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Experiences of people with mild learning disabilities in Scottish supported living settings

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Experiences of people with mild learning disabilities in Scottish supported living settings

Fellex Mediseni

A thesis submitted in partial fulfilment of the requirements of Sheffield Hallam University for
the degree of Doctor of Philosophy

May 2025

Candidate Declaration

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Abstract

Background & problem

In Scotland, supported living housing schemes are regarded as a viable option for people with learning disabilities who transition from large hospitals to community-based living, where they receive care and support from paid support workers, enabling them to live independently. However, there were cases of failed placements of specific individuals with learning disabilities moving into supported living, resulting in readmissions of those affected into the hospital wards for people with learning disabilities. It turned out that the underlying bigger challenge was the under-researched experiences of support for residents in supported living settings. The main objective of this qualitative study was to investigate the experiences of support for individuals with mild learning disabilities in Scottish supported living settings.

Methodology

Data collection incorporated semi-structured interviews, participant observations, field notes, and reflexive notes. The semi-structured interviews involved 16 participants, including six service users and their support staff: one care support worker, four senior care support workers, and five Assistant Care & Support Workers. Participant observations included 18 individuals: six service users, eight care support workers, and four senior care support workers within supported living environments. All data were analysed using reflective thematic analysis.

Key Findings

The key findings on service users' experiences with support are organised into four themes: personalised approach, valued social support, positive impact, and challenges. Service users' findings were confirmed through discussions, which included perspectives from their support managers, focusing on overarching themes such as support culture, organizational readiness, service users' needs and expectations, and an optimistic outlook. These perspectives offered valuable insights and a deeper understanding of service users' experiences with support.

Implications: These findings were insightful. The social and practical implications of conducting research with people with learning disabilities, and the ethical implications involved in respectfully using FE in supported living settings. The implication opened new avenues for future research. It contributed to the study's feasibility by drawing on the existing body of knowledge about experiences with support in supported living settings.

Future Research

This study provides a strong foundation for future research. It suggests a broader scope for future studies involving participants from other support providers to enrich our current understanding of the experiences of support, thereby continuing to improve quality of life in supported living settings.

Conclusion

This study showed that individualised and person-centred approaches are vital for the positive experiences of support for people with learning disabilities in supported living settings. The study demonstrated that with proper preparation, appropriate documentation, and methodology, people with learning disabilities can participate in research as a platform for their voice on their experiences of support, needs, and choices in Scottish supported living settings towards their social inclusion and community alongside mainstream populations.

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Table 1.1: List of Abbreviations

| | |
|--------|---|
| AAIDD | American Association on Intellectual & Development Disabilities |
| AC&SWs | Assistant Care and Support Managers |
| ADHD | Attention Deficit Hyperactivity Disorder |
| ADP | Adult Disability Payment |
| ADL | Activities Of Daily Living |
| ANZ | Aotearoa New Zealand |
| ASSIA | Applied Social Sciences Index & Abstracts |
| BBC | British Broadcasting Corporation |
| CINAHL | Cumulative Index to Nursing and Allied Health Literature |
| COREQ | Consolidated Criteria for Reporting Qualitative Research |
| CPA | Care Programme Approach |
| CRPD | Convention of the Rights of Persons with Disabilities |
| CSW | Care Support Worker |
| CSWs | Care Support Workers |
| DSM-5 | Diagnostic and Statistical Manual of Mental Disorders |
| DLA | Disability Living Allowance |
| DLS | Daily Living Skills |
| FE | Focused Ethnography |
| FINER | Feasible, Interesting, Novel, Ethical, and Relevant, |
| GDPR | General Data Protection Regulation |
| HMO | House in multiple occupation |
| HSCP | Health and Social Care Partnerships |
| IADL | Instrumental Activities of Daily Living |
| ICF | International Classification of Functioning |
| IRAS | Integrated Research Application System |
| IPA | Interpretative Phenomenological Analysis |
| JBI | Joanna Briggs Institute |
| MDT | Multidisciplinary Team |
| NHS | National Health System |

| | |
|------------|--|
| PAAR | Participatory Appreciative Action and Reflection |
| PCC | Person-Centred Care |
| PIP | Personal Independence Payment |
| PPI | Public and Patient Involvement |
| PRISMA-ScR | Preferred Reporting Items for Systematic Reviews and Meta-Analyses |
| PsycINFO | Psychological Information Database |
| RCN | Royal College of Nursing |
| SCSW(s) | Senior Care Support Worker(s) |
| SCSW | Senior Care Support Worker |
| SCW | Support Care Worker |
| SCW(s) | Support Care Worker(s) |
| SHU | Xxxx University |
| TA | Thematic Analysis |
| UREC | University's Research Ethics Committee |
| UK | United Kingdom |
| WHO | World Health Organisation |

Chapter 1

Introduction

1.1 Background

This research study critically analyses diverse perspectives and experiences of people with mild learning disabilities living in supported living in Scotland. Scottish supported living settings provide housing and support arrangements for individuals with learning disabilities, enabling them to live in flats as individual tenants, in shared accommodation, or in core and cluster arrangements with staff on-site, 24 hours a day (McPherson et al., 2018). Accommodation is often provided by local housing associations, charities, social enterprises, and private care providers (Harrison et al., 2024). The Scottish housing and social services account for over half and a third of sector organisation income, with a budget allocation totalling £3.2 billion (Findlay & McQuarrie, 2023). This demonstrates the Scottish government's commitment to the welfare of individuals with learning disabilities in supported living settings.

Supported living is an ongoing part of the national transformation of care aimed at promoting independence through person-centred care, enabling individuals with learning disabilities to live within their communities with appropriate support. The motivation for this study initially arose from the researcher's observations as a registered learning disability nurse in the learning disabilities inpatient wards, involving individual cases of failed community placements for certain patients from supported living. Failed community placement describes the situation where individuals with learning disabilities fail to live in supported living due to numerous factors and end up being placed in a supported living setting, which cannot sustain their placements successfully, such as relocation to a hospital, institutional care, or an out-of-area placement (Phillips & Rose, 2010; Allen, 1999). The specific reasons include avoidant behaviours, less suitable social environments, poorer overall quality of life, and a lack of external support and advice from specialist services, which sometimes lead to challenging behaviour towards support staff (Broadhurst & Mansell, 2007; Allen, 1999). As a matter of policy for the discharging Trust, and depending on the patient's circumstances, the bed space would be kept open from one to four weeks in the case of a failed community placement, which may require immediate readmission to the hospital.

The chapter opens with the research problem, aims and objectives, background, clarification of learning and intellectual disabilities, the voice of people with learning disabilities, the Scottish context, and the study's potential significance.

1.2 Research problem

Supported living for people with a learning disability is a progressive idea that promotes personal identity and independence by customising housing services to meet the tenant's requirements. It involves regular homes or apartment flats throughout neighbourhoods, either as individual units or in clusters of self-contained residences, all with 24-hour supervision (McConkey, 2007). The community placement of supported living utilises the theoretical construct of 'goodness of fit' to describe the match between client needs and the nature of available placement (Heilbrum et al., 1994). The concept of goodness of fit is applicable in social care. It involves determining and matching a client's needs, such as abilities, values, interests, and personal objectives, with the resources of community placements, including support services, community culture, and additional assets, within a community setting. This alignment is crucial for achieving the client's long-term objectives. When a client's personal characteristics, needs, and objectives align well with the available resources and environment of the community placement, it leads to a better fit, often resulting in positive outcomes and tremendous success for the client in social care settings.

Supported living empowers people with learning disabilities to build a sense of identity while expanding their choices and participation in meaningful activities and roles within the community (Piat et al., 2020). Evidence of beneficial outcomes includes improved social inclusion (Killaspy et al., 2016) and reduced hospitalisation (Kyle & Dun Barts, 2007). This approach empowers individuals to choose where they live, whom they live with, how they receive support, and what happens in their homes. As of 2019, in Xxxx , there were 3,446 individuals with learning disabilities living in supported settings, accounting for 14.7% of the 23,584 individuals with learning disabilities known to local authorities (Scottish Commission for People with Learning Disability, 2019). However, there have been cases of failed community placements for certain patients with learning disabilities in supported living, which have led to their readmissions to inpatient care. At the time of commencing the thesis, the researcher was a member of the hospital multidisciplinary team responsible for placing eligible patients with a learning disability into supported living.

Some of these challenges seem intuitively evident, but they were primarily based on anecdotal observations rather than empirical evidence. One of the challenges is illustrated by an example known to the researcher where a community placement failed. This relates to a 35-year-old female patient who spent 20 years in a learning disabilities ward in the hospital, under institutional conditions and restrictions. Despite collaborative preparations for her community placement in a supported living, a few weeks into this supported living, she had an altercation with her neighbours. Police were involved, but the details of the incident remained unclear. She was readmitted to the hospital and subsequently lost her tenancy; however, her neighbours were unaffected.

Being placed in a supportive living environment among strangers is likely to have been traumatic for this person after being in the hospital for a long time. Trauma is an exposure to actual or threatened death, serious injury, or sexual violence (American Psychiatric Association, 2013). Leaving institutional care can be overwhelming, and without suitable housing options, individuals might end up in unstable living conditions. The patient's readmission may have caused the risk of re-traumatisation and disempowerment (Harris & Fallot, 2001). The re-traumatisation was from readmission of going back to institutional care and the disempowerment of losing her independence and autonomy during her short-lived stay in supported living. Such traumatic experiences can have enduring effects on a person's behaviours, emotions, and overall health (Sweeney et al., 2016). Similar incidents along a related path would fit the criteria for trauma. The challenges associated with supported living arrangements have become a significant concern, as they undermine the aspirations of affected individuals.

The second challenge is that the "voice" of individuals with learning disabilities is not always heard. Unlike institutional care, where individuals are housed in extensive, centralised facilities, supported living includes geographically dispersed houses or flats in urban areas. Upon hospital discharge, patients were placed in different residential places under different support providers. However, there were efforts to capture the views of individuals who received social care support, but this was not always straightforward. People with learning disabilities are regarded as vulnerable and may feel anxious, fearful, or uncomfortable expressing their views on social issues (Cheah et al., 2023). They are a marginalised, vulnerable group whose views are often overlooked (Lewis et al., 2021; Cheah, 2019). Service users must be regarded as "experts by experience" to gain greater control over their care and support (Social Care Institute for Excellence, 2011). The term "experts by

experience” refers to individuals who have lived through specific situations and can provide valuable insights, not from formal education but from first-hand involvement. Each patient shared a story about their experiences living in the old, corrugated hospital buildings, highlighting that individuals who live under such circumstances possess profound knowledge about hospital life and the challenges of waiting for community placement.

After observing several instances in his practice, the researcher focused on failed community placements. Failed placements occur when a patient’s needs do not align with the placement requirements. For those fortunate enough to be placed in the community, the experience was often short-lived and led to hospital readmission. Despite increased attention, the perspectives of individuals with learning disabilities are frequently overlooked, and their experiences with support remain under-recognised. Further research is required to address this gap.

1.3 Research Motivation

1.3.1 Personal level

The motivation for conducting this study stems from both personal and professional perspectives. First, the researcher’s motivation was driven by personal curiosity about understanding how the individuals with mild-moderate learning disabilities support meets their needs, promotes autonomy, and respects their choices. As a learning disabilities nurse in practice, each working day, the conversations revolved around sensitive disclosures of patients’ personal matters, lives, families, and untold stories. The researcher felt privileged to support this marginalised population, yet there was a realisation that community placements significantly shaped the patients’ lives. The cases of failed placements signified the unexplored phenomena of support of individuals with mild-moderate learning disabilities, whose diagnosis is not obvious, but can lead to misunderstandings from others, even when they are generally able to perform most everyday tasks independently.

The researcher felt some individuals with mild-moderate disabilities were sometimes unnoticed or confused because others may still perform adequately in many aspects of their lives in supported living. Yet, others faced the wrath of stigma and were labelled. People with mild learning disabilities may be misunderstood or labelled. Labels may confer eligibility for rights, services, and resources, but may also exclude or marginalise. Labels may suggest belonging and pride or rejection and stigmatisation. Swain et al. (2003) acknowledged that the label of ‘disability’ is often socially laden with negative connotations, reflecting “dominant discourses of tragedy and inferiority”. The categorisation is socially constructed

under the medical labels and diagnoses, often giving the appearance of being rational and neutral because they are ‘discovered’ and interpreted by prestigious professions, such as psychology (Powell, 2003). The medical model concentrates on the biophysical anomalies and overlooks the fact that the experience of people with learning disabilities can vary drastically depending on the culture and social structure (Ho, 2004). It became a personal matter, given that there was very little that those affected could change. The researcher’s analysis of a situation, compounded by the diagnosis of learning disabilities, and the social construction of the labels evoked ambivalence and a resolve to augment the focus on the support experiences of people with mild-moderate learning disabilities in supported living settings.

1.3.2 Professional level

Secondly, the motivation for this study stemmed from the researcher’s professional environment. The researcher felt motivated to contribute to research findings for marginalised population groups. There appears to be a lack of research providing evidence for practice as late as the 1990s (Parahoo et al., 2000). Learning & Kerr (1997) observed that learning disabilities remain inadequately investigated. It was also noted that the review of the contribution of learning disabilities nurses has never been commissioned (Turnbull, 1997). However, that historical situation has since changed, and those observations were inspirational for this research on learning disabilities.

The partnership between health services (such as NHS Lothian) and social care (local authorities such as the local councils) motivated the researcher to investigate community placements for people with learning disabilities in supported living. The research community often provides opportunities for collaboration and interaction with other passionate individuals. Community placements for people with learning disabilities are ongoing, and over time, the results can be reinvested in supported living. The hope is that this PhD study will help dispel the myths, complexities, and challenges associated with conducting research with people with learning disabilities. It is intrinsically rewarding to be involved in improving the support experiences for people with mild-moderate learning disabilities in supported living environments.

Section 1.4 below outlines the study aim, research questions, and objectives, and explores the experiences of support in supported living among people with learning disabilities. The

background section contextualises the research problem, highlights its key issues, trends, and challenges.

1.4. Research Aim, Questions, and Objectives

1.4.1 Research Aim

To explore the experiences of support for adults with mild learning disabilities in supported living in the Lothian area.

1.4.2 Research Questions

- i. What are the experiences of support for adults with mild learning disabilities in supported living in Scotland?
- ii. What are staff perspectives on support for adults with mild learning disabilities in supported living?
- iii. What are the values of support for adults with mild learning disabilities in supported living?
- iv. How do contextual factors influence the culture of support in supported living?
- v. What are the implications of experiences of support for adults with mild learning disabilities in supported living?

1.4.3 Research Objectives

Objective 1: To describe the experiences of support for adults with mild learning disabilities residing in supportive accommodation.

Objective 2: To critically analyse the managers' and support workers' perspectives of support in supported living.

Objective 3: To evaluate the core values that guide the provision of support for adults with mild learning disabilities in supported living.

Objective 4: To draw implications from the experiences of support for adults with mild learning disabilities in supported living.

The background of this thesis draws from the research question and objectives, providing context and a foundation for the scope of the broader research conversation. Section 1.5 below begins the thesis by defining the key terms learning disability, intellectual disabilities, service users, and community placement.

1.5 Study standard terms

1.5.1 Learning disabilities

The following definitions provide context for readers. It is worth understanding the following terms used in this thesis: “learning disabilities”, “intellectual disabilities”, “service users”, and “community placement”. In the UK, the Valuing People White Paper on health and social care for people with learning disabilities uses the term ‘learning disabilities’ in the context of professional, academic, government legislation, and policy (Department of Health, 2001). For a definition of learning disabilities:

A significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning), which started before adulthood, with a lasting effect on development.
(Department of Health, 2001)

A learning disability is different for everyone. The degree of disability can vary greatly, classified as mild, moderate, severe, or profound. In all cases, a learning disability is a lifelong condition. In this context, intellectual disability is used in international literature as explained in Section 1.5.2 below.

This condition typically appears before the age of 18 and is characterised by limitations in conceptual, social, and practical skills. These difficulties may impact communication, self-care, academic abilities, social participation, and independent living. The condition often requires tailored support and interventions to help individuals achieve their full potential.

1.5.2 Intellectual disabilities

The term “intellectual disabilities” refers to a neuro-developmental disorder characterised by impaired cognitive functioning, which leads to significant limitations in adaptive behaviour. This condition typically appears before the age of 18 and is characterised by limitations in conceptual, social, and practical skills (American Psychiatric Association, 2022). These difficulties may impact communication, self-care, academic abilities, social participation, and independent living. The condition often requires tailored support and interventions to help individuals achieve their full potential. Understanding and explaining the meaning of intellectual disabilities helps minimise stereotypes and stigma, particularly when the research

involves vulnerable populations. Intellectual disabilities are more commonly used in academic literature in the United States of America (USA), including organisations such as the American Association on Intellectual and Developmental Disabilities (AAIDD) and the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) (American Psychiatric Association, 2013). This terminology is also recognised in Canada (Canadian Association of Community Living, 2017), Ireland (Inclusion Ireland, 2013), Australia, and New Zealand (Haggins, 2014). In summary, intellectual disabilities are crucial because they support the clarity, validity, ethical standards, and scholarly credibility of the entire thesis.

In the UK, the terms “learning disabilities” and “intellectual disabilities” are increasingly used interchangeably, with “learning disabilities” more prominent in professional discourse (British Institute of Learning Disabilities, 2017). However, in the USA, a distinction exists between “learning disabilities” and “intellectual disabilities”, where the former refers explicitly to difficulties in learning and comprehending abstract concepts (e.g., dyslexia, dysgraphia). In contrast, the UK often uses the term “learning difficulties” to describe challenges in specific areas of learning, even when individuals possess normal or above-average intellectual abilities.

Although some international literature uses the term “intellectual disabilities”, this thesis adopts “learning disabilities” because of its popularity in professional and academic literature, Scottish government legislation, and UK policy terminology, to ensure clarity and relevance to the supported living context. Furthermore, the term “learning disabilities” is used consistently throughout this thesis, in line with the Scottish Commission for Learning Disability (SCLD) and the Scottish Government’s positions.

1.5.3 Service users

Service users are individuals with learning disabilities who seek a role in how services are developed and delivered, as they are the sole beneficiaries (McLaughlin, 2009). The thesis exclusively uses the title "service user", reflecting the participants' preferred terminology within their support organisations and as the primary participants in this study.

1.5.4 Community placement

Community placement is an option for care for selected people with learning disabilities as an alternative to continued institutionalisation, where people are placed in supported living to provide a less restrictive and more normalised living environment (Sutter et al., 1981). It is

used to describe the transition of individuals with learning disabilities from hospitals to supported living in the community

1.6 Background

The background of this thesis relates to the context in which individuals with learning disabilities who had been living in large hospitals were placed in supported living. With the phased closure of extensive institutional services, adult social care has become a longer-term goal across the UK (Hudson, 2022; Bubb, 2014; Mencap and the Challenging Behaviour Foundation, 2012; Green, 2012). These individuals with learning disabilities reside in flats and receive varying forms of support in a homely, supported living environment (Meys et al., 2020; Bigby & Beadle-Brown, 2018). Other reasons for this move to supported living include issues of poor quality of life, mistreatment, and costly hospital services, with average weekly costs of £3,500 and annual costs of approximately £180,000 per person (Mencap, 2019; National Audit Office, 2017). Ongoing funding of an institutional model of care created a negative cycle of diverting funds to hospitals instead of community care (Montgomery & Cooper, 2024). In addition to improving the social and psychological issues of people with learning disabilities, it was logical to reduce the costs involved in institutional care.

1.7 Scottish Context

The middle of the 20th century marked significant changes in ideologies and guidelines for services aimed at people with mental and learning disabilities. Under the Mental Deficiency Act of 1913, individuals with learning disabilities could still be forced to live in asylums, with many never returning to their families. However, in the 21st century, societal awareness and understanding gradually evolved, leading to changes in policies related to learning disabilities. By the late 20th century, the perception of learning disabilities shifted toward recognising more issues related to learning, adaptation, and others' views (Jarrett, 2020). This was a milestone for the better things to come for people with learning disabilities.

The changes across Europe and the UK had an impact on the lives of people with learning disabilities in Scotland. Across Europe, deinstitutionalisation has led to the development of community-based living for people with learning disabilities (Sandhu et al., 2017). In the UK, the vision of normalisation has emerged as a dominant paradigm in policymaking. As articulated by Wolfensberger in 1972, the principle of normalisation is central to the development of humanistic rehabilitation services. Normalisation emphasises the importance of community participation and integrating individuals with learning disabilities into social

life, especially in supported living contexts (Verdonschot et al., 2009). This principle influenced the approach of upholding human rights and supporting the most disadvantaged members of local communities, who deserve to live as equal citizens.

Furthermore, Scotland supports the United Nations Convention on the Rights of Persons with Disabilities in advocating for individuals' full and active participation in society as a fundamental right (United Nations, 2006). Scotland's *Same as You* policy (Scottish Executive, 2000) exemplifies this commitment. It promotes key themes, including making choices, personal decision-making, and enjoying equal rights, establishing citizenship, fostering social inclusion, and promoting empowerment. Over the years, welfare for individuals with learning disabilities has undergone significant revisions (Stainton & Claire, 2012), with countries such as the UK and Australia focusing on enhancing individual needs and functional capabilities through similarly intended policies (Bigby, 2020).

The UK subscribes to the United Nations Convention on the Rights of Persons with Disabilities, which supports, protects, and promotes the human rights and freedoms of persons with disabilities (The United Nations, 2006). In Scotland, the *Same as You* policy (Scottish Executive, 2000) acknowledged the historic issues for people with learning disabilities. The Community Care Act of 1990 empowered local authorities and health boards to place eligible individuals with learning disabilities in community-based living arrangements. For example, there was a proliferation of supported living in the community and a transition for people with learning disabilities into community-based settings of supported living. Building on the *Same as You* policy (Scottish Executive, 2000), *Keys to Life* was adopted as a strategic policy to improve the lives of people with learning disabilities, advocating for their healthy lives, choice and control, independence, and active citizenship (Scottish Government, 2013). For continuation, the *Keys to Life Implementation Framework 2019-2021* (Scottish Government, 2013) proposed improving the lives of the population with learning disabilities (Scottish Commission for Learning Disability, 2019). A national strategy like this supports the social inclusion of individuals with learning disabilities in the broader community, enabling them to become more independent (McCarron et al., 2019). Promoting community inclusion and increased social inclusion aimed to improve health and social care, personal choices and control, and to give people with learning disabilities equal opportunities, rights, and access to services, enabling them to lead integrated lives.

Similarly, in health and social care, there has been a shift from hospital-based care to supporting people with learning disabilities in supported living schemes (Abbott &

McConkey, 2006). The NHS and Community Care Act 1990 led to the establishment of a range of supported living options, including those provided by local authorities and third-sector organisations. The outcome has been that more people with learning disabilities have become visible in supported living in communities (Tessa et al., 2017). Social care providers offer a range of community placements for people with learning disabilities in supported living, which are sometimes referred to as “Supported Housing”, “Supported Accommodation”, or “Supported Living”. The titles of these placements suggest different approaches adopted for establishing effectiveness, particularly in contrast to the standardised approach that aims to end institutional care through inflexible routines (Hope & Homes Organisation, 2019). Despite this reasonably noticeable change in communities, there is limited research evidence on the experiences of support for people with learning disabilities in supported living.

1.8 Rights-based approaches

People with learning disabilities and their advocates have always demanded fundamental rights to reduce inequalities. They insist on being recognised as individuals first, and having the autonomy to choose their support system, including who is part of their community who cares for them, and having the authority to make crucial life decisions (Van Loon & Van Hove, 2001; Lakin & Smull, 1995). The United Nations Convention on the Rights of Persons with Disabilities (Articles 3 & 4, UNCPRD) supports people with learning disabilities in research that promotes social inclusion and self-advocacy (United Nations, 2006). The maxims *"No researching about us without us"* (Jones et al., 2020) and *"Nothing about us without us"* (Charlton, 1988) underscore the importance of a participatory and inclusive approach, particularly for groups such as people with learning disabilities. The combined statements encapsulate the principle of directly involving marginalised groups affected by situations impacting their lives. The emphasis is on the importance of their voices being central in creating policies, services, and research that concern them. However, failure to fully acknowledge these fundamental rights remains evident in practice and has deprived some marginalised populations from having better lives (Whiteley et al., 2016). With the closure of the large institutions, there was a need for agencies to collaborate to support people with learning disabilities from becoming homeless and being readmitted to hospitals because of inadequate housing and support for those in the community. Ultimately, the Scottish Government's "Same as You?" (2000) and "The Keys to Life" (2013 and 2018)

acknowledged the need to support people with learning disabilities in living independently and in a supported way.

1.9 Supported living and normalisation

In supported living, the concepts of normalisation and Social Role Valorisation (SRV) have been central to the agenda of individuals with learning disabilities, promoting a transition away from life in large-scale institutions towards community-based living. The movement towards deinstitutionalisation has increased the number of individuals with learning disabilities living in community settings (Fakhoury & Priebe, 2007).

First, normalisation advocates for addressing the historical segregation and marginalisation of people with disabilities by shifting toward community-based support that recognises them as equal citizens in society (Culham & Nind, 2003). Normalisation challenges the medical and institutional models aimed at reducing segregation and institutionalisation by promoting inclusion and enabling individuals with disabilities to experience everyday life like that of the general population (Cocke, 2001). The implementation of policies associated with deinstitutionalisation has dominated the development of services for people with learning disabilities in most, although not all, of the world's wealthier countries (Braddock et al., 2001; Hatton & Emerson, 1995). The fundamental principle is that community living promotes normalisation (Burrell & Trip, 2011; Nirje, 1980; Wolfensberger, 1980) in various ways. As a guiding principle, normalisation emphasises that individuals with learning disabilities be treated with dignity and respect, be encouraged to participate in ordinary daily routines, and supported in making choices and exercising autonomy over their lives and time; they should be socially integrated into the community rather than isolated in institutions, and provided with development opportunities, including accessing education, relationships, work, and leisure that reflect typical developmental experiences (Wolfensberger, 1980).

The NHS also offers residential "places" for people with a learning disability. This includes all forms of residential provision operated by the NHS in which residents are formally "discharged" from hospital care. In Scotland, the living conditions in long-stay institutions influenced the design of new service provisions of supported living, guided by the principle of normalisation. In Scottish supported living settings, the normalisation principle is reflected in values such as inclusion, self-determination, and person-centred support. For example, instead of placing people with learning disabilities in an institution, normalisation supports them to live in homes in the community, going about their personal, day-to-day lives as the mainstream population, with jobs and leading ordinary life patterns. Normalisation provides

the typical life experiences to people with learning disabilities, some of whom had been denied in life in institutions.

Second, building on normalisation, the SRV theory (Wolfensberger, 1983) emphasises the significance of valued social roles in enhancing the lives of individuals at risk of social devaluation. The principles of SRV (Wolfensberger, 1983) emphasise how *social roles* affect society's perception and treatment of individuals. *Role enhancement* allows individuals with learning disabilities to develop *positive* and *socially valued values*. In addition, the *role and image* that fosters significant social connections are crucial. This encourages integration and participation in community activities by emphasising the importance of relationships towards fostering social connections and networks. SRV provides a framework for designing services that help individuals with disabilities or other marginalised conditions attain valued social roles, which leads to greater inclusion, respect, and quality of life. SRV emphasises the significance of societal perceptions, ensuring that individuals are treated with respect and afforded opportunities commensurate with their social roles. It also includes practical strategies such as supporting skills development, ensuring attractive personal presentation, and enabling contributions to community life.

In the context of Scottish supported living for people with mild learning disabilities, normalisation underpins the idea that supported living replicates the rhythms of ordinary home life and not institutional models. SRV explains why providing housing alone is insufficient; instead, it supports roles that foster values, such as being a responsible tenant, active community member, or a voluntary worker, which directly influence social integration and inclusion. Their normalisation and SRV have contributed to supporting the development of living services, particularly for people with learning disabilities, where the ideas first emerged.

The third development was O'Brien's Five Service Accomplishments, which provided the framework for person-centred planning and disability support services (O'Brien & Tyne, 1981), benefiting the lives of people with learning disabilities guided by the following principles:

- i Community presence plays a role in ensuring that individuals with learning disabilities are integrated into the same areas of the community as people without learning disabilities, whether at work or during recreational activities.

- ii The choices of supporting individuals with learning disabilities to make choices about their lives across various aspects and issues, while maximising their autonomy, involve a thoughtful balance of respect, empowerment, and practical support.
- iii Competence in encouraging the development of significant skills and abilities within the immediate culture helps reduce dependency on others.
- iv Respect afforded to individuals with learning disabilities from other community members by promoting lifestyles that convey positive images of people with learning disabilities.
- v Participation in assisting individuals with learning disabilities to maintain relationships with family members and form new connections with other people.

The five principles are used in disability support planning, inclusive knowledge, and community services. In this study, testimony indicated that the five service establishments were a crucial source of support for service users in their respective flats.

In the context of supported living, normalisation fosters environments in which individuals can exercise choice and control, integrate into their communities, and live as independently as possible while receiving necessary support. This approach has significantly contributed to the transition from institutional care models to more community-based support for individuals with disabilities.

In summary, supported living offers a practical approach that guides the normalisation concept, ensuring that people with learning disabilities are treated as equals and fully integrated members of society. These concepts have evolved from segregated, institutional care to environments in which everyone lives in the least restrictive manner possible.

1.10 Participation and Community Inclusion

The promotion of community participation and inclusion has become central to policy responses that shape services for people with learning disabilities across the UK and abroad. There is considerable evidence supporting the notion that living arrangements provide quality support, leading to positive life outcomes for people with learning disabilities (Mansell & Beadle-Brown, 2012; Walsh et al., 2010; Kozma et al., 2009). More encouragingly, supported living promotes autonomy, freedom of choice, and independence for people with learning disabilities (Wood & Greig, 2010). The shift involves transitioning from institutional care to receiving support in home-like environments within the framework of supported living (Lauren et al., 2010). It is, however, essential to acknowledge that, despite a policy commitment to inclusion, individuals with learning disabilities often face exclusion in their

lives (Filton et al., 2021; Harrison et al., 2021) and lack opportunities to participate in research (Lester & Nusbaum, 2018). This PhD study aims to provide a research platform for individuals with learning disabilities to share their experiences of support and have their voices heard. People with learning disabilities seek ownership of their circumstances to foster equitable and sustainable communities through participation and inclusion, allowing them to contribute their experiences and feel valued in supported living.

1.11 The voice

It is essential to give people with learning disabilities a voice to channel their views and concerns about their lives through research. Research can transform the lives of people with learning disabilities and those who support them. However, research has had a poor history of focusing on the voices and experiences of people with learning disabilities (Locock et al., 2022; Northway, 2000; Kaley et al., 2019; Cluley, 2017; Nind, 2014). There is evidence in the literature that, historically, people with learning disabilities have been excluded from research participation, partly to protect the vulnerable population (Crook et al., 2016).

There are several significant cases of mistreatment of people with a learning disability that have been deemed national scandals in institutional care in the UK. These prominent cases include Winterbourne View in England in 2011 (Flynn & Citarella, 2013) and Muckamore Abbey Hospital in Northern Ireland (Ireton, 2024; Coyle, 2022). In 2017, a British Broadcasting Corporation (BBC) Panorama programme investigated the abuse and neglect experienced by individuals in long-stay care settings, particularly highlighting the situation at Winterbourne View, a private hospital near Bristol. This facility closed later that same year after shocking revelations about the mistreatment of its patients came to light.

The Winterbourne View scandal exposed systemic failures to protect people with learning disabilities in institutional settings (McKitterick, 2016). As a result, it generated discussions about the ongoing marginalisation of people with learning disabilities within both the healthcare systems and societies abroad. The scandal advocated for greater inclusion and better care practices, which shape the discourse around learning disabilities today.

In 2017, a major scandal surrounding abuse at Muckamore Abbey Hospital drew widespread public attention. This was an inpatient assessment and treatment facility for people with learning disabilities and mental health needs in Northern Ireland, and the investigation found that, between the years 2012 and 2017 and 2017-18, 1,500 crimes related to the physical and psychological abuse of patients occurred (Coyle, 2022; Flynn et al., 2019). Some members of staff allegedly perpetrated the abuse. In context, the Winterbourne and Muckamore Abbey

scandals highlighted the vulnerability of people with learning disabilities at the hands of people who were meant to protect them. In Scotland, 34 patients died due to a ‘superbug’ at the Vale of Leven Hospital in West Dunbartonshire (MacLean, 2016). The Vale of Leven outbreak report narrated the complex series of events that led to the death of those patients. The report explained the superbug *C. diff* (*Clostridium difficile*) and its potential dangers, gave an overview of how the outbreak was detected, and described its impact on the Vale of Leven Hospital. Like Winterbourne and Makomore Abbey Hospital scandals, there were staff shortcomings among the medical staff, which were unable to detect the outbreak despite surveying national systems, policies, and standards of care. A detailed examination was conducted of the organisational changes occurring at the Vale of Leven Hospital before and during the outbreak.

According to a new report from Scotland’s human rights watchdog, people with learning disabilities and autism in Scotland are still being held in institutions in breach of their human rights (Bloomer, 2025). The report identifies significant gaps in human rights standards and the progress made under the Scottish Government’s Coming Home Implementation Plan (Scottish Human Rights Commission, 2022). As if that were bad enough, the same report claimed that the commitment was to facilitate the transition from hospital to independent living, thereby reducing unnecessary admissions for reasons other than medical need. The Commission suggested that more than £12.5 million of a £20 million public fund, “the Community Living Change Fund,” remained unspent going into the final year of the fund. Instead, it was reported that the money was not spent on supporting people with learning disabilities into community living as intended, but on refurbishing institutional settings. This development would directly contravene the requirements for the right to independent living. It was the hypocrisy of the narratives of the issues of community integration and the support of people with learning disabilities. There will always be a need for a voice. In addition, a BBC report, broadcast on March 4, 2025, covered an autistic woman with a learning disability who was wrongly locked up in a mental health hospital for 45 years from when she was just seven years old. A woman, believed to be initially from Sierra Leone, and whose name was given as Kasibba by the local authority to protect her identity, was also held on her own in long-term segregation for 25 years. Kasibba cannot speak and has no family (Bloomer, 2025). Such an example of people with learning disabilities presents challenges for supported providers and other relevant authorities.

As per procedure, the government promised to act after the BBC undercover investigation in 2011 exposed the criminal abuse of people with learning disabilities at Winterbourne View private hospital near Bristol (McDonnell, 2025; Parker, 2016; Crime, 2015). Nevertheless, it was another repeat of the tragedy of injustice for people with learning disabilities. Such cases typify institutional failures, often arising from a combination of errors, violations, risks, and systemic factors that are erroneous and contrary to an organisation's established functions (Lei, Naveh & Novikov, 2016). Such scandals often involve the participation of those affected or their families to share valuable contextual information; however, reconciling the adverse events can lead to significant psychological distress. All these scandals reinforce the need for empowering individuals with learning disabilities to have a louder voice in the care and services they receive.

Examples of inclusive research frequently highlight the denial of the voices of people with learning disabilities in research (Milner & Frawley, 2019). Identifying and gaining access to prospective participants have been identified as potential barriers to research participation (Lewis & Porte, 2004). Some argue that people with learning disabilities are often undervalued as knowledge producers and learners (Mikulak et al., 2022). As a result, they are not so often heard (Locock et al., 2022). However, this situation is gradually changing. There has been a call to employ inclusive, participatory research, where people with learning disabilities are active participants rather than subjects of the research (Walmsley, 2011). The inclusive research paradigm, then, is heralded as a welcome and much-needed antidote to this shortcoming, although some claim that the 'voices' of people with multiple and profound learning disabilities continue to be lost (de Haas et al., 2022). Due to the historical experiences of people with learning disabilities facing social injustice and disempowerment, it is essential to capture their voices. This study explores the experiences of support for individuals with mild-moderate learning disabilities in supported living environments through participatory research.

1.12 The significance of this study

This study is significant as it addresses a genuine social problem of the under-researched experiences of supported living for individuals with mild-moderate learning disabilities. Support experiences are a vital component of service users' well-being, and involving service users in participatory experiences can empower marginalised population groups (Vorhaus, 2017). This study promotes inclusivity for the less privileged members of society, ensuring their voices are heard and allowing them to raise concerns and suggest improvements. The

research findings will significantly contribute to the literature and potentially stimulate dialogue among various stakeholders, including care workers, support managers, and health and social care professionals.

Whilst the literature review conducted as part of this study (Chapter 2) revealed examples of qualitative research on the experiences of people with a learning disability in supported living, it also revealed a methodological gap regarding truly participatory approaches. As discussed in Chapter 5, adopting a focused ethnographic approach, which includes observational practices and interviews with service users and staff, offers a novel method for generating evidence to inform best practices. This participatory method provided first-hand experiences and observations of the interactions and routines involving service users, care support workers, and their support managers.

This study has practical implications and recommendations for service providers and care staff. The findings offer a nuanced understanding of support experiences and yield valuable insights into the daily lives of individuals with learning disabilities residing in supported living environments.

1.13. Thesis overview

Chapter 1 provides a brief introduction and background, an overview of the research, the aim and objectives, and the study background and significance. The following section provides the structure of this thesis in the context of explaining the motivation behind the chosen topic.

Chapter 2 presents a scoping review of the research topic. The review systematically maps the topic using the Joanna Briggs Institute (JBI) approach and an overview of existing research evidence on the experiences of support for individuals in supported living settings. Synthesising the evidence reveals a methodological gap in the current literature.

Chapter 3 outlines the qualitative research methodology, focusing on focused ethnography (FE). The Research Onion Model forms the theoretical underpinning for the study. Participant recruitment strategies included pilot testing, public and patient involvement, and careful attention to ethical considerations for individuals with learning disabilities.

Chapter 4 describes the data collection process undertaken in supported living for this study. The main participants comprised service users, their support workers, and support managers. Data were collected using semi-structured interviews, participant observations, field notes, and reflexive diaries. All participants took part in interviews, while only service users and care support workers were observed being supported by the care support workers.

Chapter 5 describes reflexive thematic analysis of data in Chapter 4. The chapter ends with a discussion of the researcher's positionality and ethical challenges encountered during recruitment.

Chapter 6 presents findings in the form of themes and sub-themes from all participants, with a focus on the service users. The findings are divided into two sections. The first focuses on the experiences of support for people with mild and moderate learning disabilities in supported living. The second discusses findings (views and experiences) of managers with those of the service users for a fuller picture of supported living.

Chapter 7 discusses the thesis findings in relation to the original research questions and the broader literature, highlighting key findings relevant to the research topic and the literature.

The **Conclusion** summarises the thesis, revisits the research questions, and presents the original contribution to knowledge. It concludes with implications that highlight the future direction of research and practice.

Chapter 2

Scoping Review

2.1 Introduction

This chapter presents the scoping review, which followed the Joanna Briggs Institute (JBI) protocol (Peters et al., 2020) that includes the following steps: i) scoping review approach; ii) development of a scoping review protocol; iii) title, developing the title and question; iv) inclusion criteria; v) search strategy; vi) source of evidence selection; vii) data extraction; analysis of evidence; viii) presentation of results; ix) the scoping review and summary of the evidence; x) strengths and limitations; xi) implications of the evidence with the scoping review question; xii) knowledge gap.

This scoping review excludes papers on people with severe to profound learning disabilities, often with unique needs and characteristics that differ significantly from those with mild learning disabilities (Titley et al., 2020). This highlights the importance of not treating all people with learning disabilities as if they were the same. Instead, it suggests the need for personalised, specialised approaches when supporting individuals with significant cognitive impairments. The scoping review was conducted based on the experiences of individuals with mild-moderate learning disabilities, like those in the researcher's current caseload who had contact with the social care systems and processes, as well as those who had passed through the justice system as vulnerable victims or witnesses. However, persistent gaps in understanding, support, and communication frequently lead to injustice. This scoping review highlighted a methodological gap and reinforced the importance of examining the experiences of individuals with mild and moderate learning disabilities in Scottish supported living settings. The researcher expanded the criteria to include mild to moderate learning disabilities because many individuals with these disabilities fall within that range. Studies that include both groups offer findings more relevant to real-world situations and are more likely to influence policy, education, and practice effectively because they apply to a broader population (Hamilton et al., 2017). By including both groups, the researcher used this criterion to ensure that the findings accurately represent individuals with mild-moderate learning disabilities in supported living settings.

2.2 Scoping Review Approach

A scoping review systematically investigates existing literature, identifying key concepts, theories, evidence sources, and research gaps (Grimshaw, 2020). It maps and summarises evidence, informs future research, and addresses knowledge gaps (Munn et al., 2018; Tricco et al., 2018). The approach follows rigorous and transparent methods to analyse relevant literature (DiCenso et al., 2010). Supported living is a community-oriented alternative to residential care, offering support at home in collaboration with healthcare and social care entities (Keogh et al., 2019). The review aims to summarise the experiences of adults with mild learning disabilities in supported living, considering participatory research methodologies (Mietola et al., 2017). The rationale for the scoping review centres on the research history of people with learning disabilities and their involvement in research. Unlike systematic reviews, scoping reviews map the literature without a narrowly defined research question and incorporate diverse evidence (Arksey & O'Malley, 2005).

The review objective was based on the core elements of the Population, Concept, and Context (PCC) mnemonic, which guided the inclusion criteria for sources in the scoping review. The PCC is a framework of phrases or words used to define key components in developing the research question for a scoping review. The P stands for Population, referring to the service users with mild learning disabilities being studied; C stands for Concept, denoting the experiences of support being investigated by the participants; and C stands for Context, indicating the geographic location where the study will be undertaken. The PCC framework helped to ensure that the research question was narrow and that all three aspects were considered when defining the inclusion and exclusion criteria of the scoping review.

2.3 Development of a scoping review protocol

This study used the scoping review guided by the Joanna Briggs Institute (JBI) adapted PRISMA-P to provide a comprehensive plan for conducting and reporting the subsequent scoping review report (Moher et al., 2015). The Joanna Briggs Institute Manual for Evidence Synthesis recommends that authors develop their protocols for scoping reviews beyond the template presented (Peters et al., 2020). The scoping review protocol outlined the inclusion and exclusion criteria, specified the evidence sources, and described the relevant data and methods for extracting and presenting results (Anthony et al., 2024).

2.4 Title, developing the title, and question

The review title was:

Experiences of support for people with mild learning disabilities in supported living: a scoping review.

2.5 Preliminary stakeholder engagement

Preliminary stakeholder engagement helped identify what matters most and allowed resources to be focused on the highest-value areas. Stakeholder engagement is a widely recognised concept in business and society research, as noted in related literature (Kujala et al., 2022). Engaging patients and other healthcare stakeholders was increasingly viewed as essential for patient-centred care, as it aims to address questions important to patients and their caregivers (Hoffman et al., 2010). Literature indicates that patient stakeholders design the study and select outcomes to develop meaningful, culturally appropriate materials that improve recruitment (Sheridan et al., 2017; Dudley et al., 2015). The first step in formulating the research question is vital (Thomas et al., 2017; Levac et al., 2010). It involved stakeholder engagement and discussions during supervision meetings. The aim was to prevent the research question from becoming too broad, and so stakeholder engagement helped ensure that the research was inclusive, meaningful, and impactful rather than isolated. In this research, key stakeholders included primary participants with learning disabilities, their support workers, and managers. Other involved stakeholders included community members interested in learning disabilities, such as policymakers, health practitioners, managers, learning disability groups, advocacy organisations, and family members of people with learning disabilities. It was important to recognise that some groups might hesitate to collaborate with research teams due to past mistrust stemming from negative experiences within health institutions.

The rationale was to guard against too broad a research question. They would increase the number of papers for consideration, potentially affecting the feasibility of the review. On the other hand, a narrow research question would compromise the review's breadth and depth (Levac et al., 2010). Stakeholder engagement was enabled by the researcher's role as a registered learning disability nurse in a community team. It fostered a dynamic context of interaction, dialogue, and change (Manetti & Toccafondi, 2012). It included contact with

individuals with learning disabilities attending local activity centres, learning disabilities nurses, allied health professionals, and social workers.

The stakeholder engagement also revealed how people with learning disabilities had little or no participation in research. Literature suggested that people with learning disabilities had difficulties with recruitment, consent issues, and adapting to interventions (Bishop et al., 2024). Research has highlighted that people with learning disabilities often face significant barriers when it comes to participation in clinical or research settings. The situation with prospective participants with learning disabilities, who had not been fully aware of their rights to take part in research, was that no one had participated in any research, let alone come across the opportunities available to them. Nonetheless, conducting a preliminary literature search is instrumental in mapping the research question within the framework of a scoping review.

2.6 Inclusion criteria

This study applied explicit inclusion and exclusion criteria to align with its research objectives. The inclusion criteria focused on studies that examined the experiences of support for individual adults with mild-moderate learning disabilities residing in supported living settings in Scotland. These studies were sourced from English peer-reviewed journal articles and literature reviews published between 2014 and 2024. This timeframe was selected to reflect the policy era following “The Same as You” (Scottish Executive, 2000) and related policy frameworks, ensuring that the findings remain relevant to contemporary social care contexts.

2.7 Exclusion Criteria

The exclusion criteria eliminated studies that (1) focused on children, individuals with profound to severe learning disabilities, or institutional/hospital-based settings, as these groups have different support needs and policies; (2) dealt with experiences of support in care homes, nursing homes, group homes, or hostels; (3) included case studies, editorials, dissertations, conference abstracts, research letters, clinical intervention studies, or any literature published before 2014, since these did not concentrate on the lived experiences within supported living. Importantly, no ethnographic research was conducted or included in this review. Consequently, while the study captures rich reported experiences, it does not claim to represent the everyday micro-level interactions that occur within supported living environments.

These decisions established clarity and consistency throughout the thesis, defining the boundaries of the claims made. It does not aim to represent everyday micro-level interactions within supported living arrangements. Overall, these choices helped frame the scope of the thesis's arguments.

2.8 Types of Participants

The PCC framework focuses on P, representing people with mild-moderate learning disabilities aged 18 years or older who reside in supported living. C represents the concept of daily experiences involving paid support workers. C represents the context of supported living.

2.9 Type of sources

Based on the JBI guidance, this scoping review considered the following sources: primary and secondary research, peer-reviewed journal articles, literature reviews, and reference lists. Grey literature was excluded because it did not meet the criteria for peer-reviewed publications. The justification behind their exclusion was documented and recorded for future reference.

2.10 Methodology

The JBI scoping review methodology (Peters, 2015) and the Preferred Reporting Items for Systematic Reviews Extension for Scoping Reviews guidelines (PRISMA-ScR) (Tricco et al., 2018) were employed to address the review question (Appendix B). The search was conducted on the following databases and electronic journal collections. It was limited to the English language: Medline, PsycINFO, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Scopus, and Applied Social Sciences Index & Abstracts (ASSIA). These databases were selected for their relevance to healthcare research (Medline and PsycINFO) and their multidisciplinary, broad coverage (Scopus), which encompasses all subject areas. Additionally, they are keyword databases or resources that focus on research into patient experiences and healthcare in sociological studies (ASSIA).

2.11 Search strategy

The author undertook a broad systematic search, which involved the initial searches. There was reflexive engagement at each stage and, where necessary, the literature was iteratively

ensured to be covered comprehensively, demonstrating the thoroughness and rigour of the study (Arksey & O'Malley, 2005).

A three-step search strategy was used to locate published and unpublished studies.

- i. The initial search was piloted on two relevant databases, Medline and ASSIA. It refined and identified keywords and phrases in the titles, abstracts, and indexes of papers that would be useful in the review. It was then adapted to search for information using a combination of three terms across the five databases.
- ii. The second search was conducted in five academic electronic databases: Medline, PsycINFO, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Scopus, and ASSIA. The mentioned articles were incorporated into the final PRISMA flowchart.

The third strategy involved a reference list search, where the author searched for a reference list from all identified studies. The identified studies were incorporated into the PRISMA flow chart (Tricco, Lillie et al., 2018). (Appendix B).

iii. *Time frame*

The search period lasted from January 2014 to January 2024.

iv. *Search terms*

The following search terms were used: “learning disabilities” OR “learning disability” OR “learning difficult*” OR “learning disabilities” OR “intellectual disability” OR “intellectual impairment*” OR “intellectual impairments” OR “mental retard” And “supported living” OR “supported accommodation” OR “supported housing” OR “social care” OR “social cared living” OR “community living” OR “learning disability community placement” OR “independent living” OR “cared living” OR “residential cared living” OR “supervised housing” OR “supervised accommodation” OR “sheltered accommodation.” And “experiences” AND “support” AND “support experiences”.

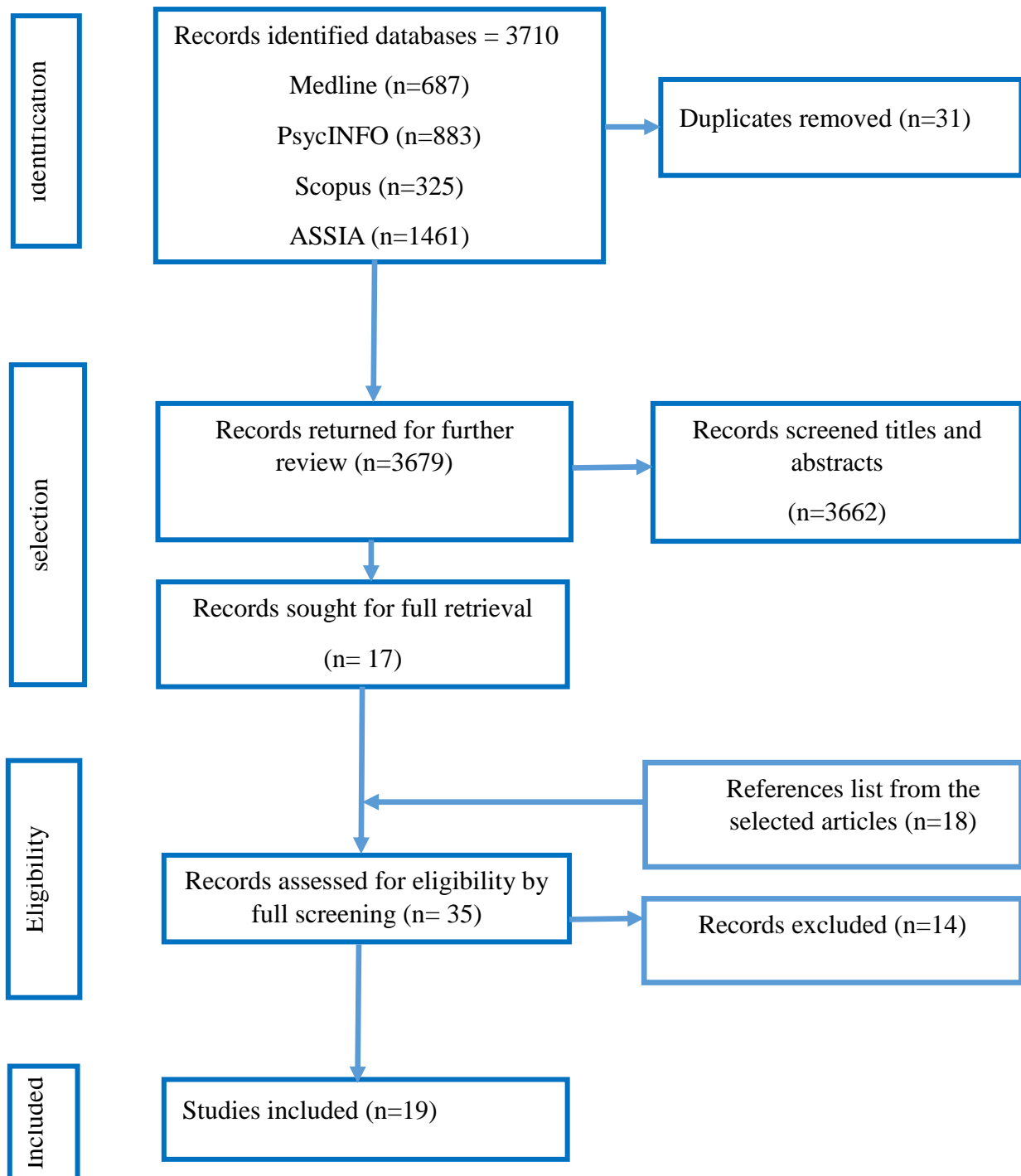
The final search outcomes were exported to Mendeley, and any duplicates were removed from the reference lists.

2.12 Source of evidence selection

Following the search, the screening process was conducted in two stages: reviewing the titles and abstracts of the studies. The next step was to include studies that mentioned the information experiences of support for people with learning disabilities in supported living settings. A summary of the evidence selection process, as outlined in the PRISMA guidelines, is presented in Figure 1.1, which illustrates that 3,710 studies were initially identified. The

screening phase removed 3,662 articles, and 48 articles were retained. Thirty-one duplicates were excluded, with 17 articles being retained. A further 18 papers were obtained from the reference list, and 14 articles were excluded. This resulted in a final total of 19 studies being included (Figure 1,1).

Figure 1.1: PRISM DIAGRAM



2.13 Data Extraction

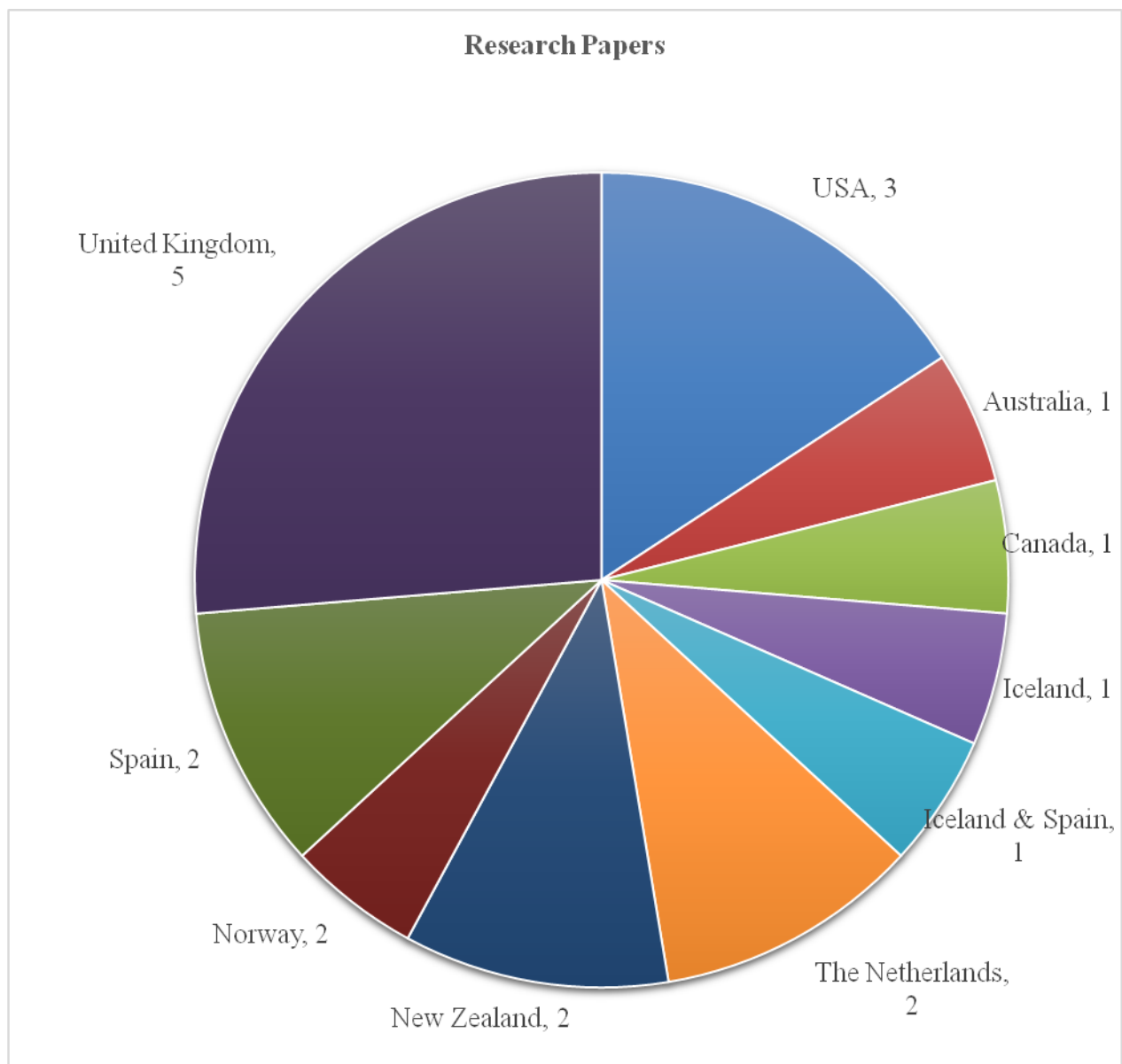
The general characteristics of each study included in this scoping review are reported in individual tabular form in Appendix C. The data extraction process provided the reader with a logical and descriptive summary of the results that aligned with the objectives and questions of the scoping review. The general characteristics included:

1. Author(s)
2. Year of publication
3. Origin/country of origin
4. Aims/purpose
5. Population and sample size within the source of evidence
6. Methodology/methods
7. Outcomes and details of articles
8. Key findings that relate to the scoping review question/s

The results of the scoping review were presented in both tabular and descriptive formats, aligning with the review's objectives and scope. Figure 1.2 represents the distribution of studies by their country of origin. The most informative evidence used to compile this report comes from qualitative data generated through a series of in-depth interviews with professionals working in Health and Social Care Partnerships (HSCPs). Furthermore, discussions with individuals with learning disabilities, particularly those from the Scottish Commission for People with Learning Disabilities (SCLD) Expert Group and their families, also contributed valuable insights.

All the qualitative studies were from the USA, Spain, the Netherlands, the UK, New Zealand, Australia, Iceland, Canada, and Norway (Figure 1.2).

Figure 1.2: Country of Origin



This scoping review aimed to explore the literature on the experiences of individuals with mild learning disabilities in supported living settings in Scotland.

The scoping review revealed that no empirical studies from Scotland were included among the countries of origin. This is notable, especially given Scotland's strong policy commitment to supported living and inclusion for people with learning disabilities, particularly since the publication of "Same as You?" in 2000 and "Keys to Life" in 2013. The absence of Scottish studies highlights a broader gap in policy research: although Scotland has developed

progressive frameworks, there has been limited academic research capturing the lived experiences of individuals with mild learning disabilities in supported living contexts. In contrast, much of the existing evidence comes from international settings, including England, Ireland, the Nordic countries, and Australia. This gap highlights the originality and importance of the present study, which aims to provide the much-needed Scottish-specific evidence currently lacking in the literature.

Scotland was not represented among the countries of origin, primarily due to a lack of published research focusing on individuals with mild-moderate learning disabilities in the Scottish context. People with learning disabilities are one of the most marginalised groups, often facing severe personal, social, and institutional neglect and discrimination (Hall, 2005). Relevant insights may exist in reports or evaluations by local authorities or third-sector organisations, which are often excluded from traditional academic databases. The scarcity of robust data on learning disabilities complicates efforts to reconcile government ambitions to improve the lives of individuals affected, making effective, evidence-based policymaking nearly impossible.

As discussed in Chapter 1, inclusive research involving people with learning disabilities has been a persistent focus. However, Scottish studies often focus on broader categories that encompass all learning disabilities or residential care, without isolating cases specifically labelled as "mild" or "supported living" (Black et al., 2020). Despite a unique policy and social care environment that influences outcomes for people with mild-moderate learning disabilities, no studies from have been identified.

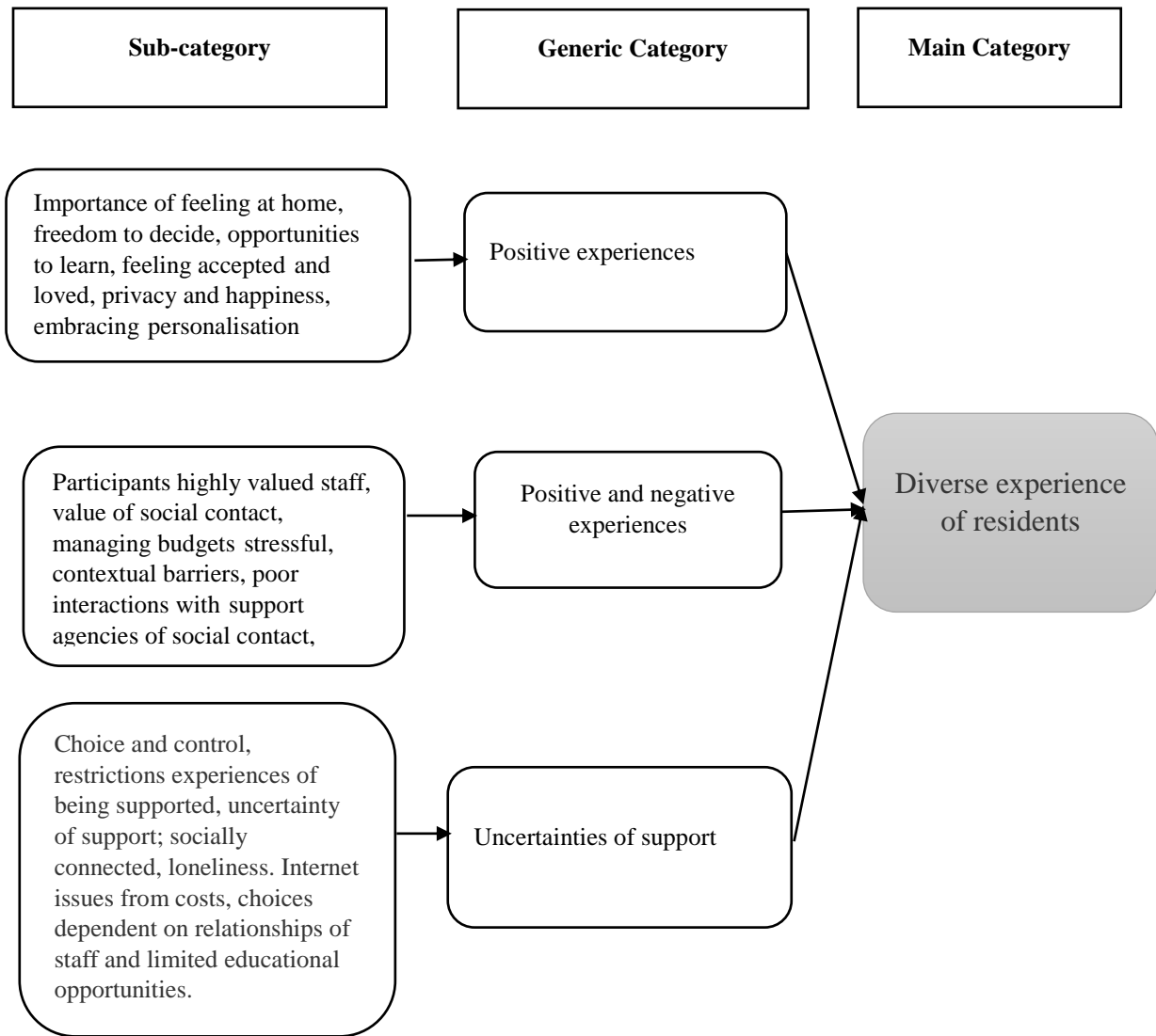
This scoping review aimed to understand the extent and type of evidence, as well as the gaps, concerning the experiences of support for people with learning disabilities in supported living settings.

2.14 Analysis of evidence

The scoping review employed fundamental content analysis, which involved basic data coding (Krippendorff, 2013; Schreier, 2012). Successful content analysis uses data to reduce it to concepts that describe the research phenomenon by creating categories, concepts, a model, a conceptual system, or a conceptual map (Elo & Kyngas, 2008). The rationale was to categorise similarities and differences in the data, thereby illuminating the experiences of support for people in supported living. The scoping review results provided a summary of data coded to categories of experiences of support. Figure 1.3 illustrates how data were analysed using fundamental content analysis from a sub-category, generic, and primary

category (Tricco et al., 2018). The researcher used content analysis, simple frequency, and descriptive statistics to identify the main categories.

Figure 1.3: Example of basic qualitative content analysis of diverse experiences of residents



2.15. Type of studies

This led to the identification of five main categories describing the aspects of experiences with support for people with mild-to-moderate learning disabilities in supported living. The supervisory team checked the credibility of this stage. The sub-categories and overarching categories were evaluated separately. Following a discussion, consensus was achieved on the organisation of the overarching categories.

All 19 studies were qualitative, mainly involving interviews (9) and scoping reviews (2), with one adopting an interpretative phenomenological approach (3) and one study (12) a scoping review, Participatory Appreciative Action Reflection (1), focus groups (3), and body maps (1).

This research used a qualitative approach to explore the support experiences of individuals with mild-moderate learning disabilities in supported living settings. The scoping review excluded quantitative studies to avoid relying on statistical data to explain lived experiences. Qualitative research offers deep insights into real-world issues (Moser & Korsten, 2017). The focus was on qualitative methods aligned with the research aim and question, producing inherently interpretive results rather than the predictive outcomes typical of quantitative studies. Although useful for background and identifying trends, combining both types of literature could have enhanced the study's credibility. However, the researcher believed that epistemological differences, such as positivism and post-positivism for quantitative research versus phenomenology or interpretivism for qualitative, might intentionally limit the integration of qualitative traditions in understanding knowledge (Creswell & Poth, 2016).

Unlike quantitative assessments that reduce experiences to numbers, qualitative research yields rich, contextual insights into participants' personal viewpoints. It uses open-ended questions such as "how" and "why" and does not follow a linear path (Cleland, 2017). Thus, it aligns with the nature of this study's research question, which sought the primary participants' experiences of support. Qualitative methods are particularly suited to highly individualised, relational environments characterised by interpersonal dynamics, staff-client relationships, housing, support levels, and policy constraints, factors that are not readily quantified. Additionally, no ethnographic studies based in Scotland were identified during the scoping review.

Therefore, focusing on qualitative papers allowed this study to prioritise the voices and experiences of people with learning disabilities and generate context-specific themes relevant to Scottish supported living settings. Qualitative papers were necessary to address the core research aim and objectives.

2.16 Number of participants

The studies varied in size, with the number of participants with learning disabilities ranging from 3 to 41, the number of staff ranging from 13 to 30 (two studies), and one study involving 34 family members.

2.17 Discussion

2.18 Presentation of the results

The scoping review aimed to deepen understanding of the experiences of support for people with learning disabilities in supported living settings. It examined the extent, range, and nature of research activity, revealing research gaps in the existing literature (Arksey & O'Malley, 2005). Identifying research gaps is essential to reviewing the literature (Webster & Watson, 2002).

The review question was: *What are the experiences of support for people with learning disabilities in supported living settings?* The reviewing objective was to map the experiences of support for people with learning disabilities in supported living settings.

The level of evidence is based on studies conducted with individuals who have learning disabilities and work with their care workers in supported living settings across the globe. The discussion is on the experiences of support for people with learning disabilities in supported living settings. This section describes five categories linking them to the review question and objective. The five categories are: “diverse experiences”, “tailored education support for a healthy lifestyle”, “choice and control”, “limited autonomy”, and “technical gadgets”. Each category is discussed in line with its alignment with the review question and objective.

The categories involved evidence of the various perspectives, backgrounds, and life situations that individuals or groups bring to a particular context.

2.18.1 Diverse Experiences

This first category analysed the “diverse experiences” of people with learning disabilities in supported living (Estaban et al., 2023; Puyaltó & Pallisera, 2020; Giesbers et al., 2019; Rushbrooke et al., 2014). Estaban et al. (2023) contend that community living has significantly improved the positive emotional well-being of individuals, offering more opportunities to participate in activities and greater control over their lives.

Puyaltó & Pallisera’s (2020) study highlighted the barriers and opportunities that people with learning disabilities encounter in their endeavours to live independently in Spain. Giesbers et al. (2019) established that crucial relationships between individuals with learning disabilities and their care staff are based on their personal lives with the support providers.

Rushbrooke et al. (2014) found that people in supported living had limited access to intimate relationships, and there were difficulties expressing sexuality and determining who had control in these issues.

2.18.2 Choice and Control

The second category has evidence of “choice and control” (Pallisera et al., 2021; Bigby et al., 2017; Williams & Porter, 2017; Conder & Mirth-Veith, 2020; Dew et al., 2019). Choice and control are essential components that empower individuals in supported living to receive the support they need. The participants in these studies appreciated the choice and control they had over certain aspects of the support they received in supported living, with support staff serving as facilitators. However, there was evidence of contradictions in the experience of the type of support expected in supported living for these marginalised population groups. Pallisera et al.’s (2021) study found that support is determined by professionals’ assessment of the person’s autonomy, despite personalised solutions in supported living. Bigby et al. (2017) identified greater autonomy and control for people with learning disabilities. However, a limitation of this study was the absence of the voices of people with learning disabilities on how support is provided. Conder & Mirth-Veith’s (2020) study demonstrated that social inequities within Aotearoa New Zealand (ANZ) are not being addressed. They stated that without other financial support, people on benefits struggle to afford medical and dental care, as well as holidays and other leisure activities. Williams and Porter’s (2017) study found that people with learning disabilities gain confidence in their decision-making abilities through peer support and trust the control and choice of others in their budget processes and identity. Dew et al.’s (2019) study used body mapping to examine the planning

experiences of individuals with a strong sense of self-leveraging resources and support. The approach enables people with learning disabilities and complex support needs to articulate their goals, recognise their choices, and achieve meaningful outcomes.

2.18.3 Tailored Education Support for a Healthy Lifestyle

The third category had evidence of personalised learning resources, strategies, and guidance designed to help individuals with learning disabilities adopt and maintain a healthy lifestyle. Two studies focused on “tailored education support for a healthy lifestyle” for people with disabilities (Hatzikiriakidis et al., 2023; Witso & Hager, 2020). The study by Hatzikiriakidis et al. (2023) sheds light on the health lifestyles of individuals with learning disabilities, including health education, exercise programmes, nutrition interventions, and health promotion training for staff, to gain tailored education support for their healthy lifestyles as they navigate social inequities. However, the study identified slight changes despite significant obstacles to supporting patients, stemming from a lack of training and resources, thereby depriving patients of the guidance essential for maintaining a healthy lifestyle in supported living situations (Hatzikiriakidis et al., 2023). Many of these interventions were designed to support staff in promoting healthy lifestyles; as such, changes in lifestyle behaviours may have been dependent on changes in staff practices. Similarly, Witso & Hager (2020) explored physical support using the Participatory Appreciative Action and Reflection (PAAR) model. They reported relying on the support of family members and staff. Once again, there was an element of interdependence and mutual reliance between people with learning disabilities and support staff. Many of these interventions were designed to support staff in promoting healthy lifestyles and, as such, changes in lifestyle behaviours may have been dependent on changes in staff practices.

2.18.4 Limited Autonomy

There was evidence regarding the issues of “limited autonomy” in supported living settings (Hamilton et al., 2017; Whitehead et al., 2016; Björnsdóttir et al., 2015; Petner-Arrey & Copeland, 2015). The findings provided evidence of limited autonomy, where residents negotiated autonomy daily, renegotiated it during staff changes, and often sought to increase it (Whitehead et al., 2016). These studies use qualitative approaches, and the participants self-reported their discontent with limited autonomy. One study investigated autonomy, and participants highlighted that they felt support workers cared more about safeguarding their own roles than enabling the residents’ autonomy (Petner-Arrey & Copeland, 2015). In

another study, participants revealed limitations on their autonomy decisions on things such as clothes to wear, when to go to bed, and what to eat – simple, daily tasks through staff’s subtle restrictions placed on them (Björnsdóttir et al., 2015). Many participants lacked access to essential information (problem-solving, mindfulness, self-reflection, or assertiveness) necessary to develop individual autonomy and independence. External factors in social care budgets were also identified as a factor in curtailing service users’ autonomy (Hamilton et al., 2017). The studies found that participants experienced isolation and exclusion, limited agency in their lives, and the breakdown of their social networks of friends.

2.18.5 Technical Gadgets

Several studies examined the use of “technical gadgets”, including video-based technology, to enhance communication and care in supported living. The technical gadgets included smartphones, personal computers, and tablets, which enabled people with learning disabilities to stay in contact with family, friends, and even their support staff. Five studies identified technical gadgets as improving the experiences of support for people with learning disabilities in supported living settings (Stierle et al., 2023; Lawrason et al., 2023; Zaagsma et al., 2023; Tassé et al., 2020; Dew et al., 2019). There was evidence from the use of an online support service of video conferencing (Zaasgama et al., 2023). Many studies have identified the role of support staff in assisting users with online devices, such as smartphones, personal computers, and tablets, to facilitate communication. The level of support provided depends on the individual’s needs, capabilities, and preferences.

2.19 Strengths and Limitations of the Scoping Review

The strength of this scoping review lies in its foundation on the JBI methodology and its adherence to PRISMA guidelines for reporting the search and screening process. The peer-reviewed study was based on a clear and precise protocol, and a rigorous methodology was used to plan and conduct it. A comprehensive literature search was conducted using a search strategy across electronic bibliographic databases, resulting in the inclusion of 19 studies in the final analysis. The limitation was excluding grey literature from specific agencies and websites, such as GLOBAL HEALTH and Google, with helpful information. Excluding grey literature helped reduce the risk of bias in this review and ensured the findings were based on peer-reviewed sources.

2.20 The scoping review and summary of evidence

In summary, the review question explored the experiences of individuals with learning disabilities in supported living settings. This section identified five themes from the 19 studies reviewed.

Category 1: “diverse experience.”

This category analysed the “diverse experiences” of people with learning disabilities in supported living (Estaban et al., 2023; Puyaltó & Pallisera, 2020; Giesbers et al., 2019; Bigby et al., 2017; Rushbrooke et al., 2014).

Category 2: “tailored education support for a healthy lifestyle.”

Two studies focused on “tailored education support for a healthy lifestyle” and “financial obligations” for people with disabilities (Hatzikiriakidis et al., 2023; Witso & Hager, 2020).

Category 3: “choice and control.”

Three studies focused on the significance of “choice and control” in support experiences (Pallisera et al., 2021; Conder & Mirth-Veith, 2020; Williams & Porter, 2017).

Category 4: “limited autonomy.”

Four studies examined support experiences of “limited autonomy” and how they can be promoted (Hamilton et al., 2017; Whitehead et al., 2016; Petner-Arrey & Copeland, 2015; Björnsdóttir et al., 2015).

Category 5: “Technical gadgets.”

Five studies identified technical devices that improved support experiences for people with learning disabilities in supported living settings (Zaagsma et al., 2023; Stierle et al., 2023; Lawrason et al., 2023; Tassé et al., 2020; Dew et al., 2019). The key issues encompass a range of positive and some negative experiences. The main issue for service users is having as much choice and control as possible over their daily lives. There appears to be a role for using technologies to enhance communication and promote greater autonomy.

2.21 Areas for further research

The scoping review identified evidence for the categories derived from different qualitative approaches, primarily interviews, Interpretative Phenomenological Analysis (IPA), Participant Appreciative Action Reflection, focus groups, and surveys. The review identified

that most of the support experiences in supported living rely on small-scale qualitative interviews and surveys with limited direct involvement of individuals with mild-moderate learning disabilities. This highlighted that a methodological gap exists in the inclusive, participatory approaches that prioritise the voices of service users.

International research mainly focused on the perspectives of supported living, with little exploration beyond this framework. To date, there has been no integration of ethnographic approaches that would capture rich, in-depth support experiences of participants within supported living research and access to social care. As a result, residents' voices in their day-to-day living are often unheard, and their holistic perspectives are still lacking. Müller, Bloch, and Kranz (2015) rightly argue that diversifying research methods can benefit areas that are predominantly explored using limited standard methods.

In FE, field notes were structured records of observations, interactions, and researcher reflections within a specific research setting. The ethnographic approach involves interviews, participant observations, and field notes, and emphasises the importance of context for both the researcher and the study participants (Jones, 1995). In addition to reflexive observations regarding emerging patterns and themes, the researcher documented descriptive details of events and social interactions. The field notes were collected from living environments and daily routines, as well as relationships with staff and peers, feelings of independence or lack of control, challenges in communication and decision-making, experiences of inclusion in community life, and access to information and rights. The researcher took notes during fieldwork in supported living settings, drawing on written field notes, recorded interactions, and reflections to reflect on the observations. This involved everyday life activities and work relationships of service users and their support workers. It included detailed accounts of interactions, environment, behaviours, and atmosphere. The researcher also captured key phrases, emotions, and body language notes, as well as participant quotes from participant interviews. The observations and field forms (Appendix O & P) are tools to help the researcher capture rich, contextual data that inform the coding and reflexive thematic analysis.

The artefacts convey the meaning and values of supported living. Artefacts enhance the focus on aspects underlying values and motivations, as well as experiences and needed functionality (Segelström & Holmlid, 2014). Artefacts such as personal photographs, certificates, schedules, or assistive devices also provided meaningful, non-verbal data that revealed aspects of the participants' social identities, autonomy, and social roles. The

researcher used artefacts to document, describe, and analyse field notes, thereby triangulating and enriching the understanding of participants' experiences of support. This study acknowledged the role of field notes and artefacts, highlighted the additional contextual insights provided by direct observations, and clarified the reported experiences in supported living settings. Artefacts encode routines, values, and norms that participants articulated directly (Pentland & Haerem, 2015). For example, in some instances, the unspoken rules allowed service users to complete routines such as preparing food and tidying their flats. The detailed field notes were reflective and crucial for capturing nuances of observed behaviours and interactions. Through those notes, the researcher understood that supported living was not just about being in the community but about feeling part of it. Many participants were content with their lives in supported living. Their findings were reported transparently, using the participants' speeches to support the themes and sub-themes, and to reflect on their significance.

2.22 Reflections on the Scoping Review

Reflecting on the scoping review is an integral part of research. This study was on the experiences of support for people with learning disabilities in supported living. Further research is needed to assess and understand the research topic. The researcher critically reflected on his role in the study to ensure it was reliable, ethical, and meaningful. Reflection is a key attribute of competent healthcare professionals. (Mann et al., 2009), facilitating deeper learning (Wain, 2017), enhancing understanding of the concepts being studied (Farahhana et al., 2018), and improving professional practice (Pretorius & Ford, 2016). The researcher, a nurse by profession, experienced the review landscape of support experiences to sustain awareness of their own beliefs, values, and assumptions, which could influence this study. Unlike systematic reviews, which focus on specific questions to assess the feasibility and effectiveness of interventions (Munn et al., 2018), this scoping review mapped existing knowledge in a field with limited research (Peters et al., 2020). The researcher found using the Joanna Briggs Institute (JBI) protocol (Peters et al., 2020) and the PRISMA-ScR checklist a daunting task, yet transparent and systematic. As a result, five electronic databases, Medline, PsycINFO, CINAHL, Scopus, and ASSIA, were accessed, and 19 studies were identified. The scoping review fulfilled its role in mapping the literature on this topic for the disadvantaged population groups across different countries (Figure 2). In this case, there was no collaborative team of researchers to ensure alignment on the process. The researcher found that the JBI protocol was slow, and there were no valuable differing views to strengthen the

review analysis, as in the case of a team of researchers. Nonetheless, five categories identified were “diverse experiences,” “tailored education support for a healthy lifestyle,” “choice and control”, “limited autonomy,” and “technical gadgets”, as reported in Chapter 3 of this thesis. A notable observation was the increase in literature on experiences of support for people with learning disabilities across five continents. The researcher found the mapping phase required academic judgement to identify effective patterns and categories.

The grey literature was a good source of information from government publications, public policies, and organisation web-based resources on this topic. It could have lessened bias and provided a wider perspective on useful information. However, literature suggests that grey literature is difficult, time-consuming, and labour-intensive (Brown, 2025). It is often considered hard to document and organise (Paez, 2017). Grey literature does not subscribe to the publishing conventions that characterise white literature and poses challenges for data management, extraction, and synthesis. Nonetheless, the researcher believed that including grey literature could have offered additional insights into the support experiences of people with learning disabilities, yet it would prolong the review.

The researcher acknowledged that grey literature in scoping reviews can reveal insights that are not available in peer-reviewed publications since research is too specialised. The researcher preferred an adopted structured, transparent approach to evaluating and reporting on grey literature to ensure the integrity and robustness of the scoping review process. Overall, conducting the scoping review deepened the researcher`s understanding of the research landscape and improved skills in literature searching, critical analysis, and evidence synthesis. The rewarding aspect of the review process was identifying the methodological gap that required further investigation. The researcher acknowledged that the scoping review highlighted the ongoing need for improvements in practice, as well as prioritised the voices and experiences of people with learning disabilities. The review emphasised both the complexity and the fascinating aspects of the topic, underscoring the need for further focused research to address existing gaps.

2.23 Chapter Summary

Chapter 2 employed a scoping review to map the evidence from studies on the experiences of support for adults with learning disabilities in supported living. The review followed the JBI protocol for alignment with the review process. The review process was straightforward, characterised by refining the research question, developing inclusive search strategies, synthesising diverse evidence, and presenting findings in a clear, effective way. The five

categories were: diverse experience, tailored education support for a healthy lifestyle, choice and control, limited autonomy, and technical gadgets. The review identified a methodological gap for further investigation.

The chapter ends with the reflections on the exclusion of the grey literature on the grounds of its lack of peer-reviewed publications, and the absence of collaboration and a dynamic team of researchers to reflect on different perspectives and encourage critical thinking of the review.

Chapter 3

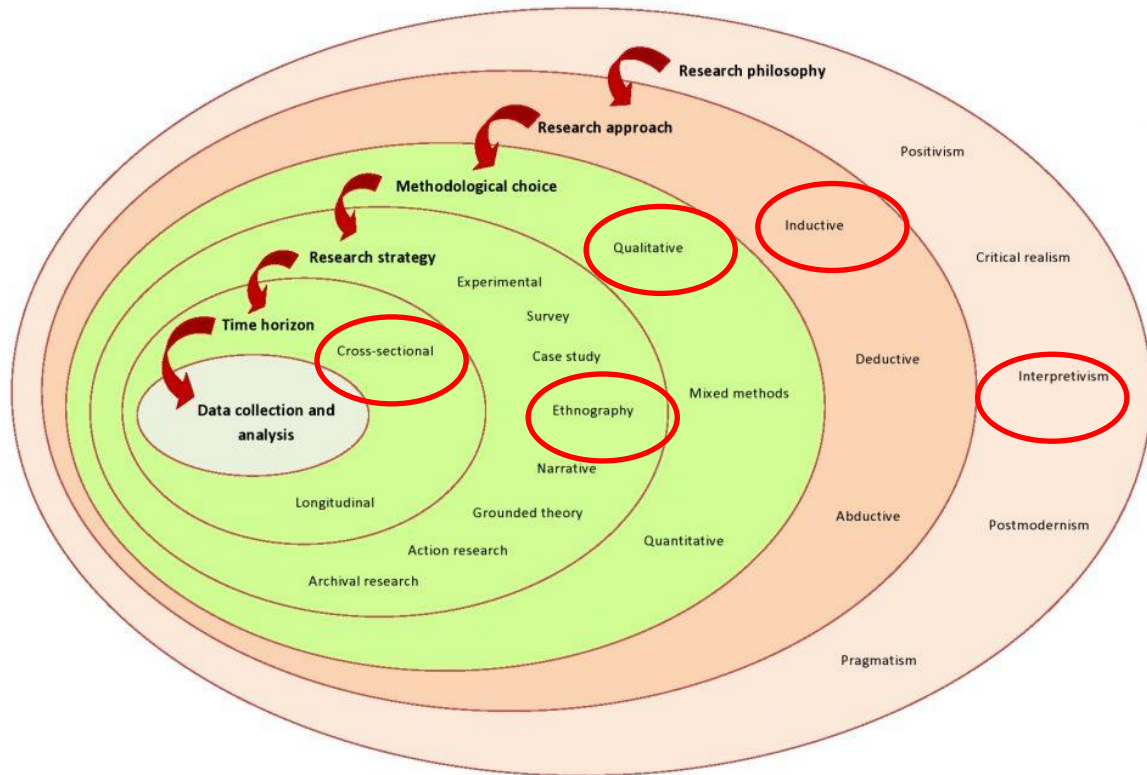
Research Methodology and Research Methods

3.1. Introduction

This chapter justifies the philosophical underpinning of the chosen methodology used in this study. In Chapter 2, the scoping review identified a knowledge gap, the lack of depth and breadth of experiences with support for service users in supported living. This chapter is in two parts. Firstly, in sections 3.2–3.9, the philosophical underpinnings of the chosen methodology, focused ethnography, will be presented. Secondly, from section 3.10 onward, a description of the research methods adopted to identify participants, collect, and analyse the data will be provided.

The Onion Model (Saunders et al., 2016) has been adopted to systematically describe the design decisions made throughout this study in addressing the knowledge gap. The chapter considers the research's philosophical beliefs and assumptions in relation to the purpose of the study and, in particular, this study (research approach, methodological choices, research strategy, and time horizon). This chapter discusses how interpretivism has influenced axiology, ontology, methodology, and methods. Each option is encircled in Figure 4 (below).

Figure 1.4: Onion Model



Source: Saunders et al., 2016

3.2. Research Philosophy

The beliefs and assumptions underlying research represent various worldviews and philosophical perspectives that shape how researchers approach their investigations, helping them understand phenomena and interpret data (Creswell, 2009). The research philosophy informs the choice of research paradigm, which guides the research design, methodology, and methods. The research paradigm refers to the human constructions that indicate where the researcher is coming from to construct meaning embedded in the data (Lincoln, 2011). Research paradigms comprise a set of shared beliefs and practices within research communities that govern inquiries across various disciplines. Ontological, epistemological, and methodological approaches characterise the paradigms that are essential for conceptualising, conducting research, and contributing to knowledge generation (Weaver & Olson, 2006). Interpretivism was adopted to align itself with the research topic of this study.

Interpretivism in qualitative research is a philosophical approach that focuses on understanding human behaviour, experiences, and social phenomena by exploring the meanings that people assign to them within their specific contexts.

3.3. Interpretivism

The interpretive and qualitative methods enabled researchers to gain further depth by seeking experiences and perceptions of a particular social context. Interpretivist researchers contend that reality is shaped by individuals' subjective experiences, emphasising the need for understanding human behaviour and social phenomena through interpretation (Walt, 2020; Pulla & Carter, 2018). This study aimed to explore the experiences of support for service users in supported living. Interpretivism assumes that all knowledge is grounded in human experience (Alharahsheh & Pius, 2020). Individuals construct their knowledge of the work through their experiences, and the interpretivism framework aims to understand a particular concept through those individuals' personal experiences in a specific setting (Hiller, 2016). The topic of this study assumed that the participants construct their experiences of support from fulfilling the activities of daily living in supported living.

Interpretivism asserts that understanding the research context is essential for making sense of the gathered data (Willis, 2007). Context was essential in enhancing validity and credibility, as it provided the background, circumstances, and framework necessary to interpret information accurately. Researchers use observations, field notes, personal notes, and document analysis (Rehman & Alharthi, 2016). This study used participant observations, semi-structured interviews, and field notes, emphasising the importance of deep engagement with the context to understand the social norms, values, and relationships that influence participants' behaviours and perceptions.

The key philosophical underpinnings of interpretivism provide a simple sequence of interrelationships between axiology, ontology, epistemology, methodology, and methods. Each principle is discussed in the context of this study.

3.4. Axiology

Axiology focuses on the ethical values researchers attach to their studies and the guiding principles that shape their pursuit of knowledge (Creswell, 2013). The axiological assumption of the study motivated the researcher's values in shaping the research process. The researcher valued the ethical standards of participants to have a participatory role in this study. People with learning disabilities are often overlooked and socially excluded in many ways in

research due to being deemed incapable; they face social exclusion manifested in various ways (Scully, 2014). Therefore, the relevant documents (Appendix C) facilitated the service users' participation in the study, fulfilling ethical considerations to mitigate potential harm. The researcher was fair and truthful to all study participants. The ethical approval of the study ensured the autonomy, informed consent, respect, privacy, and confidentiality of participants. All participants were aware of the study's purpose and the ethical requirements before providing their consent. In essence, the axiology of this research highlights its moral dimensions within a broader social context.

3.5. Ontology

Ontology is a field that examines the nature of reality and existence (Blaikie, 2010). This study is interpretivist, based on the assumption that human beings inhabit the world under investigation through their thoughts, interpretations, and the meanings they assign to it. In this context, ontology aims to establish the nature of reality underlying a research question, thereby identifying the type of knowledge that exists. The study aimed to understand the subjective experiences of support for key participants, specifically individuals with learning disabilities, within the context of supported living. Using authentic voices from different individuals provides a spectrum of perspectives that reflect the presence of multiple realities (Creswell, 2007). This study employed a qualitative approach, utilising semi-structured interviews to gather non-numerical data on the research topic, exploring multiple, diverse interpretations of reality in supported living.

3.6. Epistemology

This study employed an interpretivist epistemological stance to answer the research question and understand the meaning created within the social context of supported living. Epistemology is closely related to ontology (what can be known). It is a theory of knowledge that concerns beliefs about how phenomena are understood (Giacomini, 2010). Epistemology provides a framework for understanding knowledge and its acquisition methods (Crotty, 2003). It focuses on exploring knowledge and the relationship between the knower and what is regarded as knowledge (Guba & Lincoln, 1994). Methods used to generate, interpret, and apply knowledge.

Epistemology is grounded in a range of theoretical beliefs about the nature of the relationship between the researcher and their research subjects (Hiller, 2016). In qualitative research, positionality draws the attention of different scholars (Berkovic et al., 2020; Mason-Bish,

2019). Positionality refers to the stance that the researcher adopts within the socio-political context in which the research study is conducted (Sultana, 2007). This can influence whether the researcher assumes the positionality of an ‘outsider’ or an ‘insider’ (Sanghera & Thapar-Björkert, 2008). In this case, the researcher was an outsider to the experience as a nurse specialising in learning disabilities in the community environment. However, without knowing the participants, there was an inclination to establish a relationship of trust with them, considering them insiders in this study. Familiarisation visits were conducted to meet with prospective participants. Epistemology is reflected in the theoretical perspectives, methodologies, and methods employed in the research.

3.7. Research approach

The research approach is a strategy that formulates theories or generations based on observations or specific instances. That strategy employed an inductive approach, allowing the research findings to emerge from the significant or frequent themes in the raw data (Thomas, 2003). The inductive approach condensed extensive and varied raw text data into a summary format, drawing on interviews, field notes, and participant observations in this study. This established clear links between the research objectives. The summary findings were derived from the raw data, and generations of the participants’ experiences and views were developed.

3.8. Methodological choice: Qualitative

The interpretive focus of this study influenced the methodological choice of qualitative research. A qualitative approach provides rich, subjective insights by explaining the processes and patterns of human behaviour and experiences that may be difficult to quantify (Tenny et al., 2017). Therefore, it allowed the exploration of the context in which behaviours and experiences occurred, enabling the interpretation of data, identification of patterns and themes, and uncovering of subtle details. The qualitative approach was also flexible enough to allow a nuanced understanding of human behaviour and the views, experiences, and insights of service users and their care support workers.

3.9. Research Strategy: Focused Ethnography

Focused ethnography (FE) emphasises participant observation and direct interaction with a selected group, leading to rich, contextual data that addresses the methodological gap in Chapter 2. FE approaches allowed the researcher access to participants to explore complex cultural norms and phenomena through long-term engagement in the field of research.

Applying the ethnographic approaches to address the methodological gap identified in Chapter 2 was imperative. For this study, the supported living facility protected its service users from harm, abuse, and neglect. Accessing supported living was strictly by appointment, and permission had to be granted by the supported living management.

FE is underpinned by traditional ethnography, which aims to understand people and their activities from their perspectives based on the researcher's presence and participation in their daily lives (Holloway et al., 2010). It is grounded in traditional ethnography, provides insights into specific settings within a relatively short time frame, and concentrates on observations (Andreassen et al., 2020). It would be influential in capturing the contextual insights behind daily practices and how individuals navigate their environment. In so doing, it created rich descriptions of events and their significance in supported living.

This study allowed the researcher to explore the context of supported living by interviewing participants about their personal experiences and feelings regarding the support they receive. The study's content was guided by a clearly defined research question, relying on short-term field visits and intensive data collection (Higginbottom et al., 2013; Erickson, 2011; Knoblauch, 2005). In this study, FE's flexible qualitative approach, which includes semi-structured interviews, participant observations, and field notes, captures the experiences of support for individuals with learning disabilities in supported living.

FE is ideal when the study is limited in scope, the research question or phenomenon has been understudied, or when addressing critical questions relevant to the profession (Cruz & Higginbottom, 2013; Roper & Shapira, 2000). The researcher narrowed the scope by defining a specific problem of experiences of support, studying a group of people with mild to moderate learning disabilities, and observing specific interactions and activities in supported living settings.

FE was chosen as an appropriate method to operationalise the inductive approach, facilitating deeper insights and first-hand experiences of support in supported living settings. This method addresses specific issues within a defined context (Forchuk et al., 2022). FE is particularly suited for exploring supported groups of people using short-term field visits (Lauritzen et al., 2019).

FE transforms traditional ethnographic methods into a philosophical inquiry. Engaging hermeneutic philosophy emphasises the interpretation of texts, symbols, and meanings. Understanding through interpretation is crucial (Gadamer, 1979). The objective is to observe

and interpret the meanings and implications of practices, for example, how philosophical inquiry seeks to uncover deeper layers of meaning in life. This is often illustrated when researchers utilise texts or excerpts to demonstrate their interpretations. In this interpretive process, the interaction between textual interpretation (ontology) and self-interpretation (epistemology) is evident (Baker, 1999). It is collected through various methods within FE; viable sources include semi-structured interviews, observations, and documents (Higginbottom et al., 2013). The findings were produced through the relationship between the text (findings) and the interpreter, with each text arising from a specific linguistic tradition. This study utilises an interpretive approach to understand the experiences and meanings of support for individuals in supported living.

Furthermore, this study needed to allow the participants to continue with an ordinary, active part in the research process. Ethnography represents a validated methodological approach to studying experiences and behaviours by directly observing situations unfolding in their natural settings (Higginbottom et al., 2013). FE entailed entering the field with a defined research question (Andreassen et al., 2020) and undertaking fieldwork in a short timeline (Higginbottom et al., 2013). Participant observations enabled prolonged social interaction between care workers and service users, during which observational field notes were collected. The researcher kept the original notes and interviews intact, used a Reflective log to record changes in interpretation and link them to generated themes, and triangulated the findings with other data from interview artefacts and repeated observations. Artefacts such as clothing, digital content, or physical objects such as decorations and wall hangings served as tangible representations of the services users' values, routines, and social meanings. These artefacts helped the researcher gain deeper insights into the everyday practices and symbolic world of participation. By analysing the artefacts used, their usage, and the meanings attached to them, the researcher interpreted the uncovered norms and cultural assumptions that shape the participants' behaviour. Furthermore, artefacts complemented observations and interviews, offering a more holistic understanding and grounding abstract concepts in real-world materials. The findings were reported transparently, using participants' speeches to support the themes and sub-themes and reflect on their significance.

The field notes provided context and insights to support understanding of the service users' experiences. This study was consistent with the existing support literature, which encompasses activities of daily living and forms the basis of experiences with support for people with learning disabilities in supported living. This study seeks responses to the

research question: What do the experiences of support for people with mild learning disabilities look like in supported living? The qualitative methods, including participant observations, semi-structured interviews, and field notes, were employed as described in section 3.11 of the data collection.

3.10. Time horizon

Although the project spanned a protracted period, it was cross-sectional in design, meaning the data were gathered as a single exercise (over three months) rather than participants being followed up repeatedly (Setia, 2016). In this study, a cross-sectional approach was used to collect data at a single point in time to examine a population,

3.11. Data collection

In FE, traditional methods such as participant observations, field notes, and interviews are commonly employed (Knoblauch, 2005). The application of these methods will be described in detail in the remainder of this chapter. The research philosophy provided the foundational beliefs that shape the qualitative methods to explore and deeply understand human behaviour, experiences, and social phenomena. Research strategies were devised to enhance the participation of individuals with learning disabilities. These were the public and patient engagement to help develop the research documents (i.e., participant information sheets and consent forms). There was formal ethical approval from two organisations for the recruitment of participants. The remaining part of this chapter details the research design FE and its justification of its associated methods, such as semi-structured interviews, participant observations, field notes, and reflexivity, all tailored to address the research question. Purposive and snowball sampling were used to select participants from supported living. The chapter concludes with a reflection on ethical considerations and the research process.

3.12. Research Strategies

The rationale for the research strategies acknowledged the issues and complexities associated with adults with learning disabilities participating in this study. Research strategies were implemented to facilitate information assimilation, enhance understanding and engagement with participants and their significant others, and to discuss issues before exploring the concepts (Cook & Inglis, 2008). Research strategies were enhanced to improve participant comprehension, recruitment, and data collection, ensuring that the study effectively addressed the research question. The strategies employed included research documents per research planning, Public and Patient Involvement (PPI), ethical approval, a well-designed recruitment

process, and clearly stated inclusion and exclusion criteria. The research strategies guided the study's conduct, including data collection, analysis, and interpretation.

3.12.1. Public and Patient Involvement (PPI)

In the interest of the service users' participatory role in this study, the input of people with learning disabilities was vital to ensure participants experienced ownership of the study as their project. Patient and public involvement was sought from the relevant ethics committee (Bos et al., 2013). The ethics committee verified the safety, integrity, and rights of the participants in a research study.

Input from PPI provides unique insights that are often overlooked and can ensure that research and health services align with the needs and requirements of service users. It generally makes research more relevant with more precise outcomes and impacts (Greenhalgh et al., 2019). The rationale was that PPI was used to enhance the relevance of the documents with input from healthcare professionals and researchers, thereby improving the research procedures (Abelson et al., 2016). The intention was to make the interviewing questions ethical and transparent, tailoring them to the service users of this study. This was done through the proper channels by using one of the researcher's supervisors, one who was a patron of that group. PPI was achieved in the following stages.

3.12.2. Partners in Learning

Partners in Learning is a Sheffield-based group for people with learning disabilities, working in partnership with others to increase the service user voice in topics that support matters involving people with learning disabilities, local charities, support groups, advocacy organisations, and academics. The researcher believed that Partners in Learning provided relevant and invaluable input for the interview questions, encouraging the primary participants of this study to share their experiences of support. Partners in Learning shared experiences that resonated with these research objectives. The researcher approached Partners in Learning in Sheffield through one of the researcher's supervisors, who worked with that group. In recognition of the work contribution of the researcher's supervisor, Partners in Learning agreed to provide the PPI input at no cost, as described below.

3.12.3. Stages of PPI in this study

3.12.3.1. Identifying the requirements

The researcher identified the primary participants, who had no research experience and were often difficult to reach. They presumed that the challenges in the context of supported living necessitated prioritising interview questions and conducting viable interviews as part of the agreed-upon FE to facilitate ethical approvals for the study. The researcher also acknowledged the literature highlighting low literacy rates among adults with learning disabilities (Grove & Bakhshi, 2011). The immediate need was to make a conscientious effort to ensure that the interview was both ethically viable and friendly for the participants.

3.12.3.2. Design stage

During the design stage, PPI was involved in designing and advising on documents for people with learning disabilities in a study (INVOLVE, 2012). The purpose of PPI in health and social care research is to create research that is of high quality, relevant, impactful, and of integrity (McMenamin et al., 2020). The researcher of this study provided a draft interview schedule for people with learning disabilities, which had received input from a speech and language therapist. Partners in Learning, as PPI contributors, reviewed the scheduled interview guide and participant materials, suggesting simplified language, easy-to-read formats, and providing clarity to improvements. They reviewed and co-designed interview guides to ensure that questions were clear, appropriate, and non-leading.

The PPI input also improved the interview questions for people with learning disabilities. The work for Partners in Learning was verified through additional feedback and input on the service users' interview schedule questions (Appendix P) from a patient ambassador, a medical education practice, and a lived experience educator.

3.12.3.3. Piloting stage

In the piloting stage, they participated in mock interviews to identify confusing or sensitive questions. The same interview questions were piloted on six patients with mild learning disabilities in a low-level forensic unit to enhance the patient experience (The Patient Experience Book, 2013). This pilot confirmed that the interview questions were well suited for the interviewees. There was similar input for the Participant Information Sheets and consent forms for service users. The Interview Schedules and Participant Information Sheets were piloted on patients with learning disabilities. The patients could identify the questions

and material they understood, and the feedback was incorporated into the final documents used in this study. The other documents had input from a local speech and language therapist's team that sought to change the documents to an easy-to-read format. Working with PPI contributors helped to improve the relevance, methodological quality, and accessibility of the documents for service users during the study.

Finally, across all stages, PPI enhanced the relevance, accessibility, and ethical rigour of the study, ensuring that the voices of people with mild learning disabilities were central to the research. PPI was integrated throughout the research. It helped refine the interview in anticipation of potential difficulties service users might encounter during interviews.

3.13. Research Documents

A range of research documents was developed for the study, serving as a key aspect of the governance and approval processes. The following sections will review the range of documents and then the specific governance processes, including the researcher's reflections on obtaining approvals. Furthermore, there were two separate approval processes involving Sheffield Hallam University. The council provider's ethics approvals were obtained for the overall PhD research to include advertisements and newsletters (Appendices F & G), individual invitation letters (Appendices H, K & L), consent forms (Appendices J & O), observation notes forms (Appendix P), field notes forms (Appendix Q), and interview schedule for service users (Appendix N).

3.14. Participant Recruitment

This section describes how participants were recruited during the COVID-19 pandemic. The participant recruitment process identified, engaged, and enrolled individuals who met the study's specific criteria. The prospective participants were recruited through their support provider management. Introductory letters were sent to the managers of the shortlisted support providers. The names of local supported living services were drawn from the Care Inspectorate data store section. The data store section provides contact details for local supported living services, and their websites are accessible. Seven support providers were identified and contacted using an introductory one-page summary of the proposed study (Appendix E) based on their role in supporting people with learning disabilities in Lothian.

The researcher employed a multi-step approach to participant recruitment, which included identifying names of supported living services, identifying managers of these services, making initial contact with managers, sending formal invitations to participants, developing a

sampling plan, using purposive/snowball sampling, conducting iterative recruitment, screening participants, and conducting familiarisation visits.

3.14.1. Administrators or managers of support providers

To expedite decisions, the recruitment process and transparency, the following were sent to the managers or administrators of the prospective support providers: advertisements and newsletters (Appendices F & G), individual invitation letters (Appendices H, K& L), consent forms (Appendices J & O), observation note forms (Appendix P), field notes forms (Appendix Q) and Incident Intervention and Reporting form (S). Interview question schedules for service users were distributed to managers of the supported living services.

3.14.2. Individual prospective participants

The individual perspective participants were formally invited through letters sent via their support provider. The invitations included advertisements (Appendix F), newsletters (Appendix G), individual invitation letters (Appendix H), participant information sheets (Appendix I), and consent forms (Appendix J). The prospective participants responded within a two-week response period. All prospective participants received formal invitations and responded through their support provider's internal mail system, after which sampling commenced.

3.15. Purposive/snowball sampling

Purposive and snowball sampling were used to select participants based on specific experiences or criteria. Purposive sampling was used to select individuals with verbal communication abilities who were knowledgeable about the phenomenon under investigation (Creswell et al., 2011). Snowball sampling helped identify participants connected to other service users and actively engaged in community interactions through their social gatherings.

There was some attrition during the study, primarily due to the impact of the COVID-19 pandemic. Of the 11 prospective participants, two service users chose not to be involved, two declined to participate, and one was removed from the study by her support management team after disclosing involvement in a low-level offence. All participants had prior experience with support within supported living settings. Purposive and snowball sampling were used to select participants based on specific criteria. Snowball sampling helped identify participants who were connected to other service users and actively engaged in community interactions through their social gatherings.

3.16. Inclusion/Exclusion Criteria

These criteria are essential for defining the target population in research. Inclusion criteria help researchers to effectively address their research questions and collect relevant, meaningful data (Kumar et al., 2020). On the other hand, exclusion criteria identify attributes that might hinder the study's success or increase the risk of adverse outcomes, even if those individuals meet the inclusion criteria. Inclusion and exclusion criteria were applied to various participants in this study.

3.17. Participants

The overview of 27 participants in a hierarchy had service users as recipients of support, then care support workers (CSWs), senior care support workers (SCSWs), and Assistant Care & Support Managers (AC&SMs) (Table 2.2). Each group of participants is briefly discussed below, commencing with service users.

Table 2.2: Overview of Participants

| Participants | Participants Assessed for Eligibility | Participants Excluded | Participants Recruited | Completed Study | Final Analysis |
|---------------------|--|------------------------------|-------------------------------|------------------------|-----------------------|
| Service users | 8 | 2 | 6 | 6 | 6 |
| CSWs | 5 | none | 7 | 7 | 7 |
| SCSWs | 4 | none | 4 | 4 | 4 |
| Intermediaries | 5 | none | 5 | 5 | 5 |
| AC&SMs | 5 | none | 5 | 5 | 5 |

3.17.1. Service Users

The first group consisted of six individual service users in supported living. They were individuals with learning and physical disabilities who used health or social care services to live independently and receive support in the community (Strudwick, 2021). The service users enjoyed their independence of support in activities such as cooking, taking medication, or shopping. All the service users were aged 18 years and above and agreed to be in this study. They also met the criteria of possessing the capacity to consent and express a willingness to join the study, with an active support experience, and had clear

communication, whether spoken or written. The exclusion criteria apply to those with mental health issues or behavioural difficulties, such as being unable to engage in the study or unwilling to follow the procedures.

A total of eight prospective participants were identified from six supported living, one declined, and one withdrew due to changes in their personal circumstances. The researcher needs to gain access to supported living to gain understanding and insight about what happens and listen to what is said (O'Reilly, 2005). There was a need for a study that would allow service users to express their experiences of support. The most valuable evidence about what is most helpful comes from the experiential insights of service users (Faulkner & Layzell, 2000). The essence of the study revolved around their experiences of support in supported living settings. The service users were the significant group as primary participants whose support experiences were sought.

3.17.2. Care Support Workers

The second group had seven care support workers who were on the shop floor assisting service users in supported living flats daily and working on research days. They were crucial in helping service users with daily living activities and promoting skills development through guidance. Inclusion criteria for support care workers included working for the local council provider for at least one year, with experience supporting individuals with learning disabilities or a strong interest in doing so. They needed to have a willingness to be in the study, participate during their work hours, and be flexible enough to act as intermediaries if needed. Those who did not meet the criteria were excluded.

3.17.3. Senior Care Support Workers

The fourth group was senior care support workers who had an administrative role of supervising care support workers and support service users in the respective supported living. They had more than a year's experience in their roles. These experienced workers provided round-the-clock support to service users living independently in the community. They also exhibited a readiness to share their insights during semi-structured interviews and through participant observations.

3.17.4. Intermediaries

The fifth group comprised five intermediaries who were either support care workers or senior support care workers, but who requested to take on an additional role of explaining research

information in plain language to service users who might be illiterate. The criteria of being intermediaries included being current council employees with at least 12 months of relevant experience as support care workers. These individuals explained the study to service users and assisted with written communication from the researcher. Possessing practical communication skills in English was essential for collaborating with service users with mild to moderate learning disabilities.

3.17.5. Assistant Care & Support Managers

The last group comprised managers of supported living in Lothian. The Assistant Care and Support Managers were responsible for the smooth administrative work of their care support workers and service users in designated supported living flats. They were all current employees of the council provider with at least one year of experience within the organisation. Another criterion was a willingness to participate and contribute to the study. Those who did not meet the inclusion criteria were excluded from the study.

3.18. Screened sample

The five Assistant Care and Support Managers requested a joint screening exercise with the researcher. The rationale was based on their knowledge and experience of service users under their management. They provided a list of prospective service users from all their supported living sites who met the study's criteria, specifically those with mild to moderate learning disabilities and verbal communication skills. A total of 27 participants were screened, as shown in Table 3.

3.19. Familiarisation

The researcher had a familiarisation visit to two of the five supported living flats. The purpose of the visit was to meet the service users and care support staff informally and familiarise them with the research sites. This was to familiarise the researcher with their environment and provide them with the opportunity to ask any questions about the study before it began. Similarly, another essential component of participant recruitment was ethical approval from the two ethical committees.

3.20 Ethical approval

Ethical approval was sought and obtained from the SHU and Council Providers Research Ethics Committee before the study commenced. The process of preparing ethical applications with academic advisors involved monthly Zoom meetings. As Walker & Reed (2011) pointed out, the ethical approval process consists of some level of gatekeeping. Given that the

approval process was conducted during the COVID-19 pandemic, most of this process had to be undertaken remotely. Securing approval from Xxx University was done through a series of emails rather than through the Research and Development Offices, and the response time to emails seeking advice and direction varied, as many respondents were working from home. The arrangements were more established, and it was more challenging to obtain ethical approval for qualitative research involving vulnerable service users (Hannigan & Allen, 2003). Furthermore, the ethical application also addressed the practicalities of managing participants with mild-moderate learning disabilities. Ethical approval was sought from one support provider, the council provider, and SHU.

3.20.1 Council Provider

Ethical approval was granted by a council provider on August 23, 2021, within less than a month (Appendix T). The support provider's area manager instructed five Assistant Care and Support Managers to meet with the researcher to discuss safety measures for the prospective participants from the support organisation.

The first issue that informed the development of this study was the vulnerability of the key participants: people with mild learning disabilities in supported living. Drawing from a publication entitled 'No Secrets' (Department of Health & Home Office, 2000), the following is a definition of the adjective 'vulnerable' when relating it to adults:

A vulnerable adult is a person who is or may need community care services by reason of mental or other disability, age, or illness; and who may be unable to take care of himself or herself, or unable to protect himself or herself against significant harm or exploitation.

During discussions with the Assistant Care and Support Managers, the role of culture and social status was considered, as service users were vulnerable due to care from staff that rely on paid care support within supported living settings. There was the aspect of risk being perceived as "risk", as vulnerability. The risk assessment and safety of service users must be enabling and protective. All service users deemed as having profound learning disabilities were excluded from participation due to the possibility of high levels of vulnerability. The Assistant Care and Support Managers further requested documentation of the study's risk management plan, including those considered eligible for participation.

While the SHU Research Ethics Committee was processing the application, an organisation supporting the council provider showed interest in participating in the proposed study. The council provider confirmed receipt of the initial introduction letter and a one-page research summary (Appendix E) and requested the ethical application. The Research Access Form was completed and submitted to the council provider. It is crucial to obtain ethical approval to ensure the safety and well-being of both participants and researchers (McDermott et al., 2019). The requirement for ethical approval was a safety measure for service users with learning disabilities, as mandated by the Research Ethics Committee.

The council provider's requirements included information sheets, consent forms for potential participants, details on participant involvement, study confidentiality, a research agreement, the council provider's relevance, and additional information about the proposed study. The Insight Unit Corporate Services of the City Provider approved the ethical application within a month.

3.20.2 Sheffield Hallam University

Ethical approval was sought from the researcher's university and the support provider. It was initially assumed that ethical approval would also be needed through the Integrated Research Application System (IRAS). A new ethical guideline required all researchers to follow official procedures for obtaining ethical consent in social services (Boxall & Ralph, 2011). The student lived in Scotland, worked for the NHS, and was a part-time student in England. The study was to be conducted in Edinburgh but overseen by a university in England. The main challenge arose from involving participants who were no longer NHS patients but were now in social care. During a Zoom meeting, the ethical application was under discussion when an unusual situation arose. Due to the lockdown, contacting critical participants via email was essential, as many worked from home. Seeking ethical approval through IRAS and the local university ethics committee was time-consuming. The governance arrangements were well established, ensuring due consideration when obtaining ethical approval for qualitative research involving vulnerable service users (Hannigan & Allen, 2003). Eventually, the Research & Development team clarified that we should seek ethical approval only from the relevant university and service provider, rather than through the IRAS.

The academic advisors understood how the local university ethics committee worked. The ethical approval included specific gatekeeping measures (Walker & Reed, 2011). The ethical

application also addressed the practicalities of managing the critical participants with learning disabilities. The ethical approval sought from SHU was granted after one resubmission.

On November 26th, 2021, Xxxx University's Research Ethics Committee (UREC) approved the study with advisory amendments (see Ethical Review ID: ER33153588 in Appendix U). The advisory amendments highlighted that the risk form needed to be modified, and that the resident information sheet required a legal basis for research and a data protection statement.

The second issue that informed the development of the study was "risk". The UREC identified that the risk form required amendment. It underscored the significance of risk assessment for the key participants. The ethics application was successful after resubmission with amendments. Risk management is concerned with reducing negative risk experiences (Parley, 2011). Therefore, risk and vulnerability were considered equivalent for people with learning disabilities in informing the study's development.

The SHU and council provider ethical reviewers were fair and demonstrated their commitment to the study's integrity by raising constructive concerns. The delayed clarification process contributed to further improvements in the proposed research.

3.21 Reflexivity on ethical considerations

Assistant Care and Support Managers were involved in the screening process for eligible service users; others were considered potentially vulnerable. This vulnerability was closely associated with perceived risk. Therefore, the risk assessment needed to prioritise both the empowerment and safety of service users. Gatekeepers play a crucial role in providing access to research participants, and their responsibilities are grounded in upholding integrity and altruism (Crowhurst, 2013). As a learning disability nurse practitioner, the researcher recognised that ethical approval from two organisations addressed the participants' vulnerability. However, my dual insider-outsider roles introduced potential bias, which could complicate the power dynamics between the researcher and the participants. The collaborative effort between the Assistant Care and Support Managers and the researcher facilitated the screening process, but also generated tension, as they sought to protect prospective participants while influencing the outcomes of the joint screening exercise.

Throughout the ethical approval process, the researcher experienced a tension between procedural ethics (formal approval protocols) and situational ethics, which arose from specific circumstances (Tracy, 2010). The procedural aspect involved obtaining ethical approval from a university in England overseeing the study, while an NHS employee and a

part-time student residing in Edinburgh. The research was carried out in Edinburgh with participants who were not NHS inpatients but lived in the community under social care. This posed challenges in reconciling these different contexts.

Ethical approval was not obtained through the IRAS, and navigating this process involved shuttling between various Research and Development offices in Edinburgh with no clear guidance. That unusual situation highlighted the significance of ethical dilemmas. Ethical approval to safeguard human subjects is essential for adhering to ethical standards (Fernandez et al., 2018). Ultimately, it required obtaining authorisation from the overseeing university and navigating the bureaucratic complexities of the Scottish regulations, putting the researcher's morals and professional principles to the test.

3.22 Reflections on the Recruitment Process

This chapter has included the difficulties in recruiting participants from supported living. The recruitment process involved service users and their support staff. However, the reflections of the recruitment process mirrored the reflexivity, entailing recognition of the researcher's position within a specific social, political, cultural, and linguistic framework (Alvesson, 2002). The service users were individuals with mild-moderate learning disabilities and residing in supported community placements. The recruitment process encountered unexpected hurdles that could impact recruitment, since some individuals still needed to participate in this research. The unforeseen factor, COVID-19, hampered the recruitment process. The recruitment process documents were designed in easy read to enable prospective service users to communicate effectively in their own language (Liamputtong, 2010). The researcher's insightful review of early interview transcripts heightened self-awareness during subsequent interviews, yielding valuable initial insights. The study identified sample size limitations due to its exclusive focus on a single support organisation. There was an adult protection measure with active engagement of Assistant Care and Support Managers in screening and researchers in short-listing prospective participants. The researcher and managers' joint screening of service users was in the interest of safeguarding service users; it may also have been perceived as conflicting with valued ethical principles, such as autonomy and consent, in health and social care. For the researcher, it was in the interest of mitigating selection bias, which fitted well for this study. A record was kept of all support providers and participants who declined to participate in the study.

3.23 Chapter Summary

Chapter 3 adopted the Onion Model to establish a suitable research methodology for this study. The discussion included the research philosophy, approach, methodological choices, strategy, and time horizon most suitable for this study. Examining theoretical foundational assumptions related to axiology, ontology, and epistemology guided the selection of interpretivism, a qualitative approach, and the research design of FE.

The dynamics and challenges of working with primary participants who have learning disabilities were addressed through the research strategies of creating easy-to-read documents, PPI, and effective recruitment processes. SHU and another council support provider granted ethical approval for this study. Six service users, five care support workers, four support care workers, and five Assistant Care & Support Managers were recruited from a council provider.

The researcher reflected on ethical considerations of the dual positionality of two institutions, the one overseeing the study in England and the support provider for all the participants in Scotland. The reflections were on participants during an already complex process under normal circumstances, and now even more challenging during the COVID-19 pandemic. It affected the ability to engage face-to-face with prospective participants, and for people with learning disabilities, this created additional barriers. Under lockdown measures, this made it harder to reach people, and so the researcher used alternative methods of recruitment, such as phone calls and emails, if it was feasible.

Chapter 4

Data collection

4.1 Introduction

This section describes the data collection process, utilising methods such as FE semi-structured interviews, participant observations, and field notes in supported living environments. Below is the overview of service users, which presents the primary participants interviewed, together with all support staff (Table 3.3).

Table 3.3: Overview of Service Users

| Service User | Gender | Interview | Participant Observation 1 | Participant Observation 2 |
|---------------------|---------------|-----------------------|----------------------------------|----------------------------------|
| 1. Boyd | Male | Supported living A | Supported living | Supported living |
| 2. Heather | Female | Supported living B | Supported living | Supported living |
| 3. Graeme | Male | Supported living C | Supported living | Supported living |
| 4. Fraser | Male | Supported living D | Supported living | Supported living |
| 5. Rab | Male | Supported living D | Supported living | Supported living |
| 6. Cameron | Male | Supported living E | Supported living | Supported living |

4.2 Protocol

A protocol was established to guide the research process. The protocol facilitates timely approval, ensures the smooth progression of research activities, and supports completion within the designated timeframe (Rout & Aldous, 2016). It is essential because it provides a clear and structured plan for conducting the study. For instance, during data collection periods, senior care support workers communicated updates on COVID-19 developments to address potential impacts on care support workers and service users in supported living environments.

The support worker on duty led the researcher to the interview room (usually in a spare, quiet bedroom). The participants were informed about the consent process and their right to withdraw from the study. Written consent, obtained in duplicate, one copy for the participants and one for the researcher, was signed. Non-participants were also asked to agree to data collection in their presence, especially for participant observations. The participants were once again reminded of the duration of the interviews. The service users were interviewed first, followed by their care support staff. The data collection was agreed upon with the participants, with the advice of their support staff.

This proposed study adopted an inclusive approach to engage with marginalised people, seeking the perspectives of service users and their support staff in selected supported living settings. The emphasis was on participants' extraordinary voices as holders of valid perspectives and insights into their experiences and social worlds (Nind, 2014). Semi-structured interviews, participant observations, field notes, and reflexives are associated with the ethnographic approach (Hammersley & Atkinson, 2007; Knoblauch, 2005). The timeline (Appendix A) served as a roadmap for the data collection process, providing structured schedules and clearly defined data-gathering activities to ensure efficiency and systematic organisation. Below are some of them:

4.3 Semi-structured interviews

Before the interviews took place, semi-structured interview questions were prepared for the service users to increase the likelihood of obtaining the desired results. The intermediaries helped participants with reading difficulties. Regular support staff, acting as key workers, provided guidance and helped individuals with difficulties speaking (Mietola et al., 2017). The semi-structured interviews were recorded using a Dictaphone. Before the recording, all participants were informed about the use of a recording device and reassured that their data would be safeguarded in accordance with the General Data Protection Regulation (GDPR) (2018).

4.3.1 Service users

The six service users were the first to be interviewed as key participants of this study. The interviews took place on the agreed-upon dates and times for each selected service user in the supported living setting. The service user interviews had ten questions, and the time allocation ranged from 30 to 60 minutes. Consent was obtained from participants in writing and verbally to indicate their willingness to participate in the study (Freedom, 2001).

Upon introduction, the purpose of the visit and interviews was formally reiterated. The researcher obtained the participants' consent and reiterated the importance of anonymity and confidentiality. In the event of withdrawing from this study, participants would not necessarily explain or face any consequences. That approach fostered an environment of trust, encouraging participants to provide open and honest responses.

The participants were informed that their confidentiality was not absolute if they disclosed serious issues. Any serious concerns or adverse incidents would be raised with the responsible managers of supported living or the area manager. The Protocol for Incident Intervention and Reporting Form (Appendix S) was developed in accordance with adverse reporting regulations (Nursing and Midwifery Council, 2018). The completed Protocol for Incident Intervention and Reporting Form would be submitted to the administrators or managers of supported living within 24 hours or to the area manager within seven days. Similarly, if the same protocol were followed in an emergency that warrants a participant's withdrawal from the study due to anticipated circumstances or consequences of a participant's decision, the participant would withdraw. If necessary, such measures are applied to all participants and during all data collection processes. The semi-structured interviews were recorded.

4.3.2 Senior Care Support Workers

The senior care support workers were also interviewed after their service users. Their interviews focus on the seniors' perspectives regarding the service users' experiences of support in supported living (Appendix N). The interview sessions lasted 60 minutes and were recorded in audio format. The same interview formality was followed.

4.3.3 Assistant Care & Support Managers

The Assistant Care and Support Managers were interviewed to ascertain their views on their influence and role in the experiences of support for service users in supported living (Appendix N).

4.4 Participant Observations

Following semi-structured interviews, participant observations were scheduled on dates and times agreed upon with the Assistant Care and Support Managers of supported living. Participant observations, a crucial component of the research, were conducted using an ethnographic approach with service users and their support workers. The use of a non-interference strategy was instrumental, as it allowed for follow-up events and significantly

enhanced the quality of the research (Mietola, 2017). This strategy was chosen because participant observations, which provide insights into everyday life, complement semi-structured interviews, which articulate and explain everyday social life (Reeves et al., 2013). It involved observing service users' activities in their flats with support from their care support workers. The activities took place during business hours when the researcher visited service users' flats.

The recorded details of the participant observations were comprehensive, including the people involved, activities conducted, the sequencing of events, the objectives of key participants, and the emotions expressed (Stacey, 1998). These details were meticulously recorded on the observation notes form (Appendix P), providing a thorough understanding of the observed events.

The protocol involved calling the supported living manager to confirm the participant observation appointments. The researcher visited the supported living to confirm the participants' observation appointments and sought updates on any developments that might affect the day's research appointment. The purpose of the study and the participants' consent (service users and support workers) were discussed before observations. Where issues arose, assistance from the Assistant Care and Support Managers and intermediaries was sought. Participants were assured that they would not be recorded in a manner that could reveal their identity. The same applies to the Protocol for Incident Intervention and Reporting Form (Appendix S) if an adverse incident was observed or reported during data collection. The participants' observations were conducted discreetly in supported living to minimise any interference with ongoing activities. The participants' observations involved two participants (service users and support workers) within and outside of supported living. On average, the observations were three to four hours per week during business hours from March to August 2022, as shown in the Timeline (Appendix A).

4.5 Field notes and reflexives

The field and reflexive notes were recorded on observation sheets and in a notebook discreetly during and immediately after each participant observation visit. Field notes were based on participants' actions (verbal or non-verbal) and the researcher's thoughts, feelings, impressions, and insights (Flick, 2014; Morrow, 2007; Mack et al., 2005; Miles & Huberman, 1994). There were interactions in the supported living, depending on the activities taking place at the time of the participant observations. Written field notes provided rich accounts of

the participants being researched (Phillipi & Lauderdale, 2018; Helleso, 2015). There were summaries of the interviews, sometimes even bullet points extracted from more complete field notes taken during the interviews. Regarding participant observations, the recorded field notes were taken in a less obtrusive manner in the supported living environment. The recorded meaningful notes covered everything observed and thought about, based on the activities involving people and objects. The field notes were written accounts recorded as soon as possible after leaving the field site to maintain the accuracy of descriptions against any distortions or time lapse (Appendix Q).

In addition, reflexive journal accounts documented the learning journey and reflected the researcher's feelings and experiences of being with the participants. This personal connection was crucial in generating credible stories about participants' lives and behaviour throughout the entire research process (Von Koskull, 2020). All pertinent information, such as ethical considerations, observed behaviours, and documented progress, was diligently noted to enhance the support experiences for the service users. At the conclusion of the data collection, the participants were informed of the study's termination, and the researcher expressed gratitude and appreciation by presenting each participant with a certificate of participation (Appendix R). The collected data were then ready for analysis.

4.6 Reflexivity of data collection

The researcher collected data through semi-structured interviews, participant observations, field notes, and reflexive journals. The data collection process consisted of 16 semi-structured interviews and 12 participant observations conducted over four months. During the participant observations, the researcher, a learning disability nurse by profession, concealed their lack of research experience. The researcher experienced emotional tension due to the dual roles of researcher and learning disability nurse.

Maintaining reflexivity throughout the data collection process was essential and required mindfulness, given the nature of the primary participants with mild and moderate learning disabilities in this study. This approach enhanced the researcher's mindfulness regarding their role in the study environment (Berger, 2015). The researcher was careful to focus objectively on the participants' experiences. The researcher realised that his personal background, identity, and experiences may affect how he approaches the research. There was a consciousness to recognise that one's own background was essential to understanding how

these factors may shape the interview questions, participant observations, field notes, and interpretation of data.

During the interview, the way the researcher interacts with participants could influence the data collected. The researcher's tone, body language, or phrasing of questions could affect how participants respond, especially in qualitative methods. In this study, the researcher became aware of his own attitude, gestures, and reactions, which may discourage certain responses. Similarly, biases and preconceptions may influence data collection. The researcher used reflexivity to develop an insight and was open to conflicting or unexpected findings, which aligned with the purpose of data collection.

Lastly, the researcher used rapport conforming to the level of the participant's abilities empathetically, while maintaining a more neutral demeanour appropriate for engaging each of the participants.

4.7. Chapter Summary

This chapter demonstrated the significance of data collection involving service users (people with learning disabilities) as primary participants with no research experience. Chapter 4 is a culmination of the detailed planning in Chapter 3. The study chose three sets of participants: service users, senior and care support workers, and Assistant Care and Support Managers from supported living. Focused Ethnography was chosen to encourage participation and data collection using its associated methods, including semi-structured interviews, participant observations, reflexives, and field notes. Participant observations involved service users being observed while working through their daily routines, assisted by their care support workers. The researcher interviewed all the service users and their support workers on their views and experiences of support in supported living.

In summary, data collection in supported living improved data collection for the service users, gave them a voice for their experiences of support, and showed the feasibility and merit, with appropriate preparation, to include people with learning disabilities in research.

Chapter 5

Data analysis

5.1 Introduction

This chapter integrates significant qualitative large data with the philosophical underpinnings discussed in Chapter 2. Gathered qualitative data is transformed using Reflexive Thematic Analysis (RTA). Qualitative research collects large amounts of text or narrative data and provides meaningful insights from interview transcripts or observations. This chapter explains how patterns, trends, and relationships are used to answer your research questions.

5.2 Reflexive Thematic Analysis

Data were analysed using reflexive thematic analysis (RTA) in accordance with Braun and Clarke's six-phase model (Braun & Clarke, 2021a, 2019). Table 4.4 summarises the actions taken in each phase.

This analytic method was selected for its epistemological flexibility and is appropriate for exploring under-researched topics, particularly where the aim is to centre participants' voices and meaning-making processes. RTA also acknowledges the active role of the researcher in theme development and interpretation, aligned with the research aims (Braun & Clarke, 2021a). RTA is a flexible, recursive process of coding, theme development, and interpretation that allows refinement as understanding deepens (Milkins et al., 2025). This approach was particularly suitable for analysing the experiences of support for people with mild learning disabilities in supported living, as it allows for deep engagement with participants' perspectives, respects the richness of their narratives, and acknowledges the co-constructed nature of qualitative interpretation.

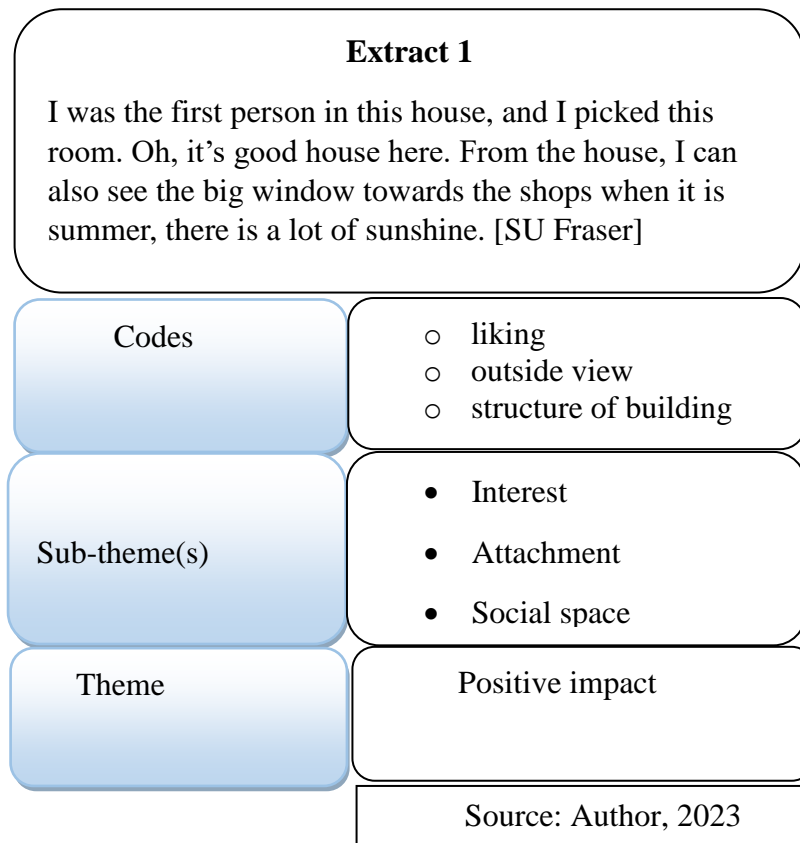
Table 4.4: Summary of tasks used during Reflexive Thematic Analysis

| Phase | Actions taken for this study |
|--|--|
| <i>Data familiarisation</i> | The researcher carefully read and re-read transcripts, recording initial thoughts and feelings in a reflexive diary, and taking note of data that appeared related to the research question. |
| <i>Data coding</i> | The researcher coded both descriptive (semantic) and interpretive (latent) codes to capture patterns and facilitate deeper interpretation. The coding line-by-line identified texts relevant to the research question (Extract 1). |
| <i>Generating initial themes</i> | The researcher formed initial themes by reviewing coded data extracts, considering each theme's narrative, relationships between themes, and the overall patterning of the data. |
| <i>Reviewing & developing initial themes</i> | Themes were reviewed for coherence, meaningfulness, and 'thickness', leading to the development of additional themes and sub-themes. Each theme's boundaries and significance were clearly defined. |
| <i>Refining, defining, and naming themes</i> | <p>A draft 'definition' for each theme and sub-theme was created to assist in reviewing the cohesiveness and validity of the central organising concept. Subsequently, themes and sub-themes were consolidated, named, and renamed as needed.</p> <p>The iterative process of examining the data multiple times was undertaken, and members of the supervisory team reviewed the coded data extracts to identify consistent and coherent patterns within the entire dataset.</p> |
| <i>Producing the report</i> | The researcher and the supervisory teams agreed on themes, sub-themes, and definitions, selected key quotes, and finalised the narrative |

Adopted from Braun & Clarke (2021a)

A professional transcription service converted all interviews into transcripts, and Quirkos software was used to manage the RTA data. Contextual data from participant observations and field notes were organised into three groups: service users, the support care workers, and

their care managers. The transcripts were read verbatim multiple times to facilitate involvement and familiarisation with the data. Key phrases and other meaningful information were identified, and initial codes were created and assigned. Coding involved assigning concise phrases or words to data, capturing the salient and summative essence of the material (Saldana, 2016). For example, the opening coding line-by-line identified texts relevant to the research question (Extract 1).



The relationship between codes, themes, and sub-themes was formulated. Codes were scrutinised in reference to the research aims to assess their applicability. Identifying information, such as names and service references, was removed to ensure confidentiality and anonymity. An inductive approach to coding was employed, enabling patterns of meaning to form directly from the data. The analytic approach prioritised participants' subjective experiences and perspectives. Initial coding was conducted through close, iterative readings of the transcripts. Codes were subsequently reviewed, grouped, and developed into candidate themes through a process of refinement and reorganisation over multiple analytic cycles.

Finally, in preparing this manuscript, the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist was used to report a study (Tong et al., 2007). The concluding step was to compile the findings and select quotes to support the results. Chapter 5 discusses the overarching themes produced in this section of this thesis.

5.3 Establishing Rigour

Establishing rigour requires creating systems and processes that ensure consistency and standards in this thesis. The iterative process is essential in developing a research question that meets specific criteria. A research question should be feasible, attractive, novel, ethical, and relevant, and use the acronym FINER (Johnson et al., 2020). The acronym FINER, represents feasible, interesting, novel, ethical, and relevant, and is answerable and researchable. Developing a FINER research question is critical to study rigour and quality and should not be rushed, as all other aspects of research design depend on the focus and clarity of the research question(s) guiding the study (Agee, 2009). This study meets FINER criteria for the research question with 12 words approved and worth pursuing. The feasibility aspect of the study assessed its practicality in the local community, including the sample size and available resources. The attractive component aimed to capture the attention of a wider audience, including stakeholders. The novelty factor aimed to introduce new insights and perspectives to the existing body of knowledge. The ethical aspect was given utmost importance, ensuring that the study was conducted with integrity, respect, and responsibility, while safeguarding the dignity and well-being of all participants. The relevance aspect resonated with the theoretical and practical implications of influencing social care practice, policy, and social well-being. Straightforward research questions are critical for designing a successful study. The iterative approach involves creating a guiding question to guide the inquiry process and developing sub-questions and news during the study (Agee, 2009). The criteria for answering questions involved the research focus, context, timescale, and available resources. The rigour for this thesis was of reproducibility, credibility, and legitimacy (Creswell, 2009). Each form of rigour is examined in terms of how it is applied in this thesis.

5.3.1 Reproducibility

Reproducibility ensures that other researchers can obtain comparable results; a detailed description of the research protocol, methodology, sampling, and data collection is essential. A scoping review systematically examined the literature using targeted search terms and

research strategies, including patient and public involvement (PPI), recruitment processes, and relevant documentation for key participants with learning disabilities. It helped to ensure reproducibility and increase the transparency of the research process.

5.3.2 Credibility

The study's credibility relied on data collected through interviews, participant observations, and field notes from representative groups in supported living. The study ensured trustworthiness and integrity within the data analysis process. For instance, there was manual coding and analysis of qualitative data from written texts, observational field notes, and interview transcriptions. After completing the data analysis, the researcher actively sought out and scrutinised data that did not support the researcher's interpretation (Creswell, 2013). The discussion section included an interpretation of the results and recommendations for practice. The researcher utilised the discussion section and actual quotations from the semi-structured interviews to provide a concise narrative and interpretation of the study's results, thereby enhancing the understanding of the research topic.

5.3.3 Legitimacy

The third strategy enhanced the legitimacy of this study, adhering to established ethical standards. Legitimacy involves widespread belief that the behaviour of an object is fitting, suitable, or acceptable within a socially established framework of norms, values, and beliefs (Suchman, 1995). In the thesis, transparency played a crucial role in enhancing legitimacy, as the researcher shared and explained the research documents, study methodology, data collection methods, and participant information. Thus, the study's legitimacy is in the practical implications of socially constructed values within supported living.

Legitimacy is also linked to the credibility of data collection that meets the high standards widely accepted in the research community (Flickinger et al., 2014). This qualitative study collected data from three groups: service users, care support workers, and their managers. The research employed an ethnographic approach, using semi-structured interviews, participant observations, and field notes in the context of supported living.

5.3.4 Morally credible

The study was morally credible. The research demonstrated a strong moral standing, possessing qualities that inspired trust and confidence in its ethical integrity. This involved consistently upholding values and principles that society recognised as good and just. Ethical

approval from the researcher's university and a support provider ensured the safety and well-being of the participants. The researcher treated the participants with dignity and respect, and they openly shared their experiences of support during the interviews, aligning with the researcher's ethical principles. Maintaining this integrity was crucial for establishing and upholding moral credibility. All participant data was kept confidential to maintain the study's integrity.

5.4 Storing Data

Data storage was conducted in accordance with the data management plan. Collected data was securely stored in accordance with the General Data Protection Regulation (GDPR) and SHU University's research data management policy. Non-identifiable participant information was treated with the utmost confidentiality. No participant or representative of an organisation was identifiable in any reports or publications resulting from the research. Pseudonyms safeguard participants' identities, while organisations are code-named. Thus, the researcher addressed all the concerns raised by the support provider's senior care support workers during the recruitment of participants. All data was securely stored on a password-protected computer system, adhering to SHU's stringent data management policy. Data were stored throughout the collection process and retained for the period specified by the funder, in accordance with the University's Research and Knowledge Transfer Records Retention Schedule. Only the researcher and supervisory team can access the data, ensuring its security and integrity.

Based on SHU's research data management policy, the study holds a strong ethical obligation to store all live research data in the University's networked storage facilities. Permission was received from the University and a support provider. Furthermore, all data gathered during the study were stored using the SHU research store service (Q:\Research drive), which provides confidential shared storage for currently active research projects to ensure their integrity. The participants were notified that SHU, the study's funder, retained their data for educational purposes, if necessary.

5.5 Reflexivity of data collection

The researcher collected data through semi-structured interviews, participant observations, field notes, and reflexive journals. The data collection process consisted of 16 semi-structured interviews and 12 participant observations conducted over four months. During the participant observations, the researcher, a learning disability nurse by profession, concealed

their lack of research experience. The researcher experienced emotional tension due to the dual roles of researcher and learning disability nurse.

Maintaining reflexivity throughout the data collection process required the researcher to be mindful of how their conduct influenced the findings. This approach enhanced the researcher's mindfulness regarding their role in the study environment (Berger, 2015). The researcher was careful to focus objectively on the participants' experiences.

5.6 Reflexivity and Data Analysis

In this qualitative study, maintaining reflexivity was essential to ensure that the researcher's biases did not compromise the credibility and reliability of the study. Reflexivity is a critical process that enables researchers to examine their work and grasp how their assumptions, values, and preconceptions shape the research they produce (Hsuing, 2010). It involves researchers being mindful of their potential biases and prejudices, as well as their influence on the research process and results. The researcher paid close attention to the detailed data analysis of three groups: service users, care support workers, and senior care support workers. This provided invaluable support experiences of people with learning disabilities in supported living. For instance, this entailed engaging in critical self-reflection, continuously questioning, critically evaluating interpretations, exploring alternative explanations, and being receptive to conflicting evidence. There was a need to reflect on the immersion in the data while maintaining objectivity and neutrality, and to record everything in the notes.

This study's main data analysis approach was narrative, and data were treated in their entirety to construct comprehensive, interrelated ideas and interpretations. As a result, the data were evaluated based on participants' comments and remarks on their support experiences, providing context for their interpretations of existing literature. The researcher employed the strategy of ensuring rigour from reflexivity (Houghton et al., 2013). For example, it involved using intuition, creativity, and imagination in reading substantial data from different participants. The primary aim was to enhance credibility and ethical integrity by analysing data in a nuanced manner within the framework of research questions and objectives. Using reflexivity, the researcher could situate themselves in relation to the research topic. It became the source of motivation, driven by the findings from the analysed data on the research topic. A clear coding framework enabled the identification of themes, grounded in both data and personal biases.

5.7 Researcher Positionality

The PhD programme requires students to investigate a chosen topic. Positionality refers to both an individual's worldview and the stance they take towards a research task within its social and political setting (Savin-Baden & Major, 2013). It is identified by examining the researcher's relationship to the subject matter, the research participants, and the research setting and process (Holmes, 2020). Researcher positionality entails awareness of and reflection on how one's position affects the research process and data interpretation. This process demands time for deep self-reflection, fostering an understanding and acknowledgement of the researcher's role in health and social care studies. In this study, the researcher assumed a dual role of a researcher (outsider) and a learning disability nurse (insider) while working with individuals with mild-moderate learning disabilities in Lothian. An interpretive approach was used, which suggests that reality is socially constructed through relationships within a specific context. In interpretive research, the researcher is central to the interpretation and uncovering of situated knowledge (Cohen et al., 2007). The researcher also incorporated three key elements: approachability, rapport, and credibility to recognise and address how positionality influences the research.

5.7.1. Approachability

According to Adu-Ampong & Adams (2020), approachability is critical to reflexive research, especially for the insider role. It involves fostering a non-threatening approach that allows participants to feel safe while disclosing information and engaging in extended discussions without fear of judgment (Gallo & Horde-Freeman, 2016). The researcher ensured that the study met the ethical requirements of inclusivity and respect for the participants' values in supported living.

5.7.2. Rapport

The researcher navigated the insider-outsider dichotomy in each context with professionalism and impartiality. The relationship between the researcher and participants is a central element of reflexive practice (Reeves et al., 2008). When acting as an insider, the researcher leveraged shared experiences and understanding to build trust and elicit richer data, while remaining vigilant against assuming shared meanings. As an outsider, the researcher adopted a respectful and inquisitive stance, allowing participants' perspectives to guide interpretation. An inclusive atmosphere was fostered by providing clear study information and ensuring that all participants had the opportunity to ask questions before giving consent.

The researcher remained attentive to the dynamic between objectivity and subjectivity in this context (Freire, 2000) and addressed any issues that emerged during the study. Throughout the study, the researcher demonstrated integrity and honesty, maintaining effective rapport with the care support managers during face-to-face meetings and with all participants in supported living environments. Participants reported feeling listened to and respected.

5.7.3. Self-Introspection

The researcher employed self-introspection in relation to the insider-outsider spectrum (Braun & Clarke, 2013). The researcher reflected on how prior experiences, background, or professional roles might shape research questions, interactions with participants, and interpretations of data. The researcher engaged in continuous reflexive practice of keeping field notes and reflective journals while seeking feedback from academic supervisors to challenge interpretations and reduce the influence of personal perspectives. The researcher employed the balancing act of using insider knowledge while maintaining ethical conduct, ensuring the study remained within its ethical guidelines. Overall, self-introspection enhanced credibility, ethical integrity, and impartiality by ensuring that the researcher remained critically aware of their influence on the study rather than unconsciously imposing it.

5.7.4. Credibility

Another essential element of positionality was credibility. In ethnographic research, earning participants' trust is necessary for them to believe the research is worth their time (Adu-Ampong & Adams, 2020). In this instance, the researcher shared information sheets and consent forms. This effort resulted from extensive communication between the participants' management and the researcher. The ethical engagement showed how the researcher presented the study to service users from a marginalised population group. Credibility further came from ethical approval from the researcher's university and support provider management as proof of the moral position.

5.7.5. Context and Research Process

This aspect of positionality encompassed both the research context and process. Context is defined as a set of characteristics and circumstances comprising active and unique factors that influence implementation (Pfadenhauer et al., 2016). It extends beyond the physical setting to include roles, interactions, and relationships. The research process introduced new experiences through distinct stages, including data collection and data analysis across various settings. In this study, the researcher briefed participants on the study's developments and

addressed their concerns, acknowledging the influence of context at every stage of the research process and implementing ethical safeguards to ensure participants' well-being. For instance, participants' well-being was monitored before and after each data collection session. Reflexivity and self-introspection were employed to continuously assess how contextual factors and researcher positionality influenced decisions and interpretations.

5.7.6. Impact of researcher positionality

Throughout the research process, the impact of the researcher's positionality was assessed using reflexive journals. The journals documented the researcher's thoughts, emotions, and reactions to the study. In addition, a team of academic supervisors regularly identified and addressed potential biases. All such strategies contributed to the study's transparency, rigour, and ethical responsibility.

In summary, the researcher's positionality is integral, as evidenced by the researcher's navigation through the research stages. The researcher engaged in critical self-reflection to address potential biases, actively managed power dynamics by recognising the influence on data collection, and maintained fairness, respect, and transparency in interactions with participants.

5.8 Chapter Summary

Chapter 5 discussed the researcher's positionality, ethical approval, data collection and analysis procedures, and recruitment strategies.

It provides an account of the RTA process applied to substantial data. The concept of positionality is further examined in terms of approachability, rapport, and credibility, which serve to increase transparency and facilitate the acknowledgment and management of potential bias.

The chapter demonstrates rigour by establishing credibility, reproducibility, and legitimacy through transparency and reflexivity. Rigour was ensured through the use of Reflexive Thematic Analysis (RTA), which facilitated transparent coding and theme development. Ongoing reflexivity was maintained to acknowledge the researcher's influence, and a clear explanation of theme development was provided. (see Table 4.4). RTA systematically transformed raw data into meaningful insights, as evidenced in Chapter 6. It was useful for service users to capture their support experiences and practical insights, and managerial perspectives of the Assistant Care and Support Managers, as shown by data analysed in a nuanced way. It was appropriate for understanding participants' thoughts, feelings, and lived

experiences, particularly in support of living settings. All raw and analysed data were securely stored in accordance with the General Data Protection Regulation (GDPR) and Sheffield Hallam University's research data management policy. This chapter helped to link methodology to findings (Chapter 6) and provided evidence for a credible, academically sound thesis.

Chapter 6

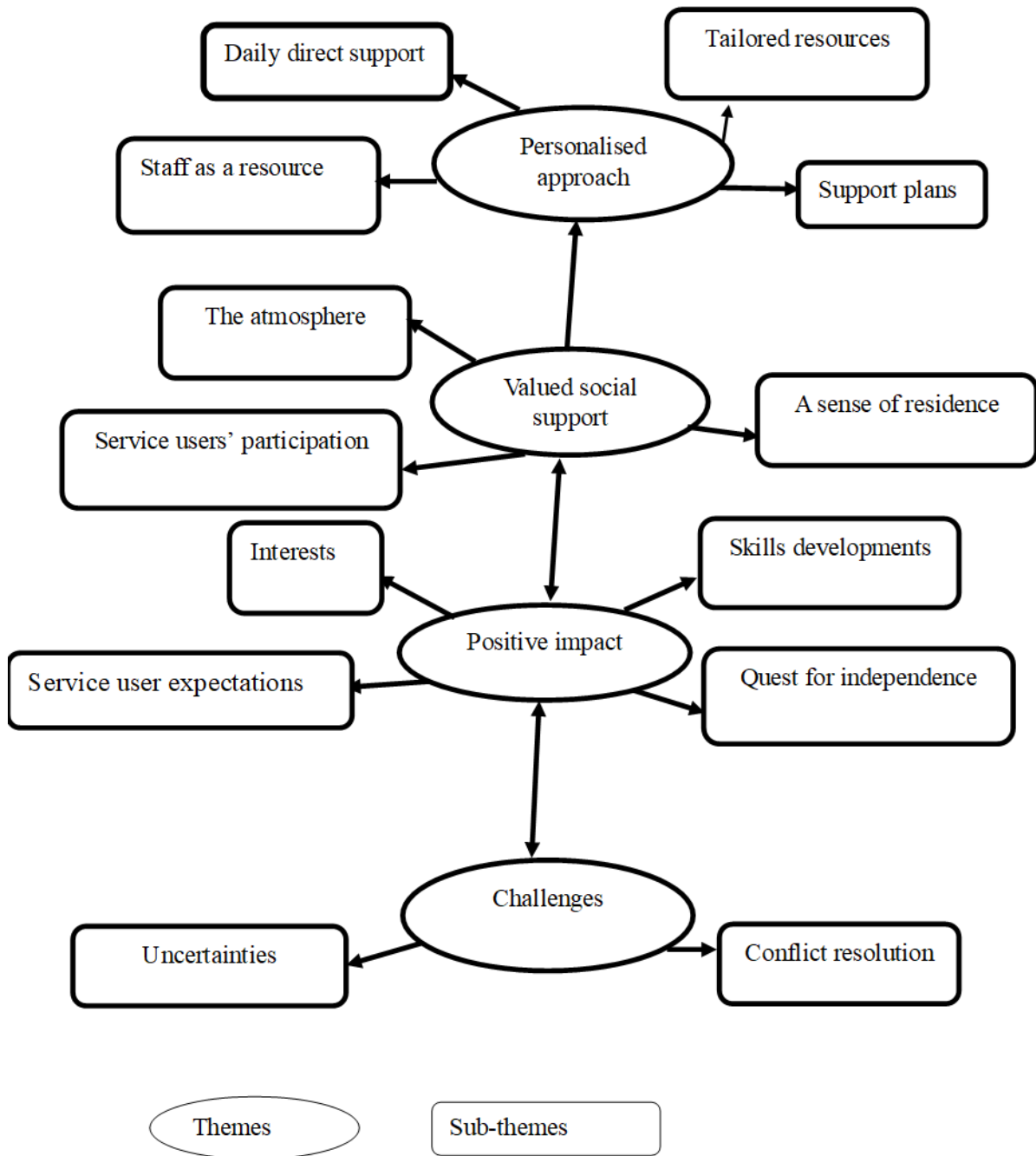
Results

6.1 Introduction

This chapter presents findings on support experiences for individuals with mild to moderate learning disabilities in supported living settings. It features the perspectives of adults with these disabilities. The findings are organised into two sections. Part 1 explores themes from service users, based on semi-structured interviews with service users and support workers, participant observations, field notes, and insights from managers. Four main themes emerged: (1) personalised approach, (2) valued social support, (3) positive impact, and (4) challenges, each with related sub-themes (Figure 1.5). Part 2 looks at themes from Assistant Care and Support Managers, based on interviews about their views on support for the service users they oversee. The three key themes are: (1) organisational readiness, (2) culture of support, and (3) service users' needs and expectations (Figure 1.6).

The chapter discusses findings from the perspectives of service users with the Assistant Care and Support Managers, providing a deeper understanding of the experience of support. First-hand accounts and practical insights from care support workers and senior care support workers offer a broader understanding of hands-on care and oversight responsibilities in supported living. Combining these findings provides a complete and balanced view of support experiences, which is central to the study's research question.

Figure 1. 5: Service users Themes



6.2 Service Users Overview

This chapter begins with an overview of the six participants recruited from different supported living environments. Table 5.5 provides an overview of the six service users, five males and one female, who were interviewed and observed in their supported living arrangements. The overviews provide participants' essential biographies for each service user (Rosenthal, 2004).

Table 5.5: Overview of Service Users Demography & Diagnosis

| Variable | Participants (pseudonyms) | | | | | |
|-----------------------------------|--|----------------------------|----------------------------|--------------------------------|--------------------------------|-----------------------------|
| | Boyd | Heather | Graeme | Fraser | Rab | Cameron |
| <i>Gender</i> | Male | Female | Male | Male | Male | Male |
| <i>Age/Years</i> | 36 | 32 | 50 | 42 | 52 | 35 |
| <i>Living situation</i> | Individually | Individually | Individually | With the other 2 service users | With the other 2 service users | With another 1 service user |
| <i>Period in Supported living</i> | 13 years | 12 years | 12 years | 14 years | 15 years | 2 years |
| <i>Diagnosis</i> | mild learning disabilities & Down Syndrome | mild learning disabilities | mild learning disabilities | mild learning disabilities | mild learning disabilities | mild learning disabilities |
| <i>Level of support</i> | Living with support | Living with support | Living with support | Living with support | Living with support | Living with support |
| <i>Number of support hours</i> | 24/7 hours | 24/7 hours | 24/7 hours | 24/7 hours | 24/7 hours | 24/7 hours |

Furthermore, the service users` profiles help readers understand their backgrounds and how their experiences of support were shaped. It should be borne in mind that those primary participants were from the under-researched population group. In this instance, knowing each participant`s background enhances the researcher`s ability to interpret the responses more accurately.

6.2.1 Boyd

Boyd is a 36-year-old male with Down syndrome and a mild learning disability, who has been living in supported living for 13 years. Boyd receives 24/7 care and a support package. A sleepover was in place for the night. Boyd enjoys football, cooking, music, colouring, watching TV/films, and spending time with his friends or family. The staff team supports him in attending his football game every Wednesday and reminds him to get along well with team members. Boyd is skilled in the kitchen and knows numerous recipes. Boyd enjoys family support and visits his family every Friday or Sunday at their home in a suburb of Edinburgh. Boyd enjoys family meals, shares his weekly events with them, and values these visits as part of his routine.

6.2.2 Heather

Heather is a 32-year-old woman with learning disabilities and an autism spectrum disorder. She has lived in the two-bedroom flat on a single tenancy for 12 years. The second bedroom is used as an office during the day and for staff sleepovers. Heather enjoys karaoke, dancing, music, and spending time with friends. She receives round-the-clock support from staff and has regular contact with her mother, who also lives in Edinburgh. Heather receives support to maintain a healthy lifestyle. Heather has a mobility car, which her care support workers drive to take her to appointments and other social activities. Care support workers and Heather plan her meals and shopping to ensure a balanced diet. Heather regularly contacts her family, and care support workers assist her in maintaining relationships with other service users through weekly phone calls and social gatherings.

6.2.3 Graeme

Graeme is a 50-year-old man with mild learning disabilities. Graeme has received support throughout his adult life. In early 2002, he received weekend visiting support services and sleepovers. However, due to risk and vulnerability, Graeme moved to a supported accommodation with 24-hour support and a sleepover. Graeme likes his flat and has lived in his present flat in Edinburgh for over 12 years. He enjoys cooking, music, 1970s television

programmes, and mini golf. Graeme is a volunteer worker at the British Heart Foundation, working 2 hours a day, 4 days a week. Care support workers leave Graeme at his workplace. The British Heart Foundation staff described Graeme as very hardworking but sometimes needs to be reminded not to ask customers personal questions.

6.2.4 Fraser

Fraser is a 42-year-old man with learning disabilities. He has lived in his current supported living flat for 14 years, sharing it with two other service users. Fraser claims to be the first in his current flat, so he chose his bedroom first. Fraser works independently at McDonald's. His hobbies include football (Hearts), socialising, watching television, and going to the cinema. He also likes travelling, as shown by his trip to America in 2022.

Fraser loves music, mainly from the 80s, and believes he is a great dancer. He often tries to break dance when the opportunity arises. Fraser dislikes house chores and sometimes asks Rab to help him, but then Fraser leaves Rab to do it all. His favourite activity is watching movies, and he loves going to the cinema. Fraser hates getting up early, and staff must start waking him at 9.15 am to begin his shift at McDonald's at noon. His afternoon shifts start at 1 pm and last until 8 or 9 pm. Fraser is very polite and has gentle mannerisms. He goes out with staff for a coffee one-on-one, has his own flat keys and bank card, and manages himself well during the outing.

6.2.5 Rab

Rab is a 52-year-old man with learning disabilities who has lived in his flat for about 15 years with 24/7 support. Rab shares a flat with Fraser and another service user who was not in this study. He previously lived in residential support with the same provider. Rab enjoys art, socialising with friends, going on car trips, parties, and loves music. He enjoys baking chocolate cakes, keeps the kitchen clean, and does not watch TV. He has limited verbal communication but understands verbal instructions. Rab regularly visits a local barber for a clean shave and takes pride in his neat appearance. He recently joined an organisation that offers one-to-one holidays and outings. Rab is looking forward to his first outing in September. He has expressed a desire for one-to-one staffing in his flat.

6.2.6 Cameron

Cameron is 35 years old and has mild learning disabilities. He has been in the current supported living facility for two years, having previously resided in a short-break service

respite unit. Cameron shares a three-bedroom flat with another service user with more complex needs. Cameron shares a mobility car with the other service user. Care support workers or the manager on duty drive Cameron for shopping trips, appointments, or other errands.

Cameron enjoys completing his daily routine and chores. His hobbies include football, driving with the staff, shopping, tidying his flat, and meeting his friends. He is independent and completes household chores with minimal assistance from staff. Cameron likes to keep himself busy while at home.

The following section presents the results of qualitative data from interviews, participant observations, and field notes from six service users, all care support workers, and care assistant and support managers. The sources were triangulated to address the experiences of support for people with mild learning disabilities in supported living. The findings are presented in four significant themes and their sub-themes, demonstrating the experiences of support for service users.

6.3. Part 1-Service Users` Themes

6.3.1. Overarching theme 1: Personalised approach

The theme of a personalised approach emerged throughout the interviews, participant observations, and field notes. A personalised approach is an innovative and flexible way of meeting individuals' needs, preferences, and rights (Parker & Fisher, 2010). The person-centred approach underpins a personalised approach by placing the individual at the heart of all decisions, care, and support. It focuses on viewing the individual, respecting their unique identity, experiences, beliefs, and preferences, and valuing their choice, autonomy, dignity, and empathy. A person-centred approach involves professionals working collaboratively with people to support them in managing and making informed decisions about their own situation and tailoring the services provided to individual needs (The Health Foundation, 2016). Support was tailored to the individual's specific needs, goals, and preferences and was flexible, adapting as the person's circumstances changed. The person-centred approach provided the philosophical foundation for a personalised approach to respecting individuals, promoting choice, and empowering service users to meet their unique needs. Service users and their care support workers identified several key elements based on their experiences of support in supported living. In the interviews, all service users explained how they assisted with the individualised planning of their support, managing basic everyday tasks, and

accessing the local community. It led to the stability of their tenancy, a sense of security and acceptance within the local community, and the establishment of social connections and acceptance. The support systems and available resources made this possible. Below, the first overarching theme of a personalised approach is discussed under the sub-themes: support plans, tailored resources, staff as a resource, and daily direct support.

6.3.1.1. Sub-theme: Support plans

The first sub-theme of support plans covers pathways of structured service offerings that provide resources and tools to help individuals manage their care. Each service user had a personalised support plan outlining their personal information, care needs, goals and outcomes, risk management, community engagement activity preferences, and choices. The support plans were developed collaboratively by service users and care workers, ensuring that they reflected the central choices and voices of the service users. The standard support plans were comprehensive, yet open to periodic reviews. Each service user had a daily and weekly planner, as well as a personal diary.

Service users alluded to the structure and predictability that reduce uncertainty and enhance emotional regulation. One service user spoke about his personalised plans for meeting and engaging with other service users in the supported living community.

I attend a weekly group chat on Mondays. On Monday, we also go to different pubs and have a drink with friends.
[Cameron]

During a participatory observation of Boyd and one of his support workers, he was involved in adding up the shopping receipts and tallying the change and receipts after each shopping trip. This aligned with the support plan to improve Boyd's numerical skills and interest in figures.

SCSW 010 asks Boyd to count money, starting with the notes, then count the coins, and finally add them up. The total of the receipts, when we subtract it from £10.00, should give us the change also to be counted. [PO 1]

Heather had had support plans designed to help her manage her anxiety. All the carer support workers used this when needed, and for what was suggested to be effective. The support plan is explained briefly below by one of Heather's senior support care workers.

What do we do with Heather if she is angry or anxious about something? We ask Heather to write her feelings down on a piece of paper, and that way, it is like she is pouring out her heart or whatever on a piece of paper, and then she hands it over to me. She has written down whatever on a piece of paper, and then she hands it back, and you discover that she is feeling much better... [SCSW 030]

Heather spoke about her weekly planner. It gave her something to look forward to. Meeting friends mitigated loneliness and gave a sense of belonging to the community. Heather pointed out:

I usually have lunch with my friends, like Hazel and Hanna, once a week. I usually have lunch with them most of the week. [Heather]

Rab's support plans addressed his home entertainment requirements, enabling him to have a relaxing and enjoyable home environment. A sizeable 25-inch television screen provided home entertainment. Home entertainment was taken seriously as a means of relaxation and a way to disconnect from the daily pressures of supported living. Its entertainment value, derived from films, programmes, and music, had mental benefits, including mood stabilisation and improved well-being. Rab could not contain his excitement.

The television is twenty-five inches. My big telly can play back to us... [Rab]

Graeme had a support plan that facilitated voluntary employment for people with learning disabilities, which is essential for promoting their independence, social inclusion, and overall well-being. The British Heart Foundation employs Graeme as a part-time employee, and he was enthusiastic about his job, doing two-hour shifts twice per week. He boasted:

I start at 1 pm and finish at 3 pm. I do the till. [Graeme]

As highlighted in this section, each service user had a support plan in place for managing various situations, which the care support workers utilised effectively. One of the managers highlighted the meaningful collaboration between service users and care support workers.

All service users will have their personalised support plan and risk assessments, and we will utilise other strategies, such as Keys to Life. [AC&SM Interview 012]

6.3.1.2. Sub-theme: Tailored resources

The second sub-theme was tailored resources. It involved customised resources that enhance efficiency, relevance, and user satisfaction by offering solutions that match service users' specific needs and preferences.

All the supported living flats had sleepover facilities for a care support worker staying overnight in a room within a supported living facility to provide emergency support. These sleepovers strategically support service users with unique needs based on personalised plans. They provide security and ongoing support, fostering a sense of family and belonging. This arrangement helped service users feel included and more integrated into society. One service user pointed this out:

It has got three rooms, so it is not neglected. This house has three rooms. Yes, two bedrooms plus a sleepover. [Cameron]

Service users' holiday groups were integral to person-centred planning for community access and participation, providing service users with various opportunities in line with their needs and preferences. The holiday group was designed to enhance service users' confidence, choice, and autonomy. By strengthening support networks, they ensured that service users could create lasting, positive memories from their trips, enriching their lives with unforgettable experiences.

I am going to Las Vegas on October 11. I am going to call this holiday group Jolly Holidays. [Fraser]

The SCSWs discussed using facilities and resources available from their support provider organisation to sustain the care and support for service users. Based on their person-centredness and assessment, certain service users were unable to walk short distances without experiencing severe discomfort. One service user had a mobility car to mitigate his severe pain from walking. The senior care support workers spoke of a service user who had a mobility limitation:

Cameron has a mobility car. As you know, there are times when SCWs drive him on short trips in the car. Um, just a short... [SCSW 090]

6.3.1.3. Sub-theme: Staff as a resource

The third sub-theme focused on the role of the care support workers as a resource. This suggests the importance of a supported living environment where key staff contribute to the overall support and efficiency of the services provided. Care support workers were observed imparting necessary skills to their service users. The care support workers were responsible for implementing the personalised plans and aligning personal goals with each service user's independence and community involvement. There was good evidence of established relationships and trust with service users, thereby gaining their confidence in the care they received. One service user remarked with delight:

Well, we can go out anywhere, like going to the cinema sometimes. Sometimes I go swimming. [Fraser]

Care Support Workers help service users make informed choices and take control of their lives intuitively. They ensured that individuals have the freedom to make decisions about their own lives, as observed in supported living flats:

CSW 080 asks Fraser which shoes he would like for his work. There was another choice of shoes with Velcro,

which should be an easy tie-up. Fraser looks up at the shoes and, with the advice from the CSW 080, selects the right pair. [PO 6]

Viewing staff as a resource demonstrated trust and confidence in the supported living model to deliver quality care and service. Recognising and appreciating staff members positively impacts morale and job satisfaction. This practice fosters long-term relationships, often leading to improved outcomes, enhanced teamwork, greater empathy, and increased respect. Boyd praised his CSW during an interview.

My support staff likes to support me. My key worker is the best. They make my dinner. [Boyd]

Care Support Workers were responsible for supporting dietary intake. In their capacity as key workers, they managed the service users' health through individual meal plans.

The observations highlighted the nutritional value and hydration for people with learning disabilities in supported living. Boyd received support for preparing his meal plan a week in advance. The senior care support workers managed the food items that needed to be purchased. Senior care support workers assisted Boyd in making his meal plan, shopping list, and staff sheet. The observations showed senior care support workers behaving professionally and patiently, directing and prompting the service user on the details to use. [PO1 (1)]

The sub-theme of considering staff as a resource contributed to support for the services, as explained in 6.3.1.4.

6.3.1.4. Sub-theme: Daily direct support

The fourth sub-theme describes the daily direct support service users receive from senior care support workers. They help service users complete their daily chores and tasks in their supported living environments. They discuss the service users' daily and weekly plans and

personal diaries, which help them stay on track with their scheduled activities. In supported living, service users experience support from staff on duty.

All the supported living support team members involved service users in working alongside the staff, usually directing and depending on their abilities to follow the guided steps. Any success was celebrated with verbal praise. Senior care support workers closely monitored the activities during laundry, cooking, or tidying. In this case, Boyd used body language to seek reassurance from the senior care support workers, who occasionally acknowledged it, allowing the service users to promote independence. Boyd asked if it was time to complete his weekly diary. [Field Notes... SL A]

Each service user's independence was managed to maximise their ability. All service users, including those who required additional support, were encouraged to be as independent as possible. A service user self-reported that:

They make my dinner; they put my washing on; they play with me. [Boyd]

Outdoor activities that help service users access their local community. Care support workers provided direct support by driving Heather's mobility car, which enabled Heather to travel to various locations for appointments, social events, and shopping. Heather explained:

I go out for daily walks with my staff on Wednesday, and then I have lunch here, return home, and relax on Wednesday. [Heather]

The senior care support workers described how they designed sheets for daily tasks to engage service users as part of routine care, aiming to develop the social and physical skills necessary to become more independent. All senior care support workers worked daily with service users to complete tasks within their supported living arrangements. Other household chores included cleaning the house, doing laundry, and managing the weekly budget. One senior care support worker mentioned that:

We have some daily task sheets that the workers follow. The care support workers check and tick the tasks completed; we have a diary to record what needs to be done on a particular day. [SCSW 030]

This personalised approach was evident in its human-centred approach to ensuring that service users were valued, heard, and supported according to their circumstances and preferences during one-to-one engagement. One example of clear, informational support is a short trip for Rab to have a haircut at a nearby barber shop. The clear instructions to the other residents in the flat were informative and empowered service users with the knowledge and guidance needed to make informed decisions.

SCSW 070 informed the other two service users that she would be taking Rab for a wet shave while Fraser would be going to work, so that Ewan [another service user not directly participating in the study] would stay in the flat. SCSW 070 turns to Rab and checks if Rab still has the change from a £10 note. SCSW 070 checks if Rab is ready and has an umbrella to go to the nearby barbershop for a wet shave. [PO 8]

The personalised approach theme describes the services and support to meet the unique needs, preferences, values, and circumstances of individual service users. Unlike one-size-fits-all models, the personalised approach enhanced individual autonomy, increased social engagement and outcomes, fostered inclusive participation, and helped build relationships between support staff and service users. However, while the idea of a personalised approach is promoted in policy, its actual benefits must be examined in the socio-political context. There is a risk that a personalised approach may be beneficial without addressing the structural inequalities, power imbalances, and resource limitations that affect its implementation in Scottish supported living settings. Nevertheless, in this study, the personalised approach presented a significant shift towards more respectful, responsive, and empowering practices. This leads to the second theme of positive impact.

6.3.2. Overarching Theme 2: Valued social support

The second theme, valued social support, involves emotional, informational, or practical assistance for service users received from their family, friends, colleagues, and community. It was perceived as helpful, meaningful, and beneficial to their well-being. Valued social support is examined under the sub-themes of service user participation, sense of tenancy, atmosphere, and staff. Service users reflected on their experiences of direct or indirect support from care support workers in the context of supported living.

6.3.2.1. Sub-theme: Service users' participation

The first sub-theme, service users' participation, related to developing a sense of responsibility for managing their interests and routines. The support plans for service user participation focused on ensuring that services are delivered based on professional expertise and reflective of the service users' needs, experiences, and preferences. For example, Boyd was supported in actively advocating for his needs and rights to increase his confidence in the kitchen of his four-room flat:

I make my lunch. [Boyd]

Cameron talked about how it improves his daily life and keeps him busy by following his daily planner:

On Sunday, it is just stripping my bed, making it, doing all the chores, and checking my fire alarms. [Cameron]

During participant observation, Cameron was seen to be supported in improving his abilities and skills and developing independence.

Care support workers and service users worked together. SCSW 090 reminded Cameron that the washing machine had stopped. The two went outside the supported living flat to hang the laundry on the line. They put all the clothes on the line to dry. [PO 12(2)]

This example illustrates an observed pattern of empowering service users in the confines of their homes. Similarly, another example involving Fraser related to financial matters. Budgeting and saving money can present challenges, and the care support workers were

encouraged to involve service users in money matters. Service users struggled to save money for their needs, and it became a shared responsibility with the support of senior care support workers. Fraser pointed out:

I am trying to budget my money. I am trying not to spend it in one week. If I buy something, I keep it for another week. [Fraser]

The conversation summary revolves around Fraser's interests and life. Fraser engaged in activities that interested him, such as football, his work, and his family. Daily, Fraser is independent and travels to and from work. He is only supported when the care support workers feel that Fraser might delay getting to work by taking an alternative route. [PO 9]

Daily direct support involved helping the service users with hands-on assistance to assist the service user with routine needs to live independently and with dignity:

A senior care support worker reminds Cameron that the machine is done and that they will dry the laundry outside once it has been done. Cameron and SCSW 090 take out the wet clothes to dry outside. Cameron takes most of the clothes from the laundry basket while SCSW 090 puts them on the line. [PO12]

Service users access the community to interact with others and enhance their overall well-being. The experiences of going into the community always required preparation, as shown below:

Graeme prepares to go out for mini golf on his day off from work and keeps asking his care support worker what they will be doing that day and if there is a need to take his coat and umbrella. Even with the reassurances, the question-and-answer became part of the

conversation, even when one felt impatient with answering routine questions. [Field notes–SL C]

The service users demonstrated a strong connection to their support workers, which also helped make their environments homely. Heather referred to them as “my staff”, suggesting a very close working understanding between the care support workers and service users, which should be based on the knowledge, trust, and understanding of the assessed needs developed over time. Boyd valued his support worker and declared:

She is the best. It is good to have staff in the house.

[Boyd]

Heather appreciated being driven by her care support workers to various places in her community, particularly in the summer when the weather was ideal for outdoor activities.

I enjoy taking my staff on various outings, such as different summer day trips, and they are enjoyable.

[Heather]

6.3.2.2. Sub-theme: A sense of tenancy

The second sub-theme captured the sense of tenancy, as service users expressed pleasure in the physical environment of their supported living settings within the local community. Each service user had a flat fully furnished with round-the-clock support. The flats were two-bedroom, with one flat available for sleepovers and a four-bedroom flat for one service user, which had three shared tenancies. Their sense of belonging was evident in their connection to the local community. The physical environment highlighted the context of support. The service users were excited to hold the tenancy for the property they regarded as home. They were happy to talk about their flats and the length of time they had lived there, welcoming visitors and showing off their supported living flats. Service users often spoke about the length of the tenancy in their current supported living flat. It was clear that they had developed an attachment and a feeling of connectivity to the properties, particularly their bedrooms. One of the service users claimed to be the first resident:

I was the first person to move in five years ago. It was Brett and I first before Rab moved in here, and I picked my room here first. [Fraser]

All supported living flats looked well-decorated inside, generating a sense of community and showcasing service users' tastes, including their favourite football colours in the bedrooms. The participant observations below describe the layout of supported living, demonstrating a sense of tenancy.

The flat had two bedrooms, a kitchen, a bathroom, a living room, and a lounge with a homely feel, and each service user had a distinct role. The second bedroom was used as an office during the day and a sleeping area at night. The atmosphere was very calm. The decor featured a mix of light green and white colours that complemented the living and sitting room arrangement, which included the television and stereo. The bedrooms had neutral colours for bedding when viewed from the corridors. [PO 3(1)]

Cameron shared a three-bedroom flat in a joint tenancy with another service user and two support staff. The flat had two bedrooms for service users and one for staff sleepovers. The bedrooms were all on the first floor. One of the managers clarified the tenancy arrangement.

...it may be shared accommodation. It may be that the person also needs weekend night staff. Therefore, it all depends on the individual's specific needs. If someone is coming into services, they already have an established house. Instead of a tenancy agreement, they may rent a bedroom as part of a house in multiple occupation (HMO). So, they will then use their bedroom as a building and include the whole occupancy agreement instead of a tenancy. [AC&SM 031]

Nonetheless, for service users, a sense of tenancy shaped the atmosphere during the interviews and the participants' observations. The atmosphere of supported living resonated with the following theme.

6.3.2.3. Sub-theme: The atmosphere

The third sub-theme of the atmosphere contributed to the environment under which the service users received support. All the flats visited had a general feeling or mood of a warm, structured, and relaxed environment in supported living flats. The designs and features of the supported living flats generated a subconscious feeling of safety and security. The activities primarily took place in the communal living areas, such as the living room and kitchen, as observed below.

The smell from the kitchen seems to permeate other rooms, notably the living room adjacent to the kitchen. The music in the living room comes from the television, yet there is tranquillity. Rab seems to behave appropriately, more so in the presence of the visitor observing them. [PO 8]

The observations revealed that the senior care support worker contributed to the atmosphere of supported living through their frontline roles. They provided full-time support and were always available to the service users. One example of this was observed in SL D. Rab was preparing to bake a chocolate cake. It was a three-bedroom flat with a kitchen, living room, bathroom, and toilet. The flat had one care support worker and two service users. The supported living flat was on the third floor of the main block. The other two service users appeared to tolerate Rab's noises in the kitchen. A positive, welcoming, and secure atmosphere fostered the service users' emotional attachment to their space, enhancing their overall satisfaction and commitment to the property. Rab's excitement during cake-making was heard.

The smell of chocolate filled the entire flat. [PO 12]

Boom! Boom! Boom! [Rab exclaimed]

Two or more people in a single tenancy, including service users and care support workers, created the atmosphere in each flat. The care support workers assisted service users to live

harmoniously, as observed below in one of the flats, where three service users and two care support workers.

The atmosphere supports the in-house activities of service users working with CSW 100. Rab is in the kitchen, Fraser is in the living room watching television, and the third service user, who was not in the study, is in his bedroom. The CSW 100 had time to complete his paperwork in the sleepover office, as the three service users kept themselves occupied in one way or another. [Field Notes-SL F]

This flat had a double tenancy with one of the service users, who was not included in this study but shared that flat. Cameron used to do the main chores, including assisting his flatmate. The two service users and their SCSW 090 had a good rapport.

The silence of the flat atmosphere was filled by the sound of the television, which was showing a local programme. The spacious kitchen has ample room to accommodate three people. However, there was Cameron and one staff member. The smell of the food filled the entire ground floor, giving the impression that the food must be delicious. [Field Notes-SL E]

The theme of valued social support fostered a sense of belonging and mutual aid, facilitating access to information and resources that positively impacted the physical health and behaviour of service users. However, while valued social support was beneficial, it faced the challenges of a delicate balance between service users receiving assistance and maintaining independence, as failure to achieve balance might result in increased dependence on care support workers rather than service users' individual independence. While the valued social support was well-established, its function must be examined within the wider social and structural framework. This was because it can be embedded in complex relationships and social systems that manifest power dynamics and inequalities. Therefore, valued social support is a valuable and multifaceted resource that positively impacts well-being, resilience, and community connectedness in supported living settings. This takes us to the theme of positive impact (6.3.3).

6.3.3. Overarching Theme 3: Positive impact

The fourth overarching theme of positive impact describes the beneficial outcomes (emotional, physical, or social) derived from experiences of support for enhancing the well-being of individuals with learning disabilities in supported living. The theme highlights the aspects that the six service users in this study valued based on their life choices. The positive impact theme is examined under the sub-themes of interests, service user expectations, the quest for independence and autonomy, and skills development.

6.3.3.1. Sub-theme: Interests

All service users shared their interests, and several aspects they liked as individuals were identified within the context of supported living. They desired to increase their community connections and participation opportunities. Supported living allowed them to experience the local community, form friendships, and develop a sense of belonging, being known, and being accepted.

All the service users expressed interest in their two-, three-, or four-bedroom flats. The interior decoration of the flats showed the service users' preferences. The key features were self-contained units (kitchen, bedrooms, and bathroom) with on-site staff who supported personal care and daily living tasks. A service user expressed interest in sharing a supported living flat with others.

I love living here because I think it is a good house. I keep up all the tasks, all the housework, and it is brilliant.
[Cameron]

Another service user shared his interest in travelling. He talked about a trip to London, even though he had no vivid memory of the places he visited. However, television programmes, books, films, and magazines refreshed Graeme's vague memories of London. Graeme spoke about London and why he thought it was a clever idea to visit. He commented:

London, but I cannot remember which part I visited.
[Graeme]

Graeme and CSW 050 were both watching television and began discussing the event in general. CSW 050 indicated

that Graeme had been in London with another care support worker and had enjoyed it. Graeme's blood language revealed excitement through a smile and pacing, acknowledging the topic of interest – travelling. [PO 5(1)]

Heather shared her interest in taking short trips to different places with the care support worker, whom she believed was close to her. For Heather, weekend trips were possible because she had a mobility car for trips.

I like going out on day trips with my staff, and I like to go out to different summer day trips. The staff is good.
[Heather]

A senior care support worker emphasised the significance of service users' interests and their connection to care support workers. These frontline staff members possess a comprehensive understanding of service users' preferences and actively work to support these interests in both indoor and outdoor activities. One senior care support worker acknowledged:

Yes. They enjoy working with their regular staff, the value they bring, and their staff team. They enjoy working with us. They always look forward to seeing them, yes. [SCSW 090]

The sub-theme was significant in how capturing and understanding the interests of service users was essential for enhancing the experiences of support in supported living. The interests of several users included identifying the individuals' preferences for each other's services, such as outings, music, hobbies, and diet, as observed in supported living. Two service users cohabited yet still appreciated their support because they felt their interests were acknowledged and had a better quality of life. [Field Notes... SL C, D, E]

6.3.3.2. Sub-theme: Service User Expectations

The service users shared their expectations. They stated various aspects, including daytime activities, staffing, suitable accommodation, choice, control over their living arrangements, forming new friendships, and socialising over food. The service users considered the possibility that the events might become a reality. The service users were enthusiastic, with some stating two or more hobbies, and some having planned participation in these as recognised:

We look forward to attending the Edinburgh Tattoo next week. Oh! That would be brilliant, as well as going for dinner beforehand. So, I am looking forward to that.

[Cameron]

Understanding and meeting individual service users' expectations strengthens the working relationship with other service users and fulfils their expectations in supported living. For example, Rab was enthusiastic when discussing expectations of purchasing a big television, which he talked about while making his chocolate cake, and showed his elation, which he could not contain:

I am getting modern furniture. It is a 25-inch television.

[Rab]

The senior care support workers also spent time with the service users in supported living. They had time in their senior roles to complete administrative duties while supporting service users. Therefore, there was time to plan according to the service users' hobbies, activities, dietary preferences, or music tastes. Expectations can be more joyous than the ultimate relaxation; therefore, it was important for service users to enjoy the fulfilment of their expectations. One senior care support worker shared her adopted philosophical approach towards understanding expectations and making them a reality in support living. She pointed out that:

Sure. My background is in nursing. Okay, I suppose I will come in when I arrive. I prefer not to be perceived as the manager. I like to be seen as one of the staff. Who is very hands-on? Who will come in and help the man out, making their day as good as possible for them? If

they have any concerns, address their questions and help them feel more at ease about the situation. [SCSW 090]

There was an acknowledgement of the service users' interests. The inclusive approach benefited from continuity of relevant support and better outcomes for resident interests. One senior care support worker stated how they upheld the interests of the service users, as noted below:

A manager must consult with their guardian or a family member. Therefore, many people are involved, and it is essential to ensure that everyone is on the same page, as failure to do so would result in the project's failure. [AC&SM Interview 031]

6.3.3.3. Sub-theme: The Quest for Independence

The sub-theme of the quest for independence relates to the positive experience of receiving support that allows service users to be as independent as possible in managing daily activities, such as feeding, personal care, dressing, and toileting. All the service users were keen to show their independence and expressed a desire to manage tasks with minimal support. The service users received assistance in planning and organising activities such as shopping, managing finances, cleaning, taking medications, and communicating with relatives and other service providers. For example, Boyd independently counted money in SL A and balanced the shopping receipts. The shared responsibilities involved the collaboration of the service user and the performance of the same activity, with the latter being guided. The goal was to develop relevant self-management skills for completing tasks effectively.

After each weekly shopping trip, Boyd counted the money and compiled the receipts to encourage his independence and autonomy. SCSW 010 asked Boyd to count money, starting with the notes, counting the coins, and then adding them up. If £10 was the total receipt, the change was counted. [PO 1]

In SL B, Heather independently practised hospitality for visitors in her flat. Each visit, Heather offered hot drinks in a customer-friendly fashion.

Heather politely offered coffee to the researcher on each visit (one semi-structured interview and two participant observations) of this study. Heather used politeness when offering a drink, letting the visitor (researcher) inside and out of the flat, and being seen at the door. Heather made the coffee and then sat next to her visitor, seeking confirmation of how good the coffee was. [PO 3]

In SL C, autonomy involved making choices about life to gain independence and self-determination. Graeme's CSW 050 reported that service users exercised their autonomy by creating individual food menus. In supported living, food choices involved meal preparation and cooking, which fostered a sense of independence.

Well, Graeme does that himself on a Monday; he plans what he is going to eat from Monday to Wednesday, and then from Wednesday to Sunday. [CSW 050]

The field notes recorded during participant observation in Graeme's supported living flat illustrated the example below.

Meal preparations and cooking were centred on the service user experience. Graeme prepared a meal according to his meal plan. He wore an apron, used an easy-to-read recipe for guidance, and placed all the ingredients on the kitchen table. The kitchen clock was used to keep track of cooking times. The smell of the pasta permeated the entire supported living flats. In the background, the high volume of the television was 1960s music with Care Support Workers nearby to provide verbal praise and reassurance. [Field Notes-SL C]

During the SL D session, Fraser expressed that maintaining independence in managing his finances was important to him. Fraser confidently and proudly used a fob at the flat to open the door of the main block of their flats. There is a walk up the stairs to the third floor, and

Fraser opens the door to the flat using the key. This is a route he uses to go to his local bank every Wednesday morning.

I do my banking every Wednesday in town. [Fraser]

Rab prepared a chocolate cake independently in the kitchen. Of course, from time to time, he called on his care support worker if he needed extra help.

Rab arranges plates and cutlery on the sink and puts the Nutella on his chocolate cake. Rab is baking while also cleaning the stove. [PO 7]

In SL E, Cameron spoke about how independent he is with his daily living skills in his flat. He was observed completing all the chores in the flat, including personal care, meal preparation, house management, cleaning dishes, and taking medications correctly. Cameron lived in a three-bedroom house with another service user and was supported by care workers.

I start doing all my housework around the house, and any other jobs or tasks I need to do. I do the tasks. Okay, I do the washing. [Cameron]

6.3.3.4. Sub-theme: Skills development

All the service users received support for their skills development, which involved functional and self-management skills. Functional skills were acquired through experience and self-directed learning, while self-management involved adapting to diverse situations. The service users received support on skills for daily tasks, such as crossing roads or budgeting. Tasks and chores were an integral part of daily life in supported living, with specific individuals requiring assistance with fundamental activities.

The service users were mainly observed in their flats, where the skills development involved household management skills, which also contributed to the service users' independence and autonomy. There was a deliberate, systematic, continuous, and transfer of knowledge and skills. The following observations were recorded in SL A.

SCSW 010, working in the kitchen while making coffee drinks, used prompts to support and guide the service users in the kitchen. The daily chores include washing, loading clothes into the washing machine, doing laundry, doing dishes, ironing, folding clean clothes, general cleaning, and hovering. SCSW 010 allowed Boyd to take the lead role. [Field notes- SL A]

Simple language and clear instructions were used to facilitate understanding, promote faster learning, and encourage repetition. Boyd completed the tasks in his flat with confidence.

Boyd was able to add what had been discussed based on his understanding. The language was simple, and the instructions were clear. [PO1]

In SL B, Heather is reminded by her care support worker to order her Thursday takeaway meal as per her support plan. Heather was involved in activities combining skills such as understanding the ordering process, recognising the shop's opening hours, recalling the meal name, and placing an order. Heather demonstrated the skills developed to order a takeaway meal. Heather picked up the cordless phone and remarked:

Watch the independent me. [Heather]

SCSW 030 reassures Heather that since Heather orders a takeaway each Thursday, there is a chance that Heather's address is known to the Chinese shop. Heather picked up the telephone, and after a brief silence, she ordered her Chinese takeaway meal. Heather ordered dried rice, a Diet Coke, and ribs, which cost £14.90. SCSW 030 asked Heather if she had given the address for delivery. Heather was proud to place orders independently using the cordless phone. [PO 3]

In SL C, Graeme illustrated organisational skills in his flat. He applied self-management and cooking skills to complete daily chores towards gaining independence. Graeme promoted the care engagement of care support workers and their service users. The senior care support

workers assisted with Graeme's plan, managed to leave for work and return, and enhanced the numerical skills of timekeeping and prioritising.

One to three at work, I do the till. [Graeme]

Graeme talked about his work and was observed demonstrating his cooking skills. SCW 050 reminded Graeme to wear an apron, put all the ingredients on the kitchen table, and remove all the pots and cutlery from the cupboards. SCW 050 sat strategically in the flat in view of Graeme in the kitchen. Graeme developed various skills, including timing for mixing ingredients, multi-tasking, and knowledge of ingredients. Graeme looked at SCW 050 for reassurance and patience whenever he was uncertain about the other stages. Graeme showed his basic reading skills of the easy-to-read recipe:

Graeme cooked pasta with minimal staff assistance. He mixed and changed the small pot for a bigger one while maintaining eye contact with his care support workers for reassurance. Graeme checked whether he needed more water for the pasta, which smelled delicious. The care support worker praised Graeme for his clever idea of using a large pot. [PO 5(1)]

The daily routines demonstrated the ease and familiarity with which they were conducted in the respective flats. Care support workers facilitated daily routines and prioritised them according to the service users' skills and preferences. The daily routines formed the core of the activity, and daily planners were stuck on the fridge as reminders. Some of the service users accepted the responsibility for doing the laundry and dishes. Care support workers facilitated service users' community access to the local shops. The situation involved the development of decision-making skills in making the right choice for purchase in a shop, as follows:

CSW 080 advises Fraser that the first pair has a good grip for work and asks for the price from the salesperson. It cost £109. CSW 080 asks Fraser if he would like one or two pairs, one for work and one for his outings. Fraser

took a moment to decide, and then he would take them all.

[PO 9]

In SL E, a service user's keen interest in household chores demonstrated their domestic skills through preparing snacks and lunch, setting tables, and tidying the flat. SCSW 090 supported Cameron in completing the dishes using a step-by-step sequence, focusing on manual dexterity while handling slippery plates, glasses, and utensils. Cameron washed the dishes, dried them, and put them in the cupboards. The observations were:

Cameron is busy washing dishes in the kitchen with another service user. It has a clean kitchen smell. The dishes are immediately dried and put away. The service users take turns doing the dishes, supported by the Senior Care Support Worker. [PO 10]

This was a skills development in SL D. The communication skills identified involve service users and their care support workers, promoting social relationships and nurturing socially acceptable behaviours in the supported living environment:

In the barber shop, SCSW 070 confirms with Rab, and Rab immediately responds to the barber's request to go over to the chair for his turn. Rab had a haircut and then a wet shave, looking at his SCSW 070 for reassurances to get the usual short side cut. [PO 8]

The theme of positive impact is central to understanding the value and effectiveness of support experiences in supported living settings. It captures how services transform lives, empowering individuals with learning disabilities and fostering meaningful change in supported living settings. Managing these service users' expectations was crucial to achieving a positive impact. However, at times, there was a mismatch between service users' expectations and what support providers delivered, considering their resources, policies, and limitations. For example, during the COVID-19 pandemic, their supported providers were expected to provide extra support to help service users continue with their everyday lives. Where nothing happened, a mismatch occurred, leading to frustration or disappointment

expressed by service users during the interviews. A critical perspective reveals that, while the positive impact was perceived as beneficial, its superficial nature had a downside. Nonetheless, the key to genuine positive impact lies in teamwork, personalised support, and continuous evaluation, ensuring that services remain responsive and respectful of service users' needs.

The interaction of service users' interests, expectations, independence, and skills development shaped how the positive impact was experienced and evaluated in Scottish supported living settings. This critical analysis leads to the last central theme on challenge in the next section.

6.3.4. Overarching Theme: Challenges

The last overarching theme, "challenges", presents incidents or episodes that impact the service users' independence, welfare, and quality of life. However, the challenges were managed amicably between service users and the care support workers. Challenges are discussed under the following sub-themes: trust versus relationships, difficult conversations, uncertainties during adversity, and conflict resolution.

6.1. Sub-theme: Trust versus relationships

A case of trust going against the relationship emerged during one of the participant observations. There was a conversation between the care support worker and the service user. The service user's trust of the care support worker conflicted with the service user's relationship with an outsider. For example, Heather was increasingly interested in changing her friendship to an intimate one with a male friend (Samuel, not a real name), who was believed not to be interested in intimate relationships with women. According to her CSW 050, Heather was unaware of her male friend's preferences. As a result, Heather became vocal about the situation during the day when the participant observations were taking place in her flat. CSW 050 disclosed the background of this issue to the researcher. According to CSW 050, a few weeks before the study participant's observation date, Heather increasingly requested to speak to her friend, even as late as 9 pm. Samuel had asked the care support workers to reduce the frequency of telephone calls.

Samuel's birthday was approaching, and Heather wanted to attend the party. The care support workers found it challenging to explain the situation to Heather, fearing she would be hurt. However, Heather told CSW 050 that she was feeling angry. She was advised that it was because she had been asking to call Samuel, sometimes late at night, which would be an

inconvenience for Samuel. CSW 050 resolved the issue by offering assurance to Heather, who protested:

Why am I not being allowed to speak to or see him? He is my friend, and I am allowed to talk to him? If that is the case, I will speak to the SCSW 030 about it [Heather].

This case highlighted the issues surrounding the involvement of trust and relationships among adult service users, as Heather's protest demonstrated.

During the participant observation, Heather openly expressed her frustration and disappointment over her right of association in front of the researcher and her SCW 050. Heather insisted that she would speak to the senior (SCSW 030) about it. Heather believed she had a right to association while the care support worker exercised her duty of care. [PO 2]

6.2. Sub-theme: Uncertainties during adversity

The sub-theme of uncertainties during adversity involved service users and their senior care support workers sharing their experience of the impact of COVID-19. Scotland confirmed its first case of COVID-19 on March 1, 2020. This disrupted support and care for service users in supported living settings. For people with learning disabilities, being suspected of being infected by COVID-19 took a long time to process. All service users struggled with their usual lives as the news about the pandemic affected them. The lockdown was in operation in Scotland from March 26, 2020, until May 29, 2020. As for service users in supported living, the impact was felt through isolation, infections, feeling unwell, social distancing, and COVID-19 testing. The lockdown enabled people to access medical care, provide care to others, and make essential trips, with the only exception being to leave home for necessities. Nonetheless, it was overwhelming for service users to comprehend. During the interviews, service users shared how COVID-19 affected their social lives:

I did not feel like I had all the full symptoms; it felt like a cold, and I did not feel it. It was awful. I could not go out;

I could not go anywhere. We could not meet friends because we thought we would do that. They would end up catching it. [Cameron]

During the COVID-19 pandemic, I was confined to my room. I was told to stay in my bedroom and use the bathroom during COVID-19. [Boyd]

I had COVID-19, but I did not even know I had it. I find myself rushing to the toilet occasionally. I was stuck in this room for about 13 days. [Fraser]

According to service users, the impact of COVID-19 was overwhelming. To help address the challenges brought on by COVID-19, Assistant Care and Support Managers introduced technological innovations, including iPads and laptops, for service users. These tools aimed to reduce the effects of isolation, disrupted routines, and loss of contact. The acknowledgement read:

At the same time, the work of one of the service users, who began using technology such as the iPad and a laptop, which we had not previously used, highlighted a need for these skills. It was positive, quite good, and informative. I guess new things, such as the person-centredness approach, came into play, and we had to download that information as well. [AC&SM 011]

6.3.Sub-theme: conflict resolution

The sub-theme, illustrated using conflict resolution, was also a challenge in supported living. Service users faced difficult conversations about support, mainly when decisions or developments contradicted their expectations. Service users who participated in this study expressed their disappointment with the issues of transition. Transition involved certain service users with learning disabilities and forensic issues (offending issues) who requested clinical expertise to support them. The forensic issues involving those who have offended

were complex to manage, as they engaged in sexual behaviours of offending. For example, service users who had past offences against children, girls, or female staff had been informed about the transition of certain service users to their support provider. No names have been disclosed, except that the move involved providers transitioning to other providers. The service users were not happy about it. It was important to understand the factors related to these transitions, as relocation is a significant life challenge that requires skills and resources such as social and psychological support. At the time of the study, the relevant support still had to be provided by the Assistant Care and Support Managers. Nonetheless, it was sensible not to move those service users with issues of vulnerability and risk between support providers.

The concern for specific service users was that they would lose everything they had worked so hard for over the years in their current supported living. It was apparent that there were communication difficulties, which became a source of conflict, both with what they were being told and with their individual understanding. One service user did not conceal his disappointment.

All right, and because obviously, it has been a bit of a hard moment, not finding out what is going on with the, what is this called? Transition! Transition!

So obviously, it is hard with that now and not knowing what is going on. [Cameron]

As for the Assistant Care and Support Managers dealing with transitions was a standard practice. However, this transition was overshadowed by the revelation that those who remained with their current support providers were those with forensic issues (history of offending behaviour). In contrast, those with learning disabilities but without any forensic issues were the ones who would be required to move. The transition logic would still be sound and irrational from the service user's perspective if they maintain that they have not done anything to warrant being moved. However, from the perspectives of the Assistant Care and Support Managers they acknowledged the anxieties of eligible service users and clarified the transition:

Um, well, yes. Generally, if you go back quite a few years, which was always the intention, you know, once they got

their habits and the other support staff in place, that will just continue. However, as time passes, support workers must deal with more forensic service users. So, services not deemed part of a forensic service are being transitioned to other support providers. This will free up space for support work staff to be taken on support for men or women who are coming out of the main hospital but are in the hospital with forensic issues. [AC&SM 090]

The theme of challenges, which revolves around trust issues in relationships, uncertainties during tough times, and the resolution of conflicts, underscores the complexities that individuals and support services face in delivering adequate care and community support. The emergence of COVID-19 introduced unprecedented difficulties, leading to anxiety and disruption in daily life. Nonetheless, this situation encouraged adaptive strategies, such as using technology and fostering open communication, to navigate uncertainties constructively. Support staff lacking practical conflict resolution skills must engage in active listening and consider power dynamics, allowing them to turn conflicts into opportunities for strengthening relationships.

The difficulties faced by individuals with learning disabilities in Scottish supported living are intricate and systemic, stemming from factors like insufficient funding and cultural attitudes, rather than solely from personal limitations.

Themes from service users' individual experiences are integrated with Part 2 of the findings, which presents Assistant Care and Support Managers' organisational and operational perspectives. This combined approach provides a balanced and multi-perspective understanding of the study topic.

6.4. Part 2-AC&SMs' themes

6.5. Assistant Care & Support Managers' Overview

Table 6.6: AC&SMs Overview

| Study Title | Job Title | Gender | Period in the job |
|--------------------|------------------|---------------|--------------------------|
| AC&SM 011 | Manager | Male | 12 years |
| AC&SM 021 | Manager | Male | 2 years |
| AC&SM 031 | Manager | Female | 10 years |
| AC&SM 041 | Manager | Female | 20 years |
| AC&SM 052 | Manager | Female | 2 years |

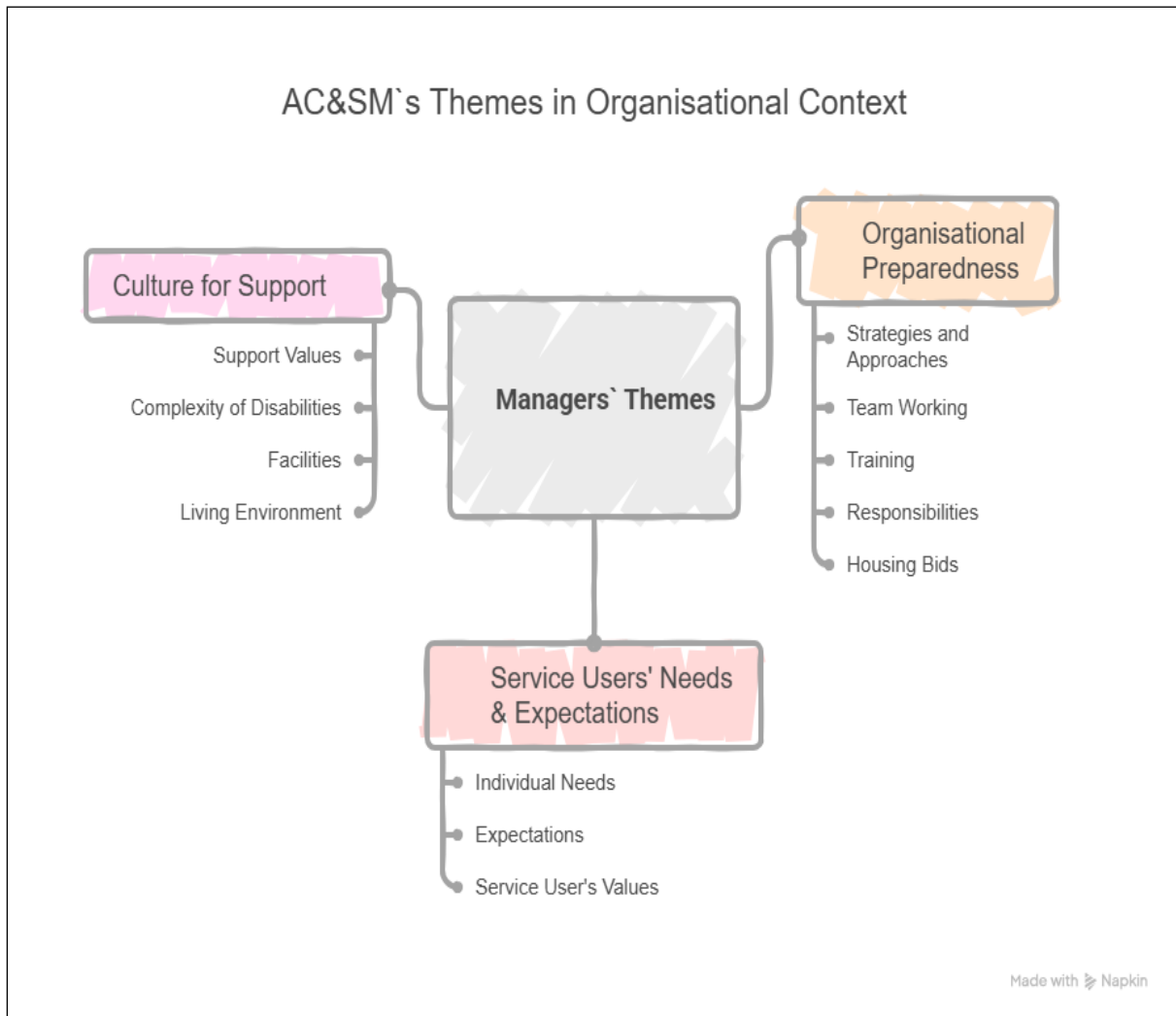
This section highlights the themes and perspectives identified by Assistant Care and Support Managers regarding the support experiences of service users in supported living settings (Table 6.6). The overview shows that the team included two males and four females, all with extensive managerial experience within a council support provider organisation.

The Council support provider is part of a city council in Edinburgh. The support provider provides care and support by assessing the individual's needs and conducting an assessment, using the agreed-upon criteria, of the individual's substantial, moderate, and low needs. The Council support provider and NHS Lothian have integrated the planning and delivery of community health and social care services for most people from hospital discharges, as well as services provided by charities for people with learning disabilities.

The roles of the five Assistant Care and Support Managers are essential in providing the support and motivation required to assist their frontline care support workers in the service users' flats. This facilitates support that focuses on encouraging and empowering service users' autonomy. In doing so, this section presents the Assistant Care and Support Managers' views on their role, their experiences of support, and particular challenges they are currently facing in fulfilling their roles.

Section 7.7 below presents the findings of Assistant Care and Support Managers' views aligned with their operational values of enhancing the service users' experiences of support in supported living. The dominant themes are culture of support, organisational preparedness, and service users' needs and expectations. They are examined with their sub-themes to demonstrate how their roles shaped the experiences of support.

Table 7.7: AC&SMs Themes



6.5.1. Overarching Theme 1: Culture for support

The first theme, the culture of support, encourages collaboration, understanding, and a sense of belonging in supported living communities. The Assistant Care and Support Managers used their roles to develop and promote support through collaboration and communication with service users and support staff in supported living settings. The culture of support theme

is examined under the sub-themes of support values, disabilities, life changes, facilities, living environment, and support standards. The description of each sub-theme will follow.

6.5.1.1. Sub-theme: Support values

The Assistant Care and Support Managers expressed their support for adopting a values-based approach to support, which involves a person-centred approach to communication, ensuring tailored support and advice that aligns with the service users' values. During the interviews with the Assistant Care and Support Managers, they highlighted the priority accorded to a personalised approach that promoted the service users' values, such as respect, dignity, choice, autonomy, independence, and inclusion. The personalised approach, underpinned by the person-centred care model, enabled the Assistant Care and Support Managers to prepare to provide service users with the needed support. Service users value their independence and support in the supported living flats. One participant explained:

I said person-centred is a good example of their tenancy for living independently. Moreover, as an organisation, we also focus on personalising services for our service users, as per their wishes, because when they first come in, they are often far away. After all, they just came out of the community, which is something to work towards. Coming out is a new venture, and with proper support and care, participants and service users can do anything. It is just literally trying to give them the best life. [AC&SM Interview 011]

6.5.1.2. Sub-theme: Complexity of Disabilities

The sub-theme 'complexity of disabilities' involves the varied challenges faced by individuals, including physical, sensory, and learning disabilities, ranging from mild to profound learning disabilities. Many individuals also have comorbidities, such as diabetes, stress, anxiety, or depression. This creates multiple physical and sensory needs, intellectual and developmental challenges, and support required. Understanding these complexities is vital, as they have significant social, medical, legal, and psychological implications. Recognising the diversity among individuals with mild learning disabilities highlights the need to view them as unique individuals with specific support needs.

One AC&SM acknowledged a complexity of disabilities:

Within that, we support people with autism, and we support people with mental health and forensic backgrounds. We have people with Down syndrome and Prader-Willi. Therefore, there is a wide range of additional needs within the learning disability bracket. However, the learning disability is about support needs that primarily support workers are there to provide support. [AC&SM Interview 021]

6.5.1.3. Sub-theme: Support resources

The AC&SMs mentioned that all service users had individual plans and risk assessments. The support resources included assistive technology (laptops and iPads) and support materials in line with the risk assessments and personalised plans. There was a need to manage risks associated with various conditions effectively. One Assistant Care and Support Managers acknowledged:

At the same time, the work of one of the service users, who started using technology such as iPads and laptops we had not used before, highlighted the need for new skills. It was positive, quite good, and particularly so, given the changing information. I suppose new things, such as the person-centredness approach, came into play, and we had to download that information as well. [AC&SM Interview 021]

Another facility was the Disability Living Allowance (DLA), which people with learning disabilities are entitled to receive. All service users in this study received their DLA weekly to cover essential living expenses, including food, electricity, and other necessities. It was observed that:

Most community members can access Personal Independence Payment (PiP) or Disability Living Allowance (DLA). We can access employment support allowances or old income support. The Department of

Pension Works will provide the new benefits. [AC&SM
Interview 041]

Support resources for mobility were available to eligible service users, Heather and Cameron. Their permanent care support workers operated the mobility cars to transport them to various appointments and social activities.

Two service users were on the Motability scheme due to physical disability and the inability to walk long distances. After the assessment, the claimant qualified for the higher rate Motability part of the PIP from the Department for Work & Pensions.

They qualified for enhanced-rate mobility for the Adult Disability Payment (ADP) administered by Social Security Xxxx . The two service users have mobility cars that their care support workers, who hold a driver's licence, drive them around. [PO 3 & PO12]

6.5.1.4. Sub-theme: Living Environment

During the interviews, the Assistant Care and Support Managers described the conditions in the supported living where the service users' needs were assessed. The process depended on the accommodation's availability and nature, which matched the service users' needs and requirements. The tranquil living environment characterised all the managers' planning and implementation efforts in all the houses for all the service users.

Evidence shows that the room was tidied, so the flat smells fresh. As witnessed on Angus's first visit, every item in the living room is in its place. The kitchen is always tidied as three service users use the unit, particularly during meals. There is a cleaning routine for service users, which also includes maintaining other communal areas, such as bathrooms and toilets. [PO 9]

The culture of support theme underscores the role of Assistant Care and Support Managers in a community-based environment where individuals, particularly those with disabilities, feel understood, valued, and empowered through mutual respect, empathy, and an appropriate support system. In this study, physical, social, and attitudinal aspects of the living environment facilitated independence. The theme complexity of disabilities showed that

understanding the diversity of needs reflects that disabilities are not homogeneous across physical, cognitive, emotional, and sensory aspects. However, the culture of support risked being tokenistic if it only addressed the visible or easily accommodated disabilities. This situation increased the marginalisation of uneven access to more nuanced disabilities. The culture of support should have an urban plan and policy that promotes community engagement, accessibility, and social inclusivity of people with learning disabilities in supported living. This leads to the following theme (4.10).

6.5.2. Overarching theme 2: Organisational preparedness

The second theme focuses on staff preparedness for providing direct or indirect support to service users in supported living. This refers to the level of preparedness for responding to emergencies or unexpected events in supported living, including communication protocols, staff training, and risk assessments. The theme encompasses sub-themes on strategies and approaches, teamwork, training, and housing bids.

6.5.2.1. Sub-theme: Strategies and approaches

The strategies and approaches under this sub-theme will include review meetings, training, risk assessment, a hands-on approach, and the grading system. Each is discussed in the context of supported living, as devised by the Assistant Care and Support Managers.

The Assistant Care and Support Managers discussed their strategies and approaches during review meetings with service users throughout the year. They facilitated review meetings with service users to identify and address their concerns. These review meetings were also open to everyone else involved with service users. The review meetings allowed the service user to meet all their support staff, including the Assistant Care and Support Managers, and discuss possible changes in their circumstances and daily needs. One AC&SM explained:

Each service user will have or has been invited to their six-month review meetings as part of the service review. In addition, if a social worker is appointed annually, they will conduct an annual review with the service user to ensure that their needs are being addressed or met at the local level. [AC&SM Interview 021]

Organisational preparedness for the future is underpinned by training. All care support workers received mandatory training to keep them current. Given that they work with service

users who have learning disabilities and forensic issues, the partnership with the NHS department helped meet the skills and knowledge requirements for care support staff. One Assistant Care and Support Manager pointed out:

Training is a process that will undergo continual improvement.

I would say significantly better than many organisations, and it certainly is improving all the time. I mean, when I started 20 years ago, it was pretty few and far between, and it was very ad hoc. Now, all council employees receive mandatory training before they start... [AC&SM 041]

The risk assessment in preparation for transition to another provider is crucial in ensuring that the individual's support needs are thoroughly understood and can be effectively met by the new service provider. The Assistant Care and Support Managers recommended involving service users' families to ensure everyone is engaged in the individual's well-being and support plans, and to help the service user understand the process. This approach enhances organisational preparedness for service users eligible for transition. One Assistant Care and Support Managers explained:

It is about identifying services within the local community to which they tap. What we must do now is revisit this regularly. So, when somebody has been assessed and is ready to transition to another provider, we go back over the entire process to ensure that the person understands what is happening and the family support... [AC&SM 031]

The hands-on approach in supported living involves providing direct, personalised assistance to individuals. This approach promotes personalised independence. These observations were made through the development of skills in cooking, cleaning, personal hygiene, and money management. The hands-on approach enhanced the confidence and self-esteem of service users as they accessed their communities. For example, service users were supported as they engaged in social activities, such as shopping, visiting their general practitioners, or attending

social gatherings. The hands-on approach is active and responsive, enabling the Assistant Care and Support Managers to provide adequate support.

As the manager of the service, you are not as hands-on as you would be as a senior who sees the person regularly, but you would also have regular meetings. You would have regular meetings, including the service users if appropriate. [AC&SM 051]

The support provider used the grading system based on the roles and responsibilities of each grade. CSWs were graded 4, the SCSW was graded 6, the Assistant Care and Support Managers was graded 7, and the Area Manager was graded 9. The grading system worked by cascading authority down the lower grades and the outcomes back to the Assistant Care and Support Managers. The grade 7 Assistant Care and Support Managers were the architects of all administrative work, preparing the documentation used by the lower grade 4, who did most of the direct support in their supported living. The grading system is suitable for accountability and consistency of service as described:

Our grade 4 staff represent the entry-level in our support team, yet they handle most of the workload. It does not reflect the responsibility of the work, but there is an element of work, and they do the day-to-day work. Grade six is our senior staff, so they have line management responsibilities for their teams. Grade 7 is me. I oversee up to 10 grade sixes, and grade sixes can supervise up to six staff members. The line manager (name provided) is a Grade 9, and that is the pyramid. [AC&SM 041]

6.5.2.2. Sub-theme: Partnership

The AC&SMs emphasised the theme of organisational preparedness for partnership. Both approaches share the underlying character of collaboration for a common purpose. There is a partnership between NHS departments and social care partners during the placement of patients into supported living. The partnerships involved sharing clinical expertise to benefit primarily patients with learning disabilities and forensic issues of inappropriate sexual behaviours. In addition, the Assistant Care and Support Managers acknowledged the significance of partnership on cost-effectiveness for support providers. The Assistant Care

and Support Managers had professionals from their organisations working with other health and social care partners:

The partnership with Community Learning Disability Teams involves working more closely with colleagues in other disciplines, such as NHS community teams.
[AC&SM Interview 021]

6.5.2.3. Sub-theme: Staff training

The Assistant Care and Support Managers indicated they were responsible for organising mandatory training for care support workers in a supported living environment. The training focuses on positive behaviours, medication administration, and specialised skills for managing service users with learning disabilities and behavioural issues. This training is essential for ensuring compliance with laws and regulations, thereby maintaining the health and safety of both staff and service users. One manager described the range of training provided:

So again, it depends on the grade of the staff. The training is delivered based on the needs of their role through mandatory training that covers topics such as moving and handling, epilepsy awareness, and medication management, which all Council employees have to undertake. Data protection training will also include first aid and personal safety. We also offer additional training that supports our service, including Positive Behavioural Support training, New to Forensics training, CAMHS training (which focuses on managing patients with suicidal tendencies and other issues), and Autism training.
[AC&SM Interview 021]

6.5.2.4. Sub-theme: Housing Bids

The Assistant Care and Support Managers described a pragmatic approach to securing accommodation, recognising competition from the mainstream population bidding for the same flats they wish to secure for supported living purposes. They described the challenge as the lack of an allocated quota of supported living flats for people with learning disabilities discharged from the hospitals into the community. Bids for flats were open to the whole

population, which meant securing new accommodation was not straightforward. However, one of the managers highlighted their strategy as:

Now, dealing with that, we are taking the entire block. So, as a block of six or eight, we will take the whole lot and house people there. Again, there were opinions over the years that I suggested that they would be castigated as a block of people with learning disabilities, as they are housed. Our organisation is acquiring a purpose-built forensic block that will house 6 people in bedrooms with wheelchair access. The block features high-specification functions and day-to-day building materials that have been discontinued. [AC&SM Interview 011]

The theme of organisational preparedness reflects how ready and capable a support provider organisation is to meet the needs of its service users, such as supporting individuals with diverse disabilities. It included systems-level planning, proactive strategies, resource allocation, and staff capability. However, the strategy may have existed on paper but was limited in practice due to bureaucracy, which the Assistant Care and Support Managers did not elaborate on.

Evidence-based practices were employed, and adaptive frameworks were utilised to address the evolving needs of service users who utilised laptops and iPads during the COVID-19 pandemic. There were strategic partnerships among families, service users, and the broader community towards enhancing organisational readiness. However, power imbalances were evident in the decision-making. Assistant Care and Support Managers explained that organisational preparedness should have involved embedding plans or policies that incorporate responsiveness, reflexivity, and relational capacity into the core of service design and delivery.

6.5.3. Overarching Theme 3: Service users' needs and expectations

The third theme, 'service users' needs and expectations', described the essentials for service users and their expectations for new lives in supported living settings. The Assistant Care and Support Managers' responsibility was to ensure that the service users realised their needs and expectations in supported living. The sub-themes included expectations, unmet needs, and service users' values.

6.5.3.1. Sub-theme: Individual needs

The AC&SMs explained the importance of meeting individual psychological and social needs, given that the service users were from diverse backgrounds. It was vital to meet safety, social, and psychological needs. One Assistant Care and Support Manager described service users reminiscing about the past and yet cherishing their new life in supported living:

They feel respected that their opinions are taken on board, and that they matter. You know, they all talk about the past, and they do so fondly. I think where people are delighted, they are, you know, getting to live life at the end of the day. [AC&SM Interview 031]

6.5.3.2. Sub-theme: Service users' values

The Assistant Care and Support Managers expressed their support for a personalised approach to engage meaningfully towards ensuring tailored support and advice that suits the service users' needs and aspirations. For example, special services provide a sense of safety and security, social lives through community access, and care support workers as a proxy for family through a good rapport. It was explained:

I believe in maintaining the organisation's values, just like person-centred. A good example of this is when a person thrives on living with others, rather than living independently. You know, people who do well like company. The manager must also consider the needs of the service users. If they are part of a small staff team, such as a team of one or a team of three staff supporting one service user, you must examine everything. [AC&SM 051]

Consulting with service users about their choices was a good practice that empowered them. As residents, people with learning disabilities came together. They agreed on a preferred term: "service users," who had rights and preferences in decision-making processes and were not passive recipients of support. It demonstrated the awareness of service users' status

as equal community members. The AC&SMs respected their wholesome decision and choice, as explained by one of the managers below:

We were asked in consultation with our service users, whom we call people we support. It was done in consultation with the people we support, as many preferred to be called service users rather than clients. They felt there were connotations of specific residential care, possibly hospitalised care, or similar things. So, a service is a more generic term because it involves receiving service from other users and us. So, it is a blanket term, and I think people who get the service find it offensive, if you know what I mean. [AC&SM Interview 041]

6.5.3.3. Sub-theme: Optimistic future

The managers were positive that bespoke houses were a step ahead of supported living as they are tailored to meet the needs and aspirations of the service users. Bespoke houses were considered, considering the disabilities and forensic needs of some service users. There was an admission that the bespoke houses would be the vision of the future in supported living. So, it was explained:

Getting on with a bold speech is better, so there is more awareness of the potential that they needed a bespoke house rather than creating one. This is a new experience for us. This is the first time we have been actively asked what its support needs are. [AC&SM 041]

The COVID-19 pandemic was unprecedented, and no one had anticipated it. The service users were affected in a way that prevented them from accessing the previously used communication method. However, the AC&SMs were innovative in supporting the service users and their SCSWs, following the impact of COVID-19. The AC&SMs shared optimism:

...and just so, there is no point in stressing, worrying, or thinking about what could be. Moreover, I would like to maintain a positive mindset, as this ensures that the staff

filters down to your staff and the service users. [AC&SM
051]

The theme service users' needs and expectations highlighted respect for person-centredness and responsive service delivery of users' voices, choices, and aspirations. Findings under the theme "Service Users' Needs and Expectations" illuminated the evolving role of service users as active agents of their support. To meet these expectations, services must cater to individual needs, be value-aligned, and be oriented towards the future. The findings reinforced the service users' diverse, complex, and evolving needs. However, there were equity gaps as not all service users articulated their needs. This led to potential inequity. Not all service users had the same capacity to communicate their needs, which could potentially lead to inequitable service quality. Services that align with service users' values tend to build trust, increase satisfaction, and encourage sustained engagement as reported by the Assistant Care and Support Managers.

6.6. Chapter Summary

The chapter identified the service users' experiences of support. The main participants in the study included service users and Assistant Care and Support Managers. The findings from service users and assistant care and support workers were important because they provide different but complementary perspectives on care and support experiences. Six profiles were presented to provide essential background information about the primary participants of this study.

The findings were drawn from interviews, participant observations, and field notes, highlighting several themes, including a personalised approach, the importance of social support, and the overall positive impact of these services. However, challenges were also identified through interviews and participant observations. The themes identified by the Assistant Care and Support Managers, such as the culture of support, organisational preparedness, and the needs and expectations of service users, highlighted that the services remain responsive, inclusive, and protective. This was evident in the positive experiences reported by service users.

The study presented a more balanced and comprehensive understanding of the service. In supported living settings, service users' themes captured their individual experiences of satisfaction, autonomy, and social inclusion, while the managers' themes played a pivotal role in shaping their support experiences. Themes explained the organisational environment

shaping the experiences of staffing, training, support standards, and regulations. For that reason, the themes endorsed the findings of the service users' experiences of support in supported living. The next chapter discusses the central themes addressed in this study's research questions. The analysis centred on identifying key themes emerging from the data and demonstrating how these themes addressed the research question.

Chapter 7

Discussion

7.1 Introduction

This study explored the experiences of support for people with mild learning disabilities in Scottish supported living settings. One of the most striking aspects of this study was the overwhelmingly positive feedback from an underrepresented population of service users, whose voices are often marginalised in mainstream evaluations. Contrary to common assumptions that individuals with learning disabilities primarily report dissatisfaction or unmet needs, the findings revealed a sense of appreciation for the support designed by Assistant Care and Support Managers and delivered by care support workers and senior care support workers in supported living settings. The findings from the service users were grouped in four key themes: a personalised approach, valued social support, positive impact, and challenges (Figure 1.5). This chapter discusses the results of the care support workers, senior care support workers, and Assistant Care and Support Managers in relation to the research question. In addition, the discussion of interviews with service users and care support workers provided additional holistic insights into understanding the alignment between service delivery and users' first-hand experiences of support. The chapter concludes with a discussion of its strengths and limitations, original contributions, implications, and future research practice.

The Assistant Care and Support Managers' themes "service users' needs and expectations", "organisational preparedness", and "culture of support" gave insight into organisational priorities, limitations, and strategies for delivering support (Figure 1.7). On the other hand, the service users' voices highlighted their needs, expectations, and satisfaction. Each theme is summarised and then discussed in relation to the research aim of this study.

7.2 Discussion of key findings

The results illustrate that service users drew on their experiences of support, underpinned by the significance of support managers' responsibility for promoting service users' opportunities for active participation. The Assistant Care and Support Managers were the architects responsible for designing the support provided by care support workers for service

users in supported living. These experiences of support are presented in a sequence upon admission into supported living: (1) personalised approach, (2) valued social support, (3) positive impact, (4) challenges, and Assistant Care and Support Managers` three themes.

7.2.1 Personalised approach

The first theme is tailored services to fit individuals' needs and preferences. It has sub-themes of support plans, staff as a resource, and tailored resources. It shows how to support service users based on their needs and preferences. Each service user has an individualised support plan.

The study focuses on individualised support plans and tailored resources, including consideration of staff as a valuable resource. The approach was inclusive and empowering for service users. A personalised approach is essential for a user-centred understanding of their needs as they adjust; care professionals or support workers can appreciate what matters to the resident, rather than focusing on what might be necessary (Hodge et al., 2023). The structured approach to supported living included shared living and collaboration among service users and their care support workers. It gives the "focus on fostering an atmosphere of everydayness" (Kelley et al., 2019). In this case, a personalised approach enabled service users to make informed decisions in day-to-day situations, as some had varying learning disabilities. The Assistant Care and Support Managers designed individualised care plans for each service user based on their needs and choices, then delegated senior care support workers or key workers on the floor to discuss the care plans with the service users to gather their input. The care plans were reviewed yearly to meet the service users' changing needs to create a holistic view of their needs, and to ensure their support resonated with the choices and control.

Within this study, the Assistant Care and Support Managers enhanced the quality of life for individuals in supported living by helping them to achieve their full potential. Some living settings involved service users and staff living and working together, such as in single-tenancy, core, and cluster flats. Shared facilities, including lounge areas, communal kitchens, workspaces, fitness facilities, bathrooms, and laundry rooms, facilitated social activities for users (Osborne, 2018). Service users shared common resources, such as kitchens, bathrooms, and communal areas, and this generated a sense of community and family. Therefore, this

personalised approach was integral to providing person-centred care in supported living settings. Supported living provided the context of service users' support experiences.

7.2.2 Valued social support

The second theme describes service users who experienced valued social support through emotional, practical, and psychological assistance from their care support workers in the context of supported living. The theme has the sub-themes of a sense of tenancy, service user participation, and atmosphere.

All service users appreciated the social support they received in their supported living arrangements. Valued social support is discussed under the sub-themes of service users' participation, sense of tenancy, and atmosphere, as seen during participant observations. Service users' participation encouraged their planning, design, delivery, and evaluation. They enjoyed the positive experience of a sense of tenancy. Three of the six service users shared their tenancy, while three were in single tenancy, usually watching television and doing things together as a family.

Social support is a complex construct defined and measured in various ways. Social support encourages social interaction and relationships that provide individuals with assistance or a sense of attachment to a person or group perceived as loving and caring (Hobfoll & Soles, 1988). Support is a building block of social, psychological, and biological integrity (Hobfoll et al., 1990). Whether formal or informal, the central component of support is "valued" because it is considered beneficial and genuinely helpful; it addresses an individual's needs, and challenges social capital as a valuable resource, contributing to better health chances (Cattell, 2001). Service users and the care support workers came to acknowledge and understand the support as social and valuable.

In the study, valued social support played a crucial role in promoting service user participation and fostering a sense of belonging among service users in the place they now call home, under ideal conditions. Literature indicates that perceived available support differs from received support, which refers to help that is received as part of social support (Uchino, 2009; Goodwin et al., 2004). While perceived support involves what people believe is available to them in supported living, care support workers gave "received" support – actual assistance given in the form of emotional and informational support to help service users

make decisions, solve problems, and understand complex situations. It should be borne in mind that these recipients have mild to moderate learning disabilities, and so there was a commitment to enable their independent lives with real support.

In this context, valued support aligned with the service users' interests and expectations, as described by all participants in this study.

7.2.3 Positive impact

The third theme, positive impact, which all service user participants experienced in the supported environment, has a beneficial effect, increased happiness and fulfilment, and a sense of gaining something from the support. The theme is discussed under the sub-themes of interests, service user expectations, the quest for independence and autonomy, and skills development. The positive impact brought about beneficial changes, improving the lives of service users who had previously been living in supported accommodation. The experiences of support fulfilled their service users' interests (football and cooking in their flats) and expectations (to live in the community). Social, physical, environmental, and cognitive factors collectively determine an individual's ability to function autonomously in everyday life (Bruderer-Hofstetter et al., 2020). Skills development focused on service users acquiring the skills to live independently. It involved creating opportunities to learn and develop practical, social, and emotional skills for quality of life. The range of skills includes daily living skills for personal care, cooking, and meal preparation; social skills for communication and interaction; life skills for integration and community participation, as well as recreational activities; coping strategies for self-esteem; and, more recently, technical skills for using smartphones, tablets, and laptops.

All service users were involved in activities of daily living (ADL) and instrumental activities of daily living (IADL). ADL includes basic, daily functioning and self-care activities such as bathing, showering, dressing, eating, and toileting, while IADL are higher-level, organisational, and more complex activities related to the ability to live independently in the community (Raimo et al., 2024; Guo & Sapra, 2020). IADL is more complex than ADL, such as shopping, housekeeping, using gadgets, and cooking, among more independent service users. For example, service users, under the guidance and supervision of their care support workers, used telephones, went shopping, prepared meals, did housework, used private or public transportation, took medication, and managed their budgets. All depended on the service user's abilities, needs, preferences, and goals. At times, skills development was a

source of conflict between service users and care support workers when the service users felt too autonomous to be taught new skills. Nonetheless, care support workers were observed closely engaging with their service users, consistently applying positive reinforcement and patience to help them achieve their aspirations.

7.2.4 Challenges

The theme of challenges is highly pertinent within the context of supported living. In this study, service users faced various difficulties, such as navigating complex conversations, resolving conflicts, and managing uncertainties in their supported living environments. These findings underscore the complex interpersonal and emotional dynamics inherent in supported living, underscoring the need for comprehensive support systems and effective communication strategies.

During interviews and participant observations, several service users expressed negative experiences related to transitions and voiced concerns about rumours suggesting that some individuals would be moved to different support providers. Many felt stressed, as they faced separation from their regular care support workers, whom they viewed as part of their extended family due to the strong relationships they had developed.

Any change brought about specific challenges that need to be addressed through conflict resolution. Chetkow-Yanoov (2013) acknowledges that such conflicts could reduce motivation, lower satisfaction, and heighten stress levels. Disruptions to establish routines and delays beyond anyone's control required careful management in line with support plans, verbal redirection, and reassurance. If these issues were not adequately addressed, they affected the smooth operation of support as observed in the meticulous routines for service users,

During the COVID-19 pandemic, unexpected and poorly communicated developments posed significant challenges. All service users shared their experiences of how the pandemic changed their daily lives, routines, and interactions with family members. Despite having support plans and risk assessments in place, the situation required effective conflict resolution to navigate the uncertainties that arose. The COVID-19 pandemic caused untold inconveniences and disruptions to the lives of service users. Despite the care support workers offering reassurances and optimism about their situation, the service users expressed their displeasure with the pandemic during the interviews. This leads to the section below (7.3), which discusses the themes of Assistant Care and Support Managers.

7.3 AC&SMs' three themes

The section briefly discusses how Assistant Care and Support Managers' themes are overarching themes: (1) service users' needs and expectations, (2) organisational preparedness, and (3) culture for support in conjunction with those of service users on their lived experiences of support. The rationale of managers and service users together helps present a more responsive, balanced understanding of the pursued experiences of support in supported living.

As claimed in theme 1, the Assistant Care and Support Managers assessed the needs and expectations of service users, which were identified and risk-assessed upon admission to supported living. The Assistant Care and Support Managers' responsibility was to ensure that the service users realised their needs and expectations in supported living. The sub-themes included expectations, unmet needs, and the service users' values. The Assistant Care and Support Managers discussed how they addressed the service users' expectations, unmet needs, and values (least restrictions, tenancy). Theme 1 formed the foundation for determining service users' experiences of support in supported living.

The second theme identified was organisational preparedness, highlighting staff readiness to provide both direct and indirect support to service users in supported living settings. The sub-themes were responsibilities, strategies, approaches, housing bids, support, teamwork, and training. Care support workers and service users evidenced all those aspects.

Over time, the support provider developed a culture of support, as evidenced by theme 3 identified during the interviews. The culture of support encourages collaboration, understanding, and belonging in supported living communities. The culture of support theme encompasses sub-themes of support values, disabilities, life changes, facilities, living environment, and support standards. Culture shapes social environments by defining what is correct, moral, valuable, accurate, and practical. It establishes policies, practices, and norms, aids in aligning individuals' interactions and identities across various institutions, organisations, and groups (Hamedani et al., 2023). The Assistant Care and Support Managers discussed fostering a culture that values individual achievements and collaboration for shared success. Therefore, comparing service users' views with managers' themes highlighted areas of agreement, such as the value of personalised support and service users' expectations and autonomy. In contrast, managers contextualised how systems, culture, and structures either

enable or constrain. Such a comparison helped recognise the gaps between what was provided and what service users experienced.

7.4 Comparing the Results with Previous Research

The previous studies from the scoping review mapped data available on the experiences of support. Scoping reviews help assess the size of the literature on a given topic and capture salient issues (Moriarty et al., 2011). The reviews of previous studies employed individual methods, such as individual interviews, focus groups, and Interpretive Phenomenological Analysis (IPA), and reviewed the methodological gap. It was addressed by adopting the FE. This research makes a significant contribution to knowledge by providing a methodological approach, grounded in ethnography that can be applied in future studies. The contribution lies in the characteristics of FE, including the inclusivity of methods, context, and field notes, as well as methodological reflexivity. The following sections (7.4.1, 7.4.2, 7.4.3) describe the significance of contribution to knowledge.

7.4.1 Inclusivity of methods

Inclusivity of methods encourages the adoption of research methods that ensure the participation, representation, and voices of diverse groups, including marginalised groups. The researcher used FE to address the methodological gap revealed by the scoping review. The methods were deliberately chosen to encourage the primary participants (service users) to have a participatory role. The researcher utilised FE to systematically investigate the social phenomena related to experiences of support. In addition, FE's associated methods gather in-depth data through semi-structured interviews, participant observations, field notes, and reflexive accounts (Higginbottom, 2013; Knoblauch, 2005; Millen, 2002; Morse & Richards, 2002). Several methods were available to generate data on the research topic. In the current study, service users were offered a participatory role in answering interview questions about their experiences of support during individual interviews. They were also included in participant observations during scheduled visits to observe them receiving support in their flats. Participant observations encompass all participants, including those who are both cognitively and less cognitively competent (Hammersley & Atkinson, 2019). The competence was assessed based on the active participants who spoke more and those who spoke less about their experience of support. Participant observations and semi-structured interviews complemented each other, including those from less competent speakers who still made valuable contributions to their topic. This was a significant development in this study, given that the FE catered to the abilities of all eligible primary participants who were the

service users. This data collection stage was crucial and made all the difference, as it contributed significantly to the study's knowledge using this innovative method.

7.4.2 Context and field notes

The context and field notes made a significant contribution by capturing rich details of events in case they might be missed in this study. The context improved the accuracy, minimising the chances of misinterpreting the facts and findings of this research, located in an urban setting within the suburban areas of the mainstream population. The flats were 2-4 bedrooms, depending on the number of service users. Researchers use field notes to detail the overall setting, providing rich context for the study (Phillippi & Lauderdale, 2011). The main activities were capturing contextual and descriptive data from the interviews and participant observations. The researcher recorded all field notes from each interview in a notebook. Field notes provided evidence of what was taking place. The field notes were appropriate, as the participants were informed about the notes to remind the researcher, depending on the context at the time of the study (Fazey et al., 2013). The participants' demeanour and non-verbal behaviours were also recorded immediately. This created a transparent record of what was observed and how conclusions were formed.

Field notes prompt researchers to observe the environment and interactions closely, document the sights, smells, and sounds of the physical environment, and record their impressions. It encourages researchers to reflect on their experiences and identify potential biases to increase rigour and trustworthiness and provide essential context to inform data analysis (Tsai et al., 2016). The data collection involved 12 semi-structured interviews and 12 participant observations. Of course, for interviews, one had to guard against acquiescence with specific participants. People with learning disabilities tend to exhibit higher levels of acquiescence than those without (Keywood & Flynn, 2006; Clare & Gudjonsson, 1993). Nonetheless, their participation empowered them to share their experiences of support in their home settings. Chapter 4 also included field notes, which constitute a significant contribution to knowledge. Taking field notes required active engagement and immersion in the research setting, unobtrusively, as follow-up activities in the service users' flats. Field notes were key parts of the inductive process in qualitative research (Hinds et al., 1997). This process enabled the researcher to connect more deeply with the study's environment and participants and gather substantial data.

In summary, the researcher had substantial field notes, which significantly contributed to understanding and interpretation of the participants' experiences with support, making a valuable contribution to the overall research.

7.4.3 Methodological reflexivity as a tool

In this study, methodological reflexivity involved the researcher critically reflecting on the data collection, analysis, and interpretation processes. Reflexive practices extend beyond the formulation of research questions and data collection (Jason & Glenwick, 2016). Methodological reflexivity enabled the researcher to be self-aware of their assumptions and how they might influence the findings. Reflexive practices were carried out at each stage with the supervisory team to assess how the research process aligned with the research question and how research tools, choices, and procedures, such as interview techniques, sampling strategies, or data analysis methods, shaped the findings. The outsider status was worth noting, as the participants were aware that the researcher was a learning disabilities nurse by profession, but the researcher did not know the participants' backgrounds. There was an iterative process of reflexivity to reconsider the researcher's positionality in the study.

The researcher utilised professional nursing awareness of roles to facilitate cooperation in engaging service users. The data collection process helps to mitigate the power differences between the researcher and participants, encouraging even the most vulnerable individuals in society to participate in the research (Carter & Coyne, 2018; Cornwall & Jewkes, 1995). During participant observations, service users actively went about their chores as usual, almost oblivious of the observer present in their flats. The presence of regular care support workers helped maintain the situation as planned, and they remained calm. Furthermore, participants continued with their activity in the direction of the research. Drawing upon previous inpatient clinical experience, the researcher, who is a learning disability nurse, provided verbal reassurance to service users. The approach contributed to a sense of trustworthiness and accountability of the knowledge generated.

7.5 Reflexivity

Reflexivity is the final theme in this study, encapsulating the central activities of planning, methodology, and conclusion. Reflexivity is a journey of learning and, at times, a process of learning about various levels, including personal, methodological, and theoretical (Engward & Davis, 2015). This reflexive sums up the researcher's experiences. In academic research, reflexivity is an activity in which the researcher accounts for their positionality and its impact

(Serra Undurraga, 2021). Here, the researcher addressed three key ethical considerations: recruitment process (3.14), data analysis (3.27), and researcher positionality (3.33). It was a way of producing something specifically related to the research question and the findings. This journey encompassed all the stages of this academic endeavour aimed at contributing to knowledge. In a practice environment, nurses now apply reflexivity as a common practice (Freshwater & Rolfe, 2001) and researchers (Finlay, 2002). This was the time when the researcher was able to reflect on the five years from the inception of this research to its conclusion. As a researcher, one remains an insider with experience of this provider of supported living as a learning disabilities nurse, but without knowing the participants. The researcher's position as an insider or outsider is important when experiences have reshaped the participants (Teh & Lek, 2018; Berger, 2015). The researcher shared his role in visiting the flats of the six service users and, through interviews and participant observations, obtained their cooperation and working interconnectedness during the research process. Berger (2015) describes reflexivity as the researcher's lens being brought back onto oneself to acknowledge and take responsibility for self-introspection on the research and its effects on the setting and the people studied, the questions being asked, and the data collected and interpreted. The study examined how service users' participation may influence their interpretation of support experiences within supported living settings.

At this juncture, the researcher, being a part-time PhD student and a full-time health employee, felt like a novice yet triumphant in gathering considerable data from primary participants often overlooked due to their social support. Throughout the research process, the researcher experienced a range of emotions. Engaging in reflexive practice and reflection was integral to generating incisive insights about the research topic.

7.6 Study strengths

The first strength was obtaining the voices of the service users from a disadvantaged population group. They described their experiences of support using FE. The approach allowed us to gain access to the supported living context. This study gave the service user a voice by describing their experiences. The study used FE, which offers a practical, flexible, and in-depth approach to qualitative research. It allowed for more time-efficient and detailed exploration of specific social phenomena (Higginbottom et al., 2013). The approach allowed interviews with all the participants in their familiar, supported living context.

The second strength was the public and patient involvement, which encouraged the generation of rich data. PPI brought vital strength of trust and commitment to ethical inclusivity that involves service users and the public. There was PPI input to documents for service users on shaping research questions, design, and outcomes to reflect real needs and priorities, making findings more applicable and valuable. PPI input empowered service users, an underrepresented population, to contribute meaningfully and reduce power imbalances between researchers and service users.

The third strength was the triangulation of participant observations, semi-structured interviews, field notes, and reflexivity. It avoided privileging only one viewpoint and demonstrated fairness in representing the voices of all stakeholders. Relevant data were collected in accordance with the study's objectives.

The study's last strength was its rigorous credibility. As pointed out (Chapter 3, section 5.2), the academic supervisors regularly discussed the study findings. This involved checking the veracity of the findings and researcher bias by determining that certain data sets from the service users, such as the support workers and managers, were available

7.7 Study limitations

Due to time constraints, there was no opportunity to revisit Partners in Learning in Sheffield with service user interview question feedback. (Appendix P). Partners in Learning contributed to the development of interview questions for service users, which were piloted on a group of individuals with mild to moderate learning disabilities and subsequently used for the service users in this study. By not following up with feedback to Partners in Learning, the researcher may have missed valuable opportunities to improve interview questions based on input from the pilot group and to address other important aspects of the support experiences. Nonetheless, the feedback will be done through the researcher's supervisor at SHU University.

While the study provides valuable insights into support experiences, there is limited generalisability since the findings are from one organisation and may not apply to other support living environments. However, the study aimed to explore the phenomenon of support experiences and to understand their complexity and context. Of course, there are theoretical and conceptual elements of the findings that resonate with other supported living contexts.

Another limitation of this significant study was the temporal constraint, where the support experiences varied over time. This cross-sectional study analysed data from a population at a single point in time, so the study might have missed any changes or trends. The study provides an overview of findings at that time, and there is no follow-up research planned. Hopefully, these limitations will be addressed in future research on a similar topic in diverse contexts.

7.8 Chapter Summary

The chapter discussed the main findings for the service users (key participants) and the Assistant Care and Support Managers. The four themes of the service users were a personalised approach, valued social support, positive impact, and challenges. The managers collectively shared their views through themes such as service users' needs and expectations, organisational preparedness, and culture of support. The aim of comparing the service users' experiences of support with the Assistant Care and Support Managers was for accountability, transparency, and an evaluation reflecting the positive experiences of support. The chapter also covered other themes related to care support workers who spend more time with the service users. The discussion offered a balanced understanding of how support experiences function in supported living.

The chapter acknowledged and discussed the positive contributions of other inclusive methods, context, and field notes, and methodological reflexivity as a tool. The application of focused ethnography, combined with the analysis of supported living field notes, greatly deepened the understanding and interpretation of participants' support experiences. Methodological reflexivity helped the researcher consider whether the chosen methods answered the research question. In this case, focused ethnography, a practical and flexible approach involving semi-structured interviews, participant observations, and field notes, proved effective in gaining access to the research context and capturing relevant data from supported living. The discussion incorporated the perspectives of all participants to address the research question.

Conclusion

8.1 Introduction

The study was conducted to investigate the support experiences for people with mild to moderate learning disabilities (service users) in Scottish supported living settings. This chapter provides the study's summary of the main findings, their implications, limitations, and suggestions for future research. By synthesising the findings, this chapter highlighted the overall contribution of the study to both academic literature and practical application to supported living.

8.2 Overview of findings

8.2.1. Revisiting the study aim/ Review the Research objectives

In conclusion, this chapter is a reminder and summary of the research topic of this study. The study aimed to explore the experiences of support for people with mild-moderate learning disabilities in supported living settings. This section summarises the key findings in relation to the study's research objectives (1.4.3)

- **Objective 1: To describe the experiences of support for adults with mild learning disabilities residing in supported accommodation.**

The first objective described the experiences of support of primary participants with mild-moderate learning disabilities in supported living. The study used a focused ethnographic approach with its associated methods. The significant findings included positive outcomes from the main theme on personalised approach which focused on the experiences of support for the service users support designed to fit their needs, preferences and circumstances in a flexible and adaptable manner involving being listened to; valued social support which was important and beneficial to service user's emotional, practical and informational support, a positive impact on changing their lives to the living environment, relationships with support staff and peers, to have good towards a better quality of life health and challenges there were challenges related to conflict resolution, transitions of services to other supported providers, and unprecedented adversities from the COVID-19 pandemic. These challenges presented considerable hurdles for service users and their support workers in terms of adaptability, resilience, and innovation in their support experiences.

The thesis presents first-hand experiences of support that enhance service users' opportunities to enjoy social inclusion and successful community integration. The Assistant Care and Support Managers offered valuable insights into the organisational preparedness, culture of support, and strategic planning. The thesis discussed the Assistant Care and Support Managers' contributions and the service users' experiences of support to provide a holistic understanding of support in supported living. The dual perspectives compared expectations against reality to provide a nuanced analysis aligned with organisational intentions and service users' needs and expectations. Objective 1 was achieved as it described the experiences of support for the service users.

- **Objective 2: To critically analyse the managers' and support workers' perspectives of support in supported living.**

The Assistant Care and Support Managers' overarching themes, including a culture of support, organisational preparedness, and the needs and expectations of service users, underpin the material perspectives. The culture of support is examined through support values, the resources employed, and the complexities associated with disabilities in the living environment. Open communication and the respectful treatment of service users facilitate effective teamwork, person-centred care, and the promotion of autonomy. Service users and care support staff also confirmed the importance of a person-centred approach, respect, and dignity. However, as Assistant Care and Support Managers were not consistently present on the shop floor, their managerial perspectives may not fully reflect the realities within supported living environments, where care support workers spend more time with service users. Consequently, potential gaps in policy implementation cannot be excluded completely.

The second theme identified was organisational preparedness, which contributed to effective support in meeting challenges while adhering to policies, standards, and service users' needs. This encompassed strategies and approaches, partnerships, staff training, and housing bids. The interviews with Assistant Care and Support Managers offered valuable insights into how they organise support, which in turn shapes service users' experiences. However, while they described established processes, it remained uncertain whether these filtered down to service users, some of whom were able to elaborate on their experiences. There was no ample time for the researcher to observe the implementation of existing policies in practice. Notably, none of the Assistant Care and Support Managers openly criticised the challenges faced by service users; rather, their responses were measured and demonstrated professional astuteness.

The last theme on service users' needs and expectations was discussed under the subthemes of individual needs, service users' values, and they shared their optimism for the future. Senior care support workers and care support workers shared positive views of service users' support experiences in the frontline position, while the Assistant Care and Support Managers shared their managerial views of the experiences of support for service users. For an outsider, there was an alignment of the views on most aspects of support and an equally true gap. The researcher addressed the gap by discussing the views of Assistant Care and Support Managers and the service users together so as to validate and align the perspectives in the interest of presenting a broader, balanced position of the experiences of support in supported living settings. Therefore, objective 2 was critically analysed in line with the research topic.

- **Objective 3: To evaluate the core values that guide the provision of support for adults with mild learning disabilities in supported living.**

The third objective evaluated the following core values: person-centred support, respect and dignity; choice and autonomy; and independence. They were generated during the interviews of service users, senior care support workers, care support workers, and Assistant care & support managers) of this study. Supporting evidence came from the 12 participant observations (2 per service user).

A primary core value identified was that person-centred support facilitated through individualised support plans met the needs and choices of service users. This approach resulted in positive and meaningful outcomes, as it effectively addressed the needs of all service users, who expressed satisfaction with the support experiences. However, the manager pointed out that securing adequate funding remained a significant challenge.

The remaining core values, in any order, respect and dignity; choice and autonomy; and independence, were linked to the success core value of person-centred. The researcher got the impression that respect and dignity were manifested under person-centredness, where service users had input on planning their meals, choice of hobbies, and daily and weekly schedules, which each service followed. The care support workers were knowledgeable of the service users' personalised plans and roles, as the Assistant Care and Support Managers insisted that it was their responsibility to ensure that service users were treated with respect and dignity. While certain service users required structured support, respect, and dignity, evidence during participants' observations showed support for independence and empowerment of service users.

The third core value identified in this study, as discussed in Chapter 4, is choice and autonomy. This value is associated with individuals' capacity to make independent decisions and manage their own lives, thereby challenging social stigmas and enhancing quality of life. For instance, service users were able to select their meals and participate in preferred social activities. The fourth theme identified among service users` independence, which included cooking, using public transportation, and managing personal finances. The researcher observed that service users demonstrated confidence and competence in managing various daily routines within supported living environments, often requiring minimal assistance from care support workers.

Although these values offer a robust ethical and practical foundation, their implementation presents ongoing challenges. Assistant Care and Support Managers and their care support workers regularly navigate competing priorities, including autonomy, independence, and individual needs. Assistant Care and Support Managers identified staff training, organisational culture, and sufficient funding as essential for upholding the values identified in this study within supported living environments. Based on the evidence of the activities and data collected from the six supported living settings examined by the researcher, objective 3 of this study was achieved. Similarly, objective 4 on implications from the experiences of support for adults with mild learning disabilities in supported living was achieved as described in section 8.4

This study successfully met its aims and research objectives by using a focused ethnography approach. This enabled an in-depth understanding of participants in supported living settings, captured their perspectives through interviews and participant observations, and identified key observational and interview data patterns through reflexive thematic analysis, and ensured findings were grounded in real-world contexts by integrating multiple data sources and thereby contributing to knowledge.

8.3 Original Contribution to Existing Knowledge

This thesis makes four key contributions (8.3.1; 8.3.2; 8.3.3; 8.3.4) to knowledge for learning disability research and supported living and social care practice.

8.3.1. Methodological contribution: use of Focused Ethnography

This thesis makes a novel methodological contribution by applying a focused ethnographic approach to gather the rich experiences of support among individuals with mild-moderate learning disabilities. This approach demonstrated the feasibility of combining participant

observation and semi-structured interviews to illuminate subtle aspects of support experiences. By employing focused ethnography, the thesis generated new knowledge about service users' experiences, particularly highlighting the perspectives of those in supported living, amplifying their voices and relationships, and yielding positive insights.

8.3.2. Contextual Contribution: Scottish Supported Living

This thesis offers a contextual contribution by providing specific insights into the experiences of people with mild-moderate learning disabilities living in Scottish supported living settings of a population underrepresented in Scottish research. It broadens understanding of service users' experiences of support, moving beyond a deficit-focused perspective to present a more nuanced account of support practices in real-world contexts.

8.3.3. Amplification of the service user voice

This thesis contributes amplified voices of the marginalised group of people with mild-moderate learning disabilities. It contributes to the rights-based, person-centred approach to research. This study makes an original contribution by featuring the voices of an underrepresented population of service users who are seldom involved in formal evaluations of Scottish supported living. Through qualitative insights from both service users and AC&SMs, the study highlighted a notable divergence of perceived support needs and service outcomes. The findings challenged the dominant narratives, which regard people with learning disabilities as passive recipients of care and support, when they show that they aspire and are active.

8.3.4. Relational and Practice-based insights

Lastly, this thesis contributes relational and practice-based insights, highlighting the significance of the relationship between care support workers and service users in fostering trust and autonomy. On the other hand, practice-based insights revealed how the real-life experience of support in everyday routines influences service users' daily experiences, emotional well-being, and individual autonomy. The findings revealed that care support workers occupy a dual role as gatekeepers with control and professional judgement over who gets access to common contexts, and as facilitators in shaping support experiences by fostering trust, listening, advocating for service users, and tailoring support to individual needs.

In summary, the thesis contributed new knowledge by employing FE to capture the service users' experiences of support, the voice of service users, and the relationship, yielding

positive insights. In practice, the highlighted contributions lead to the implications of the findings.

8.4 Implications of the findings

The experiences of support for service users in supported living are essential, given that individuals with learning disabilities are unique and require significant preparation of documentation, communication, and engagement. Such an approach contributed to social and practical implications for professionals who might consider researching people with learning disabilities. This study showed that individualised and person-centred approaches are vital for the positive experiences of service users in their supported living settings. The implication suggests that the approaches provide a sense of empowerment and ownership of their research involvement.

The scoping review revealed that other studies conducted in different continents investigated varied experiences of support for individuals with learning disabilities in their supported settings. With available funding, it is important to conduct larger-scale studies in collaboration with other support providers to enhance the quality of support experiences in supported living settings.

This study demonstrated the ethical implications of focused ethnography in being respectful and ethically engaging with participants, aligning with the principles of social inclusion and community integration. The researcher gained access to the safeguarded service users in their flats and built rapport to amplify their voices using research. Similarly, for professionals, the study approach suggests that people with learning disabilities appreciate having a voice through research.

8.5 Suggestions for Future Research

Future research should expand the sample size and diversity to validate these findings across broader contexts. Longitudinal studies could explore how sustained PPI influences service outcomes over time. Furthermore, comparative studies involving different service contexts could help determine whether the positive experiences observed here are specific to a model of practice or a broader trend in effectively supported living settings.

The future implication suggests exploring other innovative ways of involving individuals with learning disabilities from other support providers to enhance the experiences of the

support base, including managing negative experiences such as inconsistent support and difficult conversations, which may lead to anxiety or feelings of helplessness.

Future research should prioritise the inclusion of people with learning disabilities to challenge the prevailing narrative that has often excluded them from participating in research as equal members of our communities. Formal provisions must be established for individuals with learning disabilities in supported living settings, alongside broader opportunities for meaningful involvement in research that reflects their interests and lived experiences. The findings from this study are anticipated to foster dialogue among a diverse range of stakeholders, including care organisations, support managers, and professionals in health and social care. Such dialogue could play a significant role in shaping policies and strategies to enhance support experiences for people with learning disabilities. In addition, comparative studies examining other marginalised populations may shed light on the cultural and socio-economic factors that shape support experiences.

8.6 Final Reflections

In conclusion, this study provides a comprehensive, empirically grounded understanding of the experiences of people with mild-moderate learning disabilities in Scottish supported living settings. The researcher embarked on a journey which to seek knowledge and understanding of a population group often excluded from research. This involved coming up with the research topic of interest, its approval and then the written work putting the thoughts on paper for supervisors and others to know and challenge. All culminated with the actual data collection out there as a single researcher. The researcher acquired the planning skills of how the research was conducted, developed data analysis skills sifting through substantial qualitative data gathered from participants, analytical skills from discerning information and listening skills from interviews with all the participants and writing skills of the study report. The emotional roller coaster and learning curve boosted the ego to attain results.

The researcher realised that the views of service users are seldom solicited; the findings indicated their desire for greater autonomy, and frustration when their voices are overlooked and at the same time express appreciation when their input influences their support experiences. The researcher cherishes the success of completing a PhD thesis an intellectual achievement and buoyancy of applying academic knowledge in research to understand the experiences of support for people with mild-moderate learning disabilities in Scottish supported living settings.

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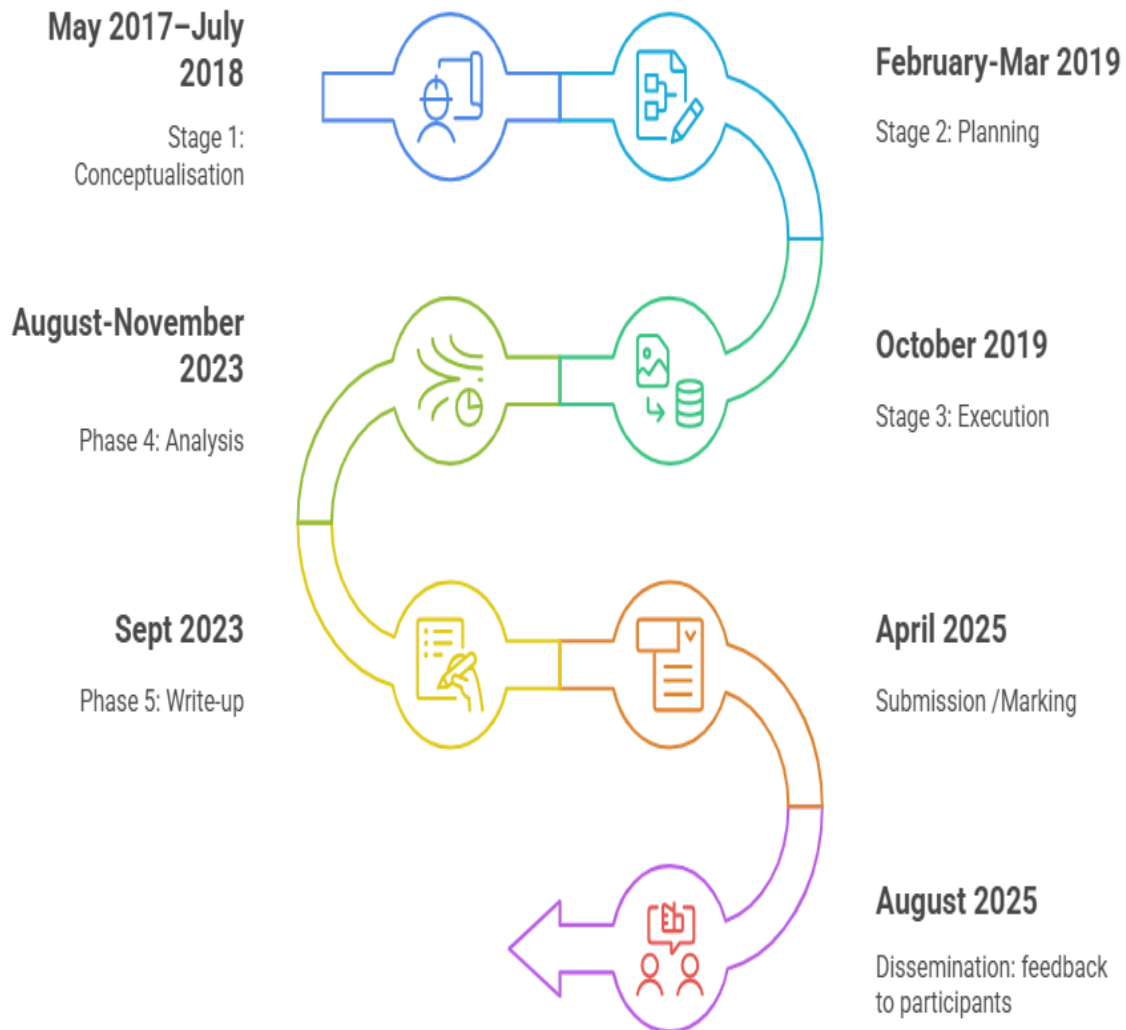
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Appendices

Appendix A: Timeline

PhD Research Journey: From Concept to Completion



Appendix B: PRISMA-ScR Checklist

| SECTION | ITEM | PRISMA-ScR CHECKLIST ITEM | REPORTED ON PAGE # |
|---------------------------|------|--|--------------------|
| TITLE | | | |
| Title | 1 | Identify the report as a scoping review. | |
| ABSTRACT | | | |
| Structured summary | 2 | Provide a structured summary that includes (as applicable) the background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions related to the review questions and objectives. | |
| INTRODUCTION | | | |
| Rationale | 3 | Describe the rationale for the review in the context of what is already known. Please explain why the review questions/objectives lend themselves to a scoping review approach. | |
| Objectives | 4 | Provide an explicit statement of the questions and objectives being addressed concerning their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualise the review questions and/or objectives. | |
| METHODS | | | |
| Protocol and registration | 5 | Indicate whether a review protocol exists, and if so, state where it can be accessed (e.g., a Web address). Provide registration information, including the registration number if available. | NA |
| Eligibility criteria | 6 | Specify characteristics of the sources of evidence | |

| SECTION | ITEM | PRISMA-ScR CHECKLIST ITEM | REPORTED ON PAGE # |
|--|------|--|--------------------|
| | | used as eligibility criteria (e.g., years considered, language, and publication status) and provide a rationale. | |
| Information sources* | 7 | Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources) and the date the most recent search was executed. | |
| Search | 8 | Present the complete electronic search strategy for at least one database, including any limits used, so it can be repeated. | |
| Selection of sources of evidence | 9 | State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review. | |
| Data charting process | 10 | Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that the team has tested before their use and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators. | |
| Data items | 11 | List and define all variables for which data were sought and any assumptions and simplifications made. | |
| Critical appraisal of individual Sources of evidence | 12 | If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate). | NA |
| Synthesis of results | 13 | Describe the methods of handling and summarising the data that were charted. | |

| SECTION | ITEM | PRISMA-ScR CHECKLIST ITEM | REPORTED ON PAGE # |
|---|------|---|--------------------|
| RESULTS | | | |
| Selection of sources of evidence | 14 | Give the number of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram. | |
| Characteristics of sources of evidence | 15 | For each source of evidence, present characteristics for which data were charted and provide the citations. | |
| Critical appraisal within sources of evidence | 16 | If done, present data on critical appraisal of included sources of evidence (see item 12). | NA |
| Results of individual sources of evidence | 17 | For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives. | |
| Synthesis of results | 18 | Summarise and/or present the charting results related to the review questions and objectives. | |
| DISCUSSION | | | |
| Summary of evidence | 19 | Summarise the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups. | |
| Limitations | 20 | Discuss the limitations of the scoping review process. | |
| Conclusions | 21 | Provide a general interpretation of the results concerning the review questions and objectives and potential implications and/or next steps. | |
| FUNDING | | | |

| SECTION | ITEM | PRISMA-ScR CHECKLIST ITEM | REPORTED ON PAGE # |
|---------|------|---|--------------------|
| Funding | 22 | Describe funding sources for the included sources of evidence and the scoping review. Describe the role of the funders of the scoping review. | N/A |

Appendices C

Appendix C 1: Giebers et al., 2019

| | |
|---|---|
| Title: Living with support: Experiences of people with mild intellectual disability | |
| First Author & Year | Giesbers, et al. 2019 |
| Type of evidence source Primary, evidence synthesis, conference abstract, discussion article | Primary |
| Country | The Netherlands |
| Research type | Qualitative |
| Aim/Purpose | To gain insight into how people with intellectual disabilities perceive the support they receive from professionals or staff |
| Population | Six individuals with mild intellectual disability |
| Methodology/ Methods | Interpretative Phenomenological Analysis (IPA) approach: interviews |
| Key findings | When examining staff relationships, three main themes were to be considered: personal history, organisational context, and staff support. |

Appendix C 2: Esteban et al., 2023

| | |
|--|---|
| Title: A community living experience: Views of people with intellectual disability with extensive support needs, families, and professionals | |
| First Author & Year | Esteban et al., 2023 |
| Country | Ireland & Spain |
| Type of evidence source | Primary |
| Research type | Qualitative |
| Aim/Purpose | To qualitatively analyse the perceptions of individuals with intellectual disabilities and their family members six months after implementing 11 community homes housing 47 people |
| Population | 13 individuals with intellectual disabilities, 30 professionals and 34 family members |
| Methodology/Methods | Individual interviews |
| Key findings | Seven themes were found: (1) “the room as I like it”, (2) “sometimes I don’t obey”, (3) “here I do a bit of everything”, (4) “lots of people love me here”, (5) “all thanks to them, who have helped me” (6) “I miss my mom”, and (7) “I’m happy here”. |

Appendix C 3: Puyalto & Pallisera, 2020

| | |
|---|--|
| Title: Living Independently in Spain: Barriers and Supports from the Views of People with Intellectual Disabilities | |
| First Author & Year | Puyaltó & Pallisera, 2020 |
| Country | Spain |
| Type of evidence source | Primary |
| Research type | Qualitative study |
| Aim/Purpose | The purpose of this study is to investigate and better understand the perspectives of individuals with intellectual disabilities on the supports and obstacles that impact their right to live independently in Spain. |
| Population | 20 people with intellectual disability |
| Methodology/Methods | Qualitative approach: individual interview |
| Key findings | Highlighted barriers and supports in different areas affecting opportunities to live and participate in the community. |

Appendix C 4: Bigby et al., 2017

| | |
|---|--|
| Title: Conundrums of supported living: The experiences of people with intellectual disability | |
| First Author & Year | Bigby et al. 2017 |
| Country | Australia |
| Type of evidence source | Primary |
| Research type | Qualitative |
| Aim/Purpose | Explore how people with intellectual disabilities experience living in supported living arrangements. |
| Population | Thirty-four people with intellectual disability, aged 18 years and above |
| Methodology/Methods | Constructivist grounded theory, focus groups, and individual interviews |
| Key findings | Participants in the study reported having greater autonomy and control over their daily lives; they felt that they had little say in how support was provided to them. |

Appendix C 5: Björnsdóttir et al., 2015

| | |
|---|---|
| Title: 'It's my life': Autonomy and people with intellectual disabilities | |
| First Author & Year | Björnsdóttir et al. 2015 |
| Country | Iceland |
| Research type | Qualitative |
| Aim/Purpose | To discuss autonomy in the lives of adults with intellectual disabilities |
| Population | 41 participants with learning disabilities |
| Methodology/Methods | Qualitative approach: Semi-structured interviews and participant observations |
| Key findings | Individuals with intellectual disabilities make choices in their daily lives by looking through the lenses of relational autonomy. Autonomy has improved with time and has become less paternalistic. |

Appendix C 6: Hamilton et al. 2017

| | |
|--|---|
| Title: ‘There’s a lot of places I’d like to go and things I’d like to do’: The daily living experiences of adults with mild to moderate intellectual disabilities during a time of personalised social care reform in the United Kingdom | |
| First Author & Year | Hamilton et al. 2017 |
| Country | United Kingdom |
| Type of evidence source | Primary data |
| Research type | Qualitative study |
| Aim/Purpose | To explore the daily living experiences of adults with mild/moderate intellectual disabilities in a city in the north of England and its outskirts. |
| Population | 26 adults with intellectual disabilities (19 males and seven females) and 13 support workers (six males and seven females) |
| Methodology/Methods | Focus group discussions |
| Key findings | The key themes were Independence and agency, Prioritisation of needs, social capital, and well-being. |

Appendix C 7: Conder & Mirfin, 2020

| | |
|--|--|
| Title: 'Getting by': People with learning disability and the financial responsibility of independent living. | |
| First Author & Year | Conder & Mirfin, 2020 |
| Country | New Zealand |
| Type of evidence source | Primary |
| Research type | Qualitative study |
| Aim/Purpose | Explore the experiences and outcomes of independent living from the perspectives of adults with learning disabilities in Aotearoa. |
| Population | 20 participants with learning disabilities, 22-65 years |
| Methodology/Methods | Semi-structured interviews |
| Key findings | Managing a budget can be challenging, and people's limited finances can significantly impact their quality of life. It is important to consider how budget constraints affect people's ability to live comfortably and make ends meet. |

Appendix C 8: Pallisera et al. 2020

| | |
|--|---|
| Title: Being in control: Choice and control of support received in supported living. A study based on the narratives of people with intellectual disability and support staff. | |
| First Author & Year | Pallisera et al. 2021 |
| Country | Spain |
| Type of evidence source | Primary |
| Research type | Qualitative study |
| Aim/Purpose | To investigate the involvement of individuals with intellectual disability receiving supported living in decision-making about professional support to reach self-determined goals. |
| Population | 31 people with intellectual disability |
| Methodology/Methods | Qualitative study: Semi-structured interviews |
| Key findings | Support in supported living is conditioned by professionals' assessment of the person's autonomy, despite personalised solutions. |

Appendix C 9: Williams & Porter, 2017

| | |
|--|--|
| Title: The meaning of ‘choice and control’ for people with intellectual disabilities who are planning their social care and support. | |
| First Author & Year | Williams & Porter, 2017 |
| Country | United Kingdom |
| Type of evidence source | Primary |
| Research type | Qualitative study |
| Aim/Purpose | To better understand how choice and control are defined as significant aspects in the lives of people with intellectual disabilities. |
| Population | 9 adults with intellectual disabilities |
| Methodology/Methods | An interpretative approach: interviews |
| Key findings | People need to gain confidence in their decision-making abilities through peer support and trust others to have control and choice in their budget processes and identity. |

Appendix C 10: Whitehead et al. 2016

| | |
|---|---|
| Title: Negotiated autonomy in diabetes self-management: The experiences of adults with intellectual disability and their support workers. | |
| First Author & Year | Whitehead et al. 2016 |
| Country | New Zealand & Australia |
| Research type | Qualitative |
| Aim/Purpose | To investigate the experiences and self-management practices of diabetes among people with intellectual disabilities who live in independent living settings, as well as the role of their support staff. |
| Population | 11 people with mild learning disabilities and type 2 diabetes |
| Methodology/Methods | Interviews |
| Key findings | There are three main themes related to diabetes management: 1. Negotiating autonomy daily; 2. Renegotiating autonomy during times of transition, and 3. Negotiating for increased autonomy. |

Appendix C 11: Petner-Arrey et al. 2015

| | |
|---|---|
| Title: ‘You have to care.’ Perceptions of promoting autonomy in support settings for adults with intellectual disability. | |
| First Author & Year | Petner-Arrey et al. 2015 |
| Country | USA |
| Research type | Qualitative |
| Aim/Purpose | To examine and analyse the perceptions of people with intellectual disabilities who are receiving support, as well as those who are providing support, regarding the level of autonomy that individuals with intellectual disabilities should be given. |
| Population | 10 people with learning disabilities and 10 support workers |
| Methodology/Methods | Qualitative study: interviews |
| Key findings | The study findings indicated that numerous factors in support systems and relationships can influence the expression of autonomy in adults with intellectual disability. |

Appendix C 12: Zaagsma et al. 2023

| | |
|---|---|
| Title: ‘When I need them, I call them, and they will be there for me.’ Experiences of independently living people with intellectual disabilities with 24/7 available online support | |
| First Author & Year | Zaagsma et al. 2023 |
| Country | The Netherlands |
| Research type | Qualitative |
| Aim/Purpose | To describe in detail how they experience online support and give meaning to their experiences |
| Population | 5 participants DigiContact is an online support service that uses videoconferencing techniques to enable people with ID to contact a team of specially trained support workers 24/7 |
| Methodology/Methods | Qualitative research design: Interview eHealth applications are increasingly being used in services for people with intellectual disabilities |
| Key findings | Results indicate that the suitability of online support depends on each support user’s needs, capabilities, and preferences. eHealth applications, such as online devices (e.g., smartphones, personal computers, and tablets), enable individuals to stay in contact with each other. |

Appendix C 13: Stierle et al. 2023

| | |
|--|--|
| Title: Using Smartphone technology to improve daily living skills for individuals with intellectual disabilities | |
| First Author & Year | Stierle et al. 2023 |
| Country | South Carolina, USA |
| Type of evidence source | Primary |
| Research type | Qualitative study |
| Aim/Purpose | To examine the effectiveness of a customisable smartphone app in helping young adults with intellectual disabilities |
| Population | Three young adults with intellectual disabilities, aged 21, 20, and 20, respectively. |
| Methodology/Methods | Cooking tasks using Assistive Technology in the on-campus apartment |
| Key findings | Individuals with intellectual disabilities can now access their video prompts to learn how to cook, clean, wrap gifts, use an ATM, garden, shops, use other technology and complete laundry. |

Appendix C 14: Lawrason et al. 2023

| | |
|---|--|
| Title: Remote support for individuals with intellectual disabilities living independently: a scoping review | |
| First Author & Year | Lawrason et al. 2023 |
| Country | Canada |
| Research type | Qualitative review |
| Aim/Purpose | To understand factors related to remote support provision among individuals with intellectual disabilities in independent living |
| Population | 22 articles were reviewed |
| Methodology/Methods | Scoping review |
| Key findings | Most studies have used mobile apps or video self-modelling/prompting and found that remote support provision is associated with positive outcomes, such as improved academic skills. |

Appendix C15: Witso et al. 2018

| | |
|--|---|
| Title: 'It's our everyday life.' The perspectives of persons with intellectual disabilities in Norway. | |
| First Author & Year | Witso et al. 2018 |
| Country | Norway |
| Research type | Qualitative |
| Aim/Purpose | To explore the perspectives and experiences of their everyday life and its shortcomings. |
| Population | 9 participants, three men and six women, aged from 22 to 58 |
| Methodology/Methods | <i>Participatory, appreciative, action and reflection (PAAR)</i> model talking about an ordinary week for them. talking about friendship. talking about photos and stories about their family, leisure activities, holidays, and high feasts. the fourth workshop included talking about daytime activities and work. |
| Key findings | People with intellectual disabilities desire social participation and prefer having their own apartments and going to work daily. |

Appendix C 16: Dew et al. 2019

| | |
|---|--|
| Title: ‘Living the Life I want’: A Framework for planning engagement with People with intellectual disability and Complex Support Needs | |
| First Author & Year | Dew et al. 2019 |
| Country | United Kingdom |
| Research type | Qualitative |
| Aim/Purpose | To plan experiences of adults with intellectual disability and complex support needs. |
| Population | 31 adults with learning disabilities |
| Methodology/Methods | Body maps for a guided group-based process and planning |
| Key findings | The findings revealed a sense of self-involvement, shaped by contextual barriers and facilitators, and influenced by both helpful and unhelpful support, centred on the principles of autonomy, agency, choice, and control. |

Appendix C 17: Tassé et al. 2020

| | |
|--|---|
| Title: Using technology and remote support services to promote independent living of adults with intellectual disability and related developmental disabilities. | |
| First Author & Year | Tassé et al. 2020 |
| Country | Ohio, USA |
| Research type | Qualitative |
| Aim/Purpose | To identify obstacles to using this technology (video cameras, motion detectors, medication dispensers) and enhance its usability for individuals with intellectual and developmental disabilities. |
| Population | 24 participants were adults with intellectual disability, alongside 24 other participants. |
| Methodology/Methods | Focus groups and telephone interviews. |
| Key findings | The occupants' level of independence and perceived sense of security have risen. Additionally, the need to establish safety measures within the confines of their home has been brought to their attention. |

Appendix C 18: Rushbrooke et al. 2014

| | |
|---|---|
| Title: The experiences of intimate relationships by people with intellectual disabilities: A qualitative study. | |
| First Author & Year | Rushbrooke et al. 2014 |
| Country | United Kingdom |
| Type of evidence source | Primary |
| Research type | Qualitative study |
| Aim/Purpose | To investigate the intimate relationship experiences of nine adults with intellectual disabilities. |
| Population | 9 adults with intellectual disabilities |
| Methodology/Methods | Interpretative phenomenological analysis |
| Key findings | The study identified four primary themes related to intimate relationships: desiring relationships, expressing sexuality, having relationships, and determining who has control. These themes exemplified that all participants desired and considered intimate relationships essential to fulfilling their various needs. However, participants also experienced several challenges related to intimate relationships, including a lack of staff training. |

Appendix C 19: Hatzikiriakidis et al. 2023

| | |
|---|--|
| Title: The Delivery of Healthy Lifestyle Interventions for People with Disabilities Living in Supported Accommodation: A Scoping Review of Intervention Efficacy and Consumer Involvement | |
| First Author & Year | Hatzikiriakidis et al. 2023 |
| Country | United Kingdom |
| Type of evidence source | Primary |
| Research type | Qualitative study |
| Aim/Purpose | Examine the efficacy of healthy lifestyle interventions for people with disabilities living in supported accommodation. |
| Population | People with learning disabilities |
| Methodology/Methods | The scoping review |
| Key findings | The review included 32 studies that identified intervention types, such as training and education, exercise programmes, and multi-component interventions. Although a broad range of outcomes were examined, the efficacy of the interventions was mixed due to significant heterogeneity and the underreporting of consistently measured outcomes. Furthermore, the co-design of interventions in consultation with people with disability was found to be underexplored, warranting further attention. |

Appendix D: An example of a systematic search strategy using ASSIA.

Search Strategy from ProQuest

28 February 2024 23:09

Search Strategy

| Set# | Searched for | Databases | Results |
|------|--|---|---------|
| S1 | “Learning disabilities” AND PEER (yes) | Applied Social Sciences Index & Abstracts (ASSIA) | 18796 |
| S2 | (“learning disabilities” OR “learning disability” OR “learning disability”) AND PEER (yes) | Applied Social Sciences Index & Abstracts (ASSIA) | 21979 |
| S3 | “learning difficult” AND PEER (yes) | Applied Social Sciences Index & Abstracts (ASSIA) | 48 |
| S4 | [S1] OR [S2] OR [S3] | Applied Social Sciences Index & Abstracts (ASSIA) These databases are searched for part of your query. | 22009 |
| S5 | “intellectual disabilities” AND PEER (yes) | Applied Social Sciences Index & Abstracts (ASSIA) | 13192 |
| S6 | (“intellectual impairment” OR “impairments”) AND PEER (yes) | Applied Social Sciences Index & Abstracts (ASSIA) | 23266 |
| S7 | “mental retard” AND PEER (yes) | Applied Social Sciences Index & Abstracts (ASSIA) | 81 |
| S8 | (“intellectual disabilities” OR “intellectual disability”) AND PEER (yes) | Applied Social Sciences Index & Abstracts (ASSIA) | 21610 |
| S9 | [S5] OR [S6] OR [S7] OR [S8] | Applied Social Sciences Index & Abstracts (ASSIA) These databases are searched for part of your query. | 40506 |
| S10 | impair* AND PEER (yes) | Applied Social Sciences Index & Abstracts (ASSIA) | 82127 |
| S11 | cognitiv* AND PEER (yes) | Applied Social Sciences Index & Abstracts (ASSIA) | 157895 |
| S12 | disab* AND PEER (yes) | Applied Social Sciences Index & Abstracts (ASSIA) | 90835 |
| S13 | [S10] OR [S11] OR [S12] | Applied Social Sciences Index & Abstracts (ASSIA) These databases are searched for part of your query. | 243790 |
| S14 | [S4] OR [S9] OR [S13] | Applied Social Sciences Index & Abstracts (ASSIA) These databases are searched for part of your query. | 247657 |

| | | | |
|-----|--|---|-------|
| S15 | “Supported living” | Applied Social Sciences Index & Abstracts (ASSIA) | 868 |
| S16 | “Supported accommodation” AND PEER (yes) | Applied Social Sciences Index & Abstracts (ASSIA) | 556 |
| S17 | “Supported housing” AND PEER (yes) | Applied Social Sciences Index & Abstracts (ASSIA) | 904 |
| S18 | [S15] OR [S16] OR [S17] | Applied Social Sciences Index & Abstracts (ASSIA) These databases are searched for part of your query. | 2041 |
| S19 | “Sheltered housing” | Applied Social Sciences Index & Abstracts (ASSIA) | 723 |
| S20 | “Social care living” | Applied Social Sciences Index & Abstracts (ASSIA) | 0 |
| S21 | “Care independent living” AND PEER (yes) | Applied Social Sciences Index & Abstracts (ASSIA) | 49 |
| S22 | “Social care supported living” AND PEER (yes) | Applied Social Sciences Index & Abstracts (ASSIA) | 0 |
| S23 | [S19] OR [S20] OR [S21] OR [S22] | Applied Social Sciences Index & Abstracts (ASSIA) These databases are searched for part of your query. | 771 |
| S24 | “Community living” | Applied Social Sciences Index & Abstracts (ASSIA) | 3842 |
| S25 | “Independent living” | Applied Social Sciences Index & Abstracts (ASSIA) | 5672 |
| S26 | “Care living” | Applied Social Sciences Index & Abstracts (ASSIA) | 182 |
| S27 | “Residential care living” | Applied Social Sciences Index & Abstracts (ASSIA) | 11 |
| S28 | “Residential care living” | Applied Social Sciences Index & Abstracts (ASSIA) | 11 |
| S29 | [S24] OR [S25] OR [S26] OR [S27] OR [S28] | Applied Social Sciences Index & Abstracts (ASSIA) These databases are searched for part of your query. | 9181 |
| S30 | “Supervised accommodation” | Applied Social Sciences Index & Abstracts (ASSIA) | 26 |
| S31 | “Supervised housing” | Applied Social Sciences Index & Abstracts (ASSIA) | 71 |
| S32 | “Sheltered accommodation” | Applied Social Sciences Index & Abstracts (ASSIA) | 422 |
| S33 | [S30] OR [S31] OR [S32] | Applied Social Sciences Index & Abstracts (ASSIA) These databases are searched for part of your query. | 516 |
| S34 | [S18] OR [S23] OR [S29] OR [S33] | Applied Social Sciences Index & Abstracts (ASSIA) These databases are searched for part of your query. | 11657 |
| S35 | [S14] AND [S34] | Applied Social Sciences Index & Abstracts (ASSIA) | 6783 |

| | | | |
|-----|-------------------------|---|--------|
| | | These databases are searched for part of your query. | |
| S36 | “experiences” | Applied Social Sciences Index & Abstracts (ASSIA) | 179841 |
| S37 | “support” | Applied Social Sciences Index & Abstracts (ASSIA) | 325300 |
| S38 | “Support experiences” | Applied Social Sciences Index & Abstracts (ASSIA) | 232 |
| S39 | [S36] OR [S37] OR [S38] | Applied Social Sciences Index & Abstracts (ASSIA) These databases are searched for part of your query. | 400577 |
| S40 | [S34] OR [S39] | Applied Social Sciences Index & Abstracts (ASSIA) These databases are searched for part of your query. | 403842 |
| S41 | [S35] AND [S40] | Applied Social Sciences Index & Abstracts (ASSIA) These databases are searched for part of your query. | 6783 |

One Page Summary of Proposed research

a. Topic: The experiences of people with learning disabilities in supported living settings:
focused ethnography

b. Background

Many adults with learning disabilities in health care units have and continue to be placed in supported living to live independently. While there are successful learning disability community placements, not all have registered expected success. First-hand experiences of individuals involved in community placements in supported living remain under-researched.

c. Purpose of the study

To explore and describe the experiences of those in supported living in learning disability community placements in Xxxx .

d. Research Question

What are the support experiences of service users in supported living in Xxxx ?

e. Research design

Qualitative design: focused ethnography.

f. Participant permission and recruitment

Participant permission was obtained from the local management of the supported living service. Purposive sample of at least thirty participants (five managers of supported living, 10 support workers, six service users) from supported living units in Scotland.

g. Sampling: purposive/snowball

h. Data collection: semi-structured interviews, participant observations, field notes and

reflexives.

- i. Data analysis: thematic analysis.
- j. Ethical approval: Xxxx University Ethics Committee in England and the local Research Ethics Committee (South-East Region XXXX) in Scotland.
- k. Research findings and dissemination.

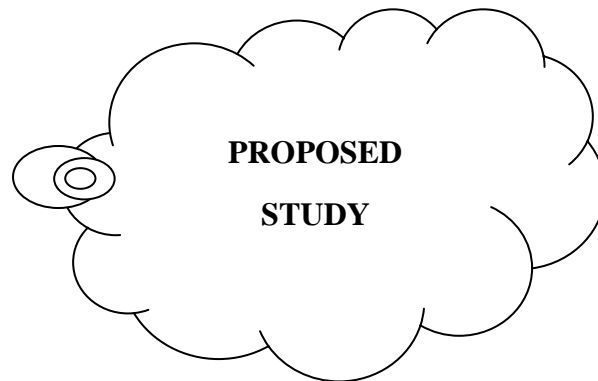
Participants, supported living providers' management, relevant NHS Lothian practitioners

- l. Significance of the study

Contribution of insights into support experiences of people with learning disabilities towards a nuanced understanding and improving their support in supported living settings.

**SHARE
YOUR EXPERIENCE OF SUPPORT IN
SUPPORTED LIVING**

JOIN THE PROPOSED STUDY



SPEAK TO STAFF TO CONATCT

Name: Xxxxx xxxx



Mobile: xxxx




Email: xxxxxxxxx

Appendix G: Newsletter for service users

| | |
|--|---|
| <p>OUR LEARNING DISABILITIES NEWSLETTER</p>  | |
|  | <p>WE WELCOME YOU TO OUR USUAL NEWSLETTER</p> |
|  | <p>WE INVITE YOU TO NOMINATE THE SUPPORTED LIVING UNIT YOU KNOW</p> |
|  | <p>TO TAKE PART IN A STUDY ABOUT OUR EXPERIENCES IN SUPPORTED LIVING</p> |
| <p>Xxxx xxx</p> | <p>IF YOU HAVE ANY, PLEASE GIVE THE NAME TO YOUR MANAGER, WHO WILL TELL THE INVESTIGATOR FELLEX</p> |
| <p>Name: Xxxx xxxx</p> | |
| <p>xxxx xxxx xxxx</p> | <p>xxxx</p> |
| <p>xxxxxxx</p> | |

Appendix H: Individual invitation letters-service users

| | |
|--|--|
| An invitation to take part in the research study | |
| <p>Picture of a university Here</p> | <p>My name is Fellex. I am a student at Xxxx University in England.</p> |
|  | <p>I kindly invite you to take part in a study about life in your home.</p> |
|  | <p>I am interested in learning more about your events and what you do in your home. I will talk and see you being supported by your staff.</p> |

| | |
|---|---|
|  | <p>This will take place on an agreed date and time in your home for four months in 2021.</p> |
|  | <p>Please find more information on the study. Please take time to read the sheet carefully. You can ask the staff for help with reading. If you agree, please complete the form and return it by first-class mail to the address below by April 30, 2019.</p> |
|  | <p>Xxxx xxxx xxxx xxxx xxxx</p> |

| | |
|--|--------------------------------------|
| | Xxxx xxxx xxxx Xxxx |
|--|--------------------------------------|

I will be happy to answer any questions you might have

I will have and give you more information if needed.


Thank you for your support.

Yours faithfully

Xxxx xxxx (researcher)

Introduction



I am Fellex. I am a learning disability nurse. I work in Edinburgh.

My school  is Xxxx University in England. I would like to know how things are going in your house.

Purpose of the study

I would like to tell you about things in your  house, how things are like every day.

Why have I been asked to take part?


You have been asked to take part because you live in. You also know what it is to be supported by staff   .





Do I have to take part?

You only need to take part in this study if you want to.


If you do not want to, that is fine. If you choose to take part, your staff who knows you well will tell me. I will then arrange to visit you several times at your home and see where you live. Both times should be good for you.

What will happen during the study?


On this visit, I will also stay for a while. I will see how things work in your house . I will write things down.


I will talk to others in different   houses. I will come back to see you. I may visit you up to five  times during the study. I will thank  you for taking part.

What happens if I do not want to take part?













You only need to take part in this study if you want to. If staff and I see that you do not want to be seen, no one will make you change your mind. If you say yes, tell your change of mind anytime. If you feel worried , the staff will tell me anytime. If you want to stop being seen by me in your house, then that is fine, and no one will mind.

What happens with my information?

Everything seen by me will be kept safe. I write  it down, no one will know your name or where you live. You can choose a name for yourself for the project. Or you can make up one for yourself.

I keep all the project information. I keep it at my school locked in a computer . The computer has a password that I only know. After the study, information is kept for teaching others.

What did you like about taking part in the study?



Talking about things you like and those you want changed. You have the chance to talk about how you feel  . What you and other **people**      say will be very helpful. Lots of people like nurses  , doctors , social workers, and care staff  . It will help them understand how you live. This may help them do things differently.

I will write a report about what I found out. It will be shared with lots of other people in Xxxx. People can all learn things about your homes. No one will know you have taken part.




Who has looked at the study?

Two groups of people have looked at this study.

The Ethics Committee in Xxxx and

one in England at my school . They help see if the project is done properly. They make sure that you are treated well  if you take part.

What will happen to the information when the study is over?

Information will be kept safely in my school  for a few years . It will then be destroyed afterwards .

Who is doing the project?

I have my teachers   from my school . They keep me right with my study.

What do I do now?

Look back on taking part as an opportunity for you as a person. Think about whether you would want to take part again in the future.

How long will the study last?

It will take two more years from 2021 📅. I will come to report what I have found out in January 2023 📅.

What happens when the study ends?

I will give you certificates for taking part in the study. I will thank 🙏 you.

How will the results of the research get to me?

I will give you what I found out in easy-read reports.

What if there is a problem?

If you want to contact me, ask the staff to telephone me. I will speak to you. Staff have my telephone numbers.

THANK YOU FOR READING

Appendix J: Consent Form (Service users)

Talking about my life in supported living

My Name _____

Please tick each box

Yes/ No

- | | | | | |
|---------------|--|--|--|--|
| 1. | I can say that I have read and understood what I will do in the study, and I can ask questions if I do not understand. | <table border="1" style="display: inline-table; border-collapse: collapse;"> <tr> <td style="width: 30px; height: 25px;"></td> <td style="width: 30px; height: 25px;"></td> </tr> </table> | | |
| | | | | |
| 2. | I am happy that my questions about the study have been answered, and I may ask more if I have any | <table border="1" style="display: inline-table; border-collapse: collapse;"> <tr> <td style="width: 30px; height: 25px;"></td> <td style="width: 30px; height: 25px;"></td> </tr> </table> | | |
| | | | | |
| 3. | I agree to have my talk to the staff recorded for the study | <table border="1" style="display: inline-table; border-collapse: collapse;"> <tr> <td style="width: 30px; height: 25px;"></td> <td style="width: 30px; height: 25px;"></td> </tr> </table> | | |
| | | | | |
| 4. | I am free to leave the study without giving a reason or answering any questions, without anything happening to me | <table border="1" style="display: inline-table; border-collapse: collapse;"> <tr> <td style="width: 30px; height: 25px;"></td> <td style="width: 30px; height: 25px;"></td> </tr> </table> | | |
| | | | | |
| 5. | I agree to be in the study without anyone mentioning my name | <table border="1" style="display: inline-table; border-collapse: collapse;"> <tr> <td style="width: 60px; height: 25px;"></td> </tr> </table> | | |
| | | | | |
| 6. | I agree to be in the study as set by the staff | <table border="1" style="display: inline-table; border-collapse: collapse;"> <tr> <td style="width: 30px; height: 25px;"></td> <td style="width: 30px; height: 25px;"></td> </tr> </table> | | |
| | | | | |
| 7. | It is all right for staff to use what I said for future learning | <table border="1" style="display: inline-table; border-collapse: collapse;"> <tr> <td style="width: 30px; height: 25px;"></td> <td style="width: 30px; height: 25px;"></td> </tr> </table> | | |
| | | | | |
| My Name _____ | My signature _____ | <table border="1" style="display: inline-table; border-collapse: collapse;"> <tr> <td style="width: 30px; height: 25px;"></td> <td style="width: 30px; height: 25px;"></td> </tr> </table> | | |
| | | | | |

Date _____

Staff Name _____ Staff Signature _____ Date _____

Appendix K: Invitation letter-CSWs & SCSWs

Xxxx xxxx

xxxx xxxx xxxx

Xxxx xxxx xxxx

.....

Dear Sir/Madam

Invitation:

I kindly invite you to take part in a research study on experiences for people with learning disabilities in supported living in Scotland.

I am a part-time PhD student with Xxx University and a full-time learning disabilities nurse with **Xxxx xxxx xxx xxxx**. I am interested in learning disabilities community placement of adults with learning disabilities in supported living, and this research is also a requirement for my PhD qualification.

Your role will be important to the success of this study. You will share your views on the experiences of residents you support. You will also be observed by the investigator while supporting your residents.

There will be at least five visits to your respective supported living during the study. Visits will include familiarisation, for interviews, participant observations, feedback on results, thanksgiving, and termination of the study. The visits will span over 12 months, typically three months apart, following each data collection stage. Your volunteer role will be anonymised and held in strict confidentiality.

Do not hesitate to ask any questions regarding this study. I hope my request will be accepted. I thank you.

Regards

Xxxx xxxxx (Researcher)

Appendix L: Invitation Letter-Intermediaries

Xxxx xxxx

xxxx xxxx xxxx

Xxxx xxxx xxxx

.....

Dear Sir/Madam

Invitation:

I kindly invite you to volunteer as an intermediary in a research study on the experiences of people with learning disabilities in supported living in Scotland.

I am a part-time PhD student with Xxxx University and a full-time learning disabilities nurse with Xxxx xxxx xxx xxxx. I am interested in learning disabilities community placement of adults with learning disabilities in supported living, and this research is also a requirement for my PhD qualification.

Your role will be important to the success of this study. You will assist selected residents with reading and explaining the study using simple, layman's language.

There will be at least five visits to your respective supported living during the study. Visits will include familiarisation, for interviews, participant observations, feedback on results, thanksgiving, and termination of the study. The visits will span over 12 months, typically three months apart, following each data collection stage. Your volunteer role will be anonymised and held in strict confidentiality.

Do not hesitate to ask any questions regarding this study. I hope my request will be accepted.

Thank you.

Regards

Xxxx xxxxx (Researcher)

Appendix M: Information Sheet-Intermediaries, CSWs & SCSWs

Topic

The experiences of people with learning disabilities in supported living

Introduction

My name is Fellex Mediseni, and I am a PhD student in the Faculty of Health and Wellbeing at Xxxx University, undertaking a research study.

Purpose of the study

I would like to describe the experiences of people with learning disabilities in supported living.

Why have I been invited?

You have been invited as a member of staff with relevant experience in working with adults with mild learning disabilities in supported living settings. You will explain and clarify the study to some of the selected participants. You will be informed about dates and times for the interviews, participant observations and meetings.

During the study, the investigator will interview selected participants and observe them as their support staff supports them. Your assistance will be before and after the data collection only. The semi-structured interview will be up to sixty minutes or longer. This will take place in a private room at your workplace, conveniently located for participants. The last research visit will be feedback on results, thanksgiving, and termination of the study.

What are the possible benefits of taking part?

There is no payment, but the study's literature and findings will be useful towards understanding the needs of the service users in supported living settings in Scotland.

Who has reviewed the study?

The local Research Ethics Committee (South-East Lothian) in Scotland and the Xxxx University Ethics Committee

Who is conducting the research?

Fellex Mediseni, a PhD student, is undertaking this study. He is supervised by a staff team from the Health and Well Being faculty of Xxxx University and supported locally in Scotland

by the Chief Nurse, Research and Development.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the investigator, who will do his best to answer your questions. If you are unable to resolve your concern or wish to make a complaint regarding the study, please contact the relevant local Research Ethics Committee (South-East Lothian) in Scotland or the **Xxxx** University Ethics Committee. Thank you.

Your faithfully

Xxxx xxxxx (researcher)

Appendix N: Interview Schedules

Interview Schedule- service users, care support workers & AC&SMs

Time of interview:

Date:

Place:

Interviewee:

Position of interviewee:

Introduction

- Self-introduction by the interviewer
- PhD study
- Courtesy of Faculty of Health and Wellbeing, Xxxx University
- Topic and aim of the research.
- Purpose, procedure, and duration of the semi-structured interview
- Obtain consent for participation and recording interview, use of data collected, reassure confidentiality and voluntary participation,

Time allocation for the interview

Service Users

- i. Do you enjoy living here?
- ii. Have you lived here long?
- iii. Who are your friends?
- iv. What sort of things do you do each day in this place?
- v. What is the best thing you like doing with staff?
- vi. What do you like doing on your own in the house?
- vii. What do you like most about being here?
- viii. How do you get staff to help you?
- ix. Are you listened to by staff?

- x. How do you feel about having staff in your home?
- xi. Is there any difference you see between the earlier house and this one?
- xii. Prompt: If so, what is it?
- xiii. Do you have anything to add about your life in supported living?
 - a. Prompt: Something you might want to say.

Care Support Workers

- i. How long have you been in this post?
- ii. What does your job involve?
- iii. What do you think is your key role in relation to the service users` experiences?
- iv. What are your views of your residents?
- v. How do you think you shape the experiences of the service users under your support?
- vi. What do you think is your key role in relation to the residents` experiences?
- vii. What do you think facilitates your role from day to day?
- viii. What are your views of the experiences of the residents under your support?

AC& SMs

- i. How many residents do you have here?
- ii. Which groups live in your supported living?
- iii. Is it a social, voluntary, and privately owned organisation?
- iv. Which key support policies or frameworks guide your support to residents?
- v. What could you say about the support systems and process of your residents in your supported living?
- vi. How do support systems and processes promote residents` experiences?
- vii. How is supported living commissioned?

viii. What are your views on your role in the experiences of residents in supported living here?

Closing the interview

- Interviewer informs of ending the interview.
- Offer an opportunity to address any relevant issues or ask any questions.
- Inform of the approximate data process and feedback on the results of the study

Participant Consent Form

Experiences for people with learning disabilities in supported living settings: focused ethnography.

Name _____

Please answer the following questions by ticking the response that applies: Yes/No

- 1. I confirm that I have read and understood the participant information sheet and can ask questions.
- 2. My questions about the study have been answered to my satisfaction, and I understand that I may ask further questions at any point.
- 3. I agree for my interview to be audio-taped for transcription.
- 4. I understand that I am free to withdraw from the study within the time limits outlined in the Information Sheet, without giving a reason for me withdrawal or to decline to answer any questions in the study without any consequences for my future treatment by the researcher.
- 5. I agree to provide information to the researchers under the conditions of confidentiality set out in the Information Sheet.
- 6. I wish to participate in the study under the conditions set out in the Information Sheet.
- 7. I consent to the information collected for this research study, once anonymised (so that I cannot be identified), to be used for any other purpose for research purposes.

Participant's Signature: _____

Participant's Name (Printed): _____ **Date:** _____

Researcher's Signature _____ **Researcher's Name (Printed):** _____

Date _____

Appendix P: Observations Notes Form

| <u>Observation Notes Form</u> | | |
|----------------------------------|---|-------------------|
| Participant: | | |
| Date: | | |
| Start Time: | | |
| Place of observation: | | |
| Observer: | | |
| No of days spent in observation | | |
| No of hours spent in observation | | |
| Time | Activities | Descriptive Notes |
| | Setting: Specific facts, numbers, details of what happens at the site | |
| | Sensory impressions: sights, sounds, textures, smells, taste | |
| | Personal responses to the fact of recording field notes | |
| | Specific words, phrases, summaries of conversations, and insider language | |
| | Questions about people or behaviours at the site for future investigation | |
| | Page numbers to help keep observations in order | |
| Jottings | | |
| Analysis | | |
| Reflection | | |

Appendix Q: Field Notes Form

| <u>Field Notes Form</u> | | |
|---|---|-------------------|
| Participant: | | |
| Date: | | |
| Start Time: | | |
| Place of observations: | | |
| Observer: | | |
| No of days spent in the field | | |
| No of minutes/hours spent in observations | | |
| Time | Activities | Descriptive Notes |
| | Setting: Specific facts, numbers, details of what happens at the site | |
| | sights, sounds, textures, smells, | |
| | Personal responses to the fact of recording field notes | |
| | Specific words, phrases, summaries of conversations, and insider language | |
| | Questions about people or behaviours at the site for future investigation | |
| | Page numbers to help keep observations in order | |
| Jottings | | |
| Analysis | | |
| Reflexives | | |

Appendix R: Certificate of Participation

Certification of Participation



Thank 🙏 you to *PARTICIPANT'S NAME*

For taking part in the study on Supported Living in 2022

Signature here.....

Signature.....

Researcher: Fellex Mediseni

Date.....

Date.....

Appendix S: Incident Intervention and Reporting Form

Incident Intervention and Reporting Form

Protocol Title _____

Protocol Number _____ Site Number _____

Participant ID _____

1. Onset Date: _____ (dd/mm/yyyy)

2. End Date: _____ (dd/mm/yyyy)

3. Location of adverse incident (e.g. at study site or elsewhere):

4. Was this an unexpected adverse incident? Yes No

5. Brief description of participant with no personal identifiers:

Sex: Female Male Age: _____

6. Adverse Event Term(s):

7. Brief description of the nature of the adverse incident (attach description if more space needed)

8. Category of the adverse incident event:

date _____

Circumstantial _____ Psychological _____

Physical _____ Hospitalisation _____

disability / incapacity _____ other: _____

9. Intervention type:

Medication or redirection: specify _____

Therapy: Specify: _____

Counselling: Specify: _____

Behavioural/Lifestyle: Specify:

10. Relationship of incident

Possible (may be related to intervention)

Definite (clearly related to intervention)

11. Was study intervention discontinued due to incident? Yes No

12. What medications or other steps were taken to manage adverse incident?

13. List any relevant background, previous medical history, including pre-existing medical conditions

14. Type of report:

Initial

Follow-up

Final

Signature of Principal Investigator: _____ Date: _____

Appendix T: Council Provider Ethical Approval

City Provider Ethical approval

“H:\FMediseni\Personal\Study material\ Xxxx xxxx Ethical Approval
Research_Access_Form.docx”

Xxxx

Xxxx xxxx Xxxx xxxx via xxxxxxxxxxxx 23 Aug
2021,
09:45 (3
days
ago)

to FELLEX, Xxxx, Xxxx, Xxxx, Xxxx, Xxxx, Xxxx

Hi Fellex,

Thanks for your email.

The people who use our service are supported in their tenancies across xxxx; we don't have units as such; however, we are happy to help if we can.

I've copied in the 6 Assistant Managers responsible for supervising staff and overseeing people's support packages. If you liaise with them directly, they can support you with the help of their Senior staff to set up meetings, etc. They also have a wealth of knowledge on which service users best meet your criteria for research purposes.

If I can be of any help, please let me know.

Kind Regards

Xxxx xxxx

Xxxx xxxx Xxxx xxxx

Xxxx xxxx xxx xxxx

Xxxx xxxx

Xxxx xxxx

Xxxx xxxx

Tel: xxxx xxxx xxxx xxxx

Mob:xxxx xxxx

| Assistant Manager | Email addresses |
|--------------------------|------------------------|
| 1. Xxxx xxxx | Xxxx.Xxxx xxxx |
| 2. Xxxx xxxx | Xxxx.Xxxx xxxx |
| 3. Xxxx xxxx | Xxxx.Xxxx xxxx |
| 4. Xxxx xxxx | Xxxx.Xxxx xxxx |
| 5. Xxxx xxxx | Xxxx.Xxxx xxxx |
| 6. Xxxx xxxx | Xxxx.Xxxx xxxx |

Appendix U: SHU Ethical Approval

SHU Ethics Approved ER33153588.

Converis-Ethics Review–Approval with Advisory Amendments

External

converis@shu.ac.uk

26 Nov

2021, 14:40

to Fellex

Status change comment

DO NOT WRITE ANYTHING IN THIS NOTES BOX AS IT CAN BE SEEN BY ALL OTHER USERS. Proceed to select the workflow status and click Done.

Dear Fellex

Title of Ethics Review: Experiences of adults with mild learning disabilities in supported living in Scotland

Ethic Review ID: ER33153588

The University has reviewed your ethics application named above and can confirm that the project has been approved.

The following advisory amendments were suggested, which you may wish to address:

If this is a second resubmission, the Lead reviewers' comments will appear below:

You are expected to deliver the project in accordance with the University's research ethics and integrity policies and procedures <https://www.shu.ac.uk/research/ethics-integrity-and-practice>.

As the Principal Investigator, you are responsible for monitoring the project on an ongoing basis and ensuring that the approved documentation is used. The project may be audited by the University during or after its lifetime.

Should any changes to the delivery of the project be required, you are required to submit an amendment for review.

If you have a query regarding your application, please contact your Faculty Ethics

Administrator in the first instance.

XXX - xxxx xxxx

XXX - Xxxx xxxx

XXX - xxxx xxxx

XXX - Xxxx xxxx

Wishing you success with your study

Kind regards,

Ethics Research Support