

The Everyday Lives of Adults with Learning Disabilities Who Have Moved Out of Hospital through Transforming Care

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“You've got to have something to eat and a little love in your life before you can hold still for any damn body's sermon on how to behave.” Billie Holiday

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Abstract

The UK's Transforming Care programme has aimed to reduce the number of people with intellectual disabilities being placed in mental health hospitals. However, a lack of good quality community provision has been linked to delays the discharge, as well as community placement breakdown and hospital readmission. Recent UK government plans recognise the importance of the perspectives of people with intellectual disabilities in developing better community support. However, the voices of people who have moved through Transforming Care are largely absent from the research being built around its long-term impacts. There is therefore limited in understanding on the factors that support this group of people to have a good quality of life in the community. The current study used a qualitative design to explore the everyday experiences of people with ID who have moved out of hospital through Transforming Care from their own perspective, in order to deepen the understanding of what enhances/undermines their QoL in the community. It had a secondary aim to understand the impact of the Coronavirus pandemic on this group of people's everyday lives. Data was used from the existing Making Positive Moves research programme (The University of Hertfordshire), including 19 semi-structured interviews from 10 people. Key Support People, who knew the person well, supported people in some of the interviews ($n=7$). Using thematic analysis, four main themes were developed in relation to how participants spent their everyday lives, including 'Leisure', 'Work', 'Personal Development', and 'Connecting with Others'. In addition, six main themes were developed in relation to the more in-depth meaning given to everyday experiences: 'The Value of Autonomy', 'The Continued Impact of Hospital', 'The Value of Supportive Relationships', 'Safety through Support', 'Being Included', and 'The Importance of Giving to Others'. A novel finding was that support (most

notably from staff working with the individuals) was key in supporting people to be autonomous following a move from hospital. The Coronavirus pandemic was found to have a range of impacts of people's activities and wellbeing and seemed to have a more neutral/less significant impact for some. A number of clinical implications are discussed, relevant for staff working with adults who have moved out of hospital through Transforming Care.

1. Introduction

1.1 Chapter Overview

This research focuses on the experiences of everyday living for people with intellectual disabilities (ID) who have moved out of hospital through the Transforming Care ¹(TC) programme. Its primary aim is to deepen the understanding of what enhances/undermines this group of people's current quality of life (QoL).

In this chapter, I will first introduce and define the key concepts used throughout the report, then situate myself in the research and state the epistemological position adopted. An in-depth exploration of the historical context of the lives of people with ID in the UK- including the processes of institutionalisation, deinstitutionalisation and the development of the TC programme- is then presented, which provides important background to the research. I will then explore the current experiences of community life for people with ID, including for people who have moved from hospital. This will focus on aspects related to the QoL of people with ID.

A systematic literature view is presented, which focuses on the subjective experiences of QoL in the everyday lives of adults with ID living in specialist community accommodation (supported housing and residential care homes). The aim of this review is to synthesise and critique the existing literature in this area, providing important background to the current study. The chapter will close with an

¹ A detailed description of the TC programme is included in section 1.5.2. The programme was a government response to the uncovering of abuse towards adults with ID in an independent hospital in England (Winterbourne View) (Department of Health, 2012). The programme's main aims were to significantly reduce the number of people with ID (and autistic people) placed in hospitals, as well as the length of people's stay in hospital.

in-depth rationale justifying the importance of research that explores the everyday experiences of adults with ID who have moved out of hospital through TC.

1.2 Introduction and Definition of Key Concepts

1.2.1. Intellectual disabilities.

In accordance with the British Psychological Society (BPS, 2015), intellectual disability (ID) is characterised by “significant limitations both in intellectual functioning and in adaptive behaviour as expressed in conceptual, social and practical adaptive skills. The disability originates before age 18.” (p.12). Section 1.3 explores how this conceptualisation is bound to the values around ability that currently exist in British society and could be viewed as socially constructed. In addition, given the significant persisting inequities people with ID experience, the identity may be understood through human rights/social issues paradigms; these ideas are elaborated on further in the below introductory sections.

1.2.2 Hospitals and institutions.

Specialist inpatient mental health services exist for people with ID, who are detained under the Mental Health Act (1983). These include specialist forensic inpatient services for people with ID who typically have concurrent mental health difficulties and have committed, or are thought to be at risk of committing, criminal offences (Quinn et al., 2022). The term ‘hospital’ will be used throughout to encompass all mental health inpatient services for people with ID. Whilst I recognise that the terms ‘institution/institutional’ can be used in the literature to depict restrictive practices that go beyond the types of buildings/services themselves, the term ‘institution’ will be used in this thesis to refer to a more historical concept, characterised by larger-scale practice and, in the UK, largely shut-down during the 1970/80s deinstitutionalisation movement (Mansell & Beadle-Brown, 2010).

1.2.3. Detention in hospitals for people with intellectual disabilities.

Up until its reform in 2007, ID was included in the Mental Health Act's (1983) definition of a 'mental disorder', meaning that people could be detained in hospital under the act on the basis of an ID diagnosis if they were thought to pose risk to the health and safety of themselves or others. Whilst the 2007 reform removed ID from its definition of 'mental disorder', an exception was made; in section 2 of the currently applied Mental Health Act (2007), people with ID can be detained for both assessment and treatment in hospital if the disability is thought to be associated with aggression or conduct deemed to be "abnormal" or "seriously irresponsible", irrespective of whether they have a co-occurring mental health condition. This means that people with ID who show severe or intense of behaviours related to distress, often labelled 'behaviours that challenge' by healthcare services, can be detained under the current act (Murphy, 2019). Examples of these behaviours include self-injury, physically hurting others (e.g., hitting), or damaging property/environment (e.g., destroying items). Whilst previous epidemiological studies report prevalence rates ranging between 50-84% for co-occurring mental health conditions in adults with ID treated in UK mental health hospitals (Morgan et al., 2008; Tajuddin et al., 2004), up-to-date figures do not appear to be published.

Within clinical practice, it has been proposed that 'behaviours that challenge' are more frequently seen in people with ID due to their associated difficulties in communicating their needs and/or difficulties in getting their needs met by others (which can be linked to the lack of control people experience in their lives) (McGill, 1993). The currently applied Mental Health Act (2007), therefore, has been criticised for its potential to pathologise distressed behaviour, overshadowing the many reasons a person may be displaying it (e.g., difficulties adapting to their environment,

communication difficulties/differences, or a response to abuse from a care provider) (Hollins et al., 2019). Linked to this reasoning, in its most recent draft mental health bill (June 2022), the UK government proposed a reform to the Mental Health Act that would mean that people with ID cannot be detained for treatment in instances where, following a period of assessment, no mental health condition is identified (Department of Health and Social Care, 2022).

1.2.4. Supported housing and residential care homes.

A range of specialist living circumstances exist for adults with ID who live in the community. The term 'supported housing' (also known as 'supported living') refers to a range of living circumstances in which people have their own tenancies and a separately established funded level of support (ranging from visiting to 24-hour) (Mencap, n.d.). In these set-ups, people may live alone, with support, or in a shared home with a small number of people with ID or other disabilities. Distinct to this, residential care homes provide accommodation with 24-hour staff support, and people do not have their own tenancies (Beadle-Brown, 2022). In the UK, 'group homes' are the most common type of residential care home, typically housing between 3-8 residents (Beadle-Brown, 2022).

1.3 My Position in the Research

I came to this research as someone who has consistently chosen to work with and alongside people labelled as having ID, mostly in clinical roles as a psychologist. This decision has at least in part been influenced by my experience growing up with a family member with ID, who has experienced distress in relation to marginalisation and exclusion by society.

I was particularly drawn to research with people with ID who have transitioned from hospital after my previous role as an Assistant Psychologist in an Intensive

Support Team, created as part of the TC agenda. This team's role was to provide community support to those at risk of community placement breakdown and admission to hospital, as well as people moving out of hospital through TC. In this work, I witnessed the long-lasting psychological impacts of repeated community placement breakdowns and long stays in hospital on people's lives, including the impacts of repeated relationship loss. In fact, in this, I was often very aware of my potential position as another lost attachment for someone, given that the team typically only supported people for 10-12 weeks.

I also was sharply struck by the restrictive narratives often held about the people we worked with. For example, the discourses around 'high profile', 'complex' and 'revolving door' service users who experienced repeated placement breakdowns in the community, that located the problem in the person as opposed to the contexts they had found themselves in. These experiences chime with Gillman et al.'s (1997) reflections on the 'tyranny of professional discourse', in which the rich, multifaceted stories of who someone is become lost and overshadowed by 'professional' information, such as historical risk assessments.

Given the lack of control people with ID have had about knowledges produced about themselves (detailed further below), and the more restrictive discourses that I have experienced being held about people who have spent significant time in hospital, it feels fundamental to me that research and policy includes the stories from people themselves. I acknowledge that my understanding of these experiences will always be through the lens of someone who is not labelled with ID. Within the research process I have, therefore, consulted with experts with ID where possible, and critically reflected on my assumptions and biases. An example of the latter can

be found in Appendix A, which depicts my assumptions about the research made prior to beginning the project.

1.4 Epistemological Position

Social constructionist frameworks of understanding question taken-for-granted knowledge, arguing that it is not necessarily based on objective, unbiased perceptions of reality (Burr, 2015). Such frameworks posit that knowledge is constructed and sustained via social processes (i.e., our interactions with each other and the world), relative to our historical and cultural context and its associated values systems. Within these frameworks, the above BPS definition of ID is therefore not an objective 'self-evident truth' but is constructed and bound to cultural values systems. These include Western concepts around ability and 'productivity, including which types of abilities are valued above others within a given society (Gleeson, 2010). For instance, as is explored further within the subsequent section, in previous historical periods within the UK, people we would now label as having ID were viewed and treated differently in society. An example given by Sinason (2010) is that 300 years ago, when only the socially and economically privileged were taught to read, someone we now label with "mild ID" would have been viewed as more 'intelligent'.

In line with the BPS definition, people with ID are often characterised by the things they are unable to do, based on value systems, leaving less room for discourses around their strengths and abilities. As is highlighted in the below sections, such social discourses mediate the social systems in which power is enacted (Fisher et al., 2007); here, some groups defined as 'other', outside of the normal curve, are placed within less socially powerful positions, and are often subject to social control. Examples of this for people with ID could be argued to

include their mass institutionalisation in the UK in the nineteenth century, the outcomes of the eugenics doctrine of degeneration, and the continued scandals in which people working with people with ID abuse their power (all detailed further in the sections below).

However, social constructionist frameworks of understanding could be argued to leave less room for the acknowledgement of the ‘truths’ concerning the lived realities of people with ID (Webb, 2013). These include the challenges that having disabilities with biological and neurological origins present, in addition to the further disabling barriers that society can impose (e.g., lack of accessible communication). As Sinason (2010) importantly argues “We cannot minimise the plight of those considered handicapped [to have an ID] now by saying they would not have been perceived that way 300 years ago” (p. 21). Aligned with this, whilst the BPS definition of ID may be considered limited to contextual values that could be said to continue to oppress certain people, it could be also argued to have clinical utility that allows people to get support for the very real difficulties they experience (e.g., specialist Speech and Language Therapists to support communication challenges).

Each of the above ideas and positions has influenced the critical realist position adopted in the current research study. Contrary to social constructionism, this framework assumes that stable ‘truths’ exist outside of our conceptualisation of knowledge (ontological realism), however, recognises that worldviews are shaped and changed by social, historical and cultural contexts (epistemological relativism) (Bhaskar, 1978). In addition, critical realism acknowledges that our subjective realities, and the differences between them, shape the different meanings we give to our experiences; in this, language is thought to reflect but not create reality (Pilgrim, 2019).

1.5 The Context of Everyday Life for Adults with ID in the UK

1.5.1. The historical context of everyday life.

Evidence suggests that, in the eighteenth century, people who may have later been labelled as having ID lived and worked within the communities they grew up in (Jarrett, 2015; Smith, 2005). Accounts indicate that, whilst people 'with ID' could be ostracised by certain community members/sub-communities on account of their perceived undesirability and vulnerability, informal neighbourhood networks within significant sections of the community provided support and protection (Jarrett, 2015).

1.5.1.1. Shifts towards Institutionalisation.

The construct of ID, and the increased societal segregation for people thought to have an intellectual 'deficit', developed during the changing post-industrial social values of the Victorian era, which placed emphasis on paid employment and, within this, productivity and fast-paced labour power (Gleeson, 2010). Through the Poor Laws of the 1830s, care for those deemed 'unproductive' in this sense became the responsibility of the emergent state, and people were confined to workhouses, poorhouses and, in some cases, asylums (Gleeson, 2010). Over time, as people with ID became increasingly marginalised and less tolerated by the state and communities, more were admitted to 'mainstream' asylums, which had been compulsory 'care' in all UK counties since 1845 (Wright, 2001). Eventually, specialist asylums were created for people with ID, in line with the sudden scientific enquiry into, and medicalisation of, this group of people (Smith, 2005). The expansion of these asylums across the UK meant that, by 1870, it had increasingly become the norm for people 'with ID' to be institutionalised (Jarrett, 2015).

The narratives surrounding people with ID further shifted in line with eugenic doctrines of degeneration in the 1880s, which criminalised this constructed social

group (Goddard, 1912, as cited in Holland et al., 2002). Based on 'scientific' theory and vague tautological definitions, criminality was linked to "feeble-mindedness". This provided further grounds for the segregation of people in asylums, based on the alleged protection of both the welfare of society and the 'patient' themselves.

These eugenic policies were heavily influenced by the work of prominent psychologists working within the frameworks of the nineteenth century institutions. For instance, famous studies pioneered by the American psychologist Henry Goddard were used to make claims about the heritability of intellectual disabilities, leading to the proposal of violent 'solutions' to the 'problems' people labelled with ID posed to the gene pool, in the form of both segregation and sterilisation (Smith & Wehmeyer, 2012). Further, psychologists' reinterpretation of Albert Binet's Intelligence Quotient (IQ) was used to identify and categorise people assessed to have intellectual 'deficits', providing justification of their removal from society in the form of institutionalisation (Yakushko, 2019). As such, psychological 'science', including the assessment of 'intelligence' and 'capacity', enabled the violent dehumanisation and segregation of this group of people.

Crystallised in government policies (Mental Deficiency Act, 1913, as cited in Holland et al., 2002), the expanding detention of people with ID in institutions during this period has been formulated as the splitting and projection of societal anxieties about rising crime and perceived moral decline onto a less socially and economically powerful group (Philo & Metzel, 2005). In line with this, it is theorised that a societal desire to cut-off from this othered group manifested itself in policies which meant that people with ID were physically distanced from the rest of society (Sianson, 2010; Smith, 2005).

Both policy and a lack of alternative support meant that, once detained in an institution, it was difficult for people to leave (Mansell & Beadle-Brown, 2010). Institutional practices meant people's lives were significantly different to members of the wider society. These included a lack of opportunities for privacy, a stripping of individuality (e.g., no personal possessions), rigid and strict routines, and clear and marked hierarchies between staff and residents (Mansell & Beadle-Brown, 2010).

1.5.1.2 Shifts towards deinstitutionalisation.

The 1980s and 1990s in England and Wales saw significant progress in both the closure of long-stay hospitals for people with ID (previously asylums, prior to the creation of the NHS in 1948), and the development of community-based services as a replacement (Felce, 1996). Mansell and Ericsson (2013) proposed that this change was caused by a number of factors. Firstly, in the 1960s, the UK media exposed a series of scandals in Ely Hospital, showing poor environmental conditions and treatment of residents (Willis, 2020). Further, shifts in societal ideologies, including increased emphasis on the importance of social roles for marginalised people

(Lemay, 1999), underpinned the UK's national agenda of 'community living' for individuals with ID. Such ideas were present in the Department of Health's (DH) 1971 white paper 'Better services for people with mental handicap' (DH, 1971), which set out plans to reduce institutional residences through an increase in the provision of community-based residential homes. In addition, community-based support was viewed as better value for money (Mansell & Ericsson, 2013).

Despite progress in the closure of many long-stay hospitals between the 1970s-1990s, a small number of people with ID continued to be admitted to hospital (Murphy, 2019). People were usually detained under Mental Health Act (1983), and

many of them showed behaviours related to distress that were challenging to services (e.g., self-injury, aggression).

1.5.2 Transforming Care.

1.5.2.1 The Transforming Care Agenda.

Despite the policies of the deinstitutionalisation period, similar events to that of Ely Hospital continued to happen to people with ID. A particularly disturbing, and widely reported, scandal occurred in Winterbourne View. In 2011, a Panorama programme uncovered serious cases of abuse from staff to residents in the 24-bedded hospital for adults with ID (BBC, 2011). In response to this, the government commissioned inspections from the Care Quality Commission (CQC) in similar settings caring for people with ID and autistic people. Whilst these did not uncover abuse on the scale of that found in Winterbourne, they found that 48% of hospitals did not meet CQC standards for care, welfare and safeguarding (DH, 2012). These events seriously called into question the ethics of prolonged hospital stays for people with ID, with comparisons being drawn between these and the restrictive institutional care of the 'past' (DH, 2012).

In response to these events, the government published 'Transforming Care: A National Response to Winterbourne View Hospital' (DH, 2012). This created a focussed workstream, with the aim to significantly reduce the number of people with ID (and autistic people) placed in hospitals- which was recorded to be 3,400 in 2012(DH, 2012). Within this were intentions to shift the focus of hospital stay to rehabilitation and recovery, and therefore a pledge to reduce the length of hospital stays, where hospital treatment was indicated, was also made.

Targets set by the agenda have been consistently missed since 2012, and goalposts have frequently shifted. In 2015, the government, NHS and local authority

published the 'Building the Right Support' (BtRS) plan (NHS England, 2015), which set out plans to reduce the use of hospital provision by 35-50% by 2018 through greater investment in community provision. This target was not met, and the Transforming Care (TC) work stream came to an end in 2019. However, the 2019 NHS Long Term Plan (NHS England, 2019) declared that the work would continue and set new targets to reduce the 2015 inpatient numbers by at least half (on a like-for-like basis, accounting for population growth) by 2023-2024. Figures from the Department of Health and Social Care (DHSC) in May 2022 reveal that at least 2,010 people with ID (and autistic people) are in hospital, which is a net reduction of 30.7% since May 2015 (DHSC, 2022).

Echoing a disturbing past, in May 2019 a televised Panorama programme uncovered shocking abuse from staff towards people with ID and autistic people residing in the independent hospital Whorlton Hall (BBC, 2019). Against this backdrop, and the slow progress the TC agenda, people with ID, autistic people, and their families have continually protested the adequacy and appropriateness of hospital placements and called for more radical shifts in the improvement of community-based services (Challenging Behaviour Foundation, Mencap, Rightful Lives & Learning Disability England, 2021).

1.5.2.1.1 The role of clinical psychology in Transforming Care

Clinical Psychologists play a key role in the delivery of work streams associated with the TC agenda, some of which have been outlined by the Division of Clinical Psychology- Faculty for Intellectual Disabilities' response to the service model proposed by the government's 2015 BtRS plan (British Psychological Society, 2016). These include leadership roles on the design and delivery of health services aiming to enhance community support for people with ID and mental health

conditions and or/behaviour related to distress, and reduce inappropriate hospital admission. For instance, the development and delivery of care pathways in NHS community Intensive Support Teams for people with ID, which utilise core skills of the profession (assessment, formulation, intervention) to flexibly offer intensive support to people in times of crisis and potential community placement breakdown. Clinical Psychologists also have a specialised role in training and consultation for community providers (e.g., social care staff teams in residential care homes/supported housing arrangements), to support services to offer high quality care and support within the community (e.g., training in approaches to supporting behaviour associated with distress). Further, the profession's specialist training in clinical research has been utilised to evaluate the impact of the early piloting of TC work streams, leading to recommendations for future service design and delivery.

1.5.2.2 Plans for improved community provision.

Despite significant investment in the TC programme, not all moves to the community are successful and cycles of discharge and readmission are a recognised problem (Royal College of Nursing, 2016). This places a burden on the NHS and causes significant distress and uncertainty for the people it effects. This is in part due to a lack of specialist community services, including appropriate housing and a workforce with the right skills to support people (DHSC, 2022).

A reduction of expensive NHS-financed hospital placements for people with ID is meant to free up money for council-commissioned community services (DH, 2012). However, a recent government-commissioned independent report indicated that more recent cohorts of people being discharged from hospital have more 'complex' needs that require more specialist provision than previous cohorts (RedQuadrant, 2022). This means that costs for support in the community are

increasingly exceeding costs of hospital admission. The report concludes that this may disincentivise discharges, and called for an additional, ring-fenced funding stream to support community provision.

A new BtRS action plan (DHSC, 2022) was published alongside the RedQuadrant report in July 2022, which set out funding plans to strengthen discharge and community support for people with ID and autistic people. This comprises an investment of £91 million between 2022-2023 in community services and discharge, including £40 million on specialist multidisciplinary and crisis support for people with ID and autistic people. The plan also details pledges to invest in funding schemes and partnerships to increase community accessibility for people with ID, including in the areas of housing, employment, and leisure opportunities.

It is recognised that the improvement of community support requires increased understanding of what good community support looks like from the perspectives of people with ID. As part of a “What Good Looks Like” project, the Association of Directors of Adult Social Service and Local Government are completing work with the BtRS Advisory group- which includes people with ID and their families- to develop a co-produced report detailing practice examples of good community provision. Based on this work, key principles for good community-based services were outlined in the 2022 BtRS action plan; for example: “Personalised: they use conversations (not standardised assessments) based on asking “What matters to you?” rather than “What is the matter with you?” (DHSC, 2022, p. 53).

1.5.3 Community Living.

This sub-section explores the current context of life in the community for adults with ID.

1.5.3.1 The concept of community living.

Community living has been defined as having the following aim:

To enable people with disabilities to use the same range of accommodation, living arrangements and patterns of living that are available to the rest of the population, and to have a good quality of life, participating as full citizens in social, cultural and economic activities to the extent and in the ways the individual chooses. (Mansell & Beadle-Brown, 2010, p. 106).

As Beadle-Brown (2022) highlights, this means that responsibility to make the community more accessible to and welcoming for people with ID does not only fall on specialist accommodation and support services, but to the wider community, including generic services (e.g., employment, leisure, healthcare).

Calling for a redistribution of power in community support, the 1990s disability movement in the US and UK championed the emergence of a 'personalisation' and 'independent living' concepts. These place emphasis on people's choice and control around the assistance they get, to support them to have equal access to the community (Office for Disability Issues, 2008). Linked with this, the concept of 'person-centred' support emerged for people with ID, which focuses on empowerment through privileging people's individual needs and preferences in decisions around support (DH, 2001). These values were promoted in the UK's 'Putting People First' (DH, 2008) policies, which emphasised collaborative support planning between the person, their family (if appropriate) and services.

The principles of these ideologies are also enshrined in the UK white paper 'Valuing People Now' (DH, 2009), as well as internationally in the United Nations Convention on the Rights of Persons with Disabilities (United Nations, 2006, as cited in Beadle-Brown, 2022). These policies position the experiences of people with disabilities as a human rights and social issue and call to action government

responsibilities in ensuring their equal rights and full inclusion in society. For example, the principles of “Rights, Independence, Choice, Inclusion” are centred in the government’s ‘Valuing People’ proposals (DH, 2001, p. 3).

However, it has been highlighted that principles in these policies have been manipulated by neoliberal agendas that place emphasis on individual responsibility over collective, interdependent care, to the detriment of some people with ID (Power et al., 2022). For instance, the overemphasis on principles of ‘Independence’ has been argued to deny the reality of the challenges people with ID can face, leading to further disabling barriers. For example, financial exploitation in instances where people have not been given adequate assessment and support around financial understanding (Simpson & Price, 2010).

1.5.3.2 The current experiences of community life for adults with ID in the UK.

In the UK, adults with ID live in a range of circumstances. In accordance with statistics from Public Health England (2020), between 2017-2018, 131,415 working age (18-64 years) adults with ID were in receipt of long-term social service support in England. Of these, 77.3% were living in settled accommodation with their own tenancies and 18.4% were living in unsettled accommodation without tenancy rights (e.g., residential care homes). In the overall sample, 36.7% were living in settled accommodation with friends/family, 22.8% were living in supported housing and 16.1% resided in residential care homes. Whilst, to my knowledge, a full breakdown of the types of living circumstances held by adults with ID who have moved through TC is not available, evidence suggests that, due to their more complex needs, this cohort typically require more specialist living arrangements, including supported housing and residential care homes (DH, 2012; DHSC, 2022; RedQuadrant, 2022).

Despite twenty-years of policies that emphasise rights and inclusion in the community for people with ID, stark and disturbing inequalities still exist. A 2021 report revealed that, in England, 60% of people with ID die before the age of 65, compared to 10% of the general population (White et al., 2022); disproportionate levels of preventable, treatable or avoidable deaths are found within the ID population (University of Bristol, 2021). In terms of employment, 5.1% of working-age adults with ID were reported to be in paid employment in 2020/21 (NHS Digital, 2022); 53.5% of working-age adults with any disability and 75.2% of working-age adults in the general population were in paid work in the first quarter of 2021 (ONS, 2021). Research reveals non-inclusive workplace cultures, low societal aspirations for including people with ID in the workforce, and a lack of access to training and qualifications all contribute to this stark gap (Ellenkamp et al., 2016). In addition, shocking levels of social isolation and loneliness are reported by and observed for people with ID (Tilly, 2019).

1.5.3.2. The impact of the Coronavirus pandemic on the everyday lives of adults with ID in the UK.

Studies and reports suggest that the Coronavirus pandemic has exacerbated some of the pre-existing inequities in health, wellbeing and social participation for people with ID. UK data from 2021 suggests that people with ID were more likely to contract Covid and be admitted to hospital with Covid than people without ID and were at least three times more likely than people without ID to die from Covid (Henderson et al., 2021; Williamson et al., 2021). Reports from ID self-advocacy groups, families and support providers indicated significant challenges related to infection control, social restriction, and sudden changes to statutory services (Maguire et al., 2020). The suspension of social care packages and personal

budgets for support (direct payments), closure of day centres and respite services, reduced contact with Community Learning Disability Teams, and replacement of face-to face support with digital services was reported to create significant distress and uncertainty for people with ID and their families and support systems.

The 'Coronavirus and People with Learning Disabilities Study' (Flynn et al., 2021) explored the everyday experiences of adults with ID living in the community the UK, at three time-points throughout the pandemic (between December 2020-August 2021). The findings revealed adults with ID experienced difficulties with their wellbeing during the pandemic. The majority of people reported experiencing difficult emotions (including feeling sad or down, anxious, and angry) in both the early (December 2020-February 2021) and final (July-August 2021) stages of data collection. In addition, in the final data collection stage, 41% of people who took part in verbal interviews reported feelings of loneliness and an absence of someone to speak to.

The study also revealed the negative impacts of the pandemic on access to services. Data from the final collection stage revealed that community support had not returned to pre-pandemic levels. The study found that, for the cohort of people able to take part in verbal interviews, 27% had not returned to day services and 26% received less community support than before the pandemic.

1.5.3. Section summary.

In summary, prior to mass institutionalisation in mid-late eighteenth century, people who may now be labelled as having an ID appeared to be relatively included in society in the UK. Despite the de-institutionalisation movement commencing in the 1970s, and the TC Agenda from 2012, the number of people with ID in hospital is thought to be inappropriately overrepresented and, in part linked to this, specialist

community provision is still deemed inadequate. In addition, despite government policies and action plans to make the community more inclusive for people with ID, stark and shocking inequities persist. Further, research indicates that the Coronavirus pandemic has exacerbated some of the existing health and social inequities for adults with ID in the UK. The next section will explore literature that specifically relates to the quality of life (QoL) of adults with ID, including those who have moved out of hospital.

1.6 Quality of Life

Researchers across disciplines often refer to the concept of QoL as multifaceted and amorphous (Brown et al., 2004). This section will examine the way in which it is conceptualised in the current study and explore key QoL literature in the ID field.

1.6.1 The Conceptualisation of QoL.

Realist conceptualisations of QoL divide components in terms of the subjective and 'objective' (i.e., subjective experiences and objective 'facts', such as health and economic status) (Cummins, 2005). However, objective QoL indicators have modest relationships with people's subjective experiences (Schalock, 2002).

The current study explores people's subjective experiences to understand what aspects of their lives enhance or undermine their QoL. In doing this, it draws on the World Health Organisation's (WHO) conceptualisation of QoL, which centres people's subjective perceptions:

[It is] an individual's perception of their position in life in the context of the culture and value system in which they live and in relation to their goals, expectations and standards and concerns. It is broad ranging concept affected in a complex way by the person's physical health, psychological

state, level of independence, social relationships, and their relationship to salient features of their environment. (Whoqol group, 1995, p. 1403).

Whilst models of QoL exist in the ID field (explored in the below sub-section) these models have been developed with people in the general ID population (i.e., not with people who have moved out of hospital), and therefore may be less relevant to the study. Given the paucity of QoL models specific to adults with ID who have moved out of hospital, a more general operationalisation of the concept (i.e., in line with the WHO's conceptualisation) was adopted in the current study.

1.6.2 The concept of QoL in the ID field.

In the ID field, Schalock's cross-culturally validated QoL conceptual framework is widely used to guide practice and assess personal outcomes (Schalock et al., 2002; Verdugo et al. 2012). This consists of eight domains and corresponding exemplary indicators, which sit within three higher order factors (Table 1, Verdugo et al., 2012, p. 1038). Indicators were developed on the basis of expert panels, stakeholder focus groups (including people with ID) and empirical research.

Earlier QoL research in the ID field typically used 'objective' QoL measures that excluded the perspectives of people with ID. More recent research has begun to include the voices of people with ID when exploring such concepts. For instance,

Carlsson and Adolfsson's (2018) QoL model, developed in consultation with people with ID, proposes components of QoL to include: social belonging, personal safety, control of life and, unique to the literature, experiences of adult social status. The latter component speaks to societal norms in which people with ID are often denied adult responsibility.

Table 1.*Schalock's Quality of Life Conceptual Framework*

Factor	Domain	Exemplary Indicators
Independence	Self-determination	Choices, decisions, personal goals
	Personal development	Skills development
Social	Interpersonal relations	Interactions, affiliations, social networks, friendships
	Participation	Community involvement, social inclusion
	Rights	Human and legal
Wellbeing	Emotional wellbeing	Safety and security; predictable environments
	Physical wellbeing	Healthcare, nutrition
	Material wellbeing	Employment, financial status

Note. Adapted from “The concept of quality of life and its role in enhancing human rights in the field of intellectual disability”, by Verdugo, M.A., Navas, P, Gomez, L.E., Schalock, R.L, 2012, *Journal of Intellectual Disability Research*, 56(11), p. 1038.

1.6.2.2 Quality of support and quality of life.

Research consistently finds that the way in which people with ID are supported by others directly links to their QoL (Bigby & Beadle-Brown, 2018). In this, collaborative, enabling approaches centred on doing things with people (as opposed to *for* or *to*) have been found to significantly improve people's QoL. This is in line

with a type of evidence-based person-centred support known as ‘active support’, which is described as:

An enabling relationship by which staff and other carers provide graded assistance to ensure success—assistance that is tailored to the needs, pace and preferences of the individual delivered in a person-centred, warm and respectful way and making the most of all the opportunities available (Beadle-Brown, 2022, p. 933).

Research has found that the implementation of active support approaches in services for people with ID has led to improvements in a range of areas associated with QoL, including service user’s relationships with staff, emotional wellbeing, independence, everyday living skills, and community participation (Beadle-Brown et al., 2016; Jones et al., 2001; Stancliffe et al., 2010).

1.6.2.3 The QoL of adults with ID who have moved out of hospital.

A number of studies have explored the QoL of people with ID after they have moved out of hospital. McCarron et al.’s (2019) systematic literature review of 13 international studies reported improved QoL for adults with ID who had moved out of a hospital/institution to any community setting, both in the initial stages after the move (up to one year) and longer-term (after one year). However, mixed findings were reported regarding social integration into the wider community: some individuals reported increased feelings of loneliness following the move, and genuine community participation was absent from some people’s lives. For some, this was linked to differing expectations of staff support in the community to hospitals/institutions, which the authors concluded may relate to an increased emphasis on the development of independence placed on people in the community, meaning people are less supported to make connections with others. The vital role

of staff in supporting people to adjust to community life was indicated, which is in line with the findings of Lennard et al.'s (2020) systematic literature review exploring the factors that support people to move out of the institutional environment and begin fulfilled lives in the community.

Specific to the UK, Niven et al. (2019) explored the QoL of fifteen people with ID a decade after they had transitioned from hospital, after hospital closures in Cornwall (UK) in 2007 (prior to TC). Findings, which relied on proxy informants for 14/15 participants, revealed that this group of people had lower levels of community participation than population norms for people with ID, as well as a lack of social relationships beyond professionals. In addition, 'institutionalised behaviour' was reported in 12/15 of the participants, such as ritualistic behaviours and excessive permission seeking.

There has been little research specific to the everyday lives of people who have transitioned from hospital through the TC agenda in the UK. Head et al. (2018) interviewed 11 people with ID about their move out of hospital through TC. The researchers developed a 'moving process' model that showed that people held restricted, and often negative, stories about themselves whilst they were in hospital. Moving out of hospital enabled people to 'widen' these stories- through new opportunities and differences in how others treated them- and supported them to hold more positive identities about themselves. This research has implications for practices used to construct people's 'problems' and identities, including the narratives teams hold about people who have moved/are moving from hospital.

1.6.2. Section summary.

Research has indicated some of the factors important to the QoL of adults with ID living in the community more generally, as well as those specific to people

who have moved out of hospital. Common to both is the importance of the ways in which people are supported, including relationships with staff, which appear play a significant role in helping people adjust to life in the community following a move from hospital. Whilst recent government reports indicate that more recent cohorts of people being discharged from hospital have more complex needs that require more specialist provision than previous cohorts (RedQuadrant, 2022), there is a paucity of research exploring the experiences of people who have moved out of hospital through the UK's TC agenda. The factors that enhance and undermine this group's QoL in the community is therefore not well understood.

2. Systematic Literature Review

2.1. Introduction to Literature Review

The current study focused on the everyday experiences of adults with ID who have moved through TC, to understand aspects that support and undermine their QoL. Evidence suggests that, due to their more complex needs, people moving from hospital through TC typically require more specialist living arrangements with staff support, including supported housing and residential care homes (DH, 2012; DHSC, 2022; RedQuadrant, 2022). A systematic literature review (SLR) was, therefore, conducted to understand the subjective experiences of QoL in the everyday lives of adults with ID living in supported housing and residential care homes. This used the methodology of a systematic literature review, which aims to systematically search, appraise and synthesise research related to a research question/topic area (Siddaway et al., 2019).

The aim of the review was to synthesise and critique the existing literature in this area, in order to establish robust conclusions on QoL experiences in adults with ID living in supported housing/residential homes more generally (i.e., not specific to people who have moved out of hospital). This provides important background to the current study, which focuses specifically on these experiences in adults with ID who have moved out of hospital.

Existing literature reviews exploring the QoL of adults with ID living in the community often compare outcomes across different types of living circumstances (e.g., residential homes versus supported housing) (e.g., Bigby & Beadle-Brown, 2018; Walsh et al., 2010). These typically encompass studies using 'objective' QoL measures (e.g., ratings of adaptive behaviour, quantitative measures of community participation) that omit the subjective experiences of the person with ID. Subjective

experiences are recognised as fundamental to our understanding of people's QoL, and relationships between objective indicators (e.g., economic status) and subjective experiences of wellbeing are found to be modest (Schalock, 2002). The current review, therefore, chose to explore people's subjective experiences only.

Through systematically reviewing existing empirical literature, the review aimed to:

Understand the subjective experiences of QoL in the everyday lives of adults with ID living in supported housing and residential care homes.

2.2 Search strategy

2.2.1 Operationalisation of concepts.

2.2.1.1 Quality of life.

As previously discussed, QoL is a multifaceted construct with many potential definitions. The current review operationalised 'experiences of QoL' using Schalock's quality of life conceptual framework (Verdugo et al., 2012). The review therefore included studies relating to experiences of one or more of the eight domains comprised in the model, as shown in Table 1. These domains include self-determination, personal development, interpersonal relations, participation, rights, emotional wellbeing, physical wellbeing, and material wellbeing.

2.2.1.2 Supported housing and residential care homes.

Supported housing and residential care homes were operationalised using the definitions outlined in section 1.2.3. In line with these definitions, residential care homes included 'group homes'. These definitions exclude any living set-up where people do not have established funded support. In addition, clustered settings in which more than one home for people with ID are grouped on a site were excluded (e.g., campus settings, village communities), as these are typically less integrated

with the wider community and therefore may relate to distinct experiences.

Congregate settings where people are housed in larger groups under one roof, usually for specified treatment, were also excluded (e.g., rehabilitation/step-down services).

Terms for specialist living arrangements are often used interchangeably and vary between countries. As such, decisions to include and exclude studies were made on the basis of the descriptions of living circumstances given in studies. I used these to determine inclusion, based off the review's operationalised definitions. For transparency, the details of living circumstances for each study are included in Table 3.

2.2.2. Search terms.

Relevant abstracts and past doctoral projects (Head, 2017) were surveyed to obtain key search terms for the concepts explored. Scoping searches were run and refined based on returns (see Appendix B for full details on search terms). Three bibliographic databases were accessed via the University of Hertfordshire in August 2022, including Scopus, Cinahl Plus and PubMed. These databases were selected based on their relevance to review question and topic area, with each housing literature from health and social sciences. They include the largest citation database for peer-reviewed literature in health and social science fields (Scopus), as well as the most comprehensive full-text database for nursing and allied health journals (Cinahl Plus).

2.2.3 Inclusion and exclusion criteria.

The review was interested in the subjective experiences of people with ID living in supported housing/residential care homes. This included both data collected directly from people with ID or from proxy informants, as well as other means of data

collection that attempted to capture the subjective experiences of the person with ID, such as ethnographic studies (e.g., using observations). The use of objective measures, as well as data capturing the experiences of alternative viewpoints (e.g., experiences of staff members in supported housing, experiences of family members) were excluded. In addition, studies that combined data from supported housing/residential care homes and other types of living circumstances (i.e., where results specific to supported housing/residential care homes could not be separated) were also excluded.

There are a number of reviews that include QoL studies conducted in the deinstitutionalisation period (i.e., 1970-1990), which often focus on changes in QoL between institutions and community living (Chowdhury & Benson, 2011; McCarron et al., 2019). The current SLR sought to reflect the more contemporary experiences of community living for adults with ID. As such, the review includes publications from 2001-2022. These dates encompass studies following key policy changes related to the quality of community living for people with ID including 1) The UK's Valuing People (DH, 2001) white paper and 2) United Nations Convention on the Rights of Persons with Disabilities (United Nations, 2006, as cited in Beadle-Brown, 2022).

Given the lack of research in this area, studies from outside the UK were included. However, it is appreciated that different geographical, cultural and sociopolitical contexts are likely to impact the experiences of people. Only English language papers were included, due to the timescale and resources of the project; this led to the exclusion of two papers before full text screening (Gracia et al., 2017; Martínez-Rivera et al., 2020). Table 2 provides a full summary of inclusion and exclusion criteria.

Grey literature is not housed in the databases used in the review and therefore grey literature was excluded. A decision to exclude grey literature was made due to the challenges with transparently and systematically searching for this kind of literature, and the related issue of clearly and transparently reporting search methods in a way that renders them reproducible (Boland et al., 2017). This decision, however, poses limits to the diversity of evidence sources included in the review, such as non-peer-reviewed literature published by (self) advocacy learning disability groups and charities, which often captures the first-hand collective voices of impacted communities (e.g., Challenging Behaviour Foundation et al., 2021). In addition, it prevents the inclusion of ongoing studies, meaning that data from ongoing studies exploring the emergent impacts of more recent events on everyday living/quality of life (e.g., the Coronavirus pandemic) will have been missed in the review. Table 2 provides a full summary of inclusion and exclusion criteria.

2.3 Results

Full details of the searches conducted can be found in Appendix B. An initial search was conducted with search terms for concepts around ID, supported housing/residential care homes and QoL; this yielded 660 articles after duplicates were removed. However, a low number of articles met the review's inclusion criteria, and the search did not appear to capture experiences across all QoL domains of interest. It was considered that it would not be feasible to reliably capture all relevant research by using search terms (and synonyms) to reflect all of the QoL domains within Schalock's quality of life conceptual framework (Verdugo et al., 2012). Therefore, a broader search strategy was used to ensure inclusivity: the QoL search concept was removed from the initial search, and the search was re-run. This yielded 1,487 returns after duplicates were removed. Inclusion and

exclusion criteria were then used to screen titles and abstracts, and 15 papers were identified for full text reading. Of these, nine articles met the review's inclusion criteria. Reference lists were checked for further potential studies meeting inclusion criteria, with one further study identified. A final ten studies were included in the review.

Table 2.

Inclusion and Exclusion criteria

Inclusion Criteria	Exclusion Criteria
<ul style="list-style-type: none"> • Adults (aged 18 years and over) diagnosed with ID living in supported housing or residential care homes. • Research which attempts to gather information on people's current everyday experiences (i.e., not linked to past experiences, such as hospital admission). • Research which attempts to gather information about the subjective experiences of QoL. That is, research which considers experiences related to one or more domains of QoL, as defined by Schalock's conceptual framework (Verdugo et al., 2012). • Research published in the English language. • Original peer-reviewed research. 	<ul style="list-style-type: none"> • Research on children (below 18 years old). • Intervention and outcome studies (e.g., research exploring the impact of an active support intervention). • Research on alternative experiences or perspectives (e.g., family of the person with ID, staff supporting the person with ID). • Research solely using objective measures that do not relate to how QoL is experienced by the person, including behavioural outcomes (e.g., adaptive and challenging behaviour measures). • Research focused on transitions between services (e.g., changes in QoL between hospital and community settings).

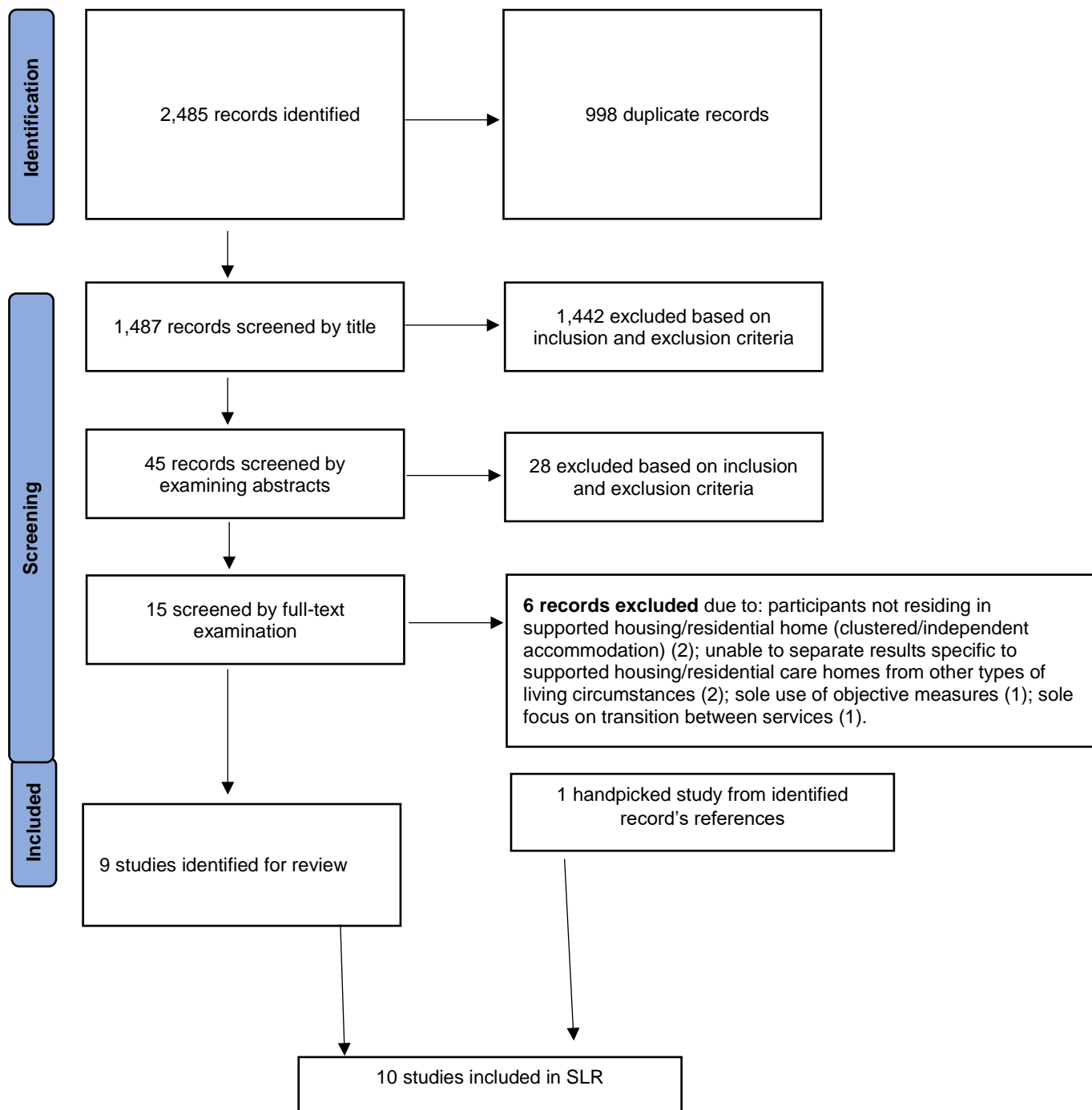


Figure 1.

Prisma flow diagram for study selection procedure.

Full study details can be found in Table 3. The studies were conducted in a range of countries, including Northern Ireland (1), Australia (3), Sweden (2), Norway (1), Spain (1), The Netherlands (1), and Canada (1). Nine studies used qualitative methodology and one study used mixed methods. Three studies used ethnographic methodology, including interviews and observations; the mixed methods study used interviews and a quantitative self-report survey; and the further six studies used interviews, focus groups or workshops. Of the studies using interviews as part of the methodology, six used interviews directly with the participant with ID, three used interviews with the participant with ID and proxy informants (staff/family), and one study, which explored the experiences of people with “moderate-profound” ID, used interviews with proxy informants only. Five of the studies included people living in supported housing, three studies included people living in residential care homes (namely, group homes), and two studies included a mixture of people residing in either residential care homes or supported housing.

Table 3.*Summary of Included Studies.*

No.	Title; Location	Authors	Primary Aims	Methodology	Participant Details, Including Living Circumstance	Key Findings Relevant to Review	Strengths and Limitations
1.	The barriers to social inclusion as perceived by people with intellectual disabilities Northern Ireland	(Abbott & McConkey, 2006)	To understand the perspectives of people with ID living in supported housing on the barriers to social inclusion and how these can be overcome.	Study design and data collection: Qualitative. Focus groups including workshop activities and small group discussions, resulting in written documents including comments from discussions.	68 adults with ID 45 women, 23 men; age range: 21-82 years 55% of participants lived in supported housing, 36% lived in group	Four main themes related to experiences of being in community settings: "talking to people, being accepted, using community facilities, opportunities", p. 281. Four main themes related to barriers to social inclusion: the	<u>Strength/s:</u> Large sample size including people from a range of living circumstances (supported housing, group homes, residential homes) with varying levels of staff support, increasing the transferability of the findings. <u>Limitation/s:</u> Themes related to barriers to social inclusion

				Data analysis: Latent content analysis	homes, 9% lived in residential homes. Varying levels of staff support (from visiting to 24-hour staff live-in)	community; staff and management; the home/scheme; personal abilities and skills.	lacked thick description and illustrative quotes, making it difficult to substantiate the claims made.
2.	The home environments and occupational engagement of people with intellectual disabilities in supported living Australia	(Ashley, Fossey, Bigby, 2018)	1)To describe the characteristics of the home environments of people with intellectual disabilities in supported living, and 2) to explore people’s experiences of how these environments impacted their engagement in home and community activities.	Study design & data collection: Collective case study. Mixed methods; concurrent triangulation design. Semi-structured interviews and observation of home environments using Residential Environment Impact Survey-Short Form (REIS-SF; Parkinson et al., 2011). Data analysis:	Six adults with ID 3 men, 3 women; age range: 24-58 Either living alone or with up to three other people, with visiting staff support (‘supported living’ model, in line with supported housing).	Participant’s living arrangements were limited in enabling occupational engagement in the home and community. Identified barriers to this engagement included limitations in social support, resources and opportunities, as well as the physical home environment.	Strengths: Use of concurrent triangulation mixed methods design allowed for a more nuanced, complex understanding of experiences. Purposive sampling improved sample representation in terms of living circumstances, age and gender. Research process was relatively sensitive to adaptations based on participant’s communication preferences. Limitations: Small sample size limits study’s transferability.

				<p>Undertaken individually for each case, followed by cross-case analysis.</p> <p>Visual representation of quantitative measures.</p> <p>Inductive qualitative analysis of transcribed interviews, guided by category outcomes on the REIS-SF.</p> <p>Qualitative data analysis method not specified.</p>			<p>Whilst the impact of researcher subjectivity is noted as a limitation, the researchers to not go further to make sense of how researcher biases shaped the research and findings.</p>
3.	<p>Conundrums of supported living: The experiences of people with intellectual disability</p> <p>Australia</p>	<p>(Bigby, Bould & Beadle-Brown, 2017)</p>	<p>To explore how people with ID experience living in supported living arrangements.</p> <p>Self-determination;</p>	<p>Study design & data collection: Qualitative. Semi-structured focus groups and interviews.</p> <p>Data analysis: Grounded Theory</p>	<p>34 adults with ID</p> <p>17 women, 17 men; age range: 38-55 years</p>	<p>Identified three main themes related to life areas: having choice and control; being supported; being connected. Though participants experienced greater choice and control</p>	<p>Strengths: Approach and epistemological position clearly detailed and coherent throughout the research process. Use of both interviews and focus groups facilitated a more nuanced, in-depth</p>

					<p>Living either alone or with up to three other people, with a range of visiting support levels ('supported living' model, in line with supported housing).</p> <p>34 participated in focus groups of 3-8 participants; 6 participated in further individual interviews.</p>	<p>compared to other living situations, restricted opportunities, related to low income, were reported. Both experiences of security and uncertainty in relation to available support was found. Whilst participants had various social connections, most experienced loneliness.</p>	<p>understanding of issues. Use of reference group, including people with ID and people with experiences of supported living, facilitated more nuanced, in-depth analysis.</p> <p>Limitations: Lack of rationale for participants selected for semi-structured interviews, rendering this aspect of the research process difficult to situate. A lack of detail regarding methodological challenges and/or developments limits sincerity.</p>
4.	Identifying Good Group Homes: Qualitative Indicators Using a Quality of Life Framework	(Bigby, Knox, Beadle-Brown & Bould, 2014)	To compare resident outcomes and staff practices across seven group homes (identified externally as the best of their type,	Study design and data collection: Ethnographic; qualitative. Unstructured observations of day-to-practices in the group homes.	Residents in 7 group homes (4-7 residents per home) with "moderate-profound" levels of ID. Collectively across homes:	Enjoyment and satisfaction predominantly came from social interactions with staff and family, or activities initiated by staff. Staff had very significant role in	Strength/s: Study contributes to area often neglected in ID research: the experiences/quality of life of people with 'severe-profound' ID. In-depth ethnographic approach, comprising multiple data

	Australia		<p>or underperforming), using a QoL framework.</p> <p>To explore whether resident outcomes and staff practices in the group homes could be rated as consistently good across QoL domains.</p>	<p>Review of documents about policy, procedure, and organisational structure in homes. Semi-structured interviews with staff members and family members of residents.</p> <p>Data analysis: Template analytic approach. Data was categorised in QoL domains from Schalock et al.'s (2002) QoL framework and coded in relation to good or poor examples of resident outcomes and staff practices.</p>	19 men, 18 women; age range: 21-70.	<p>people's lives; very few people had relationships outside of staff and family. Personal(ised) items/environments were linked to positive experiences of material wellbeing. Staff practice both limited and facilitated personal development (engagement in activities); inconsistent staff support was found to limit experiences in this area. Personal care that considered peoples personal preferences was associated with positive experiences of physical wellbeing.</p>	<p>collection approaches across 9-12 months in seven different homes, facilitates in-depth, complex understanding of the phenomenon. Findings provide framework that can, and have been, directly used to implement practical changes in local guidance and policy.</p> <p>Limitation/s: A lack of detail regarding procedure of the semi-structured interviews (i.e., topics, length, number) renders the research more difficult to situate and replicate. Absence of researcher's experiences and reflexivity in relation to ethnography limit contextual understanding of the findings.</p>
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<p>5.</p>	<p>Living with support: Experiences of people with mild intellectual disability</p> <p>The Netherlands</p>	<p>(Giesbers, Hendriks, Jahoda, Hastings, & Embregts, 2018)</p>	<p>To explore the thoughts and feelings of people with ID on their support from staff, in the context of their broader lives.</p>	<p>Study design and data collection: Qualitative; semi-structured interviews.</p> <p>Data analysis: Interpretative Phenomenological Analysis</p>	<p>6 adults with “mild ID”</p> <p>Four men, 2 women; age range: 23-32 years.</p> <p>Living individually or with another person with ID in own home, with live-in staff support (in line with supported housing model).</p>	<p>Identified three main themes in relation perceptions of staff support: “relationships with staff placed within a personal history, relationships with staff in an organisational context, and staff support and interviewee’s place in the world” p.446</p>	<p><u>Strength/s:</u> Use of IPA technique allowed understanding of support experiences to be contextualised in individuals’ broader life/circumstances, addressing prior research gap. Piloting interview schedule with people with ID with experiences of services is likely to have increased research relevance and the accessibility of data collection methods. In-depth presentation of connections between themes applied to one participant’s experiences increased resonance of findings.</p> <p><u>Limitation/s:</u> Despite author acknowledgement of researcher’s influence on both accessing and interpreting participant experience in the</p>
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							methods used, and mention of a use of a reflective journal in the analysis process, a lack of detail on researcher reflexivity limits contextualisation of the research and findings.
6.	Choice and control for people ageing with intellectual disability in group homes Sweden	(Kåhlin, Kjellberg & Hagberg, 2016)	To investigate how choice and control is expressed and performed in semi-private spaces in group homes in the everyday lives of older adults with ID.	Study design and data collection: Ethnographic method; qualitative. Unstructured qualitative observations of activities and interactions in the group home. Semi-structured interviews with both residents with ID (focussing on internal preconditions for choice and control) and support staff in group home	Observations undertaken in four community-based group homes for people with ID with older residents (defined as people aged 50 or older). Total of 32 residents across the group homes. Mean age= 62; "mild-profound" levels of ID. Resident interview informants: 12	Four categories of meaning identified in relation to aspects of choice and control in semi-private spaces in participant's everyday lives: time and routine, privacy, person-centred approaches, space and objects. Habitual routines based on the group collective/staff preferences limited choice and control over activities in semi-private spaces. Discussion of private matters in	Strength/s: Study provides contribution to understudied group (older people with ID) and situates findings within contextual experiences of this cohort (i.e., long-term institutional living). Ethnographic approach, utilising multiple data sources gathered across 7-months, facilitated an in-depth, complex understanding of phenomenon. Limitation/s: The presence of 'psychiatric conditions' and dementia in some participants observed in

				<p>(focussing on external preconditions for choice and control).</p> <p>Data analysis: Descriptive conventional content analysis. Two stages: 1) categories of meaning derived from observation field notes; 2) interview transcripts coded into these categories of meaning (resident and staff interviews treated as separate datasets).</p>	<p>individuals; 5 male, 7 female; mean age= 64; “mild-moderate” ID.</p>	<p>semi-private spaces inhibited people’s control over spaces.</p>	<p>the residential homes was noted in the participant information; however, the impact of these contexts on the experiences studied was not made sense of in the analysis and findings, making the claims made difficult to situate. Self-reflexivity around impact of researcher presence within the observations was lacking.</p>
7.	<p><i>Being in control:</i> Choice and control of support received in supported</p>	<p>(Pallisera, Vilà, Fullana & Valls, 2021)</p>	<p>To explore the role of people with ID in supported living arrangements in exercising choice</p>	<p>Study design and data collection: Qualitative. Semi-structured interviews</p>	<p>13 adults with ID 8 women, 5 men; age range: 31-63</p>	<p>Two main patterns identified in relation to individual’s choice and control of support received: 1) <i>person in control</i>,</p>	<p>Strength/s: Clear, thoughtful adaptations made to interview techniques to facilitate individual to express themselves from</p>

	<p>living. A study based on the narratives of people with intellectual disabilities and support staff.</p> <p>Spain</p>		<p>and control in relation to the support they receive.</p>	<p>conducted with person with ID, as well as support staff. Interviews focussed on the viewpoint of the informant regarding the support the person with ID had received.</p> <p>Data analysis: Deductive content analysis</p>	<p>Living in own home or rented home, with established staff support in the same supported living programme (in line with supported housing model); purposive sampling of people who were “generally satisfied” with the supported housing programme.</p>	<p>where support is positively experienced as tailored to person’s choices; 2) <i>Person controlled by professionals</i>, where support is negatively experienced as based on professional’s decisions.</p> <p>Professional’s views on people’s ability to be independent in aspects of living seemed to be internalised by participants receiving support, and were linked to level of autonomy people had in decisions around their support.</p>	<p>their own perspective (e.g., creative use of visual materials). Clear, detailed description of data collection and analysis allows for the study to be situated and replicated.</p> <p>Limitation/s: Focus on individuals access a specific supported living program, accessible only to individuals with a reasonable level of autonomy; therefore, findings may not transfer to individuals needing higher levels of support.</p>
<p>8.</p>	<p>Self-Determination and Leisure Experiences of</p>	<p>(Regina & Rossow-Kimball, 2009)</p>	<p>To understand how women with ID in two group homes</p>	<p>Study design and data collection:</p>	<p>5 women with ID</p>	<p>Three main themes around leisure identified: leisure at home, leisure in the</p>	<p>Strength/s: Use of multiple data sources facilitated a more in-depth, nuanced</p>

	<p>Women Living in Two Group Homes</p> <p>Canada</p>		<p>experience leisure, including the opportunities they have to self-determine their leisure experiences.</p>	<p>Intrinsic case study approach informed by ethnographic methodology; qualitative Semi-structured interviews with people with ID and staff working in the homes, as well as active interviews with people with ID during leisure outings. Observations of people's experiences of home-based and community leisure time. Notes from group home's daily log books</p> <p>Data analysis: Inductive thematic analysis on interview data; qualitative</p>	<p>Age range: 44-60 years.</p> <p>Participants were living in two separate group homes</p>	<p>community, leisure with family and friends.</p> <p>Leisure was experienced differently between the women in the two group homes, largely due to differences in staff practices. More self-determined leisure experiences were linked to staff input around the encouragement of independence, creation of opportunities for self-directed leisure, and teaching of skills associated with leisure activities.</p>	<p>understanding of the phenomenon. Particular attention was taken in adapting data collection methods to better enable participants with ID to express themselves authentically, including the use of active interviews that allowed for more spontaneous, conversational styles within leisure contexts.</p> <p>Limitation/s: Despite data collection adaptations, interview data was not deemed to be rich and was therefore deprioritised in analysis, meaning that first-person accounts of the people with ID were more peripheral in the findings. The study does not detail attempts to adapt analysis to better fit with the interview data collected (i.e., it is noted that communication in</p>
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				analysis applied to observational and artifact data unclear.			interviews was through body language but does not attempt to incorporate this in the analysis).
9.	No ordinary adult life: Living conditions from the perspectives of adults with intellectual disabilities Sweden	(Carlsson& Adolfsson, 2022)	To investigate the experiences of living conditions for adults with ID, from the perspective of the person with ID, using a QoL framework exploring control of life, safety, social belonging and adult social status.	Study design and data collection: Qualitative. Semi-structured interviews. Interview guide and analysis model developed collaboratively with people with ID. Data analysis: Top-down thematic analysis using UQoL2 model, encompassing the factors: adult social status, control of life,	11 adults with ID 7 women, 4 men; age range: 45-59 6 participants lived in group homes, 5 in their own homes with varying levels of established visiting staff support (in line with supported housing model).	<i>Adult social status</i> Staff practices were found to be both barriers and facilitators to responsible roles and choices in lifestyle. <i>Control of life</i> Dependence on staff support for activities was found to restrict control over leisure experiences due to sometimes limited staff availability. <i>Personal safety</i> Experiences of safety were linked to staff predictability	Strength/s: Use of interview guide and coding model developed In consultation with people with ID increased relevance of research topics explored and accessibility of data collection measures. Purposive sampling enhanced sample representation across age, gender, life situation. Limitation/s: Though the analysis model was developed by a group of people with ID, this group was not consulted during the analysis process, and member reflections were

				<p>personal safety, social belonging, and wellbeing (Carlsson & Adolfsson, 2018) to deductively code QoL features.</p>		<p>and continuity, routines surrounding everyday chores, the home environment, and maintenance of family connections.</p> <p><i>Social belonging</i> Relationships outside of family generally depended on staff support. Staff and other residents created a sense of social belonging for people in group homes.</p> <p><i>Wellbeing</i> Belonging to a social community (staff, family, co-residents/co-workers) was discussed as fundamental to wellbeing.</p>	<p>not sought, therefore limiting multivocality in aspects of the research process. Whilst the researchers worked alongside people with ID in aspects of the research process, self-reflexivity on how their own positions and biases shaped the research and findings were not detailed.</p>
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<p>10.</p>	<p>'It's our everyday life'- The perspectives of persons with intellectual disabilities in Norway</p> <p>Norway</p>	<p>(Witsø & Hauger, 2018)</p>	<p>To explore the perspectives and experiences of everyday life for persons with intellectual disabilities.</p>	<p>Study design & data collection: Participatory action research design, inspired by participatory, appreciative, action and reflection (PAAR) model. Qualitative. Four group workshops exploring aspects of everyday life for participants, e.g., an ordinary week. Data included filed notes and transcribed text from workshops.</p> <p>Data analysis: Inductive thematic analysis</p>	<p>Nine adults with "mild ID"</p> <p>6 women, 3 men; age range: 26-58 years.</p> <p>Participants lived in their own flat within shared houses with 24-hour access to staff support (in line with supported housing model).</p>	<p>Three main themes around everyday life were identified: everyday life-context, rhythm and structure; social participation; staff-an ambiguous part of everyday life.</p> <p>Friendships were considered important but challenging. Uncertainty around relationships with staff were reported when they were experienced to lack reciprocity/mutuality, and where a lack of communication around staff changes was experienced.</p>	<p>Strengths: Use of a collaborative group approach (Bigby et al., 2014) and PAAR design promoted reciprocity with participants during the research process, thus centring values of mutual respect and dignity and enhancing multivocality. PAAR approach facilitated practical changes as part of research process, through stakeholder ownership of issues. Use of multiple data collection methods, which evolved over time based on participant and researcher feedback, facilitated a more in-depth, nuanced understanding of the issues.</p> <p>Limitations:</p>

2.4 Critical Evaluation of Study Quality

The quality of studies included in this review was appraised using two different tools, in line with the two different methodologies (qualitative and mixed-methods) used in the studies selected. Methodologically specific quality appraisal tools were preferred over the use of one quality assessment framework as these are more recently published than tools consolidating evaluation of different methodology (e.g., Elliott, Fischer & Rennie, 1999), and better tailored to more rigorously appraise the method in question.

The nine qualitative studies were appraised using the “Big-Tent” Criteria for Excellent Qualitative Research (Tracy, 2010). This tool was considered advantageous as it conceptualises different qualitative methodological paradigms and is therefore appropriate for the varying epistemological stances and data collection measures employed in the studies selected in the review (Tracy & Hinrichs, 2017). The mixed-methods study was evaluated using the Mixed-Methods Appraisal Tool (MMAT; Hong et al., 2018). This tool was deemed preferable over the use of separate qualitative and quantitative appraisal frameworks as it evaluates the integration of the methods in the research; this was particularly advantageous as the included mixed-methods study used a triangulation design. For the completed quality appraisal frameworks, see Appendix C.

All studies had clear aims and rationales, situated within the existing literature, and made meaningful contributions to the knowledge base. Some studies were noteworthy for their practically significant contributions (Bigby et al., 2014; Witsø & Hauger, 2018). For example, Witsø & Hauger’s (2018) PAAR design built in improved working practices through stakeholder ownership of issues and

raised participants consciousness about their rights to speak out about injustice in their everyday living, leading to involvement in further self-advocacy projects.

Some studies made methodologically significant contributions, particularly useful to ID research (Carlsson & Afolsson, 2022; Witsø & Hauger, 2018). For example, Carlsson and Adolsson (2022) used a QoL analytic coding model developed in consultation with people with ID, which hoped to increase the relevance and utility of the research for people with ID.

All studies used methods suited to the research aims and provided clear rationales for the methods used. There was a global omission of demographic information around the ethnicity and cultural backgrounds of participants, limiting understanding of the results transferability. Further, some studies lacked rigor in their detailing around data collection and/or analysis (Abbott & McConkey, 2006; Bigby et al., 2014; Regina and Rossow Kimball, 2009; Witsø & Hauger, 2018). For example, Regina and Rossow Kimball (2009) note that the collected interview data was deprioritised in the research as it was deemed less rich than the observational data obtained, though do not adequately detail how the different data sources were selected and organised in the analysis to reflect this and are unclear about the specific qualitative methodologies used to analyse the observational data. In Abbott and McConkey's (2006) study, there was a lack of thick description of the data in parts, meaning that not enough data was shown to support some of the claims made in the findings relating to the themes speaking to 'barriers to social inclusion'.

Some studies provided reasonable transparency around methodological decisions and research activities (Carlsson & Adolsson, 2022; Kåhlin et al., 2016; Pallisera et al., 2021; Witsø & Hauger, 2018). For example, Kåhlin et al. (2016)

gave detail on the level of immersion/participation in the ethnographic approach. None of the studies conveyed self-reflexivity through naming researcher biases, feelings and experiences and making sense of how these shaped the research. Given the societal power differentials between the researchers and participants with ID, and the focus of relational collaborative working in some of the studies, this examination feels an important step in terms of both the ethics of the research and trustworthiness of the findings.

All studies noted procedural ethics, including gaining ethical clearance and informed consent. All studies detailed adaptations made to support people to participate in the research, such as adaptations to communication styles in interviews and use of visuals to support understanding, except for Bigby et al. (2014), where data was not directly collected from the participant with ID. Three of the studies noted attempts to disseminate the findings to participants/audiences of people with ID in accessible ways (Abbott & McConkey, 2006; Carlsson & Adolfsson, 2022; Witsø & Hauger, 2018).

Of note, most studies used data collection methods requiring language and communication levels that would allow people to participate in interview and/or focus groups. In addition, the interview data collection methods were noted to be too complex for many participants to engage in one study (Regina & Rossow-Kimball, 2009). Therefore, people with more significant intellectual and/or communication difficulties appear to be mostly excluded from this research area. Despite challenges, further research in the area therefore needs to consider the use of more inclusive, adapted methodologies that can better capture the perspectives of a broader range of people with ID.

2.5 Synthesis of Findings

The review synthesised 10 studies, based on the recommendations of Siddaway et al. (2019). Thematic synthesis techniques (Thomas & Harden, 2008) were used to synthesise the findings. These techniques have been developed and applied specifically for systematic reviews that examine individual's perspectives and experiences (Thomas & Harden, 2008) therefore were thought to be applicable to the current review.

Following familiarisation with the articles, I extracted findings from each of the studies and entered them verbatim into NVivo software. In line with Thomas and Harden's (2008) techniques, findings were classed as text within 'findings' or 'results' sections of articles. I then engaged in line-by-line coding of the text to develop codes based on the text's meaning and content. Codes were then grouped into themes, which clustered codes based on shared patterns of meaning at both a semantic level (staying close to the original meaning/content of the text) and analytical level (going 'beyond' the original content described in the findings of the primary studies, and moving towards underlying patterns).

This resulted in the following four key themes:

- Barriers to and Facilitators of Independence
- The Significance of Relationships with Staff
- (A lack of) Wider Relationships and Community Inclusion
- Safety and Security

These themes largely relate to self-determination, personal development, interpersonal relationships, participation, and emotional well-being QoL domains. Whilst experiences associated with rights were not often explicitly spoken to in the

studies, findings related to choice, inclusion, and being treated with respect are reported within the below categories. Experiences related to material wellbeing were relatively rare in the literature reviewed; however, some studies reported the impact of low-income on leisure opportunities (Abbott & McConkey, 2006; Ashley et al., 2018; Bigby et al., 2017). Experiences related to physical wellbeing were found to be mostly absent in the studies reviewed, though a wish for more choice and control around health promotion measures was reported in one study (Carlsson & Adolfsson, 2022).

2.5.1 Barriers to and Facilitators of Autonomy.

A number of studies found that people valued having autonomy in aspects of their everyday lives. Participants across studies reported enjoying doing domestic work independently (Bigby et al., 2017; Carlsson & Adolfsson, 2022), and shared positive emotions around being perceived by others to be able to do things by themselves (Carlsson & Adolfsson, 2022). In addition, the importance of having control over decisions relating to support (Pallisera et al., 2021) was reported.

The literature highlights that the culture and practice of professionals and services impacts people's experiences of autonomy. Some studies exploring the experiences of people living in group homes reported the limiting nature of practices involving group-oriented decisions and routines that do not allow for individual choice and personal expression. This included the use of set menus and meal times in some group homes supporting people with "moderate-profound" ID (Bigby et al., 2014) and habitual routines based on the group collective or staff preferences (e.g., around meal preparation or choice of TV programme) in semi-private spaces within group homes in which older people with ID live (Kåhlin et al., 2016). Cultures associated with more individualised living include the personalisation of people's rooms, such as

personal adaptations (Bigby et al., 2014) and the right to own your own things (Rossow-Kimball & Goodwin, 2009).

Studies focussing on group homes spoke to ways in which staff approaches facilitated people's autonomy. Bigby et al.'s (2014) ethnographic study exploring the experiences of people with "moderate-profound" ID across seven group homes reported the observed positive impacts of staff interpreting and acting on people's preferences (e.g., by knowing and interpreting idiosyncratic 'yells') and presenting choices in a way that was accessible to the person. The authors spoke to how practices to enhance autonomy appeared to depend on the depth of knowledge staff held about the people they were supporting, as well as the consistency of staff practices. In particular, inconsistent practices between staff were observed to negatively impact opportunities for people to develop skills to do things more independently, such as drink from a cup. Rossow-Kimball and Goodwin's (2009) phenomenological case study on the leisure experiences of women with ID in two separate group homes reported increased experiences of self-determination in leisure activities for people living in a service where professionals made efforts to determine people's activity preferences, helped to create and support opportunities for people to act on these, and supported the learning of skills to allow people to actively do them (e.g., skills around the handling of money for shopping trips).

Some studies exploring the experiences of people in supported housing spoke to how the living set-up allowed more autonomy in everyday living than previous arrangements participants had lived in, such as family homes and group homes (Ashley et al., 2018; Bigby et al., 2017). For example, the freedom to have a job, when family members had previously restricted this opportunity (Ashley et al., 2018). However, staff and organisation practices in supported housing were also

found to restrict people's autonomy in some studies. A lack of availability of staff support was reported to limit people's ability to do activities that were meaningful to them outside of the home, such as walking to local amenities and going to concerts (Ashley et al., 2018; Witsø & Hauger, 2018). However, in Ashley et al.'s (2018) study, participant accounts indicated that staff assistance in supported housing restricted some people's ability to do daily tasks (e.g., grocery shopping) more independently; for example, in instances where staff did things for the person, as opposed to giving tailored support or supporting skills development.

Furthermore, studies reported that, despite a general satisfaction with their support arrangements in supported housing, some participants perceived their support to be excessively strict and controlling (Bigby et al., 2017; Pallisera et al., 2021). Pallisera, et al.'s (2021) study exploring people's perceptions of choice and control of the support they received in supported housing reported the prominent role professional and organisational views play in determining the level of autonomy people with ID had in choosing their support set-up, such as the type of home they live in, who is employed to support them, and who visits their home. The authors highlighted that participant accounts indicated that they had internalised the views of staff on whether they had mastered the skills and conditions needed to exercise autonomy in their decision making around support, suggesting a lack of awareness of their rights to make decisions about their lifestyle.

Whilst studies predominantly spoke to the impact of factors associated with staff and organisational support, some other themes were discussed. Low personal income was reported to restrict opportunities for participating in preferred hobbies and leisure activities for people in supported housing (Bigby et al., 2017; Ashley et al., 2018). In addition, individualised funding was linked to more personalised and

less routinised experiences in group homes supporting people with “moderate-profound” ID (Bigby et al., 2014). Kåhlin et al.’s (2016) study revealed that some older people with ID relied on staff to make decisions for them, which seemed to be linked with feelings of safety and trust; the authors suggested that this may be linked to the life course of older people with ID, who are likely to have been less used to and encouraged to make their own decisions during their earlier lives (spent in institutions).

2.5.2 The Significance of Relationships with Staff

Studies revealed that support staff were the most significant relationships and social contacts in many participants’ lives (Bigby et al., 2014; Bigby et al., 2017; Giesbers et al., 2018). Bigby et al., (2017) reported that some participants saw staff as friends, particularly those who had more limited broader relationships (e.g., friend/family contact). In Giesbers et al.’s (2018) study exploring experiences of support from staff in supported housing, some participants emphasised the importance of staff being unconditionally there for them, juxtaposing this with the challenges they faced with forming close, stable relationships in the wider community. Interactions with staff that were not solely support-related, (e.g., playing videogames, chatting, going out together) were found to be valued (Carlsson & Adolfsson, 2022; Giesbers et al., 2018). However, some participants expressed valuing support from staff primarily for advice and practical support and did not centre the importance of social interaction (Giesbers et al., 2018).

Warm and respectful social interactions, involving social touch and joking, between staff and participants living in group homes supporting people with

“moderate-profound” ID were observed to be associated with visible expressions of satisfaction (Bigby et al., 2014). In addition, bonds based on

honesty were reported to be valued (Carlsson & Adolfsson, 2022), and being treated as equal to staff was linked to trust (Giesbers et al., 2018).

Challenges in relationships with staff were also found to have significant negative impacts on people's lives. Witsø and Hauger (2018) found that uncertainty around staff relationships was present when the relationship wasn't experienced as mutual and reciprocal (e.g., mutual respect and kindness). In addition, more distant, formal interactions that socially separated staff from those they support were reported to negatively impact participants in some studies (Bigby et al., 2014; Giesbers et al., 2018).

Challenges in relationships with staff were experienced when people didn't feel they were being listened to (Bigby et al., 2017), or when staff listened to their problems empathetically but did not act on them (Witsø & Hauger, 2018). In addition, participants in some studies spoke to challenges associated with being supported by people with a different gender identity to them, citing the discomfort of being attracted to staff support (Giesbers et al., 2018), or the struggle of confiding about things like intimate relationships (Bigby et al., 2017).

The emotional pain and feelings of powerlessness associated with the loss of relationships with staff members, through changes in support, was also spoken to (Giesbers et al., 2018; Witsø and Hauger, 2018). Challenges related to a sense of uncertainty (Giesbers et al., 2018) and lack of communication (Witsø and Hauger, 2018) about staff leaving were reported. Studies revealed people's wish to be consulted about decisions in changes to their staff support (Bigby et al., 2017; Giesbers et al., 2018). The impact of the sudden loss of staff relationships is encapsulated in Maria's response to watching media about a staff member quitting without prior communication: "Do you know what I identified with? I felt the same

loneliness, the same sadness, the same sorrow.” (Witsø and Hauger, 2018, p. 153).

2.5.3 (A Lack of) Wider Relationships and Community Inclusion

A number of studies spoke to experiences of loneliness and a stark lack of relationships outside of paid support (Ashley et al., 2018; Bigby et al., 2017; Giesbers et al., 2018). Participant accounts discussed perceptions of the importance of friendships, and the desire to have more friends (Ashley et al., 2018; Giesbers et al., 2018; Witsø and Hauger, 2018). However, difficulties with forming and keeping friendships were reported, including experiences of social rejection and exclusion (Bigby et al., 2017), and difficulties with finding people that could be trusted, or resolving disputes in friendships (Witsø and Hauger, 2018).

The literature reviewed did not generally speak to experiences of romantic relationships; however, Witsø and Hauger (2018) reported that younger participants generally enthusiastically expressed a desire for boyfriends/girlfriends, whereas older participants accounted that they had found these difficult to manage and were not a priority for them. In addition, some participants in Giesbers et al.’s (2018) study spoke to the loneliness associated with a lack of romantic relationships.

The sharp emotional pain associated with experiences of loneliness was present in many participants narratives across studies, as can be seen in Kenneth’s account:

“So I became friends with myself, just trying to keep myself as a friend. You are born alone and eventually you will die alone as well. That is just how it is. And in the meantime, you have to be lucky to meet someone. I have not been lucky in that way. I have not been that lucky when it comes to love, because I

have never had a girlfriend. And that is frustrating, you know. Really, it is the most frustrating thing.” (Giesbers et al., 2018 p. 449).

Whilst relationships with those in the wider community were often reported as challenging, some studies found that a sense of social belonging came from relationships with people from the same support organisation (Abbott & McConkey, 2006; Carlsson & Adolfsson, 2022). However, perceptions that friendships should be based on interests and not disabilities were also expressed (Carlsson & Adolfsson, 2022). The importance of close connections with family members (mostly parents), for both emotional and practical support, was also discussed in studies (Ashley et al., 2018; Carlsson, 2022; Witsø & Hauger, 2018). Staff were reported to play an important role in supporting people’s connections with their families (Bigby et al., 2014), and the importance of good relationships between staff and family were discussed (Giesbers et al., 2018; Witsø & Hauger, 2018).

Studies spoke to experiences of social and community exclusion (Abbott & McConkey, 2006; Ashley et al., 2018; Carlsson, 2022; Giesbers et al., 2018).

Giesbers et al.’s (2018) study revealed experiences of prejudice and rejection by people in the community; for example, based on knowledge of their need for additional support. Abbott and McConkey’s (2006) study reported a number of barriers to social inclusion experienced by people with ID living in supported housing/group homes, including: location of home, lack of accessible transport, low income/affordability of activities, service policies and lack of staff availability, reduced confidence and motivation resulting from concerns about personal skills, and a lack of trust in others/fears of exploitation.

Positive experiences of social inclusion were discussed in relation to being known by others in the local community who were not necessarily friends but

stopped and spoke to participants; for example, when they visited local amenities (Bigby et al., 2014; Carlsson & Adolfsson, 2022). Ashley et al.'s (2018) study revealed that employment (paid, voluntary, and work experience) was found to provide opportunities for social contact outside of home and gave people a sense of value about their contribution. Being useful to and helping out family was important to participant's identity of being a family member (Carlsson & Adolfsson, 2022; Witsø and Hauger); Carlsson and Adolfsson (2022) suggested this gave participants a sense of being part of the 'adult community' (i.e., seen to have the same social status as other adults).

2.5.4 Safety and Security

A number of studies spoke to a sense of psychological safety and security created through relationships. The importance of consistency of staff support to this was found. People discussed feelings of safety in relation to the predictability and continuity of support (Carlsson, 2022; Giesbers et al., 2018), and awareness that help is there when needed (Bigby et al., 2017). For example, participants in Giesbers et al. (2018) shared that staff continuity helped support staff to get to know their personal needs, and cuts to support hours created feelings of abandonment. In addition, being part of a family and maintaining close, continuous connections with family members was related to feelings of personal safety and security (Carlsson, 2022; Witsø and Hauger, 2018).

Some factors were linked to feelings of unsafety and insecurity. For instance, discord between co-residents (e.g., fighting, insults) was reported to make participants living in shared accommodation feel unsafe (Carlsson and Adolfsson, 2022). In addition, fears around negative encounters with people in

public, such as being exploited/taken advantage of, were linked to feelings of insecurity (Abbott & McConkey, 2006; Bigby et al., 2017).

2.6 Implications

Based on the review's synthesis, this section will consider key implications for practice and policy in relation to the QoL of adults with ID who live in supported housing and residential care homes.

2.6.1. The central role of staff relationships and staff approaches to support

The review highlights how people's relationships with staff/staff's approaches to support play a central role in aspects related to QoL for this group of people. Staff were found to bolster or limit independence/autonomy; support connections with others (e.g., family), in turn promoting social/community inclusion; and foster a sense of psychological safety and security. In particular, person-centred approaches, as well as and practices that fostered positive/safe relationships with staff were noted to be valued by participants. These factors should be considered in the delivery of training and support for staff supporting this group of people.

2.6.1.1 Person-centred approaches

The review's synthesis indicates that staff support should be tailored to individual preferences, and collaborative in a way that enhances people's existing skills/attributes and/or creates opportunities for their personal development. Importantly, this was distinguished from practices in which support was chosen for/ 'done to' people, or where support was lacking or unavailable. These ideas are akin to the evidence-based support approach known as 'active support' (Beadle-Brown,

2022). These findings suggest that approaches in line with active support should be promoted in the training of staff supporting adults with ID in these settings.

2.6.1.2. Practices fostering positive relationships with staff

The review's synthesis indicates that staff should consider a number of key factors to promote positive relationships and/or bolster feelings of safety in relationships with those they support. These include honesty (e.g., not promising things that cannot be delivered), listening to others (i.e., making people feel genuinely heard), treated others as equal/creating relationships that are reciprocal in nature, having an in-depth knowledge of the people being supported, and promoting consistency/predictability in staff support/support approaches. Care plans, including Positive Behaviour Support (PBS) plans, can be used to promote the sharing of knowledge and understanding about someone, and consistent approaches towards care and support for someone (NICE, 2015). In addition, these findings indicate that it may be helpful for staff training/support to include psychoeducation around factors that promote safety in relationships, such as ideas related to attachment and emotional validation and containment (e.g., 'Circle of Security'; Cooper et al., 2011).

2.6.2. Social and community inclusion.

The review's synthesis indicated the loneliness and lack of social inclusion this group of people experience, and thus the need for more investment in support for people to have meaningful relationships outside of support staff. Some studies indicated that issues with accessibility to services (e.g., lack accessible transport, lack of workplace inclusion initiatives) exacerbated social/community exclusion. As such, it is fundamental that mainstream services are invested in to make them accessible and welcoming to people with ID. Examples of these include schemes to

increase access to employment and community leisure facilities for people with ID residing in England, as detailed in the recent BtRS plan (DHSC, 2022).

Some studies in the review revealed the challenges that people with ID living in supported housing/residential care homes may face in navigating relationships, including both finding and maintaining friendships (e.g., resolving disputes when they arise). Staff training may therefore help staff to become aware of the ways in which they can support people to seek/maintain relationships outside of staff support (e.g., supporting to people to find/access places where they can meet others, providing support around navigating relationships with others). This should also include making people aware of community services people can be signposted to for this support (e.g., 'People First', 'Supported Loving').

2.7 Strengths and Limitations

The review's focus on peoples' subjective experiences enabled a more contextualised understanding of QoL experiences for people with ID in supported housing/residential care homes than many previous literature reviews in this area, which have typically focussed on 'objective' QoL measures that can be reductive in nature and risk simplification of this complex phenomena (Schalock, 2002). In addition, the review's search methods/strategies were systematic and transparent, and therefore reproducible. For instance, concepts used in the search strategy/inclusion and exclusion criteria were carefully operationalised using published models/definitions from the ID/QoL fields.

The studies included in the review were all conducted in Western countries, namely Australia, Canada, and countries in Europe, limiting understanding of the phenomenon at a global level. Global conceptualisations/constructions of 'intellectual disability' differ markedly across the globe (Grünke & Cavendish, 2016). In addition,

worldwide, there are differing cultures of social treatment and living circumstances for people who could be labelled as having an 'intellectual disability' in the UK, including different trajectories of institutionalisation/de-institutionalisation between countries (Walmsley, 2005). As such, QoL experiences for people 'with ID' across the globe are likely to be variable. Furthermore, the studies included in the review did not detail whether participants had previously resided in hospitals/institutions, which further limits contextual understanding of the review's findings.

2.8 Conclusion

Ten studies were identified in relation to the subjective experiences of QoL in the everyday lives of adults with ID living in supported housing and residential care homes. To note, only one of these was conducted in the UK (Northern Ireland). Searches using alternative databases and/or including studies in other languages may have yielded other results.

Synthesis of the literature findings indicated that staff approaches and organisational cultures could enhance or limit experiences of autonomy for people residing in both supported living and residential care homes. Barriers to autonomy included group-orientated decisions and routines in group homes, as well as a lack available staff support in supported housing, or support in which people did things for people without involving them. Practices that enhanced people's autonomy included staff with in-depth knowledge of a person, and practices that centred people's preferences and supported the development of new skills.

Staff were revealed to be the most significant relationships and social contacts in many people's lives, and challenges in relationships with staff were found to have a significant negative impact on people. A lack of wider relationships and community inclusion outside of staff support was found, and feelings of

loneliness were commonly reported. Feelings of safety were created through consistent and predictable staff support, as well as close, continuous relationships with family members. In addition, feelings of insecurity were linked to discord between residents in the home and fears of being exploited/taken advantage of by people in public.

2.9 Rationale for the Current Study

There are a relatively large number of studies exploring factors related to the QoL of adults with ID who live in the community (i.e., people who have not necessarily moved out of hospital), including those that live in specialist community settings (e.g., supported housing and residential care homes). In addition, some studies have explored factors relating to the QoL of adults who have moved out of hospital and live in the community. However, there is a paucity of research exploring this area for adults with ID who have moved of hospital through TC. As discussed, people who have transitioned through TC in the last decade are reported to have more complex needs to people who moved during earlier periods of deinstitutionalisation/hospital moves (RedQuadrant, 2022). There is therefore a need to understand the experiences of this group of people, in order to develop better tailored policy and practice guidance that enhances their QoL.

A lack of good quality community provision has recently been linked to delays in the discharge of people with ID from hospital, as well as community placement breakdown and hospital readmission. The latest BtRS Action Plan (DHSC, 2022) details policies and funding streams to improve community services for people with

ID, but also recognises that the perspectives of people with ID are essential to developing better community support that enhances the quality of people's lives.

However, the voices of people who have moved through TC are largely absent from the research being built around the long-term impacts of TC (Head et al., 2018). The current study aims to address this gap by exploring the everyday lives of people with ID who have moved out of hospital through TC from their own perspective, in order to deepen the understanding of what enhances/undermines their QoL in the community.

Further, whilst at least one study has explored the experiences of the Coronavirus pandemic for the general population of adults with ID in the UK (Flynn et al., 2021), to my knowledge, no study has explored the experiences of this from the perspectives of people now living in the community, who have moved out of hospital through TC. As this group of people has a distinct set of experiences and needs, the study has a secondary aim to understand the impact of the Coronavirus pandemic on their everyday lives.

2.10 Research Questions

The study aimed to address the following research questions, which all relate to the experiences of adults with ID who have moved out of hospital through TC:

1. What experiences (e.g., events, relationships, activities) make up people's everyday lives in the community?
2. What aspects of everyday living enhance or undermine their quality of life in the community?
3. What is the impact of the Coronavirus pandemic on people's everyday experiences?

3. Methodology

3.1 The Broader Research Programme

3.1.2. Making Positive Moves study.

'Making Positive Moves' (MPM) is an NIHR funded study (award ID: PB-PG1217-20032) that is currently being conducted by the University of Hertfordshire (UH) and Hertfordshire Partnership University NHS Foundation Trust (HPFT). This is an ongoing three-year longitudinal Grounded Theory study that aims to understand the factors which allow people with ID to remain living in the community after moving under the TC programme. Specifically, the MPM study seeks to develop a model to explore the factors that sustain or undermine community living over time. The study uses a qualitative methodology in which in-depth semi-structured interviews are being conducted with 22 participants with ID who have moved out of hospital under the TC programme (since 2012). The interviews are taking place over a 2-year time-period; participants are interviewed twice, one year apart.

3.1.3. The current study's situation within Making Positive Moves.

The current study complements the aims of this core research programme. Whereas the MPM study explores factors sustaining/undermining community living over time, the current study has a particular focus on the experiences of people's current everyday lives, and aspects that enhance/undermine their current QoL. As such, the current study explores participants' lives during one time-point only, to allow for an in-depth focus on the rich accounts of people's everyday lives.

3.1.4. My involvement in Making Positive Moves.

The current study used pre-collected data from the core MPM study. I joined the MPM research programme after data had been collected for 22 participants

within the first time-point of the core MPM study. This came following the termination of a study I originally developed as part of my doctoral major research project, in which I had received ethical approval and commenced recruitment and data collection; this termination occurred due to the significant impact of the Coronavirus pandemic on participant recruitment in the study.

I was, therefore, not involved in the following areas of the core MPM study: obtaining ethical approval; design, including initial consultation with Experts by Experience (EBEs) around study design, the development of data collection methods and research materials used (e.g., consent forms, interview topic guides), or the development of the original inclusion and exclusion criteria; participant recruitment; consent procedures; data collection. I, however, led on the development of the design of the current study, including epistemological and theoretical positioning, development of additional inclusion/exclusion criteria, and data analysis methodology. I also led on the conduction of data analysis in the current study, which involved consultation with experts by experience from the MPM consultation group.

The decision to develop the current study as part of the broader MPM research programme was made in collaboration with the core MPM research team, including the expert by experience consultation group (see further details on this in sub-section 3.8). This consultation identified a gap in the MPM research programme/broader research field in the understanding of the experiences of current everyday living/QoL for adults with ID who have moved out of hospital through TC, leading to the current study.

3.2 Qualitative Paradigm

The qualitative paradigm used in the current study was in line with its aims to obtain an in-depth understanding of complex experiences from the participant's

perspective (Harper & Thomsson, 2013). This differed from aims to establish causality between phenomena, or broader population trends, for which a quantitative methodology would have been more suitable (Roberts, 2014). In addition, whereas qualitative methodology aims to generate contextualised meaning, quantitative methodology is more reductive in nature and therefore risks simplifications of complex phenomena (Barker et al., 2015). In line with the aims of the current study, qualitative designs are also thought to be effective for the exploration of under-researched areas (Moriarty, 2011). Crucially, the design allows the centring of marginalised voices; exclusion of the rich, multifaceted perspectives of people with ID in research mirrors the broader “othering” forces in society (Beresford, 2013).

3.3 Revisiting the Epistemological Position

As outlined in section 1.4, the current study adopts a critical realist stance. From this position, the data collected was viewed as informative of the phenomenon being explored but not a direct reflection; as such, a layer of interpretation was required to access its underpinning structures (Willig, 2013). This included consideration of the underlying social and psychological constructs in participant accounts, as well as the experience and knowledge that I brought to the creation of the interpretations made in the analysis. As detailed in section 1.3, this includes, for example, assumptions based on my experience working with people with ID in clinical settings, such my sense of injustice around the adequacy provision for people with ID. This also includes my relationship with the concept of QoL, from the perspective of someone who does not have an ID (Appendix A).

In line with critical realism’s stance that knowledge is contextually situated, the researcher’s subjectivity was not viewed as problematic per se, as long it was

engaged with reflexively and appropriately scrutinised (Gough & Madill, 2012). To aid this, a reflective journal was kept throughout the research process (Appendices A, P and R), which allowed me to consider where my own viewpoint was being foregrounded in the research process (e.g., in analytic interpretations).

3.4 Choosing Thematic Analysis

A number of reasons underpinned the Thematic Analysis (TA) approach chosen in the current study. Firstly, the approach is suited to the current study's research questions, given their emphasis on a group's conceptualisation of experiences (Joffe, 2011). TA aims to identify patterns of meaning across the participants' experiences (Clarke & Braun, 2021); it was therefore considered to be more suitable than methodologies utilising idiographic approaches that provide in-depth analysis of individual experiences prior to making broader claims, such as Interpretive Phenomenological Analysis (IPA) (Smith & Fieldsend, 2021). IPA also requires rich verbal accounts from participants (Willig, 2013), which is exclusionary to some participants included in the current study, who speak less/describe things using fewer words or use ways of communicating other than speaking.

Further, IPA has a particular focus on amplifying the individual lived experience of participants, which involves 'stepping into participants' shoes' in order to produce deep, interpretative analysis (Smith & Fieldsend, 2021). Therefore, whilst important to many qualitative approaches, the researcher's observations and reflections relating to the rapport between the interviewer and interviewee, and the way in which things are said by participants, are particularly central to IPA (Smith & Fieldsend, 2021). Such observations and reflections are enhanced by having researchers who both collect and analyse the data, or through repeatedly listening to/watching data in addition to reading transcripts, to enhance complete immersion.

These means of analysis were not available in the current study as it used pre-collected data, and participant consent for the use of the data in subsequent studies/for secondary analysis limited the researcher to accessing written transcripts only. This provided further justification against using IPA in the current study.

Importantly, TA's flexibility in application enabled the analysis to offer both descriptive and interpretive accounts of the dataset that captured both semantic and latent meaning. This fit with the breadth of the study's research questions, which related to different aspects of the data. For instance, question one "*What experiences (e.g., events, relationships, activities) make up their everyday lives in the community?*" requires a more descriptive account, that is likely to capture a more semantic level of meaning. Whereas question two "*What aspects of everyday living enhance or undermine their QoL in the community?*" requires a more interpretive account of the data, that is likely to capture the underlying assumptions and meanings in the content (i.e., latent meaning). In addition, TA is theoretically flexible, and does not require the application of pre-existing theories in analysis (Clarke & Braun, 2021). This allowed for an inductive, data-driven approach, which was appropriate given the paucity of existing research and theory in the area studied.

The Grounded Theory approach used in the wider MPM study was thought to be less suited to the current study. This is because the study aimed to account for the rich, nuanced experiences of everyday living for participants, and placed less emphasis on processes within and between these components (e.g., change over time). The development of a model of processes and interactions between phenomena therefore fit less well (Charmaz, 2008).

3.5 Assessing Suitability for Secondary Analysis

Guidance suggests that primary qualitative data should be assessed for its potential to address the aims of secondary research (Heaton, 2004). Researchers have recommended that the data has relevant detail and sufficient depth in the area/s of interest (Charmaz, 2006; Hinds et al., 1997).

The original MPM dataset was considered to be suited to the research questions in the current study as the interviews included specific domains of enquiry that were sufficiently close to them (everyday life and impact on wellbeing, factors that sustain and undermine community living, the impact of the Coronavirus pandemic on everyday life/community living; see section 3.7.5 for examples of interview questions relating to these areas). Assessment of the data when preparing for secondary analysis (reading of interview transcripts, liaison with the primary research team), indicated that the data had the appropriate depth and relevance to allow for enquiry in relation to the current study's aims/research questions.

Recommendations for secondary analysis of qualitative data also suggest that data collection and analysis procedures in the primary dataset are 'similar' to those applied in secondary analysis, though not necessarily the same (Heaton, 2004). What constitutes as 'similar' is not specifically defined, though suggestions indicate that the theoretical and epistemological underpinnings of the studies' designs should not be incongruent (Heaton, 2004); for instance, the application of a constructionist framework for data collected within a positivist paradigm.

The original MPM study used grounded theory, which aims to produce a theory grounded in the data; this differed from the TA used in the current study, which aims to produce interpretations of the data, not a theory. However, the design of the two studies were deemed to have sufficient theoretical and epistemological

overlap to consider TA to be an appropriate fit for the secondary analysis of the original MPM dataset. Firstly, the methodology used in the original MPM study and current study both sought to generate and interpret broader patterns in the dataset, with a focus on a group's conceptualisation of an experience/phenomenon. Secondly, they both primarily used an inductive, data-driven approach, which did not apply existing theories to data analysis. In addition, both study designs adopted a relativist epistemological positioning, rooted in critical realism.

3.6 Participants

3.6.1 Recruitment.

Participants were identified and recruited through seven NHS commissioned services and one health and social care service in England. Participants were identified by a member of their local TC or clinical team. In addition, participants who had taken part in the research team's 'moving process' study (Head et al., 2018), and had consented to be approached for future research, were recruited. Recruitment strategies were tailored to participant communication needs (tailoring information and discussion of the study, having flexibility around how this is delivered- e.g., breaks, having support present).

Twenty-two participants were recruited in the first phase of the MPM study, through purposive sampling. Given the scope of the doctoral project, the current study used 19 interviews collected from 10 of these participants, which is in line with guidance on reasonable sample sizes for TA in 'small' projects (Fugard & Potts, 2015). This included the 10 participants who had spent the longest period of time in their previous hospital setting. This selection criterion was chosen as it fit the study's focus on people who had experienced relatively long stays in hospital. This is in line with the sub-group of people which TC most aimed to support; that

is, the discharge of people who had experienced inappropriately long stays in hospital (Department of Health, 2012).

3.6.2 Inclusion criteria.

People were eligible to participate in the core MPM study if they:

- Had a mild to moderate intellectual disability (to ensure they were more likely to have capacity to consent and take part in the interview process).
- Were over the age of 18
- Had capacity to give or withhold consent to participate in this study, as defined within the Mental Capacity Act (2007)
- At the time of recruitment, were under the care of a TC Team or Community Learning Disability Team
- Had moved from a mental health hospital setting into the community (either in a supported placement provided by private sector or social services or living independently) since the TC programme began in 2012.
- Had means of communication to participate in an interview. This could include verbal communication, Makaton, talking mats or a combination of methods.

The current study placed no additional inclusion/exclusion criteria, but selected participants who had spent the longest period in their previous hospital setting out of the MPM sample.

3.6.3 Participant Details.

See Table 4 for full participant details. Pseudonyms were used to maintain confidentiality Eight participants identified as male and 2 identified as female; all identified as White British. The participants ranged in age from 31-70 years (mean:

42 years; median: 40 years). Four participants moved from forensic mental health hospitals and 6 from mental health hospitals. The length of previous hospital stay ranged from 2-37 years (mean: 10 years 2 months; median: 6 years). To note, information on hospital stay was self-reported by the participant or (with consent) someone who knew them well (e.g., someone in their TC or clinical team); approximate estimates were given for some participants, and this was not corroborated with other sources (e.g., healthcare files). Time since move through TC ranged from 1-7 years (mean: 4 years; median 3.5 years). Nine participants lived in supported housing or residential care homes and one participant lived independently (without a support provider). Eight participants had full-time staff support, one had part-time staff support, and one did not have any external staff support.

Table 4.*Participant Details.*

Name	Gender	Age	Length of time in previous hospital setting	Type of setting prior to move through TC	Time since move through TC
Mark	Male	35-40	9 years	Forensic mental health hospital	2.5 years
Paul	Male	30-35	4 years	Forensic mental health hospital	4 years
Sabrina	Female	30-35	10 years	Mental health hospital	3 years
Max	Male	50-55	2 years 6 months	Mental health hospital	7 years
Pamela	Female	70-75	37 years	Mental health hospital	6 years
Clive	Male	40-45	3 years 4 months	Mental health hospital	6 years
George	Male	30-35	2 years	Forensic mental health hospital	7 years
Mick	Male	45-50	2 years	Forensic mental health hospital	1 year
Chris	Male	35-40	8 years 6 months	Mental health hospital	3 years
Gerry	Male	40-45	21 years	Mental health hospital	1 year

3.7 Data Collection

The current study used data collected (semi-structured interviews) from participants in the first time-point of the MPM study. These interviews were conducted between December 2020-April 2022.

3.7.1. Interview procedure.

Nine participants took part in two semi-structured interviews, held between 721 days apart. One participant took part in only one semi-structured interview, as they withdrew from the study following the first interview (but did not withdraw their data). All interviews were audio recorded and then transcribed and lasted between 32-80 minutes (mean length: 55 minutes).

The first interview was an individual interview with the participant. Participants could choose to have someone they knew well with them in the interview if it supported them, but all questions were directed to the participant. The second interview drew on the 'dyadic interview' technique (Caldwell, 2013) and was a joint interview with the participant and their 'Key Support Person' (KSP). The KSP was someone who knew the participant well, such as a family member or professional in their care team. The KSP's role was to support the participant to express their views, as opposed to share their own perspective.

The dyadic technique values interdependence in interviews (Caldwell, 2013), thus the rationale of using this was to enrich and deepen the data. Participants were therefore encouraged to involve a KSP, though this was not a participation requirement. Of the 9 participants that took part in a second interview, two chose not to involve a KSP.

In order to ensure the participants' voice was still centred in the data, "internalised other" interviewing, drawn from Karl Tomm's systemic therapy techniques (Mundry et al., 2016), was used in the second interview. In this, the KSP was asked similar questions to the participant, and were invited to answer 'as if' they were the participant, in order to develop key points in the interview. The power difference in the dyad (between the participant with ID and KSP) was considered and attempts were made in the interview to redress this. This included frequently asking the participant to comment on what the KSP has said and agree with or amend it.

It should be acknowledged that the difference in societal power held between the participant with ID and KSP may have increased socially desirable responses in the participant with ID. In this, it is important to highlight research that proposes that people with ID are no more at risk of 'acquiescence bias' in research interviews than people 'without ID' (Rapley & Antaki, 1996). Regardless, it can be argued that, due to the power differences in the KSP/participant dyad in the current study, demand responses may have been more likely; for example, due to participants' concerns about criticising services/care, through fear of losing it (Meeriman & Beail, 2009). For instance, the participant with ID may agree with what the KSP has said during the "internalised other" interviewing, regardless of the accuracy of the KSP's responses. Ways in which I accounted for this in data analysis are described in sub-section 3.10.2 of the Data Analysis section (3.10).

3.7.2 Adjustments in line with the Coronavirus Pandemic.

In line with government restrictions and/or UH guidelines, interviews conducted during times of risk in the pandemic were done remotely over telephone or video call. Where government and UH guidelines permitted,

participants could choose to hold the interview in person. Seven participants completed the interviews online, one completed the interviews via telephone, and two completed the interviews in person in their home.

3.7.3 Adaptations for research in the ID field.

A number of procedural techniques were considered in the interviews, to ensure they were adapted to the needs and preferences of each participant. These were made based on the individual participant, and discussions were had with the participant before the first interview to plan for this. This included the use of visual stimuli supplementary to verbal questions (Appendix D). Talking mats were also offered as a communication method, though no participants in the current study used these. In addition, questions were kept simple and adapted to facilitate understanding (Finlay & Lyons, 2001). For example, questions that involved sequencing events, which can be challenging for some people with ID (Ramcharan & Grant, 2001), were avoided.

3.7.4 Interview timings and the context of the Coronavirus pandemic.

The semi-structured interviews were conducted during various levels of restrictions and measures related to the Coronavirus pandemic. This context is important given the study's exploration of everyday living, and the potential impact measures and restrictions had on people's lives. Appendix E contextualises these interviews to key UK government Coronavirus lockdowns and measures in the time they were conducted, which is important to consider when situating the findings. As is shown in Appendix E, the majority of the interviews were conducted from January 2022 onwards, when social restrictions were no longer in place.

3.7.5 Interview topic guide.

The topic guide for the interviews (Appendix F) was designed by the core MPM research team. The same topic guide was used for both the participant who had moved and their KSP. In line with the broader Grounded Theory methodology adopted in the MPM study, questions were flexible and open to change, to allow for different aspects of a model to develop (Charmaz, 2008). However, the questions covered specific domains of enquiry that mapped onto the current study's aims, including:

1. **Everyday Experiences.** Potential questions included: *'What is a normal day like living here?'*, *'How much do you go out in the community?'* *'What do you value/like now?'*

2. **Factors that support and undermine community living and QoL.** Potential questions included: *'What helps you live here?'*, *'What does a good day look like?'*, *'What sort of problems have you faced living here?'*, *'Has anything helped you manage these problems?'*

3. **The impact of the Coronavirus pandemic on everyday living.** Potential questions included: *'Has your daily life changed due to [Covid]?''*, *'How much do you see your friends and family now? Has this changed since Covid?'*

3.8 Ethical Considerations

3.8.1 Ethical approval.

The MPM study has ethical approval from the Health Research Authority (HRA) and Hampstead Research Ethics Committee (REC) (Appendix G) and UH (Ethics Committee reference number: aLMS/PGR/NHS/02316(2)). The current study used pre-collected data from the MPM study and was in line with objectives and aims of the MPM study (i.e., did not alter the study in any way). In addition,

the participants in the current study had given verbal and written consent for their data to be used for subsequent research during the consent processes in the MPM study (Appendix H). As such, no further ethical approval was required. The research team consulted the UH Ethics Committee to see if further UH ethical approval was required for this study; it was confirmed that it was not (Appendix I).

3.8.2 Consent.

All consent procedures were carried out by the core MPM team. As above, during consent processes in the MPM study, all participants in the current study gave written and verbal consent for their data to be used in subsequent research studies.

Following identification, potential participants and/or their carer were contacted by the research team about the study, using an information sheet (Appendix J), and to begin assessing capacity and eligibility. A further meeting was held approximately 514 days following this initial meeting, to complete the capacity assessment and assess and establish consent. The delay between these meetings was designed to give the participants time to think and process the information and discuss with others if they wish. A 'Record for Assessing Consent' form (Appendix K), based on the work of Cameron and Murphy (2007), was used during the assessment of consent, to ensure that verbal and non-verbal cues were considered. Written and verbal consent was taken for the participant who had moved prior to the first interview (Appendix H). Verbal consent was taken for the participant who had moved at the beginning of the interview, and the KSP was given a study information sheet (Appendix L) and consent form (Appendix M) ahead of this.

3.8.3 Confidentiality.

Confidentiality and its limits were explained to participants during the initial consent processes and reiterated throughout the MPM study.

All MPM study data was stored on a university encrypted drive, accessible only to MPM research team. A unique Participant Identification Number (PIN) was generated for each MPM participant. For the current study, the researcher had access to the anonymised transcripts and relevant participant details of the included participants, stored under the PIN. These were accessed through the encrypted drive only.

3.8.4 Participant distress.

The topics covered in the study's interviews had the potential to be distressing to participants. To support this, the MPM research team developed a risk assessment and management plan, including idiosyncratic signs of distress and related support strategies, which was personalised as appropriate ahead of each interview.

3.9 Consultation with Experts by Experience

The core MPM research team, which designed the original grant application and are tasked with the delivery of the research, includes an EbE, who has contributed to all aspects of the design and delivery of the broader project. In addition, as part of the strategic set up of the MPM research, an EbE Consultation group (EECG) has been established, which members of the core research team meet with quarterly. The EECG is made up of people with various lived experience related to the project, all of whom have ID.

Insights from the EECG are shared as a standing agenda item with the MPM Steering Group which oversees the work. EECG insights and recommendations also feed into the decision-making process in the MPM

management group meetings. The EECG is organised and chaired by the core member of the MPM team who is themselves an EbE and the Steering group is also co-chaired by our EbE core team member. In the current study, these recommendations influenced the area researched, in addition to the areas included in the topic guide.

I also consulted with the EECG during the data analysis of the current study, during a 2-hour remote meeting. This enabled me to understand the developing themes from the position of someone with ID, which helped me to deepen my interpretation of the data (described further in section 2.6.4 below), as well as begin to make links with the potential implications of the data (Appendix N). Thought needed to be given to how to communicate the developing themes to people in a way that would be accessible to them; Appendix O gives some examples of what was presented.

MPM has also developed creative and responsive ways to disseminate research findings to people with ID and their carers. This includes a website coproduced with service-users and carers connected with the TC programme containing, for example, easier to read blogs on emerging findings in real-time. I am currently working with the MPM team and EECG to co-develop a blog on the current study for the website.

In my approach to consultation, I have remained mindful of the existing, sustained relationships and communities with EbEs in the broader MPM research programme. I have attempted to consult with the EECG in a way that respects the work that has gone before and will continue after me; for example, by avoiding creating disruption to the current ways the teams work with each other or forging new relationships with EbEs outside of the broader project, that cannot be

sustained. This approach has been informed by my experience of employing an EbE to co-develop aspects of the study in my originally developed Major Research Project, which taught me the time and resource needed to develop relationships and processes to adequately share power in the research process. For example, the time needed to develop ways of communicating tailored to the persons needs and preferences, and to develop relationships to safely discuss research topics which may be distressing to someone with lived experience of them.

3.10 Data Analysis

All 19 semi-structured interview transcripts were analysed using the six stages outlined by Braun and Clarke (2006; 2021). This included 10 transcripts from individual interviews and nine from the dyadic interviews. The method largely drew on the principles and guidance from Braun and Clarke's reflexive TA (Clarke & Braun, 2021). This iteration was chosen as it centres reflexivity as a resource for interpreting the data; this is line with the study's philosophical assumptions of the inescapable subjectivity of the researcher in the analytic process, and the need for its consideration in interpretations (Willig, 2013). However, as noted by many TA scholars (Braun & Clarke, 2021; Trainer & Bundon, 2020), specific TA approaches are not designed to give prescriptive and potentially restrictive 'recipes' for data analysis, but to offer a particular orientation to TA. Decisions on the specific aspects of the process (detailed below) were, therefore, informed by this reflexive TA orientation, as well as the broader aims of the study.

3.10.1 Phase one: familiarisation.

This stage involved developing close familiarity with the data ('immersion'). As I had not collected the data myself, this was a particularly important part of the

analysis. In this, I read and re-read the transcripts to get a sense of the broad content of the data as well as its diverse meaning, points of particular interest/significance and possible patterns, both in the dataset as a whole and individual data items. In addition, I engaged in active 'critical engagement' (Clarke & Braun, 2021) with the data, in which I reflexively questioned the data to begin to make sense of it from my own position (see Appendix P for examples of notes on this process).

Within this phase, I also made the decision to focus my analysis on aspects of the transcripts pertinent to my research aims and exclude analysis of content that only related to the broader aims of the MPM study. This included a focus of content related to participants' lives in the community, following their move through TC, as opposed to past experiences of hospital and experiences of the move from hospital (where these were not explicitly linked to their experience of community living following the move through TC). Whilst the analysis remained data-driven, this ensured analysis did not go beyond the scope of the current study. Inclusion and exclusion guides for this are found in Table 5.

Table 5.

Inclusion and exclusion guides for data analysis of the interview transcripts.

Content Included in Analysis	Content Excluded from Analysis
<ul style="list-style-type: none"> • Experiences of life in the community follow their move from hospital through TC. • Previous descriptions of hospital and moves from hospital, where the participant explicitly links this to their experience of community living following their move through TC (e.g., how relationships in hospital inform the way they related to people after their move). 	<ul style="list-style-type: none"> • Content about past experiences in hospital/the transition from hospital, that the participant does not link to their present experience of living in the community, including: <ul style="list-style-type: none"> ○ Experiences in hospital. ○ Experiences related to the transition from hospital/process of moving.

3.10.2 Phase two: data coding.

Following phase one, I coded each transcript in turn. This involved coding and developing coding labels for data pertinent to the study's research questions, as per the inclusion and exclusion guides in Table 5, using NVivo software (see Appendix Q for an excerpt of a coded transcript).

In the dyadic interviews, KSP responses were only included in analysis if participant both agreed and then further developed/elaborated a point the KSP had made. This was done to ensure the participant's voice was kept central in the analysis, and to account for the potential influence of power the KSP may have had in the interview (described in section 3.7.1). An example of this, taken from the coded excerpt included in Appendix Q, can be seen below:

Interviewer: *Yeah. Okay, so it's a bit about knowing that there's other people there for you, if you need them?*

KSP: *Yeah, I think so, and it's, it's nice to feel part of the community, so part of the, the street and the community.*

Interviewer: *[...] [KSP] said it was important to feel part of the community.*

Pamela: *Yeah, I feel that as well.*

Interviewer: *Say that again, sorry.*

Pamela: *I said I - I agree, I feel the same; I feel I belong. [...] It felt really good, because, er, I could go and - I can go to them if I need any, any help-...*

In this extract, the participant's follow up "*I belong*" adds nuance to the point the KSP has previously made, which the participant then follows up with a more in-depth explanation. This was therefore included in the data analysis.

KSP responses were not included in analysis if the participant simply indicated agreement without this development/elaboration; such as, said "yes" and then went on to speak about something different/make a different point to what the KSP has just made. For example:

"KSP: I like the park, don't we Clive?."

Clive: Yes. Do you like coke?"

In addition, KSP responses were not coded if the participant disagreed with or amended the point the KSP has just made.

As per the theoretical reasons outlined in section 3.4, an inductive data-driven stance was taken, in which latent and semantic codes were developed. Codes were

frequently reviewed through the process, and duplicated codes were removed/codes that were not distinct were collapsed. Use of my reflective diary and conversations with my supervisory team enabled me to reflect on the reasons I was drawn to specific aspects of the data and the positions I was taking to frame the codes/code labels (see Appendix R for an example of this process).

3.10.3. Phase three: generating initial themes.

In this phase I 'stepped back' from the data and began to cluster the codes, based on initial patterns I saw in the data. From these clusters, I constructed initial themes and sub-themes. As per Braun and Clarke's (2021) guidance, these were based on my in-depth knowledge of the data, gleaned from the prior two phases, as well as the data codes themselves. A list of initial themes can be found in Appendix S.

3.10.3. Phase four: developing and reviewing themes.

This phase involved iterative processes, running alongside each other, that aided the progression from initial themes towards final themes; full details of these can be found in Table 6. The development of various thematic maps through this stage can be found in Appendix T.

Table 6.*Processes of Developing and Reviewing Themes.*

Process	Details of specific actions with supporting examples
1. <i>Returning to the main dataset</i>	<p>I reviewed my initial tentative themes against the coded data and full interview transcripts, checking they 1) each captured multiple facets of a (distinct) centralised concept and 2) captured the diverse nuances of the full dataset (Braun & Clarke, 2021).</p>
2. <i>Supervisory conversations</i>	<p>Conversations with supervisory team deepened my ability to sharpen the boundaries of distinct themes, whilst recognising connections between them, and considering important meanings I had left out. For instance, my initial themes largely centred around life-enhancing concepts of community living, such as ‘freedom’, leaving out the nuance of how past experiences/restrictions continued to place limits on people’s lives. I reflected that I may be being drawn to “stories of success” in the data and neglecting “stories of continued struggle” (Appendix T). This prompted me to return to the codes and make sense of patterns of ‘continued restriction’ in the data.</p>
3. <i>Consultation with the EECG</i>	<p>One key influence was the EbEs’ ideas around my original conceptualisations in the theme ‘The Value of Freedom’. The EbEs deepened my understanding of the idea that this ‘freedom’ was not necessarily related to doing things by yourself or without the influence of others and could be related to having choice about how you do things. I went back to the codes and dataset and recognised a pattern of data that fit more with concepts of autonomy (i.e., having choice/control about the way you live) than individualised concepts of independence (i.e., not needing or valuing help and care from others). This also deepened my understanding of the connections between the theme around ‘autonomy’ and theme around ‘The Value of Supportive Relationships’</p>

3.10.4 Phases five and six: refining, defining, naming themes and writing up.

This involved the fine tuning of themes, which continued throughout the writing up of the rich descriptions of each theme (found in the Analysis section below). I began this process by creating a synopsis of each theme, to ensure they had appropriate distinctions and boundaries.

3.10.5 A Note on theme conceptualisation.

Of note, two types of theme conceptualisations were used in the study, guided by its aims. The key distinction between these is that one brings together areas repeatedly spoken about, whereas the other unifies patterns of shared meaning (Clarke & Braun, 2021).

Themes relating to broad ways in which participants spent their everyday lives were developed (included in sub-section 4.2- 'How Everyday Life is Spent'). These themes captured "the diversity of responses to a topic, issue or area of the data repeatedly spoken about" (Braun & Clarke, 2021, p. 230). These themes functioned more as summaries of areas of life (e.g., events) patterned in the data, thus are more in line with what Clarke and Braun (2021) refer to as 'topic summaries' in reflexive TA. A decision was made to conceptualise and present these themes in this way as it provided important descriptive context around how people generally spent their lives, which is particularly warranted given the stark lack of literature and public coverage of the lives of this group of people (i.e., people with ID who have moved out of hospital) (Braden & Williams, 2017; Head et al., 2018). Understanding how participants spent their everyday lives provided context for the more interpretative understanding of the meaning given to these

day-to-day experiences, which is spoken to in the themes generated in sub-section 4.3- 'How Everyday Life is Experienced'. Themes in this sub-section were conceptualised as “patterns of shared meaning underpinned by a central organising concept” (Braun & Clarke, p.230).

3.10.6 Reflections on completing secondary analysis.

I experienced a number of limitations associated with completing secondary analysis on pre-collected data in the current study. Firstly, as I did not complete the interviews myself, and was unable to listen to audio recordings of the interviews, some of the nuance in meaning in the interviews may have been lost in my interpretations (e.g., the first-hand experience of the way things were said and the interpreted intended meaning). This is in line with concerns raised by researchers around the application of secondary analysis to qualitative data, who have noted the limitations associated with the secondary researcher's ability to grasp the context in which the data was generated, making it difficult for them to make contextually embedded interpretations (Blommaert, 2001).

However, I was able to have regular access to the primary research team who collected the data throughout data analysis, which allowed for consultation around the contextual meaning of the transcripts. This also gave me access memos/reflections made by the primary research team during data collection, which supported my reading and understanding of the transcripts and enabled me to better contextualise my interpretations. For instance, helped me to understand what the context may have been for participants who used fewer words to answer questions (e.g., whether this may have related to communication ability/differences, lack of

interest/enthusiasm about the questioned topic, and/or nervousness during the interview).

Whilst the topic guide used for the semi-structured interviews mapped onto the current study's domains of interest, it was not specifically designed for its research questions. As such, the interviewers' questions/follow up prompts did not always tap into the current study's areas of interest in the level of detail/nuance that may have been possible if data had primarily been collected for the current study (e.g., specific details of everyday relationships, such as the nature/meaning of friendships; the more precise impacts of the Coronavirus pandemic on participant's lives).

However, there were some benefits of completing secondary analysis within the scope of a doctoral major research project. This included the opportunity to analyse data from two interviews per participant (on individual, one 'dyadic'), which served to enrich and deepen the data (through capturing the interdependence present in participant's lives). This procedure is likely to have been less realistic in the time-frame of a doctoral project.

In addition, the current study benefitted from to the existing, sustained relationships between the MPM research team and EbE consultation group, which allowed for people to know each other well, and support each other's preferred working and communication styles. For example, members of the core research team, who had close working relationships with the EbEs, were present during my data analysis consultation session, and were therefore able to facilitate supporting the EbEs within this (e.g., supporting communication, where helpful).

However, this existing consultation set-up restricted some of the ways in which I may have conducted EbE involvement in within a study, based on learnings from co-

production projects within the ID community (e.g., Chapko et al., 2021). I feel the work with EbEs around the study's design would have benefitted from a move to a co-production model, differing to the consultation model existing within the MPM study, in order to better share power between 'academic' researchers and researchers with lived experience. This would have included the generation of study ideas and research questions from and with researchers with lived experience at the point of the study's inception, as opposed to consultation within a research programme originally designed by academic researchers.

4. Results

4.1 Overview

As described in the previous section, the results are presented in two sections, which speak to different but related aspects of participants' lives. This includes: 1) How Everyday Life is Spent, and 2) How Everyday Life is Experienced (i.e., the deeper meaning given to these experiences). These sections build on and complement each other, providing a rich description of participants' everyday lives.

4.2 Section One- How Everyday Life is Spent

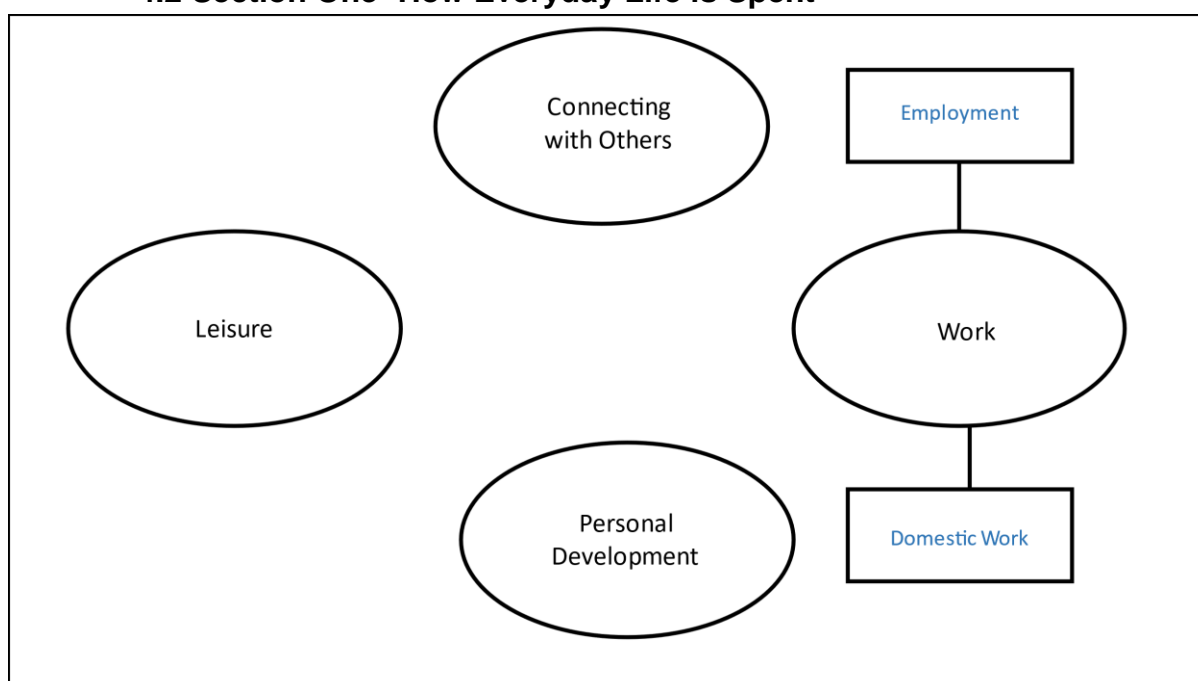


Figure 2. Thematic map of 4 themes and 2 sub-themes relating to how participants spend their everyday lives.

Note: Main themes are represented by ovals and sub-themes by rectangles.

4.2.1 Theme one- Leisure.

Participants spoke about a range of things they did out of interest and/or for fun, outside of other daily responsibilities. These appeared to be chosen by the participant; however, there seemed to be some variation in the degree of flexibility

around this choice (i.e., the extent to which these were initiated by the participants themselves).

Most activities described seemed to be led by the participants' own interests and were often instigated by them. These included home-based activities such as watching films and TV, listening to music, playing video games, crocheting, and cooking or baking. This also included regular hobbies done out of the house, such as going to the gym, playing sport in a sports club, and going to bingo. In addition, walks in participants' local area, and shopping in local shops, were also described as things done for enjoyment. Days out to visit places and things they were interested in were also spoken about by participants, including car racing tracks, seaside resorts, and sports stadiums.

Some participants living in residential care homes described doing activities with their house or a group from their home in a way that gave the impression these were based on group consensus or chosen from a range of activities offered to them. Importantly, participants did not indicate that they felt restricted by choosing things in this way:

Interviewer: [...] So do you get to choose where you go on your days out?

Mick: Yeah...You plan in the house, and we just go out, like, in a group...Like, the cinema, or things like that.

...

Gerry: I've got nothing on Monday.

Interviewer: Yeah.

Gerry: Only bowling or golf.

Interviewer: Bowling and golf?

Gerry: *I can do both.*

Interviewer: *Oh, okay, yeah. Yeah.*

Gerry: *Bowling and golf, or pool.*

Interviewer: *Oh, okay. So you get to choose? Yeah.*

Gerry: *This Monday coming, I'll be doing bowling.*

Some participants shared how they had adapted their leisure activities in line with social restrictions related to the Coronavirus pandemic. For instance, Clive and his KSP shared that he had gone to the park instead of bowling when indoor Coronavirus restrictions were in place. Paul spoke about doing activities in the house instead of going out, including colouring and baking. Interestingly, for Paul, needing to stay in for activities did not appear to impact his wellbeing:

“Interviewer: Yeah, was it difficult? Like, how did it feel when you couldn't go out as much?”

Paul: It was all right, I just - I just chilled and stayed in my room.”

Others spoke about how they continued to not do some of the activities they enjoyed, even after government restrictions had been lifted. For instance, Sabrina shared how she had chosen to not go clubbing or to pubs, due to concerns about contracting Coronavirus, which she explained were linked to her worries about her own health vulnerability. For Max, the previous restrictions in Coronavirus pandemic had impacted his confidence to do things in the present:

Because – because of with Covid, that you can't do the things what you want to really do, and some, sometimes you lose your confidence... It's like, I used to go to [city in home county] every Sunday, but I haven't been

to [city in home county] for ages, and because you lose your co-...

Because sometimes you lose your confidence.

[...] Interviewer: Oh, okay, so you – so because you haven't been able to go places very much, you'd feel like...? Yeah.

Max: No, we know when that – we know that we can still go ... But we have lost a bit of that enthusiasm.

However, some participants indicated that the Coronavirus pandemic had not had long-term impacts on their leisure activities. For instance, in an interview conducted when social restrictions had been lifted (January 2022), Chris shared:

Interviewer: [...] So have you still been able to go out and do everything that you want, even in Covid?

Chris: Er, yeah.

Interviewer: Yeah. Yeah.

Chris: Yeah, and now - now, er, the second lockdown has lifted. [...] Er, and it's been lifted for a while now, yeah, I've been, I've been... I've been - I've wandered downtown.

4.2.2 Theme two- Work.

4.2.2.1 Sub-theme one- Employment.

One participant discussed having paid employment, two shared that they were in voluntary employment in charity shops, and one spoke about working one day a week (thought it was unclear whether this was voluntary or paid).

Participants seemed to be satisfied with their jobs and discussed the benefits of being employed. For George, this included the pride of earning his own money and being more financially stable:

To be able to afford it, and just be able to buy my own stuff means a lot, like, like I've gone through some stages in my life with having no money and being, erm, sort of in a bad way, like not being able to get work. So being able to have money is like, erm, like I'm quite proud of it.

Some participants valued opportunities to connect with new people at work, including their colleagues and the public. They discussed how employment provided opportunities to socialise and make new friends; for instance, Mick shared: *“And it's good there [workplace], and you can make friends there”*.

Both those in voluntary employment expressed their desire to get paid work; Sabrina viewed her voluntary role as a steppingstone towards future paid employment. Mick spoke about how he wanted to work more days; his KSP shared that his working days had reduced after the Coronavirus pandemic.

4.2.2.2 Sub-theme two- Domestic Work

Almost all participants discussed doing domestic work as part of their daily lives, including cooking, cleaning and grocery shopping. Some participants spoke about doing this for themselves, by themselves. Others shared how they do these things with staff, to varying degrees, which seemed to depend on their ability in the area. Most participant descriptions suggested that they were involved in this type of work, and that staff were not doing this for them:

Max: *Yes, because I try and do my best before the staff comes, so I s-, I strip my bed and I put my pillowcases on. [...] And all the staff needed to do is the actual duvet cover,*

Clive: *Do - do you know how to make a cup of tea?*

Interviewer: *I do, yeah. Do you know how to make a cup of tea?*

Clive: *Yeah.*

Interviewer: *Do you do it all on your own?*

Clive: *No, somebody helps me.*

4.2.3 Theme three- Personal Development.

This theme consists of activities which participants discussed pursuing in order to progress or develop their own lives. Some participants discussed doing things to develop their skills. For instance, Mark and George spoke about attending formal educational courses in college. Gerry shared ways in which he practiced developing his writing:

Interviewer: *Erm, yes, you were going to get a book with bigger print from the library, are you, today?*

Gerry: *Yeah.*

Interviewer: *Is that something you like doing, reading?*

Gerry: *And then once I've finished reading it, I write the story out.*

I: *Oh right, okay.*

Gerry: *Practise my handwriting.*

George discussed his self-drive to achieve fitness targets and goals, which seemed to help him stay on what he felt was a more positive path for him:

Yeah, and like I research stuff to sort of like enhance it, and like be like so it gives you a point. Instead of thinking, do you know what? I'm going to stay up tonight, and drink loads of alcohol and, erm, and watch TV. It's like, no, I'm going to get an early night tonight, because I'm thinking of the gains, which like is progress, like muscle mass and stuff like that. [...] It sort of gives you a sense of belonging to do the right thing.

4.2.4 Theme four- Connecting with Others.

Connecting with others- namely family, friends and staff- was an important part of daily life for participants. The themes described in Section Two give further detail on the ways in which these connections were experienced by participants, and the meaning they had in their everyday lives.

A number of participants described seeing family on a regular basis. For some, moving closer to family following their discharge from out-of-area hospitals (i.e., hospital stays away out of the region they called home) was really important to them: *"It means everything to me, you know, knowing that I've got them [family] nearby."* (Mark).

Others spoke about the importance of having regular contact with family; for instance, when asked what had helped her to stay living in her home, Pamela shared: *"I can phone them any - I can phone [brother] any time I want, and so can I, so I can phone [other brother] any time and just have a chat, you know what I mean?"*.

Socialising and sharing interests with friends also seemed to be important to many participants. They discussed friendships from a number of contexts, including through their service provider (e.g., people in the same home/organisation as them), from hospital, from early life (e.g., school friends), and through their local community (e.g., neighbours). Some participants spoke about meeting and seeing friends in more organised settings, such as community centres or sports clubs; some discussed meeting up with friends through what appeared to be less organised/formal networks, such as going round their houses, meeting for coffee or going out for meals; and some described socialising with friends from their residential care home outside of the home (e.g., going to sports matches together).

One participant said they had a current boyfriend, who they did not live with but were in contact with over the telephone (during Covid restrictions), and another spoke about a past romantic relationship that didn't work out. Two other participants discussed wanting to find a romantic partners: Mark spoke about plans to be set up on a date with someone who had an learning disability, and George shared his hopes of having a wife and family.

Many participants spoke about spending time connecting with support staff in a way that was social in nature, such as sharing interests with them (e.g., talking about music, playing golf). A few participants referred to staff as "*friends*" or "*family*" suggesting that their relationship with them transcended 'professional' support and care. For instance, Paul classed staff and residents in his home as family, suggesting the significance of these bonds to him: "*[...] I don't see my family, because I've got my family here [in the residential care home]*".

Participants spoke about not being able to see others during the Coronavirus pandemic. This was mostly spoken about in terms of not being able to see family members, in relation to social restrictions. In addition, when asked, Pamela shared that she had not met up with her friends, even when restrictions allowed some social contact, as she had received a “*letter*” advising her not to meet in big crowds due to her health. Interestingly, no participants described using remote technology to see/socialise with others.

Some participants shared how not seeing family during government-imposed restrictions during the pandemic had been emotionally difficult for them. For instance, in an interview conducted after restrictions had been lifted, Mick described: “*I got a bit sad about it [not seeing family], but I’ve got through it*”. Sabrina shared the loneliness she experienced:

Sabrina’s KSP, speaking as Sabrina: *And - and I felt lonely.*

Sabrina: *Yes, very lonely.*

Sabrina’s KSP, speaking as Sabrina: *In Covid. Even though I had my support with me, it still made me feel really lonely.*

Sabrina: *Yeah.*

4.3 Section Two- How Everyday Life is Experienced

The thematic map (Figure 3) represents the six main themes and one subtheme conceptualised from the data, which relate to the meaning participants gave to their everyday experiences. ‘The Value of Autonomy’ and ‘The Continued Impact of Hospital’ relate to experiences of freedom and restriction in participants’

current lives. 'The Value of Supportive Relationships', 'Safety through Support', and 'Feeling Included' relate to the broader importance of relationships and connections with others, most notably staff, in participants' lives. The main themes 'Being Included' and 'The Importance of Giving to Others' and sub-theme 'Feeling Equal to Staff' all speak to a broader notion of social participation and inclusion. All of these themes, and the connections between them, are explored in more detail in the subsections below.

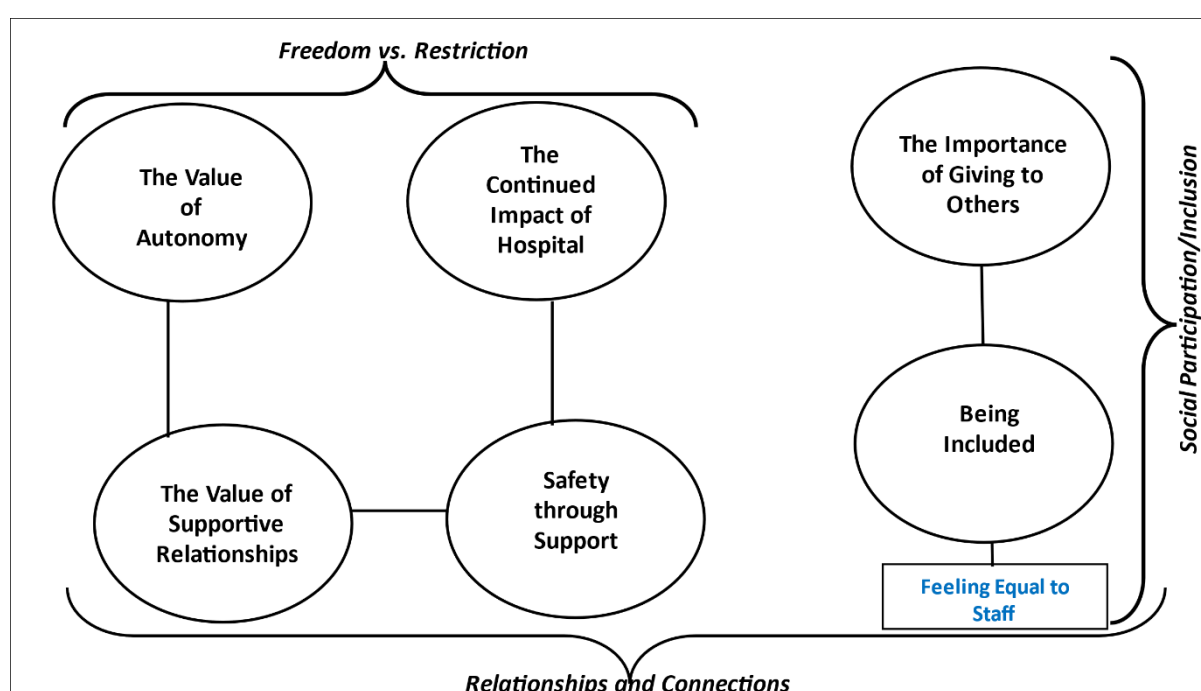


Figure 3. Thematic map of six themes and one sub-theme relating to the meaning given to everyday experiences.

Note. Main themes are represented by ovals and sub-themes by rectangles. Connections between themes are shown using solid lines.

4.3.1 Theme one- The Value of Autonomy.

This theme speaks to positive impacts of having choice and control in a range of areas associated with daily life (e.g., domestic work, socialising with others). This was often contrasted with the lack of autonomy people experienced during their time in hospital.

The absence of restrictions in the community seemed to create opportunities that enabled people to have greater choice and control. For instance, Mark spoke to the positive experience of being allowed to do activities by himself after being discharged from his Community Treatment Order² (CTO); the reference to this shift in independence as a “*big step*” indicates the magnitude of the impact of this change on his life:

And, erm, and then going out, erm, having the choice and the freedom to do, you know, things myself and what I'd like to do. And go out and go shopping, erm, food shopping and stuff like that and, erm, go to the supermarkets by myself and, erm, and go and see my family by myself as well. And - and that's kind of like a big, erm, a big step for me and it's, like, it gives me all that freedom as well.

In line with this, Chris expressed the positives of his newfound independence following his move, which he seemed to express with pride:

Yeah, and I am a most able person who is living in [residential care home], that do things for them, for themselves. [...] I do. Yeah, I do my own cooking, and my own laundry, er, cleaning. [...] Yeah, I literally, I do it, and I do everything for myself [...] And when I was at [Hospital], I, erm, I don't do hardly anything... Hardly anything, er, for myself.

George shared his goal of becoming independent from support from professionals:

“my target of just getting completely independent and doing everything for myself,

² A CTO is an order made by a Responsible Clinician in hospital, which allows support for mental health difficulties to happen in the home instead of hospital. It comes with additional conditions that must be followed (e.g., living in certain places). If deemed necessary, the Responsible Clinician can recall a person for immediate treatment in hospital (Weich et al., 2018).

and don't need any intervening, and by medical staff'. Interestingly, when asked if anything had changed for him since the Coronavirus pandemic, he shared: *"Mm. No. ... Still the same. Just still working for the same targets [towards independence]"*, suggesting that the pandemic had not disrupted goals that were important to him.

Some participants referred to themselves as being or feeling like an adult when discussing the increased autonomy in their lives out of hospital, implying that this enabled them to experience adult social status (i.e., an adult social role):

You feel like an adult, ...because you can speak your own mind, you can - like Pamela two [KSP] said - you can have a meal when you want, you can have a drink when you want, you don't have to eat all your food. (Pamela)

But like still now, I love it, like I just love being able to just being a responsible adult, and being able to make my own decisions without someone else getting involved in it. It's like, yeah, it's nice. (George).

Participants indicated the value of being able to make choices based on their own preferences, as opposed to being treated and processed as part of a group: *"I can choose what I want...what meal I want. I don't have to have the same as everybody else. ... I don't have to have horrible food from the hospital, ... I can choose what I want"* (Pamela).

In line with this, a number of participants spoke to the importance of being able to *"speak up"* or speak their own mind, which seemed to relate to opportunities to advocate for themselves, based on their own views and preferences. Some spoke proudly about how they had been able to let staff or professionals know that services weren't meeting their needs, as seen in Gerry's interaction with a healthcare professional:

Gerry: [...]and then she [healthcare professional] was getting a bit bossy. [...] I didn't like the way she put things. [...] And then I explained I didn't like it and she said, why is that? And I said, you're a bit bossy and around my way I put my food, that gets me through. [...] And what food I need, and all that sort of thing.

Interviewer: Yeah, and what did she say when you said it's a bit bossy?

Gerry: She says, I'm trying to help. I know you are, but you're not helping, you're hindering.

Some participants were clear that the way they were treated in hospital or other support services restricted their ability to speak up for themselves (e.g., staff not listening to their views, the impacts of previous medication). They spoke to how factors in the community, namely staff that heard and valued their views, supported them to express and evoke change for themselves. In these accounts, staff support facilitated people's autonomy, therefore links exist between this theme and theme three- 'The Value of Supportive Relationships'. For example:

Yes, because, erm, in our company, our manager likes to - not for the support people to speak up, she would like to find out, erm, if we've got a problem, then she says, erm, she says, ... right, and like I had a... Like I had a - like I had a problem last week, and so I said to the, the deputy manager, I said, erm, I've got this problem. And instead of my support worker speaking, my support worker let me speak to a person who I want to speak to. (Max)

4.3.2 Theme two- The Continued Impact of Hospital.

This theme encapsulates the social and psychological impact that past hospital stays had on participants' lives, beyond discharge. It speaks to the longer-term restrictive impact of experiences in hospital on peoples' lives, as well as the impact of having an identity as someone who has been in hospital.

Some participants' accounts were characterised by experiences of continued (internalised) restriction juxtaposed with increased external "*freedom*". For instance, some described a continued feeling of unsafety linked to past experiences in hospital, despite developing trusting relationships with staff teams and having more positive experiences (e.g., increased privacy and autonomy) in their current homes. For instance, after describing experiences with "*really violent people*" in hospital, Max shared the fragility of his feelings of safety in his current home:

"Interviewer: [...] So do you feel safe where you live now?"

Max: Sometimes I feel safe, yes.

Interviewer: Yeah.

Max: Yeah, but it's [experience in hospital] always in the back of your mind."

Some participants seemed to experience a continued sense of threat related to being readmitted to hospital. This appeared to give some a sense that their place in the community was fragile. Pamela alluded to this when describing how she had feared becoming stuck/left in hospital when she visited general hospital for physical health appointments. This fear seemed to have been exacerbated in a visit during the Coronavirus pandemic, when her staff could not be with her (due to restrictions). She indicated that this had been a traumatic experience for her: "*I*

felt frightened that I was going to go somewhere else. And they were saying I was getting admitted in hospital, but it was... I don't know, it was just something come back on me". In this part of her account, it was indicated that her relationships with staff created psychological safety that usually helped to mitigate this sense of threat: *"I felt a bit scared, because I couldn't see them [staff]"*, which links to Theme Four- 'Safety through Support'.

There seemed to be a particular sense of fragility around "*freedom*" in the community for some participants who had moved from forensic hospital settings, including a heightened awareness of possible hospital readmission. These beliefs were not unfounded, as many were on/had been on CTOs that imposed continued restrictions and made immediate hospital recall (if deemed necessary) a possibility. The challenges of living with this awareness were indicated:

Interviewer: *[...] if you had to say to anyone, is there anything that's made it more difficult to live in the community, is there anything?*

Mark: *I think what's made it difficult, is knowing that, you know, if you, erm, start playing up and if you start misbehaving and then, you know, and then it's going to look bad on yourself. And then if you get trouble with the police and then, you know, the more that happens and the more likely you might get recalled back to hospital.*

Here, the infantilising language Mark uses to describe his behaviour is striking ("*playing up*"; "*misbehaving*"), and perhaps speaks to narratives he has developed about himself in services/society at large, in which adult status is often denied to people with ID.

Past experiences of restricted choice and control in hospital seemed to impact some participants' relationship with autonomy in their current lives, even when restrictions were no longer in place for them. Pamela's description of the impact of the Covid restrictions on her life indicates how she has been accustomed to restricted autonomy. When asked if she misses going out (due to Covid restrictions), she responded:

Pamela: Not really. I DO, but, really and truly, I'm so used to it, being when I've been in hospital, you know, shut up, so I'm sort of used to it, I suppose. I do miss going out, yeah.

Interviewer: I see what you mean. So you're – you've had lots of experiences of not being able to go out and do your own thing.

Pamela: Yeah. Yeah.

Interviewer: So it's not a big shock?

Pamela: No.

Sabrina spoke about not wanting to have control over decisions about her money, despite having capacity: "*I want no capacity of my money*". This seems to relate to a fear that she will make "*bad decisions*" about it:

Sabrina's KSP, speaking as Sabrina: I feel it would be easier for my support to make those choices for me and to control that, because then I'm not tempted to make bad choices and bad decisions.

Sabrina: Yeah, that's it. That's it, yeah

Though Sabrina does not explicitly speak about what has led to her concern around making "*bad decisions*", in other parts of the interview, she speaks to

missing out on learning experiences during her (10 year) stay in hospital, through her teenage years. It could therefore be tentatively hypothesised that a lack of previous autonomy in managing her own money (which is likely to be more monitored in hospital) has led to an internalised belief that she is unable to make 'good' decisions around this.

The stigma of being someone who has spent time in hospital seemed to be present in some participants' lives. George described his choice to hide that he has been in hospital to people (to "*leave it in the past*"), after experiencing negative reactions to this, including "*horrified*" reactions from past girlfriends. His account indicated that this continues to impact his ability to trust and get close to people:

Interviewer: *Yeah, and so do you think - has that [people's reactions to him being in a mental health hospital] affected sort of trust in people, do you think?*

George: *Yeah, it has. Yeah. Yeah, definitely.*

Interviewer: *Yeah*

George: *I try, but I've just sort of - it make, it makes life harder, yeah, definitely.*

Interviewer: *Yeah. Yeah, in what way?*

George: *Just interacting with people, innit? It's just - it's just taking relationships to a different level, innit? And stuff like that you're just sort of always - and, in some respects, you've learnt from it, and it's made me a much [INAUDIBLE] person. But then, in some ways, it's, it's sort of it... It makes life harder.*

4.3.3 Theme three- The Value of Supportive Relationships.

This theme speaks to the importance of supportive relationships in participants' lives, which was mostly spoken about in terms of staff support. Here collaborative, enabling support was valued, in which staff did things with people to help them to learn new skills and try new things, face difficulties, and make decisions. In some instances, this type of support seemed to enable people to have more autonomy in their lives, thus links exist between this theme and Theme One- 'The Value of Autonomy'.

Some participants depicted staff as guides that helped them to adjust to life outside of hospital, by sharing knowledge and modelling skills they felt they had missed out on during their hospital stay: *"They're teaching me life skills, as I still grow, grow, because I've missed my teenage years being in hospital, they're still teaching me things that I never knew, ... you know?"*.

Sabrina gives an example of this by describing how her support staff used an opportunity during a supermarket trip with her model choosing cheaper items, teaching her skills to budget her money. In addition, Pamela shared how she sought advice from staff when choosing the paint and wallpaper for her home, as she had not done this in hospital. This guidance appeared to enable participants to begin to make decisions more autonomously; for instance, Pamela shared how the advice helped come to her own decision: *"but, in the end, I chose it myself"*.

In line with this, Chris appreciated staff working with him collaboratively to help him think through decisions, in a way that still allowed him to be in control of the overall decision. He contrasted this with less helpful experiences in hospital, where this control was taken away:

And when I was - when I asked advice, when I was in [Hospital], they would say, no. No, you're not allowed to do that. No. No. No, you can't do this, you can't do that. [...] In here [current support service], erm, they have said to me, is that wise for you to do this? [...] Or is it wise to do the - do that? [...] And think of the logic of if you - if you want to do that.

For some participants, the encouragement of others supported them be more independent in trying new things or doing things by themselves. For instance, Max shared how reassurance from his sister helped him to build his confidence (which had been impacted by the Coronavirus pandemic restrictions) to go to places independently. Paul described the value of support approaches in which he was set tasks to help him to gradually get used to going to the local shops by himself. Here, the belief staff had in Paul seemed to help him to develop the confidence to gradually do new things:

Paul's KSP, speaking as Paul: I think it, it helps me to believe in myself, what I can do, because staff push me to limits that I can do, and they know I can do. And when I don't believe in myself, they, they put that belief there.

When asked about what it meant for staff to believe in him, Paul added: *"It means they are kind of believing in me. [...] Get more comfortable, when they're believing in me, yeah.*

Interviewer: *Oh, okay, so you feel like that's helped you have more confidence?*

Paul: *Yeah."*

In addition, some participants shared how staff support helped them with difficulties with their wellbeing and mental health. Descriptions of this indicated

that having people to face these problems with was helpful. For instance, Max appreciated staff instigating conversations about his wellbeing. Mark discussed the value of being able to approach staff when he needed to:

And I think there's - I think there's so much, erm, there's so much I can, I can do with my life and, erm, and I think by talking about it and, and not keeping it inside. I think it just takes that few seconds to go out and just say to my member of staff, like, I'm not feeling too good, or I'm having a bit of a down day, and then can I talk to you? And then I go and talk to them.

Participants also indicated the value of different people in their lives working together to support them, such as community health teams and social care staff, or professionals and family members. For instance, Mick shared how it was important to him for information to be shared between staff and his family, to support him when he faced difficulties:

If there's any problems, then [staff] ring my family up and talk to them about it. If they don't know, there's always my family there to back them up, and see what, what, what is going wrong. [...] That's how I want them to do, you know what I mean? To make sure everybody is on the same line, you know what I mean? [...] And, like, not, not just my family, but staff-wise lets my mum know what, what, what is going on here.

Here, the phrase “to make sure everybody is on the same line” suggests the importance of family and professionals being unified in their approach to Mick.

4.3.4 Theme four- Safety through Support.

This theme speaks to aspects of support that seem to build participants sense of relational safety. In this context, relational safety refers to the psychological safety and emotional containment created through relationships with support staff. There seemed to be an interaction between experiences of safety and containment in relationships and the presence or absence of behaviour related to distress (e.g., self-harm, aggression).

Being able to trust staff, as well as feeling trusted, heard and taken seriously by staff, seemed to create psychological safety for participants. This was often contrasted with experiences of dishonesty and secrets during participants' hospital stay. For instance, when prompted about how her staff team show they care, Sabrina shared:

They just tell me the truth...they're honest. Because we are like a big family, where everyone knows everything. Everybody knows what's going on. Everybody gets together, and they talk about things, and it's, you know, it's much better than being in hospital, and it's much... And I also feel much better, because everybody's talking and it's all on the table, so there's no secrets.

Participants also alluded to experiences of emotional containment in relationships with people supporting them, where their communication was listened to, held, and taken seriously by others. For instance, Pamela shared how professionals, including her support staff and counsellor, “*listen to*”, “*believe*” and “*understand*” her. She spoke about how she used to hurt herself in hospital, because of the absence of these experiences. For instance, when comparing her current experiences of being listened to with past experiences in hospital, she shared:

It just felt - people would listen to me, and when I used to do that in other places where I can try, I used to hurt myself. And I think the reason is, because people didn't listen to me, or they didn't trust me.

Here, it could be hypothesised that the safety she experiences in the relationships with professionals now supports her to manage her distress, meaning she no longer manages this by hurting herself.

Max described variation within in his staff team between those who would listen to him, indicating how valuable relationships in which he felt heard were to him:

Max: And, like, if we talked to other members of staff, then he, he listens to what the customers has, has to actually say. But the other member of staff, she gives us a... She - she gives us a telling off... [...]...but, but when we go to... Well, when we go to this young man, he actually listens to the reason.

Interviewer: Oh, okay, so this guy has been really helpful because he listens to you?

Max: Yeah, he, he actually - he actually listens to us.

Here, Max's use and repetition of "actually" indicates the sincerity he experiences in his staff member's approach to listening to him, which he seems to find particularly supportive.

Consistency in staff support also appeared to create containing relationships. Here, participants depicted the value of staff continuity, which allowed people to get to know them well and therefore support them in a way that centred their needs:

“Yeah, it's very important that staff are here a long time, so they know me.”

(Paul);

Interviewer: *And so, yeah, how does it help, erm, when you have staff that know you really well?*

Max: *Erm, staff can tell when I'm depressed, staff can tell if I'm not happy and, erm, and I don't have to tell the staff all the time, but they can tell by my voice or they can tell by my looks and that.* (Max);

They're [the staff are] helpful because they - they know when I need to talk, they know when I need to be on my own. ...They're getting - some people get to know me a bit more, so they know my sense of humour and everything.
(Sabrina).

In line with this, Mick spoke to the difficulties he experienced with agency staff who do not know how to support him (which is likely to be because they are not permanent staff who regularly support him). It appeared that a lack of understanding of ways to support Mick led to an escalation of situations and behaviour related to distress, resulting in more extreme and punitive measures:

They [agency staff] don't care [INAUDIBLE] if I have a problem, they don't know how to work with me, they just [...] They don't - they don't help, they just sit there and just on their, on their arses [INAUDIBLE] anything. They sit there and the next minute, I'm like kicking off. And they see me kicking off, and they

don't know what to do, and they call the police. [...] Because this is what they do, and they threaten me with the police.

4.3.5 Theme five- Being Included

This theme encapsulates participants' experiences of social inclusion and belonging- at both a community and societal level. This was spoken about in terms of connections to social groups and the broader community people live in, as well as experiences of having a more equal social status to staff.

Clive and his KSP described how he is known by, and interacts with, people in his local community, which seemed important to him. For example, being known by people in one of the local pubs, who make his favourite apple pie, as well as speaking to people he sees regularly in his local park, including the groundsman:

Clive's KSP, speaking as Clive: *I like to, you know, engage with people, and chat. And, erm, there's not many people down the park that we don't know. You know, faces, and we might not have seen them for three weeks, but, er, they always stop and have a chat.*

[....]Interviewer: *I just wonder a little bit about knowing people in the park, and whether that helps you feel like you belong in a lo-...in your local area, if you know people to say hello to?*

Clive: *Yeah.*

Interviewer: *Yeah?*

Clive: *Me likes it there.*

Pamela described how meeting and socialising with her neighbours made her feel included in her local community after her move from hospital: "*It felt really good, really. It felt that I belonged. ... It felt that I belonged in the area*". Others described connecting socially with people through shared interests and activities, such as attending sports clubs. Chris contrasted this with the social isolation he experienced in hospital:

Erm, I think, er, things what I do in the community, er, before when I was in hospital, er, I had no outside friends. [...] Er, now I've got, er, I've got loads of outside friends. [...] Yeah, I've got my football friends, go-karting friends.

George derived a sense of belonging at his gym, through being around likeminded people who shared similar goals to him:

Suppose if you go somewhere else, like to a pub or something, you don't get people doing targets and stuff.[...] But you go to the gym and then like we're all - we're all doing the same sort of thing. We're all setting goals and targets and stuff, and we're all working towards it, innit? So it sort of gets a bit of sense of belonging from that.

4.3.5.1 Sub-theme- Feeling Equal to Staff.

This sub-theme speaks to participants' experiences of having more equal social status to staff in their present live. This was often contrasted with past experiences of more socially distanced, hierarchical relationships with staff in hospital. These experiences seemed to contribute towards a sense of social/community inclusion.

Being on a more equal footing with staff appeared to enable participants to relate socially to them, in a way that felt reciprocal, which differed to their experiences of staff relationships in hospital:

Like, because they dress normally and, like, the staff at the hospital, they had, erm, a uniform and it had, erm, NHS on it. And, obviously, they don't here, so that's why, you know, it's like, erm, different. Yeah. [...] I think, erm, what the difference is, it's like when I go out with the staff, you know, they're just, like, they're just like myself, you know, dressed in normal clothes. And it's just you can have a normal conversation and talk about, like, football, music, erm, films, erm, and you're just having, like, a normal, civilised conversation and they just become like your friends. And that's what's, like, different about it. (Mark).

For Mark and Pamela, the absence of staff uniform seemed to help breakdown social hierarchies between them and their current support staff, particularly when out in public with them. Pamela felt that this also impacted society's perception of her. For instance, when recalling past experiences of her hospital stay, she depicted how, during trips out of hospital, she felt segregated and marked out as different: *"it felt everybody was looking at you, because there's a group of you. And they were looking at staff, because they had uniforms on, and it felt horrible."* She contrasts this with her current experiences of going out in her local area staff; her description indicated that she now feels more included in society/her community: *"I can walk around. I can...look up. I can talk to people. I can walk in front, or beside the staff."*

Sabrina described the mutual care and support that exists between her and staff. Here, she depicts that they are able to relate to each other *"both ways"*,

implying that their relationship is not disrupted by hierarchical boundaries, as typified in her comment "*We're all human*":

Sabrina: *Support are there for me, but I'm, I'm there for support. [...] If I talk to them about something and they think, oh, well, that's the same thing that I was thinking, you know, so both ways.*

Interviewer: *Oh, okay. So support sometimes feel the same way that you do about something?*

Sabrina: *Yeah.*

Interviewer: *Oh, okay. And do you find that helpful?*

Sabrina: *Yeah. [...] We're all human.*

4.3.6 Theme six- The Importance of Giving to Others

This theme captures the value participants associated with giving to or helping others- either specific people/groups of people, or society more generally. In some instances, participating in society through "*giving back*" or helping others (e.g., through work or paying tax) seemed to be associated with being included in society in the same way as others, therefore connections exist between this theme and Theme Five- 'Being Included'.

Some participants spoke to the satisfaction they got from helping others (e.g., family, residents in their home) in their day-to-day lives, both practically and emotionally. For instance:

Paul: *It makes me happy, when, when I help everybody else.*

Interviewer: *[...] So do you - and do you help the other residents out as well?*

Paul: *I do, yeah.*

Interviewer: *Yeah, what sort of things do you help them with?*

Paul: *I'll help them in - I help one of them when he, when he, when he shouts, yeah? I help him calm down.*

A number of participants spoke to using their experiences as people with ID, mental health difficulties, or experience in hospital to help others. For some, this related to larger-scale projects; for instance, Mark shared that he was making a film documentary about mental health. For others, this happened in more day-to-day life, in which they provided guidance and support to people they encountered who had been through similar things to them. For instance, when describing helping people “move on”, Mick shared: *“I'll talk them through it, right? [...]Because I've been telling them what, what you must not do, and what you shouldn't do. A bit like what I did to myself.”*

For some, being trusted in their ability to help and contribute to things appeared to create a sense of value. For instance, Max shared his pride at being chosen to help staff with various jobs, such as posting letters and getting keys cut, as well as clearing a farm: *“I was quite honoured”*. When describing carrying out these tasks, he notes that he is *“responsible”* and *“trustworthy”* and describes that the staff member who asks him to do these jobs *“knows I'm quite able”*, suggesting self-value he derives from being entrusted with this.

Participants spoke to a strong wish to *“give back”*, which seemed to stem from the sense that things had been *“given”* to them. For some, this was spoken about in terms of giving to people they knew; for example, Pamela shared how important it was for her to be able to *“give something back”* to her staff:

I used to buy little - the staff a little present, you know, for being like caring for me, and helping me to understand the outside world. But I can't do that now, and it sort of upsets me, but I've always done it everywhere I've been. I've always done it, and I like spending my money on people. It makes me feel - it makes me feel ...appreciated, and it makes me feel...I can give something back, because what they gave me is love and care, what I, what I never had before.

For others, there was a notion that they wanted or needed to “give back” to society more broadly. This spoke to an idea that they were indebted to society for the things that had been given to them- seemingly financial support and care. Sabrina spoke about this sense when describing what her voluntary work meant to her: *“I feel it's time to give back. [...] You know what I mean? Because everything's been given to me, and now I need to give back.”*

Max discussed his motivation behind getting a job to help people with intellectual disability as two-fold: to use his “voice” and lived experience to help others, and to financially contribute to/pay back society (e.g., through paying tax). It seemed that paying back in this way would help him feel he was part of society in the same way as others:

Max: And I - and I really, and I really... I really want to pay my way in, in society. [...] I want to pay towards poll tax, so I, I pay... I want to put something back in the society. [...] That is really - that is really... That is really what I would like to do.

Interviewer: *Yeah. Why do you think that that's so important to you?*

Max: *Because I don't like - I don't like people paying for people like us.*

Sabrina and Max's accounts allude to narratives in the West's neoliberal capitalist societies around people earning their place in society through productivity and 'paying their way'. Both accounts suggest a belief that the support they have received should come at a cost to them (financially or otherwise). Max's use of the phrase "*people like us*" seems to group people with ID as people who don't contribute to society in the same way as others. This view, which could be seen as self-stigmatising, may have been internalised from broader societal narratives about people with a disability and/or groups of people labelled as less 'productive'.

5. Discussion

5.1 Revisiting the Study's Aims

The study aimed to explore the experiences of everyday life for adults with ID who have moved out of hospital through TC, to deepen the understanding of what enhances/undermines people's QoL in the community. A secondary aim was to understand the impact of the Coronavirus pandemic on the everyday lives of this group of people. The study aimed to address the following research questions, which all relate to the experiences of adults with ID who have moved out of hospital through TC:

- 3.11 What experiences (e.g., events, relationships, activities) make up people's everyday lives in the community?
- 3.12 What aspects of everyday living enhance or undermine people's QoL in the community?
- 3.13 What is the impact of the Coronavirus pandemic on people's everyday experiences?

5.2 Summary of Findings

Two separate thematic maps were developed, to address the different aspects of the study's broader aims and research questions. In the first, four themes with two associated sub-themes were developed in relation to how participants spent their everyday lives, including the main themes 'Leisure', 'Work', 'Personal Development', and 'Connecting with Others'. In the second, six themes and one associated subtheme were developed, which spoke to the more in-depth meaning related to everyday experiences. These included the main themes 'The Value of Autonomy',

'The Continued Impact of Hospital', 'The Value of Supportive Relationships', 'Safety through Support', 'Being Included', and 'The Importance of Giving to Others'.

People spoke to experiences of both enhanced freedom and continued restriction in their lives in the community. Many valued the increased autonomy they experienced; however, some seemed to experience ongoing social and psychological impacts from past experiences of hospital, that appeared to continue to restrict their lives. Relationships and connections with others were important to participants; relationships with staff were particularly centred in this. They valued collaborative and enabling support that helped them to learn new skills and try new things, make decisions, and face difficulties; this type of support seemed to enhance or facilitate some people's autonomy. Psychological safety and emotional containment seemed to be developed through consistent support from staff members who knew people well, as well as relationships in which people felt able to trust staff, and/or felt heard and taken seriously by staff. Experiences of social inclusion were facilitated by connections with social groups and the broader community, as well as experiencing a more equal social status to staff. Being able to help and give to others/society at large was important to people and, for some, seemed to give a sense of inclusion in society.

5.3 Making Sense of the Findings

In striving to make sense of the study's analysis, I will discuss findings in relation to each research question, whilst making links with pertinent literature.

5.3.1 Research Question 1: What experiences (e.g., events, relationships, activities) make up people's everyday lives in the community?

Participants spoke of a range of leisure activities they enjoyed doing. For many, these seemed to be instigated by them, based off their own ideas (e.g.,

baking, going to the pub). However, whilst this was not universally spoken to, for some in residential care homes, choice around activities appeared to be less flexible; that is, based on group consensus or chosen from a range of activities offered to them (e.g., bowling, golf). This may relate to the tendency for adults with ID in residential homes or shared accommodation to be treated as a homogenised group, with less attention to personal preferences (Carlsson & Adolfsson, 2022). However, of note, these participants did not express negative emotions in relation to this seemingly less flexible way of choosing things, which may indicate that choice in this way (i.e., choosing from options offered to them) is acceptable to or supportive for them. This is in line with the evidence that people with ID have different needs when making choices, that require different types of support (e.g., choosing from a range of options versus instigating decisions completely independently) (Smyth & Bell, 2006).

Limited employment and educational opportunities exist for people with ID in the general population, related to a number of structural and societal barriers (e.g., stigmatising societal attitudes, lack of accessible courses) (Ellenkamp et al., 2016; Stonier, 2013). In the current study, some participants spoke about being in employment, with one participant explicitly referring to paid employment; the two people in voluntary employed spoke about wanting paid employment. Benefits of employment were in line with those found in the broader ID literature, including social contact and financial stability (Ashley et al., 2018; Hamilton et al., 2017). In addition, a minority of participants spoke about attending formal educational courses, and some discussed developing their skills by doing their own practices (e.g., practicing handwriting, developing fitness).

Participants spoke to the importance of relationships with family, friends, and support staff. In line with literature in the current project's SLR, as well as previous studies on the experiences of adults with ID who have moved out of hospital/institutions (Lennard et al., 2020; McCarron et al., 2019), for some participants, staff were seen as friends/family, and people valued spending social time with them. In addition, some participants spoke to the importance of support services/professionals and family members working together to support them, which is in line with studies noting the importance of interdependent relationships between support providers and family for people with ID (Hall, 2011). Further, people spoke about having friends from a range of contexts, and connections with others (e.g., neighbours, friends through sports clubs, the community at the gym) seemed to foster a sense of social/community inclusion.

Interestingly, participants did not generally speak to experiences of loneliness or social exclusion, as has been found in previous studies of adults with ID who have moved out of hospital (McCarron et al., 2019; Niven et al., 2019), as well as more generally for adults with ID living in specialist community accommodation (evidenced in the current project's SLR). It is, however, noteworthy that participant's descriptions of community participation and social relationships perhaps differed to what would be expected of adults in the general population. For instance, out of 10 participants, four spoke about being in employment (with only one making clear reference to paid employment) and one spoke about having a current romantic partner. In addition, relationships with staff seemed to be the most central source of support and connection in many people's lives. It could be hypothesised that, after periods of societal exclusion in hospital and/or as someone labelled with ID in the community, participants had become accustomed to/accepting of social exclusion and therefore

less moved by it. It may also be the case that participants did not generally place value on these more typical, normalised indicators of social and community inclusion (e.g., romantic partners, formal employment), and therefore did not experience their absence as significant.

5.3.2 Research Question Two: What aspects of everyday living enhance or undermine people's QoL in the community?

It is noteworthy that many of the factors that appeared to enhance/undermine participant's QoL are in line with existing models on the factors important to the QoL of adults in the general ID population. For instance, the factors relating to autonomy (control of life), having adult social status, safety (through relationships), and social belonging are consistent with Carlsson and Adolfsson's (2018) model. The following sub-sections will explore a range of factors, including these, in more detail.

5.3.2.1 Relationships and Support.

The findings speak to the significance of interpersonal relationships to participant's QoL. Whilst family, friends and connections with people in the community are positioned as important in the participant's lives, the centrality of relationships with staff in the findings is striking. This is consistent with findings that staff are the most significant relationships for many people with ID who live in specialist community accommodation, as was found in the current project's SLR. It is also in line with findings on the important role staff have in supporting people with ID to adjust to life outside of hospital (Head et al., 2018; Lennard et al., 2020). The sections below detail the specific approaches to support valued by the participants in the study.

5.3.2.1.1 Person-centred approaches.

The findings indicate that support enhanced people's emotional wellbeing and choice/control when it was collaborative, enabling and tailored to the person's needs. For example, when staff worked with participants to think decisions through, made space to think about the challenges they were having with their mental health, or gave assistance to help them to gradually develop skills and confidence to do new things (e.g., the graded assistance Paul's staff gave to him, to support him to begin going to the local shops independently). This is in line with person-centred approaches, such as active support, that have been consistently found to improve the QoL of people with ID in a range of settings (Beadle-Brown et al., 2012). It contrasts approaches in which support is imposed on and done for/to others, akin to the descriptions of support in hospital that some participants shared.

5.3.2.1.2 Relational Safety.

In the current study, participants valued relationships with staff that knew them well and therefore offered a consistent, tailored approach to support. In addition, they appreciated relationships in which they felt able to trust staff, and/or felt heard and genuinely taken seriously when they communicated their difficulties. These descriptions are in line with psychological literature on relational safety, which speaks to the importance of the following components: 1) consistent and predictable relationships, in which relational boundaries are clear and respected, creating a sense of trust (Clarkson, 2003); 2) emotional containment in relationships, in which one person hears and understands another's distress, without becoming overwhelmed, and communicates this recognition and understanding back to the person (Bion, 1962).

Relational safety is consistently found to be important to people's wellbeing, particularly in the context of therapeutic support for people who have experienced

significant disruptions in relationships (Clarkson, 2003). In line with this, relationship loss and disruption commonly characterise the lives of people with ID who have had long hospital stays or patterns of readmission (Royal College of Nursing, 2016). In the current study, some participants alluded to how the absence of relational safety, in previous hospital stays or in current support by impermanent agency staff, was linked to the presence of behaviours related to distress, that may be labelled as challenging to services (e.g., self-injury, aggression). These findings are in line with

Head et al.'s (2018) study on the experiences of moves through TC, where safety in relationships in new staff teams was found to enable people to speak about their distress with others, instead of communicating it through behaviour that services find challenging. They also speak to broader findings on how secure relationships with professionals in ID services can modulate distress and anxiety (De Schipper & Schuengel, 2010).

5.3.2.2 *Autonomy.*

In the current study, participants spoke to the importance of having choice and control in different aspects of their lives, with many noting that this had increased following their move from hospital. This pattern of findings is consistent with the large number of QoL studies showing improvements in people's choice and control in daily life following moves from institutions/hospitals (Chowdhury & Benson, 2011; McCarron et al., 2019). In the current study, some participants spoke to how their increased opportunities to exercise autonomy gave them positive experiences of feeling like/being like an 'adult'. This links to Carlsson and Adolfsson's (2018) findings of the importance of 'adult social status' (i.e., being able to fulfil an 'adult role' with adult responsibilities in society) to the QoL of adults with ID living in the community. It contrasts the findings of some studies of adults with ID who have

moved out of hospital, where continued limited choice and control has been linked to staff support characterised by an “institutional” approach involving relationships in which people are infantilised (Hubert & Hollins, 2010).

5.3.2.2.1 Relational Autonomy.

In the current study, some participants valued/strove towards doing things independently from staff and professionals. However, many spoke to how support from others (most notably staff) facilitated, enabled or enhanced autonomy in their lives. For instance, staff input supported the development of skills and confidence that enabled participants to begin to weigh things up and make more autonomous decisions- such as how to decorate their home or budget money during a supermarket shop. In addition, staff helped people advocate for their needs and preferences in the services they receive. This finding is unique to the literature surrounding the experiences of people who have moved through TC and suggests that support can be key to helping people feel able to make choices and do things in a way that allows them to feel in control of their lives. This is consistent with the findings in the project’s SLR, where staff practices were found to both enhance or restrict the autonomy of adults with ID living in specialist community accommodation (supported housing/residential care homes).

These findings support ideas of ‘relational autonomy’ in feminist care ethics (Davy, 2019), which challenge individualised conceptualisations of self-determination. Nedelsky (1989) argues: “what actually enables people to be autonomous...is not isolation, but relationships- with parents, teachers, friends, loved ones that provide the support and guidance necessary for the development and experience of autonomy” (p. 12). These positions are in line with systemic theories of selfhood, which view our identities, problems and resistances as relational (i.e.,

emerging through relationships and contexts) as opposed to individually bound (Patton, 2007). As argued by disabled feminists, such as Swain and French (2008), they call into question discourses in the wider disability community that decentre ideas of (inter)dependence and prioritise individualised conceptions of agency, such as those found in some of the manifestations of ID policy around 'Independence' (Simpson & Price, 2010).

Studies exploring the experiences of adults with ID living in the community in UK have also found the importance of relationships (e.g., with staff, neighbours, self-advocacy groups) to people's capacity for autonomy (e.g., to develop confidence to make autonomous arrangements to see friends) (Power et al., 2022). The current study adds nuance to this existing literature through its finding that relationships and networks that facilitate autonomy may be of particular importance to people with ID moving out of hospital, due to their limited opportunities to develop or continue to have agency during their hospital stay. For instance, as Sabrina put it: "*They're [the staff are] teaching me life skills, as I still grow, grow, because I've missed my teenage years being in hospital, they're still teaching me things that I never knew, ... you know?*". In this study, participants valued staff approaches that helped them to adjust making choices in the community by gradually giving them the skills to problem solve and weight things up, in line with the person-centred support approaches referred to in sub-section 5.3.2.1.1.

5.3.2.3 The Continued Impact of Hospital.

The continued social and psychological impacts of stays in hospital on participants in the current study are in line with existing literature. For instance, Niven et al. (2019) reported that 12/15 participants were still showing "signs of institutionalisation" a decade after moving from hospital, including permission

seeking/waiting for prompts and seeking ritualised routines. In the current study, past experiences of hospital appeared to continue to impact on the ways people saw themselves and related to the world. This included a guardedness and a lack of trust in relationships, continued feelings of unsafety, a reluctance to have choice and control over aspects of life, and a sense of threat around being readmitted back to hospital.

These ongoing impacts, which seemed to mostly be related to previous challenging/traumatic experiences and past restriction in autonomy, are perhaps unsurprising. As Wolfensberger (1983) highlights, the “wounds” and burdens carried by someone who has experienced segregation and differential treatment to the rest of society- sometimes for most of their adult life- are enduring and will not simply disappear upon discharge.

It is also important to consider that, for this group of people, the possibility of being readmitted to hospital is a reality. TC workstreams are clear that hospital treatment should still be considered if indicated, and CTOs for people on forensic pathways make immediate hospital recall a possibility (DHSC, 2022). In Head et al.’s (2018) study with people moving out of hospital through TC, the challenges of living with the threat of readmission were also described, and the potential of hospital readmission appeared to be used by some staff teams as a form of behaviour management.

5.3.2.4 Social Participation/Inclusion.

In the current study, a sense of inclusion in the community/society at large seemed to be derived from connections with people in the community, feeling equal in social status to staff, and contributing (“*giving back*”) to society.

In line with Head et al. (2018), in the current study, the absence of staff uniforms seemed to help participants feel more similar in identity/social status staff. This also appeared to help some people feel more socially accepted when out with staff in society. In addition to more physical indicators of equality, having mutual, reciprocal relationships with staff seemed to help participants in the current study feel more equal to them. This is consistent with Carlsson and Adolfsson's (2018) findings that, for adults with ID living in the community, being shown respect by other adults is linked to a sense of equality and, in turn, inclusion in an 'adult community'.

In the current study, value was derived from contributing to and helping others in a variety of ways, including but not limited to employment. For instance, supporting people who had been through similar things (e.g., hospital) or helping out with errands in residential homes (and being recognised as having the qualities to do this). This is in line with The Helping People Thrive publication on the 'Stories and Lessons in Transforming Care' (Wood, 2020), which highlight how "giving" to others can foster a sense of community belonging for people with ID or autistic people who have moved out of hospital.

5.3.3 Research Question Three: What is the impact of the Coronavirus pandemic on people's everyday experiences?

In the current study, some participants spoke of difficult emotions (e.g., sadness, loneliness) associated with experiences of social restrictions. This is in line with findings about the general experiences of people with ID in the Coronavirus pandemic (Flynn et al., 2021). In the current study, these negative emotions were linked to being unable to see family during restrictions, as well as fear related to being unaccompanied by staff when attending hospital appointments.

In addition, some participants also noted that the Coronavirus pandemic had resulted in longer-term changes to the things they did out of the home, even after government restrictions had been lifted. This included not going to places people had previously enjoyed visiting and not seeing friends. This was related to reduced confidence after time spent not doing things, as well as concerns related to health vulnerability (for which once participant appeared to have received medical guidance on). The latter finding fits with research indicating that people with ID experienced increased health vulnerability to Coronavirus, related to both underlying physical conditions as well as health and social inequalities (Henderson et al., 2021). Taken together, these findings add nuance to the research literature in this area; for example, Flynn et al. (2021) found that loss of social contact and activity was experienced by adults with ID in the UK due to specialist community support and services not returning to pre-pandemic levels.

Interestingly, some participants spoke about the pandemic in ways that indicated it had a more limited/neutral impact to their lives- in terms of both everyday activities and wellbeing. For instance, some indicated that that the pandemic had not had any longer-term impacts that prevented them from pursuing things important to them, such as activities or long-term goals. In addition, some people indicated that staying in during social restrictions had not notably impacted their wellbeing. These findings are perhaps surprising, given the significant disturbance the pandemic had to many people's lives, including the reported impacts to wellbeing and social participation for people with ID (Flynn et al., 2021; Maguire et al., 2021).

When interpreting the findings, it should be considered that the majority of the interviews took place after government social restrictions had been lifted.

Regardless, it could be hypothesised that the impact of the restrictions during the

pandemic/the longer-term impacts of the pandemic may have been less marked for some of this group of people as they have been more accustomed to restriction. That is, the restriction characterising significant parts of participant's lives (i.e., long hospital stays, forensic conditions). Pamela, who was in hospital for 37-years, alludes to this when she is asked about the impact of social restrictions on her: *"I'm so used to it, being when I've been in hospital, you know, shut up, so I'm sort of used to it"*.

5.4 Implications

This section will consider recommendations for practice and policy for adults with ID who have moved out of hospital through TC, based on the study's findings.

5.4.1 Learning and Development for the Workforce.

The findings provide important insights which should be used to develop teaching and training resources for staff teams supporting adults with ID who have moved out of hospital through TC. These include specialist community support providers; social care teams; and NHS Community Learning Disability Teams (CLDTs) and Intensive Support Teams (ISTs), who are commissioned to support people at risk of hospital admission/being discharged out of hospital.

The study demonstrates the central role staff in people's support provider play in supporting them following a move from hospital. People described the importance of continuity of staff support, which enabled staff to know them well and therefore provide tailored support. Literature suggests that staff retention is improved by training that enables social care workforces to feel confident in their skills to support people with ID (e.g., Beadle-Brown et al., 2012), which provides further justification for the need for comprehensive training, tailored to staff working with this group of people. The following sub-sections explore the ways in which this learning and

development could be embedded in the current UK context and consider specific areas that should be included in this, based off the study's findings.

5.4.1.1 Approach to teaching and training in the current UK context.

Austerity measures in the UK have led to significant cuts to social care funding in the last decade. Relatedly, there are significant challenges to the recruitment and retention of staff with the right expertise to support people with ID (Mali et al., 2018). Whilst the study's recommendations must be considered within this context, it is noteworthy that the DHSC's recent 'Building the Right Support' (BtRS) action plan (DHSC, 2022) includes a number of government-funded schemes and agendas that aim to support employers in the social care sector to lead and develop a workforce with the right confidence and skills. Programmes which may particularly benefit from the insights of the current study include:

- **Bespoke learning and development for social care workforces working with people being discharged from hospital/at risk of hospital admission (commitment 3F of the BtRS plan).** The plan details that this will include personalised training and supervision sessions. In addition, it suggests that this may include sessions that bring together a range of people from someone's support network (e.g., family and support providers); the current study's findings suggest that this approach is important for some people.
- **Advanced consultant level practice training for CLDTs and ISTs (commitment 1J of the BtRS plan).** This training is being developed for 2023 and is designed to enable CLDTs and ISTs to deliver timely and specialist support, including consultation to community support providers.

In addition, the current study demonstrates the important contribution that people who have moved out of hospital can make towards suggestions for improved

care and support. Training/aspects of training in these programmes should therefore utilise the current study's findings and be co-produced and co-delivered by people with ID who have experienced moves from hospital, to increase its meaningfulness and sustainability. This co-production model has been successfully trialled in England in 2021, in the delivery of the Oliver McGowan Mandatory training to 8,000 health and social care workers supporting autistic people and people with ID (Foster, 2022).

5.4.1.2 Areas of consideration for support and development programmes.

5.4.1.2.1 Person centred approaches that consider relational autonomy.

The study's findings highlighted how staff approaches can support people to adjust to the different demands of life outside of hospital, including increased autonomy; they indicate that this adjustment may occur beyond the initial discharge period. Specifically, they suggest that approaches to support work best when they are gradual, collaborative, and are tailored to a person's needs and preferences.

Training should be provided on these types of person-centred approaches, which may include theoretical ideas as well as practical learning. In the latter, for instance, staff may shadow other professionals (e.g., Healthcare Assistants in CLDTs) to understand how a graded approach to developing independence in certain activities can be implemented (e.g., going out locally). Social care staff and community clinicians should work with people to plan this support (prior to hospital discharge, where possible) so that people can gradually adjust to becoming more autonomous in the community.

It is important for staff to be aware that, due to time in hospital, people may have not had opportunities to continue agency or develop agency in certain areas of

their life or day-to-day decisions (e.g., budgeting money, choosing items to buy) and therefore may need gradual support with this. It should be held in mind that expectations of people to do things without support following discharge, in the name of increasing someone's 'independence', may be counterintuitive and further disabling for some.

5.4.1.2.2 Understanding people's histories and context.

The study's findings highlight people who have moved out of hospital may continue to experience the social and psychological impacts of this experience for some time after. These contexts need to be considered when getting to know people and developing an understanding of their current experiences, including behaviour related to distress (e.g., withdrawal from others, aggression). Clinicians in CLDTs and ISTs should support staff teams to think about how people's historical contexts may impact their presenting difficulties, as part of the development of a clinical formulation and appropriate support strategies. Where possible, networks should work together to begin developing these formulations prior to the person moving out of hospital, so that support can be planned. These formulations should be included in the development of Positive Behaviour Support (PBS) plans (NICE, 2015), which are commonplace in ID services and aim to understand people's distress in relation to their environmental context.

Related to this, consultation with staff teams may consider how staff can support people to prepare them for situations that may be particularly challenging to them. For instance, contact with healthcare professionals (e.g., general hospital appointments) or forensic services (both of which may trigger fears of readmission).

In order to contain people's distress related to this, staff should feel confident in the advice and support they offer to people. This support should be compassionate,

as well as honest and realistic (i.e., not promising that people will never be readmitted to hospital). In addition, given that some people may experience uncertainty about the permanence of their place in the community, staff should be mindful about the language they use about the person's placement. For instance, statements indicating that the placement is likely to breakdown because of someone's 'behaviour' are likely to increase people's anxiety and behaviours related to distress.

5.4.1.2.3 Developing Relational Safety.

The current study found that relationships with staff could promote feelings of safety. In some instances, this appeared to support people with the psychological impacts of past experiences in hospital (e.g., continued feelings of unsafety). Training may benefit from the inclusion of psychoeducation around trauma, attachment difficulties, and emotional containment (e.g., 'Circle of Security'; Cooper et al., 2011). It is important to hold in mind that in order to provide emotional containment, staff need to feel emotionally contained (Carpenter et al., 2012). Supervision that makes space for discussion of difficult emotions related to supporting someone should be provided. This is in line with plans to include supervision sessions in the government-funded learning and development scheme for the UK social care workforce (detailed in subsection 5.4.1)

In addition, in line with the study's findings, staff should consider following practices to bolster feelings of safety in relationships:

- Validating people's distress by not being dismissive and showing that you are listening and taking them seriously.

- Developing trust in relationships by being transparent and honest with the person about their care and support. This includes not promising things that cannot be delivered and communicating to people when plans change.
- Get to know the person well, so that approaches to support can be consistent and predictable. Sharing information about the person's support in staff handovers and through support plans (e.g., PBS plans) can also promote consistency in support approaches.

4.1.2.4 Social and Community Inclusion.

The study highlighted how connections and relationships with others helped to scaffold people's autonomy and helped people to feel included in their community after time spent in hospital. This included, for example, connections with neighbours, figures in the local community, and friends through sports clubs. Where indicated, practitioners should consider how they can support people to link in with existing/build new relational networks. For instance, in line with people's preferences, people may be signposted and supported to access groups activities in the community (e.g., those run by the organisations People First or Heart n Soul). The studies findings should also be disseminated to groups and charities supporting people with ID, so to improve understanding of the support needs of people who have moved out of hospital.

5.4.2 Policy and Funding.

As explored in sub-section 1.5.3, person-centred policy for people with ID has been criticised for its overemphasis on notions around independence that can be isolating and/or further disabling for some people (Hamilton et al., 2017; Simpson & Price, 2010). The current study adds to this, suggesting the fundamental role of

support and relationships in the facilitation of the autonomy of some adults with ID who have moved out of hospital. It is therefore important for policy to reflect this, and not disavow the importance of interdependence and collective care for some. For instance, to emphasise that some people may benefit from support that is planned collectively between them and other support networks in their life (e.g., support provider, family, community health teams).

The study found that connecting with people in the community, as well as being able to contribute to others/society, fostered a sense of inclusion for people. This highlights the importance of investing in community services to make to them accessible and welcoming to people with ID, including services for leisure and employment. The BtRS plan details important proposals for this, such as partnerships between the Department of Health and Social Care and Sport England to ensure equitable access to sport for people with ID, in addition to schemes to increase access to employment, such as supported internship programmes. It should be held in mind that employment may not be an aspiration for everyone; useful support may involve helping people think of alternative ways they can help and contribute, in line with their preferences and attributes (e.g., providing help with tasks in their home).

5.5 Quality Appraisal: Strengths and Limitations

Tracy's "Big-Tent" Criteria for Excellent Qualitative Research (Tracy, 2010) has been used to appraise the quality of the current study. Three of the areas are considered in-depth below; appraisal of the further four areas can be found in Table 7.

5.5.1 Worthy topic.

The study is highly timely and relevant to the current political climate. This includes very recent policy and funding developments for people with ID who have

moved out of hospital in the UK. For instance, the RedQuadrant (2022) report that called for ring-fenced funding for community-provision for people with ID who have moved of hospital, and the associated BtRS action plan (DHSC, 2022).

In addition, the study provides some unique insights into the impact of the Coronavirus pandemic for people with ID who have moved out of mental health hospitals. These are important to begin to understand given that the risks and impacts of this pandemic, and potential future health pandemics, are a continued part of all of our everyday lives and pose particular health and social risks for people with ID (Maguire et al., 2020).

Finally, the broad topic areas explored in the study were developed in expert consultation with people with ID and experiences related to the study. The topic therefore appears pertinent to the people it aims to serve.

5.5.2 Research rigor.

Overall, the report provides rich and detailed explanations and descriptions of data collection and analysis processes, that allow the reader to contextualise its findings. For example, detailed context of events in the Coronavirus pandemic in relation to times of data collection, as well explanations of how reflective journaling, supervision, and EbE consultation were used during the analysis process. The appropriateness of the data collection and analysis methods are considered further below.

Given that the study completed secondary analysis on pre-collected data, the topic guide used for the semi-structured interviews was not designed with the specific study aims and research questions in mind. Whilst questions broadly mapped onto the study's domains of interest, the questions and follow-up prompts were less likely to tap into the nuance of areas explored, such as more detailed

descriptions around the everyday activities in people's lives pertinent to QoL, or the impact of the Coronavirus pandemic. As such, the data collected on these topics may have been less rich, and important experiences may not have been captured.

The use of the dyadic interview and internalised other technique provided innovative ways to capture the complexity of people's experiences, through recognising and valuing the interdependence in people's lives (Caldwell, 2014), whilst still keeping the voice of the person with ID central. However, the presence of staff in interviews (used as KSPs for majority of participants) has been found to increase socially desirable responses (Young & Chesson, 2006). The participants, however, chose the KSPs themselves, and it could be argued that having someone they knew well made them feel more comfortable, perhaps mitigating tendencies to try and 'please' the interviewer. This can perhaps be seen in Gerry's interviews, in which he independently gave more spontaneous, in-depth responses when a KSP was present than when he interviewed alone.

The interview methods did not allow for anonymity from the interviewer/researchers, which may have shaped what the participants chose to speak about. Research has noted a reluctance for people with ID to criticise the support they receive in relation to fears of losing access to help, linked to the lack of social capital people with ID typically have (Meeriman & Beail, 2009). The current study's findings indicate the sense of threat that some participants felt about their place in the community, meaning that they may have been particularly fearful to criticise aspects of support. Studies have also noted the understandable tendencies of people with ID who have moved out of hospital to present in certain ways in research interviews, to indicate they are not liable for hospital treatment (e.g., proving they are independent through their answers) (Rapley & Antaki, 1996). These

influences are potentially reflected in the current study's findings which, with the exception of one theme, relate to positive, life-enhancing aspects of people's lives and are generally uncritical of current support.

5.5.3 Resonance.

The study's transferability is enhanced by the inclusion of people with a range of experiences, including people who have moved from both mental health and forensic hospitals, and people living in a range of living set-ups in the community (residential care homes, supported housing, living independently).

Limitations to the transferability of the findings, however, exist. Notably, all participants were White British, limiting the transferability of the findings to people in other ethnic groups and/or cultural backgrounds. Whilst the core MPM sample has ensured greater variability in participant ethnicity and cultural background, sampling in the current study did not consider this and based selection criteria off length of hospital stay only.

In addition to broader experiences of institutional racism, systemic barriers exist in the access of community-based forensic and mental health services for people with ID in the global majority³ (Coleman, 2021; Robertson et al., 2019). Further, systemic racism and inequity is widely reported for people in the global majority in inpatient mental health systems (Nazroo et al., 2020). As such, the experiences of people in the global majority who have moved through TC may differ from the participants in the current study. Given the noted exclusion of the voices of

³ "We use the term 'Global majority' to include all people of African, Caribbean, East Asian, West Asian, or Southern Asian descent, and people who identify as dual heritage. It reclaims the previously held minority status given to Black and Brown people in Western societies" (Afuape et al., 2022, p.17).

with ID from the global majority in research (Shah Kent, 2021), their exclusion in the current study is also a significant ethical concern.

In addition, participant demographic information was limited, and excluded a range of social differences/identities. For instance, no information was provided on participants' social class, culture, economics, or sexuality. Exclusion of these details parallels society's tendency to reduce understanding of people labelled with ID to experiences of their (dis)ability only (e.g., ignoring or even denying people's sexual orientation) (Hernández-Saca et al., 2018). The exclusion of this information in the current study limits understanding of the participants' multiple, potentially intersecting, identities and therefore limits the reader's ability to situate the study's findings in context. It also prevents understanding of the transferability of the study's outcomes across social identities.

Table 7.

Quality Appraisal of the Current Study Using Tracy's "Big-Tent" Criteria for Excellent Qualitative Research (Tracy, 2010): sincerity, credibility, significant contribution, ethical.

Quality Criteria	Quality Appraisal of the Current Study
Sincerity	The report has made reference to both my personal and epistemological positioning throughout, including through excerpts of a reflective journal kept throughout the research process. This has allowed me to scrutinise my own influences and biases in research process, and has given the reader insight into these processes, providing them with additional context to situate the study's findings in.
Credibility	The findings include thick descriptions of analysis and supporting quotes, supported by both descriptive and interpretative narratives that aim to 'show' the reader the meanings as opposed to telling them what to think. Consultation with EbEs in the analysis stages allowed for multivocality in the research, increasing its credibility.
Significant Contribution	The study has contributed to a significantly under-researched area, leading to meaningful and practical clinical implications. Importantly, the current study centres the perspectives of people with ID who have moved through TC, who have previously been left out of research on the long-term impacts of TC.
Ethical	Attention has been paid to both the procedural and relational aspects of ethics throughout the study. The research has carefully considered adaptations in order to make the process more accessible to participants (e.g., use of adapted visual stimuli in interviews). I will continue to work in line with these ethics during the dissemination stages of the study- e.g., in the creation of a blog on the findings/implications, that is accessible to people with ID.

5.6 Directions for Future Research

The following section considers valuable areas for future research on the experiences of people with ID who move out of hospital. Research in these areas would allow for more tailored policy, that better considers the diversity of experiences of adults with ID who move out of hospital through TC.

5.6.1 Research specific to the experiences of people with ID from the global majority.

People with ID from the global majority experience institutional racism and inequity in treatment in both hospital (Nazroo et al., 2020) and community ID services (Coleman, 2021). Research specific to the experiences of people with ID from the global majority who have moved out of hospital is important to support understanding of the unique experiences and challenges this group of people face. This will support the development of policy and practice guidance that is sensitive to ethnic and cultural diversities and attempts to address existing ethnic and racial inequities. It is important for this research to not homogenise people from the global majority, and carefully consider cultural and ethnic diversity in its approach.

5.6.2 Research specific to the experiences of people with “severe” and “profound” ID.

People with “severe” and “profound” ID have unique support needs. For example, people typically require increased support with communication, mobility and personal hygiene, meaning their experiences of support in the community is likely to differ to people with “mild” or “moderate” ID. In line with this, studies have suggested different indicators of QoL may be pertinent to people with “severe” and “profound” ID living in the community (Bigby et al., 2014). Many people with “severe” and “profound” ID are likely to have difficulties with communicating in interviews, even with adaptations, therefore ethnographic methodologies, such as observation, could be used to capture people’s subjective experiences.

5.6.3 Research specific to the experiences of people who have moved out of forensic mental health hospitals.

The TC agenda, and its associated workstreams/action plans, have been criticised for sometimes homogenising the support needs of people moving from both forensic and 'mainstream' mental health hospitals (Sinclair, 2018). As indicated in the current study, differences exist for people in the forensic pathway (e.g., conditions that impose restrictions), which may impact experiences of community living. Research specific to the experiences of people who have moved out of forensic settings through TC may better isolate the specific factors that support and undermine people's QoL in the community.

5.7 Dissemination Strategy

The current study's outcomes will be disseminated through several channels. An easier to read blog is being co-produced with the Making Positive Moves EECG and will be published on the Making Positive Moves website, which is designed for service users, carers, and stakeholders connected to the TC programme. In addition, the study's findings and recommendations are scheduled to be presented at the Making Positive Moves national conference, which will bring together key stakeholders connected to TC (service users, families, care providers/professionals from the Care Quality Commission, advocacy groups, TC commissioners, and health and social care teams working with service users connected to TC). A journal article is also being prepared, for submission to peer-reviewed journals (Journal of Applied Research in Intellectual Disabilities, Qualitative Health Research).

5.8 Concluding Comments

The present project aimed to explore the everyday lives of people with ID who have moved out of hospital through TC from their own perspective, in order to deepen the understanding of what enhances/undermines their QoL in the community. Analysis of 19 interviews from 10 participants and KSP pairs indicated a range of aspects that enhanced and undermined aspects of people's current lives, which broadly mapped onto areas of relationships/connections, social inclusion/participation, and freedom/restriction. A finding novel to the TC literature was the importance of staff in facilitating people's autonomy following a move from hospital, which speaks to the need for tailored staff approaches that do not disavow the value of interdependence.

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Appendix A: Reflective exercise completed at the beginning of the study

What does the concept of QoL mean to me? What are my expectations about the research/possible findings on the QoL of people with ID who have moved through TC?

As part of this reflective exercise, I thought about what the concept 'QoL' meant to me, in my life. I also reflected on the assumptions I had about what I may find in research about the everyday experiences of people with ID who have moved out of hospital. In doing this, recognise that people with intellectual disabilities are not a homogenised group and like for anyone, different things are important to different people when it comes to quality of life.

An excerpt from my reflective journal on the key things I noticed in this process:

- **My assumptions that relationships are important to people-** *I recognised how important relationships are to my QoL. My assumptions are that family and staff/professionals may be more central to the quality of life for people with ID in the study also, which I think is related to my assumption that people with ID are more reliant on family for social capital/to advocate for them given their less powerful position in society (particularly those who have been in hospital), as well as the more formal support that is often in people's lives. I did assume friendship may be important to people with ID but had an awareness that making and sustaining friends might be more difficult for this group of people, because of social exclusion.*
- **Safety-** *I recognised that personal safety was important to me, which was related to the threat of violence I experience as a woman. I also assumed this may be important for people with intellectual disabilities, which I think was informed by my knowledge people's vulnerability to exploitation (e.g., financial exploitation) and hate crimes.*
- **"Opportunities to feel valued"-** *I thought about how job satisfaction and doing things I care about are to many people's quality of life, and how employment might come up in this research... I thought about how the workplace might exclude a lot of people, and may not meet people's basic rights (e.g., actually being paid, being treated well, not being subjected to abuse.) I think this speaks to my awareness of the stark inequalities in employment for people with ID. I also wondered about the normative assumptions that can be made about people wanting employment... will everyone want this? In this, I thought about how 'success' for people with intellectual disabilities is often framed as these really 'big' things like sporting achievements or political achievements- such as in the book 'Made Possible' (Salman, 2020). This book centres really important stories that challenge societies low aspirations for people with ID; however, I wondered what the more everyday stories of success/contribution/'challenging' yourself looked like for people with ID, that are perhaps missed in this type of coverage. I guess it may all come down to choice and preference- I wonder how much people in the study will feel like they can choose these paths*

Appendix B: Search Strategy for Systematic Literature Review

Three electronic data bases were searched: Scopus, Cinahl Plus and PubMed. Searches were restricted to articles published between 2001-2022.

The searches used the following search terms, and had to appear in either the title, abstract, or key words of the article to optimise relevance.

Search terms used in initial search:

[learning disabilit* OR developmental disabilit* OR intellectual disabilit* OR neurodevelopmental disabilit* OR mental retardation]

AND

[community living OR supported housing OR supported living OR residential living OR residential care home OR residential service or residential home OR residential facilit* OR residential accommodation OR group home OR shared living]

AND

[quality of life OR life quality OR life satisfaction OR lifestyle satisfaction OR wellbeing OR well-being]

Search terms used in final search:

[learning disabilit* OR developmental disabilit* OR intellectual disabilit* OR neurodevelopmental disabilit* OR mental retardation]

AND

[community living OR supported housing OR supported living OR residential living OR residential care home OR residential service or residential home OR residential facilit* OR residential accommodation OR group home OR shared living]

Mixed Methods Appraisal Tool (MMAT), version 2018**Ashley, Fossey and Bigby (2019)**

Category of study designs	Methodological quality criteria	Responses			
		Yes	No	Can't tell	Comments
Screening questions (for all types)	S1. Are there clear research questions?	X			
	S2. Do the collected data allow to address the research questions?	X			
	<i>Further appraisal may not be feasible or appropriate when the answer is 'No' or 'Can't tell' to one or both screening questions.</i>				
1. Qualitative	1.1. Is the qualitative approach appropriate to answer the research question?	X			
	1.2. Are the qualitative data collection methods adequate to address the research question?	X			
	1.3. Are the findings adequately derived from the data?	X			
	1.4. Is the interpretation of results sufficiently substantiated by data?	X			
	1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation?	X			
2. Quantitative randomized controlled trials	2.1. Is randomization appropriately performed?				N/A
	2.2. Are the groups comparable at baseline?				N/A
	2.3. Are there complete outcome data?				N/A
	2.4. Are outcome assessors blinded to the intervention provided?				N/A
	2.5. Did the participants adhere to the assigned intervention?				N/A
3. Quantitative non-randomized	3.1. Are the participants representative of the target population?				N/A
	3.2. Are measurements appropriate regarding both the outcome and intervention (or exposure)?				N/A
	3.3. Are there complete outcome data?				N/A

	3.4. Are the confounders accounted for in the design and analysis?				N/A
	3.5. During the study period, is the intervention administered (or exposure occurred) as intended?				N/A
4. Quantitative descriptive	4.1. Is the sampling strategy relevant to address the research question?	X			
	4.2. Is the sample representative of the target population?	X			
	4.3. Are the measurements appropriate?	X			
	4.4. Is the risk of nonresponse bias low?	X			
	4.5. Is the statistical analysis appropriate to answer the research question?	X			
5. Mixed methods	5.1. Is there an adequate rationale for using a mixed methods design to address the research question?	X			
	5.2. Are the different components of the study effectively integrated to answer the research question?	X			
	5.3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted?	X			
	5.4. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?	X			
	5.5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?	X			

Appendix D: Visual Stimuli Used in Interviews to Supplement Verbal Information


Making Positive Moves research project
Interview example visual prompts





















IRAS reference number: 200695



You now live in _____ [insert name of current residence]

What do you think about living here?

<p>A normal day</p> 	 <p>Good</p>	 <p>Ok</p>	 <p>Not good</p>
<p>Who you live with</p> 	 <p>Good</p>	 <p>Ok</p>	 <p>Not good</p>

<p>The staff</p> 	 <p>Good</p>	 <p>Ok</p>	 <p>Not good</p>
<p>The food</p> 	 <p>Good</p>	 <p>Ok</p>	 <p>Not good</p>
<p>Your bedroom</p> 	 <p>Good</p>	 <p>Ok</p>	 <p>Not good</p>
<p>Activities</p> 	 <p>Good</p>	 <p>Ok</p>	 <p>Not good</p>
<p>The garden</p> 	 <p>Good</p>	 <p>Ok</p>	 <p>Not good</p>

Appendix E: Key UK government Coronavirus lockdowns and measures between June 2020-March 2021 and number of studies conducted within this time range

Adapted from Institute for Government (n.d.): [Timeline of UK government Coronavirus lockdowns and restrictions | The Institute for Government](#)

Month And Year	Number of Time 1 Interviews Conducted	Number of Time 2 Interviews Conducted	Restriction/Measure
December 2020	1	0	<ul style="list-style-type: none"> • Early December- second lockdown (enforced in November 2020) ends • Late December- “tier 4” restrictions enforced in London and South East England
January 2021	0	1	<ul style="list-style-type: none"> • Early January- England enters third national lockdown
February 2021	0	0	<ul style="list-style-type: none"> • “Roadmap” for easing lockdown restrictions published
March 2021	1	0	<ul style="list-style-type: none"> • Early March- recreation in outdoor space allowed between two people • Late March- outdoor gatherings of 6 people/two households permitted. ‘Stay at home’ order ends but people encourage to ‘stay local.
April 2021	0	0	<ul style="list-style-type: none"> • Mid-April <ul style="list-style-type: none"> ○ Non-essential retail opens ○ Outdoor venues (e.g., pubs, themeparks) re-open ○ Wider social contact rules apply in all settings
May-June 2021	2	0	<ul style="list-style-type: none"> • Mid-May- Indoor venues re-open (pubs, cinemas); 6 people or two households can meet indoors.

July-December 2021	1	2	<ul style="list-style-type: none"> • Mid-July- most legal limits on social contact removed
December 2021	0	0	<ul style="list-style-type: none"> • Early December- “Plan B” announced, following spread of Omicron variant <ul style="list-style-type: none"> ○ NHS Covid Pass becomes mandatory in some venues; face masks become compulsory in most public indoor venues
January 2022 onwards	5	4	<ul style="list-style-type: none"> • Late January- Plan B measures lifted; no further restrictions to social contact introduced

Appendix F: Semi-structured Interview Topic Guide

1. What life is like and impact on well-being.

Examples of questions:

Here and Now

- a. What is a normal day like living here now? (prompt to look at photos, for example, of daily life, who you live with and important people in your life together)
 - o What is your daily routine like? (prompt to look at/ create weekly activity chart together). What kind of activities do you do? Where do you go? What do you do? Is that how you'd like it to be? Has it changed since Covid?
 - What do you like about the activity?
 - What does it do for you?
 - Is it about the other people?
 - Is it about the activity itself?
 - Is it about how it makes you feel?

(Prompts to include day-centre, self-advocacy, religious group)
 - o Are there any restrictions on what you can do now? If so, what are they? How does that impact your life?
 - o Has your daily life changed due to [Covid]?
 - o What does a good day look like for [insert name]? What does a bad day look like for [insert name]? What do you do when you have a bad day? What stops it from getting to a really bad day? (If other people are mentioned) – What is it that they do that's helpful? What do they say? What do they do? Would it help to think of an example? (Is this OK to talk about?) What happened? Why did it get bad? What stopped it from getting worse? How is it different from when you used to have a bad day?
 - o Is this how you want your life to be in the community? Is this how you thought your life would be living in the community?
- b. Who do you live with?
- c. How do you feel about living here?
 - o Do you like the people you live with, the staff, the support, the house and garden, the food, your bedroom?
 - o Do you like the things you do? (do you have enough time for the activities you enjoy doing? Do you do activities at times that suit you? Do you have transport to get to the activities you like doing?)
 - o Do you have enough money?
 - o Do you like the local area? (Do you feel you belong in the community you live in? Are you able to get around your local area- bus pass, car, walking?)
 - o Did you feel the same as before [Covid]?
- d. How would you describe yourself living here?

Reflecting on the impact of living here

- e. How has living here changed your life/ health/ thinking and feeling?

- f. How has it changed how safe you feel? How come?
- g. How much do you do for yourself now?
- h. How much do you manage money now?
- i. How much choice do you have about what you do and when you do it?
- Has this changed since moving here?
 - Has this changed since [Covid]?
 - What is it like having choices?
 - What choices do you make? What choices do staff make?
 - Do you have enough choices in your life now?
- j. How much do you see your friends and family now?
- Has this changed since moving here?
 - Has this changed since [Covid]?
- k. How much do you go out in the community now?
- Has this changed since moving here?
 - Has this changed since [Covid]?
- l. How much freedom do you have now?
- Has this changed since moving?
 - How do restrictions affect you now?

Identity

- m. What sort of person are you now?
- n. What do you value/like about yourself now?
- o. What's important to you in your life now?
- Some people spoke about being helpful being important. What do you think?
 - What do other people value/like about you?

2. What factors support and undermine community living.

What helps?

Examples of questions:

- a. What helps you to stay living here?
- b. What has helped you to stay living here over time?
- Is it to do with the people you live with?
 - Is it to do with your support staff?
 - Is it to do with the house?
 - Is it to do with the activities?
 - Is it to do with family or friends?
 - Is it to do with your local area?
 - Is it to do with how easy it is to get around?
 - Is it to do with how much you do for yourself?
 - Is it to do with how many choices you have?
 - Is it to do with freedom?
 - Is it to do with having someone there?
 - Is it to do with money?
 - Is it about others trusting in you and believing you?

- Is it about your day-to-day activities/routine?
- Is it to do with any [Covid] changes?
 - What is it about it that helps you stay living here? (Prompt for all questions)

What hinders?

- c. What sort of problems have you faced living here?
- d. Has anything helped you to manage these problems?
- e. What makes it harder to stay living here?
 - Is it to do with the people you live with?
 - Is it to do with your support staff?
 - Is it to do with the house?
 - Is it to do with the activities?
 - Is it to do with family or friends?
 - Is it to do with your local area?
 - Is it to do with how easy it is to get around?
 - Is it to do with how much you do for yourself?
 - Is it to do with any [Covid] changes?
 - What is it about it that makes it harder to stay living here? (Prompt for all questions)

Appendix G: Ethical Approval

1. REC favourable opinion for original study:



Health Research Authority

London - Hampstead Research Ethics Committee

Barlow House
3rd Floor
4 Minshull Street
Manchester
M1 3DZ

Telephone: 0207 104 8009

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

06 June 2016

Dr Helen Ellis-Caird

DClinPsy, Health Research Building

University of Hertfordshire

Hatfield

AL10 9AB

Dear Dr Ellis-Caird

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

Thank you for your letter of 1st June 2016, responding to the Committee's request for further information on the above research [and submitting revised documentation](#).

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

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

Confirmation of ethical opinion

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

Conditions of the favourable opinion

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

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

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

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

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

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

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

Registration of Clinical Trials

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

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

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

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

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

Ethical review of research sites

NHS sites

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

Non-NHS sites

Approved documents

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

<i>Document</i>	<i>Version</i>	<i>Date</i>
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Letter of insurance]	1.0	11 April 2016
Interview schedules or topic guides for participants [Interview schedule example]	1.0	21 April 2016
Interview schedules or topic guides for participants [Visual prompt sheet interview example]	1.0	21 April 2016

Interview schedules or topic guides for participants [Visual prompt sheet interview example]	2	01 June 2016
Letter from sponsor [Letter from sponsor]	0.1	11 April 2016
Other [Record sheet for assessing consent]	1.0	21 April 2016
Other [Explanation of recruitment criteria]	2	01 June 2016
Participant consent form [Consent form - easy read]	1.0	21 April 2016
Participant consent form [Consent form for Key Support Person]	1.0	21 April 2016
Participant consent form [Consent form - easy read]	2	01 June 2016
Participant information sheet (PIS) [Easy read initial infor]	1.0	21 April 2016
Participant information sheet (PIS) [Easy read full info sheet]	1.0	21 April 2016
Participant information sheet (PIS) [Information - choosing someone to support me]	1.0	21 April 2016
Participant information sheet (PIS) [information for Key Support Person]	1.0	21 April 2016
Participant information sheet (PIS) [Easy read initial infor]	2	01 June 2016
Participant information sheet (PIS) [Easy read full info sheet]	2	01 June 2016
Participant information sheet (PIS) [Information - choosing someone to support me]	2	01 June 2016
REC Application Form	5.3.0	22 April 2016
Research protocol or project proposal [Protocol V0.1]	1	31 March 2016
Summary CV for Chief Investigator (CI)	1	30 March 2016
Summary CV for student	1	31 March 2016
Summary CV for supervisor (student research) [Supervisor CV]	1.0	12 April 2016
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Recruitment process summary]	1.0	21 April 2016

Statement of compliance

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

After ethical review

Reporting requirements

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

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

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

User Feedback

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

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

HRA Training

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

16/LO/0816	Please quote this number on all correspondence
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With the Committee's best wishes for the success of this project.

Yours sincerely



Signed on behalf of Miss Stephanie Ellis Chair

Email: nrescommittee.london-hampstead@nhs.net

Enclosures: "After ethical review – guidance for researchers"

Copy to: *Professor John Senior*

Rishma Bhatti, East & North Herts NHS Trust

2. HRA approval for original study



Health Research Authority

Dr Helen Ellis-Caird
DClinPsy, Health Research Building

Email: hra.approval@nhs.net

University of Hertfordshire

Ha
tfie
ld
AL
10
9A
B

h.ellis-caird@herts.ac.uk

11 August 2016

Dear Dr Ellis-Caird

Letter of HRA Approval

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

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

Participation of NHS Organisations in England

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

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

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

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

Page 1 of 8

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

Appendices

The HRA Approval letter contains the following appendices:

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

After HRA Approval

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

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

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

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

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

Scope

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

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

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

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please email the HRA at hra.approval@nhs.net. Additionally, one of our staff would be happy to call and discuss your experience of HRA Approval.

HRA Training

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

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

Yours sincerely

Beverley Mashegede

Assessor

Email: hra.approval@nhs.net

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

Rishma Bhatti (East & North Herts NHS Trust),
researchanddevelopment.enh-tr@nhs.net, Lead NHS R&D Contact

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

Appendix A - List of Documents

The final document set assessed and approved by HRA Approval is listed below.

<i>Document</i>	<i>Version</i>	<i>Date</i>
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Letter of insurance]	1.0	11 April 2016
Interview schedules or topic guides for participants [Interview schedule example]	1.0	21 April 2016
Interview schedules or topic guides for participants [Visual prompt sheet interview example]	1.0	21 April 2016
Interview schedules or topic guides for participants [Visual prompt sheet interview example]	2	01 June 2016
Letter from sponsor [Letter from sponsor]	0.1	11 April 2016
Other [Record sheet for assessing consent]	1.0	21 April 2016
Other [Explanation of recruitment criteria]	2	01 June 2016
Other [Honorary contract - A. Head]		
Other [Statement of Activities]		11 August 2016

Other [Schedule of Events]		11 August 2016
Notice of Minor Amendment		21 July 2016
Participant consent form [Consent form for Key Support Person]	3	18 July 2016
Participant consent form [Consent form - easy read]	3	18 July 2016
Participant information sheet (PIS) [information for Key Support Person]	2	18 July 2016
Participant information sheet (PIS) [Easy read initial infor]	3	18 July 2016
Participant information sheet (PIS) [Easy read full info sheet]	3	18 July 2016
Participant information sheet (PIS) [Information - choosing someone to support me]	3	18 July 2016
REC Application Form	5.3.0	22 April 2016
Research protocol or project proposal [Protocol V0.1]	1	31 March 2016
Summary CV for Chief Investigator (CI)	1	30 March 2016
Summary CV for student	1	31 March 2016
Summary CV for supervisor (student research) [Supervisor CV]	1.0	12 April 2016
Summary, synopsis or diagram (flowchart) of protocol in nontechnical language [Recruitment process summary]	1.0	21 April 2016

Appendix B - Summary of HRA Assessment

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

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

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

Professor John Senior, j.m.senior@herts.ac.uk

HRA assessment criteria

Section	HRA Assessment Criteria	Compliant with Standards	Comments
1.1	IRAS application completed correctly	Yes	No comments
2.1	Participant information/consent documents and consent process	Yes	The participant information sheets and consent forms have been updated to bring them in line with HRA standards. A minor amendment has been submitted for this.
3.1	Protocol assessment	Yes	No comments
4.1	Allocation of responsibilities and rights are agreed and documented	Yes	The Statement of Activities will act as an agreement between the Sponsor and the participating NHS sites to confirm capacity and capability to undertake their role in this research. The Sponsor is not requesting and does not require any other site agreement.
4.2	Insurance/indemnity	Yes	Where applicable, independent
Section	HRA Assessment Criteria	Compliant with Standards	Comments
	arrangements assessed		contractors (e.g. General Practitioners) should ensure that the professional indemnity provided by their medical defence organisation covers the activities expected of them for this research study

4.3	Financial arrangements assessed	Yes	No funds will be provided to the participating organisation.
5.1	Compliance with the Data Protection Act and data security issues assessed	Yes	No comments
5.2	CTIMPS – Arrangements for compliance with the Clinical Trials Regulations assessed	Not Applicable	No comments
5.3	Compliance with any applicable laws or regulations	Yes	No comments
6.1	NHS Research Ethics Committee favourable opinion received for applicable studies	Yes	REC Provisional opinion request for further information was issued on 20 May 2016. This was followed by Favourable Opinion on 6 June 2016.
6.2	CTIMPS – Clinical Trials Authorisation (CTA) letter received	Not Applicable	No comments
6.3	Devices – MHRA notice of no objection received	Not Applicable	No comments
6.4	Other regulatory approvals and authorisations received	Not Applicable	No comments

Participating NHS Organisations in England

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

This is a PhD student study and there is one site type.

Potential participants will be identified by a member of their care team from Hertfordshire Partnership NHS Foundation Trust. This staff member will approach them initially and offer them an initial information sheet. If they are interested, the main researcher will make contact to meet with the person to present and talk through a more in-depth information sheet. Written consent will be recorded.

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

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

Confirmation of Capacity and Capability

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

Participating NHS organisations in England **will be expected to formally confirm their capacity and capability to host this research.**

- Following issue of this letter, participating NHS organisations in England may now confirm to the sponsor their capacity and capability to host this research, when ready to do so. How capacity and capability will be confirmed is detailed in the *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* section of this appendix.
- The [Assessing, Arranging, and Confirming](#) document on the HRA website provides further information for the sponsor and NHS organisations on assessing, arranging and confirming capacity and capability.

Principal Investigator Suitability

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

A Local Collaborator is expected at the participating organisation.

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

HR Good Practice Resource Pack Expectations

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

The external researcher has an Honorary contract in place with the participating organisation. A Letter or Access will not be needed.

Other Information to Aid Study Set-up

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

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

3. HRA Approval for amendment to original study, allowing Making Positive Moves Research Study

From:

To:

Cc:

Subject:

Date:

Attachments:

Dear all,

Following this approval I will send the relevant documentation to ethics so that a revised protocol number can be issued and research can continue.

Kind regards,

Stephanie

Stephanie Dixon

Research Office Administrator
 Research Office
 Extension 5794

From: John Senior <>
Sent: 12 February 2020 12:58
To: Research Sponsorship <research-sponsorship@herts.ac.uk>
Subject: IRAS PROJECT ID 200695, REC Reference 16/LO/0816 Confirmation of favourable opinion for substantial amendment

Copy for your file. Regards, Jill

From: NRESCommittee.London-Hampstead@nhs.net <noreply@harp.org.uk>
Sent: 12 February 2020 10:11
To: Helen Ellis-Caird <>; John Senior <>
Subject: IRAS PROJECT ID 200695, REC Reference 16/LO/0816 Confirmation of favourable opinion for substantial amendment

Dear Dr Ellis-Caird

IRAS project ID:	200695
REC reference:	16/LO/0816
Short Study title:	People with ID moving under Transforming Care
Date complete amendment submission received:	27 January 2020
Amendment No./ Sponsor Ref:	04
Amendment Date:	22 January 2020
Amendment Type:	Substantial
Outcome of HRA Assessment	This email also constitutes HRA and HCRW Approval for the amendment, and you should not expect anything further.

received a Favourable Opinion. Please find attached a copy of the Favourable Opinion letter.

HRA and HCRW Approval Status

As detailed above, **this email also constitutes HRA and HCRW Approval for the amendment.** No separate notice of HRA and HCRW Approval will be issued. You should implement this amendment at NHS organisations in England and/or Wales, in line with the conditions outlined in your categorisation email.

- If this study has HRA and HCRW Approval, this amendment may be implemented at participating NHS organisations in England and/or Wales once the conditions detailed in the categorisation section above have been met
- If this study is a pre-HRA Approval study, this amendment may be implemented at participating NHS organisations in England and/or Wales that have NHS Permission, once the conditions detailed in the categorisation section above have been met. For participating NHS organisations in England and/or Wales that do not have NHS Permission, these sites should be covered by HRA and HCRW Approval before the amendment is implemented at them, please see below;
- If this study is awaiting HRA and HCRW Approval, I have passed your amendment to my colleague and you should receive separate notification that the study has received HRA and HCRW Approval, incorporating approval for this amendment.

User Feedback

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

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

If you require further information, please contact hra.amendments@nhs.net

16/LO/0816/AM04 Please quote this number on all correspondence

Kind regards

Kevin Ahmed Approvals Manager

Health Research Authority

Barlow House | 3rd Floor | HRA RES Centre Manchester | M1 3DZ

T. 0207 104 8171

E. NRESCommittee.London-Hampstead@nhs.net

W. www.hra.nhs.uk

Sign up to receive our newsletter [HRA Latest](#).









Appendix H: Participant consent form used in MPM Study.







To note, the consent form includes consent for use of data in subsequent research studies on page 2.





Participant ID _____

Making Positive Moves research study Consent Form

IRAS reference number: 200695

Please circle		
 YES	 NO	I have seen the information sheet.
 YES	 NO	I have met with a researcher to talk about the project.
 YES	 NO	I have been able to ask questions about the project.
 YES	 NO	I know what I will be asked to do to help find things out.

 YES	 NO	<p>I know that I can say “no” to taking part at any time in the project.</p>
 YES	 NO	<p>I know that this means I can stop at any time in the interview. I can also call the researchers at any time to tell them I don’t want to take part any more.</p>
 YES	 NO	<p>I know that information about me will be “confidential” – this means private. However, I know that if the researchers are worried about me or someone else they might need to talk to someone else.</p>
 YES	 NO	<p>I know that the researchers will record my interview.</p>
 YES	 NO	<p>I know that the researchers will type things up. This might be things that I say, or questionnaires that I answer. I know that the researchers will not use my real name.</p>
 YES	 NO	<p>I know that my interviews will be used to write reports and these might be published.</p>
 YES	 NO	<p>I know that if I stop taking part more than 1 week after an interview, my interviews will still be used in reports</p>
 YES	 NO	<p>I know how to contact the researchers</p>

 YES	 NO	I know that the researchers will write to me to tell me what they found.
 YES	 NO	I say “yes” to taking part in the project.

My name is

Signed here:.....

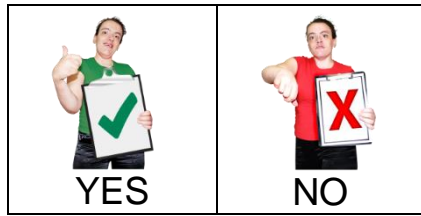
Date:

Researcher’s name

Researcher’s signature.....

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

We will only share the typed version of your interview without your name.



One copy of the consent form to be kept by the participant and one copy to be kept by the researcher.

Appendix I: E-mail Correspondence with Ethics Committee (University of Hertfordshire) regarding ethical approval

Email sent from researcher to UH Ethics Committee on 29/04/22:

Good morning,

I am a student on the Doctorate in Clinical Psychology, meaning I am a post-doctoral student at UH and have an honorary contract with Hertfordshire Partnership NHS Foundation Trust. As part of my major research project, am hoping to commence a study to conduct secondary analysis on existing data collected by the research team for a study which already has NHS Ethics (REC) and UH approval.

The details for this study are:

Long title: Making positive moves: What support do people with Learning Disabilities need to remain living in the community after moving under the Transforming Care Programme. A qualitative longitudinal study.

Short title: Making Positive Moves

Lead Sponsor: University of Hertfordshire

REC Reference Number: 16/LO/0816

UH Reference Number: aLMS/PGR/NHS/02316(2)

The aims of my study, which will use secondary analysis, fit with the existing aims of the approved research project, which all participants consented to (please find my proposal attached, for reference, if required). In addition, informed consent for secondary analysis was specifically sought and granted for all participants in the Making Positive Moves research project.

I would be grateful if you could advise of whether it is necessary for me to register my study with the UH ethics committee.

Please do not hesitate to contact if further clarification is required.

*Best wishes,
Olivia*

Response from UH Ethics Committee received on 06/05/22:

Morning Olivia,

We just need to see the consent form which was used which confirms that participants have agreed to secondary analysis of the data for completeness.

Please sent this across, I can't seem to find this on record.

Best,
[staff member University of Hertfordshire Ethics Committee]
Response from the researcher, sent 06/05/22:

Good morning,

Many thanks for your response.

Please find the consent for participants attached (permission for this is at the bottom of the form).

Only participants who have consented to this will be used in the study.

Please can you inform whether this project needs to be registered with UH ethics, or whether we can proceed without this?

Many thanks,
Olivia

Responses from UH Ethics Committee on 10/05/22:

Morning Olivia,

If you are only analysing secondary data from an existing protocol and consent allows you to do so, as evidenced, then no you do not need any further approval paperwork. Analysis of secondary data does not require ethics approval or a protocol number.

Many Thanks,
[Governance Services Administrator (Ethics)]

Governance Services Administrator (Ethics)
Governance Services
University of Hertfordshire

Appendix J: Information Sheet- for participant who has moved

Making Positive Moves research study

IRAS reference number: 200695

Would you like to help find things out about living in the community after moving out of hospital?

Our names are [insert names and pictures of research assistant and research fellow]. We are researchers at the University of Hertfordshire.



We want to talk to people who have moved out of hospital. This will help us find things out about what helps people to stay living in the community.



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

Contents



1. What do we want to find out?

2. How will we find things out?

3. Saying 'yes' or 'no'.

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

5. What happens after taking part?

6. Who can I contact?



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

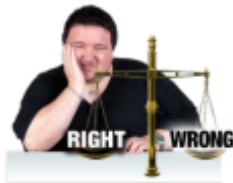
1. What do we want to find out?



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



We would like to hear the stories of people who have moved out of hospital to find out more about their lives in the community.



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



We will start finding things out now. We will finish in three years – 2023

2. How will we find things out?



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

We can contact you by telephone or video call.

It is up to you.



We will ask you if it is ok for us to speak to someone who knows you well.

This might be a family member or a carer.

We would like to talk to them about the best ways we can work together.



You can ask us questions.



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



We will ask you some questions about yourself, where you live now and where you used to live.



Don't worry if you don't know the answer to all the questions.

We can ask someone who knows you well, for example a friend, family member, carer or someone from Transforming Care



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



We will ask you questions about your life since moving out of hospital.



We will have a second **interview**.

You can choose if you want someone who knows you well to come to our second meeting.

We will ask them questions too.



Or we will have our second **interview** on our own.

It is up to you.



The information you talk to us about is private.

In the reports we will not use your name so no one will be able to know it is about you.

This means it is **confidential**.



We will contact you again in one year to ask you more questions about your life

3. Saying 'yes' or 'no'.



You do not have to take part.

It is your choice. It is up to you to decide.



You can talk to other people to help you choose.



If you want to take part we will ask you to sign a consent form.

This means saying "yes, I agree."



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



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



You do not have to give a reason for saying "no".

Saying "no" will not change how people treat you.



If you choose to say "no" at any time you can contact us to tell us.



If you choose to say “no” within 7 days of an interview we can take data from that interview out of the research.



If you choose to say “no” more than 7 days after an interview we will still use what you have told us in our research.

4. More details if you want to say ‘yes’



So that we can hear your story, it is important we talk to just you for the first **interview**.

But it is ok for someone you know to be outside the door or in the next room, or they can be in the same room as you



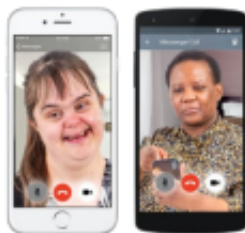
We will **interview** you by asking you questions.



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

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

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



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



We might meet for one or two hours.

The information you talk to us about is private.



No one will be able to know it is about you in the reports.

This means it is **confidential**.



You can choose to have a break.



Remember, you can choose to say "no" to taking part.



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

5. What happens after taking part?



We will type up the **interviews** on a computer.



We will change information, like your name.

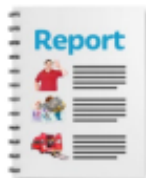
The information will be **anonymous**– this means no-one will know it is you.

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



We might write about things that you said.

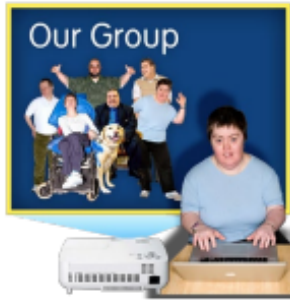
We will not use your name.



We will write a report about what we have found out.



We will put things on a website.



We will talk about what we found out at **conferences.**

This is a big meeting where lots of staff and people with learning disabilities will find out what it is like to move out of hospital.



We will send you a letter to let you know what we found out.

Appendix K: Record for Assessing Consent

Making Positive Moves

Record sheet for assessing consent

IRAS reference number: 200695

Time 1: First information meeting

Date:.....

Researcher's name:

What are the signs that the person has understood information?

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

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

Signs that the person is not listening / has not understood	Was this happening (please tick)	Details
Is the person unengaged with the researcher or conversation? Are they avoiding eye contact? Do they seem indifferent?		
Are there concerns that the person is acquiescing with the researcher? Do they agree to things without clearly understanding?		
Do they appear to be ambivalent or disinterested? Any negative non verbal signs, such as facial expressions?		

Time 1: Second information meeting

Date:.....

Researcher's name:

How much can the person remember about the project?

Researcher's name

Any non verbal signs they are interested – for example, nodding?		
--	--	--

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

Signs that the person is not listening / has not understood	Was this happening (please tick)	Details
Is the person unengaged with the researcher or conversation? Are they avoiding eye contact? Do they seem indifferent?		
Are there concerns that the person is acquiescing with the researcher? Do they agree to things without clearly understanding?		
Do they appear to be ambivalent or disinterested? Any negative nonverbal signs, such as facial expressions?		

Please note any changes during either Interview 1 or Interview 2:

Appendix L: Information Sheet for KSP

Making Positive Moves Research Study

Information sheet for participating as a Key Support Person (KSP)

IRAS Reference Number: 200695

What is this information sheet for?

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

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

Background to the research

Following reports of abuse at long-stay hospitals and treatment units, NHS England introduced the Transforming Care programme in 2011. This programme hopes to support people to move out of inappropriate hospital placements, and to find them accommodation and support in the community. Currently there is little research into how people who have moved under the Transforming Care programme have found their experiences.

What is the purpose of the research?

For this research project we are interviewing people with Intellectual Disabilities who have moved as part of the Transforming Care programme. We hope to find out about people's lives in the community after moving and to increase clinicians' understanding of what helps people to successfully remain living in the community after discharge from hospital. On the whole there is very little research which focuses solely on the stories of people with intellectual disabilities, rather than for example their carers or professionals. As such this research hopes to allow people with intellectual disabilities to contribute more to research about their lives.

Being a Key Support Person

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

If you have any questions about the project, you can contact us using the details later on in this information sheet. The choice whether to participate is completely up to you, and you would be able to withdraw from the study at any time. Furthermore, there are no expectations

that you should take part if nominated; whether or not you participate will not affect the person's data in any way. If you choose to participate, we will ask you to read and sign a consent form.

For the interview, we will meet with you and the participant via telephone or video call. We will ask you broad questions about the person's experience of life in the community after moving under the Transforming Care programme; these questions will ask you to 'step into the shoes' of the person and try to answer from their perspective. They will then be interviewed as well to respond to what you have said about their experiences.

An interview will typically last between 1-2 hours. The interviews will be recorded, and will be transcribed.

Are there any disadvantages to taking part in this research?

It is unlikely that you, as the Key Support Person, will experience any disadvantages or risks from taking part in the visit.

What happens after the interview?

We will make the transcripts anonymous by changing any identifiable information, such as names. We will use the transcripts of the interview data to help me to understand what helps people to remain living in the community after discharge from hospital.

As part of the research we will write a research report from the findings of the study. This will be submitted to the National Institute for Health Research. To enable the findings from this research project to be used to inform other clinicians about best practice or recommendations for supporting people after moving, we will share our findings in academic journals, through newsletters and at meetings.

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

We will send a report about the study to you at the end of the project.

Is it compulsory to take part?

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

Will your information be kept confidential?

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

The recordings will be stored securely on password-protected computers. Consent forms and recordings will be destroyed 12 months after the study has ended. The anonymised transcripts will be saved on a laptop as password protected documents, and will be destroyed 5 years after the study ends.

Hertfordshire Partnership University NHS Foundation Trust and University of Hertfordshire (both based in the United Kingdom) are the Sponsors and will act as the data controllers for the study. This means we are responsible for looking after your information and using it properly.

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

What will happen if you chose to withdraw?

If you would like to stop participating in the study at any time, please contact one of the research team using the contact details below. If you contact us within 7 days of an interview we can withdraw the data from that interview from the study. If it has been more than 7 days since you were interviewed we will continue to use the data you have supplied but we will make no further contact with you regarding the research (unless requested by you).

Who has reviewed this study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee. This committee is here to protect your interests. This study has been approved by a Research Ethics Committee (16/LO/0816; IRAS reference number: 200695).

This research is being conducted under the Research for Patient Benefit stream of the National Institute for Health Research.

Who to contact

[insert name and contact details of research assistant]

[insert name and contact details of research fellow]

Dr Silvana Mengoni
Academic Lead, University of Hertfordshire
Tel: 01707 284494
Email: s.mengoni@herts.ac.uk

Dr Louisa Rhodes

Clinical Psychologist and Chief Investigator, Hertfordshire Partnership University Foundation NHS Trust
Email: louisa.rhodes@nhs.net

What if there is a problem?

If you have any concern about any aspects of this study, you should ask to speak to the Chief Investigator (Dr Louisa Rhodes) who will do their best to answer your questions (louisa.rhodes@nhs.net).

The sponsors of the study are the University of Hertfordshire and Hertfordshire Partnership University NHS Foundation Trust (HPFT). You may also contact the representatives of the sponsors if you have any concerns or complaints:

Professor J M Senior, Pro Vice-Chancellor (Research and International), University of Hertfordshire,

j.m.senior@herts.ac.uk

Professor T M Gale, Lead, Research & Development Department, Hertfordshire Partnership University Foundation Trust, t.gale@herts.ac.uk

The Data Protection Officer at the University of Hertfordshire can be contacted by email (dataprotection@herts.ac.uk) or telephone (01707 284000)

You can also contact your local Patient Advice and Liaison Service (PALS):

{details to be inserted for each Trust}

General Data Protection Regulation (GDPR) information**How will we use information about you?**

We will need to use information from you for this research project.

This information will include your name and contact details. People will use this information to do the research or to check your records to make sure that the research is being done properly. Your name and contact details will not be on your transcript, this will have a code number instead.

We will keep all information about you safe and secure.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

What are your choices about how your information is used?

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.

If you agree to take part in this study, you will have the option to take part in future research using your data saved from this study.

Where can you find out more about how your information is used?

You can find out more about how we use your information at the websites below or by asking one of the research team on the contact details above

www.hra.nhs.uk/information-about-patients/

www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/data-protection-and-information-governance/gdpr-guidance/templates/template-wording-for-generic-information-document/

Appendix M: Consent form for KSP

To note: consent for use of data in subsequent studies included within this form.

Making Positive Moves Research Study

Consent form for KSP

IRAS reference number: 200695

- I have seen and read the information sheet dated {insert date and version number}, and had the chance to have my questions answered.
- I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.
- I have been given contact information for the research team involved in the project.
- I understand the aims of the project, and what my involvement will be.
- I understand that if I decide to withdraw more than 1 week after an interview has taken place, my data will still be used in the study.
- I understand that the information I discuss will be confidential. The limits of this confidentiality have been fully explained to me.
- I understand that the interviews will be recorded. These recordings will be stored password protected on a password-protected laptop and will be permanently deleted after the transcriptions have been completed and checked. .
- I understand that typed information about the person I care for, myself and others will be fully anonymised.
- I understand that information from the interviews, including direct quotations, may be used in a report for the National Institute for Health Research under the Research for Patient Benefit stream.
- I agree that information I provide as part of the project (including anonymised direct quotations) may be shared through publications and presentations.
- I give my consent to taking part in the present research study.**

Name of Participant

Date

Signature

_____	_____	_____
Name of Person taking consent	Date	Signature

Additional consent:

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

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

One copy of the consent form to be kept by the participant and one copy to be kept by the researcher.

Appendix N: Notes taken from consultation meeting with the EECG (Experts by Experience in Making Positive Moves Study)

Date of meeting: 07/07/22

Below are the notes I took from what the advisors shared at the meeting. I frequently checked I had understood what they meant as the meeting progressed.

Ideas shared around 'Value of Freedom' initial theme cluster:

- It's the freedom to make choices
- It's about staff knowing you well so they can help you make choices, if you want that
- Freedom is a right, not a service
- Getting your independence back is having the freedom to make choices
- The charity 'Stay Up Late' talks about this when they talk about not rushing people home

Ideas around 'Feeling Equal' initial theme cluster:

- It's about being able to be part of a community
- It's about earning respect, doing stuff with people, not being babysat by staff, they're doing it with you
- Being part of the community is not the feeling of "them and us"
- People talking to you when you are out

Ideas suggested that made me think of possible clinical/societal implications for the data:

- The things around you matter for your independence
 - Transport- what it allows you to do and what it doesn't allow you to do
 - Where people live- what is it like? Is it a town or city that helps them to go places?
- Let people stay up late, don't rush them home. They might need help to stay up late and support to meet people.
- Members of the EECG told me to look at the 'Good Lives' package, which is a document produced on the basis of views of self-advocates with ID and autistic self-advocates, which details views and recommendations for the promotion of 'good lives'. Being signposted to this document also really helped me when thinking about the study's implications (e.g., the diverse ways people can 'contribute' that aren't based on normative assumptions)<https://www.learningdisabilityengland.org.uk/what-members-are-saying-and-doing/good-lives-building-change-together/>.

Appendix O: Examples of presentation of initial theme clusters to EEGG members

Presentation of ideas around initial theme clustering 'everyday activities':

Things People Do



- Go to work
 - Voluntary
 - Paid



- Meet new people



- Learn new things

Presentation of ideas around initial theme cluster 'Feeling Equal':



Feeling Equal

- Walking with staff



- Staff don't wear uniform



- Going to the gym and talking about training with people. We are the same.

Appendix P: Excerpt from reflective diary: notes made in 'familiarisation' stage of data analysis

Entry made on 18th May, 2022

- ***There's some sort of pattern around being part of something***
 - *Pamela uses the striking metaphor: I didn't have my head up, I had it down (when out in public). Now she has her head up. -> could be speaking about confidence/shyness-> but also seems like she is speaking about now being part of something.... Not being inferior anymore- being part of society.... She doesn't have to walk behind staff now... Something about having closer relationships now, having company, having a company that feelings on an equal footing to her?*
 - *Clive seems to be known by others in the community... it seems important to him. Is this 'real' connection with people? Is this inclusion or a sign that he is so excluded that this is what I am paying attention to. He speaks of this fondly, he gives more spontaneous comments than the rest of the interview... The people in the pub seem to notice the things he likes- his favourite apple pie- signs of affection? Signs he is known?. I'm reminded of ideas that people spoke about in the Coronavirus pandemic of the comfort of 'familiar strangers'- perhaps this is connection; connection that helps him feel included.*

Appendix R: Excerpt from reflective diary: decisions made during the coding process

Entry made on 3rd June, 2022, following supervision meeting:

- **Reflections on codes for people 'having a fixed range of activities' or 'being grouped for activities'**

We thought about Braun and Clarke's recommended reflexive questioning, about how I might feel if I was in this situation, what social norms I am seeing the data through? I have noticed that some participants seem to have quite a fixed range of activities to choose from, seemingly offered by their support provider. I have a strong (fairly negative) initial reaction when I hear people listing the choice of cinema, bowling or pool which I think comes from when I used to volunteer as a support worker, and these activities were just alternated for people, with so little freedom and choice. But this isn't necessarily what is being described in THIS data- the participants don't seem to feel restricted by these less flexible choice of activities.

We thought about how it's important that my own feelings about a choice of bowling or golf etc. don't dominate, but the also the interpretation that perhaps he's become so accustomed to this lack of choice (e.g., lots of time in hospital- 21 years) that he is less aware of his right to choose/is very accustomed to this way of being. There is something about the idea that different levels of choice suit different people- maybe having full range to instigate things yourself doesn't suit everyone and being able to choose from fixed range suits some. I need to not jump to themes at this stage, however, and focus on what the data is saying in relation to these codes. The code "Choosing from fixed range of activities"/"being grouped for activities" doesn't necessarily have a negative connotation, and I need to be careful that the framing of these codes doesn't suggest it is negative/restrictive for people, as that is not what they are saying.

Appendix S: List of initial themes and sub-themes

Screenshot taken from NVivo software. 'Experiences with Freedom', 'Feeling Safe', 'Recognising my Value (in society)' and 'Valuing Support from Others' and 'Everyday Living' were initial main themes. The folders beneath each main-theme are the initial sub-themes.

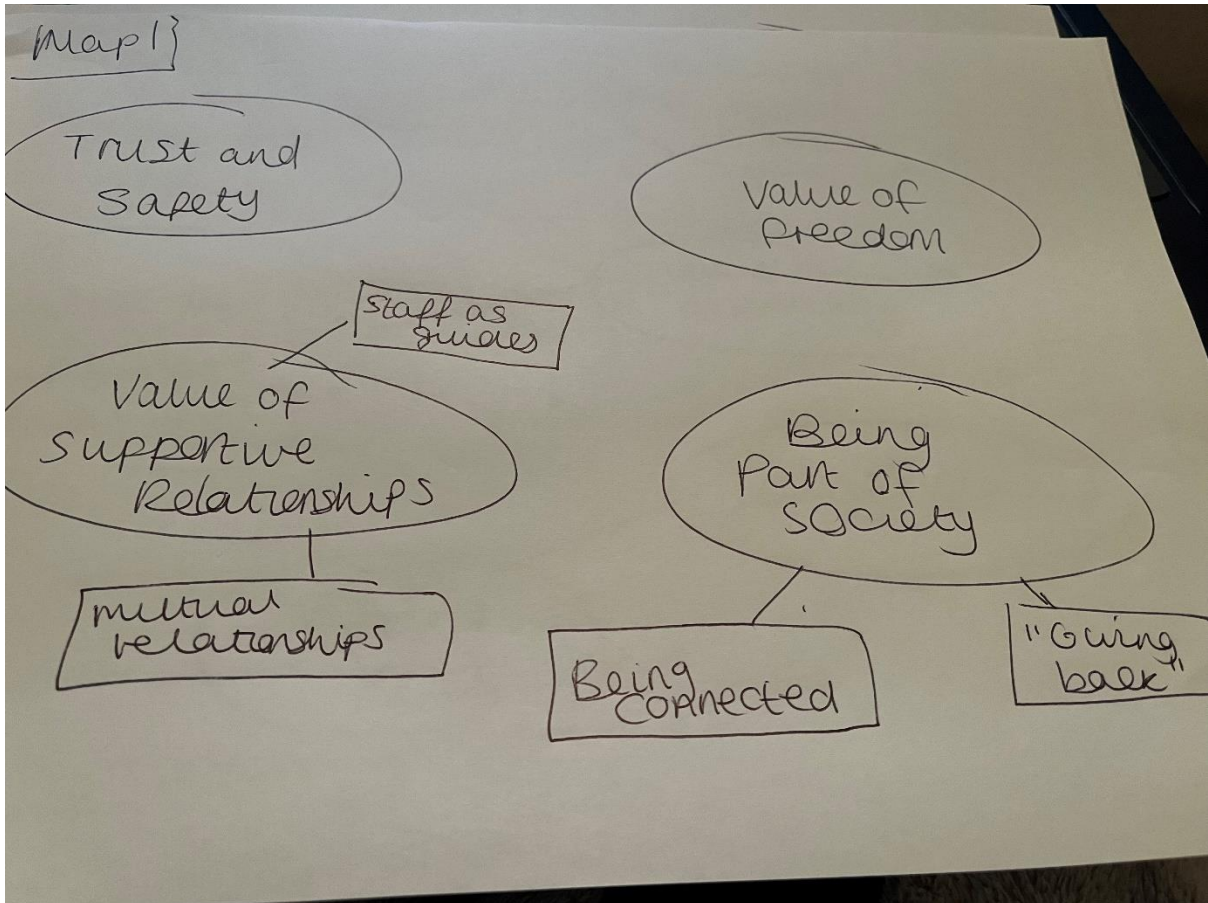
- ▶ Experiences with Freedom
- ▲ Feeling Safe
 - ▶ Through Autonomy
 - ▶ Through Relationships
- ▲ Recognising my Value (in society)
 - ▶ Feeling connected
 - ▶ Feeling Equal
 - ▶ The way others see me
 - ▶ Through 'giving back'
 - ▶ Through my sense of achievement
- ▲ Valuing Support from Others
 - ▶ Facing challenges with others
 - ▶ Support staff as guides
 - ▶ The value of mutuality
- ▶ Everyday Living
 - ▶ Connecting with others
 - ▶ Leisure
 - ▶ Personal development
 - ▶ Work

Appendix T: Process of Evolving Thematic Maps in Data Analysis

Separate thematic maps were developed around different aspects of the data: 'How Everyday Life is Spent' and 'How everyday life is Experienced'. Below shows the development of the latter.

Map 1- 'How Everyday Life is Experienced'

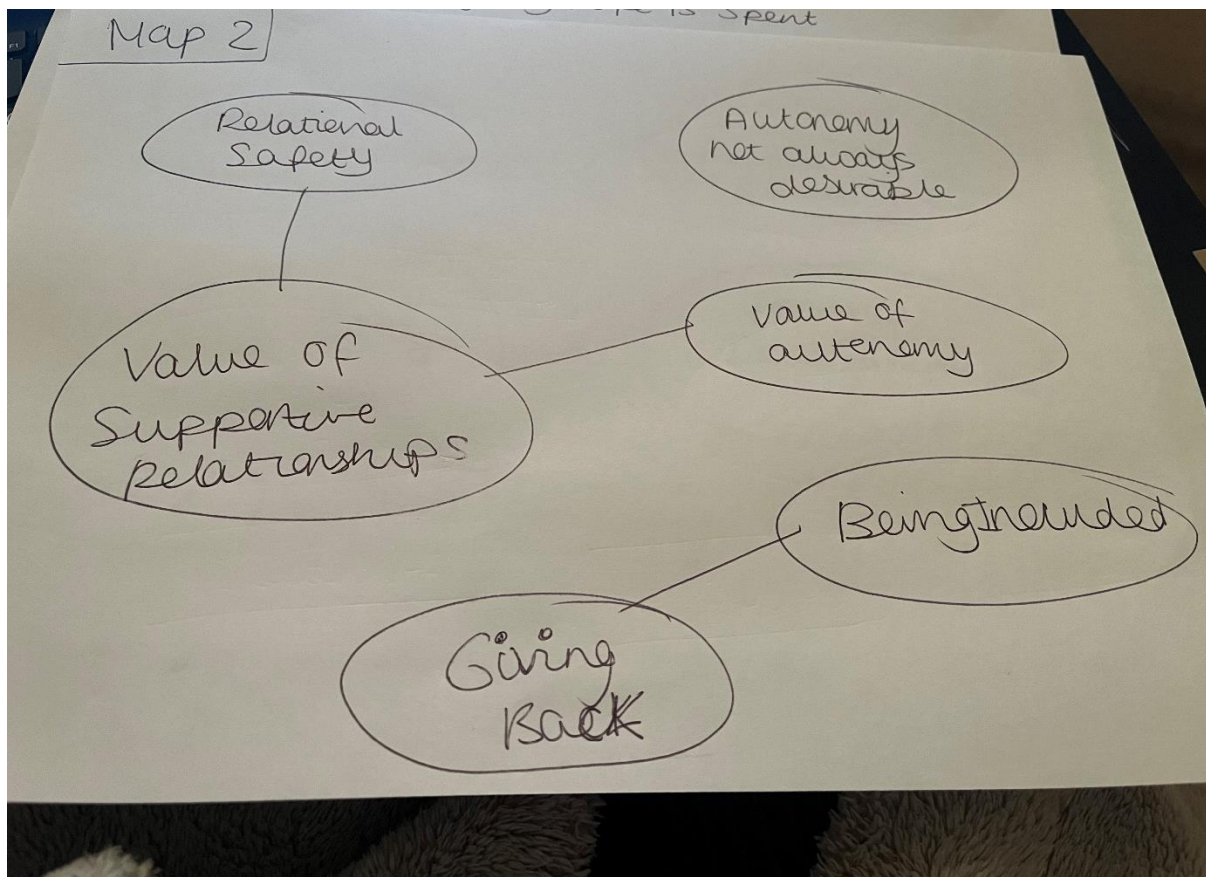
Main themes are depicted in ovals, sub-themes are depicted in rectangles.



Map 2- 'How Everyday Life is Experienced'

Consultation with EECG changed conceptualisation of theme 'value of freedom' to 'value of autonomy', which included codes broadly related to choice and control; links between themes 'value of autonomy' and 'value of supportive relationships' were made.

Critically engaged conversations with supervisory team helped me recognise I was neglecting codes around stories of continued struggle, such as the continual impacts of hospital and how this seemed to place (mostly internalised) restrictions on people's autonomy. We thought about how I might be being more drawn to stories of success (i.e., life enhancing factors) in the data, which there were many, but there was also ongoing impact of hospital. The them 'Autonomy not always desirable' was added



Map 3- 'How Everyday Life is Experienced'

It was recognised that not all continued impacts of hospital related specifically to experiences of restricted autonomy, therefore the theme was reconceptualised to capture broader lasting social and psychological impacts of hospital ('Continued Impact of Hospital').

