would like to take part in the research we will arrange a date and time to meet

	We would meet at least twice for around one hour each time If you would like to meet for a different length of time that is okay too
	We will talk together about your journey from hospital to the community
	We can use paper pens and pictures to help us talk about your journey I will take a photo of any documents we create You can take any documents that we create with you at the end of our meeting

	If you need a break while we are meeting that is okay We will make sure to have breaks when we meet
	It is okay to share whatever you like about your journey from the hospital into the community

 	All our discussions will be confidential This means only me and my university supervisor will know what you have said to me The only time I will tell someone else what you have told me is if you have told me: - You are not safe - Or you talked to me about harming yourself or someone else

I hope to write up the stories as a thesis

A thesis is a piece of research done at University

This will be available for people to read online

I hope to share the research to different places

This may include learning disability services or hospitals

	When completing the research I will not include any personal information from the people I have spoken with The research will be anonymised This means people who read about the research will not have any private information about you This means I will not use your name I will use a made up name instead

	I will keep all information in a safe place Or on computer equipment that has passwords to protect it
	You can ask me any questions about the research
	If you feel sad or worried after meeting with me you can talk with __________________________ (Insert name)

Picture of Maria	If you are unhappy with anything that happens during the research you can contact my supervisor Her name is Maria Qureshi Her email address is m.qureshi2@uel.ac.uk
	Remember it is your choice if you would like to take part It is your choice if you would like to meet with me
	It is also okay to change your mind about talking to me You can do this at any time This is fine and no problem Nothing bad will happen

	If you would like to take part in this research please let me know My email address is U2195634@uel.ac.uk

Appendix E: University of East London Ethical Approval Letter

University of East London

School of Psychology Ethics Committee

NOTICE OF ETHICS REVIEW DECISION LETTER

For research involving human participants

BSc/MSc/MA/Professional Doctorates in Clinical, Counselling and Educational Psychology

Reviewer: Please complete sections in blue | **Student:** Please complete/read sections in orange

Details	
Reviewer:	Please type your full name **Luis Jimenez**
Supervisor:	Please type supervisor's full name **Maria Qureshi**
Student:	Please type student's full name **Max Tupper**
Course:	Please type course name **Prof Doc in Clinical Psychology**
Title of proposed study:	**Experiences of People with Learning Disabilities on Discharge from Hospital into the Community: A Narrative Analysis**

Checklist (Optional)			
	YES	**NO**	**N/A**

Concerns regarding study aims (e.g., ethically/morally questionable, unsuitable topic area for level of study, etc.)	☐	☐	☐
Detailed account of participants, including inclusion and exclusion criteria	☐	☐	☐
Concerns regarding participants/target sample	☐	☐	☐
Detailed account of recruitment strategy	☐	☐	☐
Concerns regarding recruitment strategy	☐	☐	☐
All relevant study materials attached (e.g., freely available questionnaires, interview schedules, tests, etc.)	☐	☐	☐
Study materials (e.g., questionnaires, tests, etc.) are appropriate for target sample	☐	☐	☐
Clear and detailed outline of data collection	☐	☐	☐
Data collection appropriate for target sample	☐	☐	☐
If deception being used, rationale provided, and appropriate steps followed to communicate study aims at a later point	☐	☐	☐
If data collection is not anonymous, appropriate steps taken at later stages to ensure participant anonymity (e.g., data analysis, dissemination, etc.) – anonymisation, pseudonymisation	☐	☐	☐
Concerns regarding data storage (e.g., location, type of data, etc.)	☐	☐	☐
Concerns regarding data sharing (e.g., who will have access and how)	☐	☐	☐
Concerns regarding data retention (e.g., unspecified length of time, unclear why data will be retained/who will have access/where stored)	☐	☐	☐
If required, General Risk Assessment form attached	☐	☐	☐
Any physical/psychological risks/burdens to participants have been sufficiently considered and appropriate attempts will be made to minimise	☐	☐	☐
Any physical/psychological risks to the researcher have been sufficiently considered and appropriate attempts will be made to minimise	☐	☐	☐
If required, Country-Specific Risk Assessment form attached	☐	☐	☐
If required, a DBS or equivalent certificate number/information provided	☐	☐	☐
If required, permissions from recruiting organisations attached (e.g., school, charity organisation, etc.)	☐	☐	☐
All relevant information included in the participant information sheet (PIS)	☐	☐	☐
Information in the PIS is study specific	☐	☐	☐
Language used in the PIS is appropriate for the target audience	☐	☐	☐
All issues specific to the study are covered in the consent form	☐	☐	☐
Language used in the consent form is appropriate for the target audience	☐	☐	☐
All necessary information included in the participant debrief sheet	☐	☐	☐
Language used in the debrief sheet is appropriate for the target audience	☐	☐	☐
Study advertisement included	☐	☐	☐

Content of study advertisement is appropriate (e.g., researcher’s personal contact details are not shared, appropriate language/visual material used, etc.)	☐	☐	☐

Decision options	
APPROVED	Ethics approval for the above-named research study has been granted from the date of approval (see end of this notice), to the date it is submitted for assessment.
APPROVED - BUT MINOR AMENDMENTS ARE REQUIRED BEFORE THE RESEARCH COMMENCES	In this circumstance, the student must confirm with their supervisor that all minor amendments have been made **before** the research commences. Students are to do this by filling in the confirmation box at the end of this form once all amendments have been attended to and emailing a copy of this decision notice to the supervisor. The supervisor will then forward the student’s confirmation to the School for its records. **Minor amendments guidance:** typically involve clarifying/amending information presented to participants (e.g., in the PIS, instructions), further detailing of how data will be securely handled/stored, and/or ensuring consistency in information presented across materials.
NOT APPROVED - MAJOR AMENDMENTS AND RE-SUBMISSION REQUIRED	In this circumstance, a revised ethics application **must** be submitted and approved **before** any research takes place. The revised application will be reviewed by the same reviewer. If in doubt, students should ask their supervisor for support in revising their ethics application. **Major amendments guidance:** typically insufficient information has been provided, insufficient consideration given to several key aspects, there are serious concerns regarding any aspect of the project, and/or serious concerns in the candidate’s ability to ethically, safely and sensitively execute the study.

Decision on the above-named proposed research study	
Please indicate the decision:	**APPROVED**

Minor amendments
Please clearly detail the amendments the student is required to make

Major amendments
Please clearly detail the amendments the student is required to make

Assessment of risk to researcher		
Has an adequate risk assessment been offered in the application form?	**YES** ☐	**NO** ☐
	If no, please request resubmission with an **adequate risk assessment.**	
If the proposed research could expose the researcher to any kind of emotional, physical or health and safety hazard, please rate the degree of risk:		
HIGH	Please **do not approve a high-risk** application. Travel to countries/provinces/areas deemed to be high risk should not be permitted and an application not be approved on this basis. If unsure, please refer to the Chair of Ethics.	☐
MEDIUM	Approve but include appropriate recommendations in the below box.	☐

LOW	Approve and if necessary, include any recommendations in the below box.	☒
Reviewer recommendations in relation to risk (if any):	Please insert any recommendations	

Reviewer's signature	
Reviewer: (Typed name to act as signature)	**Dr Luis Jimenez**
Date:	**03/10/2023**
This reviewer has assessed the ethics application for the named research study on behalf of the School of Psychology Ethics Committee	

Appendix F: Participant Consent Form

Consent Form

Research on experiences of people with learning disabilities discharge from hospital into the community

Please read each sentence and circle yes or no ✓ YES ✗ NO

	I have read the information sheet about this research	✓ YES ✗ NO
	I have a copy of the information sheet to keep for myself	✓ YES ✗ NO
	The research has been explained to me	✓ YES ✗ NO

	I have been able to ask questions about the research	✓ YES ✗ NO
	I understand what the research will involve	✓ YES ✗ NO
	I understand that it is my choice to take part in the research	✓ YES ✗ NO
	I understand I can choose not to take part at any time	✓ YES ✗ NO
	I understand that the research will be confidential	✓ YES ✗ NO
	I would like to take part in the research	✓ YES ✗ NO

Please write your name here

……………………………………………………………………………

Please sign here

……………………………………………………………………………

Researcher's Name

……………………………………………………………………………

Researcher's Signature

……………………………………………………………………………

Date

……………………………………………………………………………

Appendix G: Research Data Management Plan

UEL Data Management Plan

Completed plans **must** be sent to researchdata@uel.ac.uk for review

If you are bidding for funding from an external body, complete the Data Management Plan required by the funder (if specified).

Research data is defined as information or material captured or created during the course of research, and which underpins, tests, or validates the content of the final research output. The nature of it can vary greatly according to discipline. It is often empirical or statistical, but also includes material such as drafts, prototypes, and multimedia objects that underpin creative or 'non-traditional' outputs. Research data is often digital, but includes a wide range of paper-based and other physical objects.

Administrative Data	
PI/Researcher	Max Tupper
PI/Researcher ID (e.g. ORCiD)	0009-0001-8145-2169
PI/Researcher email	U2195634@uel.ac.uk
Research Title	Experiences of People with Learning Disabilities on Discharge from Hospital into the Community: A Narrative Analysis
Project ID	Ethics application number to be added when known
Research start date and duration	Point of ethical approval – 20th May 2024
Research Description	Many people with learning disabilities currently live within hospital settings in the UK. The Transforming Care Agenda aimed to support people to move from hospitals to live in the community, but the success of this programme has been limited. A key part of this process is ensuring effective discharge into the community. There

	has been inadequate research into the perspective of people with learning disabilities around discharge from hospital. The proposed research will adopt a narrative methodology to explore the journey of people with learning disabilities being discharged from hospital into the community, via a series of narrative case studies. Participants will be recruited from supported living and residential care settings within London. It is hoped that the research will provide further knowledge into the discharge experience for people with learning disabilities and may be used to inform clinical practice.
Funder	N/A – part of professional doctorate
Grant Reference Number (Post-award)	N/A
Date of first version (of DMP)	04/10/23
Date of last update (of DMP)	N/A
Related Policies	UEL Research Data Management Policy UEL Data Backup Policy UEL Statement on Research Integrity UEL Statement on Research Ethics The Data Protection Act
Does this research follow on from previous research? If so, provide details	No
Data Collection	
What data will you collect or create?	Demographic data for up to five participants (age, gender, ethnicity) will be collected to provide context to the interviews. This data will be stored in a single Excel spreadsheet (.xlsx), password-protected and saved on the researcher's UEL OneDrive. The approximate file size is 10KB. Personal data, such as participants' names and signatures, will be collected on consent forms. Hard copies of consent forms will be scanned and saved as individual pdf files (one each per participant). The hard copies will then be shredded. Electronic scans of consent forms containing identifiable information (e.g., names) will be stored as password-protected files and saved in a

	separate folder on UEL OneDrive, accessible only to the researcher. The approximate total file size is 20KB. Up to 10 audio recordings of interviews (two per participant) will be created. Interviews will be audio-recorded using a password-protected a recording device, saved as audio files (.mp3), and transcribed by the researcher. Participants will be asked to provide a pseudonym. Any identifiable information shared during the interview will be removed or altered at the time of transcription (e.g. names). Each transcript will be saved as an individual Word document (.docx). Audio recordings will be deleted once transcription has taken place. The approximate file sizes are 10GB (in total). Up to 10 photos of visual documents created by participants during sessions may be created (depending on whether participants choose to engage with the materials available in sessions). These documents will be taken using a password-protected photographic device and saved as image files (.jpeg). All identifiable information within these photos will be concealed before the photo is taken. The approximate file sizes are 1.3MB. The researcher will keep a reflexive log. This will contain no identifiable participant information and will be stored as a single Word document (.docx). The approximate file size is 20KB. Documents will be stored on the researcher's UEL OneDrive. Data will be saved and organised using folders and subfolders on UEL OneDrive.
How will the data be collected or created?	Consent information will be collected (for research participants) via consent forms. Paper consent forms will be transported securely by the researcher and scanned at the earliest opportunity. (They will be stored in a locked cabinet until they have been scanned and shredded). Electronic consent forms containing identifiable information (e.g., names) will be saved as password-protected files in a separate folder on UEL OneDrive, accessible only to the researcher. The primary data will be collected in person via semi-structured interviews of approximately 2 x 60-minute interviews per participant (length dependent upon needs and preferences of participant). These interviews will be audio-recorded using a password-protected Dictaphone audio recording device. Any visual resources will be recorded using a password-protected photographic device.

	Data (audio and image files) will be transferred from the recording devices to the researcher's password-protected computer via USB connection at the earliest opportunity (i.e., on the researcher's return from the interview) and stored on the researcher's UEL OneDrive. This device will be stored in a lockable cabinet. The transcripts will be manually typed up from the Dictaphone recording. All data will be saved on the Researcher's UEL OneDrive for business cloud. Two folders will be created. One which will contain all the pseudonymised data titled "Thesis Project" and one which will hold any identifiable information, tilted "Sensitive thesis related data", stored for participants being able to withdraw/be contacted about the results of this project.
Documentation and Metadata	
What documentation and metadata will accompany the data?	A blank consent form (for participants), Participant information sheet (two versions, one for clients and one for parents/carers), semi-structured interview schedule, researchers reflexive log.
Ethics and Intellectual Property	
Identify any ethical issues and how these will be managed	Potential participants and, if appropriate, their relatives/carers will be provided with an information sheet about the study and allowed to ask questions before consenting to participate. They will be informed where the data will be shared post project. Participants will be informed of their right to withdraw from the study at any time, without providing a reason and without negative consequences. Participants will be informed they can withdraw their research data within 3 weeks of participation. If they request this, their data will be destroyed. To protect the anonymity of participants, all interview transcripts will be pseudonymised and any identifiable information will be altered/ removed. Quotations and data from participants will be carefully monitored for anonymity and any potentially identifiable information removed or altered prior to inclusion. All images will have identifiable information concealed before the images/photos are taken.

	They will be required to sign a consent form if they would like to take part. Consent forms will be stored as password-protected files and separately to other UEL OneDrive research data. Confidentiality, and the limits to confidentiality, will be discussed with each participant and revisited at the time of the interview. To minimise the amount of data stored, audio recordings of the interviews will be destroyed as soon as they have been transcribed. Only anonymised transcripts of the interviews will be stored. All data, which are stored on the UEL One Drive, are encrypted. Access to the transcripts will be limited to the research supervisor and will be used solely for the project.
Identify any copyright and Intellectual Property Rights issues and how these will be managed	N/A – No known copyright or Intellectual Property Rights issues. No copyrighted materials are planned to be used.
Storage and Backup	
How will the data be stored and backed up during the research?	Research data will be stored securely using the researcher's UEL OneDrive, which is accessible only to the researcher via the researcher's username and password. Electronic scans of consent forms containing identifiable information (e.g., names) will be stored as password-protected files and saved in a folder on UEL OneDrive, accessible only to the researcher. The spreadsheet of participant's contact information will also be stored in this way, in a pseudonymised logbook before it's deletion. An external hard drive will be used to back up data, which included anonymised interview transcripts and images.
How will you manage access and security?	Only the researcher, supervisor and examiners will have access to the One Drive Data files. No one else will have access to the research data. Any data shared with the research supervisor or examiners will be done so through the faculty of the OneDrive secure links. The Data will not be shared with anyone else Data stored in OneDrive is encrypted, access is limited to me and secured through multi-factor authentication. I will share data with

	my supervisor upon request using OneDrive secure links. My password-secured laptop will be used to access UEL storage, but no data will be stored locally on the laptop itself and synching of files will be deactivated. Consent forms will be stored in a located cabinet with the researcher. The hard drive upon which the data is backed up will also be kept within a locked cabinet. An electronic device used for interviews will be encrypted and data will be transferred from the device to UEL OneDrive immediately, after which it will be permanently deleted from the device. The same process will occur for images taken.
Data Sharing	
How will you share the data?	The thesis will be publicly accessible via UEL Research Repository. Participants will be required to consent to this before participation and will be informed via the information sheet. Quotations, and any feedback from participants, included in the research thesis (or any subsequent presentations/dissemination) will be carefully monitored for anonymity and any potentially identifiable information will be removed or altered before inclusion.
Are any restrictions on data sharing required?	No one outside of the research team will have access to the research data files. Only anonymised data will be shared with the research supervisor(s) and examiners. Only anonymised data will be included in the thesis and any subsequent dissemination. Anonymised data underpinning the research (e.g. full interview transcripts) will not be deposited on the UEL Research Repository. This is to protect participant confidentiality best.
Selection and Preservation	
Which data are of long-term value and should be retained, shared, and/or preserved?	The anonymised transcripts will be retained for 3 years, post examination. This is to allow for the research to be written up. During this time, the data would be transferred to the supervisor's OneDrive, to be safely and securely stored. The data will not be shared with any other researchers.

What is the long-term preservation plan for the data?	The anonymised transcripts and images will be retained for 3 years post-examination. During this time, the data would be transferred to the supervisor's OneDrive, to be safely and securely stored. Only the supervisor and researcher would have access to the password-protected files.
Responsibilities and Resources	
Who will be responsible for data management?	Max Tupper (Researcher) Dr Maria Qureshi (Director of Studies/Research Supervisor) Dr Dave Harper (Second Research Supervisor) The researcher will collect, store and organise the research data. The research supervisor(s) will be responsible for retaining anonymised data once the researcher has left UEL and deleting this data once the retention period has elapsed.
What resources will you require to deliver your plan?	UEL OneDrive Password-protected audio-recording device and photographic device (obtained) Lockable cabinet (obtained) Microsoft Office software (e.g. Word, Excel) Access to a telephone
Review	
	Please send your plan to researchdata@uel.ac.uk **We will review within 5 working days and request further information or amendments as required before signing**

Date: 04/10/2023	Reviewer name: Joshua Fallon Assistant Librarian RDM

Appendix H: Semi-Structured Interview Guide

Semi-Structured Interview Guide

Additional Materials

Participants will be offered the chance to use paper, pens, pictures, and photos to help share their journey and significant chapters within this. The first meeting together may help inform relevant visual materials for the second meeting.

Adaption of Schedule

This interview schedule should be adapted to each participant's specific communication needs and preferences. It should be used to provide a guide in scaffolding the conversation following the initial question.

Initial Question

- Can you tell me your story of discharge from hospital into the community?

Further Questions/Prompts/Clarifications

- What happened when you left hospital and went back to the community?
    - What was it like for you?
- Did you face any problems when you left hospital?
    - How did you handle/manage these problems?
- Did you receive any help/support when you left hospital?
    - Can you tell me about the things/people that supported you the most
- How did you feel inside when you were moving from hospital to your community?
    - Did you have any strong feelings inside?
    - How did you deal with these feelings?
- Did you feel ready to leave hospital?
    - Did the hospital give you any information?
    - Did you find it useful?
- Were staff involved when you left hospital?
    - How did they make you feel?
    - Did they help during the move?
- Were your family or people who provide support involved when you left hospital?
    - Hoe did they make you feel?
    - Did they help you with anything?
- Did/do you have wishes or goals about moving back to the community?
    - Were these listened to?

- When you think about what happened – is there anything you wish was different or better when you left hospital?
- Do you have any ideas on how to make it easier for PWLD to move from hospital into the community?
- What were they key events or moments that were important for you?
- Wat kind of support did you receive?
    - What was the most helpful and why?

More General Follow-up Questions

- How did you manage this?
- What kept you going then?
- What do you think might have helped?
- Can you give me an example?
- What do you think you have learned? / What skills have you learned?
- Why was that important to you?
- How did this impact upon your discharge?
- Who else knows about these skills/strengths?
- If X was here (important person in journey), what would they say about your strengths?

Appendix I: Transcription Convention

Transcription Convention

- *[Inaudible]* - inaudible
- / - Interruption
- (Laugh) - Laugh
- [name] **–** name
- [location] - Location
- (.) Pause or silence
- (…) Long Pause or silence
- **Bold -** Words spoken loudly
- CAPITALS Words that are shouted
- …. Speech trails off

Appendix J: Narrative Analysis Guidance

Narrative Analysis: Guidance Questions

Narrative analysis guidance questions, based upon Riessman's NA methods (2005) and adapted from previous research utilising similar narrative analysis (Cole, 2019; O'Connor, 2023).

Areas of Focus:

- Content (Key narratives)
- Context
- Performance
- Interactions between the participant and researcher

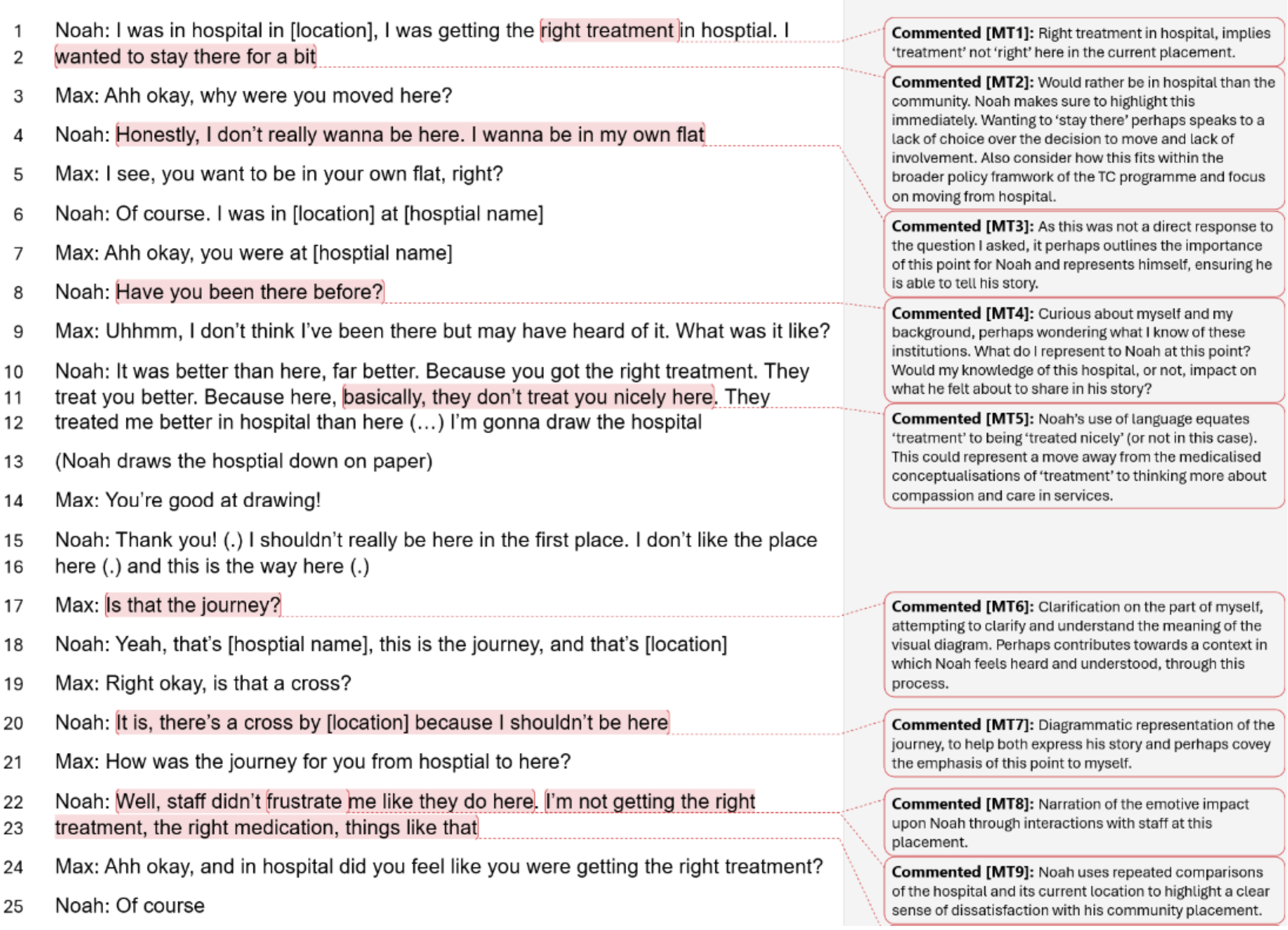
Questions to consider for analysis:

- What is being conveyed?
- How is the narrator attempting to communicate their story?
- What is the purpose of the story? What is being performed, and why?
- What other narratives are being referenced?
- What types of stories are being told?
- What cultural and socio-psychological influences impact both the narrator and the researcher?
- In what context is the narrative situated?
- How is the narrator constructing their identity?
- Does the researcher reinforce or challenge this construction?
- How does the narrator want me to perceive them? What kind of person are they trying to present themselves as?
- Who is the intended audience of the story, and for what purpose?
- What is being omitted or forgotten?
- What recurring themes or stories can be identified, both major and minor?
- How has the researcher influenced the narrative?

- How did the presence of additional people (e.g., support staff) affect the narrative?
- What resources is the participant using to tell their story?
- What strengths and resources is the participant highlighting in their story?
- Considering the professional power of the researcher, is it possible that certain stories are being told for purposes other than self-expression, such as to receive professional support?
- Do these stories of resistance indicate a struggle against oppression?

Appendix K: Example Analysis Excerpt of Individual Account

The following is an example excerpt of the narrative analysis of a participant's transcript.



Noah: I was in hospital in [location], I was getting the right treatment in hosptial. I wanted to stay there for a bit

Max: Ahh okay, why were you moved here?

Noah: Honestly, I don't really wanna be here. I wanna be in my own flat

Max: I see, you want to be in your own flat, right?

Noah: Of course. I was in [location] at [hosptial name]

Max: Ahh okay, you were at [hosptial name]

Noah: Have you been there before?

Max: Uhhmm, I don't think I've been there but may have heard of it. What was it like?

Noah: It was better than here, far better. Because you got the right treatment. They treat you better. Because here, basically, they don't treat you nicely here. They treated me better in hospital than here (…) I'm gonna draw the hospital

(Noah draws the hosptial down on paper)

Max: You're good at drawing!

Noah: Thank you! (.) I shouldn't really be here in the first place. I don't like the place here (.) and this is the way here (.)

Max: Is that the journey?

Noah: Yeah, that's [hosptial name], this is the journey, and that's [location]

Max: Right okay, is that a cross?

Noah: It is, there's a cross by [location] because I shouldn't be here

Max: How was the journey for you from hosptial to here?

Noah: Well, staff didn't frustrate me like they do here. I'm not getting the right treatment, the right medication, things like that

Max: Ahh okay, and in hospital did you feel like you were getting the right treatment?

Noah: Of course

Commented [MT1]: Right treatment in hospital, implies 'treatment' not 'right' here in the current placement.

Commented [MT2]: Would rather be in hospital than the community. Noah makes sure to highlight this immediately. Wanting to 'stay there' perhaps speaks to a lack of choice over the decision to move and lack of involvement. Also consider how this fits within the broader policy framwork of the TC programme and focus on moving from hospital.

Commented [MT3]: As this was not a direct response to the question I asked, it perhaps outlines the importance of this point for Noah and represents himself, ensuring he is able to tell his story.

Commented [MT4]: Curious about myself and my background, perhaps wondering what I know of these institutions. What do I represent to Noah at this point? Would my knowledge of this hospital, or not, impact on what he felt about to share in his story?

Commented [MT5]: Noah's use of language equates 'treatment' to being 'treated nicely' (or not in this case). This could represent a move away from the medicalised conceptualisations of 'treatment' to thinking more about compassion and care in services.

Commented [MT6]: Clarification on the part of myself, attempting to clarify and understand the meaning of the visual diagram. Perhaps contributes towards a context in which Noah feels heard and understood, through this process.

Commented [MT7]: Diagrammatic representation of the journey, to help both express his story and perhaps covey the emphasis of this point to myself.

Commented [MT8]: Narration of the emotive impact upon Noah through interactions with staff at this placement.

Commented [MT9]: Noah uses repeated comparisons of the hospital and its current location to highlight a clear sense of dissatisfaction with his community placement.

Appendix L: Example Analysis Excerpt of Storyline Data Analysis

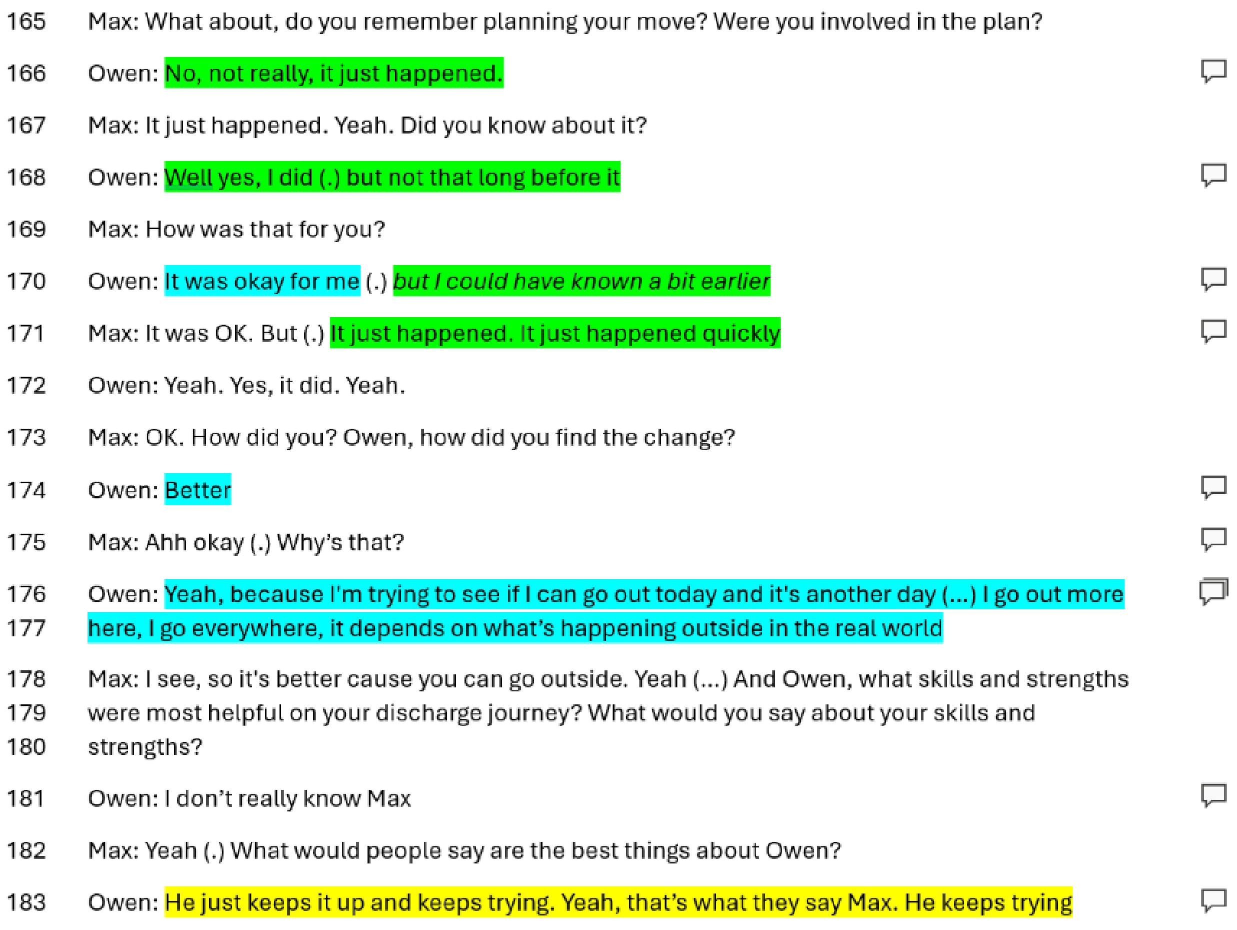
The following is an example excerpt from a transcript that was revisited to verify the collective storylines identified in one participant's account.

Identified Storyline

Challenges in Navigating the Discharge Process

Drawing on Strengths, Support and Resources

Realities of ‘Community’ Life



Max: What about, do you remember planning your move? Were you involved in the plan?
Owen: No, not really, it just happened.
Max: It just happened. Yeah. Did you know about it?
Owen: Well yes, I did (.) but not that long before it
Max: How was that for you?
Owen: It was okay for me (.) *but I could have known a bit earlier*
Max: It was OK. But (.) It just happened. It just happened quickly
Owen: Yeah. Yes, it did. Yeah.
Max: OK. How did you? Owen, how did you find the change?
Owen: Better
Max: Ahh okay (.) Why’s that?
Owen: Yeah, because I'm trying to see if I can go out today and it's another day (...) I go out more here, I go everywhere, it depends on what’s happening outside in the real world
Max: I see, so it's better cause you can go outside. Yeah (...) And Owen, what skills and strengths were most helpful on your discharge journey? What would you say about your skills and strengths?
Owen: I don’t really know Max
Max: Yeah (.) What would people say are the best things about Owen?
Owen: He just keeps it up and keeps trying. Yeah, that’s what they say Max. He keeps trying

Appendix M: Reflexive Journal Excerpts

Entry related to the recruitment strategy.

Who do I get to meet? Who don't I get to meet? Today the service manager drove me around to meet potential participants in the local area; in truth, it's been really helpful with recruitment… But who were the people missing from the drive? Who was 'allowed' to be introduced to me, and whose stories am I missing?... Where am I not being driven? Being introduced through the service manager, a position/figure of authority, raises questions about the power differential in the participant-researcher relationship. People check with me if I'm the researcher they've been spoken to about. What's already been discussed and does the introduction via service manager create a sense of obligation or pressure to participate?

Entry related to the impact of researcher positionality on participant narratives and power dynamics in the research

In my role as a researcher, I am acutely aware of the power I hold, particularly as a male, white British professional. I often consider the context of the interviews with the presence of staff, and how this influences the dynamics of the stories shared. However, reflecting on the interpersonal context I co-construct with each participant is equally important. I cannot ignore that I may represent figures who have historically, and currently, made significant decisions about their lives, and this positionality likely affects the narratives they share with me. Further, despite my assurances about the voluntary nature of their participation and the importance of their stories, I also grapple with the reality that participants may not feel fully empowered to decline or express dissent. I aim to use this awareness to carefully think through consent processes. This reflection further leads me to question how much the familiar power dynamic between a professional and a 'service user' might have constrained their ability to share their stories honestly.

Entry related to the service requirement for staff joining interviews

Initially, it was intended to provide the choice of having significant people join conversations to <u>support</u> participants in taking part, but in this case, the reality seems to contradict this. Service requirements dictate the presence of numerous staff members around the room to 'keep everyone safe'. It feels different from other interviews. How does the mandated inclusion of staff influence the ability of the person to share? Are they comfortable sharing, or does this cast a shadow over the narrative?

Entry related to balance between researcher interpretation and participant narratives

In the first draft of the results, I discussed them with my supervisor, and we felt that my initial structure overshadowed the participants' narratives with my interpretations. This prompted me to reflect on my approach and recognise the power, responsibility, and privilege of my position in this research. I also further acknowledge that I bring the lens of a non-disabled white man in interpreting the stories shared with me. Acknowledging this, through the research process, I hope, aim, and am committed to co-constructing an understanding of their experiences that truly reflect the participants’ perspectives.

Entry related to my current perspective in relation to inpatient settings during the research process

I have worked in several inpatient settings throughout my career, which has fuelled my desire to be involved in a research project in this area. In addition, during the research data collection phase and write-up for this thesis, I am currently on placement in a secure forensic ward. I personally find this a challenging environment to work in, given (what I perceive to be) broader systemic issues and a restrictive and punitive culture of care. I am increasingly aware that I hold critical views of inpatient settings and the culture permeated through them and that my own experiences of the current placement are likely exacerbating these! Acknowledging this, I hope to use this awareness to ensure that I do not impose my critical perspective onto the participants' stories, whether during our meetings or in the subsequent analysis. My goal is to remain neutral and open, allowing the participants' voices to guide the interpretation of their experiences authentically.

Entry related to concluding reflection of research

Through this research, I have reflected on a significant gap between policies and the stories of those affected by them. Smith (1990) describes this disconnect as 'experiences of rupture,' which expose the mismatch between policy language and everyday experiences (Jacobs, 2021). I really hope the findings of this study represent a step in some way to improve discharge processes and community care practices for people with learning disabilities.

Appendix N: Quality Evaluation of Current Study

Quality Evaluation of Current Study

The criteria suggested by Mays & Pope (2000) were used to evaluate the quality of this thesis utilising qualitative methodology. A summary is displayed in the table below.

Criteria	**Proof of Fulfilling Criteria**
Worth/Relevance	The literature review indicated a significant gap in research in this field, making this study both worthwhile and timely. It comprised a series of narrative case studies of individuals transitioning from hospital to community settings. The research has provided valuable clinical implications based on these findings.
Clear Research Question	The research question was clearly articulated at the end of the first chapter and again in the results section.
Appropriate Design	The rationale for a narrative framework to the research was clearly stated in the Methodology section
Context Well Described	The context of participants is clearly described, partly in the methodology and then through their own stories in the results section.
Sampling is Clear (and more than convenience sampling)	The sample includes a relative diversity of participants, given a reasonably small sample size.
Data & Analysis	The methodology clearly described the process of how data was collected and analysed. There are additional supports to the analysis process in the appendices (i.e., Appendix K and L)
Reflexivity of the account	I clearly articulated my epistemological stance at the outset of the thesis. Additionally, the quotes included in the results chapter encompassed contributions from all participants, highlighting the extensive data that informed the development of the main narratives and sub-narratives.