“A strange, grey area”
Care relationships between support staff and adults with a learning disability in long-term social care residential settings in England

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List of Thesis Conventions

[…] Entails an edit I have made in a quote, oftentimes to shorten the quote.

Footnotes are used in this thesis to provide additional context and analysis; I encourage the reader to engage with these notes.

Navigation Pane is highly recommended if this thesis is being read digitally. All headings have been tagged, and using the navigation pane makes navigating the different sections of the thesis much easier.

List of Abbreviations

AACODS Checklist Authority, Accuracy, Coverage, Objectivity, Date, Significance checklist (Tyndall, 2010)

ABA Applied Behaviour Analysis

APA American Psychological Association

CHAIN Network Contact, Help, Advice and Information Network

CQC Care Quality Commission

CRD Centre for Reviews and Dissemination

DBS Disclosure and Barring Service

GDPR General Data Protection Regulation

HRA Health Research Authority

IRAS Integrated Research Application System

JBI Checklist JBI Critical Appraisal Checklist (McArthur et al., 2015)

KAR Kent Academic Repository

MMAT Mixed Methods Appraisal Tool (Hong et al., 2018)

NHS National Health Service

NICE National Institute for Health and Care Excellence

NIHR National Institute for Health and Care Research

NIHR SSCR National Institute for Health and Care Research, School for Social Care Research

NIHR ENRICH National Institute for Health and Care Research, Enabling Research in Care Homes

NIHR CRN National Institute for Health and Care Research, Clinical Research Network

NIHR CPMS National Institute for Health and Care Research, Central Portfolio Management System

PBS Positive Behaviour Support

PhD Doctor of Philosophy

SPIDER model Sample, Phenomenon of Interest, Design, Evaluation, Research type (Cooke et al., 2012)

UK United Kingdom

USA United States of America

Note about Terminology

In this thesis, I adopt NHS guidelines (n.d.) and I use the term 'people with a learning disability' as opposed to 'people with learning disabilities', as people only have one learning disability each. Moreover, I employ person-first (i.e., people with a learning disability) instead of identity-first language (i.e., learning disabled people). There seems to be a preference for person-first language in the wider learning disability research (e.g., Liebowitz, 2015; Wehmeyer et al., 2000) as well as among relevant academic journals (e.g., Journal of Applied Research in Intellectual Disabilities), self-advocacy groups, and learning disability organisations (e.g., Mencap). I have also personally witnessed this preference during my care work years and in my professional involvement in other research projects where people with a learning disability have active roles. Nonetheless, I am mindful of the various debates around person-first versus identify-first language and people's preferences, for example, although not related to people with a learning disability, see Keates and colleagues (2024) for more information about language preferences among autistic people, as well as I also fully appreciate the argument that person-first language may increase social stigma (see Gernsbacher, 2017, for further discussion). Ultimately, using person-first language is a decision, one I perceive as informed, whilst acknowledging the limitations that every decision may come with.

Acknowledgements

"Thro' many dangers, toils, and snares, I have already come" writes John Newton in his hymn *Amazing Grace* published in 1779.[1] I often find myself repeating these lyrics in my head as my PhD is coming to an end. I have not experienced any real "dangers, toils, and snares" during this PhD,[2] at least in comparison with those that people have faced throughout history or are still facing. Nevertheless, I relate to these lyrics, they remind me of the journey, be it a doctoral or life journey, and dealing with its everchanging nature. I have had a happy doctoral life, and this is because I have had the privilege of having other people by my side. Their emotional, practical, epistemic, political, and material support was, directly and indirectly, key to completing this project.

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[1] For the lyrics and the historical background of the hymn, see: https://en.wikipedia.org/wiki/Amazing_Grace
[2] I started my full-time PhD in January 2021 and submitted this thesis in early January 2025.

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Abstract

Relationships are dynamic and situated at the core of human life. In England, a significant number of support staff (e.g., support workers) and adults with a learning disability provide and receive care in long-term social care residential settings such as care homes, supported living, or other residential arrangements. In these settings, support staff and residents encounter and build relationships with each other in the vastness of everyday life and care is surrounded by high staff turnover, lack of funding, considerable staff responsibilities, and a fragmented social care system. Unlike other relationships (e.g., therapy), research exploring learning disability care relationships seems to be a relatively neglected area. This has potential theoretical and care practice implications. This doctoral project aimed to explore care relationships between support staff and adults with a learning disability in long-term social care residential settings in England and further our understanding of what makes such relationships positive. To this end, I posed four research questions that explored conceptualisations of care relationships, relational processes and practices, barriers to and facilitators of positive care relationships, and the impact of relationships. Three studies were conducted as part of this research project. The first study, a systematic literature review that focused on the social care paradigm in the United Kingdom, provided valuable insights into learning disability care relationships and served as a compass for future empirical research. The second study built on the systematic literature review and employed a qualitative design to explore the views and experiences of support staff regarding care relationships. Valuable insights were offered framing the care relationship as a "a strange, grey area" and situating it in the wider material and ideological reality, whilst emphasising the range of relational skills, processes, and practices that support staff use and engage in, as well as the transformational impact of positive care relationships and the detrimental effects of lacking them. Finally, the third study built on the previous two studies and

employed an ethnographic design seeking to examine care relationships not only through people's verbal accounts but also in real-time, as they occur in the residential setting. Through the analysis, the care relationship was framed somewhat as an act of balance between conundrums and was located in the (care) home and its (care) home pragmatics. Moreover, the invisible process of staff and resident connection and the little everyday moments it entails became more concrete, and, once more, the powerful impact of care relationships on the lives of staff and residents was highlighted. Lastly, the research project draws overall conclusions about care relationships by assembling the three studies whilst exploring the threads that weave through this research as a whole, before discussing research impact and suggestions for future research, care practice, and policy.

Chapter 1: Introducing the Research Project

1.1 From the frontline

In Spring 2022, I published a short piece reflecting on my journey from the frontline of care work to research. There I wrote:

> I joined the UK health and social care frontlines in early 2013 after landing a job as a support worker. Being a young migrant from a country with ambiguous healthcare structures and a slowly developing social care system, I was rather impressed with my new role. I had a Bachelor's degree in Psychology,[3] some professional experience in my field, and a strong yet unclear interest in supporting people in their everyday lives rather than through scheduled therapy sessions. However, I did see therapeutic value in daily tasks and my new role helped me to articulate this further. This was one side of the coin, the other was having one of my superiors telling me something like, "you are too qualified, this is just care work." (Mamolis, 2022, p. 16)

The excerpt above serves two purposes. Firstly, it highlights that my interest in care relationships and, consequently, the formation of this research project are deeply rooted in my experiences and observations as a support worker. Secondly, it somewhat contrasts the rich relationships that support staff and residents can build with what my superior, who I am certain meant well, said back in 2013, demonstrating some of the contradictions and complexities that surround care work and care relationships, at least in the UK. In other words, it serves as a first indication of the care relationship as a "strange, grey area".

[3] To be precise, it is a Bachelor's degree in Philosophy, Pedagogy, and Psychology, majoring in Psychology.

But, firstly, what do I mean by terms such as 'learning disability', 'support staff', 'social care', or 'care relationships', and, most importantly, how does dwelling into these terms help us situate this research further?

1.2 Dissecting the thesis title: Contextualising learning disability care relationships

Approximately 1.2 million adults in the UK have a learning disability (Mencap, n.d.*a*). Of those people, over 950.000 live in England (Mencap, n.d.*a*). A learning disability entails "a reduced intellectual ability and difficulty with everyday activities – for example, household tasks, socialising or managing money – which affects someone for their whole life" (Mencap, n.d.*b*). Learning disabilities begin before adulthood, exist on a scale (i.e., mild, moderate, severe or profound), and have lasting developmental effects (Department of Health and Social Care, 2001). In England, and the UK in general, the term 'learning disability' is preferred to 'intellectual disability', with the latter being more common in Ireland, Canada, the USA, Australia, and New Zealand (Gates & Mafuba, 2016). However, it is not uncommon for individuals or organisations based in the UK to use both terms interchangeably.[4] A 'learning disability' should not be confused with a 'learning difficulty' (e.g., dyslexia, dyscalculia) as the latter does not affect general intellect (Mencap, n.d.*b*).

Throughout most of the 19th and part of the 20th century, large scale institutions, called asylums, were established across the UK as the typical facilities to meet the needs of people with a learning disability, as well as other groups, often accompanied by relevant Acts (e.g., the County Asylums Act in 1845 that required asylum registration; Becker, 2020).[5] Overall,

[4] For example, the Tizard Centre uses both terms on its website: https://www.kent.ac.uk/psychology/tizard

[5] In this section, I provide some historical context of social care in the UK in order for the reader to gain a more situated understanding of this research project. Nonetheless, as a thorough historical overview of social care systems and relevant policies for people with a learning disability in the UK is beyond the scope of this project, I would encourage the reader to consider Becker (2020) and specifically Chapter 3 of their doctoral dissertation as well as Atherton (2007), for a detailed historical examination.

the legacy of asylums is controversial and these institutions are considered to have contributed to the social exclusion of people with a learning disability (Mansell et al., 2007).

From the 1950s onwards, the interplay of several factors, ranging from advancements in research around social stigma (Atherton, 2007) to the influence of social movements, such as the independent living movement or the anti-psychiatry movement (Mansell et al., 2007), led to a paradigm shift emphasising disability rights, deinstitutionalisation, care in the community, and social inclusion of people with a learning disability, among other groups. Relevant UK Acts and policies followed to establish this shift systemically, with the Mental Health Act in 1959 being key in setting a plan to shut down large scale institutions and create care services based in the community (Becker, 2020).

Consequently, adult social care in England, and the UK, was born, encapsulating the support provided to people with a learning disability as well as numerous other groups, for instance, older people, people with mental health conditions or people with physical disabilities, to live fulfilling lives in the community (Foster & Harker, 2024). Over the years, adult social care has been shaped by various policies and White Papers (e.g., the Caring for People White Paper in 1989; the Putting People First policy in 2007; Becker, 2020) stirring its ideology and practice towards services that put the person who requires support at the centre of everything. Scandals related to neglect and abuse have also shaped adult social care. For instance, the incidents of mistreatment and abuse documented in 2011 at Winterbourne View, a specialist service for people with a learning disability and behaviours that challenge located in the southwest of England, sparked various policy responses ranging from changes in the domains that the CQC can regulate in care services (e.g., assessing care culture, making unannounced inspections), to further progress in relation to moving people with a learning disability away from long-term hospitals and into community-based settings (Department of Health and Social Care, 2012; Halladay & Harrington, 2015).

In adult social care, the support that people receive can range from help with personal care or domestic tasks, to offering activities in settings such as daycare centres (Foster & Harker, 2024) and everything in between. The formal social care that an adult receives can be funded privately by the person themselves or other significant people in their life, or publicly by local councils (Foster & Harker, 2024), which obtain their budget through government grants or local social care taxes (Forrester-Jones et al., 2021). Nonetheless, unlike the NHS, publicly funded social care is not available to all and is subject to a means test to assess the person's financial eligibility (Forrester-Jones et al., 2021). The majority of adult social care providers (i.e., 79%) in England are independent sector employers, with approximately 77% labelled as 'private' and 23% as 'voluntary' (Skills for Care, 2021). Residential services fall under adult social care (Foster & Harker, 2024). The term 'long-term social care residential setting' encompasses spaces that people use for a long period, if not permanently, and essentially perceive as their home, in contrast to short-term residential settings such as respite services (Mamolis et al., 2024). Residential settings are based in the community and include residential care (e.g., care homes), supported living, domiciliary care, and other residential arrangements (Mamolis et al., 2024). Approximately, 500.000 adults with a learning disability, including autistic adults, in England receive support in residential or domiciliary care settings (Skills for Care, 2021).

Residential services appear to be the primary employer of the support workforce (Skills for Care, 2021). The support staff role is common in adult social care, with around half a million workers in England providing direct care to adults with a learning disability and/or autism (Skills for Care, 2018). The support workforce is diverse with various duties and responsibilities (Rycroft-Malone et al., 2014). Support staff roles are poorly defined (Manthorpe et al., 2010) and there is a high volume of different job titles describing this group of practitioners (Cavendish, 2013), with 'support worker', 'care worker', or 'personal assistant'

being common (Mamolis et al., 2024). Throughout the thesis, I use the umbrella term ‘support staff’ to encompass all these different job titles. Moreover, with this term, I also encapsulate staff in management positions in residential settings (e.g., home managers, team leaders) as they frequently come into these positions as a career progression from direct care roles and, in addition to their management duties, they often provide support to residents to meet the services’ needs (e.g., staff turnover, high support needs of residents). Support staff “foster independence and provide assistance for a service user in areas of ordinary life such as communication, employment, social participation and may take on secondary tasks in respect of advocacy, personal care and learning” (Manthorpe et al., 2010, p. 317). They are the practitioners who are:

> providing face-to-face care and other support of a personal or confidential nature to service users in a variety of settings. However, crucially, they do not hold qualifications accredited by a professional association and are not typically formally regulated by a professional body. (Saks, 2020a, p. 1)

Relationships are dynamic and situated at the core of human life providing the context of behaviour (Reis et al., 2000). A core and necessary component of relationships is social interaction between relationship partners, and examining interactions is certainly an important avenue towards understanding relationships, as the two are connected. Nonetheless, despite interactions influencing and being influenced by relationships, exploring relationships is more than examining interactions and equating the two would be incorrect (Reis et al., 2000). Interactions can be episodic (e.g., a fleeting interaction) and will not always lead to a relationship, whereas relationships are considered more complex terrains encapsulating emotion, a sense of belonging, as well as extended periods of time whereby the interacting parties have a strong influence on each other’s behaviour (Reis et al., 2000). Moreover, relationships are constantly evolving and follow developmental courses; they have beginnings,

middles, and ends, and their terms can be challenged and restored (Reis et al., 2000). As there are different types of relationships (e.g., romantic, parent-child, employer-employee), throughout the thesis, the term 'care relationship' refers to the interpersonal professional relationship between support staff and residents with a learning disability. Interpersonal relationships are one of the eight domains of the quality of life framework (Shalock et al., 2002), used widely in the UK to assess outcomes for people with a learning disability (Department of Health and Social Care, 2001). It is no surprise that positive care relationships entail positive outcomes for adults with a learning disability (Broussine, 2012) and support staff (Hastings, 2010), are at the core of person-centred care and practice (McCormack et al., 2012), and are key to determining the quality of care provided in learning disability residential settings in the UK (Bradshaw & Goldbart, 2013; Windley & Chapman, 2010).

1.3 The rationale behind this research

Apart from establishing a shared vocabulary with the reader, I hope that the section above has also highlighted that support staff and adults with a learning disability are two large populations that encounter each other regularly, primarily in residential spaces.

Support staff comprise a significant proportion of the social networks of people with a learning disability (Harrison et al., 2021). Building care relationships in long-term residential settings has something unique; in those spaces, support is not only available when people experience a crisis, instead care is constantly provided and received in the realm of everyday life, and everyday life has uncertain boundaries and is hard to define (Felski, 1999, as cited in Gjermestad et al., 2017). Drawing on my own experiences as a support worker, support with everyday life could involve almost everything; from assisting a resident to have a shower or cook a meal, to providing psychological and social support, and everything in between. Additionally, a care relationship has the potential to become a long-term relationship; as

discussed, residential settings serve as people's homes and residents oftentimes spend several years, if not their whole lives, in a setting.

Another somewhat unique aspect of care work and care relationships is the working conditions surrounding them. It is well established[6] that the UK social care system has been subjected to austerity measures, budget cuts, and chronic underfunding (Forrester-Jones et al., 2021) and its workforce has been suffering from adverse working conditions including high support staff turnover of up to 34.4% (Skills for Care, 2021), low salaries (Skills for Care, 2019), limited training opportunities (Wilberforce et al., 2017), and, despite some welcoming social visibility amidst the Covid -19 pandemic in 2020 (e.g., Clap For Our Carers initiative[7]), limited professional recognition (National Association of Care and Support Workers, n.d.).

Unlike other relationships (e.g., therapy, nursing, social work), research exploring learning disability care relationships seems to be a relatively neglected area (Hastings, 2010). This is an important gap in our knowledge with potential theoretical and care practice implications especially when taking into account 1) the importance of care relationships and their impact on staff's and residents' lives; 2) the vagueness surrounding the role of support staff as well as the size and the working conditions of the support workforce in England; 3) the number of adults with a learning disability receiving support in residential settings and the lived experience of learning disability; and 4) the uniqueness of building care relationships in the realm of everyday life in residential spaces.

Internationally, Dutch (e.g., Penninga et al., 2022) and Australian researchers (e.g., Johnson et al., 2012) have shown a particular interest in this area. In the UK, some research has looked into rapport building (e.g., Guthrie & Beadle-Brown, 2006), and there has been a

[6] For example, upon becoming the governing party of the UK in July 2024, the Labour Party's commitments regarding Health and Social Care highlighted some of the long-standing issues discussed in this section. For more information see: https://researchbriefings.files.parliament.uk/documents/LLN-2024-0036/LLN-2024-0036.pdf

[7] See https://clapforourcarers.co.uk/

focus on understanding enabling relationships in the Active Support model[8] (Baker et al., 2017; Mansell & Beadle-Brown, 2012). Despite the undeniable importance of this work, it is perhaps worth noting that some of this research may vary scope-wise (e.g., focus on children) or conceptually (e.g., treating formal and informal carer groups as one). Additionally, in the case of international research, although some similarities are certainly to be expected, findings might not always be relevant to the UK care work experience as this research is taking place in different social care systems with possibly different regulations, policies, histories, and care practices.

1.4 Aim & research questions

Overall, this project employed primarily a qualitative design[9] and aimed to explore care relationships between support staff and adults with a learning disability in long-term social care residential settings in England and further our understanding of what makes such relationships positive. By doing so, I aspired to enrich care practice, make a contribution towards improving staff and residents' lives in residential services, and provide directions for future research. Ultimately, this research project had an applied focus, with care praxis at its core. I explored an area that during my care work years, I, and I am certain some of my colleagues too, were keen to know more about whilst navigating the services and supporting the people who were using them.

To address the aim of this project, I posed four research questions:

1. What are the conceptualisations and definitions of (positive) care relationships?

[8] Active support is a model of care for people with a learning disability that emphasises participation in meaningful everyday activities (see Totsika et al., 2008, for an overview).
[9] "Research design refers to the overall plan for, and approaches to, the research you will do" (Braun & Clarke, 2022, p. 26).

2. What processes and practices underlie positive relationships, and how can disrupted relationships be restored?
3. What factors serve as barriers to and facilitators of positive care relationships?
4. What impact do positive relationships, or lack thereof, have on support staff and residents?

1.5 The structure of the thesis

This thesis comprises six chapters. Below, I provide a summary of each chapter.

Chapter 1 serves as an introduction to the research project, outlining its rationale, aim, and objectives, while also providing a way to put learning disability care relationships in perspective by looking at the wider social care context in England and the UK.

Chapter 2 situates the project theoretically, discussing the theoretical and policy frameworks that inspired and shaped the formation and execution of this research project.

Chapter 3 reports on Study 1, a systematic literature review that served as the starting point for addressing the project's aim and research questions. This study sought to explore and summarise the volume of UK research on learning disability care relationships, synthesise findings, expand knowledge, and identify directions for future empirical research.

Chapter 4 reports on Study 2, a qualitative study that used Study 1 as a compass and focused on empirically exploring the views and experiences of support staff regarding care relationships.

Chapter 5 reports on Study 3, an ethnographic study that built on Study 2 and explored care relationships in real-time, as they unfold in everyday life within the residential setting, aiming to bring together what people say and what they actually do.

Finally, **Chapter 6** brings the three studies together and explores the threads that weave through this project and what they tell us about care relationships. The impact of the project is discussed, and suggestions for research, care practice, and policy are shared before providing concluding remarks.

Summary of Chapter 1

In this chapter, I introduced the reader to the research project, its aim, and the research questions that underpin it. I also sought to provide context to ensure that the reader understands the project rationale and the need to research care relationships in learning disability residential settings in England. I contextualised care relationships by using social care statistical data, previous academic work, and personal experiences and observations from my care work years. Finally, I provided the structure of the thesis, allowing the reader to have an overview of all the chapters that comprise the thesis.

I will now discuss the ideas, assumptions, and frameworks that served as inspiration and informed the conception of this research. In other words, I will situate the project theoretically.

Chapter 2: Situating the Research Project within Theory

2.1 Introduction

This research was conducted inductively, meaning that my answers to the project's aim and research questions were grounded in and led by the information that the research participants in my primary studies and the literature in my secondary study provided. I did not take a deductive approach, namely seeking for and analysing information through the lens of a specific theory or model (i.e., top-down) for two reasons: 1) as discussed in Chapter 1, learning disability care relationships are an under-researched area and using the relatively small number of available research findings deductively felt like taking the wrong approach to further our understanding of the subject, and 2) care relationships, and, indeed, all relationships, can be experienced differently and have various meanings depending on the individuals involved in them and the historical and social context. I felt that such crucial nuance would become impossible to detect when exploring care relationships deductively.

Perhaps the paragraph above seems to contradict the title of this chapter, but in fact, it does not. An inductive approach does not mean that this research took place in a theoretical or, indeed, social vacuum. The theoretical and policy frameworks and assumptions that I will be discussing in this chapter have, directly or indirectly, inspired and shaped the formation of this project, and influenced the data analysis and my interpretations. It is important to make a distinction though. These are explanatory frameworks (e.g., Peplau's theorisation of nurse-patient relationships, 1952) and not what Braun and Clarke (2022) call philosophical meta-theory or Big Theory, namely "the conceptual ideas about data, and research that underpin everything we do" (Braun & Clarke, 2022, p. 156) or, in other words, "the 'ologies" (Braun & Clarke, 2022, p. 166), as in ontology and epistemology. "The 'ologies" are tied to my empirical studies, and to some degree to my secondary study, in a rather practical way, hence I elaborate

on them primarily in the 'Methodology'[10] sections of Study 2 and Study 3, and to some extent Study 1, reported in subsequent chapters of the thesis (i.e., Chapters 3, 4, & 5).

2.2 Theoretical & policy frameworks

Relationship frameworks

Engaging with theories of healthcare relationships has certainly shaped the scope of this research. Yet, this was a slow process that began several years before even carrying out this project. Given my academic background in psychology, positive therapeutic relationships, namely the relationship between the therapist and the client, have always been my focus, with a special interest in Carl Rogers' (1957) work on the conditions needed to establish a positive relationship and achieve therapeutic change. More specifically, Rogers emphasised relational elements such as empathy, non-judgemental attitude, genuineness and authenticity from the therapist's side, and awareness of how the client perceives the therapist, as key factors to establishing positive therapeutic relationships. These values and processes were foundational to me and still serve as a compass to this day.

Entering care work with this mindset, I eventually encountered the work of Peplau (1952), who explored similar themes but from the perspective of nurse-patient relationships. As care work has historically emerged from nursing during the professionalisation of the nursing profession in the 1990s (see Saks, 2020b, for a historical overview), Peplau's (1952) framework felt even more relevant in my practice as a support worker and in the relationships I was building with the people I was supporting. These frameworks moulded my overall thinking and sowed the seeds of what researching care relationships could look like.

[10] Methodology entails "a package of theory, method and other design elements for doing research" (Braun & Clarke, 2022, p. 4) whereas "a method is a process or tool used as part of (qualitative) research – commonly to analyse or collect data" (Braun & Clarke, 2022, p. 4). I consciously use the term 'methodology' to ensure that I also capture the theoretical, conceptual, and philosophical assumptions underpinning the research I conducted.

Nevertheless, it was the model put forward by Johnson and colleagues (2012), which describes the processes underlying positive relationships between significant others and adults with a severe learning disability in the Australian context, that brought it all together and helped me articulate and conceptualise this research project. Although Johnson and colleagues focused not only on support staff but also on friends and family members, treating everyone as one group, I found their observations around sharing the moment, connecting, feeling good, and other processes to build positive relationships, very relevant to care work practice, and I was inspired to build on this work.

Person-centredness

In the UK, person-centredness is a policy and practice paradigm that dominates the provision of care to people with a learning disability (Department of Health and Social Care, 2001). Person-centredness entails "that planning should start with the individual (not with services), and take account of their wishes and aspirations […] reflecting the needs and preferences of a person with a learning disability" (Department of Health and Social Care, 2001, p. 49). This conceptualisation was prevalent in the care services where I worked and dominated organisational policies, discourse within the services, and our care practice as support workers. That is not to say that person-centredness was always straightforward, as what was considered person-centred and what was not was also subject to each organisation's and staff member's interpretation.

Engaging with Dewing and McCormack's (2017) work was crucial to viewing person-centredness through a rather critical lens, both in my care work years and during the formation of this project. Situating their observations in UK nursing practice, Dewing and McCormack argue that the need for personhood and care applies to everyone in a service. In other words, person-centredness entails healthy relationships between organisations, practitioners, clients,

and important others (McCormack & McCance, 2016). This theorisation of person-centredness has influenced how I formulated the project's research questions (e.g., by looking at the context of care relationships through barriers and facilitators) as well as the Interview Protocol for Study 2 (see Appendix 2), for instance, by exploring the impact of care relationships not only on residents but also on support staff.

Social stigma

Social stigma can be defined as a deeply discrediting attribute that reduces the holder of the stigma in the minds of others from being a regular and whole person to a discredited one (Goffman, 1963). Moreover, stigma can be conceptualised as a process whereby labelling, stereotyping, separation (i.e., 'us' and 'them'), status loss, and discrimination co-occur in a context where power relationships also occur (i.e., social, economic, or political power; Link & Phelan, 2001). From a societal point of view, a learning disability may be perceived as a difficult difference that can potentially face aversion and social intolerance (Rogers, 2016). Although people's attitudes have certainly improved and new, more empowering systems have replaced old ones, people with a learning disability around the globe are still experiencing different degrees of stigma (Scior et al., 2020).

The concept of social stigma helped me situate people with a learning disability as a group that has historically been marginalised in many societies and reflect on whether and how social stigma plays a role in care relationships nowadays. Additionally, as discussed in Chapter 1, given the devaluation of care work in the UK, I speculated that social stigma could be a useful concept for also understanding the experiences of support staff as a workforce that is not given due recognition and, hence, is to some extent stigmatised.

Ethics of care & disability studies

Lived experience, namely "reality as it is seen and lived" (De Casterlé et al., 2011, p. 234), was at the core of this research project. I affirmed that living with a learning disability or working as support staff provides people with priceless lived expertise which encompasses the "knowledge, insights, understanding and wisdom gathered through lived experience" (Sandhu, 2017, p. 5). This emphasis on lived experience as well as the key role that the concept of care plays in my research led me, somewhat inevitably, to situate this project within the ethics of care.

The ethics of care is an umbrella term that describes a range of frameworks concerned with the nature of care. Berenice Fisher and Joan Tronto, two key care ethics theoreticians, broadly defined care as:

> a species activity that includes everything that we do to maintain, continue, and repair our world so that we can live in it as well as possible. That world includes our bodies, ourselves, and our environment, all of which we seek to interweave in a complex, life-sustaining web. (Fisher & Tronto, 1990, p. 40)

Furthermore, the two theoreticians broke down the caring process into four intertwined phases (Fisher & Tronto, 1990), namely *caring about* (i.e., attentiveness to the need for caring and who requires care), *taking care of* (i.e., taking responsibility and organising care to meet identified needs), *caregiving* (i.e., the practical execution of care tasks), and *care receiving* (i.e., the response of the person receiving care to the caregiving process). In other words, care is "both value and practice" (Held, 2006, p. 9).

Importantly, ethics of care employ a feminist approach, stemming from a reflection on care in the context of the mother – child relationship and the deconstruction of care as "women's work" (Tronto, 1998, p. 16). In principle, ethics of care frameworks are critical of

notions of autonomy and independence, highlighting instead the centrality of relationships, interdependence, and vulnerability in human life, while underlining that we all provide and depend on the care of others during our lives (Held, 2006). Ultimately, this very place of interdependence and vulnerability is a key component of our humanity (Held, 2006).

More specifically, Chrissie Rogers' (2016) care ethics model of learning disability has served as a significant influence on this project. In line with the information presented thus far in this section, Rogers explores three spheres of caring work, namely the emotional, the practical, and the socio-political, ultimately reflecting on what it means to be human and how this is related to having a learning disability. Tied to this are disability studies, a discipline that aims to reshape society's understanding of disability by taking a critical, interdisciplinary, participatory, and values-based approach (Ferguson & Nusbaum, 2012). I drew particularly on the work of Goodley and colleagues (e.g., Goodley & Runswick-Cole, 2016) who, as with Rogers (2016), reflect on learning disability and the ways it disrupts normative discourses around what it means to be human.

Ethics of care and disability studies were particularly useful whilst reflecting on paid care work, care relationships, and what learning disability social care means, as I was developing this research project as well as during data analysis.

Positionality & reflexivity

"There is no simple or pure description; we always interpret from a position – or, perhaps more accurately, an aggregate of positions", Braun and Clarke (2022, p. 214) eloquently point out. Positionality and reflexivity are intertwined, the former refers to how a researcher's identity and various positions (e.g., social class, gender, professional role) influence their research and subsequent interpretations (Jafar, 2018), whilst the latter involves reflecting on this positionality and having a general "awareness of the influence the researcher

has on what is being studied and, simultaneously, of how the research process affects the researcher" (Probst & Berenson, 2014, p. 814). More specifically, drawing on Wilkinson's (1988) analysis which I have come across through Braun and Clarke (2022), reflexivity can be *personal* (i.e., reflecting on how one's values and experiences shape knowledge production), but also *functional* (i.e., reflecting on how the research design shapes knowledge production), and *disciplinary* (i.e., reflecting on how one's academic discipline shapes knowledge production). I began Chapter 1 of this thesis by introducing the research project through a reflexive piece, and I have reflected on my care work years in previous sections of this present chapter too. It is, therefore, no surprise that positionality and reflexivity played a key role in the conception and execution of this project.

My academic background is in psychology, and I worked as a support worker for different UK care organisations, supporting primarily adults with a learning disability, mainly in long-term social care residential settings from early 2013 until early 2021, when I began my PhD. I am using the words 'primarily' and 'mainly' as I have also worked as a support worker in other care settings (e.g., NHS inpatient mental health unit) and with other groups of people (e.g., autistic young people), yet for shorter periods. I do not have a learning disability myself, nor have a significant other (e.g., family member, friend, partner) in my life who has a learning disability; therefore, my interactions with people with a learning disability and my first-hand experiences of relevant UK social care services are grounded in my support staff role. This research has its roots in those interactions, experiences, observations, and, ultimately, my background as a support staff, as well as the academic discipline from which I emerged. Moreover, as a Greek migrant, I come from a country where the social care system is only partly developed, offering limited services compared with the social care system in the UK. Instead, Greece, like other countries (e.g., Turkey; Akkan, 2021), comes from a familialist tradition, whereby the family is considered the primary source of care provision to the family

members needing it. Working in social care in the UK introduced a whole new world to me, and served as an opportunity to compare care provision with the Greek paradigm, broadening my perspective and sowing the seeds for this research. Finally, my commitment to promoting positive social change was also a key driver behind this project. Although research on its own is unlikely to enact significant social change, witnessing the devaluation of social care and the impact that this has on the lives of support staff and residents served as a motivator to develop a doctoral project that aspired to have at least some practical implications for improving care work and care relationships.

Positionality and reflexivity are employed throughout this thesis and also discussed in a more applied way in Chapters 3, 4, 5, and 6 where I tailor these concepts to the three studies I conducted and elaborate on findings across the research project.

Summary of Chapter 2

In this chapter, I discussed the reasons behind employing an inductive approach to conducting this research, whilst affirming that a non-deductive orientation does not entail theoretical or social vacuums. Then, I situated the project within several theoretical and policy explanatory frameworks, and I explained how these have inspired and shaped the formation and execution of this research.

I hope that by now, I have established a shared vocabulary with the reader and I have provided sufficient context. It is now time to discuss the studies I conducted to address the aims and research questions of this project.

Chapter 3: Study 1 – A Systematic Literature Review[11]

3.1 Introduction

My first study was a systematic literature review that served as a starting point for addressing the project's aim and research questions stated in Chapter 1, section 1.4. Through this study, I sought to investigate and summarise the volume of research on learning disability care relationships, synthesise findings, expand knowledge, and identify directions for future empirical research.

3.2 Methodology

Design

Systematic literature reviews gained significant attention in the 1990s (Trinder & Reynolds, 2000, as cited in Sundberg & Taylor-Gooby, 2013) and "seek to collate evidence that fits pre-specified eligibility criteria in order to answer a specific research question. They aim to minimize bias by using explicit, systematic methods documented in advance with a protocol" (Cumpston et al., 2023, Chapter 1: Introduction). Every step of the present systematic literature review was informed by the CRD (2009) and the PRISMA 2020 (Page et al., 2021) guidelines.

Conceptual paradigm[12] *& justification*

It is important to note that, as a research design, systematic reviews have also encountered critiques revolving around, for instance, the emphasis on, and somewhat

[11] An article version of this chapter was published in the open-access Journal of Long-Term Care in May 2024 and was subsequently registered in the KAR system of the University of Kent. For more information, see Appendix 1.

[12] In the context of research, a conceptual paradigm refers to a set of values, assumptions, and principles that guide what people consider valid or invalid research practice (Braun & Clarke, 2022).

impossibility of, replication as a principle, the concept of a hierarchy of evidence which may result in important research being dismissed, as well as other issues (see Sundberg & Taylor-Gooby, 2013, for an overview).

I affirm such critiques, recognising that historically, systematic reviews have their roots in medicine and natural sciences and, hence, in a rather positivist conceptual paradigm (i.e., the assumption of an objective reality where objective knowledge can be produced; Braun & Clarke, 2022) that may seem at odds with an overall qualitative project like mine which, as discussed in Chapter 2, is situated in relationality, positionality, and lived experience. Moreover, and in the spirit of disciplinary reflexivity, as a PhD candidate, I have also felt that the systematic review was the 'go to' literature review design of the University of Kent. Nevertheless, as I will demonstrate in subsequent sections of this chapter, various scientific disciplines (e.g., social sciences) and, consequently, different types of research questions (e.g., questions beyond the effectiveness of interventions) have claimed space in systematic literature reviews, pushing them towards evolving and becoming more heterogeneous (Sundberg & Taylor-Gooby, 2013).

With this in mind, among various literature review designs (e.g., scoping review), I chose the systematic review as the most appropriate due to its rigor and emphasis on methodical work. At the same time, I hope that, as a researcher, I maintained a sensibility that went beyond a positivist paradigm while aspiring to be part of a research community that uses methodological tools that come from different scientific traditions in a more scientifically diverse way.

Search strategy

The review explored research questions beyond the effectiveness of interventions and encompassed a range of study designs. Therefore, I employed the SPIDER model (Cooke et

al., 2012) which has a focus on qualitative or mixed methods reports. In Table 1, I present a sample of search terms, Boolean operators (e.g., '*and'*, '*or'*, '*not'*; CRD, 2009), and other relevant techniques (e.g., truncation) that I employed as part of my search strategy.

Table 1

Examples of search terms, Boolean operators, and other techniques used

Concept 1: **Support Staff**	*AND*	Concept 2: **Learning Disability**	*AND*	Concept 3: **Care Relationships**
Support AND (work* OR staff OR personnel OR assistant*) OR care AND (work* OR staff OR personnel OR assistant* OR aide* OR giver* OR taker* OR provider*)		Learning AND (disab* OR defici* OR disorder*) OR intellectual* AND (disab* OR developmental disorder* OR impairment* OR developmental disab*) OR ''Down Syndrome''		Positive AND (relation* OR interaction* OR engag*) OR ''therapeutic relation*'' OR ''professional-patient relation*'' OR ''interpersonal relation*'' OR ''rapport''

Note. The search terms presented in Table 1 serve as a sample from a long list of search terms that I utilised in different databases. This sample of search terms aims to provide the reader with an idea of what terms I used, so the techniques I employed to generate my review findings are better understood. The asterisk (*) entails truncation, a technique that permits searching for all possible endings of a word; the parenthesis groups terms for more efficient searching; and the quotation marks ('') facilitate searching for exact phrases.

Eligibility criteria

Student theses, books, and all types of reviews were excluded.[13] Literature discussing intentional communities (i.e., clusters of houses, some located in rural settings; Randell & Cumella, 2009) and Shared Lives schemes[14] (i.e., support where people become part of a Shared Lives carer's family; Callaghan et al., 2017) was not eligible either. Literature that met the following criteria was included:

[13] When I started conducting this review, only Undergraduate and MSc/MRes/MPhil theses were excluded. However, during the study selection phase, I realised that including PhD theses, books, and other systematic/literature/scoping reviews was unrealistic due to time constraints and other pragmatic reasons. Consequently, I added this exclusion criterion during study selection.

[14] As the research project progressed and I embarked on empirical research, upon reflection I realised that excluding literature exploring intentional communities and Shared Lives schemes was not necessary and that perhaps I was being overly cautious. Nonetheless, I attempted to compensate for this decision in the section '3.5 Discussion' of the present chapter as well as in Study 2, and somewhat in Study 3 (see Chapters 4 and 5, respectively).

- English language.
- Empirical research or non-empirical reports (e.g., opinion pieces) published in academic journals, book chapters, or as grey literature.
- Focus only on the UK,[15] namely 'the country that consists of England, Scotland, Wales, and Northern Ireland' (Cambridge Dictionary, n.d.).
- Published between 1980 and 2021 (July), to reflect milestones in the UK community care policy and deinstitutionalisation.
- Literature exploring how others (e.g., family) view the staff-resident relationship was eligible.
- Literature exploring various populations and settings was eligible if relevant findings were presented separately.

Pilot review

The review was piloted in EBSCOHost to test the search strategy as well as the eligibility criteria. The pilot review resulted in a reduction of search term synonyms to clarify the search. The eligibility criteria worked well during the pilot phase and no changes were made at this stage.

3.3 Conduct of study & analytic framework

Existing or ongoing reviews

The following databases were searched in June 2021: the CRD database, Cochrane Database of Systematic Reviews, Epistemonikos, EBSCOHost (including Abstracts in Social

[15] Although the project is situated in England, in the systematic literature review I chose to also include the other three countries and thus focus on the entire UK as a social care paradigm. I felt that I would unnecessarily be missing important literature by only focusing on England, and targeting the entire UK gave me a rather holistic understanding of the literature around learning disability care relationships. Additionally, this somewhat compensated for the fact that I was expected to carry out empirical research only in England, a condition associated with my NIHR SSCR doctoral funding.

Gerontology; Academic Search Complete; Cinahl; Medline; APA PsycArticles; APA PsycInfo; and SocINDEX), Scopus, PROSPERO, Social Care Online, and Campbell Systematic Reviews.

Data from EBSCOHost, PROSPERO, Scopus, and Social Care Online were imported into the reference management software Mendeley©, deduplicated and screened. The rest of the data were screened on their respective websites. No relevant existing or ongoing reviews were identified.

Review protocol registration

The review protocol was registered in the International Prospective Register of Systematic Reviews, PROSPERO, in June 2021. The registration number is CRD42021262379.

Study selection

The following databases were searched between late June and mid-July 2021: Scopus (857 records),[16] Social Care Online (2109 records), PubMed (1245 records), EBSCOHost (including Abstracts in Social Gerontology; Academic Search Complete; Cinahl; Medline; APA PsycArticles; APA PsycInfo; Open Dissertations;[17] and SocINDEX, 126 records), Ethos[18] (60 records), Open grey (zero records), and Google Scholar (149 records). Moreover, records that I had identified in preliminary searches were also included under the heading

[16] According to PRISMA 2020 guidelines, a record is "the title or abstract (or both) of a report indexed in a database or website […] records that refer to reports that are merely similar (such as a similar abstract submitted to two different conferences) should be considered unique" (Page et al., 2021, p. 3).
[17] As per footnote 14, results from 'Open Dissertations' were excluded.
[18] As per footnote 14, results from 'Ethos' were excluded.

'Other Literature' (46 records). Three commentaries to original reports[19] and one original report to a commentary were also added.

The following websites were also searched between late June and mid-July 2021: Mencap (five records), Dimensions UK (zero records), British Institute of Learning Disabilities (zero records), National Association of Care and Support Workers (zero records), and Skills for Care (four records). Experts were contacted with only one expert responding to suggest one record. The overall search yielded 4.606 records.

Screening & inter-rater agreement

Of the 4.606 records, 11 (i.e., four online Mencap records and two online Skills for Care records, four commentary pieces, and the record suggested by the expert) were screened without using any software and excluded as they did not meet the inclusion criteria. The remaining 4595 records were imported into the reference management software Mendeley©. Following manual de-duplication in Mendeley©, 4.558 records remained, which were then imported into the systematic review software Rayyan© (Ouzzani et al., 2016). A second round of de-duplication took place in Rayyan© using the software's efficient systems to capture potentially missed duplicates, resulting in 4.090 records. I then screened the titles and abstracts of these records. The software's labels 'include', 'exclude', and 'maybe' were used and I provided reasons for exclusion. Records that were labelled as a 'maybe' were left to be revisited at the full-text screening phase. Of the 4.090 records, 3328 (81.4%) were excluded and 762 (18.6%) were labelled as 'include' or 'maybe'.

[19] According to PRISMA 2020 guidelines, a report is "a document (paper or electronic) supplying information about a particular study. It could be a journal article, preprint, conference abstract, study register entry, clinical study report, dissertation, unpublished manuscript, government report, or any other document providing relevant information" (Page et al., 2021, p. 3).

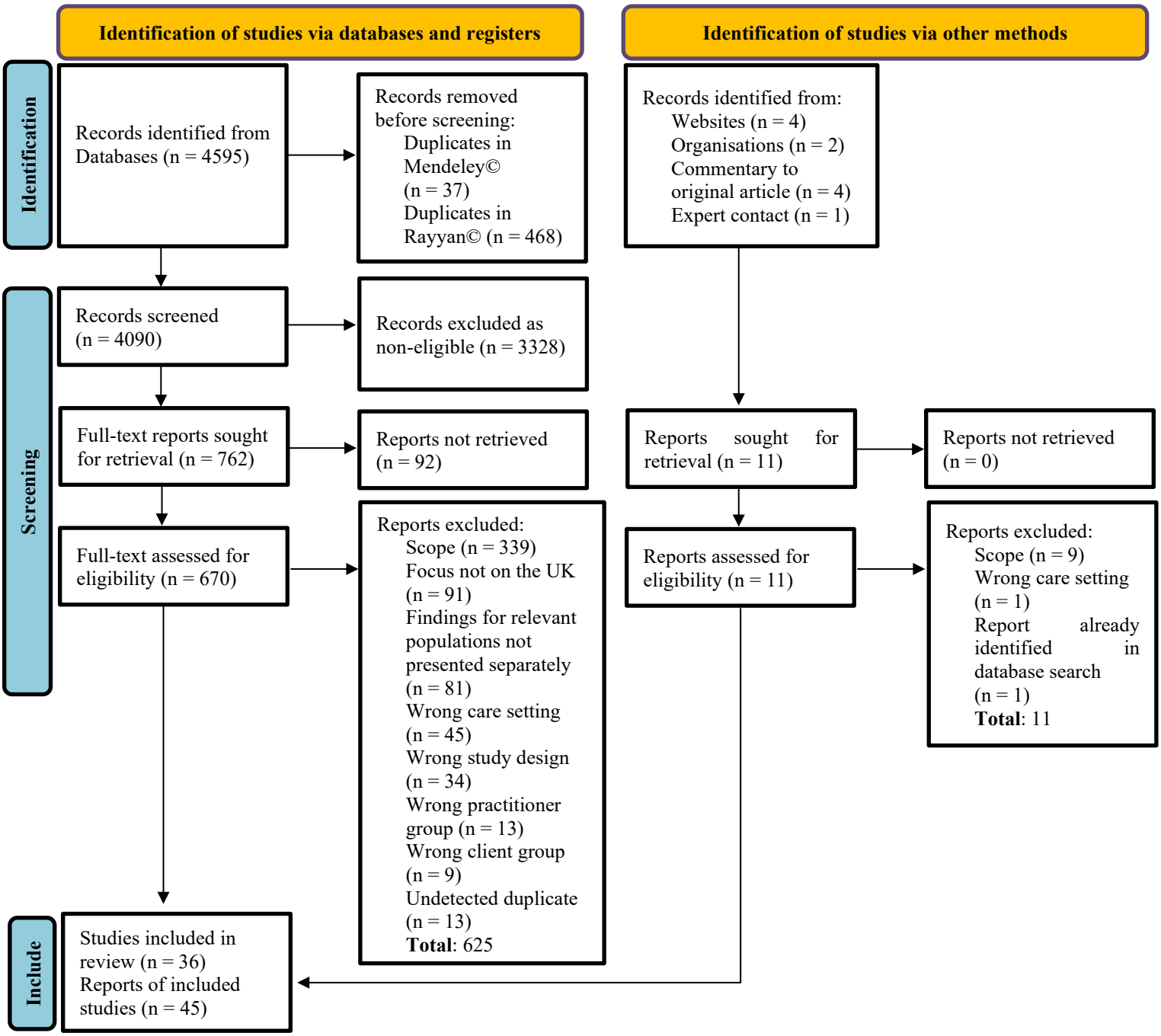
I then conducted a full-text screening of the remaining 762 reports. One report (i.e., Bradshaw & Goldbart, 2013) was unclear about the age of the residents and I enquired with the first author who confirmed that all residents were adults. To tackle bias and error (CRD, 2009), a second reviewer[20] was kindly invited to assist with the process. Full-text screening was practised together with the second reviewer to ensure familiarity with the process. Following this, 76 reports (i.e., 10% of 762) were randomly selected and shared with the second reviewer in Rayyan©. The number of reports was considered reasonable and realistic, ensuring that the second reviewer would have sufficient capacity for their other commitments and screen the reports in a timely fashion. Additionally, the fact that screening only a percentage of reports as a second reviewer has been used in other systematic reviews (e.g., Riviere et al., 2019), served as further evidence that informed my decision-making. Questions and clarifications were addressed in meetings with the second reviewer.

Cohen's kappa coefficient (κ; Cohen, 1960) for the inter-rater agreement was calculated, yielding a score of 0.81 (almost perfect agreement; Landis & Koch, 1977). To tackle bias and error further, the second reviewer was kindly asked to assist with the process once more at a later stage, when the reports had been narrowed down to 47. Following the same process, five reports (10% of 47) were randomly selected and shared with the second reviewer in Rayyan©. This time, there were no disagreements about whether a report should be included or excluded; hence κ was not calculated. Of the initial 4.606 records, only 45 reports (i.e., 1%) were included in the review. Figure 1 presents the PRISMA 2020 flow diagram (Page et al., 2021).

[20] Thank you to Jacqueline Paterson for serving as a second reviewer.

Figure 1

PRISMA 2020 flow diagram



Note. According to PRISMA 2020 guidelines, a study is "an investigation, such as a clinical trial, that includes a defined group of participants and one or more interventions and outcomes. A "study" might have multiple reports. For example, reports could include the protocol, statistical analysis plan, baseline characteristics, results for the primary outcome, results for harms, results for secondary outcomes, and results for additional mediator and moderator analyses" (Page et al., 2021, p. 3).

Data synthesis

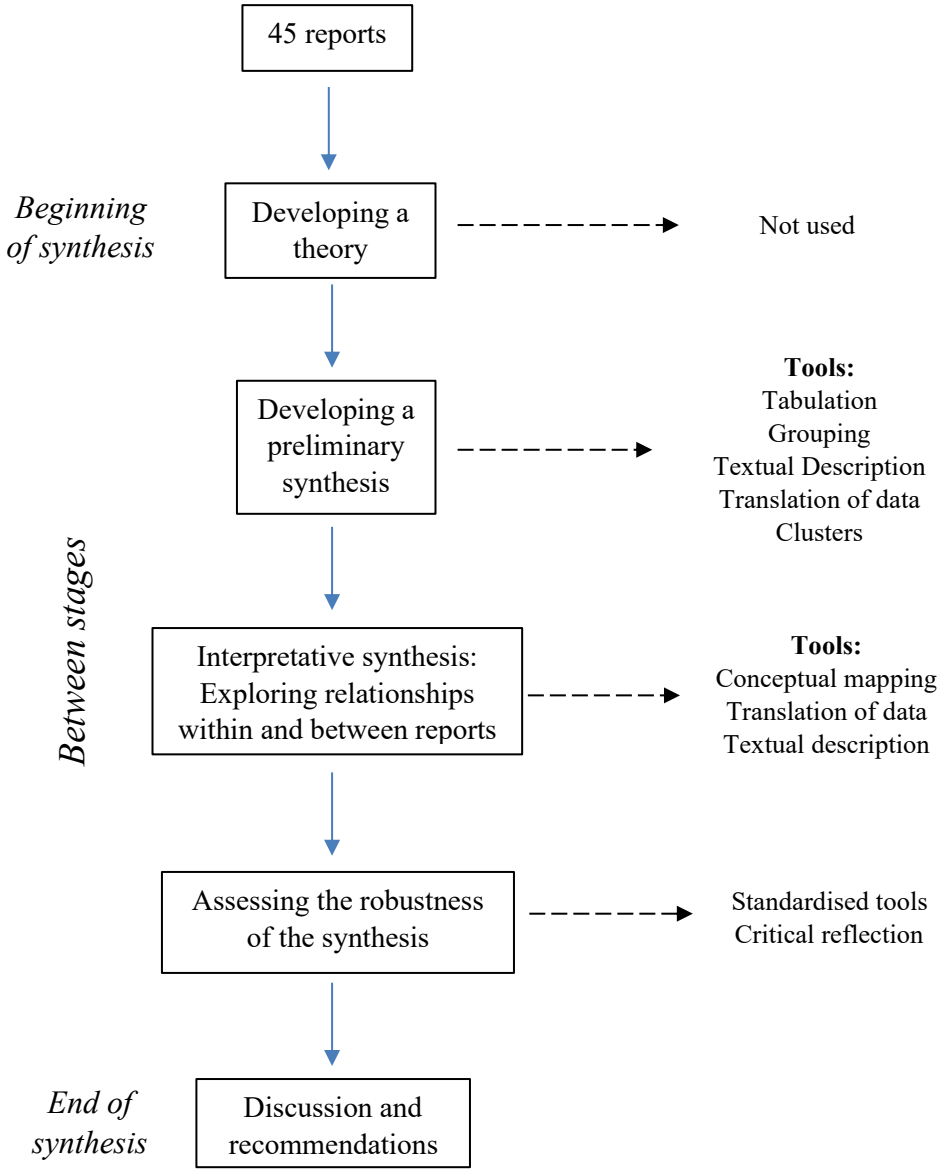
The narrative synthesis framework (Popay et al., 2006) was employed for data synthesis. Narrative synthesis "refers to an approach to the systematic review and synthesis of findings from multiple studies that relies primarily on the use of words and text to summarise and explain the findings of the synthesis" (Popay et al., 2006, p. 5). The framework is recommended for systematic reviews that go beyond the effectiveness of interventions, seek to answer a range of questions, and include reports with diverse designs (CRD, 2009; Popay et al., 2006). As my review met these criteria, the framework was considered appropriate (see Figure 2). The narrative synthesis framework is flexible, non-linear and over-arching, and involves the following key stages:

- Developing a theory
- Developing a preliminary synthesis of findings of included studies
- Exploring relationships in the data (interpretative synthesis)
- Assessing the robustness of the synthesis

In Figure 2, I provide an overview of the narrative synthesis process used in this review.

Figure 2

Narrative synthesis process and the tools used



3.4 Results

Developing a theory

Building a theory beforehand to guide data synthesis or testing an existing theory can take place, but is not a mandatory step in narrative synthesis (Popay et al., 2006). As discussed in Chapter 2, I took an inductive approach throughout this research project, locating my

responses to the project's aim and research questions into the gathered data. In line with this, I did not develop a theory beforehand or test an existing one for this systematic review. Once more, that is not to say that the review took place in a theoretical or social vacuum; I will again direct the reader to Chapter 2 where I offer relevant analysis.

Preliminary synthesis

A description of the included reports was conducted preparing the ground for further exploration (Popay et al., 2006).

Tabulation, grouping, & textual description.

Relevant data from each report were extracted, described textually, and grouped according to research design and publication type. Tables 2 to 5 present the data.

Most reports referred to a study conducted in England (i.e., 62%), whilst some referred to studies conducted in Wales (i.e., 9%) and Northern Ireland (i.e., 2%), respectively. The remaining reports (i.e., 27%) did not specify the country in the UK the study was conducted and only provided the University affiliations (e.g., University of Kent) of the first author. Of the 45 reports, 31% were published between 1998 and 2006, 49% between 2007 and 2015, and 20% between 2016 and 2021. The total number of participants was estimated to be approximately 1,659 people, with roughly half of them support staff and the other half residents. Staff's job titles were mostly 'support worker', 'personal assistant', or 'direct care staff', with a minority being team leaders or care managers. The scale of learning disability tended to be either severe or not stated, with a few reports discussing mild or moderate levels. The care home was the dominant residential setting.

Table 2

Qualitative studies published in academic journals

Report (n = 15)	**Methods**	**Care setting**	**Level of learning disability**	**Participants and perspective**	**Key findings**
Antaki et al., 2017. England	Ethnography. Video footage, conversation analysis.	Residential care home.	Severe or profound.	Nine residents. Six support workers. Perspective: Interactions between staff-residents.	The limited interactional patterns of residents and the support workers' limited understanding of how to interpret such cues can result in staff responding in 'ordinary' ways and limit the quality of contact and interactions.
Antaki et al., 2007a. England*	Recorded data (method not stated), conversation analysis.	Residential care home.	Not stated.	Two support workers and four residents. Perspective: Interactions between staff-residents.	Support workers' everyday subtle interactional practices can lead to ascribing disempowered identities to residents, shaping care relationships accordingly.
Antaki et al., 2007b. England.	Ethnography. Video footage, conversation analysis.	Residential care home.	Lower support needs, usable language skills	Four residents and four support workers. Perspective: Interactions between staff-residents.	Interactional practices to solicit talk from residents ranged from asking a direct question to teasing. Staff found themselves in a dilemma; namely, residents must be allowed to express themselves whilst staff act accordingly and manage other service demands.
Banks, 2012. England*	Ethnography. Observations, field notes, diary entries, interviews.	Residential care homes that became supported living settings.	Mild to moderate (not clearly stated).	The author reflects on their experiences as support staff. Perspective: Support worker.	Staff's various ways of interpreting social policy reforms may lead to tensions and negatively impact care relationships.
Bradshaw & Goldbart, 2013. England.	No specific qualitative approach was stated. Interviews.	Residential care homes.	Not stated.	14 members of staff. Perspective: Staff.	Support workers' personal experience of caring for residents and the process of setting boundaries were crucial to building good care relationships. Positive relationships are essential to providing effective support. Relying solely on experiential knowledge has limitations.

Report (n = 15)	**Methods**	**Care setting**	**Level of learning disability**	**Participants and perspective**	**Key findings**
Firth et al., 2008. England.	Grounded theory. Interviews, field notes, observations.	Group homes.	Severe or profound.	29 members of staff Perspective: Staff.	Intensive interaction training can improve interactions and contribute to building positive relationships. Barriers included concerns about practising intensive interaction in public, negative staff attitudes, and domestic and care tasks re-asserting their priority over time.
Haydon-Laurelut & Nunkoosing, 2010. England.	Authors reflect on using systemic psychotherapy.	Residential care home.	Not stated.	One resident, one care home manager, one systemic psychotherapist, and one counsellor. Perspective: Resident and care home manager.	Awareness of how behaviour that challenges is discoursed by staff is key. Residents feeling listened to is crucial to building positive care relationships. Systematic psychotherapy can contribute to good care relationships.
Jingree et al., 2006. England.	Audio footage of meetings, conversation analysis.	Residential care home.	Mild to moderate.	Eight residents and five support staff. Perspective: Interactions between staff-residents.	Support staff's conversational and interactional practices can disempower residents and emphasise power imbalance.
Kennedy & Brewer, 2014. England.	Life story, creative methods, and participatory research elements.	Residential care home.	Substantial support is required. Various levels of verbal communication.	Four residents. Perspective: Residents, however, conclusions about how methods can be used are drawn by the researchers.	Effective communication is essential to understanding and getting to know residents. Communication can be enhanced through creative methods.
Nagra et al., 2017. England.	Interpretative phenomenological analysis. Interviews.	Residential care homes.	Profound or severe.	Eight staff in direct care roles. Perspective: Staff.	Intensive interaction training can empower staff, change their attitudes, and lead to improved interactions and better care relationships.

Report (n = 15)	**Methods**	**Care setting**	**Level of learning disability**	**Participants and perspective**	**Key findings**
Waggett, 2012. England.	Reflections on consultation sessions.	Residential care home.	Severe and challenging.	Consultation sessions with the care home manager and three team leaders. Perspective: Consultant's perspective on care home dynamics.	Staff can act out the internal worlds of residents. Through the psychological mechanism of transference, staff may transfer negative emotions to residents or colleagues, impacting care relationships.
Walton et al., 2020. England.	Video footage, conversation analysis.	Residential care home.	Severe or profound.	Nine residents. Nine support workers. Perspective: Interactions between staff-residents.	Support workers recognising the affective stance of residents and responding accordingly is essential to effective interactions. The power imbalance is key.
Williams et al., 2009a. England.	Video footage, conversation analysis.	Home settings.	Not stated.	14 pairs of residents and their personal assistants. The focus is on two pairs. Perspective: Interactions between staff-residents.	Various factors (e.g., showing respect) underlie positive interactions and care relationships. The care relationship is complex and cannot be reduced to a set of skills.
Williams et al., 2009b. England.	Video footage, conversation analysis.	Home settings.	Two residents were not verbal. Others were more able to express themselves verbally. Many residents had additional physical or sensory impairments.	14 pairs of residents and their personal assistants. Perspective: Interactions between staff-residents.	Various factors (e.g., showing respect) underlie positive interactions and care relationships. The care relationship is complex and cannot be reduced to a set of skills.
Windley & Chapman, 2010. England.	Phenomenological approach, flexible design. Focus groups and interviews.	Supported accommodation.	Not stated.	Eight support workers. Perspective: Staff.	Having the right temperament and being caring and empathetic are important staff qualities. The care relationship is crucial for providing effective support.

Notes. a) The asterisk (*) indicates that the report did not provide explicit information about the exact UK country in which the study took place. In those cases, the UK location was determined based on the first author's affiliations. b) 'Perspective' refers to

whose perspective the included report explores. For instance, the report might explore care relationships from the perspective of staff or residents. Where perspective is not applicable, this is either due to a lack of information or because of the nature of the report (e.g., guideline document). Notes a) and b) also apply to all subsequent tables in this section of Chapter 3.

Table 3

Quantitative studies published in academic journals

Report (n = 21)	**Methods**	**Care setting**	**Level of learning disability**	**Participants and perspective**	**Key findings**
Beadle-Brown et al., 2015. England.	Quantitative descriptive study. One point in time observational/cross-sectional study. Questionnaires, observations, interviews.	Supported living and residential care homes.	Severe or profound.	110 residents. Perspective: Staff.	Low levels of support and poor outcomes for residents (e.g., engagement in activities, contact with staff) in residential services. Implementing active support is key to predicting a good quality of life, skilled support, positive interactions, and engagement in meaningful activities and relationships.
Beadle-Brown et al., 2012. England.	Quantitative non-randomised study. Pre–post-intervention. Observations, questionnaires.	Small community houses.	High support needs.	33 (baseline) and 31 (follow-up) residents. 29 residents at both time points. Perspective: Not applicable.	Training in and implementing active support increased the amount of assistance and the quality of support. Additionally, interactions and engagement were also increased.
Beadle-Brown et al., 2008. England.	Quantitative non-randomised study. Pre–post-intervention design. Questionnaires, observations.	Residential care homes.	High support needs.	29 residents. Perspective: Not applicable.	Training in and implementing active support increased the amount of assistance and the quality of support. Additionally, interactions and engagement were also increased.
Bradshaw, 1998. England*.	Quantitative non-randomised study. Case study, pre-post intervention. Observations.	Small community house.	Severe.	One resident with a learning disability and profound hearing impairment. Nine support staff. Perspective: Not applicable.	Training in communication skills (i.e., signed communication) and analysis of perceptions of the individual's behaviours increased the amount and improved the quality of interactions. Attitudinal changes also occurred.
Dagnan & Cairns, 2005. England*.	Quantitative descriptive study. Questionnaires.	Residential settings.	Not stated.	62 direct-care staff. Perspective: Staff.	Staff's attributions[21] and emotions are associated with their behaviour towards residents.

[21] Attributions refer to how staff perceive the causes of residents' difficult behaviours (e.g., as under or outside the resident's control) and how such understandings influence staff's emotional responses and behaviour (Dagnan & Cairns, 2005).

Report (n = 21)	**Methods**	**Care setting**	**Level of learning disability**	**Participants and perspective**	**Key findings**
Gillett & Stenfert-Kroese, 2003. England*.	Quantitative non-randomised study. Analytical cross-sectional pilot study. Questionnaires.	Residential units.	Ranged.	15 support staff. Perspective: Staff.	Different types of organisational culture can impact interactions and relationships between staff and residents affecting overall service performance.
Hastings et al., (2018). England.	Quantitative cluster randomised controlled trial.	Residential services.	Not stated.	236 support staff. Half of the staff completed follow-up measures. Perspective: Staff.	'Who's challenging who' training did have a small positive, but not significant, effect on staff empathy. However, the training increased the staff's positive attitudes towards residents as well as their work-related wellbeing.
Hume et al., 2021. Scotland*.	Quantitative non-randomised study. Case study, pre-post intervention. Questionnaires, observations.	Residential homes.	Severe or profound.	A person with a learning disability and 16 support staff. Perspective: Staff.	Training using capable environments[22] and practice leadership frameworks improved staff interactions, assistance, and praise. The resident's engagement in meaningful activities was also increased whereas behaviour that challenges and use of medication decreased.
Jones et al., 2001a. Wales.	Quantitative non-randomised study. Replication study, pre-post intervention. Questionnaires, observations.	Staffed houses.	Ranged.	106 residents. Perspective: Not applicable.	Training in active support increased the assistance provided to individuals with a severe learning disability. Behaviour that challenges was unaffected. People with severe learning disability appear to benefit more from active support.
Jones et al., 2001b. Wales.	Quantitative non-randomised study. Replication study, pre-post intervention. Questionnaires, focus groups, observations. Qualitative elements with no clarification on analysis.	Staffed houses.	Ranged. Focused on severe or profound.	188 residents. Perspective: Not applicable, however, the opinions of some residents were discussed.	Training in active support increased the assistance provided to residents. People with severe learning disability appeared to benefit more from active support. Residents with a less severe learning disability also found active support useful and reported positive impacts on their relationships with staff. Training trainers (e.g., managers) was unsuccessful.
Jones et al., 1999. Wales.	Quantitative non-randomised study. Pre-post intervention. Questionnaires, observations.	Staffed houses.	Severe.	19 residents and 52 support staff. Perspective: Not applicable	Training in active support increased the assistance provided to residents. People with severe learning disability appear to benefit more from active support.

[22] Capable environments is an approach that draws on positive behaviour support and seeks to reduce behaviour that challenges by providing high-quality, multifaceted care (Hume et al., 2021).

Report (n = 21)	**Methods**	**Care setting**	**Level of learning disability**	**Participants and perspective**	**Key findings**
Mansell et al., 2002. England.	Quantitative non-randomised study. Experimental, pre-post comparison group. Questionnaire, observations.	Small residential care homes.	Not stated.	49 residents. Perspective: Interactions between staff-residents.	Active support led to increased engagement in meaningful activity and more interactions. The effect was small but significant, and staff support was mixed.
McGill et al., 2018. England.	Quantitative pragmatic cluster randomised controlled trial. Questionnaires, observations.	Residential settings.	Not stated.	81 residents. Perspective: Not applicable	Adopting a positive behaviour support[23] framework in residential settings led to a reduction in behaviour that challenges.
Phillips & Rose, 2010. England.	Quantitative non-randomised study. Analytical cross-sectional. Questionnaires.	Various residential settings. Mostly residential care homes	The residents classed as 'breakdown group' had more developed language skills and were able to function more independently.	Support staff (number not specified). The breakdown group consisted of 20 residents. The non-breakdown group consisted of 23 residents. Perspective: Staff.	The services' organisational features, as well as staff's attributions and perceptions of ability, were associated with interactions with residents and placement breakdown.
Rose & Rose, 2005. England*.	Quantitative descriptive study. Questionnaires.	Residential community homes.	Not stated.	107 direct-care staff. Perspective: Staff.	The level of stress was not associated with staff's attributions, emotions, and helping behaviour towards residents.
Rose et al., 1998. Wales*.	Quantitative non-randomised study. Cross-sectional analytical. Questionnaires, observations.	Residential care homes.	Not stated. More stressed-out staff were supporting more independent individuals.	33 direct care staff. Also, various members of staff were observed. Perspective: Staff.	High stress was associated with higher demand and constraint and lower organisational support. Low stress was associated with greater assistance to residents and more positive interactions. Caution around causal relationships.
Samuel et al., 2008. England*.	Quantitative non-randomised study. Quasi-experimental interrupted time-series multiple-baseline. Video observations,	Supported living bungalows.	Profound.	Four female residents. 11 support workers and one team leader.	Intensive interaction training led to more positive interactions. Suggestions that Intensive Interaction can make care relationships more reciprocal.

[23] Positive behaviour support is an approach that draws on applied behaviour analysis and focuses on understanding the context of behaviours that challenge (McGill et al., 2018).

Report (n = 21)	**Methods**	**Care setting**	**Level of learning disability**	**Participants and perspective**	**Key findings**
	assessment schedules, and questionnaires.			Perspective: Staff and residents.	
Smith et al., 2002. Wales.	Quantitative non-randomised study. Replication study, pre-post intervention. Questionnaires, observations.	Staffed houses.	Ranged.	188 residents. Perspective: Not applicable.	Training in active support led to more efficient support and assistance. People with severe learning disability appeared to benefit more from active support.
Thomas & Rose, 2009. England*.	Quantitative descriptive study. Cross-sectional questionnaire.	Residential services.	Not stated.	95 direct care staff. Perspective: Staff.	Staff's lack of reciprocal relationships with their organisation, predicted emotional exhaustion, depersonalisation, and feelings of personal accomplishment. Those factors had a negative impact on the staff's behavioural responses to residents.
Toogood et al., 2009. Wales*.	Quantitative non-randomised study. Case study, pre-post intervention. Observations, charts.	Individual's own home.	Moderate.	One individual with a learning disability, epilepsy, and cerebral palsy. Six support staff. Perspective: Not applicable.	Active support procedures such as coaching on activity-based interactions and activity planning led to warmer and more frequent eye-level instructions by staff. Interactions were increased and engagement replaced behaviour that challenges.
Williams et al., 2015. England*.	Quantitative non-randomised study. Experimental study, repeated measures design. Vignettes, questionnaires.	Supported living and residential care homes.	Not stated.	50 support staff. Perspective: Staff.	Mitigating factors (e.g., level of communication difficulties) reduced staff's attributions of personal responsibility and led to increased sympathy.

Table 4

Text and opinion pieces, and book chapters

Report (n = 4)	**Methods**	**Care setting**	**Level of learning disability**	**Participants and perspective**	**Key conclusions**
Bowler & Nash, 2014. England.	Not applicable.	Community and domiciliary care settings.	Not stated.	Refers to non-registered support staff. Perspective: Not applicable	Setting boundaries plays an important role in the care relationship.
Broussine, 2012. England.	Not applicable.	Health and social care settings.	Not stated.	Refers to health and social care practitioners.	Person-centred processes underlie good care relationships.

				Perspective: Not applicable	
Finlay et al., 2008. England.	Not applicable.	Residential care homes.	Ranged.	Refers to residents and support workers. Perspective: Not applicable	Staff watching video footage of everyday interactions with their residents can help them improve care practices and understand how (dis)empowerment may operate within care relationships.
Thurman et al., 2005. England.	Not applicable.	Not stated.	Higher communication needs.	Not stated. Perspective: Not applicable	Effective communication is key and various frameworks exist to address communication needs. A series of steps can be taken to achieve good communication.

Table 5

Grey literature

Report (n = 5)	**Methods**	**Care setting**	**Level of learning disability**	**Participants and perspective**	**Key findings**
Ashman & Beadle-Brown, 2006. England.	Quantitative non-randomised study. Pre-post intervention. Questionnaires, observations.	Residential care and supported living.	Most services included people with a severe or profound learning disability.	Baseline: 343 residents. Post-intervention: 469 residents. Additionally, 425 staff completed questionnaires. Data was also gathered about the 649 residents that the services supported. Perspective: Interactions between staff-residents.	Training in active support led to more efficient support and assistance. Residents with severe learning disability appeared to benefit more from active support.
Grove & Mcintosh, 2005. England.	Not applicable (guidelines).	Not stated.	Not stated.	Not stated. Perspective: Not applicable	Staff can take a series of steps to ensure effective communication.
Health and Social Care, 2016. Northern Ireland.	Not applicable (guidelines).	Any health or social care setting.	Not stated.	Produced for health and social care staff. Perspective: Not applicable.	Staff can take a series of steps to ensure effective communication.
NIHR SSCR, 2020. England.	Quantitative cluster randomised controlled trial.	Residential services.	Not stated.	236 support staff. Half of the staff completed measures at the follow-up. Perspective: Staff.	'Who's challenging who' training did have a small positive, but not significant, effect on staff empathy. However, the training increased the staff's positive attitudes

					towards residents as well as their work-related well-being.
Norah Fry Research Centre, 2010. England*.	Qualitative study (no specific qualitative approach). Group and individual interviews.	Primarily rented accommodation.	Levels ranged.	50 participants, including residents and staff Perspective: Primarily residents.	Trust, independence, mutuality, and other components of good care relationships were discussed alongside barriers and grey areas.

Translation & conceptual clusters.

Translation entails identifying main concepts across reports and "seeking a common rubric for salient categories of meaning, rather than the literal translation of words or phrases" (Popay et al., 2006, p. 20). Translation can be used in syntheses that contain quantitative and qualitative data and can "involve transforming qualitative findings into quantitative form or vice versa" (Popay et al., 2006, p. 18).

Extracts containing information relevant to the project's research questions were taken from each report and imported into a spreadsheet. I then labelled relevant sections, organised, summarised, and synthesised findings, and generated the main concepts. All findings were presented in a textual format. Below, I provide an example of how I used translation with an extract from Waggett (2012). Labels are highlighted in bold. A synthesis of labels allowed me to generate the main concepts and helped me determine the research questions that the report was addressing (e.g., barriers):

> If the member of staff fails to recognise the emotion as possibly one that is being transferred onto them by the resident, they will identify it as their own 'bad object' and seek to split it off from what they think of as their 'good self' and then to get rid of it into another person (**transference and relationships**). This 'other' could be the resident, the original source of the projection, who therefore receives back the 'bad stuff' they wished to get rid of initially but in a potentially even more toxic form

> (**transference affecting relationships**). Their despair, for example, is not processed, or thought about, in any way by the worker but is fired back at the resident, perhaps with a little bit of the worker's own feelings of despair, or anger, added on for good measure (**example of transference**). (Waggett, 2012, p. 451).

Consequently, I created conceptual clusters reflecting the research questions (see Table 6). Each report was allocated to a conceptual cluster depending on its content. The same report could fall under different clusters.

Table 6

Conceptual clusters

Definitions of care relationships (n = 7)	**Processes and practices underlying positive care relationships** (n = 11)	**Barriers to and facilitators of positive care relationships** (n = 38)	**Impact of positive care relationships (or lack thereof)** (n = 4)	**Restoration of disrupted care relationships** (n = 2)
Antaki et al., 2007a. Finlay el., 2008. Bowler and Nash, 2014. Haydon-Laurelut & Nunkoosing, 2010. Jingree et al., 2006. Norah Fry Research Centre, 2010. Walton et al., 2020.	Bowler & Nash, 2014. Bradshaw & Goldbart, 2013. Broussine, 2012. Grove & Mcintosh, 2005. Haydon-Laurelut & Nunkoosing, 2010. Health & Social Care, 2016. Kennedy & Brewer, 2014. Norah Fry Research Centre, 2010. Walton et al., 2020. Williams et al., 2009a. Williams et al., 2009b.	Antaki et al., 2017. Antaki et al., 2007a. Antaki et al., 2007b. Ashman & Beadle-Brown, 2006. Banks, 2012. Beadle-Brown et al., 2015 Beadle-Brown et al., 2012. Beadle-Brown et al., 2008. Bradshaw, 1998. Dagnan & Cairns, 2005. Finlay et al., 2008. Firth et al., 2008. Gillett & Stenfert-Kroese, 2003. Grove & Mcintosh, 2005. Hastings et al., 2018. Health & Social Care, 2016. Hume et al., 2021. Jingree et al., 2006. Jones et al., 2001a. Jones et al., 2001b. Jones et al., 1999. Kennedy & Brewer, 2014. Mansell et al., 2002. McGill et al., 2018. Nagra et al., 2017. NIHR SSCR, 2020.	Bradshaw & Goldbart, 2013. Broussine, 2012. Phillips & Rose, 2010. Windley & Chapman, 2010.	Haydon-Laurelut & Nunkoosing, 2010. Toogood et al., 2009.

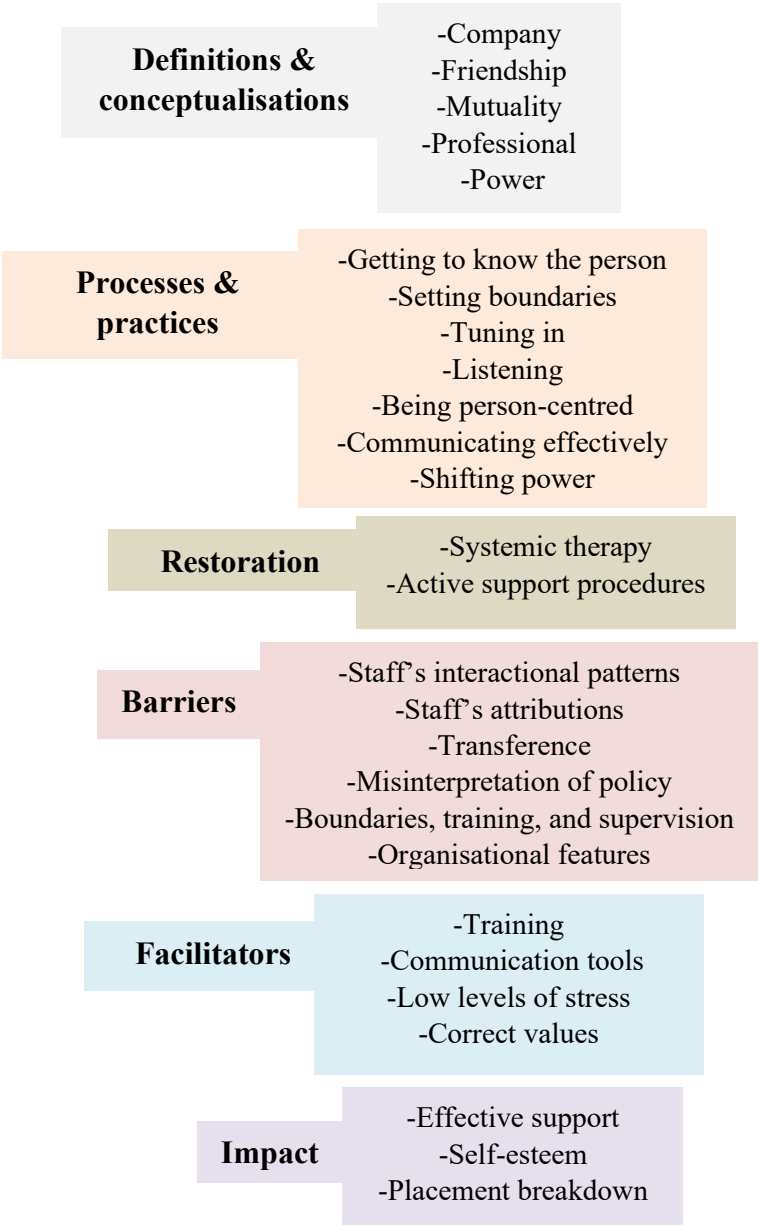
	Norah Fry Research Centre, 2010. Phillips & Rose, 2010. Rose & Rose, 2005. Rose et al., 1998. Samuel et al., 2008. Smith et al., 2002. Thomas & Rose, 2009. Thurman et al., 2005. Toogood et al., 2009. Waggett, 2012. Windley & Chapman, 2010. Williams et al., 2015.

Interpretative synthesis - Relationships within and between reports

Concept mapping, translation, and textual description were used to explore relationships within and between reports. The findings for each research question are briefly presented in Figure 3 and are textually discussed in detail below.

Figure 3

Systematic literature review findings



Definitions & conceptualisations of care relationships.

Good care relationships involve mutuality (i.e., a two-way relationship) and a sense of equality, with staff providing company and friendship (Norah Fry Research Centre, 2010). Being professional, setting, and respecting boundaries are key elements of positive relationships (Bowler & Nash, 2014). Power often accompanies relationships, with support

staff occupying a powerful position over residents (Antaki et al., 2007a; Finlay et al., 2008; Haydon-Laurelut & Nunkoosing, 2010; Jingree et al., 2006; Walton et al., 2020).

Processes & practices that underlie positive care relationships.

Getting to know the person. Getting to know each other can lead to the development of trust (Norah Fry Research Centre, 2010) and using creative (e.g., music) and life history methods can facilitate getting to know the person (Kennedy & Brewer, 2014). Shared activities and experiences (Williams et al., 2009a) can also help get to know each other. In the case of personal assistants, people with a learning disability may choose to employ individuals they already know and trust, which can potentially lead to developing a positive care relationship (Norah Fry Research Centre, 2010).

Setting boundaries. Setting boundaries entails support staff being clear about what they can and cannot do (Bradshaw & Goldbart, 2013). On the spectrum of care and support, staff should avoid the two ends, namely over-involvement and under-involvement, and operate within the "central zone of helpfulness" (Bowler & Nash, 2014, p. 14). Boundary setting is a crucial process at the early stages of the care relationship, and when a relationship has been established (Bradshaw & Goldbart, 2013).

Tuning-in. Tuning in entails staff being with residents on both a mental and a physical level (Egan, 2007, as cited in Broussine, 2012). It is an embodied process with support staff recognising, orienting to, and responding to the affective stances of residents, namely to their verbal (e.g., vocalisations) and non-verbal (e.g., gaze) expressions (Walton et al., 2020). It involves synchronised body language (e.g., mutual smiling) and joint task orientation (e.g., finishing each other's sentences), with staff following the individual's lead and acting accordingly (Williams et al., 2009a; Williams et al., 2009b). Facing and leaning towards the

individual, adopting an open posture, and being relaxed can help support staff tune in with the people they support (Egan, 2007, as cited in Broussine, 2012).

Listening. Feeling listened to by the support staff was identified as an important component of positive care relationships (Haydon-Laurelut & Nunkoosing, 2010). Listening must be active, whereby support staff consciously engage with and try to understand the residents (Broussine, 2012). Active listening can be achieved by asking relevant questions in an empathic manner or paraphrasing what people try to communicate (McNaughton et al., 2008, as cited in Broussine, 2012). Moreover, it involves being perceptive of non-verbal behaviours and taking into account the social and cultural context of people's lives (Egan, 2007, as cited in Broussine, 2012). The way support staff interact with the residents (e.g., by avoiding child-like talk patterns) can influence whether the latter are feeling listened to or not (Williams et al., 2009a).

Being person-centred. Being person-centred was conceptualised as a set of three sub-processes, namely congruence, unconditional positive regard, and self-awareness. More specifically, being congruent entails support staff being open and true to their feelings, thoughts, and behaviours (Broussine, 2012). For example, when staff make their feelings and thoughts openly known to a person they support who is behaving in a hurtful way (Broussine, 2012). Nevertheless, this level of authenticity does not always allow staff to be objective or detached from the people they support (Cumbie, 2001, as cited in Broussine, 2012).

Engaging in unconditional positive regard involves creating a compassionate atmosphere, opening up to the individual's experience, recognising their humanity, and accepting them without judgment (Broussine, 2012). To understand this process, we should consider what conditional positive regard entails; namely, to be regarded positively only when one is thinking or behaving how significant others (e.g., parents, staff) want them to think or

behave (Broussine, 2012). When engaging in empathic understanding, staff attempt to recognise the resident's experiences and feelings and communicate them back, resulting in validation (Broussine, 2012).

Being self-aware entails support staff being mindful of their own beliefs, feelings, experiences, and behaviours and how these can influence their relationship with the residents (Broussine, 2012). Staff can use the *self* therapeutically leading to growth both for the people they support and for themselves (Broussine, 2012). Nonetheless, using the *self* in their care practice can make staff less objective and less detached from the people they support (Cumbie, 2001, as cited in Broussine, 2012). It can also be emotionally demanding and is not always compatible with the daily care routines within residential services (Broussine, 2012). Being reflexive is closely related to being self-aware, whereby staff reflect on their skills, practices, attitudes, and biases and how these can prevent them from being person-centred (Broussine, 2012).

Communicating effectively. In sensitive areas such as money management, risk, and providing advice, support staff must communicate openly, yet without imposing their advice (Norah Fry Research Centre, 2010; Williams et al., 2009a). Effective communication also involves using a respectful, friendly, and adult tone of voice, allowing plenty of room for choice and support to speak up (Williams et al., 2009a; Williams et al., 2009b). Humour can be a powerful tool that can be used to soften advice (Williams et al., 2009a; Williams et al., 2009b). Getting the individual's attention, being clear, providing enough time to respond, and being mindful of one's environment are key components of effective communication (Grove & Mcintosh, 2005; Health and Social Care, 2016).

***Shifting power dynamics*.** Support staff stepping back and operating in the background allows residents to be more in control (Norah Fry Research Centre, 2010; Williams et al.,

2009a; Williams et al., 2009b). Proactiveness must be practised in a balanced way to ensure that staff deal with daily demands without making decisions on behalf of residents, thus robbing them of the opportunity to be in control of their lives (Norah Fry Research Centre, 2010). Staff and residents working as a team can facilitate a more equal, two-way relationship, emphasising mutual responsibility for the relationship to work out (Norah Fry Research Centre, 2010; Williams et al., 2009a; Williams et al., 2009b).

Restoration of disrupted care relationships.

Systemic psychotherapists can provide external input and identify reasons behind poor care relationships, investigate power imbalance, and suggest avenues towards relational restoration based on the contexts of residents and staff (Haydon-Laurelut & Nunkoosing, 2010). In a case study, Toogood and colleagues (2009) suggest that active support procedures, such as coaching on activity-based interactions and activity planning, can lead to warmer interactions replacing behaviours that challenge and other unhelpful responses.

Barriers to positive care relationships.

Staff's interactional patterns. Providing candidate answers, asking blunt 'yes-no' questions, or refusing to take into account people's utterances, are some subtle, everyday interactional patterns that support staff may engage with that may lead to disempowerment, emphasise power imbalance, and serve as a barrier to developing positive care relationships (Antaki et al., 2007a; Antaki et al., 2007b; Jingree et al., 2006). Staff responding in an ordinary fashion to residents with limited interactional capacity may impact the residents' engagement with those who support them (Antaki et al., 2017). How staff discourse themselves (e.g., as friends) as well as residential services (e.g., affirmation philosophies) during their interactions with residents may lead to ascribing deficient identities to the residents and result in care relationships that disempower (Antaki et al., 2007a; Jingree et al., 2006).

Attributions. Staff's attributions of internality, namely when the cause of the behaviour that challenges is perceived to lie within the individual, may be positively associated with staff anger and negatively with sympathy (Dagnan & Cairns, 2005). Attributions of stability, namely when the cause of the behaviour that challenges is perceived as having the potential to change over time, may correlate positively with staff sympathy (Dagnan & Cairns, 2005). Attributions of control over difficult behaviours may be associated with judging residents as personally responsible for their behaviour (Dagnan & Cairns, 2005). Attributions of control, but not challenging behaviour itself, seem to influence residential placement breakdowns (Phillips & Rose, 2010). When support staff perceive the residents as personally responsible for difficult behaviours, they are less likely to feel sympathetic towards the resident, whereas perceiving the resident as having some responsibility for finding solutions for behaviours that challenge increases sympathy (Dagnan & Cairns, 2005). In turn, feeling or lacking sympathy seems to be linked to staff's helping behaviours (Dagnan & Cairns, 2005).

Staff may judge residents with communication difficulties as less responsible for difficult behaviours, resulting in increased sympathy (Williams et al., 2015). Nonetheless, people with mild learning disability may be perceived as in control of their behaviour and receive fewer staff interactions (Phillips & Rose, 2010). Optimism, namely support staff's expectations for dealing with difficult behaviours successfully, rather than attributions of control, could be a key factor influencing interactions (Rose & Rose, 2005). Attributions, behaviour, and levels of staff stress do not necessarily correlate, as highly stressed staff still indicate a willingness to provide extra help (Rose & Rose, 2005).

Transference. Interpersonal dynamics are a key element of residential settings, and support staff often become exposed to the residents' negative emotions, frustration, or traumatic experiences (Waggett, 2012). Exposure to these emotions and experiences can be intense, and failure to process them can lead staff to somewhat perceive them as their own

(Waggett, 2012). To cope with this disturbance, staff may seek to transfer such emotions and experiences back to residents, colleagues, or the care organisation, which in turn can affect interactions and care relationships (Waggett, 2012). For example, support staff not processing a resident's feelings of despair might result in transferring them back to the individual by judging them as personally responsible for their behaviour (e.g., "Oh, I despair, you never make any effort to improve"; Waggett, 2012, p. 451).

Policy interpretation. Social care policy reforms aimed at personalising services and empowering residents may be misinterpreted by staff (Banks, 2012). Interpretations may be relatively narrow, with staff focusing on the responsibilities that the residents have in the household (Banks, 2012). Residents may resist staff demands, and tensions may arise. As a result, support staff may blame the people they support and make decisions on their behalf with an emphasis on professional agreements (e.g., resident responsibilities as tenants in the setting) over interpersonal relationships, which can disrupt relational dynamics (Banks, 2012).

Lack of boundaries, training, and supervision. Despite support staff, particularly personal assistants, emphasising the privilege of being part of the residents' lives, difficulties around setting boundaries and navigating the risk of over-involvement may threaten good care relationships (Norah Fry Research Centre, 2010). Although receiving training and supervision on boundary setting seems beneficial, personal assistants, especially those employed directly by the people they support, report very limited opportunities to access it compared to staff employed by care organisations (Norah Fry Research Centre, 2010).

Organisational factors. Residential settings with overworked care teams, lacking energy, resources, and information about their residents may experience breakdowns in residential placement (Phillips & Rose, 2010). Fewer support opportunities for employees and higher levels of demand are linked to more stressed support staff and limited engagement with

residents (Rose et al., 1998). Lack of reciprocity between employees and care organisations can predict exhaustion, depersonalisation, and feelings of personal accomplishment, which may affect staff's interactions with residents (Thomas & Rose, 2009). Oppositional (e.g., confrontation or criticism), competitive, or perfectionistic organisational cultural styles may lead to task-centred practices, preventing interpersonal relationships from flourishing (Gillett & Stenfert-Kroese, 2003).

Facilitators of positive care relationships.

Training.

Active support. Active support can lead to more positive and frequent interactions and staff assistance, increased engagement in meaningful activities, and overall better care relationships (Ashman & Beadle-Brown, 2006; Beadle-Brown et al., 2015; Beadle-Brown et al., 2012; Beadle-Brown et al., 2008; Jones et al., 2001a; Jones et al., 2001b; Jones et al., 1999; Mansell et al., 2002; Smith et al., 2002; Toogood et al., 2009).

Intensive interaction. Training in and implementation of intensive interaction is associated with more positive and frequent interactions, improved communication skills, increased staff confidence, and overall more positive, reciprocal, and enjoyable care relationships (Firth et al., 2008; Nagra et al., 2017; Samuel et al., 2008). Intensive interaction is also associated with an attitudinal change towards what constitutes meaningful interactions and what the meaning of behaviour that challenges can be (Nagra et al., 2017).

Other training. Training in signed communication and reflecting on the meaning of difficult behaviour can improve interactions and decrease judgemental attitudes among support staff (Bradshaw, 1998). The 'Who's Challenging Who' training can increase staff's sense of accomplishment and motivation, and improve attitudes towards difficult behaviours (Hastings et al., 2018; NIHR SSCR, 2020). Capable environments and practice leadership frameworks

can enhance staff interactions and praise, increasing engagement and reducing difficult behaviours (Hume et al., 2021). Behaviour that challenges can disrupt relationships and positive behaviour support training can address this (McGill et al., 2018). Filming interactions may help staff reflect on their subtle everyday practices allowing them to explore power imbalance in relationships (Finlay et al., 2008).

Communication tools. Creative methods (e.g., music, drawing, photography) combined with life history methods can enhance communication and help establish positive care relationships (Kennedy & Brewer, 2014). Interactive (e.g., proximal communication), profiling (e.g., communication passports), and consensus tools (e.g., circles of support) can also improve interactions (Thurman et al., 2005). Presenting accessible information (e.g., easy-read documents) is also key to positive interactions (Grove & Mcintosh, 2005; Health and Social Care, 2016).

Appropriate values. Having the right temperament, and being caring and empathic are core values for good care relationships (Windley & Chapman, 2010).

Impact of positive care relationships (or lack thereof).

Positive care relationships set the foundations for providing effective support (Bradshaw & Goldbart, 2013; Windley & Chapman, 2010). Good relationships have the potential to improve the self-esteem, confidence, and sense of self-worth of people with a learning disability, challenging past experiences of stigma and discrimination (Broussine, 2012). Although no definitive conclusions can be drawn, poor care relationships may be associated with the breakdowns of residential placements (Phillips & Rose, 2010).

Assessing the robustness of the synthesis

Discussions with colleagues as well as regular reflections with my supervisors on how the review was shaping and progressing, took place. To address publication bias, I included

various types of published research and grey literature, and I also contacted experts in the fields of learning disability and social care to obtain recommendations for relevant literature. Involving a second reviewer has, at least partly, reduced bias and error during the screening stage. The review included studies that involved people with a range of learning disability levels, including people with a severe or profound learning disability. This is not always the case as, for various reasons (e.g., capacity to consent, practical reasons pertinent to the care organisations participating in studies), learning disability research often focuses on people with milder levels of learning disability (Bigby et al., 2014). English was the sole language, which I appreciate that may have introduced bias; nonetheless, this was somewhat inevitable due to the focus on the UK social care paradigm. Time constraints prevented me from checking the references of included reports and searching further for the 92 non-retrieved reports. These 92 reports consisted mainly of grey literature (e.g., brief website articles, guidelines, policy reports), as well as some academic articles. The majority of these reports are dated 20 years back or longer, which may account for the difficulties around retrieving them more easily. As described in Figure 1 (i.e., PRISMA 2020 flow diagram), screening the titles and abstracts of the reports indicated potential relevance to this literature review. However, as the full text of these reports was not retrieved and, therefore, not assessed against my eligibility criteria, it is unknown how many of these reports would have been included and how this would have shaped the review. Furthermore, time limitations and other PhD-related commitments prevented me from including books, reviews, or PhD theses in the review. Applying the findings to care contexts outside the UK must be done cautiously and knowingly; however, in this review, residential arrangements and levels of learning disability ranged, which may increase applicability.

The MMAT (Hong et al., 2018) was used to critically appraise empirical studies, the JBI Checklist (McArthur et al., 2015) to appraise opinion pieces and book chapters, and the

AACODS checklist (Tyndall, 2010) to appraise grey literature. Reports were not excluded on grounds of poor methodological quality (Hong et al., 2018). Overall, most quantitative non-randomised studies, quantitative descriptive studies, and some qualitative studies met most MMAT criteria indicating higher quality. Similarly, all text and opinion and grey literature reports met most JBI Checklist and AACODS Checklist criteria, respectively. All quantitative randomised control trials were deemed of poor methodological quality.

For a detailed critical appraisal of each report, I refer the reader to Tables 7 to 12 below. In all MMAT tables, a column discussing ethics, consent, and limitations of each study was added to complement critical appraisal. Overall, less than half of the qualitative studies, half of the quantitative descriptive studies, and only a few quantitative non-randomised studies had ethics information. In contrast, most quantitative randomised control trials discussed ethics. Most qualitative studies and all quantitative randomised controlled trials had information about consent. However, less than half of the quantitative non-randomised studies and only one quantitative descriptive study discussed consent. Most reports did address limitations.

Of the 45 reports, only 15 (33%) explicitly discussed care relationships, with fewer reports addressing positive relationships. Instead, most reports explored concepts at the "periphery" of care relationships (e.g., interactions, communication). Nonetheless, I aimed to be inclusive, ensuring that relevant literature would not be excluded whilst considering the project's research questions and the review's eligibility criteria. There was some variation regarding the residential setting and the scale of learning disability; however, this variation was embraced as it allowed me to explore the care relationship from different perspectives. The job titles of the participants who were support staff varied reflecting the range of titles that are used in social care (Cavendish, 2013). Some reports contained vague job titles (e.g., direct care staff) which could potentially increase the risk of including practitioners other than support staff (e.g., nurses). Fully controlling for this was not possible or realistic; nevertheless, I felt that the

review's narrow inclusion criteria and tight search strategy as well as my work experience in residential settings, assisted me in identifying, assessing and excluding reports with ineligible practitioners and, therefore, minimising this risk.

Table 7

MMAT qualitative studies

Report (n = 16)	**Are there clear research questions?**	**Do the collected data allow to address the research questions?**	**Is the qualitative approach appropriate to answer the research question?**	**Are the qualitative data collection methods adequate to address the research question?**	**Are the findings adequately derived from the data?**	**Is the interpretation of results sufficiently substantiated by data?**	**Is there coherence between qualitative data sources, collection, analysis, and interpretation?**	**Ethics** (E), **consent** (C), **limitations** (L)
Antaki et al., 2017	Y	Y	Y	Y	Y	Y	Y	E: Y C: Y L: Y
Antaki et al., 2007a.	Y (aims)	Y	Y	Y	Y (claims were not always supported with evidence)	Y (claims were not always supported with evidence)	Y	E: N C: N L: Some information
Antaki et al., 2007b.	Y (aims)	Y	Y	Y	Y	Y	Y	E: N C: Some information L: N
Banks, 2012	Y (aims)	Y	Y	N	CT (no information about data analysis)	Y	CT (no information about data analysis)	E: N C: N L: N
Bradshaw & Goldbart, 2013	Y	Y	Y	Y	Y	Y	Y	E: Y C: Y L: Y
Firth et al., 2008	Y (aims)	Y	CT (the study did not generate a theory)	Y	Y	Y	Y	E: N C: Y L: Y
Haydon-Laurelut & Nunkoosing, 2010	Y (aims)	Y	Y (no specific qualitative approach was stated)	CT	CT	Y	N	E: N C: Some information L: Some information
Jingree et al., 2006	Y (aims)	Y	Y	Y	Y	Y	Y	E: N C: Y L: Y.

Report (n = 16)	**Are there clear research questions?**	**Do the collected data allow to address the research questions?**	**Is the qualitative approach appropriate to answer the research question?**	**Are the qualitative data collection methods adequate to address the research question?**	**Are the findings adequately derived from the data?**	**Is the interpretation of results sufficiently substantiated by data?**	**Is there coherence between qualitative data sources, collection, analysis, and interpretation?**	**Ethics** (E), **consent** (C), **limitations** (L)
Kennedy & Brewer, 2014	Y (aims)	Y	Y	Y	Y	N	Y	E: Y C: Y L: Y
Nagra et al., 2017	Y (aims)	Y	Y	Y	Y	Y	Y	E: N C: Y L: Y
Norah Fry Research Centre, 2010	Y (aims)	Y	Y (no specific qualitative approach was stated)	Y	CT	Y	N	E: N with some information about ethical recruitment C: N L: N
Waggett, 2012	Y (aims)	Y	Y	Y	Y	Y	Y	E: N C: N L: N
Walton et al., 2020	Y	Y	Y	Y	Y	Y	Y	E: Y C: N L: Y.
Williams et al., 2009a	Y (aims)	Y	Y	Y	Y	Y	Y	E: Y C: Y L: N
Williams et al., 2009b	Y (aims)	Y	Y	Y	Y	Y	Y	E: N C: Some information L: N
Windley & Chapman, 2010	Y (aims)	Y	N	CT	CT	Y (themes were not always supported by relevant qualitative quotes)	N	E: Y C: Y L: Y

Note. Yes (Y), No (N), Can't tell (CT).

Table 8

MMAT quantitative studies (randomised control trials)

Report (n = 3)	**Are there clear research questions?**	**Do the collected data allow to address the research questions?**	**Is randomization appropriately performed?**	**Are the groups comparable at baseline?**	**Are there complete outcome data?**	**Are outcome assessors blinded to the intervention provided?**	**Did the participants adhere to the assigned intervention?**	**Ethics** (E), **consent** (C), **limitations** (L)
Hastings et al., 2018	Y (aims)	Y	Y	Y	N	N	N	E: Y C: Y L: Y
McGill et al., 2018	Y (hypotheses)	Y	Y (only partial blinding took place)	Y	CT (significant reduction in the number of participants)	N (partial blinding; some measures were put in place to minimise bias)	N	E: Y C: Y L: Y
NIHR SSCR, 2020	Y (aims)	Y	Y	Y	N	N	N	E: N C: N L: Y

Note. Yes (Y), No (N), Can't tell (CT).

Table 9

MMAT quantitative studies (non-randomised studies)

Report (n = 16)	**Are there clear research questions?**	**Do the collected data allow to address the research questions?**	**Are the participants representative of the target population?**	**Are measurements appropriate regarding both the outcome and intervention (or exposure)?**	**Are there complete outcome data?**	**Are the confounders accounted for in the design and analysis?**	**During the study period, is the intervention administered (or exposure occurred) as intended?**	**Ethics** (E), **consent** (C), **limitations** (L)
Ashman & Beadle-Brown, 2006	Y (aims)	Y	Y	Y	CT	N	Y	E: N C: Y L: N
Beadle-Brown et al., 2012	Y (aims)	Y	Y	Y	Y (some ratings were possibly completed by different staff at follow-up due to turnover)	N	Y	E: Y C: Y L: Y

Report (n = 16)	**Are there clear research questions?**	**Do the collected data allow to address the research questions?**	**Are the participants representative of the target population?**	**Are measurements appropriate regarding both the outcome and intervention (or exposure)?**	**Are there complete outcome data?**	**Are the confounders accounted for in the design and analysis?**	**During the study period, is the intervention administered (or exposure occurred) as intended?**	**Ethics** (E), **consent** (C), **limitations** (L)
Beadle-Brown et al., 2008	Y (aims)	Y	Y	Y	Y	N	Y	E: Y C: Y L: N
Bradshaw, 1998	Y (aims)	Y	Y	Y	Y	N	Y	E: N C: N L: Y
Gillett & Stenfert-Kroese, 2003	Y (aims)	Y	CT (pilot study with very small sample size)	Y	Y	Y	Y	E: N C: N L: Y
Hume et al., 2021	Y (aims)	Y	Y	Y	Y	N	Y	E: N C: Y L: Y
Jones et al., 2001a	Y (aims)	Y	Y	Y	Y	Y	Y	E: N C: N L: Y
Jones et al., 2001b	Y (aims)	Y	Y	Y	Y	Y	Y	E: N C: N L: Y
Jones et al., 1999	Y (aims)	Y	Y	Y	Y	Y	Y	E: N C: N L: Y
Mansell et al., 2002	Y (aims)	Y	Y (small sample size)	Y	Y	Y	Y	E: N C: N L: Y
Phillips & Rose, 2010	Y (aims)	Y	Y	Y (unclear about how 'willingness to help' was measured)	Y	Y.	Y	E: N C: Y L: Y
Rose et al., 1998	Y (aims)	Y	Y (small sample size)	Y	Y (four participants refused to be observed)	N	Y	E: N C: N L: Y
Samuel et al., 2008	Y (hypotheses)	Y	Y	Y (measuring staff-client relationships could have been clearer)	CT	CT	Y	E: N C: Y (limited information) L: Y
Smith et al., 2002	Y (aims)	Y	Y	Y	Y	CT	Y	E: N C: N L: N
Toogood et al., 2009	Y (aims)	Y	Y	Y	Y	N	Y	E: N C: N

Report (n = 16)	**Are there clear research questions?**	**Do the collected data allow to address the research questions?**	**Are the participants representative of the target population?**	**Are measurements appropriate regarding both the outcome and intervention (or exposure)?**	**Are there complete outcome data?**	**Are the confounders accounted for in the design and analysis?**	**During the study period, is the intervention administered (or exposure occurred) as intended?**	**Ethics** (E), **consent** (C), **limitations** (L)
				(not explicit about why standardised tools were not used)				L: Y
Williams et al., 2015	Y (hypotheses)	Y	Y	Y	Y	Y	Y	E: N C: N L: Y

Note. Yes (Y), No (N), Can't tell (CT).

Table 10

MMAT quantitative studies (descriptive studies)

Report (n = 4)	**Are there clear research questions?**	**Do the collected data allow to address the research questions?**	**Is the sampling strategy relevant to address the research question?**	**Is the sample representative of the target population?**	**Are the measurements appropriate?**	**Is the risk of nonresponse bias low?**	**Is the statistical analysis appropriate to answer the research question?**	**Ethics** (E), **consent** (C), **limitations** (L)
Beadle-Brown et al., 2015	Y (aims)	Y	Y	Y	Y	Y	Y	E: Y C: Y L: Y
Dagnan & Cairns, 2005	Y (aims)	Y	CT (no information about sample frame and unclear rationale about sampling strategy)	Y	Y (the 'responsibility for the development of challenging behaviour' measure was not supported with evidence)	CT	Y	E: N C: N L: Y
Rose & Rose, 2005	Y (aims)	Y	Y	Y	Y	Y	Y	E: N C: N L: Y
Thomas & Rose, 2009	Y (aims-hypotheses)	Y	Y	Y	Y	Y	Y	E: Y (limited information) C: N L: Y

Note. Yes (Y), No (N), Can't tell (CT).

Table 11

JBI Checklist for text and opinion pieces

Report (n = 4)	**Is the source of the opinion clearly identified?**	**Does the source of opinion have standing in the field of expertise?**	**Are the interests of the relevant population the central focus of the opinion?**	**Is the stated position the result of an analytical process, and is there logic in the opinion expressed?**	**Is there reference to the extant literature?**	**Is any incongruence with the literature/sources logically defended?**
Bowler & Nash. 2014	Y	Y	Y	Y	Y	N/A (No incongruence)
Broussine, 2012	Y	Y	Y	Y	Y	N/A (No incongruence)
Finlay et al., 2008	Y	Y	Y	Y	Y	Y
Thurman et al., 2005	Y	Y	Y	Y	Y	Y

Note. Yes (Y), No (N), Can't tell (CT).

Table 12

AACODS checklist

n = 2	Grove & Mcintosh, 2005	Health and Social Care, 2016
Authority		
Individual author:		
• Associated with a reputable organisation?	Y	
• Professional qualifications or considerable experience?	Y	
• Produced/published other work (grey/black) in the field?	Y	N/A
• Recognised expert, identified in other sources?	Y	
• Cited by others? (use Google Scholar as a quick check)	Y (information only available about the first author)	
• Higher degree student under "expert" supervision?	? (no information)	
Organisation or group:		
• Is the organisation reputable? (e.g. W.H.O)	Y	Y
• Is the organisation an authority in the field?	N	Y
In all cases:	N (list of resources is provided)	Y (bibliography was not detailed)

• Does the item have a detailed reference list or bibliography?		
Accuracy		
• Does the item have a clearly stated aim or brief?	Y	Y
• If so, is this met?	Y	Y
• Does it have a stated methodology?	N	N
• If so, is it adhered to?	-	-
• Has it been peer-reviewed?	? (no information)	? (no information)
• Has it been edited by a reputable authority?	Y	Y
• Supported by authoritative, documented references or credible sources?	N	Y
• Is it representative of work in the field?	Y	Y
• If No, is it a valid counterbalance?	-	-
• Is any data collection explicit and appropriate for the research?	N	N
• If item is secondary material (e.g. a policy brief of a technical report) refer to the original. Is it an accurate, unbiased interpretation or analysis?	Y	Y
Coverage		
• Are any limits clearly stated?	N	Y
Objectivity		
• Opinion, expert or otherwise, is still opinion: is the author's standpoint clear?	Y	Y
• Does the work seem to be balanced in presentation?	Y	Y
Date		
• Does the item have a clearly stated date related to content? No easily discernible date is a strong concern.	Y	N
• If no date is given, but can be closely ascertained, is there a valid reason for its absence?	-	N
• Check the bibliography: have key contemporary material been included?	N	Y
Significance		
• Is the item meaningful? (this incorporates feasibility, utility, and relevance)	Y	Y
• Does it add context?	Y	Y

• Does it enrich or add something unique to the research?	Y	Y
• Does it strengthen or refute a current position?	Y	Y
• Would the research area be lesser without it?	?	?
• Is it integral, representative, typical?	Y	Y
• Does it have impact? (in the sense of influencing the work or behaviour of others)	Y	Y

Note. Yes (Y), No (N), Not applicable (N/A), Unknown (?).

3.5 Discussion

This systematic review synthesised literature on care relationships between support staff and adults with a learning disability in UK social care residential settings, covering 41 years of relevant work. Each area of relationships that I explored and presented results for in the section above is discussed below through the lens of the wider literature. By doing so, I aim to contextualise, reflect on, and engage critically with my findings.

Definitions & conceptualisations of care relationships

Definitions of good care relationships revolved around friendship, equality, professionalism, and power. These topics are not always mutually compatible. Residents often perceive staff as friends (Giesbers et al., 2019) while staff may seek to maintain professional distance (Pockney, 2006). Uncertain relational boundaries, although to some degree unavoidable due to the nature of care work in residential settings, may lead to differing expectations and hence damage relationships (Rogers, 2016). Staff describing themselves as friends can be interpreted as coaching residents about who their friends are, resulting in disempowerment (Antaki et al., 2007a). Equality is an ongoing objective; however, staff's roles involve a degree of power which questions the feasibility of parity of status (Pockney, 2006). Nonetheless, research suggests that in learning disability intentional communities (e.g.,

Camphill), friendships, equality, and blurred boundaries are perhaps experienced more flexibly, as an integral part of the care relationship (Randell & Cumella, 2009).

Processes & practices underlying positive care relationships

Knowing the person is key, however, staff relying solely on this can result in dismissing training as well as in poor care practices (Bradshaw & Goldbart, 2013). Tuning in reflects the wider literature exploring professional relationships (e.g., nursing; Riviere et al., 2019) and resembles the concept of 'connecting' in Johnson and colleagues' model (2012). Tuning in and listening may happen simultaneously (Broussine, 2012), however, whether other processes are sequenced is unclear.

Interestingly, person-centred processes from therapeutic relationships (Rogers, 1957) also appeared in learning disability care relationships. Similar to the 'Definitions and conceptualisations' section above, setting boundaries and shifting power were important processes, highlighting their relevance to care work. Using humour to build relationships corresponds with the model of Johnson and colleagues (2012) and reflects care relationships with other groups of people (e.g., older adults; Brown-Wilson & Davies, 2009).

Barriers to positive care relationships

Support staff's attributions reflect the wider literature around attributions and behaviour, for example, attributions and mental health stigma (Corrigan et al., 2003). Residents' communication difficulties may mitigate staff's negative attributions, with staff judging residents with communication difficulties as less responsible for difficult behaviours (Williams et al., 2015). However, support staff can often overestimate the communicative abilities of people with a learning disability (Purcell et al., 1999 as cited in Williams et al., 2015) leading to an increase in staff's attributions of difficult behaviour (Williams et al., 2015)

with potential implications for staff's emotions (i.e., less sympathy for the resident who is displaying behaviour that challenges).

Transference, a concept widely used in psychotherapy, also appeared in learning disability care relationships (Waggett, 2012). Boundaries were, once again, highlighted with an emphasis on how challenges around boundary setting can hinder good relationships (Norah Fry Research Centre, 2010). The review suggests that care dilemmas are part of the staff experience and shape the care relationship. More specifically, complying with policy reforms that emphasise autonomy versus making decisions on behalf of residents (Banks, 2012), providing emotional support versus pre-occupation with physical tasks (Nagra et al., 2017), or having multiple roles (e.g., enabler, advocate) versus handling organisational duties (Antaki et al., 2007a), can lead to managing conflicting responsibilities and create dilemmas between care and control (Antaki et al., 2007a).

Staff dilemmas correspond with the wider care literature. Brown-Wilson & Davies (2009) discuss three types of relationships in care homes for adults without learning disabilities; pragmatic (i.e., focusing on care tasks), personal (i.e., focusing on what matters to the resident), and reciprocal (i.e., focusing on shared understanding). Staff dilemmas highlight that different priorities and processes, hence different types of relationships, may co-exist, without implying that this cohabitation is always balanced. After all, care work operates in the intersection of emotions, practical everyday care, and the socio-political context (Rogers, 2016).

Facilitators of positive care relationships

Several researchers (Hume et al., 2021; Jones et al., 2001b; Smith et al., 2002) suggest that, regarding improving interactions and relationships, active support training is most effective when the full training is delivered, including the practical components. Active support can benefit adults with severe as well as milder learning disability in their relationships (Jones

et al., 2001b). More recent research has explored connections between active support and creating enabling staff-client relationships (Mansell & Beadle-Brown, 2012). The effects of active support may decrease, and practice leadership and management involvement are key to maintaining quality support (Ashman & Beadle-Brown, 2006; Toogood et al., 2009). Attitudes towards training are not always positive; for example, support staff may dismiss intensive interaction as irrelevant (Firth et al., 2008). Support staff responding with empathy and understanding towards residents with difficult behaviours is a complex situation and training designed to increase staff empathy, and consequently improve care relationships and overall care provision, does not always have significant effects (see Hastings et al., 2018 for discussion).

Impact of positive care relationships & restoration of disrupted relationships

As discussed in the 'Interpretative synthesis – Relationships within and between reports' section of this study, positive care relationships appear to play a key role in the provision of effective care and the improvement of the self-esteem of people with a learning disability. Nevertheless, the information I identified in the literature was somewhat limited and did not provide a well-rounded account of the impact of having or lacking good care relationships. For example, I remain uncertain about how relationships impact support staff or about the multifaceted impact that a lack of positive care relationships might have on residents. Similarly, limited information was found about ways to restore disrupted care relationships. Given the complexities of providing and receiving care in the realm of everyday life and the presence of behaviours that challenge among a fair number of residents with a learning disability (e.g., Hastings et al., 2018), surely there must be various everyday practices and care systems that support staff and residents engage with to restore care relationships that have been challenged.

3.6 Conclusions & project directions

I hope that through this study, I have provided a well-rounded account of learning disability care relationships by synthesising relevant UK literature, and expanded our knowledge. Importantly, the present study also served as a starting point for future empirical research both in the context of this project and, I hope, in the context of the wider scientific community. More specifically, in this review, only a limited number of included reports addressed care relationships explicitly and certain research questions (e.g., barriers to and facilitators of positive care relationships) were answered more fully, whereas others (e.g., restoring relationships, relational practices and processes, and the impact of care relationships) seemed to require further exploration. This highlighted an overall need for empirical research that explicitly examines care relationships between support staff and adults with a learning disability in UK residential settings, whilst investigating further the relational areas for which evidence was limited. Crucially, the results of this systematic review highlighted understandings of care relationships that contained some tensions, for instance, discourses of staff-resident friendship whilst remaining professional and in an inevitable position of power as support staff. This pushed me more towards enquiring about such understandings in my subsequent studies.

Moreover, there were numerous occasions where the same report would fall under different clusters, perhaps emphasising that the results of this study would be better understood in conjunction with each other; for instance, what serves as a facilitator can, at the same time, be a care practice or process, and also be used to define what we mean by care relationships. This led me to suggest with more confidence that the care relationship is complex and multifaceted and part of a wider care ecosystem,[24] where various elements, sometimes

[24] Thank you to one of the attendees of the NIHR SSCR conference 2024 who encouraged me to elaborate and reflect on whether the care relationship *is* the ecosystem, as I stated in my oral talk at the conference, or if it is best understood as *part of* an ecosystem, in our case the social care ecosystem.

operating in harmony and others in conflict, may co-exist. This pluralistic and situated understanding of care relationships was taken into account when planning and conducting the empirical studies that I discuss in the subsequent Chapters 4 and 5.

Furthermore, I observed that the voice of adults with a learning disability was not well represented in the included reports and a note was made to try and address this in my subsequent empirical studies. The study highlighted staff dilemmas during care provision, a concept I found intriguing and aspired to explore further empirically. Finally, although different levels of learning disability were included in the reports I reviewed, the studies did not explore whether or how such levels may influence the care relationship (e.g., by serving as a barrier or facilitator) and I was interested to see whether my empirical studies would cover this.

The systematic literature review encompassed a range of study designs and report formats. Although I certainly believe that every research design and format has its own merits, I felt that qualitative research designs (e.g., interviews, ethnographic observations, diaries) were particularly useful for exploring care relationships. Such methods allow the exploration of meanings and lived experiences and seem appropriate for capturing the various levels of care provision and relationships.

Summary of Chapter 3

In this chapter, I discussed the first study I conducted for this research project, which was a systematic literature review that sought to synthesise relevant UK literature, expand knowledge, and identify directions for empirical research. The review was conducted between late June and mid-July 2021 and was informed by official guidelines, covering 41 years of relevant work.

Definitions and conceptualisations of care relationships revolved around friendship, equality, professionalism, and power. Practices and processes underlying positive relationships included knowing the person, setting boundaries, and shifting power dynamics. Barriers to positive care relationships included staff interactional patterns, attributions, and staff dilemmas, whilst facilitators included receiving training and using communication tools. Good care relationships were key to effective support and ways to restore disrupted relationships included receiving input from systemic therapy. Literature was limited for certain research questions and more extensive for others. Only a few reports addressed care relationships as such and the voice of residents was limited.

Study 1 pointed towards understanding the care relationship in rather applied and practical ways whilst situating it in the wider UK social care context. Also, it highlighted that care relationships seem to contain various tensions and contradictions. Being equipped with the findings of Study 1 as a compass, I embarked on my empirical research to explore uncharted relational terrains and address the gaps identified in the systematic literature review. Focusing on the perspectives of support staff was the next logical step for this project.

Chapter 4: Study 2 – The Views and Experiences of Support Staff

4.1 Introduction

As discussed in Chapter 1, support staff play a key role in the lives of people with a learning disability in social care residential settings, and, oftentimes, staff are the only people that the residents have. At the same time, as Study 1 indicated, the care relationship involves power dynamics and support staff appear to be in a position of power compared with the position of residents. With this in mind, in this empirical study, I used the findings of Study 1 as a compass and focused on one of the key partners in the care relationship, namely the support staff themselves, seeking to hear their stories and explore their views and experiences so I address the aim and research questions of the project (see Chapter 1, section 1.4) further.

4.2 Methodology[25]

Design

In this study, I employed a qualitative design; in principle, qualitative designs focus on meaning-making, subjectivity, and contextualised knowledge (Braun & Clarke, 2022). This design was chosen as the best 'fit', corresponding with the project's rationale, aim and research questions, as well as the theoretical and policy frameworks in which the project was situated in Chapter 2, thus creating overall conceptual coherence (Braun & Clarke, 2022).

[25] Throughout this section, the reader may notice that I rely primarily, but not solely, on Braun and Clarke's (2022) text to elaborate on this study's methodology. Besides their significant contribution towards theorising and developing thematic analysis over the past two decades, Virginia Braun and Victoria Clarke have systematically engaged with the theoretical and philosophical assumptions underpinning the process of conducting research. Importantly, they have done so in an accessible, engaging, and applied manner that has always resonated with me. In their 2022 book, Braun and Clarke provide a comprehensive, concise, and well-evidenced methodological map and relevant guidelines, building on their publications over the past 20 years. After reading their book, reflecting on it, and taking into consideration its aforementioned strengths, I decided to use it as my primary source to describe this study's methodology. I made a few additional citations of the work of other scholars, yet only when I determined that it was necessary and would serve as a meaningful addition, while refraining from making citations performatively to merely demonstrate knowledge.

Qualitative conceptual paradigm

More specifically, my qualitative design was underpinned mainly by an interpretive conceptual paradigm, and I employed a predominantly experiential qualitative approach (Braun & Clarke, 2022). An interpretive paradigm and an experiential orientation entailed moving beyond a mere intellectual engagement with the world and being guided by the participants' lived experience of building relationships and providing care in learning disability residential settings, focusing on the meanings they ascribed to and their interpretations of these processes (Alharahsheh & Pius, 2020; Braun & Clarke, 2022). As a result, I leaned towards a hermeneutics[26] of empathy (Braun & Clarke, 2022), which entailed following and staying close to the aforementioned meanings and experiences of participants.

Nevertheless, qualitative approaches are best understood as a spectrum rather than neatly distinct categories (Braun & Clarke, 2022), and my position as a researcher was one of an always active interpreter whereby the analytic task looks more like "storytelling rather than truth-telling – to acknowledge the role of interpretation" (Braun & Clarke, 2022, p. 197). Considering this, taking a predominantly experiential qualitative approach did not exclude moments of moving in the spectrum and drawing on critical qualitative orientations too, leading me to a hermeneutics of suspicion (Braun & Clarke, 2022) whereby meanings, experiences, and claims presented by the participants are unpacked and somewhat interrogated by the researcher.

[26] "Hermeneutics refers to the philosophy of interpretation – the assumptions that underpin how we make sense of and interpret data" (Braun & Clarke, 2022, p. 160).

Theorisation of language & ontological and epistemological position[27]

In line with the predominantly experiential qualitative approach that I took in this study, I employed primarily an intentional theorisation of language, which assumes that participants use language to convey their views, experiences, and feelings, in other words, *their* situated realities, rather than a *universal* reality or truth (Braun & Clarke, 2022). Once more, there were moments when I moved in the spectrum and conceptualised language in a more constructionist manner too, viewing language "as something active, as creating meaning, rather than simply reflecting it" (Braun & Clarke, 2022, p. 164).

Corresponding with a mainly intentional theorisation of language, I employed a critical realist ontological[28] position. In principle, critical realism[29] assumes a reality that exists outside research practice, yet emphasises that one can only experience reality contextually, situated in language, culture, social structures, and the historical and social context (Braun & Clarke, 2022). Epistemologically,[30] and in agreement with a critical realist ontological position, I employed a contextualist approach that understands knowledge as partial, situated in the wider social and historical context, and inseparable from the subjectivity of the researcher generating it (Braun & Clarke, 2022). My epistemological position aligned with the key role that positionality and reflexivity played in this project, as in a contextualist epistemology, the

[27] The ontological and epistemological position that I employ in this study, and, generally speaking, the general spirit of this research project, are based in the so called western social science tradition. This reflects my own positionality as a White, cis-male, non-disabled researcher who was trained academically and still operates in predominantly White, cis-male, non-disabled western academic institutions. The assumption that such frameworks and traditions are universal is incorrect and I would like to direct the reader to Braun and Clarke (2022) and specifically Chapter 6, Box 6.6, for an overview of Indigenous knowledge frameworks that some people use in research.

[28] "Ontology relates to the nature of reality or being; theories of what exists/is real" (Braun & Clarke, 2022, p. 166).

[29] In this thesis, my understanding of critical realism aligns with the analysis of Braun and Clarke (2022). However, critical realism can be understood in different ways. For an overview of its variations, I would like to direct the reader to Braun and Clarke (2022) and specifically Chapter 6, Box 6.4 as well as to Willis (2022).

[30] "Epistemology relates to knowledge, theorising what it is possible to know and meaningful ways of generating knowledge" (Braun & Clarke, 2022, p. 166).

researcher ought to be reflexive to highlight the active role that their position, values, and overall context play in knowledge production (Braun & Clarke, 2022).

Methods

A short Demographics & Eligibility Questionnaire (see Appendix 2) was devised to assess people's eligibility to take part in this study and gather essential demographic and work-related information from those who would be deemed eligible to participate. The Demographics & Eligibility Questionnaire was piloted with a colleague[31] from the Tizard Centre, University of Kent, as well as with three people from my personal networks working in health and social care services in the UK and Greece. The feedback provided during the piloting phase was used to evaluate the accessibility of the questionnaire and to improve relevant areas.

Semi-structured interviews were chosen as the method to explore the views and experiences of eligible support staff. The semi-structured interview format aligned with my ontological and epistemological position and was expected to create more flexible and relational dynamics, allowing the participants and I to develop trust and have an honest conversation. As specific aims and research questions were being addressed, an unstructured interview format was not deemed appropriate. Equally, a structured interview format was rejected as too formal, as it could make participants uncomfortable and potentially influence their responses (e.g., providing socially desirable responses instead of authentic answers based on their views and experiences). Relevant literature (i.e., McGrath et al., 2018) on how to conduct qualitative interviews was consulted, and an Interview Protocol (see Appendix 2) was generated to guide the semi-structured interviews. The protocol was piloted with a colleague[32]

[31] Thank you to Dr Krysia Waldock for assisting with piloting the questionnaire.
[32] Thank you to Nicola Elson for assisting with piloting the interview protocol.

from the Tizard Centre, University of Kent, in a mock interview, and their feedback was used to make improvements.

Defining the participants: inclusion & exclusion criteria

To take part in the study, people had to be formal, paid support staff[33] working in long-term social care residential settings[34] for adults with a learning disability in England. Care could be funded privately or via local authorities, and residential settings could be managed by private or third-sector/voluntary organisations or by local councils. Support staff on zero-hour contracts or agency/bank staff were eligible, subject to assessing how often they supported adults with a learning disability. Staff must have had at least three months of care experience in the service where they were based. Drawing on my own work experiences and upon discussion with my supervisors, it was determined that three months, albeit short, was a reasonably sufficient period for a member of staff and a resident to develop an initial sense of a relationship and, hence, for the participant to be able to share their views on and experiences of care relationships in a meaningful way. Equally, it was determined that under three months of experience in a residential setting was not enough for the person to reflect on their relationship with the residents meaningfully. Nonetheless, I took a case-by-case approach to ensure that people would not be unnecessarily excluded from the study (e.g., experienced staff who have just started working in a service could be eligible). Support staff had to be 18 years old or older and able to communicate in English. Support staff from all genders, ethnicities, and backgrounds were welcome to participate.

People who were not eligible to take part in this study were learning disability support staff who worked in short-term or respite social care residential settings, Shared Lives

[33] As defined in Chapter 1, specifically the section '1.2 Dissecting the thesis title: Contextualising learning disability care relationships'.
[34] As defined in Chapter 1, specifically the section '1.2 Dissecting the thesis title: Contextualising learning disability care relationships'.

schemes,[35] community palliative settings, or long-term social care residential settings managed by the NHS as this study did not seek ethical approval required for NHS settings. Support staff who did not work with adults with a learning disability were not eligible either. Furthermore, practitioners other than support staff (e.g., nurses, psychologists, ABA specialists), volunteer carers, informal carers (i.e., friends or family providing care without payment; Foster & Harker, 2024), or new support staff with less than three months of experience and no prior experience in learning disabilities were not eligible. Support staff below the age of 18, not working in England, or not able to communicate in English were not eligible either.

Determining the number of participants

I set out to recruit 20 participants, a decision which was based on a combination of evidence-based and pragmatic reasons. More specifically, this dataset size[36] was within the suggested range for participants coming from multiple organisations, nonetheless operating in one sector (Saunders & Townsend, 2016), namely the care sector, in other words, participants that can be described as a relatively homogenous population.

Additionally, from a pragmatic point of view, I anticipated that the participants, like most social care support staff, would have heavy workloads and variable shift patterns (e.g., morning, evening, or night shifts), and setting a much larger dataset size would not be meaningful and realistic. This was also connected to my own workload and the time constraints pertinent to conducting this study; for instance, in my reports to the University of Kent as part

[35] Following the discussion in footnote 15, I was sceptical about this exclusion criterion as Study 2 was progressing, and when the opportunity arose to include a Shared Lives carer, I decided to not take into account this criterion determining that including Shared Lives carers would only enrich my research.

[36] The term 'dataset size' is borrowed from Braun and Clarke (2022) and serves as an alternative to the term 'sample size'. I affirm Braun and Clarke's (2022) critique of the language of 'sample size' and how such language is associated with research practice that is situated in a positivist paradigm, which may be at odds with conducting qualitative research that, in the case of this project, is situated in an interpretive paradigm. A 'dataset' entails all individual data items (Braun & Clarke, 2022) and a 'data item' is a piece of data, for instance, an interview transcript (Braun & Clarke, 2022).

of my doctoral milestones, I allocated five months for data collection for this study and three months for data analysis, before progressing to my next empirical research. Therefore, a much larger dataset size would not have been in line with the conditions and the pace surrounding this research project. That is not to say that there was no scope for flexibility in the project as, if needed, more time could have been potentially allocated to this study, as eventually did, not during the planning phase but during data collection as I will address later on.

Finally, saturation, namely the point at which the data are not expected to yield any new information, is often used to determine dataset size, nonetheless, as a concept, it is either employed within the Grounded Theory analytical framework (Glaser & Strauss, 1999) or, outside this framework, it is used as a general rule of thumb without, however, an elaborate understanding of how it should be employed in non-Grounded Theory contexts (see Braun & Clarke, 2021, for a critical overview of saturation and alternatives to it). As in this study, I neither used a Grounded Theory analytical framework nor wished to uncritically employ tools that I could not justify the rationale behind using them, I found the concept of information power (Malterud et al., 2015) more useful for informing my decision-making around dataset size. Information power emphasises study aspects such as narrow versus broad aims and research questions, dense versus sparse participant populations, and other factors, essentially entailing that "the larger information power the sample holds, the lower *N* is needed, and vice versa" (Malterud et al., 2015, p. 2). Given the applied focus of my research project, its aim and research questions, as well as the relatively homogenous population of participants that I intended to recruit, I anticipated "information *richness*" (Braun & Clarke, 2022, p. 28) and concluded that my chosen dataset size was sufficient.

4.3 Conduct of study & analytic framework

Recruitment, data collection, & reflexivity

The study received a favourable ethical opinion from the Tizard Centre Ethics Committee in June 2022 (see Appendix 2) and sponsorship from the University of Kent in July 2022 (see Appendix 2). The study was subsequently launched in late July 2022, and I started recruiting participants. Data collection began in late July 2022, with the first eligible individual participating in the study a few days after the launch. Recruitment of participants was carried out primarily online by targeting and reaching out to relevant individuals and care organisations and sharing a flyer containing essential information about the study (see Appendix 2), often accompanied by a brief text (e.g., email) introducing myself and the overall PhD project. Snowball recruitment also occurred with participants and organisations sharing the study information with relevant parties upon my request or on their own initiative.

More specifically, I used several avenues to reach out to parties of interest, for instance, advertising the study at the University of Kent and Tizard Centre social media and the social media of other institutions (e.g., the Centre for Care based at the University of Sheffield), sharing the study in relevant mailing lists (e.g., Tizard Centre practitioners' mailing list; Intellectual Disability – Research – UK Jisc mailing list), as well as my supervisors and I circulating the study to our professional networks and directly contacting numerous care organisations, regardless of how big or small, to bring the study to their attention, noting 79 entries associated with correspondence with relevant care organisations. Upon researching and obtaining evidence about its credibility, I also used a UK website dedicated to advertising studies to a pool of people who have expressed their interest in participating in research, hoping to identify some support staff there, too. Furthermore, I registered the study in the NIHR CRN[37]

[37] As of October 1, 2024, the NIHR Research Delivery Network has replaced the NIHR CRN.

portfolio (NIHR CPMS: 54431; IRAS ID: 322189), which made it visible to other CRNs and enabled me to utilise NIHR ENRICH, which significantly boosted my recruitment efforts in learning disability residential settings. Additionally, I also used the CHAIN Network, which helped me reach out to more support staff and care organisations who were part of the network.

A few weeks into the recruitment process (i.e., mid-August 2022), I received several similarly written expressions of interest sent primarily from accounts using the same email provider, often within minutes of each other. This made me suspicious and after assessing the situation, discussing it with colleagues, and consulting relevant NIHR guidelines, I concluded that those were fake accounts and false expressions of interest, and summarily deleted them. I suspected that advertising the study on social media and perhaps on the website I discussed earlier had attracted those fake accounts. Regarding the website, after sharing my thoughts with the administrators and enquiring about website measures to protect against fake accounts, I decided to remove the study from the website. There was a second wave of false expressions of interest a few months into the study (i.e., October 2022) which followed identical patterns and was treated the same way I treated the first wave. There were no further false expressions of interest.

Recruitment and data collection for this study were completed in April 2023, spanning a period of 10 months. This exceeded my initial recruitment and data collection timescale (i.e., July 2022 – November 2022) by five months. Some adjustments had to be made in my workload and the overall planning of the PhD project, as this additional time was necessary because recruitment was a slow process and, even though fairly steady for the most part, there were months that people would not express an interest, and a recruitment boost had to take place (i.e., re-advertising the study or exploring new recruitment avenues). Nonetheless, I exceeded the dataset size that I had initially set out (i.e., 20 participants) by three people, resulting in a total of 23 participants. As I was approaching my initial recruitment target, I felt

that the information power (Malterud et al., 2015) of the data that I had collected thus far was sufficient to address the project's aim and research questions meaningfully, and, therefore, I could conclude the study once the recruitment target was achieved. However, I felt that, as a researcher, I had a responsibility to honour the three additional people's desire to participate in the study, and I was scientifically curious about their views and experiences, anticipating that they could only offer more insight into care relationships. In light of this, and with no pragmatic obstacles in sight as the three additional participants could be fitted within the extended recruitment timescale, I included them in the study.

The recruitment process and data collection involved significant planning, coordination, communication, persistence, and problem-solving. The knowledge, understanding, and intuition that I acquired during my years as a support worker played a significant role in navigating the nuances of this process. For instance, as a former support staff, I found it easy to tune in with the realities of care organisations and staff, to approach them with confidence and explain the study, as well as to pace my reach out, deciding when I should contact them or follow up with them, to name but a few.

Procedure & reflexivity

People who expressed an interest in taking part in the study received an email that contained 1) an Information Sheet for Participants (see Appendix 2) as an attached document, with information about the purpose and conduct of the study, inclusion and exclusion criteria, payment process, services to contact if get distressed, confidentiality and data protection, dissemination, ways to provide feedback or make a complaint, and my contact details as well as the contact details of my supervisors; 2) a Comments Form (see Appendix 2) as an attached document, in case the participant wished to provide any kind of feedback or make a complaint, whilst clarifying that providing feedback was not mandatory; 3) a link to the short Consent

Form (see Appendix 2) uploaded on the experience management software Qualtrics© (University of Kent account), whilst reminding the person that the form must be filled in once the Information Sheet for Participants has been read (and not before that) and highlighting that the form takes approximately one minute to complete; and 4) a link to the Demographics & Eligibility Questionnaire (approximately five minutes to complete) uploaded on the experience management software Qualtrics© (University of Kent account), containing mandatory demographic (e.g., gender, age), professional (e.g., job title, type of residential setting), and eligibility (e.g., confirmation that the person is working in long-term residential settings for adults with a learning disability) questions so I assess whether the person expressing an interest could participate in the study and to also be able to describe the participants as a group. Providing one's official work email address (i.e., company email address) was a mandatory question in the questionnaire or this was automatically confirmed if people were using their official work email to contact me directly. This served as an additional measure to verify that people were support staff based in England and, therefore, ensure high-quality data. If the person did not have an official work email address, alternatives were considered, for instance, requesting other evidence that demonstrates their role in their organisation and using my judgment and care work experience to make a decision based on that evidence and my overall correspondence with the person. People who expressed an interest but did not complete, or only partially completed their forms, received a gentle reminder after seven to ten days. If necessary, a second gentle reminder was sent out, before eventually removing the individual from the study.

If an individual was deemed not eligible to participate in the study, they were informed of this and were explained the reasons, and their completed questionnaire and other forms were permanently deleted. Eligible individuals were contacted via email to arrange a date and time to conduct the interview. Interviews could take place either in person or online; nonetheless,

all interviews were conducted online, either on Zoom© or Microsoft Teams©, as this seemed to suit the participants and was also convenient for me, given the participants' geographical diversity across England.[38] The Interview Protocol served as a guide to conducting the interviews, while I also followed up on topics that the participants were discussing or skipped or revisited specific questions in the Interview Protocol as I saw fit. The mean ($\bar{x}$) duration per interview with participants was equal to 31 minutes, ranging from 18 minutes to an hour and a half. All interviews were recorded so they could be transcribed and analysed upon completion of data collection.

As anticipated, my previous experience as a support worker in learning disability residential settings played a key role when conducting the interviews. I disclosed my background in care work in the Information Sheet for Participants as well as in the brief introduction that preceded the interview questions (see Interview Protocol) to be transparent with the participants and establish trust. My care practitioner experiences made it easier for me to build rapport with the participants and navigate the interview process whilst understanding the realities of care work and hearing the views and experiences of participants with empathy. At the same time, I continuously reflected on the various ways that my care work background could be influencing the course of the interview, for instance, elaborating on how the participants' experiences might, or might not, resemble my work experiences and how this could be shaping my interpretations. The interviews felt genuine, and the participants' responses felt honest and authentic, with some participants even sharing their thoughts on the interview questions themselves, for example, a participant said: "I don't know whether that question is framed quite right, the way that I see how those relationships work". Overall, the participants appeared to enjoy the interviews and value the research project, for instance, a

[38] For more information about the participants' geographical diversity across England, see the section '4.4 Analysis – Participant characteristics' of this chapter.

participant said: "Can I see it when it's published? Could you send it please, because I'm really curious?"

Upon completion of the interview, participants were thanked for their time and were asked whether they wished to receive a copy of their anonymised interview transcript once it was ready, as well as a summary of the study findings once they were generated. Twelve out of 23 participants said that they wished to receive a copy of their anonymised interview transcript, and all participants indicated that they wanted a summary of the findings. I also asked the participants to indicate how they wished to be contacted (e.g., by email) so they could receive the documents mentioned above, and once they were ready, I shared the documents with them. Finally, participants were reminded that they would be receiving a Certificate of Participation (see Appendix 2) by email as well as a £10 payment[39] via bank transfer. To receive their payment, participants were asked to complete the short University of Kent - Public Advisor Payment Form (see Appendix 2) and email it back to me. Some participants accepted payment, whereas others declined it or chose to donate their payment to an appropriate organisation.

Transcription

Both Zoom© and Microsoft Teams© allow automatic transcription when audio or video recording. Those automatically generated transcriptions were used as a starting point for time efficiency. From there, I methodically went through each interview transcript while watching the corresponding video recording, checking for software errors (i.e., instances where the software had misinterpreted what I or the participant had said) and making corrections accordingly.

[39] For more information about payments, see the subsequent section 'Ethical considerations' of this chapter.

I gravitated towards a naturalised approach to transcription (Oliver et al., 2005), meaning that in each transcript I aimed to capture the interview as closely as it took place, including nuances such as overlapping speech, pauses, laughter, silences, stuttering, idioms, situations that occurred during the interview (e.g., a phone that is ringing and interrupting the interview), and conversational tokens (e.g., "yeah", "hm", "ah"). Words or sentences emphasised by the participants, or by me, during the interview, were reflected in the transcript using capital letters. Information that has been omitted for data protection purposes (e.g., names, locations) as well as necessary clarifications made by me, were indicated in the transcript with square brackets (e.g., [name], in the case of removing a person's name). Shorter pauses were indicated in the transcript with two dots (i.e., ..) and longer pauses with three dots (i.e., …). Significantly longer pauses and any other situations that occurred during the interview were indicated in the transcript by explaining what was occurring inside a double parenthesis, for instance: "supporting them to… have cups of tea ((both participant and researcher smile))". The video recordings made it easier to implement a naturalised approach to transcription as they also facilitated access to the visual aspects of the interview. There were occasions when I was unable to understand what the participant was saying (e.g., due to poor internet connection, noisy background, etc) and I indicated this in the transcript by using the word 'incomprehensible' in square brackets. Additionally, during an interview with a participant, Microsoft Teams© inexplicably stopped recording for a few minutes, therefore, for this portion of the interview, I could not compare the automatically generated transcript against the recording. I offered a highlighted explanation in the transcript to clarify what occurred. All interview transcripts were completely anonymised.[40]

[40] For more information about data anonymisation, see the subsequent section 'Ethical considerations' of this chapter.

Every approach to transcription comes with its own constraints and opportunities, and as Oliver and colleagues (2005) suggest, reflexivity is key. In line with my theorisation of language and the ontological and epistemological positions discussed previously in the section '4.2 Methodology' of this chapter, a primarily naturalised orientation to transcription allowed me to remain close to and be led by the experiences, meanings, and styles of participants. Moreover, despite making the process of transcription more time-consuming, capturing how participants were sharing their views and experiences provided more context and nuance to what they were discussing, thus making it easier for me to navigate their answers. Finally, I appreciated that the participants might feel somewhat strange reading through their naturalised transcription, as some people were already quite unsure about the way they were articulating their answers during the interviews (e.g., "Did I answer the question?", to quote one of the participants). However, I felt that it was not my place to polish people's articulations. Instead, I considered it my duty to ensure that the transcript represented, as humanly possible, what the participants had trusted me with during the interviews, as well as the way they had done it and ground my analysis in their voices. None of the participants who received their interview transcripts provided feedback on them.

Analytic framework & justification

I determined that reflexive thematic analysis (Braun & Clarke, 2022) was the appropriate analytic framework for this study. Overall, in reflexive thematic analysis, Braun and Clarke build on and expand their established and widely used conceptualisation of thematic analysis (i.e., Braun & Clarke, 2006), highlighting the key role of researcher reflexivity whilst explicitly situating their framework within a fully qualitative paradigm, also called Big Q (Braun & Clarke, 2022). A fully qualitative, or Big Q, orientation entails qualitative sensibility, namely a focus on processes and meaning; a critical, questioning and reflexive approach to life and knowledge; active and positioned engagement with the data; ability to embrace complexity

and contradiction; and tolerance towards uncertainty and the idea of subjective and situated truths, as opposed to the notion of an objective, singular universal truth that awaits to be unearthed (Braun & Clarke, 2022).

The reader may wonder about the *why* and the *how* I decided to employ reflexive thematic analysis over other qualitative analytic frameworks. "Deciding on an analytic approach it is more like deciding between which type of fruit you will choose to eat (apple, orange or banana?), than deciding whether to have fruit, a slice of cake, or a burger", playfully state Braun and Clarke (2020, p. 2). In other words, qualitative data analysis can be approached in different ways (Braun & Clarke, 2020), yet this should not be viewed as an antagonistic relationship between analytic frameworks (e.g., framework A is 'better' than framework B). Instead, it is a decision made by the researcher after assessing what serves as a good 'fit' (Braun & Clarke, 2022) for the research conducted, considering numerous pragmatic factors, and, oftentimes, taking into account the researcher's preference for or familiarity with a particular analytic approach (Braun & Clarke, 2020). Reflexive thematic analysis was the analytic framework of my choice for several reasons.

To begin with, as I situated this study within a Big Q orientation, I determined that other analytic approaches across the spectrum of thematic analysis, such as coding reliability and codebook approaches, would not satisfactorily match the aim and research questions of this study and overall project (see Chapter 1, section 1.4), my theorisation of language and ontological and epistemological position, and my methods. More specifically, coding reliability lies within a small q qualitative paradigm, which is often associated with positivist orientations and pertinent tools (e.g., reliability), is rarely fully inductive, and requires several coders for reliability (Braun & Clarke, 2022). Codebook approaches are situated within a medium q paradigm, which is placed between the values and philosophical assumptions of Big Q and a more structured orientation regarding the process of generating themes (Braun &

Clarke, 2020). Although in comparison to coding reliability, codebook approaches were perhaps more aligned with the theoretical assumptions of this study, I determined that codebook approaches would not allow me to develop themes in a nuanced manner, or at least the way that reflexive thematic analysis would; therefore I decided against employing this analytic framework.

Furthermore, Interpretative Phenomenological Analysis is a well-established, theoretically solid qualitative analytic framework that focuses on lived experience and is used widely in psychology (Eatough & Smith, 2017). Nonetheless, I decided in favour of reflexive thematic analysis over Interpretative Phenomenological Analysis for several reasons. Specifically, although mostly homogeneous, my dataset size was relatively large (i.e., 23 participants, as discussed in previous sections) as opposed to Interpretative Phenomenological Analysis which is typically used with smaller dataset sizes (Braun & Clarke, 2020). Additionally, my focus was on identifying themes across my dataset with an emphasis on implications for care practice, rather than also taking an idiographic approach which is part of conducting Interpretative Phenomenological Analysis and involves a detailed analysis of the accounts of individual participants (Eatough & Smith, 2017).

Similarly, Grounded Theory is another well-known type of qualitative research that is often used to explore social processes (Corbin, 2017). However, I chose reflexive thematic analysis over Grounded Theory primarily due to pragmatic considerations pertinent to time limitations. Specifically, while reflexive thematic analysis certainly requires the researcher to dedicate significant time to theme development and reflection, overall it is considered more straightforward and time-efficient compared to Grounded Theory (Braun & Clarke, 2020). This was an important factor which I had to take into account in a time-sensitive research project like mine. Discourse Analysis is another key qualitative analytic framework that emphasises how language is practiced and the meanings it creates (Johnstone & Andrus, 2024). As the

reader may notice in later sections of this chapter while reading through the themes, exploring the influence of language and social discourse on care relationships was an area that I investigated as part of my overall analysis. However, as this study did not have a primary focus on the effects of language, employing Discourse Analysis would not have been an appropriate analytic framework.

In the context of this study, I concluded that reflexive thematic analysis provided a comprehensive, evidence-based analytic package and its theoretical flexibility as well as the values and philosophical assumptions in which the framework is situated and outlined in this section matched the aim and research questions of this study and overall project (see Chapter 1, section 1.4), my theorisation of language and ontological and epistemological position, and my methods, and, hence, served as a good 'fit' that created conceptual coherence (Braun & Clarke, 2022).

Analytic process

Reflexive thematic analysis is an iterative process that involves six interconnected phases, which are grounded in reflexivity and the qualitative values, philosophical assumptions, and approaches that I have previously described in this section. Specifically, the six phases entail 1) familiarisation with the data; 2) coding[41] the data; 3) generating initial themes;[42] 4) reviewing and developing the themes further; 5) refining, defining and naming the themes; and 6) writing up the report (Braun & Clarke, 2022). Reflexive notes were taken for each analytic phase. The analysis was conducted using the qualitative data analysis software NVivo©, accessed through my University of Kent account. Using the various tools available

[41] In reflexive thematic analysis, codes are "the building blocks of analysis […] capturing meaning relevant to the research questions" (Braun & Clarke, 2022, p. 52).

[42] In reflexive thematic analysis, a theme is a "pattern of shared meaning organised around a central concept" Braun & Clarke, 2022, p. 77) whereas a topic summary entails reporting "all the different responses or meanings around a topic in the dataset" (Braun & Clarke, 2022, p. 77). It must be clarified that, in reflexive thematic analysis, a topic summary is not a theme (Braun & Clarke, 2022).

on NVivo© made data management and the subsequent data analysis much easier, allowing me to organise the data, create decision-making trails, and structure the analytic process.

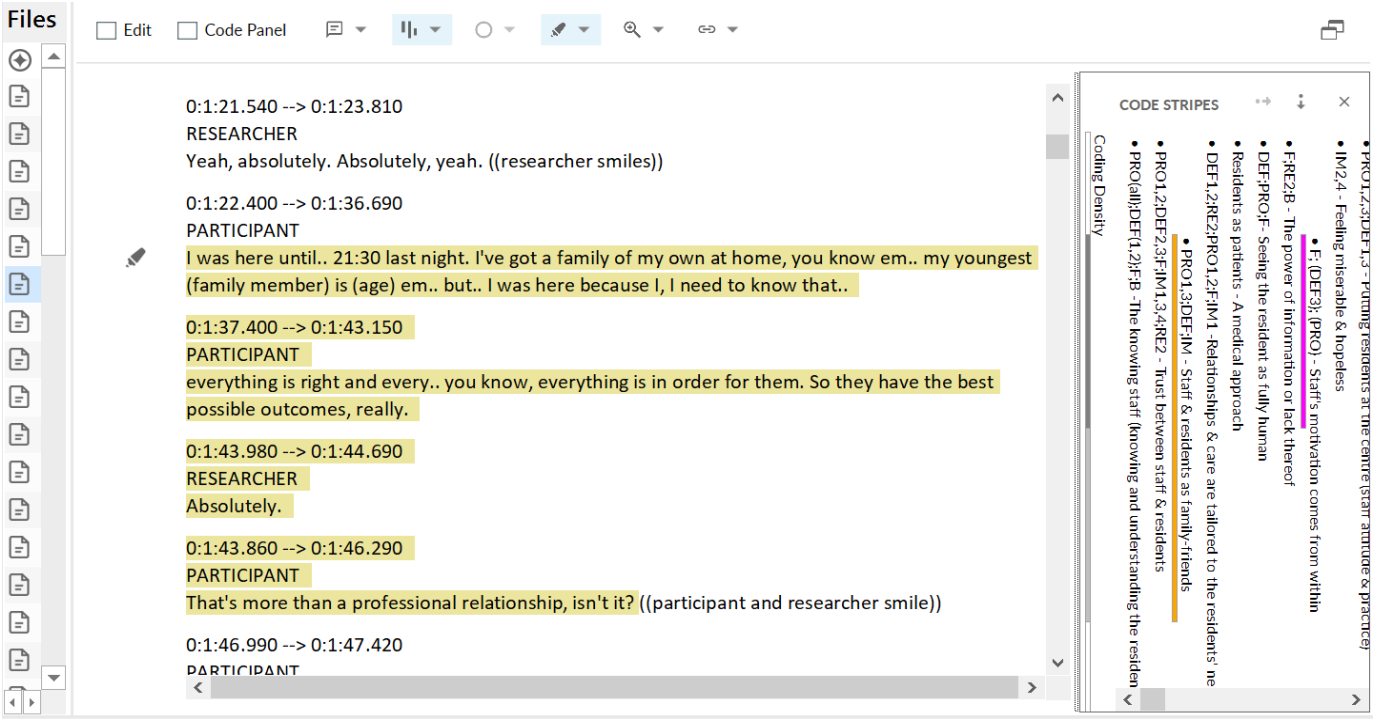
Data familiarisation was initiated during the transcription stage as I thoroughly went through each interview recording and finalised each participant's interview transcript. A few participants shared additional thoughts via email after their interview, and these comments were also included in the data analysis. Upon anonymisation, all interview transcripts and further comments were imported into NVivo©. I re-read the transcripts, reflected on them, and felt more confident in navigating the data as the familiarisation phase served as a compass, giving me an idea of what to expect in relation to the next stages of data analysis. Moreover, I roughly mapped initial topics of interest by taking notes. For instance, the following note was taken in July 2023: "Participants seemed to be driven by commitment and consciousness in terms of their role. Some participants seemed to explore more 'philosophical' concepts in relation to their practice, whereas others focused more on very practical stuff".

Next, I proceeded to code the interview transcripts. Coding is a spectrum and, for this study, I saw fit to sometimes code semantically (i.e., capturing descriptive, explicitly-expressed meaning, based on what participants were sharing; Braun & Clarke, 2022) and others latently (i.e., capturing the conceptual, more implicit level of meaning, based on my interrogations of the content of the data; Braun & Clarke, 2022) as this method allowed me a holistic interpretation of the participants' views and experiences. Often, more than one code would be applied to the same excerpt to capture different meanings and interpretations. Parts of the transcript that were not relevant to this study (e.g., when participants discussed something outside the scope of the study) were not coded. I constantly zoomed in and out of the data to ensure that I maintained perspective during coding. To this end, I added initials tailored to my research questions (e.g. DEF for 'Definitions', IM for 'Impact') in front of the codes to reference the research questions the participants were addressing. My notes in this analytic

phase captured reflections on the coding process as well as on the analytic outcomes, for instance, “clearly, coding becomes more intuitive as I go along and I become more confident” (Note, September 2023), and “the cyclical nature of things is very interesting […] good communication can facilitate good relationships […] good relationships can help you facilitate better communication” (Note, October 2023). The coding process ended once I coded the entire dataset, and I was satisfied that the codes were sufficient to proceed to the next phase. In Figure 4, I illustrate the coding process.

Figure 4

Coding process in NVivo©



I then started the process of generating initial themes by immersing myself into the codes I have created and examining them in the context of the interview transcripts whilst being mindful of my research questions. I entered this phase with 747 codes and from there I organised and subsequently merged several codes into each other to make them more concise and thicker, resulting in 285 codes. Across the codes, I looked for patterns and organised all

codes into clusters, at this stage resembling topic summaries, rather than themes. Nonetheless, I did this knowingly in the process of organising the data and making it easier to identify connections. There was constant refining and re-thinking, a process that was somewhat assisted by an approximately three-month break from data analysis due to embarking on data collection for Study 3.[43] I noted back in early February 2024 that "it feels good to have taken some distance from the analysis - despite the initial rustiness and remembering how everything works". Once I reached 30 clusters, I felt ready to dig deeper into further theme generation.

I reviewed the clusters and continued merging and bringing everything together so I could develop my themes and start telling a concise story grounded in the data. This phase involved deep thinking, interpretation, and decision-making and felt rather challenging with a lot of "frustration, going back and forth, thinking about how to best connect the dots, however, little progress at the minute" (Note, early March 2024). I created thematic maps (see Figure 5 and Figure 6), namely visual representations of tentative themes and the relationships between them (Braun & Clarke, 2022), to aid me as I was brainstorming, whilst experiencing "moments of clarity once I start experimenting more and mess around with the 'order' I created" (Note, early March 2024). Through this process, I generated four themes and one subtheme.[44]

[43] See Chapter 5.

[44] In reflexive thematic analysis, a subtheme captures and highlights "an important facet (or facets) of the central organising concept of one theme" (Braun & Clarke, 2022, p. 295).

Figure 5

Example of thematic mapping

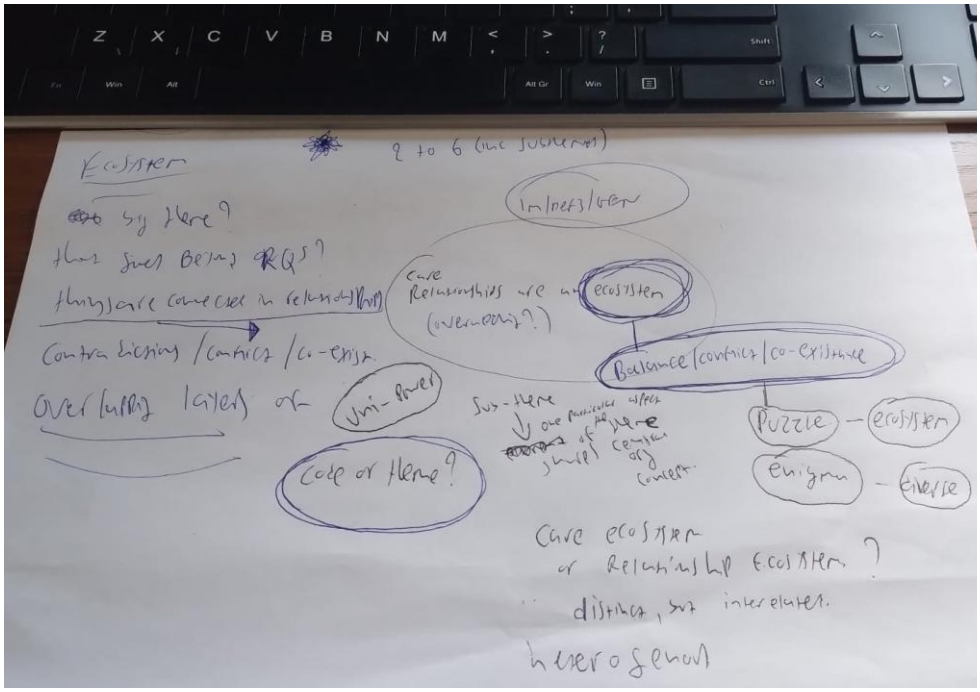
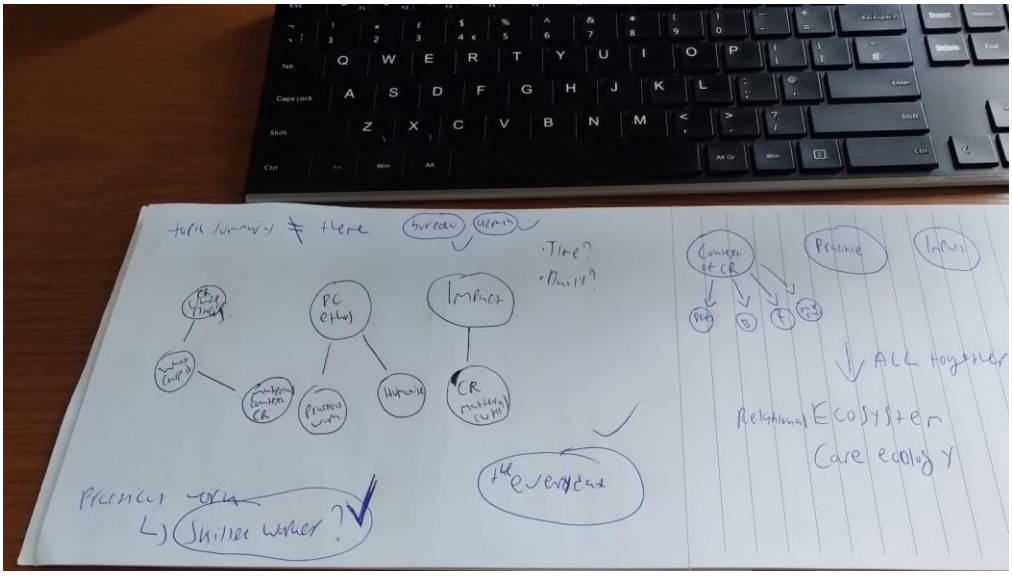


Figure 6

Example of thematic mapping

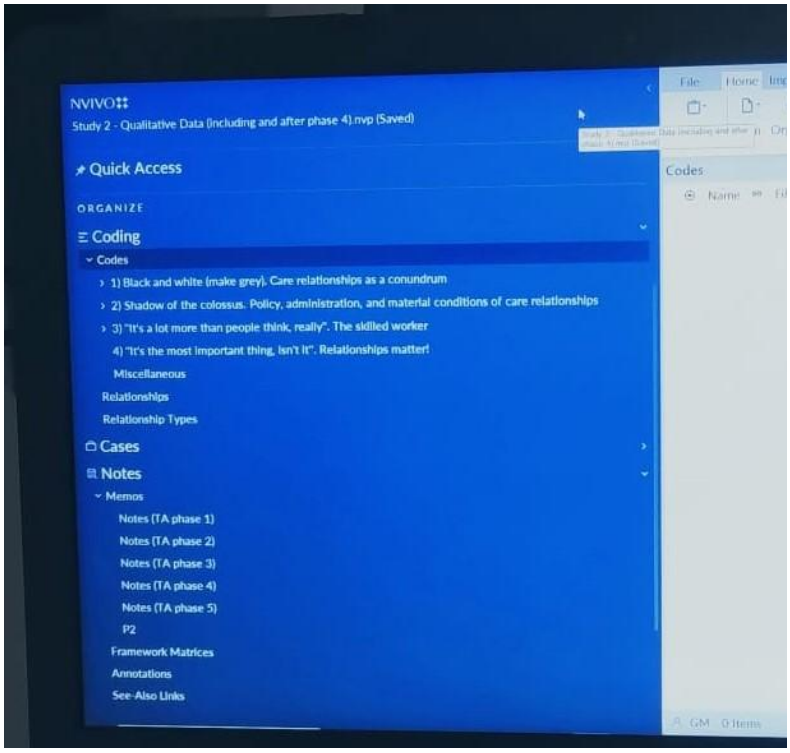


Next, I embarked on naming, refining, and defining the four themes and one subtheme that I had generated (see Figure 7 for the initial names assigned to the themes). Also, I created a ‘Miscellaneous’ category where I included a few codes that, although of interest, were not used during theme development. Refinement involved revisiting and amending the content,

boundaries and names of themes, so they are distinct, yet they also tell a concise story that addresses the project's aim and research questions. Moreover, I wrote theme definitions which resembled abstracts and highlighted each theme's core ideas and contribution to the analysis (Braun & Clarke, 2022).

Figure 7

The process of assigning initial names to the four themes

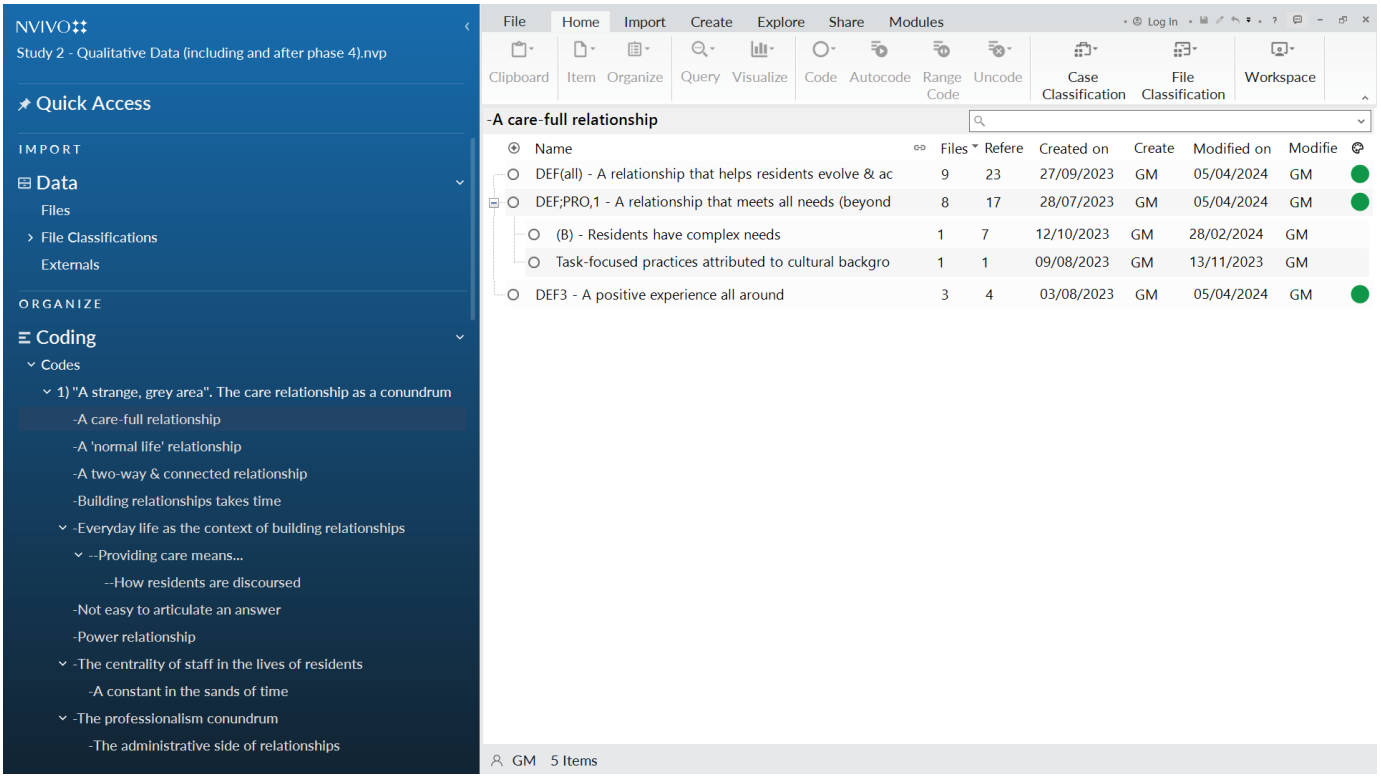


Finally, I engaged in the writing-up phase, producing my thematic analysis report where I elaborated on all aspects of the study (e.g., methodology, findings, conclusions). This phase did not only involve writing the report, instead, it was still an active part of the analytic process, in other words, "as the write-up takes place, refinement certainly continues; merging codes and thinking of theme names, etc. It is ongoing and things become more clear as I am writing the analysis" (Note, early April 2024). During the writing-up, I emphasised the value of editing the text multiple times (Braun & Clarke, 2022) and resisted the urge to 'include everything', appreciating that "storytelling is a craft" (Braun & Clarke, 2022, p. 149) whilst using the

project's aim and research questions to recentre my analysis. Regarding the four themes and one subtheme, I did not report on all of the codes that comprised each theme to achieve theme richness (Braun & Clarke, 2022). Instead, I employed a colour system on NVivo© (see Figure 8) to indicate which codes I used in the writing-up and analysis of each theme.[45]

Figure 8

An example of the colour system to indicate which codes I used per theme



Data extracts (i.e., participant quotations) played a key role in this final phase and, in line with the approach I took to data coding (i.e., coding semantically and latently, across the coding spectrum), data extracts were sometimes used illustratively, namely as snapshots of evidence to provide examples for my analysis (Braun & Clarke, 2022), and other times analytically, namely as an attempt to understand the content of a specific data extract in the

[45] Green indicated codes used in the analysis of Theme 1. Pink indicated codes used in the analysis of Theme 2 and its subtheme. Yellow indicated codes used in the analysis of Theme 3. Blue indicated codes used in the analysis of Theme 4.

process of advancing my analysis (Braun & Clarke, 2022). Both approaches were very useful, allowing me to engage with the analysis more holistically.

Lastly, I decided to take an integrated approach regarding the 'results' and 'discussion' sections (Braun & Clarke, 2022) and present them together. An integrated approach aligns well within an interpretative qualitative paradigm and entails a combined 'results' and 'discussion' section whereby study findings and the wider literature work in conjunction to tell an analytic story (Braun & Clarke, 2022). Certainly, a separate 'results' and 'discussion' section has its own merits and is compatible with reflexive thematic analysis too (Braun & Clarke, 2022) as well as with an interpretive paradigm, therefore, before proceeding to employ an integrated approach, I engaged in considerable reflection to ensure that I was making this decision knowingly (Braun & Clarke, 2022). Specifically, I felt that, in the context of this study and where it sits within this thesis, a separate 'results' and 'discussion' section would be less organic and would have resulted in presenting the findings and discussion as somewhat separate, not interconnected constructs, hence decreasing analytic depth and increasing repetition (Braun & Clarke, 2022). Additionally, I aimed to demonstrate how some of the findings of this study were connected to the findings of my systematic literature review (Study 1) while maintaining flow, and, in this case, an integrated approach seemed more appropriate. Previous research (e.g., Beres & Farvid, 2010; Hayfield et al., 2019) employing this approach was consulted and provided valuable guidance. In line with Braun and Clarke's (2022) recommendation, I used the heading 'Analysis' for this combined 'results' and 'discussion' section, to emphasise the role that the researcher's interpretation and active subjectivity play in generating qualitative findings.

Ethical considerations

Support staff shared personal details as well as information about other people and services as they discussed their personal views, experiences, and practices; hence, one of the key ethical considerations for this study was to ensure confidentiality and data protection for all. A data leak could mean 1) potential disclosure of the participants' names and other personal information; 2) potential disclosure of the names and locations of the care services in which the participants were based; 3) potential disclosure of the names of participants' colleagues and the residents they supported; and 4) disclosure of information about the participants' views on and experiences of care relationships.

To address these potential risks, I undertook GDPR training (see Appendix 2), I always used a password-protected computer, and all data were uploaded as electronic files on my University of Kent shared drive. Only I had access to those files and if my supervisory team wanted access, they had to request it from me. Nonetheless, no such access was requested. All data were completely anonymised. Anonymisation entailed the removal of names of people, organisations, services, geographical locations, and other relevant details (e.g., participants' pronouns). Participant names were replaced with numbers (e.g., 'P1' standing for 'participant 1'). Descriptions (e.g., of health conditions, specific incidents, etc) that could lead to the identification of participants, services, or organisations were removed, and a brief, vague description was provided for context. Organisation-specific terms (e.g., terminology to refer to residents) were replaced with generic, non-identifiable terms (i.e., resident). Upon reflection, I realised that I could have been slightly less cautious around anonymisation in the spirit of reducing my workload, for example, not omitting a resident's mental health condition would not have compromised data protection as I thought it might do at the time.

Moreover, following an interview with a participant, they contacted me discussing that they were anxious about their data remaining anonymous, explaining that they wished to

withdraw from the study and for their interview to be deleted. I approached such worries with empathy and understanding and explained to the participant that they could certainly withdraw from the study and have their interview deleted should they wish to. Nonetheless, to provide reassurance and explore potential avenues towards avoiding withdrawal, I kindly offered an alternative to the participant for their consideration. Upon reassuring the participant that their data would be completely anonymised, I suggested that, as per the study procedure, the participant could wait until they received their anonymised interview transcript, review it, and confirm their wishes then. The participant was pleased with this alternative. Upon sending the anonymised interview transcript to the participant, no further concerns regarding anonymity and data protection were expressed, and the participant eventually remained in the study.[46]

Furthermore, it was emphasised to all participants that taking part in the study or not would not be revealed to their respective employers. It was clarified that taking part, withdrawing from, or refusing to participate in the study could not affect one's employment in any way. Confidentiality was maintained throughout this study; nonetheless, participants were informed that confidentiality could be breached should I have serious concerns about abuse taking place (or the risk of it), or danger to self or others. In that case, I would first seek advice from my supervisors before potentially contacting the appropriate authorities. Nevertheless, no such concerns occurred.

No substantial risk was anticipated for me as a researcher during this study. Upon consultation with my supervisors, it was considered reasonable, that should the process of data collection takes place in person, a quiet, public space that allowed privacy should be chosen (e.g., booking a quiet room in a library) and that I should notify my supervisors about my

[46] I had further correspondence with this participant in the following months, as the participant enquired about the timescale for sharing the findings of the study, expressing their eagerness to read my analysis and conclusions.

whereabouts. However, as discussed in previous sections, data collection was conducted online.

I did not anticipate that this study would cause any harm to the participants; nonetheless as self-reflection is inevitable during qualitative research, it was thought that participants might come up with realisations that they had not previously explored (e.g., about how they build relationships with the residents) which, in turn, could cause some degree of confusion, doubt, or distress. To address this, I aimed to conduct the study in an empathic and non-judgemental manner, always reminding the participants that they had full autonomy to either not answer a question or, if they wished, to withdraw from the study. Additionally, in the Information Sheet for Participants, I shared information with people, directing them to the UK mental health organisations Samaritans and Mind in case they needed support over the phone or signposting.

As support staff, it was anticipated that the participants would have busy schedules, and it was thought that finding time to attend the interview might impose a minor burden on them. To tackle this, I remained flexible and planned the interview around the participants' schedules and wishes, offering in-person and online options. When the interview exceeded the expected time parameters (i.e., in the Information Sheet for Participants, I stated that the expected interview duration was approximately one hour and 15 minutes), continuation only took place with the full agreement of the participant.

A payment of £10 was available for taking part in the interview. Additionally, if any travel or parking expenses were incurred, these were expected to be reimbursed. However, such expenses did not occur. In order for participants to not hesitate to withdraw from the interview should they wish fearing that they would lose their payment or reimbursement, it was clarified in the Information Sheet for Participants that once the interview had started, withdrawing from it would not affect payment or reimbursement. As a PhD candidate, I was fortunate enough to

have an additional NIHR research allowance allocated to cover relevant research costs, and I used funds from this pot to provide payments to participants. The amount of money chosen for participant payment was informed by the UK living wage standard rate (i.e., £9.50/hour) at the time (i.e., June 2022) as well as the UK real living wage rate as defined by the Living Wage Foundation. The UK real living wage rate was, at the time, slightly above the aforementioned UK living wage standard rate. Eventually, I settled on the £10 payment using elements from both frameworks whilst maintaining a sense of fairness towards the participants.

Paying study participants appears to be a debated ethical topic among researchers, and guidance on the matter seems to be limited. Nonetheless, several studies (e.g., Polacsek et al., 2016) provide evidence for the importance of fair payment based on, for instance, the ethical treatment of research participants and the dismantling of notions that the lack of participant payment supposedly leads to more objective research. Moreover, both the HRA (2024) and the NIHR (2022) acknowledge the importance of fair payment for research participants and have produced relevant guidelines. According to the NIHR (2022) guidance, the Information Sheet for Participants emphasised that receiving payment for taking part in this study may interfere with people's benefits if they are in receipt of any, and the participants were reminded that it was their responsibility to find out whether the payment would affect their benefits entitlement. I took a clear stance in favour of providing what I perceived to be a fair payment to the study participants. Besides my moral values, my stance was also informed by the evidence that I outlined above, and, undoubtedly, it was enabled by the fact that I was fortunate enough to have additional NIHR funding. I anticipated that, at least from a material point of view, payment would allow people to perceive their participation in the study in more reciprocal and equal terms and, consequently, make them feel more motivated to take part.

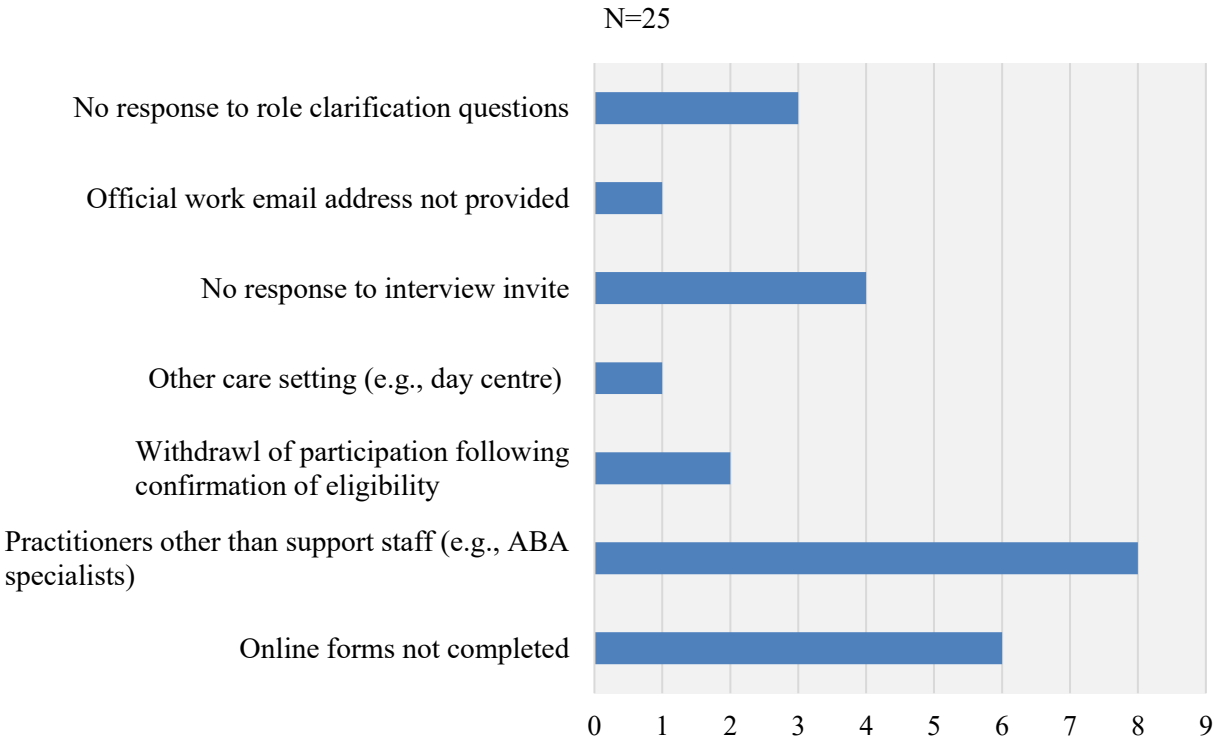
4.4 Analysis

Participant characteristics

Overall, 48 people[47] expressed an interest in taking part in the study. Of those, 23 people took part in the study, and 25 people were not eligible to participate for the reasons shown in Figure 9. The demographic and professional characteristics of the 23 participants as a group are described in Table 13. All participants confirmed in the Demographics & Eligibility Questionnaire that they provided direct support to adults with a learning disability and were based in long-term social care residential settings in England. In total, participants came from 16 different care organisations and have worked in their current setting for 3 months or more with a mean ($\bar{x}$) equal to 7 years and 8 months.

Figure 9

Reasons behind ineligibility to participate in Study 2



[47]The 48 expressions of interest reported here are genuine (e.g., official work email addresses, genuine correspondence). The fake accounts and false expressions of interest that I discussed in the section 'Recruitment, data collection, & reflexivity' of this chapter are not included in this number as they were immediately deleted.

Table 13

Demographic and professional characteristics of research participants (N=23)

Gender	
Woman	17
Man	6
Ethnicity	
White British	17
Mixed British	1
White Other	3
Asian Other	1
Black Other	1
Age range	
18 – 34	6
35 – 54	14
55+	3
Highest academic qualification	
National Vocational Qualification (NVQ)	14
Undergraduate/postgraduate degree*	9
*subjects mainly included *health and social care*, *psychology,* or *social sciences*	
Your care role	
Support worker/senior support worker/Shared Lives carer	13
Team leader/deputy team leader	5
Home manager/deputy home manager	5
Employment	

Full-time	21
Part-time/zero-hours contract	2
You support people with	
Various levels of learning disability (mild, moderate, and severe/profound)	13
Mild learning disability	2
Moderate learning disability	3
Severe/profound learning disability	5
Hours per week providing direct support	
30+	17
7 to 14	4
Various hours/other	2
Previous experience working with adults with a learning disability	
Yes	13
No	10
Residential setting	
Supported living	8
Care home	7
Multiple settings (e.g., supported living & domiciliary care)	4
Domiciliary care/Shared Lives	4
The organisation that manages the residential setting is	
Independent/voluntary/charity/third sector	14
Private sector	6
Local Authority/Council	3

You work in a setting located in	
Southern England	8
East of England	3
Midlands	6
Yorkshire & Northern England	6

Themes

In Table 14, I present the four themes and one subtheme, providing a summary of their scope before analysing them in detail and situating them in the wider literature. Given that I am using data extracts (i.e., participant quotations) throughout the analysis, in Table 15, I provide information about the caregiving role that each participant held within their respective setting, instead of including this information alongside the participant quotation. By doing so, I anticipate achieving a better flow and making reading through the analysis easier.

Table 14

Theme summary

Theme Name	Theme Summary
Theme 1 "A strange, grey area" The care relationship as a conundrum	Care takes place in the realm of everyday life and the lives of staff and residents seem to be intertwined. The care relationship is conceptualised as a conundrum, as a "strange, grey area" between the *personal* and the *professional*.
Theme 2 Shadow of the Colossus[48] Care relationships in a material and ideological reality	Care relationships do not exist in a vacuum, a material and ideological Colossus is casting its shadow on them sometimes facilitating and others hindering them.
Subtheme Person-centredness in the plural The person is *us* - the person *in* us	The person-centred ethos shapes care relationships, yet the person in person-centredness is problematised. The person includes and also goes beyond the resident, it is an *us*, involving more

[48] The heading 'Shadow of the Colossus' was inspired by the 2005 video-game with the same name, developed by Japan Studio and Team Ico, directed by Fumito Ueda, and published by Sony Computer Entertainment.

	people, their relationships, and their humanity.
Theme 3 "It's a lot more than people think" The skilled worker	Unlike the dominant discourse that frames care work as unskilled work, support staff are skilled workers who engage in various processes and practices to establish positive care relationships and restore them when disrupted.
Theme 4 "Fulfilling, rewarding, and transformational" Relationships matter	Positive care relationships can be truly transformational for both staff and residents, creating the conditions for effective care and happier lives. The absence of positive relationships can be detrimental.

Table 15

Caregiving role of each participant (N=23)

Participant	Care Role
P1	Support worker
P2	Senior support worker
P3	Deputy home manager
P4	Senior support worker
P5	Support worker
P6	Support worker
P7	Senior support worker
P8	Support worker
P9	Home manager
P10	Support worker
P11	Team leader
P12	Home manager
P13	Shared Lives carer
P14	Home manager
P15	Support worker
P16	Senior support worker

P17	Support worker
P18	Team leader
P19	Team leader
P20	Team leader
P21	Support worker
P22	Deputy team leader
P23	Home manager

Note. As discussed in the section 'Ethical considerations' of this chapter, the letter 'P' stands for 'participant'.

Theme 1: "A strange, grey area" - The care relationship as a conundrum.

Almost two minutes into our interview, P8 explains that a care relationship is "a difficult thing to, to put into words". Months later, P22 elaborates: "when you just do the job automatically and you don't necessarily.. think". As the interviews progress, I observe, and note at a later stage that the "participants seemed to find definitions and daily life questions quite hard. Hard to articulate daily, 'taken as a given' care experience". Care work is hands-on, and staff's conceptualisation of relationships perhaps comes primarily from *practising* them, rather than through intellectual abstraction. This nods to previous research situating support staff in a Communities of Practice framework (Wenger, 1998), whereby experiential learning and *doing* are at the core of learning disability care work (Bradshaw & Goldbart, 2013). Care relationships are "hard to define because everyone's different" (P16) and perhaps settling on one definition is impossible, if not unnecessary ("you could come up with.. a load of.. buzzwords and kind of cobblers", P8). Instead, there are many answers to this question that may be simultaneously valid and contradictory, framing the care relationship as a conundrum and painting it neither black nor white, but grey.

Care relationships are understood in the vastness of everyday life. Gjermestad and colleagues (2017) suggest that everyday life also entails the ways that the residents

meaningfully participate in it, privately and publicly, as members of society, and P15 explains that “it's definitely a relationship of.. caring and supporting the person […] be it.. um.. personal care or […] watch a movie or to the pub or shopping”. Enabling everyday life can create relationships that are understood as positive (“they like you because you got them up […] you enabled them to.. go […] wherever they’re going”, P5). Aligning with the findings of previous research exploring the social networks of people with a learning disability (Harrison et al., 2021), staff and residents are exposed to each other a lot (“I spend more time with the people we support than I.. do with my own.. partner”, P16) and staff are central in the lives of residents (“the people we support wouldn't be able to function without having 24-hour care. So I guess our relationship is really important”, P10). Relationships do not just happen; “it needs time to establish that communication. It needs time to establish that trust” (P6). The time spent together creates a sense of closeness which can set the foundations for something positive (“you do so many hours so they get exposed to that specific stimuli which is a certain member of staff and it's, it's just the exposure I think it makes it positive”, P7). Closeness is not always straightforward; it may create a sense of daily grind where “they can get contemptuous of you and you can get.. irritated and bored with them” (P8). Working closely also creates a sense of connection which involves intertwined emotions (“if they're having a great day […] I have a really GOOD DAY”, P2) and shared experiences (“exposing THEM to, to, to an enriched environment. Also, we're exposing ourselves as support workers to those environments”, P7). The care relationship is therefore understood as two-way whereby the work is carried out and the outcomes are enjoyed somewhat by both staff and residents (“you have to trust him as much as he trusts you and feel safe around him, just like he wants to feel safe in your, in his home with you”, P21). This seems to allude to previous work (i.e., Norah Fry Research Centre, 2010) synthesised in Study 1 pointing to the idea of mutuality as an ingredient of positive care

relationships, whilst highlighting some of the nuances and tensions that accompany the care relationship.

Relationships are constantly subjected to change as, for example, residents' needs might change ("she now has to be hoisted […] it's almost like having to rebuild a relationship", P10). In the face of change or other challenges, staff try to be "that constant, familiar face" (P4) providing consistency and continuity and creating a sense of stability: "if [residents'] behaviour goes way off the scale […] and, actually, the week after you're walking back in […] that really takes that relationship and they kind of go […] you're OK, you're here" (P6). As Gjermestad and colleagues (2017) suggest, consistency and support staff *being there* relationally as well as practically is, unsurprisingly, also highly valued among the residents themselves. Care in care work is ongoing; it is about "accepting that it's a journey and not a destination – and celebrating small steps and achievements" (P18). A care relationship full of care goes beyond task-oriented practices ("it's not just about getting them up in the morning", P5) and aims to capture the residents' complexity and meet all needs ("the social […] emotional […] the physical one, the psychological", P3). It helps residents achieve their potential ("support somebody to do something that they.. are maybe a little bit anxious about", P4) and is simply a positive experience all around ("you don't want them looking at you, thinking oh God, it's [pronoun] again", P5). Such understandings of positive care relationships indicate broader positive care cultures in residential settings, whereby the care service promotes a culture, or in other words, *does* care in a way that emphasises relational and engaging working practices and openness to potentiality (Bigby & Beadle-Brown, 2016).

Support staff are a workforce; the home of the residents is simultaneously the workplace of the staff (Levinson, 2005), and the care relationship also occurs within an administrative context. Staff's practice abides by duties, policies, and procedures ("protect my colleagues or protect other service users or even protect him from himself", P3; "when someone's saying we

should go and play football and you're going hang on, I just need to fill in your daily diary", P8), they have work patterns ("in this organisation […] it's BETTER.. but, but still it's very much these are your shifts", P12), and work entitlements ("we are allowed some holiday", P13). Care relationships are thus understood as professional relationships. Staff behave professionally ("even if […] you're getting frustrated and angry, keeping like.. calm", P15) and set professional boundaries. In line with the research synthesised in Study 1 (e.g., Bowler & Nash, 2014), boundary-setting and professionalism seem to serve positive care relationships by creating clarity regarding the scope of the relationship ("the first thing I said to him was.. if you break your conditions of your release, I'll be calling the police", P17) and preventing overinvolvement ("you don't then become or the person that you're supporting doesn't become wholly dependent on you", P9).

Acknowledging whilst somewhat contradicting professionalism is where the conundrum lies: "there's quite a strange, grey area between being a support worker and being a friend or family member of the person you support" (P17). As staff provide long-term support to residents in everyday life, they might feel more like friends or family ("worked with him for [time] now, and I do feel like a part of his family", P18) and residents might do too ("they think of me as, as a friend that they have known for a long time, because we'll go and watch football", P17; "the residents who live here don't have any family […] we become like family to them", P23). P6 describes this as the "double-edged sword of professionalism" whereby "there needs to be a certain degree of, em.. of professional distance […] and sometimes if you live very, very closely […] that can blur that boundary". The care relationship is grounded in ordinary human life, meaning that care relationships are governed by the same rules as the so-called neurotypical relationships. P15 explains that "you build a relationship with the people you support as you would build with anyone" which means that "you don't just meet someone and you're close […] you spend time with them, you get to know them" (P21). Inevitably, this

entails relating on a more personal level, where "personal relationships ARE care relationships" (P6). This is illustrated well by P12: "I've worked for local authority […] you didn't talk about your personal life […] but I think those things are natural human interactions, and I think they help build relationships". Relating with residents beyond the strictly *professional*, may, to some extent, be something to strive for and can be positive. For instance, P12 discusses how their organisation's policies allow residents to "come to your house for a cup of tea" or "attend a family event" if it enriches the resident's life, and P6 explains how during the Covid-19 pandemic there was a sense of administrative liberation where "for 18 months, ok lots of health things changed, but generally we were left to just share our relationships with our [residents], and it felt like a positive impact both ways". P13 adds that a care scheme like Shared Lives is all about having a sense of family, explaining how they do not see themselves "as a carer now […] because we don't see it as separate […] they are our family". Rogers (2016) acknowledges "these fractured boundaries" (p. 123) in how care relationships are understood and experienced and, as the study participants do, frames relationships, interactions, and communication as a need that, ultimately, is situated in being human.

In a conundrum fashion, participants often return to professionalism to somewhat balance the more personal aspects of care relationships. "It's just another member of the family", P18 explains, "but again, keeping that boundary in place so that, em.. yep, we're good friends, but some, yeah.. this limit". "Sometimes if you get too emotionally involved in the client, they can get scared", P16 warns, "allegations can come up because the client is feeling scared because, em.. they're not in control". This perhaps signals an organisational culture that safeguards residents from harmful situations and abuse (Collins & Murphy, 2021). Although staff are trying to be a source of stability, consistency, and continuity for the residents, "the detriment to that is […] that you're a PAID support worker, you're.. you're going to leave at some point" (P12). Therefore, staff also become another source of change in the relationship

whereby the relationship ends, hence maintaining some professional distance becomes imperative.

Friendship is an abstract and open-to-interpretation concept, essentially "embodied through the things that people do and experience together" (Bigby & Craig, 2016, p. 183). Friendship seems like a notion that participants use to articulate their investment in the lives of residents ("to think me […] as a good friend to share with me his concern", P1), inviting us to reflect on *friendship* versus *friendliness*. It is perhaps a form of "professional friendship" (P9) or what P8 calls "friendly without being friends" which is "the […] kind of relationship that you would have with a friend […] have a good rapport with them […] go out […] help them […] but whilst maintaining the boundary that you are not their friend". These accounts perhaps seem to gravitate towards *friendliness* rather than *friendship*. Similarly, conceptualising care relationships through the lens of family seems like a way for participants to articulate their best intentions for residents ("they're comfortable, you know, to live their life as they would with a family member", P20). Perhaps, it also reflects the residents' experience, one that is tied to the pragmatics of everyday care ("they see you as being their family […] when you ask them to budget properly, to.. the skills you're building with them. The personal care, the going out", P3).

Discoursing care relationships through the lens of friendship or family perhaps also signifies a desire to challenge and shift power dynamics and make the relationship more equal, echoing literature synthesised in Study 1 (e.g., Antaki et al., 2007a; Norah Fry Research Centre, 2010). Power between staff and residents is unequally distributed ("you have head office […] colleagues […] your family for support. But.. he, you're his support", P21; "I have to manage some very difficult behaviours on occasions, so I always keep the upper hand", P18). Residents can have some power over staff ("I [resident] will give you.. um.. anger and frustration because I'm frustrated", P16), but this seems like "kicking against the system" (P16), a manifestation

of wanting to take some power back. A critical engagement with their position of power as staff was not uncommon among participants ("we're GUESTS in their home", P11), aspiring for a relationship that looks like a "meeting of equals" (P8). The conundrum returns though as, for instance, understanding the care relationship as a "parent/child relationship" (P18) assumes a parental role among staff, which could become patronising. Indeed, discoursing residents as children ("he's an adult, but he's got a mind like a child", P21) and vulnerability as a child state ("they are such as a child […] they need […] mental support and some physical support", P1) was not uncommon among participants but also was not unproblematic ("it annoys me when people give them flipping orange squash […] I go it's not a child", P13). This point of tension alludes once more to Rogers (2016), who highlights that, unsurprisingly, the infantilisation of people with a learning disability can rob their humanity and exclude them. Echoing findings from Study 1, dilemmas arise from trying to balance the *professional* and the desire for more equality. "She's like I don't want to get up. I don't want to get dressed […] I couldn't leave her sopping wet and dirty", P22 explains, "it's HIS choice. But that's reflected on ME giving care.. to him, if he looks unkempt", P13 elaborates, both pointing towards a dilemma between their duty of care and respecting their resident's wishes.

The care relationship is not one thing; its 'greyness' is grounded in the experience of practising relationships in everyday life and the complexity of those receiving and providing care. This invites us to look at the wider context of relationships and how they influence and are influenced by it.

Theme 2: Shadow of the Colossus - Care relationships in a material and ideological reality.

The care relationship does not exist in a vacuum; a Colossus is rising above it, casting its shadow. A material and ideological Colossus that represents the reality that relationships are situated in and how this facilitates or hinders them.

In residential settings, the relational environment is material: the bedrooms, communal spaces, and geographical locations. The materiality of care spaces can elevate the relationship ("individual flats.. on a long corridor […] you then make a relationship with all the staff […] because of the way the building is set up", P3; "went to [location] to feed the ducks", P5) or hold it back ("[they] are used to drink their coffee […] if there is no coffee, it is very BAD", P1; "a lady who's recently become a wheelchair user […] we've been struggling to get bathroom access", P6). The relational environment is also immaterial; it is the vibe, the "stress-free environment" (P22) that benefits residents and relationships. The immaterial is connected to the material: "I think you need to move that [device] […] so that, you know, they can sing to their heart's content and the others can watch TV and there's NO CONFLICT'' (P5). The (im)material relational environment creates a sense of homeliness; "this is a house and a home", P6 explains, where people "can come and live a full life […] it's not like a dumping ground". Nonetheless, care pragmatics cannot always be negotiated and this shapes the (im)material and the relationship. For instance, having meals together "might not.. suit everyone but… there isn't any other way around it", P10 explains, concluding that "there are some restrictions being in a care home". Highly relevant to this, in their exploration of what 'feeling at home' means, Chinn and colleagues (2024) frame the learning disability residential setting as a physical home, whereby the way the space is organised influences the residents' sense of homeliness and feelings of belonging, and as a social home, whereby residents connect and relate with fellow residents, support staff, and other people.

The material reality also encompasses the wider material conditions (i.e., the economic and social realities; Marx, 1859) of care work, situating the care relationship in the broader socio-political sphere (Rogers, 2016). Available funding is crucial so residents can "do the things that they want to do" (P16) and, through shared experiences, they can "kind of bond with us" (P16). Reflecting the adverse conditions that surround social care in England (Forrester-Jones et al., 2021), it is not uncommon that "funding is withdrawn for people from different placements" (P9) which can lead to the inability to "use your staffing […] to give [residents] a little bit more one-to-one time" (P23) and thus hinder relationships. Staff are low-paid ("I could go to [name of supermarket] and get paid A LOT MORE", P5) and have limited career prospects ("financially it's, it's not a career as such", P18). Such conditions can affect staff's motivation and the care relationship itself as "you're gonna go in there, can't be bothered, can't, you know, why should I try […] I'm not getting paid enough for this" (P21). The job is hard ("you are required to work Christmas and bank holidays", P16) and "everybody in the sector is struggling" (P23) with staff recruitment and retention. Time in residential settings can be limited, "there are too many demands" (P18) in care homes and "even with having the minimum of an hour call, sometimes you are stretched" (P22) in domiciliary care, and inadequate staffing can exacerbate time constraints and hinder relationships ("people have hidden depths […] you don't.. see them if you don't have that time to see them. If you're, you're rushing around […] it's about taking that TIME", P14). This reflects previous work that highlights that although time is a very salient factor in social care services influencing the quality of care provision, nonetheless, time is rather fragmented (Rubery et al., 2015). Additionally, having "lots of different staff members, high turnover, agency use" (P23) may disrupt the sense of relational consistency, continuity, and stability in care ("if you're an agency member of staff […] [residents] not gonna give a monkey's […] if you're the person that's worked with them […] you're far more likely to get a.. a result", P8).

Situating care relationships in the wider socio-political sphere (Rogers, 2016) means that the material reality is also interacting with an ideological one. Uncertainty surrounds care ("people are very frightened of care homes", P6) and economic policies have changed the sector ("when we joined […] we actually dealt directly with the local authority […] as time has progressed […] it went out to […] a site with [number] private companies", P13). There appears to be a "divide almost" (P12) between health and social care, indicating low status for the latter. Staff supporting residents "day in, day out" (P12) often "don't feel supported by.. the health professionals" (P12) or do not have their opinion considered, which can be "alienating" (P8). Reflecting the wider lack of recognition for support staff (e.g., National Association of Care and Support Workers, n.d.), a dismissive narrative surrounding care work seems to be prevalent as "support workers in general, are seen as disposable and replaceable" (P7). Support staff are not valued enough with P20 explaining that "we've got the clap at the beginning of Covid, but then, you know, all you get is, like, minimum wage", comparing social to health care regarding recognition ("NHS staff […] there is […] positivity around that role […] I'm not sure, um, that the care staff feel like they're really supported by society"). Unsurprisingly, these ideological conditions might affect "people's motivation to build good relationships" (P20). The care relationship is also situated in person-centredness, a key ideology that informs learning disability care practice and policy. The *person* in person-centredness is interrogated and used to facilitate positive care relationships. I capture this facet of the theme in the subtheme below.

Subtheme: Person-centredness in the plural - The person is** us **- the person** in **us.

In line with the policy and practice paradigm that dominates the provision of care for people with a learning disability in the UK (Department of Health and Social Care, 2001), participants situated positive care relationships in person-centredness which entails putting residents at the centre of everything, principally ("they're top of the tree […] they're the sun

[…] we're here for, for them, not for us", P14) and practically ("I hate football, but I'll still sit and talk with him about football because he loves it", P22). Person-centredness means "following [residents'] lead of what they wish to do" (P19), be it wanting to do activities or spend time alone, involving them in decisions ("making care plans, including them into it […] it's from THEM, it's not institutionalised", P3), and tailoring the relationship to the residents' individuality, needs and wishes "in a way that's SYMPATHETIC to the way that that person, em, wants to be cared for" (P6). "Got younger tenants that are very independent, so you have to stand back and let them go out and take positive risks", P19 explains, "got older tenants who.. are.. very.. like to stick to a routine". The relationship is therefore dynamic, changing with "each person that you support" (P7) as "although they all have learning disabilities, that AFFECTS ALL of them in completely different ways" (P5), and unique ("that's our relationship. We can banter back at each other […] couldn't do that with everybody […] some people take it offensively", P22).

The ideological universe of person-centredness is also reflected through the widely used notions of empowerment and independence, once more reflecting the dominant learning disability policy and practice paradigms in the UK (Department of Health and Social Care, 2001). A positive relationship is facilitated through empowering the person ("I'm not there to mother them […] I try to encourage them to do something for themselves", P11) and enabling independence ("teaching him basic life skills", P18). Empowerment and independence come in many shapes and forms, for instance, enabling residents to make "their own decisions" (P11), to become confident to "speak for THEMSELVES" (P14), or simply to "use sharp objects in a kitchen" (P18). Nodding to the historical processes of deinstitutionalisation that highlighted the importance of empowerment and independence of people with a learning disability in the UK and globally (Mansell et al., 2007), participants explain how the residents' institutionalised pasts can provide a frame for emphasising empowerment and independence ("maybe they've

been in hospital for 20 years […] they've been told when they can eat and when they can drink, what time they need to go to bed", P16) and so do some staff's current disempowering practices, whereby staff "do it FOR [residents]" to make the shift easy or "tend to underestimate the capacity of that person. So, you tend to kind of wanna do everything" (P3). Banks (2012) however, observes that empowerment and independence can sometimes be interpreted narrowly in residential settings, leading to a disproportionate emphasis on the residents' responsibilities, blaming them, and thus hindering the care relationship. Tied to this, Levinson (2005) employs the concept of governmentality (Foucault, 1991, as cited in Levinson, 2005) calling for a reflection on how an emphasis on the residents' independence could be ultimately used as a way to govern the residents and, thus, exacerbate power relationships. Held (2006) questions the notion of the fully independent, autonomous individual, contrasting it with the very reality of interdependence, framing the latter as a key ingredient of what it means to be human as well as an essential factor for human survival.

Person-centredness is so far described as a singular noun whereby the *person* refers mainly to the resident; nonetheless, this is problematised. Person-centredness is discussed in the plural, the *person* is an *us*, not an *I* ("these.. people that we support, they're not just THEM […] they've got a family around them", P14). A positive care relationship can then be facilitated by working together with families. They play a key role in residents' lives and can provide information that staff "would never know without them" (P14). Staff can learn from how families are "handling that relationship" (P3) and incorporate this into their practice. The *person* is expanded more including "their friends" (P19), other residents, but also "local authority, social workers, all MDT [multidisciplinary team] people" (P13) as well as "your colleague […] your manager […] EVERYBODY" (P1). Through teamwork staff share institutional knowledge ("using the skills […] of the other staff […] you've got a wealth of experience if you're supporting the guys, so.. use it", P11), provide effective support ("because

we worked together […] the person got on [transport] and was like a child in a candy store", P4), and feel supported ("sometimes we have to lean on our colleagues […] I've had a rubbish day, I need some help", P18). Teamwork also encapsulates the "company, organisation" (P15) as "it's really important that you […] feel like.. someone else has your back" (P15). This facilitates positive relationships because "how can you support the person if you don't feel like you are supported?" (P20). Having your back entails material ("when you need any equipment […] they provide you as soon as possible", P1), emotional ("can reach out to someone and you can talk about it", P15), and managerial support ("we'll give them a brief of the month […] a good way of realising what's going well, what's going not so well", P21). It also entails organisations facilitating the conditions for relationships to thrive ("making sure that.. the employer will provide me, you know, time and space to get to know [residents]", P20) and "NOT being afraid of taking those positive risks" (P6), allowing staff autonomy. Working together with MDTs is imperative as they can offer help and give perspective ("it's not just something that one carer […] can do […] having a learning disability nurse […] speech and language assessment […] other professionals […] lets the person know that you ARE trying to develop that relationship", P6). This alludes to McCormack and McCance's (2016) theorisation of person-centredness in the context of nursing, whereby person-centred care involves broader relationships between organisations, practitioners, clients, and important others such as family members or friends.

The different components of the plural *person* do not always exist harmoniously and this influences relationships. P22 explains that "there's a couple [of residents] that […] I stopped going to […] because of their family" whilst P10 highlights that in care home settings trying to "balance EVERYONE'S needs" can be hard. Teams do not always work in unison ("if three people have got different ideas, that could maybe make it a little bit more difficult", P19), colleagues can be a source of pressure ("because I knew how to deal with [resident's

family].. CORRECTLY, other members of staff and things didn't like that, and they tried to kind of intervene to say, look, you're.. kind of a bit too.. PALLY", P2), and organisations may dismiss initiative ("you're advocating for that person […] I think this would be really good for them. No, no, we've tried that", P8). Working together with MDTs is key but health systems may not be functioning properly ("when needing therapies, CBT therapies […] we can't seem to access those", P7) which serves as a reminder that the plural *person* is influenced by its material conditions (Marx, 1859) and is situated in the socio-political sphere (Rogers, 2016).

Staff must act professionally ("we always have to have a positive attitude at work", P10), and "give 100% to the people you support" (P18). You leave "your PERSONAL life behind you" (P5), and you somewhat become "a great big brick wall" (P2). P8 explains though that "all the guidelines […] are based on the, the idea that you're coming to work in a perfect mood" and wonders "what about me? I'm having a bit of a shit time as well […] people are doing sort of two or three jobs at a time, people in support work", highlighting that "your primary focus needs to be on the person that you're supporting. But equally.. you can't do it without happy, healthy staff". The expanded *person* includes one more key component; the staff are part of the *person*. P2 emphasises: "we are human and amongst all of this great big brick wall". Staff's humanity is recognised, the *person* is an *us* and in *us* there is a person. Staff are human, they do have limits ("you can become a bit snappy or a bit tired", P21), they go home feeling "restless or hopeless" (P9) or "with a smile on your face" (P11) depending on how their shift went, and they come to work bringing their personal attributes ("I can find common interests […] relatively easily with most people", P17) and, indeed, personal circumstances ("had a really rubbish day at home […] it can affect the way that you care", P2). Equally, residents are not labels, but human ("people will go […] they've got a learning disability […] no, it's a person. They've got lots and lots of things going on", P13), with their own personalities and, indeed, flaws ("people expect you to drive them in your own car […]

they haven't got the money to pay […] they said they had money, but they didn't", P16) and their agency must be recognised by staff ("just cause you've got a learning disability, it doesn't mean that you're free, free access to anybody", P14). Staff and residents are human not only individually but in a connected sense ("this is a human being just, just like me […] their stresses are, are similar to mine", P8) and their shared humanity can facilitate relationships ("it's not only about, like.. doing, doing your role and ticking the boxes", P20). As a human relationship, the care relationship is not perfect, P17 explains that "it's an inevitability" that some staff and residents will not necessarily "get along with each other", however, "minimising the impact of that" is crucial.

Examining the Colossus reminds us that relationships are part of a larger material and ideological reality. "People look down on you a little bit, oh, you're a carer", P18 states, reflecting on narratives that dismiss support staff. Yet, building relationships is a complex process that requires a lot of skills.

Theme 3: "It's a lot more than people think" - The skilled worker.

Care relationships are not easy; demanding behaviours ("you can get called names, you might get hit", P12), difficult decision-making, and other practical responsibilities around the person, including "financial management […] fire checks, home checks" (P13). "Care for others", P3 explains, "could.. drain you", it is "not just about […] go to day service, come home […] get ready for bed […] it's a lot more than people think" (P13). The participants' accounts seem to resemble the emotional and practical spheres of care (Rogers, 2016), with the former referring to emotional responses and the ways they are negotiated, and the latter to the practical everyday care that is executed relationally. A range of skills is required to navigate all this. Staff are skilled workers who engage in various processes and practices to establish and maintain positive care relationships and restore them when disrupted.

Everyday life is a vast terrain that includes human activities (i.e., being and doing) as well as the environments through which life is lived (Pink, 2012). Care in everyday life puts staff in a unique position allowing them to understand residents on a "granular level" (P8). P23 explains:

> If, for example, you only worked in a day-care centre, so when that person arrives they're already dressed, washed, you, you don't have that understanding of, of how that person's morning's been […] you're only seeing that person presented at that time […] we're here 24 hours a day

Staff skilfully use everyday life as a vehicle to establish relationships ("some of them like orange juice […] you provide them without them asking […] they see that you can understand them because you pay attention", P1). Activities, from "cooking a meal" (P9) to "going to the cinema" (P3), serve as an avenue to building ("find an activity that I know they really enjoy so […] I can work alongside them", P2) and maintaining relationships ("suggesting things […] this disco there, there's this funfair happening", P3). This reflects previous research (e.g., Bigby & Craig, 2016; Totsika et al., 2008) that emphasises the importance of personalised activities in building relationships between people with and without a learning disability and, once more, highlights the practical everyday care that is executed relationally (Rogers, 2016). Staff use their engagement skills; they show an interest in "what [residents are] thinking and what they're feeling" (P16), take an "interest in their interests" (P15), and create similarity ("matching people who enjoy similar activities will give that extra, extra thing to that relationship", P20); they share moments with residents having "good times together" (P20); they reassure ("when you're doing personal care or medication, telling them what you're doing", P22) and praise ("smiling back at you because.. you've praised them, P11"); they are "sitting and listening" (P14) to what residents need; and use humour relationally ("in Greg's […] he made a cheeky

remark and I went, right, for that you can go buy me a doughnut", P22). Such processes allude to the literature synthesised in Study 1 (e.g., Haydon-Laurelut & Nunkoosing, 2010) and nod to some of the findings (e.g., sharing the moment, using humour) in the work of Johnson and colleagues (2012).

Staff are problem solvers, troubleshooting on the spot ("feel that if there is an issue, they can come to me", P20) or proactively by planning ("people get more upset around the death of their parent or something, so remembering that month", P16). Relationships take courage ("I would sit close to him. People didn't get to sit close to him", P3) and staff that confidently dare to try ("you've just gotta go: yeah, I'm gonna do it", P13), expanding the residents' horizons ("everybody was telling me that she will never get a job and I did it […] she's got a large community now", P7). A positive care relationship is not a static event, staff "carry on" (P18), they "always check […] how [residents are] feeling" (P10), they "follow up things" (P20) creating the conditions for consistent care, and when making a promise they are being reliable and "keep that promise" (P7).

Residents may not have "the same outlet" (P15) as staff, which may challenge relationships ("they can't tell you what they want, YOU don't know, and that then stresses them out", P2). In line with what the literature indicated in Study 1, effective communication is, therefore, a key skill, with staff tailoring their communication to the residents' preferences ("say to somebody to help them make a cup of tea, but for somebody else, they might need a little bit more of: you need a cup […] this […] that", P23) and being honest and transparent ("when you go to appointments […] asking questions when HE'S THERE", P11). Communication is embodied; staff skilfully interpret the residents' body language ("how he REACTS, his facial expression", P13) and are mindful of their own ("you walk through the door in the morning, looking disinterested, [resident is] on it", P18). To communicate is to tune

in, and staff must be perceptive of the residents' emotional states ("some people […] go into a place […] bubbly and.. all excited […] but the person […] won't.. react to that", P11). Emotional intelligence is part of a wider set of emotional skills whereby staff employ "empathy and kindness" (P12), "providing the best care for [residents] that you'd want to.. experience YOURSELF" (P10) in a "non-judgmental environment" (P7). Emotional skills also involve self-regulation as "sometimes… you can get really frustrated at, at a situation" (P15), yet being patient and giving time is key ("if somebody takes an hour and a half to HOIST […] if they want to have a conversation while they're doing that… you can't rush them", P5). These processes and practices not only point towards Carl Rogers' (1957) conditions (e.g., empathy, authenticity, non-judgemental attitude) needed to establish a positive relationship in the context of therapy, but, once more, go back to Chrissie Rogers' model (2016) and highlight the emotional sphere of care, framing emotional work as a facet of care work (Fisher, 2021) and of care relationships.

"You gotta get to know people", P13 explains, mirroring almost all participants' emphasis on the knowing process that underpins positive care relationships and reflecting the importance that some of the literature in Study 1 placed on knowledge (e.g., Williams et al., 2009a). Getting to know the residents "as a person" (P21), their "hobbies, enjoyments, favourite food" (P16), how they communicate, "what they like or they don't like" (P10) is crucial. Long-term care facilitates this as "you can build a long-term relationship. You can really get to know the person because you will support them through the difficult times […] the happy times" (P20). Being a *knowing* staff is truly a skill; it provides a deep understanding of the resident and equips staff with the intuition to navigate the relationship ("if she's [incomprehensible] shouting off the roof, then you know she doesn't want to. But if she's saying it just in general […] she does wanna get up", P22). *Knowing* staff differ from *know-it-all* staff as knowing is an ongoing process ("people say: I know he likes this. He's not ALWAYS gonna

like this thing. It's finding out what they like", P11). Being *knowing* not only encapsulates knowing the resident but also knowing yourself and being self-aware (Broussine, 2012), knowing "what you can give and what you're comfortable with" (P15). Ultimately, "trust is everything" (P14); from discussing matters that worry residents to intimate personal care "it's important for them to feel like they can trust someone" (P15). Trust is not a given ("without going in […] thinking […] this guy's gonna like me because.. I'm, I'm a carer", P11), it is delicately built using skills, processes, and practices described thus far, while navigating the residents' stories ("the person I look after has got past trauma […] not just gonna be welcoming everyone with open arms", P21). Unsurprisingly, trust appears to be a universal theme reported in relevant international research (e.g., Giesbers et al., 2019) as well as across different care settings beyond social care residential ones (e.g., NHS secure units; Fish & Morgan, 2021), and from the perspective of people with a learning disability themselves (Giesbers et al., 2019; Fish & Morgan, 2021).

Among people with a learning disability, behaviours that challenge, such as physical aggression or other challenging situations, are estimated at 5% - 15% (NICE, 2015). Additionally, providing care in the realm of everyday life, may entail that logically, disagreements and misunderstandings can arise between the people who provide and the people who receive care. These circumstances can disrupt the relational journey of staff and residents and almost all participants discussed relevant experiences where the care relationship had, at some point, experienced a challenge of varying nature. For instance, P12 discussed how disclosing a safeguarding issue led a resident feeling that "I'd broken his trust, I had told the manager something that he disclosed to me", explaining that although "it was something that had to be kind of addressed", the resident "struggled to understand" why P12 had to disclose it. P21 recalled a day where they "had a really, really, bad shift, like, he was hitting the walls", reflecting that "it was a lot easier to move on" when they compared the situation to physical

aggression directed towards staff (“if he’s hit someone, it’s probably not gonna be as easy, is it?”).

To restore care relationships, staff de-escalate (“somebody’s shouting at you […] you can't shout back […] low toned, soft voice”, P5), put a positive spin on things (“shall we go and get a Costa?”, P16), and apologise (“say, you know, I'm so.. I AM sorry, even if you don't feel you're sorry because you, you did the right thing”, P12). They try not to hold grudges against residents (“all is forgiven sort of thing”, P11), and move on and “start the next day as it comes” (P19). They engage in reflexive practice with residents (“I will say how I feel and he will say how he felt”, P7) or take time apart and reflect alone and with their teams (“too noisy […] too many people […] several setting events to that which led to them giving me a clip around the ear”, P8). Staff remain flexible and make tailored adjustments to address the disruption (“for some folks […] increasing the level of restriction […] makes their communication easier, because they've got much less on their plate […] for other people we've opened the world up a little”, P6). Relational disruptions disturb the position that staff occupy in the relationship, yet you must “continue to be yourself” (P22), “you just continue with the same support, em, and […] it just falls back into a positive relationship” (P19). A relational challenge can become a relational opportunity, “an opportunity for you to keep, to keep closer and have a better and more close communication TO HELP THEM MORE” (P1), or even motivate staff to spend “more time with that person […] so that we can create those relationships” (P17). Such relationally restorative practices must be viewed dynamically; as a process, instead of a static, whereby although staff aim to succeed in their attempts to restore a positive relationship, this does not mean that there won’t be occasions when they will fail to do so (“sometimes you aren’t successful”, P1). These restorative practices draw in everyday, human interactions, yet they also seem to reflect person-centred and PBS principles (PBS

Academy, 2015) that are embedded, as a notion and praxis, in the collective consciousness of learning disability care work in the UK.

As a construct, the *skilled worker* is situated in the individual, their motivation, and attitude. The motivation to care and build relationships comes primarily from within, from appreciating the job ("I love what I do", P23) and finding it rewarding ("gives you a lot of experience in many areas", P7). After all, several participants described care work as "more than employment" (P13), "a bit of a.. vocation" (P7), whereby staff do not do it just "for the money" (P12). Motivation also comes from a deep investment into the residents' lives ("I just want what's best for them", P4) and residents can sense motivation or lack thereof "regardless of how profound their disability" (P8). Moreover, relational skills and practices are intertwined with staff attitude. A "positive mindset" (P1), a persevering spirit ("you're not ready to get up, I'll come back […] try again", P12), an emphasis on respect ("I'm going into his home. It's his space", P21), an awareness of language ("people say: I'm taking such and such. You're not taking anybody […] you're supporting someone", P9), and an understanding of "how important some, some of the practices and our behaviours are as support workers" (P7), all signify an attitude that facilitates positive relationships. As part of their research on work orientations of support staff in care homes in England, Daly and Fisher (2023) observe this personal investment and genuine desire to help in the accounts of staff, framing such elements as key motivators to engage in care work. It is worth considering that such intrinsic motivation can also be seen as almost archetypical, reflecting normative expectations of the intensity that staff should support residents and perhaps essentialising care, framing it as part of "a person's nature or character" (Daly & Fisher, 2023, p. 82).

Nonetheless, the *skilled worker* is a *becoming* construct. Often, support staff come from diverse work backgrounds ("could have somebody who's working in a supermarket", P13), yet their existing skills can be developed, their practices can be informed further, and new things

can be learned. This is done by becoming more knowledgeable about the residents' condition and experiences (“I have done endless research […] to better understand him”, P18), and “getting to grips with the care plans […] reading their histories” (P14). It is also done by receiving “a LOT of training […] learning different aspects of learning disabilities […] how you can help […] what might make things worse” (P4). As care work is hands-on, training is not always “classroom training” (P18) but could be “training on the job” (P21), learning alongside more experienced colleagues. This, once again, nods to the work of Bradshaw and Goldbart (2013) who frame the care workforce as a Community of Practice and observe that support staff show a preference for learning by *doing* and working within their teams, rather than through external teaching. That is not to dismiss teaching-oriented training and its importance, instead, it is to emphasise that, to help build positive relationships, training needs to be meaningful. P8 elaborates on what that could be:

> `understanding autism` […] `health and safety` […] none of it really.. mentioned that it's incredibly important to have a good relationship with the person […] some sort of training around that […] there's not much discussion about.. how do you feel? -the support worker […] they need to be incorporated into the training

The range of skills, processes, and practices employed in residential settings can bring staff and residents into closer relationships. Reversing this, it is important to explore what these relationships bring to the lives of staff and residents.

Theme 4: “Fulfilling, rewarding, and transformational” - Relationships matter.

“You have to have a relationship of sorts with the people you support”, P22 explains, “you can't support them otherwise”. P9 elaborates, “doesn't matter how many bodies you've got there. If those bodies don't have a good relationship with someone […] can have a MASSIVE impact on the people we support”. P17 adds, “it's the positive relationships […]

that […] keep people in this job". Participants make it clear that the care relationship matters. It is not secondary, instead, as discussed in Study 1, it is a driver of effective care on every level (Bradshaw & Goldbart, 2013; Windley & Chapman, 2010). A positive relationship makes everyone feel good (Johnson et al., 2012), it can be "fulfilling, rewarding and transformational" (P18) for everyone involved and its absence can be detrimental.

Positive care relationships create the conditions for residents to live a happier life, "the person is happy, fulfilled" (P9), they are "smiling, singing, laughing, giggling […] having the best time which they can possibly have" (P4). The impact on their self-esteem (Broussine, 2012) becomes apparent as the residents feel valued ("they think there is one person who understands", P1), more confident ("they feel able to say what they want", P12), being "kind of like their normal selves" (P2), feeling that "care is giving something extra to their lives" (P20). Their mental well-being improves ("they achieve something and they've been praised for that achievement.. you just see a massive incline", P2), they are more engaging ("a lot of them will plan […] certain activities around that day knowing that I'm there", P17), and relational disruptions can be navigated more easily ("when he is displaying.. challenging behaviour […] he does tend to listen to the people more.. that he has the better relationships", P21). A positive relationship can help residents transform and grow, expanding their relational ("when he first come to me, you couldn't hear him […] now [incomprehensible] talk normally and people were saying: oh my God [name], he offered me a cup of tea", P13) and life skills ("baking a cake […] interacting with some neighbours", P18).

Residents achieving their potential makes staff's "heart swell" (P14), the message is often shared (Johnson et al., 2012), and the feeling spreads out to the whole team ("although, it was a couple of individuals' kind of.. initiative […] the team are reeling on that as well", P2). Positive relationships give staff a sense of enjoyment, pride, and satisfaction ("to have a good relationship […] with people that pose challenges to.. 95% of the professionals […] I'm quite

pleased with the fact that I can make these relationships", P17), and make work feel meaningful ("you actually feel like you're making a difference […] I used to work in [company in a different sector] and I was just thinking: this is so pointless, my job is pointless", P21). Staff want "to stay to work" (P9) and are motivated to "do that bit more […] to make things better for everybody", P14). Their confidence is boosted ("you feel able to support [residents] in ANY situation", P15) and they grow alongside residents ("I have learned from them", P14). As previously discussed, knowing the resident builds positive relationships, but also those relationships allow staff to get to know the resident more ("through that relationship […] be able to read most of the, how should I put it, his triggers, maybe to understand him", P3). Such accounts perhaps provide more context to previous research that evidences support staff's positive perceptions of their role (Hastings & Horne, 2004) as well as staff's reasonable job satisfaction despite adverse working conditions (Daly & Fisher, 2023).

An absence of positive relationships essentially highlights their importance. "There is no happiness in this case", P1 explains, residents can become "really withdrawn" (P2), "feel more isolated" (P23), and lose hope ("nobody cares about me", P16). They might avoid staff and refuse to work with them ("everything you ASK them to do, or try help them do, they're just defiant", P2) which can impact their overall health as "they might not come to you for things that they NEED" (P5). There might be an "increase in, in distress and behaviours […] to tell you that everything's wrong […] whether that's outwardly aggressive or, or just, like, a lack of engagement" (P6). Staff's motivation declines and care work feels like a meaningless chore, "like you banged your head against a brick wall for the day" (P11). Care standards might weaken as you are not working to "YOUR potential as a support worker" (P11) and this comes across to the residents. Staff may doubt themselves ("unsure about what it is, why you're doing it, you can feel like you're doing something wrong", P9) and uncertainty can result in a lack of engagement with residents ("lots of time support staff will be on their phone […] sometimes

it's because.. you're not sure what to do or how to support that person, and that's like an escape", P20). The absence of positive relationships can make the shifts "very draining" (P23), impacting staff mentally ("can drag you down a bit", P4), and leading to "lots of sickness" (P3) or staff turnover ("you think you are not productive […] you prefer to LEAVE", P1). It can have a knock-on effect undermining other staff's care relationships. P21 explains:

> if someone's been with him […] that doesn't have the best relationship […] and just let him sit on the sofa all day. Then you come in the next day and you have to rebuild […] he's like taking 10 steps back

Relationships matter and are one of the key forces driving care provision. Their impact may, to some extent, travel through time, whether they are positive ("the [resident] they took to the supermarket, he's still reeling off it now", P2) or have experienced challenges ("the trust there has been broken, you know, you made me do something I didn't want to do […] in some of the things that he tells, it's still there", P9).

4.5 Strengths & limitations

Inevitably, like every piece of research, this study had strengths and limitations upon which I wish to reflect.

Drawing on Table 13 which I presented in the 'Participant characteristics' section of this chapter, a significant proportion of the study participants were between 35 – 54 years old and identified as women, reflecting age and gender patterns observed in adult social care in England (Skills for Care, 2021). This leads me to conclude that, in terms of age and gender, the staff that took part in the study somewhat reflected the broader age and gender characteristics of the wider care workforce in England. A significant amount of study participants identified as White British and although Skills for Care (2021) suggest that approximately 76% of support staff come from a White ethnic background (British or other

nationality), research (e.g., Hussein, 2018) as well as the very reality of adult social care in England suggest that a growing proportion of social care support staff are migrant workers (White or otherwise). With this in mind, despite taking all feasible actions to include a range of social backgrounds (e.g., recruiting through various avenues and approaching a wide range of care organisations and services), this study could have included more migrant and non-White British support staff to ensure that the care workforce is represented more accurately. There was variation in terms of support staff's professional characteristics as well as the residential settings they were based, which reflected different care experiences and added nuance to the participants' accounts. Additionally, including a Shared Lives carer in the study offered interesting perspectives that enabled me to reflect on the similarities and differences of care relationships in growing and more conventional residential contexts. Participants came from a wide geographical range across England, which I consider an asset; nevertheless, no study participants were based in London, despite also advertising the study in London-based care organisations and services.

As discussed in the section '4.4 Analysis' of this chapter, the care relationship involves many partners; however, this study only focused on the views and experiences of support staff as one of the key relational agents. Not involving significant others (e.g., family members or friends of residents) and, crucially, the residents themselves to explore their views on and experiences of care relationships is one of the study's limitations. The support staff who took part in this study were supporting residents with different levels of learning disability. This provided a more holistic insight into care relationships as staff discussed their views and experiences not only in the context of supporting residents with a mild learning disability as may happen in learning disability research (Bigby et al., 2014) but also residents with a moderate or severe learning disability.

As expected, the self-completion of the Demographics & Eligibility Questionnaire on Qualtrics© involved the participants' interpretation of the questions. I was particularly mindful of how the participants would interpret the terms 'long-term residential setting' and 'learning disability', for instance, drawing on my own work experience in social care, my colleagues would sometimes use the term 'learning disability' to refer to autistic people too. To uphold data quality, I proactively used the wording 'learning (intellectual) disability' in all documents, including the Demographics & Eligibility Questionnaire, and I provided a definition of the terms 'long-term residential setting' and 'learning disability' in the Questionnaire. It is worth mentioning that the Questionnaire, as well as other relevant documents (e.g., information sheets) that I shared with people, could have been more explicitly informed by easy-read principles, with a focus on proportionally simplifying the language further, slightly lowering the text density, and, perhaps, adding some appropriate pictures for easier navigation through visual cues.

It could be argued that the people who chose to take part in this study represented staff who had a particular interest in positive care relationships and perhaps more specific knowledge around social care issues. Logically, an overall interest in the researched topic is inevitable when people participate in research. The study participants were certainly interested in and were enthusiastic about learning disability care relationships; however, they did not represent a somewhat care work 'vanguard', instead they were 'ordinary' support staff who came from different backgrounds, had different styles, and shared their views and experiences in an open and genuine manner. This is also demonstrated in the 'Participant characteristics' section of this chapter. Nonetheless, I do appreciate that, generally speaking, in research a vague distinction could be made between the people who are more likely to participate in a study and the people who are less likely to do so, based on factors such as motivation, attitudes,

perspectives, and context and conditions, to name but a few. Perhaps my study participants fell under the first category.

Overall, I view the fact that I conducted the interviews online as an advantage, which alludes to previous work that highlights the benefits of videoconferencing for qualitative interviews (Irani, 2019). More specifically, geographical constraints were eliminated, saving precious time and material resources that would have been used for travelling to conduct the interviews. The online interview format provided flexibility and accommodated the busy schedules of both the participants and myself. Furthermore, both the participants and I were able to engage in the interviews in an environment that was comfortable, familiar, and of our choosing, facilitating a positive experience for all. Additionally, as most people had their cameras switched on during the interview, videoconferencing maintained some access to visual cues and body language necessary to build rapport and contextualise the participants' accounts.

Although I always endeavoured to be friendly, engaging, and empathetic, I appreciate that, compared to in-person interviews, online interviews can feel more impersonal and task-focused, missing those little moments that comprise human interactions and create connectedness (e.g., embodied communication, small talk, etc). Throughout the data collection, I wondered how conducting the interviews in person might have influenced the outcomes. There were only a few occasions when either I or some of the participants had Internet connection problems, or the participant's microphone was not working properly, or the room they were using was rather noisy. This caused minor issues, both during the interview and the transcription process, interfering with comprehending what the participant was discussing. Nonetheless, such issues were overcome by quickly fixing the technical problem. I anticipated that not every participant would be familiar with Qualtrics©, Zoom© or Microsoft Teams©, or would necessarily have the technology or Internet connection to access those platforms, and I was prepared to offer alternatives to accommodate people's needs (e.g., complete the forms

together over the phone, conduct the interview in person, etc). However, none of the participants appeared to have any issues or requested alternatives.

4.6 Conclusions & project directions

In the section '4.4 Analysis' of this chapter, I nodded to the quotation that I used in the thesis title, offering further analysis. The care relationship is a "strange, grey area" (P17), a conundrum, and this is the thread that weaves through the four themes of this study, connecting concepts, contexts, processes and practices, and outcomes. The four themes assembled tell a comprehensive story about care relationships.

Building positive care relationships relies on little, yet powerful, everyday moments. Support staff build relationships by *doing* relationships in the here and now and develop their skills predominantly experientially (Bradshaw & Goldbart, 2013). Therefore, praxis appears to be at the core of care relationships and learning disability care work. The direction of the care relationship is somewhat cyclical, namely, what seems to underlie or influence the care relationship simultaneously grows stronger as a result of the care relationship. For instance, being a *knowing* staff is a process that underlies positive care relationships, and at the same time, having a positive care relationship helps support staff to get to know the resident more.

Care, and consequently care relationships, seem to operate within the intersection of three spheres, namely the emotional, the practical, and the socio-political sphere (Rogers, 2016). Drawing on this and also building on the conclusions of Study 1, the care relationship could be likened to a living organism that is connected to, operates within, influences and is influenced by the wider social care ecosystem (see Burn & Needham, 2023, for an overview of the concept of ecosystem in social care). This perhaps points towards drawing an analogy with ecological models used in the context of understanding human development (micro, meso, and macro; Bronfenbrenner, 1994), leading me to develop a care ecology. The micro-level

(Bronfenbrenner, 1994) involves the interactions and the interpersonal, everyday care practices and processes that support staff and residents engage in (i.e., the emotional and practical spheres of care work; Rogers, 2016) to establish positive care relationships; the meso-level (Bronfenbrenner, 1994) includes the effect that the agendas, approaches, and responsibilities of the care provider and other pertinent organisations as well as the desires and priorities of significant others (e.g., family members, close friends) of residents have on the care relationship; and the macro-level (Bronfenbrenner, 1994) involves the policies, regulations, and the wider material and ideological conditions as well as the societal discourses that surround learning disability and care work (i.e., the socio-political sphere of care work; Rogers, 2016) and the ways they shape the care relationship. The different levels in this care ecology are interconnected and constantly interact with each other, moulding the care relationship as well as creating conundrums and dilemmas in the care praxis.

In this care ecology schema, support staff can consciously or unconsciously reproduce stigmatising societal discourses in their relationships with residents (e.g., treating residents as children). Support staff may also witness how such discourses can target the people they support. Following a resident's behaviour in a public space that slightly deviated from social norms, P13 recalls an encounter with a member of the public: "He said, well, don't bring him [resident] out then". Crucially, such societal discourses can also be directed to support staff themselves, with the devaluation of care work ("People look down on you a little bit", recalling what P18 said in Theme 2), pointing towards the stigmatisation of support staff for being support staff (Daly & Fisher, 2023). Perhaps links can be drawn to social class and migration status, with Daly and Fisher (2023) reflecting on the accounts of some of their participants who tied care work stigma to the working-class connotations of being support staff or to notions of care work being beneath English people; a role they would undertake only if they had to, like

some migrant workers. Support staff and residents, albeit in different degrees and ways, can be stigmatised for providing and receiving care.

In this study, the individual and shared humanity of support staff and residents is emphasised and, ultimately, the care relationship itself is humanised. P6 puts it beautifully:

> We talk a lot about meeting needs and ah.. and.. giving the person what they want or what they, what they need. But, actually, for me, most people in their lives, really just want another human being to sit with them and say: it's alright, we're together, you've got somebody and we'll find a way and, you know, we'll, we'll ease if you're in pain, we'll make, we'll help you find the right help if you, if you're ill, and then we'll make sure you've got things that you enjoy to eat and drink and do, em.. and, and, and company and spend time with people, you know, that's.. that's, that's the ESSENCE of what it means to provide care in the way that we do, anyway. You know, in, in care and support.

Care is framed as a universal need and part of the human experience (Rogers, 2016). Interdependence and the similarity of human vulnerability as fundamental human conditions are highlighted (Rogers, 2016) and here it is worth recalling what P10 said in Theme 3: “providing the best care for [residents] that you'd want to.. experience YOURSELF”. To humanise the care relationship is to dare to somewhat reframe the relationship between support staff and residents, moving beyond the binary of egoism-versus-altruism and viewing those in caring positions as “acting for self-and-other together” (Held, 2006, p. 12). Care work and the care relationship are, therefore, not romanticised or reduced to “selfless or self-sacrificial” (Rogers, 2016, p. 36) acts, which nods to critiques of normative expectations of care provision in a highly feminised social care sector (Fisher, 2021). Essentially, emphasising the humanity

of support staff and residents argues for a pro-resident *and* a pro-worker approach regarding care work.

To humanise the care relationship does not mean eliminating contradiction; in contrast, it perhaps highlights the "strange, grey area" (P17), the conundrum, even more. For instance, the residents' desire to develop friendships may be acknowledged as a human need (Rogers, 2016), a need that unites support staff and residents as they both have it in common as fellow human beings. Nonetheless, returning to the care ecology approach that I discussed earlier, this is not oblivious to the wider social care ecosystem within which support staff and residents build relationships. Friendships or family relationships are more equal than professional relationships, and this problematises the care relationship as it creates a sense of equality in expectations too. Could support staff have the same expectations from residents as residents have from staff? I would imagine that this would not be feasible, or one could argue not desirable, in the context of a regulated social care system that provides support to people who are vulnerable in multiple domains.

Focusing on the *human* in care relationships expands what being human means. Goodley and Runswick-Cole (2016) explain that, reflecting the humanist tradition of the Enlightenment, rationality, autonomy, and independence are among the key elements that are used to construct traditional forms of humanness that contain value in the modern world. They coined the term dis/human to demonstrate how learning disabilities, and disability in general, disrupt the normative construction of what being human means, whilst embracing the *human*. In other words, through a dis/human position, Goodley and Runswick-Cole (2016) acknowledge the ambivalence around the *human* and simultaneously propose a way out of it, meaning that "we recognise the norm, the pragmatic and political value of claiming the norm, but we always seek to trouble the norm" (Goodley & Runswick-Cole, 2016, p. 5). As discussed, support staff build care relationships oftentimes using ordinary, everyday skills; "you build a

relationship with the people you support as you would build with anyone", to recall what P15 said in Theme 1. The care relationship could be thus framed as "simultaneously normative and non-normative" (Goodley & Runswick-Cole, 2016, p. 12) whereby 'normal life' relational processes and practices are recognised and claimed whilst being used by and with humans who disrupt the normative through their learning disability. It is worth reflecting on whether this framework can assist with revisiting understandings and conceptualisations of care relationships as friendship or family.

As a method, semi-structured interviews served as a valuable vehicle for providing insight into support staff's views and experiences of care relationships. It is worth saying that *doing* care relationships in real life is a more complex and much messier process which once observed in real-time can complement people's accounts and offer greater understanding. This points towards reflecting on how designs and methods that have traditionally been used in disciplines such as anthropology and sociology can be incorporated into psychological research to explore, on the one hand, how people *perceive* their actions and, on the other, what they *actually* do, and bring the two together.

Summary of Chapter 4

In this chapter, I elaborated on Study 2, a qualitative study that utilised the findings of Study 1 as a compass and sought to address the project's aim and research questions further and from an empirical perspective by focusing on the views and experiences of support staff regarding their care relationships. To this end, I generated four themes (i.e., "A strange, grey area" - The care relationship as a conundrum; Shadow of the Colossus - Care relationships in a material and ideological reality; "It's a lot more than people think" - The skilled worker; and "Fulfilling, rewarding, and transformational" - Relationships matter) and one subtheme (i.e., Person-centredness in the plural - The person is *us* - the person *in* us).

Study 2 highlighted that the care relationship is a "strange, grey area" that occurs in the realm of everyday life where the realities of staff and residents are intertwined. The material and ideological conditions, the Colossus, surrounding the care relationship can sometimes facilitate and other times hinder them. The *person* expands beyond the resident and involves the relationships and the humanity of others. Building positive care relationships and restoring them when challenged entails skilled workers. Positive relationships create the conditions for effective care and happier lives for both support staff and residents and the absence of a positive relationship can be detrimental.

Study 2 concluded that care praxis and *doing* seem to be at the heart of care relationships and learning disability care work. The care relationship resembles a living organism that is part of the wider social care ecosystem pointing towards a care ecology. Care relationships are humanised and the humanity of support staff and residents is emphasised, whilst reflecting on the implications for what it means to be human and for relational care practice. The four themes and the study conclusions assembled, provide a holistic account of care relationships.

In Study 1, I explored what the literature reported about care relationships and in Study 2 what support staff had to say. It was now time to embark on conducting my final study in an attempt to watch the care relationship unfold in real-time.

Chapter 5: Study 3 – Care Relationships: An Ethnographic Study

5.1 Introduction

As demonstrated thus far, the care relationship can be perceived in different ways and is a complex phenomenon that takes shape and form as a praxis in the context of *doing* relationships in everyday life. Given the practical and applied aspects of care relationships, relying solely on verbal accounts of what the care relationship entails would be somewhat limiting. After all, whilst acknowledging the highly valuable insights that the participants of Study 2 offered, it is also important to be mindful that "people do not or cannot always describe what they actually do and think during an interview" (Rashid et al., 2019, p. 1). Building on studies 1 and 2 which encompassed a range of backgrounds and experiences, the present study sought to explore the care relationship not only through verbal accounts and narratives but also by witnessing it in real-time, as it occurs in the real world, to gain a deeper understanding of it. By doing so, I aimed to explore the link between the mental representation of the care relationship (e.g., staff's views and experiences) and the actual execution of care relationships in everyday life (i.e., what people do). Additionally, Study 3 sought to address some of the limitations of Study 2 by creating the conditions for more support staff to participate (i.e., not only the people 'more likely' to participate in research) and, crucially, by involving the residents as well as the significant others that may be part of the residents' lives (e.g., family members, friends). Ethnography seemed to be the most appropriate, albeit ambitious, approach to achieve the goals of this study and, hence, address the aim and research questions of this project (see Chapter 1, section 1.4) further.

5.2 Methodology

Design

In Study 3, I employed, once more, a qualitative design, specifically an ethnographic[49] one. Having its roots in anthropology, but also used widely in disciplines such as sociology, ethnography is predominantly concerned with cultures, belief systems, practices, and social contexts (Rashid et al., 2019) and can be defined, in a nutshell, as "the description of people and their way of life" (Rashid et al., 2019, p. 1). Historically, ethnographic research involved continual long-term fieldwork that could take place over a year or more (Knoblauch, 2005); however, more contemporary theorisations of ethnography revisit and critically engage with the concept of long-term fieldwork as well as other ethnographic assumptions and practices. My ethnographic design drew on these theorisations and was particularly inspired and influenced by focused ethnography (Knoblauch, 2005; Stahlke Wall, 2015) as well as patchwork ethnography (Günel et al., 2020).

More specifically, in focused ethnography, a theoretical distinction is made between 'anthropological ethnography' and 'sociological ethnography' (Knoblauch, 2005), whereby the former refers to more 'traditional' forms of ethnography where the researcher explores 'other cultures' as an outsider to these societies, whereas the latter entails researching societies that the researcher is familiar with and already a member of. Drawing on 'sociological ethnography', focused ethnography "focuses on small elements of one own's society" (Knoblauch, 2005, "Focused Ethnography" section, para. 2). In line with its theoretical assumptions, focused ethnography's key elements include short-term fieldwork and intensive methods of data collection, focus on specific research questions, and researchers with insider

[49] Thank you to Dr Carys Banks, Dr Fawn Harrad Hyde, Dr Nikhaela Wicks, and Nicola Elson, for the valuable discussions around conducting ethnographic research in social care and other settings.

knowledge of the groups they are conducting research with (Knoblauch, 2005; Stahlke Wall, 2015). Focused ethnography has been widely used in applied social research as well as practice-based healthcare studies (e.g., Strandås et al., 2019, in the context of nursing) to make practical use of the experiences and insights gathered through research (Stahlke Wall, 2015). Although beyond the scope of this chapter, it is worth noting that focused ethnography has, perhaps unsurprisingly, generated debate around its supposed division with more 'traditional' forms of ethnography (see Knoblauch, 2005 or Trundle & Phillips, 2023, for discussion). In a similar vein to focused ethnography, patchwork ethnography refers to "ethnographic processes and protocols designed around short-term field visits, using fragmentary yet rigorous data, and other innovations that resist the fixity, holism, and certainty demanded in the publication process" (Günel et al., 2020, p. 3). The need to advocate for patchwork ethnography as a framework emerged in the context of challenging masculine narratives of the 'always available researcher' to conduct ethnographic research and, tied to that, other very pragmatic factors such as work-life balance or the Covid-19 pandemic and its implications for conducting research (Günel et al., 2020).

An ethnographic design incorporating elements from focused and patchwork ethnography was suitable for addressing the goals of this study. It corresponded with the project's rationale, aim and research questions, as well as the theoretical and policy frameworks in which I situated the project in Chapter 2. Additionally, this design was in line with the disciplinary (e.g., focused ethnography often used in practice-based fields), pragmatic (e.g., short-term, yet intensive, fieldwork accommodating my project's time restraints), and personal (e.g., my care work background served as insider knowledge when conducting research) domains of this study, thus creating overall conceptual coherence (Braun & Clarke, 2022).

Qualitative conceptual paradigm

Similarly to Study 2, this study employed an interpretive conceptual paradigm and a predominantly experiential qualitative approach (Braun & Clarke, 2022). Importantly, and as I will show in subsequent sections of this chapter, it was not only the participants' lived experience of care relationships that guided this study but also my lived experience of building relationships with the participants and witnessing them *doing* relationships. As with Study 2, in the present study, I also shifted across the continuum between a hermeneutics of empathy and a hermeneutics of suspicion (Braun & Clarke, 2022).

Theorisation of language & ontological and epistemological position

In a similar vein to Study 2, I, once more, employed a primarily intentional theorisation of language whilst occasionally moving across the spectrum and conceptualising language in a more constructionist manner too (Braun & Clarke, 2022). My ontological and epistemological position did not change either; hence, I, once again, employed a critical realist ontological position and a contextualist epistemology (Braun & Clarke, 2022). As with Study 2, reflexivity was at the core of Study 3.

Defining the participants: inclusion & exclusion criteria for care settings & individuals

For this study, I sought a care organisation that was willing to facilitate ethnographic research. To be eligible to take part in this study, a care service had to be a long-term social care residential setting[50] for adults with a learning disability in England. Care could be funded privately or via local authorities and the residential setting could be managed by a private or third-sector (i.e., voluntary) care organisation or by the local council, but not the NHS as this study did not seek the type of ethical approval required for NHS settings. The residential setting

[50] As defined in Chapter 1, specifically the section '1.2 Dissecting the thesis title: Contextualising learning disability care relationships'.

had to be structured in a group home fashion, for instance, a care home, supported living service, or another group home arrangement. This criterion was employed for the following practical reasons: 1) to make the process of data collection more straightforward, as a group home setting is, by default, a defined space that serves as a workplace to a specific number of staff and as a home to a specific number of residents, hence making it easier to organise and conduct a short-term, yet intensive, ethnographic study like mine; and 2) to ensure that I have access to the setting for long periods and at different times, both to study care relationships in the setting more holistically as well as to spend time with support staff and residents and build rapport and trust with them. In contrast, domiciliary care residential arrangements, albeit of interest and relevance as indicated in my previous studies, were anticipated to complicate the logistics around organising and completing ethnographic data collection (e.g., arranging travel to the homes of the people receiving care and synchronising data collection to the tight schedules of domiciliary support staff). Moreover, due to domiciliary care relying primarily on short visits during scheduled times at people's homes, it was thought that such arrangements were perhaps not ideal for this particular ethnographic study as they might have resulted in a more restricted ethnographic view of care relationships and, importantly, could potentially make the process of establishing rapport and trust with staff and residents harder and lengthier.

To participate in the study, the people working in the residential setting had to be formal, paid (i.e., not volunteer) support staff[51] providing direct care to the residents living in the setting. Support staff working on a full-time, part-time, zero-hour (i.e., bank staff), or agency basis were eligible to take part. Support staff had to be 18 years old or older and able to communicate in English. Staff from all genders, ethnicities, and backgrounds were welcome to participate. The residents living in the setting were eligible to participate in the study as long

[51] As defined in Chapter 1, specifically the section '1.2 Dissecting the thesis title: Contextualising learning disability care relationships'.

as they had a learning disability[52] of any level (i.e., mild, moderate, severe or profound), were 18 years of age or over, and were living in the setting on a long-term basis (i.e., not in the context of respite or emergency care). Additional conditions alongside a resident's learning disability (e.g., autism, physical disabilities) did not disqualify the resident from participating. Finally, significant others of residents, namely family members, partners, or friends, were eligible to take part in the study as long as they were 18 years old or older and had a fairly active role in the resident's life and social network. For instance, this could entail visiting the resident regularly or engaging with them in other ways. Overall, I anticipated that people's circumstances may vary and endeavoured to liaise with residential settings and individuals to assess their circumstances if needed.

Determining the location of the care setting and the number of participants

Determining the location of the care setting and the number of participants was informed by taking a pragmatic and logical approach. I sought care organisations that were in close proximity to the geographical area of England where I was located, as I anticipated that this would make organising and conducting the study much easier for everyone involved and would also facilitate work-life balance for me as a researcher. At the same time, and as I will demonstrate in subsequent sections of this chapter, I was mindful that, given the ambitious nature of this study and the hectic realities of residential services, I could not always be selective regarding the location of the setting. In other words, as long as a setting that met my inclusion criteria expressed an interest in participating in the study, I was prepared to explore ways to work with them and navigate issues related to location.

[52] As defined in Chapter 1, specifically the section '1.2 Dissecting the thesis title: Contextualising learning disability care relationships'.

I sought to conduct the study in one residential setting for pragmatic reasons that revolved around organising and carrying out the research. Nonetheless, in the spirit of gaining more insight into care relationships, I remained open to the possibility of accessing other similar settings managed by the same care organisation, should this be relevant and depending on everyone's capacity and other logistical factors. The number of participants (i.e., support staff, residents, and significant others) could not be calculated in advance, as it all depended on the size of the residential setting that would agree to facilitate the study and, subsequently, on the wishes and eligibility of the prospective participants. Additionally, in the context of this study, the data size could not be treated as a static figure, as the composition of the setting could change (e.g., staff joining or leaving the service as the study progressed). However, using my care work experience and general knowledge, I estimated that the residential setting that would agree to facilitate the study was, like many learning disability residential settings in England, likely to support approximately five to seven residents and would have a team of roughly 15 support staff. I concluded that a combination of my estimates and the immersive nature of the ethnographic design provided grounds to expect sufficient information power[53] (Malterud et al., 2015) and, therefore, rich data.

Methods

Four versions of the Demographics & Eligibility Questionnaire, which I used in Study 2, were developed to assess the eligibility of different groups of people to take part in this study and gather essential demographic, work-related, and family-related information from those who would be deemed eligible to participate (see Appendix 3). The four versions included: 1) *support staff* - for staff to complete themselves; 2) *residents* - for residents who can understand the purpose of this study and complete the questionnaire on their own or with support; 3)

[53] As defined in Chapter 4, specifically the section 'Determining the number of participants' in '4.2 Methodology'.

significant others - for significant others of residents to complete themselves; and 4) *consultees* - for consultees of residents, namely family members, partners, or friends acting as representatives, to complete on behalf of the resident due to them lacking the capacity to understand the purpose of this study and complete the questionnaire on their own or with support.

"Ethnography differs from other qualitative methods because of its use of participant observation to understand shared meanings and practices", eloquently state Rashid and colleagues (2019, p. 1). Participant observation is a method "to collect data in naturalistic settings by ethnographers who observe and/or take part in the common and uncommon activities of the people being studied" (DeWalt & DeWalt, 2011, p. 2). The term 'participant observation' might be slightly misleading as it does not only refer to observing study participants, although this is undoubtedly one of the method's key functions, but also entails that the researcher themselves participates and observes across a continuum that has pure participation on the one end, and pure observation on the other (DeWalt & DeWalt, 2011). The researcher assumes a position somewhere along the continuum (e.g., moderate participation during observations, pure observation), which retains a degree of flexibility depending on the circumstances that each time surround participant observation (DeWalt & DeWalt, 2011). In this study, participant observation was used as a method to directly observe care relationships in real-time, as they occur between support staff and residents within the reality of the residential setting. DeWalt and DeWalt's (2011) comprehensive guide was used to inform the execution of participant observation, and a Participant Observation Protocol (see Appendix 3) was devised to highlight concrete points of observation around care relationships, serving as a map for the project's aim and research questions. In line with my overall ethnographic design, I set out to conduct approximately 70 to 90 hours of participant observation within the residential setting as well as during staff and residents' outings in the community. I considered

the number of participant observation hours that I set as a pragmatic goal, anticipating that it would yield rich data without overwhelming the residential setting, the participants, and me. I endeavoured to tailor my schedule to the care setting's rhythms and shift patterns and conduct participant observation at different times of the day (e.g., early shifts, late shifts) and on different days of the week (i.e., weekdays and weekends). I anticipated doing four or eight-hour shifts in each one of my visits to the setting; nonetheless, the pattern of visits and the duration of each visit were left to be explored and determined in conjunction with the residential setting that would agree to facilitate the study.

As with Study 2, semi-structured interviews were chosen as a method to explore the views, experiences, and practices of the participants. Three versions of the Interview Protocol that I used in Study 2 were developed to guide the interviews (see Appendix 3): 1) *support staff* – for interviewing staff about their thoughts on care relationships; 2) *residents* – for interviewing residents about their thoughts on care relationships; 3) *significant others* – for interviewing significant others of residents about their thoughts on the relationships between support staff and residents. Moreover, unstructured conversations with support staff and residents were considered an important method for capturing various aspects of care relationships through naturally occurring informal chats. Such discussions could also occur between staff, between staff and residents, and among residents. Finally, document inspection was chosen as a method to explore how care relationships are reflected and discoursed in staff's daily notes, service policies, and other relevant documents in the house. In the spirit of triangulation (DeWalt & DeWalt, 2011), semi-structured interviews, unstructured conversations, and document inspection were employed as additional methods to complement participant observation, increase the validity of the gathered data, and examine care relationships from various angles.

Easy-read principles

In this study, all the documents that I generated and shared with people (see Appendix 3), either to provide study information or to collect data (e.g., Demographics & Eligibility Questionnaire), were, to some extent, underpinned by easy-read principles, regardless of whether the person had or did not have a learning disability. Such principles were reflected in the research documents broadly through an overall simplification of language, the addition of coloured pictures, and a lowering of text density. Nonetheless, I remained mindful of the unintended consequences of the easy-read format (e.g., lack of important details in the text, disempowerment of the reader; Buell et al., 2024) and tried to balance accessibility with nuance and detail whilst refraining from making assumptions about the reader.

5.3 Conduct of study & analytic framework

Recruitment, data collection, & reflexivity

Study 3 received sponsorship from the University of Kent in June 2023 (see Appendix 3) and a favourable ethical opinion from the HRA West Midlands - Coventry & Warwickshire Research Ethics Committee in September 2023 (IRAS ID: 324755; see Appendix 3). As early building of relationships with partners and organisations of interest is recommended when planning ethnographic research (Rashid et al., 2019), before putting forward my ethics application, I had already started mapping and, subsequently, approaching relevant care organisations that were local to the area I was living in, to explore whether they were interested in participating in this study. To map learning disability residential services, I utilised the CQC website as well as information that NIHR ENRICH kindly shared with me.

A short while after I first contacted a few organisations, a residential service expressed an interest in facilitating the study. I remained in contact with the service, sharing updates and study documents, whilst continuing to plan and organise the study. I tailored the HRA ethics

application to the characteristics of this service (e.g., mental capacity of residents) with the aim of launching the study upon receiving a favourable ethical opinion. However, in late August 2023, and a few days before receiving a favourable ethical opinion from HRA, the service emailed me explaining that, unfortunately, they had to withdraw from the study, suggesting that they might be able to assist in a few months. I appreciated the service's circumstances and thanked them for their assistance, indicating that I would contact them again in a few months if I had not found another care organisation, as they suggested in their email.

Following this, and after consultation with my supervisors, a third-sector (i.e., voluntary) care organisation from my supervisors' professional networks was identified, which we purposely approached to explore whether they were interested in facilitating the study. The organisation expressed its willingness to facilitate the study and, as a first step, I shared with them the study protocol that I had developed as part of my HRA ethics application, which contained essential information about the rationale of the study, its methods, and other important domains. In mid-October 2023, an online meeting was organised with the people from the care organisation who were to assume the role of coordinating the facilitation of the study. During the meeting, it was confirmed that the organisation would facilitate the study, and relevant planning started taking place. Moreover, the coordinators kindly suggested one of the organisation's residential services as the site where the study could be conducted, giving me, however, the option to explore whether a different residential setting would be more suitable. The proposed residential setting, a residential care home which from this point onwards I will be referring to as Rosewood House (a pseudonym),[54] matched my inclusion criteria and, hence, was selected as the study site. I decided that I was not going to explore

[54] 'Rosewood House' is a pseudonym that I am using for the purposes of this study and is not the real name of the residential setting. While I acknowledge that there may be actual health or social care services across the UK named 'Rosewood House,' this is not one of them and any similarities are completely accidental and unintentional.

whether accessing an additional residential setting was possible, hence having two study sites, thinking proactively and pragmatically about the time constraints of my PhD, the work already involved before, during and after ethnographic data collection in one residential setting, and the capacity of the care organisation hosting the study. As Rosewood House was not located in the geographical area of England where I was based, upon discussion, the coordinators suggested that I reside in the setting for the duration of the study. The coordinators affirmed that this would facilitate further immersion and make it easier to build rapport and trust with support staff and residents. Additionally, the coordinators emphasised that their suggestion was in line with the care organisation's ethos of promoting communal living between support staff and residents in the community.[55] An ethics amendment was put forward through the HRA amendment tool in late October 2023 to reflect the changes above, however, the amendment was deemed as non-notifiable to the HRA West Midlands - Coventry & Warwickshire Research Ethics Committee.

In the subsequent weeks, I shared all relevant study documents with the organisation's coordinators and completed various administrative tasks (e.g., agreements between the care organisation and the University of Kent) so the study could proceed. A second and final online meeting with the coordinators took place in mid-November 2023 for final updates. In preparation for my arrival and, consequently, for recruitment on the ground, the coordinators confirmed that they would approach in advance all support staff and residents in Rosewood House, as well as the residents' significant others, to give them an overview of the study and my role as a researcher, so people had time to process information. To this end, I shared a flyer containing essential information about the study and me (see Appendix 3) for the coordinators to circulate in Rosewood House and among significant others. The study was launched in mid-November 2023, and subsequently, I moved into Rosewood House in late November 2023

[55] For more information, see the subsequent section, 'Characteristics of the residential setting'.

when recruitment on the ground and data collection were initiated. The study was completed in late January 2024, spanning approximately two months and was roughly within the recruitment and data collection timescale that I had estimated before moving into the residential setting. In Table 16, I summarise the different recruitment and data collection phases for this study.

As demonstrated thus far, the recruitment and data collection process involved significant planning and revisiting of plans, coordination, communication, persistence, and problem-solving. As with Study 2, if I did not have the knowledge, understanding, and intuition that I acquired through my work experience as a support worker, it would have been much more challenging to plan and conduct this study and resolve problems as they arose. Crucially, this stage of Study 3 highlights the key role that other parties, in this case care organisations, play in successfully conducting ethnographic research and the importance of trust between the researcher and the organisation facilitating the study.

Table 16

Recruitment & data collection phases for Study 3

Phase 1 – Recruitment of the care organisation	<u>August 2023</u> Original care organisation withdraws. <u>October 2023</u> New care organisation agrees to facilitate the study. <u>November 2023</u> Study launches. Recruitment of participants and data collection are initiated in late November 2023 upon arrival at Rosewood House.
Phase 2 – Recruitment of participants & data collection	<u>December 2023</u> Ongoing recruitment of participants. Consent forms to indicate people's wishes to participate in the study or otherwise keep coming in, up to the Christmas break. Data collection 'as you go', with the people who have agreed to take part in the study thus far.

	Christmas break Away from the study site from the 24th of December 2023 until the 2nd of January 2024.
Phase 3 – Completing recruitment and data collection	January 2024 All outstanding consent forms to indicate people's wishes received by early January 2024. Full data collection with all participants. Completion of study in late January 2024.

Characteristics of the residential setting

Rosewood House was a CQC-registered residential care home, and its latest CQC rating at the point of data collection was an 'Overall: Good' with 'Good' in all five CQC areas. The setting was a domestic property in a vibrant neighbourhood relatively close to the city centre, and, from the outside, it could not be immediately distinguished from its neighbouring properties as there were no identifying signs to indicate that this was a care home. Equally, support staff were wearing ordinary clothes at all times, and nothing in their appearance indicated that they were working as staff. Rosewood House was part of a large and established care organisation providing social care services. The vision, values, and ethos of the organisation emphasised community building, belonging and social inclusion, people with and without a learning disability living together, and an appreciation of people's sense of spirituality. As expected, Rosewood House endorsed the care organisation's vision, values, and ethos.

Inside, Rosewood House contained the residents' bedrooms, functional spaces (i.e., bathrooms and kitchen) and communal areas (e.g., living room), the managers' office, a few bedrooms for the staff who were living in the house, as well as a large garden. Rosewood House was home to six residents. The core care team that provided direct support to residents and was in management positions in the house comprised 17 people, two of whom, at the time of data collection, were living in Rosewood House in line with the care organisation's ethos, as

discussed in this section. Those two live-in support staff were doing regular shifts, as with the rest of the team, yet Rosewood House also served as their home.[56] Shifts usually lasted eight hours, although there were some shorter shifts too, and included early, late, and night shifts, with staff providing 24/7 care to residents. Rosewood House was one of a number of residential settings across different locations in England managed by the care organisation.

Procedure & reflexivity

Upon arriving at Rosewood House, I immediately started mapping the setting and getting to know the support staff and residents. This involved understanding how shift patterns worked, knowing which room belonged to which resident, remembering people's names and roles, and ensuring that I introduced myself, reminding people of the reason I was in the house and explaining my role and the study further. When I introduced myself to support staff and others, I presented myself as 'the researcher from the University' and elaborated further. When I introduced myself to the residents, I presented myself as a person 'working at the University', explaining that I would be living in the house for a while, and elaborated further depending on the resident's level of understanding and interest. I also ensured that the study flyer was placed in a location in the house where everyone could see it at all times. Nonetheless, as a result of the preparatory work that the organisations' coordinators and the setting's managers had done before my arrival, most people were already familiar with my role and purpose, for instance,

[56] I did not particularly dwell into the policies of the care organisation in relation to the terms and conditions (e.g., length of stay) pertinent to support staff living in Rosewood House or other residential settings managed by the organisation. For instance, I am under the impression that the two live-in support staff at Rosewood House had an agreement with the organisation as to how long they were going to live in the setting, but perhaps this was related to their circumstances or desires. Moreover, it is my understanding that live-in support staff did not have to pay for accommodation or meals, the same way I did not have to pay for any of those things whilst living in Rosewood House, nonetheless it is worth reiterating that my knowledge of the organisation's live-in policies is rather minimal.

the residents were already told that they had ‘a visitor’ who would be staying in the house for some time.

People were friendly, welcoming, and, overall, genuinely interested in my research, and getting rooted and establishing relationships with everyone at Rosewood House was a priority. To this end, and as I was engaging in intensive data collection, my first month in the setting (i.e., from late November 2023 until the 24th of December 2023 when I left Rosewood House for the Christmas and New Year break; see Table 16 above) comprised weekday and weekend shifts,[57] lasting mostly, but not always, ten hours, usually spanning between 10am and 8pm, to make sure I had contact with support staff from both the early and the late shift and to get a good understanding of everyday life in Rosewood House. During this first month, I chose not to take any days off apart from being away from the setting for four days in early December 2023 to attend an academic conference and use the opportunity also to go home as the conference was close to the geographical area I was normally residing. My second month in the house (i.e., early to late January 2024; see Table 16 above) was less demanding, whereby I started doing eight-hour shifts (i.e., early shifts starting at 7am or 8am and finishing at 3pm or 4pm, or late shifts starting at 2pm and finishing at 10pm) which were added to the rota and I was able to afford a day off per week to rest and take a broader perspective on the data collection process. Returning to a residential setting environment, yet this time not as a support worker but as a researcher, felt natural. Unsurprisingly, my previous work experience in care made tuning in to and navigating life in Rosewood House much easier. As a result, despite doing intensive ethnographic work, the entire process felt less tiring and more energising.

[57] As Rosewood House was the place I was living and also my study site, the term ‘shift’ is used here to distinguish the time that I spent at the premises as a researcher collecting data, from the time I was at the premises and among staff and residents and was not collecting data (i.e., on a day off). The term ‘shift’ does not entail any professional association with the organisation that facilitated this research. This was an independent study and I was not employed by the care organisation.

In this study, I required every support staff and resident to indicate whether they agreed or disagreed to participate in this research. Regarding the support staff, I first had a quick conversation about the study with the member of staff and then shared with them the following forms, either through email as attached documents or physically as a printed handout depending on the staff's preference: 1) Information Sheet for Support Staff (see Appendix 3), with information about the purpose and conduct of the study, payment process, confidentiality and data protection, and other key information; 2) short Consent Form for Support Staff (see Appendix 3) where, among other things, staff indicated whether they wished or did not wish to participate in the study; 3) Demographics & Eligibility Questionnaire for Support Staff, to be completed only by staff who had agreed to participate in the study, collecting demographic and work-related information whilst assessing the staff's eligibility to take part in this research; and 4) Comments Form (see Appendix 3) in case people wished to provide any kind of feedback or make a complaint, whilst clarifying that providing feedback was not mandatory. Some staff filled in their forms digitally and emailed them back to me, whereas others completed them physically, handing them to me. As I was residing at Rosewood House and was doing long shifts daily, I was always available to answer staff's questions and was able to gently remind staff who had not completed their forms to indicate participation or otherwise in the study, to do so. Upon reviewing a staff member's completed forms, I informed them of their eligibility to take part in the study.

Regarding the residents, during the planning phase before arriving at Rosewood House, I was informed by the organisation's coordinators that although the residents had different levels of learning disability and various support needs, none of them had the capacity to make an informed decision about participating in the study. Therefore, providing or withholding consent to take part in this research would have to take place on behalf of the residents, through their consultees, while taking into account the residents' best interests. A consultee comprised

a designated family member or close friend of the resident who was known to Rosewood House and who had the ability and power to provide or withhold consent for participation in the study on behalf of the resident. The organisation's coordinators, as well as the managers of Rosewood House, kindly facilitated this process by either sharing relevant study documents with the consultees on my behalf or by sharing the consultees' details with me so I could contact them directly. Similar to staff, consultees received the following forms either through email as attached documents or physically as a printed handout depending on the consultee's preference: 1) Consultee Information Sheet (see Appendix 3), providing essential information about the study, the resident's participation, and the consultee role, to name but a few; 2) short Declaration Form for Consultees (see Appendix 3) where, among other things, consultees declared whether they agreed or disagreed for the resident to participate in the study; 3) Demographics & Eligibility Questionnaire for Consultees, to be completed only on behalf of residents for whom the consultees have agreed to take part in the study, gathering demographic and residential-related information whilst assessing the resident's eligibility to take part in this research; and 4) Comments Form. Some consultees filled out their forms digitally and emailed them back to me, whereas others completed them physically, handing them to me. I was always available to answer the consultees' questions and accommodate their needs regarding completing the forms. A gentle reminder was sent out to consultees who had not completed their forms to indicate their wishes about the resident's participation and a nudge was also given by Rosewood House's managers. Upon assessing the resident's eligibility, I informed the consultee about whether the resident could take part in the study or not.

As I will demonstrate in subsequent paragraphs and sections, all eligible support staff and residents at Rosewood House did take part in this study and no refusals or withdrawals occurred. Nonetheless, so that the reader obtains a more holistic understanding of the study procedure, should some members of staff not have given their consent or some consultees of

residents not have recommended involvement of a resident, I planned to record this and not include these individuals in any data collection activity. For instance, I was not going to approach these individuals for an interview, nor would treat informal conversations with them as data, and I was not going to carry out observations with them during participant observation, despite them being present. Moreover, although a concrete plan would have to be made should the situation occur, I did proactively consider responses to 'worst case scenarios' regarding people's participation in the study. For example, not obtaining enough participants was one of those scenarios, as it could impact the extent to which this ethnographic research could be considered methodologically sound. Exploring the possibility of carrying out the study in a different residential setting managed by the care organisation, or changing the research design to focus on conducting interviews with residents and their significant others, were some of the alternative plans I was equipped with, but did not have to use.

All consultees were also treated as potential significant others of residents. I approached four out of the six people who served as consultees to explore whether they were interested in participating in the study themselves as significant others. Those four people were selected because we had already interacted directly a few times, and had established a degree of rapport, as well as because we had established a method to communicate with each other. People received the following forms either through email as attached documents or physically as a printed handout depending on the person's preference: 1) Information Sheet for Significant Others (see Appendix 3); 2) short Consent Form for Significant Others (see Appendix 3); 3) Demographics & Eligibility Questionnaire for Significant Others, collecting demographic information and assessing the person's eligibility to take part in this research; and 4) Comments Form. Some people filled in their forms digitally and emailed them back to me, whereas others completed them physically, handing them to me. I was always available to answer people's

questions and accommodate their needs regarding completing the forms. Upon assessing the person's eligibility, I informed them about whether they qualified to participate in the study.

The Participant Observation Protocol served as a guide for conducting participant observation, a continuous process that I was engaged in every time I was on shift and for the entire duration of the shift. I employed an 'as you go' approach to participant observation, meaning that, even though I was present in the house and among staff and residents during my shifts, I collected data[58] through participant observation only from the people who, up to that particular point, had agreed to take part in the study. For instance, a ten-hour shift in my first days at Rosewood House could mean collecting data through participant observation from two support staff and one resident who, up to that particular point, had agreed to participate in the research, although I was among other staff and residents who, nevertheless, had not yet indicated what their wishes were. Moreover, participant observation also involved 'being there' and simply connecting to the pace and rhythm of Rosewood House while making broader observations, something that could be described as "just experiencing" (DeWalt & DeWalt, 2011, p. 92). Occasionally, I would turn the gaze of the observer towards myself and observe the ways I was bonding with the residents. The way I conducted participant observation evolved and became more immersive and ingrained in my everyday practice as I became more rooted in Rosewood House and built more rapport with the staff and residents. In general, I assumed a position that perhaps could be described as moderate participation (DeWalt & DeWalt, 2011), whereby I primarily observed care relationships, yet, whilst conducting my observations, I also actively participated in a number of everyday tasks in the house such as cleaning, assisting with cooking and shopping, or doing some activities with the residents (e.g., colouring). This allowed me to immerse myself in the care relationship and the care rhythms

[58] For more information about translating observations into data, see the subsequent section 'Field notes' of this chapter.

of Rosewood House in a more natural and less alienating manner. Yet, I constantly reflected and always strove to maintain boundaries, aiming to ensure that my role as a researcher whose 'job' was to observe care relationships would not be blurred by my participation in domestic tasks or, in fact, by my previous work experiences in care.[59] This position somewhat granted me a peripheral membership in the group, whereby I was part of the group but kept myself "from being completely drawn into it" (DeWalt & DeWalt, 2011, p. 24).

Inside Rosewood House, observations were conducted only in the communal areas, namely in the living room, the dining room, the kitchen, and the garden, and not inside bathrooms or the residents' bedrooms, as per the organisation's and some of the consultees' wishes for respecting those sensitive and private moments. Observations were also conducted during team meetings (i.e., staff only) and staff-resident meetings, both of which I attended regularly. Outside of Rosewood House, observations were conducted during staff and residents' attendance at organisational events, during walks, outings and trips to the community, in visits to the local medical practice, but not during the actual consultation with the doctor, and whilst going to and returning from daycare activities in day centres. Throughout the study, participant observation was conducted during both early and late shifts, on weekdays and weekends. I did not conduct observations during night shifts as these mainly involved providing support in bathrooms or the residents' bedrooms, often times helping with personal care, an aspect of care relationships that, as discussed above, I was advised not to observe, and I indeed followed that advice. Overall, I conducted 326 hours of participant observation, comprising 187 hours during the 'as you go' phase (i.e., observing participants who had agreed to take part, as consent forms kept coming in) and 139 hours from early January 2024 onwards,

[59] For more information about this balancing act, see the subsequent section 'Ethical considerations' of this chapter.

when no more consent forms were pending. The total number of hours exceeded by far my initial goal (i.e., 70 to 90), which I considered an advantage.

Over the course of the study, I approached seven staff members for an interview to hear their views on and experiences of care relationships. Six staff members agreed to participate in the interview. The staff members that I approached were chosen strategically to reflect different styles of providing care, various roles and work experience in Rosewood House, and different backgrounds. The Interview Protocol for Support Staff guided the interviews, while I also followed up on topics that the participants were discussing or skipped or revisited specific questions in the Interview Protocol as I saw fit. All interviews were conducted in person, in a private space at Rosewood House at a time convenient to staff. A digital voice recorder was used to record the interviews. The mean ($\bar{x}$) duration per interview with staff was equal to 28 minutes, ranging from 13 minutes to 36 minutes. Upon completion of the interview, staff were thanked for their time and were asked whether they wished to receive a copy of their anonymised interview transcript once it was ready, as well as a summary of the study findings once they were generated. Four out of six participants said that they wished to receive a copy of their anonymised interview transcript, and all participants indicated that they wanted a summary of the findings. I also asked the participants to indicate how they wished to be contacted (e.g., by email) so they could receive the documents above. Staff were reminded that upon completion of the study, they would receive a Certificate of Participation (see Appendix 3) and were offered an £11 cash payment[60] for taking part in the interview. Some participants accepted payment whereas others declined.

Of the four significant others who I approached for an interview, three agreed to be interviewed. One interview was conducted in person in a private space at Rosewood House at

[60] For more information about payments, see the subsequent section 'Ethical considerations' of this chapter.

a time convenient to the significant other and a digital voice recorder was used to record the interview. The other two interviews were conducted online using Microsoft Teams© and WhatsApp© and were recorded using the software's recording functions. The Interview Protocol for Significant Others guided the interviews, and the mean ($\bar{x}$) duration per interview with significant others was equal to 29 minutes, ranging from 22 to 35 minutes. All participants said that they wished to receive a copy of their anonymised interview transcript as well as a summary of the study findings via email. Significant others were reminded that upon completion of the study, they would receive a Certificate of Participation and were offered the £11 payment for taking part in the interview. Participants either declined payment or requested that the payment be donated to the care organisation.

I decided not to interview the residents of Rosewood House. For some of the residents, I concluded that, due to their support needs, they were not in a position to comprehend and reflect on the interview questions, at least not within the interview format I had employed in this study. Moreover, I felt that the residents who were perhaps more likely to comprehend and elaborate at least on some of the interview questions by themselves or with staff support, would become confused, or even distressed, by switching to a more formal type of interaction with me (e.g., finding a private space for the interview, audio recording or taking notes), as the relationship we had developed was more organic and relaxed as part of our daily interactions at Rosewood House. To them, I was a 'visitor' living in the house for a while and helping out, and trying to organise a more formal interview felt alien.

I have had various unstructured conversations (i.e., informal chats) with the support staff and the residents about numerous aspects of care relationships, care, everyday life at Rosewood House, and social care in England, and I was present and observed unstructured conversations between staff, between staff and residents, and between residents. I also completed document inspections, specifically, I reviewed the support staff's daily notes twice

(i.e., daily notes for December 2023 and January 2024) and I also examined other relevant house documents such as lists of daily and weekly tasks and food and liquid intake charts. Moreover, I went through various photo albums found in one of the communal areas of the house, documenting life at Rosewood House over the years.

A few days before the completion of the study, I spoke to the residents, explaining that I would be leaving the house soon. The study was completed in late January 2024 and included heartwarming moments such as Rosewood House making a cake to say goodbye, and all of us reflecting on and showing genuine appreciation for the time we spent together. A Certificate of Participation for Rosewood House as a whole was provided to the team as well as to the organisation's coordinators. This was accompanied by a 'thank you' card to the team as a whole and 'thank you' cards to the coordinators. As agreed in a previous team meeting, I also provided a £40 Argos gift card to Rosewood House as a material appreciation for everyone's assistance. Additionally, I shared a list of suggestions (e.g., about communication systems in the house, reflections on activities, and more) with the team and the coordinators, based on my observations. All residents received physical handouts of their Certificate of Participation, and their certificates were also emailed to their corresponding consultees, informing them that the study was now complete. All support staff and significant others received their Certificate of Participation via email. Once ready, anonymised interview transcripts were emailed to the participants who had taken part in interviews and had indicated that they wished to receive their transcripts. Upon completion of data analysis, support staff, significant others, coordinators, and consultees were emailed with a summary of study findings, both in a standard and easy-read format.

Field notes

All observations made during participant observation, unstructured conversations, and document inspections were translated into data by making detailed field notes primarily in chronological order (DeWalt & DeWalt, 2011). The field notes were written electronically almost immediately after the end of my shift, when I was back in my room, whilst using the project aim and research questions as a compass. In total, my field notes amounted to 23.957 words. I refrained from writing field notes during my shifts, as I felt that this would be rather alienating, interfering with the flow of tuning in with support staff and residents and affecting immersion. Nonetheless, as during fieldwork, memory had to be used a lot (DeWalt & DeWalt, 2011) to ensure that observations were later translated into field notes, I always had a small notebook on me and, occasionally, I made brief jot notes to be certain that I remember a particular event, interaction, or thought that I wished to elaborate on later. My field notes were primarily descriptive, namely recalling how my shift unfolded and all the relevant observations that I made, and occasionally reflexive, whereby I posed questions in relation to the gathered data and attempted to make interpretative connections. Below is an excerpt from my field notes with descriptive and reflexive note-taking:

> 10/01/24 (late shift, 2pm - 10pm)
>
> [name of resident] stands up without having finished his water. [name of staff] asks him to drink his water. [name of resident] is having a sip and then [name of staff] uses a combination of humour and reasonable request to finish the water, using a mildly humorous tone of voice: “and another sip, and another sip, and another sip please [name of resident], ok, let’s finish the water, that’s what we have to do [name of resident], and another”. [name of resident] finishes the water. [name of different staff] arrives, and while she’s serving herself some lunch, [name of different resident] initiates interaction by touching her back. [name of staff] responds with humour (“should I do this to you?”)

> and [name of resident] gives her a big smile. Later I can see [name of staff] chatting to [name of resident] and running to the kitchen to get him something. You can see the motivation/enjoyment/positive attitude in [name of staff] and [name of staff]. They are there for the residents.

Transcription

Transcription adhered to the same principles, rationale, and practices as those used in Study 2. To produce automatically generated transcriptions for the interviews recorded using a digital voice recorder, the audio files were imported into the online version of Microsoft Word©, which offers this function. In the interviews that took place online, there were a few occasions when I was unable to understand what the participant was discussing due to poor internet connection and, as with Study 2, I indicated this in the transcript by using the word 'incomprehensible' in square brackets. None of the participants who received their anonymised interview transcript provided any feedback on it.

Analytic framework & justification

Reflexive thematic analysis (Braun & Clarke, 2022) was employed once again, following the same justification I discussed in Study 2. Reflexive thematic analysis is compatible with ethnographic designs (Braun & Clarke, 2022), and the older version of Braun and Clarke's thematic analysis framework (2006) has been used in previous ethnographic work, especially in the field of sports psychology (e.g., Cavallerio et al., 2016; Devaney et al., 2017). Time was a key factor in Study 3, as given the amount of data that needed to be analysed and the fact that my PhD was gradually approaching completion, time constraints were even more relevant, and so were the time-efficient properties of reflexive thematic analysis that I discussed in Study 2. Once again, the analysis was carried out on the qualitative data analysis software

NVivo©, accessed through my University of Kent account. Reflexive notes were kept throughout the data analysis.

Analytic process

The analytic process followed the same principles, rationale, and practices discussed in Study 2. Data familiarisation was a much quicker process in Study 3 due to the extent of the work that data collection required and the role that my first-hand experience of living in Rosewood House played in this study. I kept familiarisation with information collected through interviews and information collected via field notes as two separate processes, aiming to structure the data in my mind and sense similarities and differences between the information. From the start, I felt very familiar with the data, and the fact that I had just completed the analysis for Study 2 had certainly sharpened my interpretative skills as I was processing information.

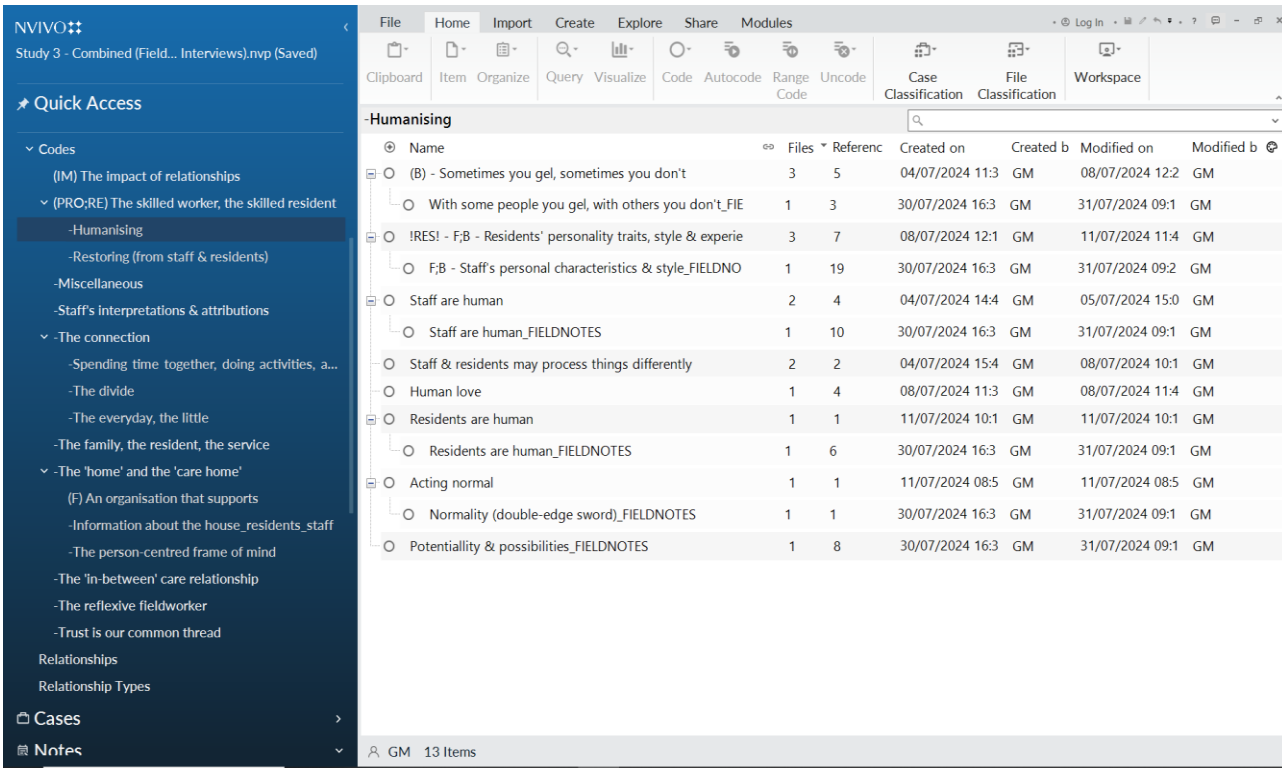
I proceeded to code the interview transcripts and the field notes and continued to do so as two separate processes, once again, as a method to arrange the data mentally and explore similarities and differences. As with Study 2, I coded sometimes semantically (Braun & Clarke, 2022) and others latently (Braun & Clarke, 2022). Nonetheless, coding in Study 3 was much quicker and, despite following similar tactics to Study 2 (e.g., adding initials tailored to my research questions in front of the codes), it was freer and less risk-averse, something that I attributed, once more, to the very nature of Study 3 and my sharpened senses following completion of data analysis for Study 2.

Next, I organised and subsequently merged several codes into each other to make them more concise and thicker as I started generating initial themes, once again, as two separate processes for interviews and field notes, respectively. Once the initial themes had been generated, I felt ready to process the data as one. I state in one of my notes in late July 2024:

"Created this new document today to work from here till final theme generation for study 3 […] that way I also engage in triangulation and have a more holistic perspective (i.e., what people said, my own observations, etc)." This was the birth of my combined analysis, namely, information from interviews and field notes processed together to generate the final themes. In Figure 10, I demonstrate what this process looked like.

Figure 10

Combined information from interviews & field notes



I continued merging and bringing everything together so I could develop the themes further, and soon enough, I had a relatively clear idea of the direction I should be taking and generated four themes. I proceeded to name, refine, and define the four themes, and as with Study 2, I created a 'Miscellaneous' category where I included a few codes that, although of interest, were not used during theme development.

Finally, I engaged in the writing-up phase, producing my thematic analysis report where I elaborated on all aspects of Study 3. The value of editing the text multiple times (Braun &

Clarke, 2022) and being selective was particularly pertinent, not only due to the great amount of data in Study 3, but also because this study was part of a series of studies that told a story both alone and together. Therefore, the aim was to allow Study 3 to tell an immersive, standalone story as well as a story in conjunction with Study 1 and Study 2, whilst ensuring that this was also reflected in the way I was writing. As with Study 2, a colour system was employed on NVivo© to indicate which codes I used in the writing-up and analysis of each theme.[61] Data extracts (i.e., participant quotations and field note excerpts) were sometimes used illustratively (Braun & Clarke, 2022) and other times analytically (Braun & Clarke, 2022) to shed light on different aspects of the data analysis.

Lastly, in this study, I adopted a separate section approach (Braun & Clarke, 2022), namely presenting the 'results' and 'discussion' sections separately, in contrast with the integrated approach that I employed in Study 2. I did this to avoid style repetition and to highlight the contributions of Study 3 while maintaining thesis flow and sustaining the attention of the reader. Moreover, as with an integrated approach, a separate section approach is also compatible with reflexive thematic analysis (Braun & Clarke, 2022) and with an interpretive paradigm. Considering this, I wished to experiment somewhat and explore how adopting a separate section approach would guide the framing of my findings. Importantly, I strived to present the two sections in an interconnected fashion, with each section relying on and complementing the other. In a similar vein to Study 2, I used the heading 'Analysis', however, this time to frame only the 'results' section (Braun & Clarke, 2022) to, once more, emphasise the role that the researcher's interpretation and active subjectivity play in generating qualitative findings.

[61] Green indicated codes used in the analysis of Theme 1. Blue indicated codes used in the analysis of Theme 2. Pink indicated codes used in the analysis of Theme 3. Yellow indicated codes used in the analysis of Theme 4.

Ethical considerations

The participants shared personal details as well as information about other people and services as they discussed their personal views, experiences, and practices, and I myself was also exposed to a plethora of personal and confidential information whilst carrying out this study, be it through conducting participant observation, interviewing people, or simply living at Rosewood House. Unsurprisingly, a key ethical consideration was managing data safely and confidentially. To address the need for data protection, I always used a password-protected computer, and all electronic data were uploaded as files on my University of Kent shared drive. Only I had access to those files and if my supervisory team wanted access, they had to request it from me. Nonetheless, no such access was requested. Physical data (e.g., completed physical forms) were stored securely in a protected location. All data in Study 3 were fully anonymised in accordance with the anonymisation process used in Study 2.

As gaining access to Rosewood House involved liaising and working together with the management team of the care organisation (i.e., coordinators), it was thought that this might create the impression that support staff, residents, significant others, and consultees were somewhat obligated to participate in the study. To this end, in all relevant documents I shared with people and in all correspondence, it was highlighted that participation was completely voluntary and that participation or otherwise would not be revealed to anybody (e.g., the participation of a resident's family member would not be revealed to the resident) and could not affect employment or residential status. Also, I ensured that I shared this information during my direct interactions with prospective participants and consultees.

Confidentiality was maintained throughout this study; nonetheless, participants were informed that confidentiality could be breached should I had serious concerns about abuse taking place (or the risk of it), or danger to self or others. To this end, I devised a Guidance for Raising Concerns & Breaking Confidentiality (see Appendix 3) to consult in case I had any

safeguarding concerns. Nevertheless, no such concerns occurred. Additionally, and looking at safeguarding from a different angle, I applied for a DBS certificate so the care organisation could assess my criminal record before giving me access to Rosewood House.

As discussed, the residents at Rosewood House lacked the capacity to make an informed decision about their involvement in the study, and their participation was determined by the consultee's decision. I did not downplay the safeguarding concerns and the historical oppression associated with the involvement of people without mental capacity in research. Nonetheless, as I have hopefully demonstrated in previous sections, instead of excluding individuals from studies altogether, I strove to address safeguarding concerns and historical oppression by implementing tailored safety measures to ensure that the residents' wishes and best interests led decisions around participation. Moreover, I adopted an 'ongoing consent' approach, meaning that despite having obtained consent from a participant, I always confirmed with them before observing a particular activity (e.g., an outing to the community). Additionally, I always remained mindful of signs of dissent (e.g., a resident's behaviour indicating that they wanted me to leave the room), and I sought to recognise and respect them.

By engaging with various individuals (i.e., staff members, residents, and significant others) and conducting direct observations, I had access to sensitive information and different perspectives around the care relationship that sometimes were, to some extent, in conflict with each other. This highlighted that my position as a researcher observing care relationships at Rosewood House entailed some degree of power and privilege. I remained reflexive and appreciative of what people were trusting me with, whether verbally or by letting me observe them. Moreover, maintaining the researcher boundary was crucial, especially when taking into consideration that I was also helping with everyday domestic tasks, I was living at Rosewood House, and I was operating closely with support staff and residents. I state in a reflexive field note:

> I feel that gradually some staff are approaching me more as another staff, asking me to do stuff (e.g., set up the table, go and buy something with a resident etc, asking for my opinion etc). When [the task is] outside my role, I remind staff that I'm not [support staff] and I cannot do the specific request, etc, but it surely puts me in a position where I'm more 'part of the team'.

My care work background contributed to this battle, especially during my first days in the house, when I occasionally found my support worker instincts 'kicking in', pushing me towards a care work mode, a situation that I had to 'tame' and reflect upon. As a researcher with insider knowledge of the topic I was researching and with genuine sympathy for the positions of staff and residents in social care services, I strove to achieve empathy and avoid identification (Bondi, 2003), ensuring a healthy research relationship with the participants and a rigorous data collection process. Unsurprisingly, navigating my positionality and the different domains of this study was a continuous process, and reflexivity was a constant. For instance, a few weeks before the completion of the study, I stated in a reflexive field note:

> I'm thinking a lot about the role of the researcher and particularly the ethnographer: it is a privileged position that entails power, that's for sure. If you zoom out, you might see it as 'nonsense': observing other people. It does have value, though, in terms of understanding practices etc. Yet, it's a power relationship, and I'm trying my best to keep it as balanced as possible. All this in the context that I know well and that I professionally come from. I don't know, imagine using ethnography in a completely different culture. How can one manage the power relationship with the people being observed?

I anticipated that during the study, I might encounter staff or resident distress, behaviours that challenge, or illness, and when I did, I used my previous work experience and

psychological skills to process and navigate such moments. I did not engage in any lone work with the residents, as participant observation always involved more than one person (e.g., staff-resident interactions), and one-to-one interviews with the residents were not conducted.

I did not anticipate that this study would pose a risk to the participants; nonetheless, ethnographic research, and qualitative research as a whole, can serve as an opportunity for people to reflect on their practices, views, experiences, and perceptions and to develop previously unexplored reflections. In turn, this may cause some degree of confusion, doubt, or distress. Additionally, it was thought that my presence as an (initially) unfamiliar person at Rosewood House might disrupt its usual rhythms and cause confusion to support staff and residents about my role. To address this, as in Study 2, I aimed to conduct the study in an empathic, flexible, tuned-in, and non-judgmental manner, while making sure that I was 'reading the room' and giving people space. Additionally, in the Information Sheet for Participants, I shared information with people, directing them to the UK mental health organisations Samaritans and Mind in case they needed support over the phone or signposting.

As discussed, a payment of £11 was available for taking part in the interview. Additionally, if any travel or parking expenses were incurred, these were expected to be reimbursed. However, such expenses did not occur. Moreover, a £40 Argos gift card was given to Rosewood House as a whole to show my appreciation for everyone's assistance. The rationale, principles and procedures for offering payment in Study 3 were in accordance with those employed in Study 2. The amount of money chosen for interview payments was informed by the April 2023 UK living wage standard rates (i.e., £10.42/hour) and the UK real living wage rates as defined by the Living Wage Foundation (i.e., £10.90/hour). Eventually, I settled on the £11 payment using elements from both frameworks to meet pragmatic and logistical considerations whilst maintaining a sense of fairness towards participants. The £40 Argos gift card was determined together with Rosewood House during a team meeting. Interview

payments were paid in cash as I was in the formal process of converting my remaining NIHR research allowance into a monthly stipend due to my NIHR doctoral funding coming to an end in late December 2023. For those administrative reasons, the payment form used in Study 2 could not be used in Study 3.

5.4 Analysis

Participant characteristics

Overall, 25 people participated in the study, and none withdrew. Of the people who participated, 16 were support staff,[62] six were residents,[63] and three were significant others, specifically family members of residents. The majority of staff have worked at Rosewood House and the wider care organisation for three months or more, with a mean ($\bar{x}$) equal to 2 years and 7 months.[64] The house served as the residents' permanent home, and the residents have been under the wing of this particular care organisation for more than three months, with a mean ($\bar{x}$) equal to 27 years and 5 months.[65] All significant others had known their respective family member living at Rosewood House for their entire lives. Tables 17, 18 and 19 show the

[62] As discussed in the section 'Characteristics of the residential setting' of this chapter, the core staff team of the house comprised 17 people. Consequently, the number of staff participants reported here (i.e., 16) represents almost every member of the staff team at Rosewood House. The one member of staff missing was the person who was only working night shifts and, as I elaborated in the section 'Procedure & reflexivity' of this chapter, night shift observations were not conducted, hence I did not explore study participation with this particular member of staff. Moreover, there were two additional support staff who were associated with Rosewood House and who I met and briefly discussed the research project with but I did not approach to explore study participation for the following reasons: one member of staff was living at Rosewood House but was working in a different setting managed by the care organisation; and one member staff used to work at Rosewood House but was currently based in a different setting managed by the care organisation.

[63] This number represents all residents at Rosewood House.

[64] This is an estimate as some staff provided a more abstract description of the time they have been working in the care organisation (e.g., "one year plus"). In cases like this, I converted the figure to the closest number (i.e., 1 year and 6 months).

[65] Several residents have lived in different residential settings managed by the care organisation before moving to Rosewood House. The figure presented here is likely to be higher as for one resident I only acquired information about the length of time he has been living in Rosewood House. Nonetheless, I am aware that prior to this, the resident has also lived in other settings managed by the care organisation.

demographic, professional, and other relevant characteristics of support staff, residents, and significant others.

Table 17

Demographic and professional characteristics of support staff (N=16)

Gender	
Woman	10
Man	6
Ethnicity	
White British	2
Multiple heritage British	1
White Other	5
Asian Other	3
Black Other	5
Age range	
18 - 24	5
25 - 34	5
35 - 44	5
55+	1
Highest academic qualification	
GCSE/A-level or equivalent	5
Undergraduate or postgraduate degree	9
*subjects mainly included *health and social care*, *psychology,* or *health sciences*	
Prefer not to say	2
Your care role	
Support worker	14

Home manager	2
Employment	
Full-time	12
Part-time or zero-hours contract (bank staff)	4
Hours per week providing direct support	
30+	10
15 to 29	4
7 to 14	2
Previous experience working with adults with a learning disability	
Yes	5
No	11

Table 18

Demographic characteristics of residents (N=6)

Gender	
Woman	2
Man	4
Ethnicity	
White British	6
Age range	
55 - 64	2
65+	4
Level of learning disability	
Moderate	3
Severe or profound	2

Not specified	1
Before this organisation, the resident lived:	
In a long-term hospital or other institution	3
With family	2
Insufficient information[66]	1

Table 19

Demographic characteristics of significant others (N=3)

Gender	
Woman	3
Ethnicity	
White British	3
Age range	
65+	3
You've known the resident for	
All my life	3
You get in touch with the resident	
Occasionally[67]	1
Weekly	2

[66] A resident's previous residential placement was in a different setting managed by the care organisation. However, I forgot to enquire about where the resident lived before joining the care organisation, hence did not obtain this particular piece of information.

[67] This item was nuanced, for instance, a family member could make an in-person visit to the resident occasionally, yet also call them on the phone, acknowledge important days such as birthdays, and stay in contact with the home managers for updates.

Themes

In Table 20, I provide a summary of the four themes. Given that I am using data extracts (i.e., participant quotations and field notes) throughout the analysis, as in Study 2, in Table 21, I provide information about the role of each participant instead of including this information in the text. Once more, by doing so, I aim to achieve better flow and make reading through the analysis easier.

Table 20

Theme summary

Theme Name	Theme Summary
Theme 1 "I feel more towards them than just my clients" Care relationships betwixt and between	The care relationship is betwixt and between, it is an act of balance between seemingly conflicting domains.
Theme 2 The care, the home, and the care home	The house is a home and the home is also a care home. The care relationship unfolds within the house, the home and the care home.
Theme 3 "They also see us as much as we see them" The connection	The connection between staff and residents is revealed, highlighting a side of care relationships that is often hidden.
Theme 4 "How the people treat you and you feel treated" The power of relationships	The care relationship can be pivotal for both staff and residents and therein lies its power.

Table 21

The role of each participant (N=25)

Participant	Care Role
S1	Support worker
S2	Support worker
S3	Support worker
S4	Support worker
S5	Support worker
S6	Support worker

S7	Support worker
S8	Support worker
S9	Home manager
S10	Support worker
S11	Home manager
S12	Support worker
S13	Support worker
S14	Support worker
S15	Support worker
S16	Support worker
R1	Resident
R2	Resident
R3	Resident
R4	Resident
R5	Resident
R6	Resident
F1	Family member
F2	Family member
F3	Family member

Note. The letter ‘S’ stands for support staff, the letter ‘R’ stands for resident, and the letter ‘F’ stands for family member (significant other).

Theme 1: "I feel more towards them than just my clients" - Care relationships betwixt and between.

I am interviewing S3 in a quiet room in the house. S3 explains: "I have a deeper relationship than just 'people I support' […] I feel.. more towards them than just 'my clients'. I have, I have feelings for them". A few weeks later, I am interviewing S16, who highlights: "I work here, it's a professional relationship". The two quotes in conjunction capture the care relationship betwixt and between. The care relationship is not one thing or the other, it is rather a midway point. During our interview, S4 struggles a little to put it into words, but this difficulty is perhaps also an articulation of the betwixt and between: "I'm working here […] but it's quite, em.. (incomprehensible) there's not a specific, em... border".

In Study 2, I framed the care relationship as a conundrum. The present theme indeed begins from there and goes further adding more nuance to the relational conundrum and perhaps, to some degree, resolving it. The staff in the house have a professional role ("it's a job, em, role you have and you're responding legally", S11) and have a professional relationship with the residents ("I'm not their friend. I'm not their [sibling]. I am.. I'm [staff]", S16). Yet, staff are at the same time in a relational *somewhere between*. Somewhere between "working for them [residents] and having a relationship in terms of.. living together and being some, some sort of friends" (S4), somewhere between the *personal* and the *professional* ("someone has fallen, or so and so is ill. That's the hardest moment because you feel it like it was […] one of your own", S11), or somewhere between a member of staff and a family member ("I see them more like my brothers and sisters than the people I care for", S3). The care relationship is betwixt and between, it is an act of balance between seemingly conflicting domains.

S1 captures this act of balance: "I'm trying to build a personal relationship with the residents […] the right level of professionality and still, like, on a personal level that, that you are not just there for the job". This very act of celebrating the *personal* whilst balancing it with

the *professional* is what makes the care relationship positive. During our interviews, some family members of residents reaffirm this position. F2 explains that "although we are, em, biologically his [resident] family […] his family, the closest people to him are those people who care for him on a daily basis" adding that "family is based on, on relationships". F3 frames the staff "just as an extended family" actively embracing the *personal* stating that "he [resident] needs to feel that this is his second family as a role and they understand his needs". The balance between the *personal* and the *professional* that makes care relationships positive is once again emphasised by F2 who is highlighting that "it's only UNSAFE if those boundaries are overstepped or misunderstood".

Another articulation of the betwixt and between is the concept of being a friend. S1 explains: "I don't really think that we are friends, but I am also not feeling like I am working with somebody who I don't want to be with". S16 adds: "it's not FRIENDSHIP, it's just working professional, I mean, I have colleagues too who are still like we are friends, we are colleagues, but we are, we are, we are vested in each other's lives". The concept of friendship is used as a vehicle to essentially articulate a care relationship whereby the *professional* is enriched by the *personal*, a relationship where there is a degree of investment, "there's a degree of mutuality" (S16). The following field note from a chat with S8 about an organisation they used to work sums it up well:

> S8 tells me about a person they used to support and how the person used to say that they're [the person] the one paying all the time when going out. S8 says that "in a relationship, when you go out with a friend, you're expected to pay as well" (Field note).

The staff are doing a job, they are "getting paid for it basically" (S3), yet "if you're in the job because you think ((chuckles)) it's gonna make you wealthy, then.. no" (F2). The staff's

motivation is primarily intrinsic. This intrinsic motivation which is "very hard to fake" (F2) provides context to the care relationship and demonstrates how the *personal* blends with and enriches the *professional*. S3 explains, "that would be a positive relationship, is when you genuinely care about someone". I witness daily the staff's intrinsic motivation to relate and care:

> Despite being on an early [shift] and at the church event, [the member of staff] stayed longer (despite personal commitments) filling up for staff who have gone away looking for their phone. I could tell the [member of staff] was quite stressed out as they had to go meet personal commitments but at the same time I could see the passion, motivation, and sense of duty (Field note).

How could the care relationship not be betwixt and between? Staff and residents share the everyday life and, hence, the *personal* which is inseparable from their relationship. The photo albums that can be found in a communal area of the house demonstrate this very well. Staff and residents live and share lives that are somewhat hidden, obscured by care work routines, duties, needs, or roles, yet still very present:

> I had a look at the photo albums that can be found in the TV room. Some of them dating 20 years back. It's the lives of staff and residents. Seeing the residents younger with fewer physical health problems (e.g., R3 walking). Seeing all the moments. Photos from different trips inside and outside the country, past events, past houses, loads of different staff faces that come and gone throughout the years (Field note).

The care relationship is more than a typical staff-client relationship. It sits between the *professional* and the *personal* and seems to be thriving in the very act of balance between the two components. The relationship takes place inside the home, but also outside of it, on terrains that, nonetheless, carry different meanings and have different relational implications.

Theme 2: The care, the home, and the care home.

"Arrival at the service today. Arrived at 3pm. Support staff welcomed me". This is how I begin my field notes on my first day in the house. I am getting home vibes and feeling at ease. Weeks later, during our interview, F2 explains how homeliness can facilitate positive relationships: "it's cosy, it's comfortable, familiar things around, it doesn't feel in ANY WAY institutionalised, it's home, it feels homely, and it's home to both [name of resident] and staff". The house is a home. It is also a care setting. This signifies the wider material and ideological reality in which the care relationship is situated, nodding at the material and ideological Colossus of Study 2, whilst expanding it.

F3 recalls past residential placements in different organisations to describe what does not feel like a home: "they let him outside and there was just a table and chairs on concrete and he'd walk up and down […] nothing like a family unit, like here". "Having that safe, happy, homely environment, I think, creates kind of those positive relationships" S9 explains, whilst S11 states that what makes the house a home is the "traditions we have, like celebrating people's birthdays […] celebrating Christmas […] traditions around Easter […] sharing our meals […] community gatherings". Home is everyday moments manifested through the material and the immaterial: "it's okay to sing songs with residents spontaneously or all of a sudden you can hear someone playing the piano and singing" (Field note) or "found almost everyone in the dining room having lunch together. It felt very wholesome" (Field note).

I reflect on the material house further, how it influences the sense of home and, ultimately, how it shapes the care relationship:

> The house seems quite old and inside there are signs of weariness (paint flaking on some surfaces/doors, some showers having a slight leak, floors squeaking). This

> perhaps may be affecting the sense of homeliness? Such things often become invisible after a while, especially in the busy care home life (Field note).

I contrast this: "I check the photo albums from the house from a few years back […] material conditions of the house were better (no marks on doors etc) which made me perceive [it] in a more homely manner" (Field note). I am chatting with S3 who says that "they will hopefully do something" about the marks. Who are they? Discussions during a team meeting provide clarity:

> Residents "queuing" [the] downstairs shower room – it's easier for some people to use this […] some stress/pressure as residents take time to receive support there. Discussion around conversion of the upstairs bathroom to meet needs. S9 says discussed this last year with responsible people from [the] org[anisation] – won't happen as they don't wish to fund it as big job (Field note).

The house is the residents' home "365 days a year" (S9). Yet, their home is also a care home, and with this comes care home pragmatics. Certain decisions are made by the organisation and "you need to abide to rules and regulations of this country" (S11). In the care home, "all residents have significant needs re[garding] personal care (e.g., showers, using the toilet/wiping, brushing teeth, shaving, support through life)" (Field note) and more complex needs ("R2 appears to have arthritis and staff note difficulties with walking and standing. Speculation as to physical pain might be causing behavioural problems", Field note). Staff try to meet those needs whilst navigating everyday circumstances ("Two staff on shift this morning as the third staff phoned sick. Manager is helping out on the ground. I also help out with cleaning, preparing breakfasts, engaging with residents to answer questions ", Field note). Care work does not always entail that a more specialised framework will be in place to help staff meet needs ("I wonder if there's an assessment […] to explain, predict, and minimise

[resident's] shouting/being upset", Field note). Being part of the wider social care system, the care home is also an administrative space whereby "lists, daily duties, reports, food orders, cleaning [records], drinking [records], toilet records, eating records" (Field note) must be completed by staff to demonstrate that care has taken place ("recording log for [residents] […] this is more focused on recording more 'traditional' care provided -personal care, GP appointments, food, but also mood, activities and outings-", Field note). This range of needs and tasks generates routines and rhythms: "morning routines, breakfast, lunch, dinner, nighttime routines, that's the wider daily context of care relationships" (Field note).

Care home routines and rhythms are twofold. They show how often "staff and residents meet in the realm of personal/physical/intimate care and how this is an important terrain for building trust and relationships" (Field note), but can also tire staff and somewhat hinder relationship building. It is a busy morning:

> As I'm helping people have breakfast, mak[ing] sure they are drinking and eating, and then mak[ing] sure that I am recording all this, I think [about] how all this is part of staff's role on a daily basis and the time and energy it consumes (Field note).

Rhythms and tasks are perhaps an inevitable part of living and working in a care home. Nonetheless, care home cultures are key in whether routines and rhythms take a more relational direction or not. In the house, "some staff tend to focus on tasks more than others" (Field note) and when there are no tasks, staff and residents may co-exist in different rooms ("staff in the kitchen or dining room, residents in the living room or their rooms", Field note). I note that "during these times, residents may spend time alone, unengaged". I frame this as a task-focused culture, exploring the ways it is creating a relational divide between staff and residents. There is variation depending on who is on shift, their personality, style, and energy levels ("S13 is good at this often coming to the TV room chatting to people, commenting on what people are

watching", Field note). Certainly, I do not suggest that "one should be all the time with [the] residents" (Field note) as "this is a tiring job and staff deserve to rest/decompress" (Field note). This is about interrogating how task-focused cultures may shift the focus away from relationships making life monotonous: "[a] focus on tasks becomes repetitive and tiring lacking creativity, this creates a lack of motivation to engage with residents beyond tasks which traps staff into this cycle/care culture" (Field note). Perhaps "incorporating small opportunities to interact/relate outside of routine tasks can enhance staff and resident life" (Field note).

More than one care cultures co-exist in the house. Former staff have now become volunteers befriending some of the residents ("R4 has a visitor who's taking him to church", Field note) and residents from other services are visiting for lunch or dinner. "As time passes by […] it becomes clear to me that one of its strengths (and a strength for every care provider?) is the culture of visitors/relationships with others" (Field note). A culture that facilitates and expands the care relationship and perhaps disrupts the sense of the house as a care home. The house feels more like a home again. Following the Festive season, "people still come, but it's significantly [fewer] people visiting" (Field note), yet a relational vision framing staff and residents as a community is always present. The fact that some staff are employed as live-ins adds to this. After their shift, they can be seen reading a book in the living room or coming down for a snack in the kitchen. What is a care home during a shift, feels more like their home after a shift, and the residents as part of their community ("I lived in [house] for [number] months, it helped me deepen my relationship with, with the people I support", S3). I attend an anniversary organisational event:

> Five decades of residents coming up on stage to sort of share their stories […] accompanied by similar decades of [staff], former [staff], and volunteers. Different generations of care providers and care receivers […] This sense of community

> continues at the drinks session, people are hugging (regardless of hierarchy/roles) in a genuine way (Field note).

Discourses of empowerment and person-centred care are prominent in the house, which take us back to the house as a care setting. “We really try to, em, to encourage them to do a lot of on their own” S4 shares. Six residents mean that staff “have to learn […] six different ways to build relationships” (S9). What was discussed in Study 2 certainly applies here; the person is an us, not an I. Staff are tailoring their support to the person, yet each person exists also in conjunction with the person in the room next door. Resident needs may clash influencing the care relationship:

> I’m cleaning the bathrooms and on my way up from the kitchen I hear R4 being upset about R2 shouting in the dining room. R2 starts shouting when hearing this. [R4 says] “I’m going to my room”, R4 repeats “it’s too busy” or something like this. I hear S12 suggesting to R4 to go to the living room but R4 says that he’s going to his room. Then I hear R4 refusing to go and have his haircut because people are being loud […] S3 is chatting with him telling him with confidence that he needs to go and R4 saying “no” (Field note).

“Her behaviour when she's with me and in a family setting is, is different to how she behaves in [house], which obviously impacts on her.. interaction with staff members and [residents]”, F1 shares. The quote highlights the unique relationship that families have with the residents. Its uniqueness is understandably not always easy to comprehend: “is that […] quite common with [residents], for them to behave so radically differently (incomprehensible) at home?”, F1 wonders. Families are part of the plural person. Teamwork between staff and families facilitates positive care relationships, and for it to occur, the organisation and families must have faith in each other (“even if he had a challenging personality, we would feel that

[organisation] and [house] would still work hard to meet his needs", F2). Staff can draw on valuable family knowledge to inform their practice: "same at home […] will say that she doesn't want to go for a walk […] but by just sort of cajoling her and saying […] it's sunny out […] she'll do it" (F1). Families have needs and desires concerning the residents, care homes have rhythms and routines to support the residents. Desires and rhythms can sometimes clash, shaping the care relationship:

> I also sense the pressure from certain family members (e.g., socks/underwear should be going into drier) and how this shapes care work duties and how such issues become real in the daily care provided to residents. A care that, to a certain degree, already revolves around tasks that do not directly involve the residents (Field note).

"People I speak to are like […] what is the house like? […] people's expectations of care homes are like hospitals", S9 explains. The house carries different meanings. The desire "to be community […] but in the same time you follow the rules" (S11) not only shapes the care relationship but also the relationship between staff. "We're […] having a different relationship with our own [staff] in these community events" S9 shares, compared to the "day-to-day when we're having supervisions and team meetings". In a sense, the care home is resisted, attempting "to make this house more than a care home" (S11). S9 elaborates: "it's just a house next door to anyone […] that in a way creates, I think, a, a space for [residents] to build relationships". Building those relationships entails meeting each other, whether one is staff or resident.

Theme 3: "They also see us as much as we see them" - The connection.

"It's very, very hard to do that sort of a job if you know that the other person.. isn't singing from the same song sheet", F2 explains. Neither the staff nor the resident alone, but both, each in their way, are the active agents in the care relationship. They influence each other,

"it's symbiotic" (S16). The connection between staff and residents unfolds, highlighting a side of relationships that is often hidden.

"It's not quite equal, but it's, it needs to be a two-way relationship", F2 states, emphasising interconnections: "[name of resident] really benefits from the relationship with the staff, but the staff […] are in their role with an understanding that […] they will benefit from [name of resident] love to them". "They also see us as much as we see them", S16 shares, "sometimes you come to work and the [resident] looks at you […] can tell that you're not looking, are you OK?". I experience these moments of connection myself: "end of my shift and R5 tells me something along the lines, 'are you leaving?', showing genuine interest. I think he asks when I'm coming back, his face is bright, he is focused, paying attention" (Field note).

The skilled worker I discussed in Study 2 is present in the house. Staff empathise: "I totally understand […] you're waking up and a person you hardly can recognise […] pretends […] as if you're good friends" (S4). They try to maintain patience at all times ("R1 throws her spoon into R5's cup which has water in it […] S10 takes a deep breath, I offer [them] another cup, we smile", Field note), and aim to expand the residents' horizons:

> S8 arrives who tells me that [they] will try to get R6 into the car so he can familiarise himself with the process of using cars and going places as agreed in team meeting […] R6 gets in the car without any issues apart from some mild physical difficulty to fit in. Sits at the back, I sit next to him, in front of us is S12 and S8 is driving. Within the first five minutes in the car, you can see the smile in R6's face, giggling, we all acknowledge this, building on it ("someone is happy"). S12 is giving praise and shares R6's happiness (Field note).

Every member of staff brings something different, yet staff are also "working as a team" (S3) influencing ("whoever is on shift will determine the tone/quality/pace of shift", Field note)

and complementing each other ("learning from each other and informing each other's areas of weakness", Field note), and building the care relationship collectively:

> Early evening meds: S7 and S10 with R3. S7 is trying but R3 is refusing and S7 leaves the room giving space. S10 takes over after a while. Approaches with confidence and calm, flat tone of voice, asking R3 to take his first medication first. R3 does it. Then S10 points at the next cup with meds. R3 takes it. S7 comes (more excited) giving praise (Field note).

Alongside the skilled worker, stands the skilled resident. The two are connected. Staff being *knowing* builds positive relationships, yet the resident is *knowing* too ("Residents know the care system and care relationships best, given all their experience over the decades. The photo albums in the TV room are a great reminder of this. So many staff-resident encounters over the years", Field note). The skilled worker engages, approaching the resident with an enquiring attitude and confidence, tailoring their communication, and skilfully using humour. Engagement entails tuned-in, one-to-one little moments of connection. I turn the gaze within, observing my own interactions with the residents: "I approach her […] ask what's going on, giving her my hand. She touches my hand and she engages with me with the way she looks" (Field note). Daily tasks can be turned into vehicles for engagement:

> S4 is in the kitchen with R6. S4 is trying to motivate R6 to help [them] with washing a frying pan. R6 doesn't seem motivated and tries to leave. S4 persists several times and each time R6 will wash a little bit more. S4 does the same with R1, spraying the kitchen surface and asking R1 to wipe the surface. R1 resists but S4 persists and R1 eventually wipes the surface (Field note).

Yet, engagement thrives when staff and residents are doing activities together ("she likes having her nails painted […] writing […] chatting", F1) and accessing the community. I attend a trip to a nearby town:

> Residents excited to be out and about in the community, [I] can [see] the smile in their faces and how happy/alert they are and how they are interacting and existing in a very different way compared to life in the house (i.e., alert, more engaged, interacting with the world, and even eating better and being more keen to cooperate regarding food). I would say that this is also relevant for staff as well, who are now not operating within the set routines of the house and the wider care context. S16 explains that we're getting the bus as one the residents loves buses and it's good to have this lived experience (Field note).

The skilled resident also engages. In the living room, I "lean near R3 to speak to R4 and R3 pretends that he's kicking me […] [I] throw myself on the floor saying, 'who did this? That man!!'. R3 responds by looking pleased, smiling" (Field note). Residents find different ways to communicate emotions and needs to staff and relate with them. F3 explains that "as soon as he, he sees [certain staff member], he's overjoyed […] pats his chest, and he's smiling" and "to say he wants to go outside, he'll go and do the door handle".

"I know that she [resident] does shout", F1 shares. The care relationship is dynamic, "you're restarting your relationship many times […] because there are conflicts" (S11). It takes two to restore as "both sides need to be [willing], if not, it doesn't work" (S4). Simple things such as "having a cup of tea together" (S11) can take relationships back to a positive place. Staff may offer an apology, reassure, and reason with the resident. From their side, residents may engage in reasoning ("I think if you explained […] he would understand […] he might be

able to suggest something", F2) and tend not to hold grudges ("they will have a problem with you at that time, and then they will move on in life", S11). The following is rather telling:

> After dinner, I ask him [R3], "stay here or go next door/TV room"? "Next door" he says. We are watching TV and [an] ad comes up. I press skip. "Don't do that" R3 says. I've seen R3 getting agitated over this before. I choose to ignore the situation. R3 carries on [being upset]. I follow what S16 has suggested at the team meeting [...] I approach R3 […] I say: "I promise I will never do that again". He seems pleased. I ask him to shake hands, we shake hands (Field note).

Everyday life is a terrain of connection. Once again, little moments matter: "R1 is in the kitchen [...] S16 is in the kitchen cooking. S16 is singing […] R1 [is] chuckling at S16's singing […] [S16] tells R1 to sing along, 'come on [name]' […] R1 carries to smile and be happy" (Field note). S11 shares, "I'm not special in any way […] to build relationships", and continues, "I think the fact that.. I was around […] Christmas, Easter, their birthdays […] there is this relationship of TRUST". If a trusting relationship is the ultimate goal, little everyday moments seem to facilitate this. Connections do not always happen. Care home pragmatics means that "you cannot really always have one-on-one time" (S1). Relationships can be temporary ("the fact that the staff change as frequently as they do", F1) which can make building a "special relationship […] very difficult" (F1). This 'relate-stop-repeat' mode can result in residents feeling "tired of having to get to know another new person" (S9). Some moments feel like missed opportunities to connect. "I don't feel that [name of resident] is encouraged to interact with staff and [residents] as much as she should be", F1 explains. I elaborate on this further:

> There seems to be a lack of activities (for some residents more than others) in the house. This may result in understimulation? […] I'm told that R1 doesn't like it when its cold

> (so perhaps Spring/Summer is different?) and that R3 will refuse to go out when offered (something that I experienced myself, eg. Xmas carols) but surely there could be more opportunities for simple activities tailored to people's needs (e.g., going for a ride, doing activities in the house, short walk around the block?) […] Each resident does have an activities board and there simple activities are mentioned but some of the time said activities are not taking place for no apparent reason (Field note).

The care relationship, the connection, is a relationship, and a connection, between humans. Staff are human; they bring their emotions ("tells me off and tries to hit me […] I do understand it, but […] after these confrontations, I'm always drained", S4) and "personalities/ideologies/beliefs/experiences" (Field note) into the relationship. Residents are human; they bring their personal style ("can appear quite difficult to get on with, but she isn't", F1) and their feelings and experiences ("I'm sitting in the living room with R5 watching TV. He tells me again about when he used to have a white rabbit ('it used to sit on my lap'). There's a mild emotional tone in his voice", Field note) into the relationship. Ultimately, beyond the role of 'staff' and 'resident', the care relationship is a human relationship too. As such, it is about recognising that some people will gel whereas others may not ("not everyone HAS to like everyone", S3). It is about understanding that somewhere within professional care perhaps lies an element of human love ("in such a way that he [resident] knows and feels that he is loved", F2). It is about potentiality and human depth:

> [At an anniversary organisational event in a venue in town]
>
> R5 is smiling to people, shaking hands, truly interacting, asks to use [the] mic[rophone] and says "hello", then asks S5 who is sitting next to him: "who died?" - we all laugh hard! R5 joins us when we're singing [...] he's excited. Later in the social, R5 smiles to

people he hasn't seen for a while, shakes their hands, "how are you?" he says. (Field note).

"We support people with learning disability who.. who are amazing, but they might NOT understand things the way you understand it", S16 explains. Yet, the connection between staff and residents creates a powerful relationship, perhaps a space for a shared experience of the world, based more on their shared humanity and less on deviations from what is discoursed as normal.

Theme 4: "How the people treat you and you feel treated" - The power of relationships.

"His life is about his relationship with staff […] it needs to be positive for him to function", F2 states. From their side, staff "want to be able to have a relationship […] otherwise they wouldn't be in that profession", F3 explains. S4 brings the two together: "the whole life perspective changes dramatically depending on how the people treat you and you feel treated". The care relationship entails "possibilities and limitations and a unique language developed with each resident and each staff" (Field note). Such is the power of care relationships that can shape the lives of staff and residents.

Similar to what was discussed in Study 2, good relationships can have a positive impact on "one's own mental health" (S1), making life in the house better for all. "There's more peace", S16 shares, and continues, "they have a better quality of life. You also have a better quality of life, you're not stressed". Through positive relationships, staff and residents can be more authentic with each other. After "starting to become on better terms" with a resident, S1 compares:

> if he's laughing or telling me stuff, it feels more real […] somebody who is.. doesn't matter for him […] he will still tell his jokes […] but I feel like as the time went on, it became more real from him

Difficult behaviours decline and work becomes much smoother. I am in the kitchen with S16 and R2: "R2 becomes upset. S16 does not become intimidated […] says, 'okay, you don't want me here, I'm gonna go' […] levelling with R2. R2 stops shouting immediately and carries on doing the book" (Field note). Willingness to cooperate also increases:

> I sat with R3 and S8 in the dining room chatting about different stuff. You can tell that S8 and R3 have a good relationship and like each other. S8 asks R3 to drink his tea and R3 does it – something that may cause conflict if it happens with other staff (Field note).

Staff remain motivated ("it makes them want to come to work", F2) and so do residents ("if he's close to someone […] he will do things", F3), and there is a sense of purpose and achievement ("makes me feel like I'm doing my job kind of effectively", S9). Perhaps, one of the greatest manifestations of the power of relationships is little moments like when residents look forward to seeing staff: "I'm in the dining room [...] R5 sees S5 from the window coming in (I showed [them] to him). He rushes to the kitchen to greet S5 and chat to [them] ('Good morning')" (Field note).

"If the people who give you care, if you are not on good terms with them […] it makes your life a bit worse" S1 explains. When positive relationships are lacking, life becomes gloomy, "they [residents] don't understand you, you don't understand them, both of you are distressed" (S16). Providing care can feel like a pointless activity ("[you] don't know why you're even doing this", S4) whilst receiving care can also feel meaningless ("he [resident] will withdraw completely into himself […] he'll just go through the motions", F2). Staff may find themselves in a place of uncertainty. "Can get in your head" S1 shares, and continues, "you

feel confident with somebody and then something minor happens and then you start questioning yourself". Residents may feel uncertain too and manifest this through their behaviour. I am in the dining room reading through the staff's daily notes when S2 brings R3 in:

> R3 does not want to take his medication. S2 uses quiet tone of voice but it appears to me that there's a lack of confidence underlying [their] interaction with R3. There seems that there hasn't been a common language established and a way to get past the medication conflict. R3 refuses ('leave me alone'). S2 leaves and returns after a while. Same situation. R3 hears S6's voice and I understand that he wants to chat to [them]. I ask him and he confirms. S6 comes in and appears to be confident. With a relative sense of humour asks R3 to take his medication. R3 takes it. S6 leaves (Field note).

"Positive relationships allow [residents] to really strive in life" (S9) and in their absence "the whole setup falls to pieces" (F2). The care relationship can be transformative for both staff and residents and therein lies its power.

5.5 Discussion

With respect to conducting primary and secondary research for this project, Study 3 served as the final act. It affirmed and built on the findings of Study 2, expanded them, and explored additional relational domains, all by using an ethnographic design to examine care relationships in real-time, as they unfold in the reality of a learning disability care home, bringing together people's perceptions of their actions and what they actually do in everyday life. The four themes and this present section tell a story together.

Unsurprisingly, care relationships at Rosewood House were rooted in the care praxis of everyday life and had powerful effects on the lives of staff and residents. Certainly, care relationships also entailed conundrums and grey areas. Yet, a way to navigate these

conundrums is to embrace them somewhat, perhaps suggesting that conundrums will always exist. The professional role is balanced with a celebration of the *personal*, and the *personal* is situated within the *professional*. This enhances the care relationship. In the realm of care work, the staff and residents live life together and their humanity is interconnected, simply making the humanisation of the care relationship a reality that, ultimately, one must affirm and navigate to achieve a nuanced understanding of relationships and make them work for all. This nods to relational principles and practices adopted in less 'conventional' residential arrangements for people with a learning disability and other groups, for instance, intentional communities (e.g., Randell & Cumella, 2009) and Shared Lives (e.g., Callaghan et al., 2017), whereby close care relationships are encouraged, and concepts such as friendship and family are expanded, negotiating, to a degree, their place in the care relationship and everyday care in a manner that challenges the normative.

Rosewood House lies at the intersection of the emotional, practical, and socio-political spheres of care (Rogers, 2016). The interplay of the micro, meso, and macro (Bronfenbrenner, 1994) in the care ecology that I described in Study 2 shapes constantly the care relationship. Consequently, as a care setting, Rosewood House is a multifaceted home that assembles the personal, physical, and social home (Chinn et al., 2024). Those *homes* within the (care) home interact constantly with each other. In the care home, domestic tasks need to be carried out to maintain the physical home (e.g., cleaning) and to meet the physical needs of the residents (e.g., cooking). Such tasks also shape the social home and, as a result, the care relationship. I recall an informal chat with a member of staff at Rosewood House who, when I asked their opinion about whether cooking takes time away from building relationships, responded that the fact that food is cooked by staff is what makes the home, homely. Tasks associated with the physical home, therefore, seem to influence the personal and social home, making it less of a care setting and potentially enhancing care relationships.

An intriguing comparison can be drawn with Bigby and Beadle-Brown's (2016) work who urge us to think about and be mindful of care cultures that are particularly focused on tasks, rather than relationships and interactions. As the care relationship is situated within the meso (i.e., care organisation) and the macro (i.e., the wider social care ecosystem), one could wonder about the relational constraints of at least certain meso and macro tasks (e.g., administrative tasks or *paperwork*; Quilliam et al., 2017) or go further and question the point of such tasks altogether in the spirit of revisiting meaningful work in capitalist societies (see Graeber, 2013, for an interesting discussion). Could minimising or allocating a number of domestic and administrative tasks to services or people other than support staff, create more space for care relationships as a whole? On our way back from a walk with a resident, S7 explains that in a sister setting to Rosewood House there "is only one member of staff per shift and that is very quiet – everyone is very independent" (Field note). Does engagement with tasks serve as a subliminal, perhaps unconscious, measure to define what counts as work that has or does not have value in care work? Johnson and colleagues (2012) describe 'simply hanging out together' as a process that underpins positive relationships, albeit primarily through observing adults with a learning disability and their family members, and it is worth reflecting on the power of staff and residents hanging out together beyond tasks.

Care cultures can unconsciously develop or be the result of concrete efforts to establish them. Strong leadership is key to influencing care practices and setting high care standards (Bigby & Beadle-Brown, 2016), and, ultimately, to accommodating the needs of the different partners that comprise the plural *person* (i.e., residents, staff, significant others) and emphasising a relational care praxis. Organisational support matters as it facilitates positive relationships ("hugely disheartening if you don't get the support you need to do the job", F2) and this may come in the form of creating relational space ("using experienced staff members

[…] the new people are shadowing these […] to, you know, show them how to build relationships", S9) or information sharing and training.

To connect is key, alluding to previous research that highlights the importance of connecting in positive care relationships (Johnson et al., 2012). Perhaps the 'task versus relationship' binary that I discussed in previous paragraphs in this section can be overcome once one realises that every moment can serve as an opportunity to connect. In the section '5.4 Analysis' of this chapter, I highlighted such moments, where simple domestic tasks (e.g., cooking, cleaning, preparing the table) are used relationally, achieving connectedness. To connect is a mutual, yet not equal, relational process, as staff and residents occupy different social positions and have various degrees of power. Once more, connecting must be placed within the *human*. Staff connect and residents connect, and, at times, staff are unable to connect with residents, nor are the residents able to connect with the staff. Humanising the connection challenges normative expectations of care provision that frame support staff as always able to provide intense care (Fisher, 2021) and highlights agency and potentiality among the residents. Corresponding with previous research (e.g., Bigby & Craig, 2016), activities are key relational devices. Engaging in activities can disrupt the usual care routines and rhythms in the care home, creating new relational dynamics and possibilities for staff and residents to develop together.

5.6 Strengths & limitations

I now turn to reflect on the strengths and limitations of Study 3, as an examination of its strengths and limitations can offer a more nuanced understanding of its contributions and areas for improvement.

Most staff participants in Study 3 identified as women reflecting the gender patterns observed in adult social care in England (Skills for Care, 2021). Nonetheless, a fair number of staff participants identified as men, thus representing a group that traditionally is less likely to

get involved in care work (Fisher, 2021). Although this study did not seek to explore the influence of gender on care relationships, including a fair amount of staff members identifying as men, could be considered an asset, perhaps indicating a shift in men's attitudes towards roles that are not traditionally gendered as masculine. Perhaps, this nods to generational differences too, as, age-wise, the staff participants came from a range of backgrounds, including but also going beyond the typical age patterns (i.e., 35 – 54 years old) observed in adult social care in England (Skills for Care, 2021). Study 3 explicitly addressed one of the limitations of Study 2, as the majority of support staff at Rosewood House were migrant workers, therefore, representing a growing proportion of the adult social care workforce in England that was not well represented in Study 2. However, I did not dwell into the role that the cultural backgrounds of the migrant support staff who participated in this study might have played in shaping their understanding of care relationships and their subsequent relational practices with the residents. Although this study did not aim to examine the influence of support staff's cultural identity on care relationships, I recognise that I could have explored this domain a little bit further, while maintaining proportionality. Therefore, I consider this a limitation of this study.

Study 3 only focused on one particular care organisation and, specifically, a particular residential setting managed by the organisation, and, inevitably, the findings are situated in and tied to those environments. Nonetheless, this is in line with an ethnographic design, especially one that, as discussed in the section '5.2 Methodology' of this chapter, was influenced by focused and patchwork ethnography and had an applied orientation.

Furthermore, it is worth reflecting on the extent to which Rosewood House was representative of a 'typical' residential care home for adults with a learning disability in England. To begin with, as a CQC-regulated residential care home, Rosewood House was representative of a type of residential setting that remains among the dominant residential arrangements for adults with a learning disability in England (Skills for Care, 2021).

Additionally, the setting had an ‘Overall: Good’ CQC rating, thus falling within more common rating values, as opposed to ‘Outstanding’ or ‘Requires improvement’ which may be considered less representative of the average rating. Moreover, as the social care system in England, and the UK in general, is rather fragmented, Rosewood House was informed by its organisation’s vision, values, and ethos, the same way most social care settings are. This problematises the notion of ‘typicality’ as ideologies, approaches, and practices can vary significantly across residential settings. For instance, some care organisations use specific frameworks (e.g., ABA) to inform care practice, whereas others do not; some try to take a more efficient approach to daily administration tasks, while others emphasise community events and activities. Oftentimes, the size of a care organisation or the resources available to it will influence its vision and approach.

With this in mind, what makes a care setting ‘typical’ when the very idea of ‘typicality’ is somewhat fluid? It must be acknowledged that the values of community building and belonging, as well as appreciation of spiritual life, and communal living between people with and without a learning disability, were distinctive features of Rosewood House and the wider care organisation. In that sense, Rosewood House was an ‘atypical’ residential care home. At the same time, and as I discussed in sections '5.4 Analysis’ and ‘5.5 Discussion’, care routines set the pace in the house, administrative and regulatory duties had to be carried out, task-focused care cultures influenced engagement with residents, and working conditions and turnover shaped care relationships, to name a few examples. Consequently, Rosewood House was also representative of a ‘typical’ residential care home as, ultimately, it operated within the UK social care ecosystem in the here and now. With this co-existence of opposites in mind, instead of focusing on ‘typicality’ in a binary manner (i.e., ‘typical’ versus ‘atypical’), it is perhaps more meaningful to explore it as a spectrum, examining what is distinctive in each care setting.

Moreover, this study addressed another limitation of Study 2 by not only involving support staff but, crucially, the perspectives and experiences of residents and family members of residents too, as key partners in the care relationships and the expanded *person* in person-centred care. This research included residents who had different levels of learning disability, including severe or profound learning disability, providing a more holistic insight into care relationships. Although interviews were not conducted with the residents of Rosewood House, participant observation, unstructured conversations with residents, and document inspection provided valuable insight into their lives, stories, and roles in the care relationship, as well as into what the residents do to build, maintain, and restore care relationships. Involving significant others of residents offered a unique perspective on care relationships as they were somewhat outsiders to everyday life at Rosewood House, yet insiders in the personal lives of the residents living in the setting. Regarding document inspection, perhaps I should have also sought information about the organisation's policies pertinent to support staff living in Rosewood House as this would have provided useful administrative context.

Self-completion of the Demographics & Eligibility Questionnaire involved the participants' interpretation of the questions; nonetheless, as I was living at Rosewood House and had a closer relationship with staff, residents, significant others, and consultees, I was able to provide clarification directly (e.g., by having a face-to-face chat) and complete the Questionnaire together with participants should they wished too. It is worth mentioning, though, that my decision not to upload the Consent form and Demographics & Eligibility Questionnaire on Qualtrics© has, occasionally, caused minor technical difficulties to some of the people who completed their forms digitally, as, for instance, not everyone had Microsoft Word© or was familiar with its functions. In those instances, I either gave the person a physical handout, allowed them to use my computer to complete the forms, or digitally filled out the forms together with them.

The ethnographic design of this study created the conditions for more people to take part in research, not only the people who are somewhat 'more likely' to participate in a study, thus addressing one potential limitation of Study 2. Intensive data collection was in line with the focused and patchwork ethnography elements of my ethnographic design, nonetheless I acknowledge that I could have incorporated more days off during my first month at Rosewood House to allow more opportunities for rest and reflection. Nevertheless, as I was driven by a sense of responsibility towards the care organisation and I wanted to keep disruption within Rosewood House to a minimum while being mindful of the deadline for completing the study, it was important to get rooted and record people's wishes regarding their participation as soon as possible. These factors led me to decide to use all available time during my first month, to ensure that I could achieve the goals above.

Despite the significant number of hours I spent at Rosewood House and the fact that data collection was conducted intensively, what the findings would look like if this was a long-term ethnography remains to be seen and, at this point, is only subject to speculation. Participant observation was a precious method to explore care relationships; however, I consider the fact that observations were not conducted during personal care or in the residents' bedrooms as a limitation of this study. Personal care is an important domain of care work, and building a trusting and respectful relationship is a prerequisite for personal care to be carried out. Also, personal care itself can serve as a vehicle for building trust and relationships, as demonstrated in Study 2. Moreover, various activities, interactions, and conversations often take place in the residents' bedrooms. Nonetheless, I fully appreciate the sensitive nature of such observations, and I completely respected the wishes of the care organisation and consultees who kindly asked me to refrain from conducting observations during said activities and in said spaces. It is also worth acknowledging that I did not observe the Christmas Day celebrations at Rosewood House as I was away for the Christmas holidays. I suspect that this

was an important occasion for support staff and residents with interesting implications for having a sense of community but also for the practical aspects of everyday care work (e.g., cooking the Christmas meal and celebrating whilst maintaining care routines).

Despite the multiple benefits of ethnography as a design and participant observation as a method, such approaches and techniques, inevitably, also have limitations (DeWalt & DeWalt, 2011; Johnson et al., 2011). It could be said that, when conducting participant observation, my presence at Rosewood House may have influenced the participants' behaviours resulting in them being more mindful of their actions or displaying behaviours that they would not display if I was not present. To some degree, this was perhaps unavoidable, particularly during my early days in the house, when trust and rapport were still being established. To tackle this, I constantly reflected on the ways I could be influencing people's behaviours, adjusted my practices, and tried to build more rapport with the participants. Nonetheless, almost from the start, most people seemed to be fairly comfortable around me, appeared open and authentic, and seemed to *do* care relationships and care work as if they were not observed. I felt that this situation only improved as time progressed and I became more integrated finding my place in the team.

Finally, in this study, a combination of in-person and online interviews were conducted with some of the participants. I did not experience any significant technical difficulties during the online interviews, and I was confident that the interviews would be conducted in an accessible manner as I had a closer relationship with the participants; thus, it was much easier to discuss ways to accommodate their needs directly. Conducting in-person interviews nodded to the thoughts I shared for Study 2 in the section '4.5 Strengths & limitations' of Chapter 4 and facilitated improved opportunities for connection during the interview, making the overall experience more enjoyable. Nonetheless, I felt that the interview format did not influence what

participants shared with me as all participants seemed to be genuine, truthful, and keen to talk about their views, experiences, and practices.

5.7 Conclusions

The care relationship is a balancing act between the *professional* and the *personal* and, perhaps, the marriage between the two realises positive care relationships. This process must give space to the humanity of residents, staff, and significant others. Building a sense of belonging and community in the residential setting, in the myriad ways that *community* can be interpreted, can be genuinely transformative for residents and staff. In all its simplicity, the connection between support staff and residents is a driving force behind building relationships in the multifaceted terrain of the care home. The ethnographic design is a valuable tool for conducting social care research, and when adopted reflexively, can lead to a positive experience for both the researcher and the participants. This perhaps nods to anthropology and sociology as relevant disciplines that could be used more frequently, either alone or in an interdisciplinary fashion, to explore various social care phenomena. Employing an ethnographic design in Study 3 made it apparent to me that the researcher should always reflect on their assumptions about people's willingness to participate in research and, simply put, have faith. In a complex environment like Rosewood House, during a busy and hectic time of the year, as we were heading towards the Christmas holidays, and with the wider conditions surrounding social care, people from different backgrounds and roles chose to participate in this study with interest and enthusiasm, and that speaks volumes.

Summary of Chapter 5

In this chapter, I elaborated on Study 3, an ethnographic study that built on Study 2 and sought to address the project's aim and research questions further by attempting to bridge what people say and what they actually do, in the context of building and maintaining learning

disability care relationships. Additionally, Study 3 aimed to include residents and significant others as key partners in the care relationship. I generated four themes (i.e., "I feel more towards them than just my clients" - Care relationships betwixt and between; The care, the home, and the care home; "They also see us as much as we see them" - The connection; and "How the people treat you and you feel treated" - The power of relationships).

This study highlighted that, given the interconnection of staff and residents through care work, conundrums in the care relationship are possibly inescapable. The residential setting is a home and a care home, a place of contradiction, that influences the care relationship in multiple ways. The connection between staff and residents entails not only skilled staff but also residents who use a range of skills too. The care relationship must allow space for the humanity of staff, residents, and others, and positive relationships are truly powerful. Study 3 concluded that embracing contradiction in a balanced fashion is perhaps the way forward to positive relationships. It also emphasised that belonging and community within the multidimensional (care) home can enhance staff and residents' sense of connectedness and lead to more fulfilling lives. Conclusions about ethnography as a research design were also drawn and discussed.

Study 3 was the last study I carried out in the context of this project. It is now time to take a step back and zoom out. It is time to explore the threads that tie this project together as a whole in the next and final chapter.

Chapter 6: "A strange, grey area" – General Discussion, Suggestions, & Project Conclusion

6.1 Introduction

"We do not live in a world of abstraction; we live in a world of relationships, in the real world", states, very eloquently, Chrissie Rogers (2016, p. 49). During our interview, in the course of Study 3, F3 describes care work in a short, yet very concise, way: "it's hard work". These two quotations encapsulate the essence and the tone of this project. They take us back to Chapter 1, in my short reflexive piece, where I stated that before even knowing what social care was and entering the care workforce, I already had "a strong yet unclear interest in supporting people in their everyday lives" (Mamolis, 2022, p. 16).

At the heart of human life lie relationships (Reis et al., 2000), and this project focused explicitly on relationships, specifically care relationships, aiming to explore the ways they occur in everyday life within long-term residential settings and what makes them positive, all in the multifaceted context of learning disability care work in England.

To this end, I posed four research questions:

1. What are the conceptualisations and definitions of (positive) care relationships?
2. What processes and practices underlie positive relationships and how can disrupted relationships be restored?
3. What factors serve as barriers to and facilitators of positive care relationships?
4. What impact do positive relationships, or lack thereof, have on support staff and residents?

I attempted to answer these questions by conducting a series of studies using various approaches and methods to gain a holistic insight into the care relationship. In my first study, I systematically reviewed what previous academic and non-academic work was suggesting

about care relationships. This review served as a compass for my second study, where I leaned towards support staff to hear their views and experiences of care relationships. Building on that, in my final study, I sought to witness care relationships unfold in the real world, in the *everyday*, where people say, but also people do.

As I demonstrated in this thesis, those three studies employ different techniques, and individually, each study tells its own story, providing valuable insights into the domains of care relationships that I explored through the project's aim and research questions. I will reiterate the importance of reading the findings of each study together with the 'analysis', 'discussion', and 'conclusions' sections, depending on the chapter, as one complements the other, resulting in a distillate that can be used to understand the care relationship further. However, the three studies are also connected; assembled, they also tell a story together. In the previous chapters, each study had an opportunity to tell its story individually. In this final chapter, I want to tell an assembled story, bringing together the three studies, and looking at the threads that weave through this project in its entirety.

6.2 Three threads

"A strange, grey area"

The heading of this section takes us back to where we started, namely the quotation used in the title of the thesis. Throughout the three studies, the care relationship was framed and experienced as a place of contradiction. A "strange, grey area" between and betwixt the *professional* and the *personal*, the member of staff and the 'friend' or the 'family member'. A conundrum with providing and receiving care in the realm of everyday life whilst operating within the material and ideological realities of the social care ecosystem and the wider society. The care relationship is "a strange, grey area", a conundrum that perhaps can be addressed by using its very own components. As particularly Study 3, but also Study 2 and Study 1,

demonstrated, the *personal* cannot (and seemingly should not) be avoided; instead, can be celebrated within the *professional* and somewhat be 'tamed' by it. In turn, the *personal* enhances the *professional*. Ultimately, this points towards framing the (positive) care relationship as, neither *only* professional, nor *only* personal, but as an act of balance; it operates among contradictions and conundrums and tries to balance the *professional* and the *personal*.

Existing, yet still growing, less 'conventional' residential models such as Shared Lives might be of interest here, as perhaps they serve as an example of a social care residential arrangement that attempts to facilitate the care relationship as an act of balance. Drawing on their theorisation of the dis/human,[68] Goodley and Runswick-Cole (2016) focus particularly on Shared Lives and suggest that the "Shared Lives scheme is an example of what we might call the dis/family" (p. 12). They continue, explaining that the "dis/family is simultaneously normative and non-normative" (p. 12) as "it appeals to the notions of traditional family and yet it troubles traditional biological kinship and parent/child relationships that underpin the 'normal' family" (p. 12). After all, and as also demonstrated in Study 2, in Shared Lives, carers do formal, paid care work, and residents receive formal, regulated care.

The points made by Goodley and Runswick-Cole (2016) nod to friendship and family, namely concepts that created relational conundrums that the support staff who took part in my studies wrestled with in their everyday practice. A dis/approach is perhaps useful for framing the care relationship as an act of balance, perhaps a dis/relationship? The desire to build friendships and to have a sense of family are recognised as part of being human (Rogers, 2016) and maybe staff, resident, and significant others' understandings of the care relationship *also* as a friendship or family relationship allude to dis/friendship and dis/family (Goodley & Runswick-Cole, 2016); namely, the need and the relational practice of having 'normal'

[68] As this was discussed a few chapters back, I am reminding the reader that they can find more information about this concept in the section '4.6 Conclusions & project directions' of Chapter 4.

friendships and family is affirmed as *human* whilst 'normal' friendship and family are disrupted as they occur within a care relationship context.

The human

All studies in this project emphasised that the care relationship operates within the *human* and space must be given to the humanity of residents, support staff, and significant others. After all, the *person* in person-centredness assembles the residents but also the support staff and others, their needs, desires, and their humanity. Navigating vulnerability and needing the care of others is a point of human interconnection and interdependence (Held, 2006), and to humanise the care relationship is to stand with residents *and* support staff and significant others as their humanity is intertwined and, inevitably, shapes the care relationship.

Moving from the level of values to a more applied and practical one, Study 2 and Study 3 indicated that recognising one's shared humanity with another can be used as a care practice that facilitates and builds positive care relationships. As Goodley and Runswick-Cole (2016) theorised, the learning disability disrupts and expands dominant notions of what being human means (i.e., dis/human) and staff recognising their shared humanity with the residents entails recognising "both sameness and difference" (Bigby et al., 2015, p. 291) whilst attaching positive value to it. Bigby and colleagues (2015) frame this as having positive regard for the residents, who are, subsequently, viewed as 'like us' by the staff. Positive regard serves as a dimension of positive care cultures in residential settings (Bigby et al., 2015), namely cultures that act as a buffer for staff burnout and resident abuse (Collins & Murphy, 2021). A methodical approach towards emphasising staff and residents' shared humanity as a practice to build positive care relationships can be attained through organisational facilitation and leadership in the residential setting (Bigby et al., 2015). For instance, on the discourse level, through

organisational policy, and on the practical level, via modelling care practice for new staff (Bigby et al., 2015), to name but a few examples.

A living organism: relational praxis within the wider conditions

The project highlighted that positive care relationships can have a profoundly transformative impact on the lives of residents as well as the work and, to some degree, the personal lives of support staff. As all studies indicated, the care relationship is a praxis. Staff in the residential setting *do* care relationships in the context of everyday care work, and their understanding of relationships stems primarily from *practising* them. A range of skills, processes, and practices are employed to build, maintain, and restore positive care relationships and all three studies provided detailed accounts of these. As particularly highlighted in Study 3, residents also *do* care relationships in the context of everyday life in the residential setting. From their side, residents utilise various skills and engage in a number of processes to build, maintain, and restore care relationships. That is not to say that being 'support staff' and being a 'resident' is the same, but rather to emphasise what is often hidden in the care relationship, namely the invisible processes that those who provide *and* those who receive care engage in, so the relationship can happen. These skills, processes and practices are partly 'self-organised', with support staff and residents using ordinary human interactions as a vehicle to build relationships, and partly informed by policies, care guidelines, care practices established within the care team, and learned behaviours.

The care relationship resembles a living organism that exists in an ecosystem. The relational praxis that happens on the ground (the micro-level; Bronfenbrenner, 1994), in other words the practical and emotional spheres of care (Rogers, 2016), is connected to the organisation's policies, procedures, and priorities (i.e., the meso-level; Bronfenbrenner, 1994), and the wider material and ideological conditions of social care as a whole and the societal

discourses around learning disability (i.e., the socio-political sphere; Rogers, 2016). The relational praxis consists of the intersection of the micro, meso, and macro levels, and is constantly influencing and being influenced by the conditions surrounding it.

6.3 The impact of this research project & dissemination reflections

Overall, this research project had an applied focus, explicitly examining care relationships in long-term learning disability residential settings in England, thereby exploring an area of care work that, at least in the context of the UK social care paradigm, has not received enough attention. I hope that I made a meaningful contribution towards care practice and learning disability and social care research by providing a holistic account of care relationships, ranging from conceptualisations, to processes, practices and impact on people's lives, using different methods to explore the various domains that comprise and influence the care relationship as a whole.

As I will demonstrate in subsequent sections of this chapter (see all 'Suggestion' sections below), the analyses, conclusions, and other aspects of this project can be used by other researchers to draw and build upon, but also to revisit or reimagine, in their pursuit to investigate care relationships further. Moreover, the outcomes of this research could be relevant, at least to some extent, to policy-makers and social care campaigners. Crucially, the findings of this project could inform and potentially improve how care relationships are understood and practised in the realm of everyday life by care services, support staff, residents with a learning disability, and other relevant parties in UK long-term residential settings.

The process of dissemination is tied to the impact of a research project, as research findings cannot be used meaningfully unless they reach the relevant people, organisations, and institutions. As discussed in Chapter 3, Study 1 has already been published in the open-access Journal of Long-Term Care. In the subsequent months, I also aim to submit Study 2 and Study

3 for publication in relevant academic journals. In addition, perhaps an article reflecting on the various aspects of the ethnographic design that I employed in Study 3 may be written and submitted for publication. I believe that such an article would be useful, allowing room to share reflections on the strengths, limitations, and relational opportunities of conducting ethnographic research in long-term social care residential settings, as well as on the importance of interdisciplinarity. Additionally, this thesis will become freely available to the public upon completion of this PhD.

I appreciate, though, that within the hectic realities of care work, reading academic articles or doctoral theses is not always possible. To this end, I will also aim to present this work at conferences and other social care events via oral talks or poster presentations. Finally, I also aspire to employ a dissemination approach more tailored to the needs and rhythms of care services. For instance, this could include 1) liaising with services to deliver bitesize presentations to support staff and residents on the practical applications of this project; 2) developing a concise, practical resource around building, maintaining, and restoring care relationships in learning disability residential settings, based on the findings of this project; 3) working together with care services to incorporate my findings into existing training for support staff or collaboratively develop new training; or 4) using creative and more interactive methods (e.g., short videos, virtual reality) to disseminate my findings to care services, support staff, and residents. I would like to clarify that, at this stage, these are only preliminary ideas. Actualising such ideas takes time, labour, and resources, and, as with everybody else, I am situated on the wider material reality, thus finding the time and resources to engage in this labour whilst coping with other life and work commitments is often challenging. Nonetheless, I will try to bring some of these ideas to fruition.

Building on these dissemination suggestions, I wish to offer some reflections particularly on the development of the practical resource around building, maintaining, and

restoring care relationships in learning disability residential settings as well as on the care relationship training. Regarding the former, I envision the resource as something similar to what Dr Deborah Chinn and colleagues developed following the completion of their 'Feeling at Home' project, which explored the factors that help people with a learning disability to 'feel at home' in the residential settings they live. The 'Feeling at Home' resource is a practical toolkit that can be used by care services, support staff, and residents, and should the reader wish to review the resource, it can be accessed through the 'Feeling at Home' website (https://feelingathome.org.uk/resources/feeling-at-home-toolkit-by-section/).

In regard to training development, during their induction phase as employees of a care organisation as well as over the course of their role, support staff often receive training that may range from 'moving and handling' and 'medication administration', to 'understanding autism and learning disabilities', or more specialised training such as ABA. The training provided often depends on the approach, resources, and capacity of each care organisation. The findings of this research project could be included in training for support staff, be it adding to existing training provided by care organisations, or collaboratively developing new one focused on staff-resident relationships. For instance, this could entail a) using the conceptualisation of the care relationship as "a strange, grey area" so support staff are equipped with a more theoretical understanding of how care relationships may operate in everyday care in social care residential settings, recognise the tensions and contradictions within care relationships, and allow such conceptualisations to inform their practice; b) highlighting the various care practices identified throughout this project employed by support staff and residents to build, maintain, and restore care relationships while emphasising the importance of humanising the care relationship and its multiple agents; or c) stressing why and how care relationships matter and the practical impact they have on the lives of support staff and residents, to name but a few. Although certainly subject to collective elaboration and further

research, these examples could also serve as components of the practical resource discussed in previous paragraphs in this section. It is worth suggesting that the training upon which I reflected here could contain 'classroom' elements, but, importantly, practical elements too, incorporated into everyday care praxis and the broader care culture of the setting, in other words, integrated into "the way we do things around here" (Bigby & Beadle-Brown, 2016, p. 317).

6.4 Transferability of research findings

"Wanting to make more general claims will likely be a main driver in research", state Braun and Clarke (2022, p. 145), explaining that in reflexive thematic analysis and qualitative research as a whole, "we want to understand some issue or phenomenon, and we want to connect that to something broader" (p. 143). This project was situated in particular datasets, participant groups, and care environments, yet also strove to explore how its research inferences can be applied beyond these datasets, groups, and environments. Considering this, I determined that the concept of transferability was well-suited to a primarily qualitative project like mine.

As qualitative research does not usually claim the generalisability of findings by using statistical arguments and frameworks the same way quantitative research does, transferability is viewed "as more *qualitatively*-situated" (Braun & Clarke, 2022, p. 143). Transferability entails "qualitative research that is richly contextualised in a way that allows the reader to make a judgement about whether, and to what extent, they can safely transfer the analysis to their own context or setting" (Braun & Clarke, 2022, p. 143). In line with this, I ensured that I situated every study I conducted, and the project as a whole, in the broader socio-political context, providing as much information as possible about the micro, meso, and macro levels of the realities within which this research was located.

Anticipating some similarities regarding care relationships in, overall, different contexts is logical, and I believe that, to a certain degree, the inferences of this research could be of relevance to care circumstances other than those discussed throughout this thesis. However, I would encourage anyone transferring and applying the findings of this project to populations, care settings, or social care systems that are different to the ones described in the thesis, to do so mindfully, with reflexivity, and after careful evaluation of what these differences entail, whilst always bearing in mind the realities within which this project was located.

6.5 Suggestions for researchers & future research

Throughout my three studies as well as in this final chapter, I aspired to provide a detailed account of my methods, research findings, and conclusions in a manner that allows other researchers to engage with them in their own work. Listing said methods, findings, and conclusions again in this section would rob them of their depth and lead to repetition, and, instead, I wish to highlight a few learnings that other researchers may find useful.

Researching the care relationship provides an opportunity to analyse and understand the shared space between support staff and residents in a broader, more holistic manner. As discussed in previous chapters, interactions and communication are important components of relationships and there is certainly value in studying these elements. Nonetheless, support staff and residents do not interact and communicate in a vacuum. The context of their interactions and communication is the relationship that they have built with each other. This relationship, subsequently, influences and is influenced by interactions and communication in a dynamic manner. With this in mind, and returning to points that I made in previous chapters, it appears that care relationships are ought to be researched with the same commitment that other types of care professional-care recipient relationships have been studied, for instance, therapeutic

relationships in the context of mental health therapy, nursing relationships, or doctor-patient relationships. Moreover, the findings of this research project as well as the actions that I took and the ones I did not take during this research, can serve as a compass for other researchers, pointing towards future research directions.

Nodding to some of the topics I discussed earlier in section '6.4 Transferability', Scheffelaar and colleagues (2019) have argued that focusing on specific groups of people (e.g., people with a learning disability) who receive care and support is not required, as determinants of care relationships are oftentimes similar between different groups of people. This is certainly an interesting point, as it is logical to think that some similarities exist. Yet, assuming uniformity of experiences might underestimate how different conditions, care experiences, and the social discourses and care practices surrounding them shape the development of care relationships. Moreover, it perhaps underestimates the fact that different groups of people have different needs, something that might clash with the ethos of person-centred care. Future research could explore similarities and differences in care relationships between support staff and different groups of people who receive care. Furthermore, given that some concepts and processes that are used traditionally in therapy (e.g., positive regard, self-awareness) were somewhat also identified in care work and care relationships, future research could look into exploring overall patterns in relationships between a range of groups of people who provide support (e.g., support staff, nurses, therapists) and groups of people who receive it.

Comparative studies around different types of learning disability residential settings and care outcomes have already taken place (e.g., Bigby et al., 2017), and future comparative work could draw on this project's findings to focus explicitly on care relationships, for instance, exploring how different residential settings facilitate or hinder positive care relationships. Moreover, further research with a specific focus on less 'conventional' learning disability

residential arrangements, such as intentional communities or Shared Lives, could be carried out to investigate how such arrangements shape care relationships.

Of particular interest may be examining how incorporating volunteers as a key feature of a learning disability residential setting enhances a sense of community and strengthens relationships between support staff and residents. Moreover, the findings of this project could perhaps be translated into a standalone training course regarding understanding and building care relationships in learning disability residential settings (as discussed in section '6.3 The impact of this research project & dissemination reflections'). Research could examine how the training can be developed and, subsequently, pilot it and test its feasibility.

Future work could explore residents' views and experiences of care relationships in learning disability residential settings by conducting interviews with them to capture their direct articulations. Throughout my studies, it was highlighted that care work is gendered and classed and that care workers are often devalued and, to an extent, stigmatised. Moreover, despite improvements in societal attitudes, a degree of social stigma still surrounds learning disability. Future research could perhaps explore social stigma in the lives of support staff and people with a learning disability as a thread that weaves through their experiences of care work and care relationships. Additionally, future studies could explore how migrant support staff's different cultural understandings of care relationships might be at play when building relationships. For instance, this could entail a qualitative exploration of the influence of cultural identity on care relationships and relational practices from the perspectives of support staff or residents. Similarly, future work could investigate the impact of gender on understandings of care relationships and on relational practices. For example, this could involve a cross-sectional comparative survey measuring responses across different gender identities.

Methodologically, and as discussed in previous sections, an ethnographic design offers significant advantages to examining care relationships. With the consent of the relevant individuals and organisations, and with relevant measures in place, future ethnographic research could also include observations in residents' bedrooms during activities and care routines, as well as during personal care in private spaces. Access to those spaces and care activities could be facilitated more easily, perhaps by conducting long-term ethnographic research allowing researchers and participants to have time to develop stronger bonds before the provision of more intimate care can be observed. A long-term ethnographic study to explore care relationships in learning disability residential settings would certainly be of interest in terms of the findings and how they contrast with short-term ethnography as well as in relation to reflecting on the strengths and limitations of using long-term ethnography in social care settings. Moreover, the findings of this project could be used to inform further research that employs quantitative or mixed methods, for instance, one could draw on the skills, processes, and practices found in this project to support positive relationships, to design a survey that could be circulated to a large number of support staff and residents and explore how often people engage in these processes, their preference for certain practices over others, and so forth.

Finally, and from an analytic point of view, it may prove beneficial for future research to explore care relationships through the concept of the assemblage, as theorised by Deleuze and Guattari (1987). In summary, the concept of the assemblage critiques the centrality of individualism in understanding the self (i.e., the independent self, alone and distinct from others), and instead theorises the self and the other as an assemblage, interconnected and constantly creating new relationships and communities (Goodley & Runswick-Cole, 2016). Such concepts nod to Goodley and Runswick-Cole's (2016) theorisation of dis/human, an idea that I used in this project to reflect on the *human*, and specifically in this chapter to reflect on the care relationship as, perhaps, a dis/relationship. Future research could determine whether

the dis/relationship might be a useful concept to develop, theorise, and use it to understand the care relationship further.

6.6 Suggestions for care practice

As discussed in section '6.3 The impact of this research project & dissemination reflections' of this chapter, support staff, residents, care services, and other relevant parties (e.g., families of residents) in long-term learning disability residential settings can use the analysis and findings of this project to inform care practice and the formation of positive care relationships. More specifically, the project findings could be used 1) by support staff and care managers to inform relationship building in everyday care practice; 2) by trainers employed by the care services, to inform the training that support staff often undertake when starting their employment or during their time in the care service (see section '6.3 The impact of this research project & dissemination reflections'); 3) by residents with a learning disability and their advocates (e.g., family members) to highlight the importance of positive care relationships and ways to achieve them, and 4) by social care regulators (e.g., CQC) to inform the process of care quality evaluation in social care residential settings for adults with a learning disability.

I recognised in section '6.3 The impact of this research project & dissemination reflections' that reading and reflecting on lengthy doctoral theses, or even shorter academic articles, might not always be feasible within the hectic realities of care work. Taking this into account, and without interfering with the dissemination plans I laid out in section 6.3 above, perhaps there is value in summarising a few overarching practical learnings that learning disability care services, support staff, residents and significant others of residents, and regulators could consider in the context of care practice. More specifically:

- The base of care relationships in long-term social care residential settings is the little things that everyday life encapsulates. The *personal* and the

professional in the care relationship can exist in a non-antagonistic manner, as an act of balance where one enriches the other dynamically in the realm of everyday life. This act of balance is delicate as there are systemic power imbalances between staff and residents.

- The care relationship does not exist in a vacuum. Every care relationship is unique, constantly evolving, and resides in the intersection of practical everyday care provided by staff and received by residents, emotional responses of staff and residents, and the wider social, economic, and political conditions.
- The *person* in person-centred care relationships is not only the resident. It also involves the personhood, needs, and circumstances of support staff and the significant others of residents (e.g., family members) as well as the relationship between them. This humanises the care relationship, recognises the humanity of all parties involved, and emphasises the importance of acknowledging and using the shared humanity of staff and residents to build positive care relationships.
- Support staff employ a range of skills and techniques to build, maintain, and restore care relationships. These may include simple, yet powerful practices such as tuning to the residents' styles and rhythms and engaging, listening, and reflecting on what the residents are communicating, using humour, or not holding grudges, to name but a few. Such practices establish a sense of connection between the member of staff and the resident, a shared language which is priceless and can serve as an avenue to positive relationships. Significant others of residents can be a valuable source of knowledge regarding building relationships with residents, and care services and

significant others should work together. The residents also employ a range of skills and techniques to build relationships with support staff, including various forms of engagement, humour, and body language, to name but a few. Recognising the active role that residents play in building, maintaining, and restoring care relationships can enrich everyday care practice.

- How everyday life in residential settings unfolds and the ways subsequent activities and care routines are practised daily, signify the key role of care cultures within services (i.e., how services *do* things) and the extent to which said cultures serve care relationships. Routine tasks (e.g., personal care, medication administration, cleaning, cooking) can be seen and treated as opportunities for building trust and positive relationships (e.g., by engaging with and involving residents), and organising activities (e.g., outings, walks, community visits) can positively disrupt the sometimes repetitive rhythms in residential settings and enrich the care relationship. Staff in leadership positions within care services have a unique opportunity to instil relational care cultures and, considering that care relationships are a *praxis*, to create systems that encourage and model relational praxis in everyday care.
- Care relationships matter, and this is not only a principle, but also a practice, especially when considering the impact that positive relationships, or lack thereof, can have on the mental and physical wellbeing, behaviour, care practice, and sense of meaning of support staff and residents. Social care regulators may wish to observe particularly how care relationships play out when inspecting learning disability residential settings.

The suggestions that I am sharing in this section are distillates from this research project, and I wish to reiterate that without engaging with my analysis in this thesis, particularly

with my three studies as well as this final chapter, one will not obtain a comprehensive and contextualised understanding of my findings and conclusions regarding learning disability care relationships. Importantly, I by no means seek to suggest that there is only *one* way to understand, establish, and restore care relationships. Drawing on one of my reflexive field notes in Study 3:

> [The] residents' life is everchanging. New staff coming, old staff going, new systems, new emerging needs, new residents […] continuity/consistency are very important factors in an area where people have different styles/personalities/ways to work. Can you standardise certain aspects of care practice in this context? And importantly is this wanted/needed? Or is it a strength that somewhat needs to be 'tamed' a bit so we get the best out of it?

6.7 Suggestions for policy

This project was situated in the material and ideological realities of care work in England, and to some degree, the UK, through Study 1. Even though the project focused on exploring care relationships primarily on a practical and lived experience level and did not seek to explicitly examine the regulatory aspects of care work, policies and discourses around care certainly comprised part of the macro-level within which care relationships operated, influencing and being influenced by them. The conditions surrounding care work and adult social care as a whole shaped the care relationship. Specific findings of this project pertinent to a) participant accounts of adverse working conditions and social devaluation of care work and social care as a whole, and b) the key role that support staff play in the lives of residents, could potentially contribute to conversations and deeds around greater recognition of the social care workforce, improved overall working conditions, adequate funding for social care

services, and perhaps the reimagining of social care residential services altogether with an emphasis on relational praxis.

6.8 At the journey's end: Project conclusion

Through this project, I conducted research on care relationships for four years. As I look back, I realise how much I have learned and how many questions about care relationships I have navigated. The care relationship is a complex and powerful phenomenon that can transform one's life. It is a star in the constellation of care work that shines brightly. The care relationship is invisible; one cannot see it but can sense it is there, and I hope that this project contributed to making it a little bit more concrete.

By now, this should be clear to the reader; yet I will reiterate that this project had its roots in my care work experiences in health and social care services over the years. Considering this, the people who immediately came to mind when I was planning or conducting my studies, or when I was writing this thesis, were the unknown to me support staff and residents working and living in residential settings. Judging the impact of this project also lies with them. If a care service, a member of staff, a resident, or a significant other of a resident finds this project helpful and uses it to understand better, inform, or improve care work and care relationships, this project will have achieved one of its key goals.

Summary of Chapter 6

Chapter 6 served as the last chapter of this thesis. In this chapter, I gathered my three studies, examined the threads that tie them together and attempted to tell an assembled story about care relationships and what makes them positive. Three threads weave through my studies, emphasising the care relationship as an act of balance between conundrums and contradictions, highlighting the *human* in care relationships, and focusing on the everyday

relational praxis that is materially and ideologically situated. The overall impact of the project was discussed and suggestions for research, practice, and policy were shared, before the thesis' concluding remarks.

References

Alharahsheh, H. H., & Pius, A. (2020). A review of key paradigms: positivism VS interpretivism. *Global Academic Journal of Humanities and Social Science*, *2*(3), 39–43. Doi: 10.36348/gajhss.2020.v02i03.00

Atherton, H. (2007). A history of learning disabilities. In Gates, B., & Atherton, H. (Eds.), *Learning Disabilities: Towards Inclusion 5th Edition* (pp. 43-65). Elsevier.

Antaki, C., Crompton, R. J., Walton, C., & Finlay, W. M. L. (2017). How adults with a profound intellectual disability engage others in interaction. *Sociology of Health and Illness*, *39*(4), 581–598. https://doi.org/10.1111/1467-9566.12500

Antaki, C., Finlay, W. M. L., & Walton, C. (2007a). The staff are your friends: Intellectually disabled identities in official discourse and interactional practice. *British Journal of Social Psychology*, *46*(1), 1–18. https://doi.org/10.1348/014466606X94437

Antaki, C., Finlay, W. M. L., & Walton, C. (2007b). Conversational shaping: Staff members' solicitation of talk from people with an intellectual impairment. *Qualitative Health Research*, *17*(10), 1403–1414. https://doi.org/10.1177/1049732307308950

Ashman, B., & Beadle-Brown, J. (2006). *A Valued Life. Developing person-centred approaches so people can be more included*. Retrieved July 20, 2021, from https://www.scie-socialcareonline.org.uk/a-valued-life-developing-person-centred-approaches-so-people-can-be-more-included/r/a11G0000001834xIAA?msclkid=54f2cde7d06211ecbbcf2283c2fe0a22

Akkan, B. (2021). Global Pandemic and the Veiled Crisis of Care in Turkey: Politics of Social Reproduction and Masculinist Restoration. *Historical Social Research/Historische Sozialforschung*, *46*(4), 31–49. https://doi.org/10.12759/hsr.46.2021.4.31-49

Baker, P., Appleton, P., & Williams, R. (2017). An examination of the addition of video-informed reflective practice to the active support toolkit. *British Journal of Learning Disabilities*, *45*(3), 180–189.

Banks, C. (2012). Everyday ethnography interpreting and "doing" empowerment and protection care imperatives in a supported-living environment for intellectually disabled adults. Findings from experiences as a support worker. *Suomen Antropologi*, *37*(3), 75–88.

Beadle-Brown, J., Hutchinson, A., & Whelton, B. (2008). A better life: The implementation and effect of person-centred active support in the Avenues Trust. *Tizard Learning Disability Review*, *13*(4), 15–24. https://doi.org/10.1108/13595474200800034

Beadle-Brown, J., Hutchinson, A., & Whelton, B. (2012). Person-centred active support - increasing choice, promoting independence and reducing challenging behaviour. *Journal of Applied Research in Intellectual Disabilities*, *25*(4), 291–307. https://doi.org/10.1111/j.1468-3148.2011.00666.x

Beadle-Brown, J., Leigh, J., Whelton, B., Richardson, L., Beecham, J., Baumker, T., & Bradshaw, J. (2015). Quality of Life and Quality of Support for People with Severe Intellectual Disability and Complex Needs. *Journal of Applied Research in Intellectual Disabilities*, *29*(5), 409–421. https://doi.org/10.1111/jar.12200

Becker, R. (2020). *Meeting the Aspirations of Learning Disability Policy: The Role of the Support Worker* [Doctoral dissertation, University of Cambridge]. Apollo - University of Cambridge Repository. https://doi.org/10.17863/CAM.54728

Beres, M. A., & Farvid, P. (2010). Sexual Ethics and Young Women's Accounts of Heterosexual Casual Sex. *Sexualities*, *13*(3), 377-393. https://doi.org/10.1177/1363460709363136

Bigby, C., Bould, E., & Beadle-Brown, J. (2017). Conundrums of supported living: The experiences of people with intellectual disability. *Journal of Intellectual & Developmental Disability*, *42*(4), 309–319. https://doi.org/10.3109/13668250.2016.1253051

Bigby, C., & Beadle-Brown, J. (2016). Culture in better group homes for people with intellectual disability at severe levels. *Intellectual and Developmental Disabilities*, *54*(5), 316–331. https://doi.org/10.1352/1934-9556-54.5.316

Bigby, C., & Craig, D. (2016). A case study of an intentional friendship between a volunteer and adult with severe intellectual disability: "My life is a lot richer!" *Journal of Intellectual & Developmental Disability*, *42*(2), 180–189. https://doi.org/10.3109/13668250.2016.1219701

Bigby, C., Knox, M., Beadle-Brown, J., & Clement, T. (2015). 'We Just Call Them People': Positive Regard as a Dimension of Culture in Group Homes for People with Severe Intellectual Disability. *Journal of Applied Research in Intellectual Disabilities*, *28*(4), 283–295. https://doi.org/10.1111/jar.12128

Bigby, C., Knox, M., Beadle-Brown, J., & Bould, E. (2014). Identifying Good Group Homes: Qualitative Indicators Using a Quality of Life Framework. *Intellectual and Developmental Disabilities*, *52*(5), 348–366. https://doi.org/10.1352/1934-9556-52.5.348

Bondi, L. (2003). Empathy and identification: Conceptual resources for feminist fieldwork. *ACME: An International Journal for Critical Geographies*, *2*(1), 64–76. https://doi.org/10.14288/acme.v2i1.708

Bowler, M., & Nash, P. (2014). Professional boundaries in learning disability care. *Nursing Times*, *110*(21), 12–15.

Bradshaw, J. (1998). Assessing and intervening in the communication environment. *British Journal of Learning Disabilities*, *26*(2), 62–66. https://doi.org/10.1111/j.1468-3156.1998.tb00050.x

Bradshaw, J., & Goldbart, J. (2013). Staff Views of the Importance of Relationships for Knowledge Development: Is Training by Specialists a Waste of Money? *Journal of Applied Research in Intellectual Disabilities*, *26*(4), 284–298. https://doi.org/10.1111/jar.12020

Braun, V., & Clarke, V. (2022). Thematic Analysis: A Practical Guide. Sage.

Braun, V., & Clarke, V. (2021). To saturate or not to saturate? Questioning data saturation as a useful concept for thematic analysis and sample-size rationales. *Qualitative Research in Sport, Exercise and Health*, *13*(2), 201–216. https://doi.org/10.1080/2159676x.2019.1704846

Braun, V., & Clarke, V. (2020). Can I use TA? Should I use TA? Should I not use TA? Comparing reflexive thematic analysis and other pattern-based qualitative analytic approaches. *Counselling and Psychotherapy Research*, *21*(1), 37–47. https://doi.org/10.1002/capr.12360

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

Brown-Wilson, C., & Davies, S. (2009). Developing relationships in long term care environments: The contribution of staff. *Journal of Clinical Nursing*, *18*(12), 1746–1755. https://doi.org/10.1111/j.1365-2702.2008.02748.x

Bronfenbrenner, U. (1994). Ecological models of human development. In *International Encyclopedia of Education* (2nd ed., Volume 3). Oxford: Elsevier.

Broussine, E. (2012). Building Positive Relationships with People with Learning Disabilities. In E. Broussine & K. Scarborough (Eds.), *Supporting People with Learning Disabilities in Health & Social Care* (1st ed., pp. 99–115). SAGE Publications Ltd. https://doi.org/10.4135/9781446288191

Buell, S., Pounds, G., Langdon, P., & Bunning, K. (2024). Easy read health information for people with intellectual disabilities: A linguistic discourse analysis. What happens to language when it is simplified? *Journal of Applied Research in Intellectual Disabilities*, *37*(6). https://doi.org/10.1111/jar.13293

Burn, E., & Needham, C. (2023). *What does the concept of an ecosystem offer to social care? A narrative review of the ecosystem literature*. Retrieved December 21, 2024, from https://centreforcare.ac.uk/wp-content/uploads/2023/06/Ecosystems-Narrative-Review_FINAL.pdf

Callaghan, L., Brookes, N., & Palmer, S. (2017). Older people receiving family-based support in the community: a survey of quality of life among users of 'Shared Lives' in England.

Health & Social Care in the Community, *25*(5), 1655–1666. https://doi.org/10.1111/hsc.12422

Cambridge Dictionary (n.d.). *The United Kingdom*. Retrieved January 20, 2022, from https://dictionary.cambridge.org/dictionary/english/united-kingdom?q=United+Kingdom

Cavallerio, F., Wadey, R., & Wagstaff, C. R. (2016). Understanding overuse injuries in rhythmic gymnastics: A 12-month ethnographic study. *Psychology of Sport and Exercise*, *25*, 100–109. https://doi.org/10.1016/j.psychsport.2016.05.002

Cavendish, C. (2013). *The Cavendish Review: An Independent Review into Healthcare Assistants and Support Workers in the NHS and social care settings*. Retrieved January 20, 2022, from https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/236212/Cavendish_Review.pdf

Centre for Reviews and Dissemination. (2009). *Systematic Reviews. CRD's guidance for undertaking reviews in health care*. Retrieved April 1, 2021, from https://www.york.ac.uk/media/crd/Systematic_Reviews.pdf

Chinn, D., Levitan, T., Power, A., Brickley, K., & Ali, S. (2024). What does 'feeling at home' mean for adults with intellectual disabilities living in group homes in England? *Journal of Applied Research in Intellectual Disabilities*, *37*(5). https://doi.org/10.1111/jar.13274

Cohen, J. (1960). A coefficient of agreement for nominal scales. *Educational and psychological measurement*, *20*(1), 37-46. https://doi.org/10.1177/001316446002000104

Collins, J., & Murphy, G. H. (2021). Detection and prevention of abuse of adults with intellectual and other developmental disabilities in residential services: A systematic

review. *Journal of Applied Research in Intellectual Disabilities*, *34*(6), 1592-1604. https://doi.org/10.1111/jar.12954

Cooke, A., Smith, D., & Booth, A. (2012). Beyond PICO: the SPIDER tool for qualitative evidence synthesis. *Qualitative Health Research*, *22*(10), 1435-1443. https://doi.org/10.1177/1049732312452938

Corrigan, P., Markowitz, F. E., Watson, A., Rowan, D., & Kubiak, M. A. (2003). An attribution model of public discrimination towards persons with mental illness. *Journal of Health and Social Behavior*, *44*(2), 162-179. https://doi.org/10.2307/1519806

Corbin, J. (2017). Grounded theory. *The Journal of Positive Psychology*, *12*(3), 301-302. https://doi.org/10.1080/17439760.2016.1262614

Cumpston, M., Flemyng, E., Thomas, J., Higgins, JPT., Deeks, JJ., & Clarke, MJ. (2023). Chapter I: Introduction. In Higgins, JPT., Thomas, J., Chandler, J., Cumpston, M., Li, T., Page, MJ., & Welch, VA. (Eds.), *Cochrane Handbook for Systematic Reviews of Interventions* (Version 6.4, Part 1: About Cochrane Reviews, Introduction, key points). Retrieved May 10, 2024, from https://training.cochrane.org/handbook/current/chapter-i

Dagnan, D., & Cairns, M. (2005). Staff judgements of responsibility for the challenging behaviour of adults with intellectual disabilities. *Journal of Intellectual Disability Research*, *49*, 95–101. https://doi.org/10.1111/j.1365-2788.2005.00665.x

Daly, M., & Fisher, U. D. (2023). *The job and work orientations of workers in English care homes*. Retrieved December 19, 2024, from https://www.spi.ox.ac.uk/sitefiles/working-paper-mary-daly-and-duncan-fisher.pdf

De Casterlé, B. D., Verhaeghe, S. T., Kars, M. C., Coolbrandt, A., Stevens, M., Stubbe, M., Deweirdt, N., Vincke, J., & Grypdonck, M. (2011). Researching lived experience in health care: Significance for care ethics. *Nursing Ethics*, *18*(2), 232–242. https://doi.org/10.1177/0969733010389253

Deleuze, G., & Guattari, F. (1987). *A thousand plateaus: Capitalism and schizophrenia*. Minneapolis, MN: University of Minnesota Press.

Department of Health and Social Care. (2012). *Transforming Care: A national Response to Winterbourne View Hospital: Review Final Report*. Retrieved September 11, 2025, from https://assets.publishing.service.gov.uk/media/5a7b91f7ed915d13110601c3/final-report.pdf

Department of Health and Social Care. (2001). *Valuing People: A New Strategy for Learning Disability for the 21st Century*. Retrieved October 17, 2024, from https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/250877/5086.pdf

Devaney, D. J., Nesti, M. S., Ronkainen, N. J., Littlewood, M., & Richardson, D. (2017). Athlete lifestyle support of elite youth cricketers: an ethnography of player concerns within a national talent development program. *Journal of Applied Sport Psychology*, *30*(3), 300–320. https://doi.org/10.1080/10413200.2017.1386247

DeWalt, K., & DeWalt, B. (2011). *Participant observation: A guide for fieldworkers*. (2nd ed.). AltaMira Press.

Dewing, J., & McCormack, B. (2017). Editorial: Tell me, how do you define person-centredness? *Journal of Clinical Nursing*, *26*, 2509–2510. https://doi.org/10.1111/jocn.13681

Eatough, V., & Smith, J.A. (2017). Interpretative phenomenological analysis. In Willig, C., & Stainton-Rogers, W. (Eds.), *Handbook of Qualitative Psychology 2nd Edition* (pp. 193-211). London, UK: Sage, ISBN 9781473925212

Ferguson, P. M., & Nusbaum, E. (2012). Disability studies: What is it and what difference does it make? *Research and Practice for Persons with Severe Disabilities*, *37*(2), 70-80. https://doi.org/10.1177/154079691203700202

Finlay, W. M. L., Antaki, C., & Walton, C. (2008). A manifesto for the use of video in service improvement and staff development in residential services for people with learning disabilities. *British Journal of Learning Disabilities*, *36*(4), 227–231. https://doi.org/10.1111/j.1468-3156.2008.00511.x

Firth, G., Elford, H., Leeming, C., & Crabbe, M. (2008). Intensive interaction as a novel approach in social care: care staff's views on the practice change process. *Journal of Applied Research in Intellectual Disabilities*, *21*(1), 58–69. https://doi.org/10.1111/j.1468-3148.2007.00369.x

Fisher, D. (2021). Emotional labour and the realities of paid care work. *Proceedings of the Transforming Care Conference*. Online. Unpublished manuscript.

Fisher, B., & Tronto, J. (1990). Towards a Feminist Theory of Care. In Abel, E & Nelson, M (Eds.), *Circles of Care: Work and identity in women's lives* (pp. 35 – 63). State University of New York Press

Fish, R., & Morgan, H. (2021). “Them two are around when I need their help” The importance of good relationships in supporting people with learning disabilities to be “in a good space.” *British Journal of Learning Disabilities*, *49*(3), 293–302. https://doi.org/10.1111/bld.12410

Forrester-Jones, R., Beecham, J., Randall, A., Harrison, R., Malli, M., Sams, L., & Murphy, G. (2021). The Impact of Austerity Measures on People with Intellectual Disabilities in England. *Journal of Long-Term Care*, 241–255. https://doi.org/10.31389/jltc.59

Foster, D., & Harker, R. (2024). Funding for adult social care in England. *House of Commons Library*. Retrieved October 17, 2024, from https://commonslibrary.parliament.uk/research-briefings/cbp-7903/

Gates, B., & Mafuba, K. (2016). Use of the Term ‘Learning Disabilities’ in the United Kingdom: Issues for International Researchers and Practitioners. *Learning Disabilities: A Contemporary Journal*, *14*(1), 9–23.

Gernsbacher, M. A. (2017). Editorial Perspective: The use of person-first language in scholarly writing may accentuate stigma. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, *58*(7), 859–861. https://doi.org/10.1111/jcpp.12706

Giesbers, S. A. H., Hendriks, L., Jahoda, A., Hastings, R. P., & Embregts, P. J. C. M. (2019). Living with support: Experiences of people with mild intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, *32*(2), 446–456. https://doi.org/10.1111/jar.12542

Gillett, E., & Stenfert-Kroese, B. (2003). Investigating organizational culture: A comparison of a ’high’- and a ’low’-performing residential unit for people with intellectual disabilities.

Journal of Applied Research in Intellectual Disabilities, *16*(4), 279–284. https://doi.org/10.1046/j.1468-3148.2003.00170.x

Gjermestad, A., Luteberget, L., Midjo, T., & Witsø, A. E. (2017). Everyday life of persons with intellectual disability living in residential settings : a systematic review of qualitative studies. *Disability & Society*, *32*(2), 213–232. https://doi.org/10.1080/09687599.2017.1284649

Glaser, B., & Strauss, A. (1999). *The discovery of grounded theory: Strategies for qualitative research*. New York: Aldine de Gruyter.

Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. Englewood Cliffs, NJ: Prentice-Hall.

Goodley, D., & Runswick-Cole, K. (2016). Becoming dishuman: thinking about the human through dis/ability. *Discourse*, *37*(1), 1–15. https://doi.org/10.1080/01596306.2014.930021

Graeber, D. (2013). On the phenomenon of bullshit jobs: A work rant. *Strike Magazine*, *3*(1), 1–4.

Grove, N., & Mcintosh, B. (2005). *Communication for person-centred planning*. Retrieved July 20, 2021, from https://www.mentalhealth.org.uk/sites/default/files/communication_p_c_planning.pdf

Günel, G., Varma, S., & Watanabe, C. (2020). A manifesto for patchwork ethnography. *Member Voices*, *Fieldsights*, *9*.

Guthrie, K. S., & Beadle-Brown, J. (2006). Defining and measuring rapport: implications for supporting people with complex needs. *Tizard Learning Disability Review*, *11*(3), 21–30. https://doi.org/10.1108/13595474200600024

Halladay, P. M., & Harrington, C. (2015). Scandals of abuse: Policy responses in intellectual disabilities. *International journal of sociology and social policy*, *35*(1/2), 107-124. https://doi.org/10.1108/IJSSP-12-2013-0117

Hastings, R. P., Gillespie, D., Flynn, S., McNamara, R., Taylor, Z., Knight, R., Randell, E., Richards, L., Moody, G., Mitchell, A., Przybylak, P., Williams, B., & Hunt, P. H. (2018). Who's challenging who training for staff empathy towards adults with challenging behaviour: cluster randomised controlled trial. *Journal of Intellectual Disability Research*, *62*(9), 798–813. https://doi.org/10.1111/jir.12536

Hastings, R. P. (2010). Support staff working in intellectual disability services: the importance of relationships and positive experiences. *Journal of Intellectual and Developmental Disability*, *35*(3), 207–210.

Hastings, R., & Horne, S. (2004). Positive perceptions held by support staff in community mental retardation services. *American Journal on Mental Retardation*, *109*(1), 53-62. https://doi.org/10.1352/0895-8017(2004)109

Harrison, R. A., Bradshaw, J., Forrester-Jones, R., McCarthy, M., & Smith, S. (2021). Social networks and people with intellectual disabilities: a systematic review. *Journal of Applied Research in Intellectual Disabilities*, *34*(4), 1–20. https://doi.org/10.1111/jar.12878

Haydon-Laurelut, M., & Nunkoosing, K. (2010). 'I want to be listened to': systemic psychotherapy with a man with intellectual disabilities and his paid supporters. *Journal of Family Therapy*, *32*(1), 73–86. https://doi.org/10.1111/j.1467-6427.2009.00485.x

Hayfield, N., Terry, G., Clarke, V., & Ellis, S. (2019). "Never Say Never?" Heterosexual, Bisexual, and Lesbian Women's Accounts of Being Childfree. *Psychology of Women Quarterly*, *43*(4), 526–538. https://doi.org/10.1177/0361684319863414

Health Research Authority. (2024). *Payments and Incentives in Research.* Retrieved November 25, 2024, from https://www.hra.nhs.uk/about-us/committees-and-services/nreap/payments-and-incentives-research/

Health and Social Care Northern Ireland. (2016). *Making Communication Accessible for All. A Guide for Health and Social Care (HSC) Staff.* Retrieved July 20, 2021, from http://www.inclusionireland.ie/sites/default/files/attach/event-notice/1527/making-communication-accessible-all.pdf

Held, V. (2006). *The ethics of care. Personal, Political, and Global*. Oxford University Press. https://doi.org/10.1093/oxfordhb/9780199645121.013.12

Hong, Q. N., Fàbregues, S., Bartlett, G., Boardman, F., Cargo, M., Dagenais, P., ... & Pluye, P. (2018). The Mixed Methods Appraisal Tool (MMAT) version 2018 for information professionals and researchers. *Education for information*, *34*(4), 285-291. doi: 10.3233/efi-180221

Hume, L., Khan, N., & Reilly, M. (2021). Building capable environments using practice leadership. *Tizard Learning Disability Review*, *26*(1), 1–8. https://doi.org/10.1108/TLDR-07-2020-0017

Hussein, S. (2018). The English social care workforce: the vexed question of low wages and stress. In Christensen, K., & Pilling, D., *The Routledge handbook of social care work around the world* (pp. 74-87). Routledge. https://doi.org/10.4324/9781315612805

Irani, E. (2019). The use of videoconferencing for qualitative interviewing: Opportunities, challenges, and considerations. *Clinical nursing research*, *28*(1), 3-8. https://doi.org/10.1177/1054773818803170

Jafar, A. J. (2018). What is positionality and should it be expressed in quantitative studies? *Emergency Medicine Journal*, *35*(5), 323-324. https://doi.org/10.1136/emermed-2017-207158

Jingree, T., Finlay, W. M. L., & Antaki, C. (2006). Empowering words, disempowering actions: An analysis of interactions between staff members and people with learning disabilities in residents' meetings. *Journal of Intellectual Disability Research*, *50*(3), 212–226. https://doi.org/10.1111/j.1365-2788.2005.00771.x

Jones, E., Felce, D., Lowe, K., Bowley, C., Pagler, J., Gallagher, B., & Roper, A. (2001a). Evaluation of the dissemination of active support training in staffed community residences. *American Journal of Mental Retardation*, *106*(4), 344–358. https://doi.org/10.1352/0895-8017(2001)106<0344:EOTDOA>2.0.CO;2

Jones, E., Felce, D., Lowe, K., Bowley, C., Pagler, J., Strong, G., Gallagher, B., Roper, A., & Kurowska, K. (2001b). Evaluation of the dissemination of active support training and training trainers. *Journal of Applied Research in Intellectual Disabilities*, *14*(2), 79–99.

Jones, E., Perry, J., Lowe, K., Felce, D., Toogood, S., Dunstan, F., Allen, D., & Pagler, J., (1999). Opportunity and the promotion of activity among adults with severe intellectual

disability living in community residences: The impact of training staff in active support. *Journal of Intellectual Disability Research*, *43*(3), 164–178. https://doi.org/10.1046/j.1365-2788.1999.00177.x

Johnstone, B., & Andrus, J. (2024). *Discourse analysis*. John Wiley & Sons.

Johnson, H., Douglas, J., Bigby, C., & Iacono, T. (2012). A model of processes that underpin positive relationships for adults with severe intellectual disability. *Journal of Intellectual & Developmental Disability,* *37*(4), 324–336. https://doi.org/10.3109/13668250.2012.732221

Johnson, H., Douglas, J., Bigby, C., & Iacono, T. (2011). The challenges and benefits of using participant observation to understand the social interaction of adults with intellectual disabilities. *Augmentative and Alternative Communication*, *27*(4), 267–278. https://doi.org/10.3109/07434618.2011.587831

Keates, N., Martin, F., & Waldock, K. E. (2024). Autistic people's perspectives on functioning labels and associated reasons, and community connectedness. *Journal of Autism and Developmental Disorders*, 1-11. https://doi.org/10.1007/s10803-024-06316-3

Kennedy, L., & Brewer, G. (2014). Creative methodologies to enhance communication. *British Journal of Learning Disabilities*, *44*(1), 35–42. https://doi.org/10.1111/bld.12107

Knoblauch, H. (2005). Focused Ethnography. *Forum Qualitative Sozialforschung Forum: Qualitative Social Research*, *6*(3). https://doi.org/10.17169/fqs-6.3.20

Landis, J. R., & Koch, G. G. (1977). The measurement of observer agreement for categorical data. *Biometrics*, *33*(1), 159-174. https://doi.org/10.2307/2529310

Levinson, J. (2005). The group home workplace and the work of know-how. *Human Studies*, *28*(1), 57–85. https://doi.org/10.1007/s10746-005-3597-4

Liebowitz, C. (2015). *I am Disabled: On Identity-First Versus People-First Language*. Retrieved October 18, 2024, from https://dfwhcfoundation.org/wp-content/uploads/2018/10/I-am-Disabled.-On-Identity-First-Versus-People-First-Language-TBISNAA.pdf

Link, B. G., & Phelan, J. C. (2001). Conceptualizing stigma. *Annual Review of Sociology*, *27*, 363-385. https://doi.org/10.1146/annurev.soc.27.1.363

Malterud, K., Siersma, V. D., & Guassora, A. D. (2015). Sample size in qualitative interview studies: Guided by information power. *Qualitative Health Research*, *26*(13), 1753–1760. https://doi.org/10.1177/1049732315617444

Mamolis, G. (2022). From the frontline to research. *The GradPost*, *Spring issue*, 16-17.

Mamolis, G., Triantafyllopoulou, P., & Jones, K. (2024). Care Relationships Between Support Staff and Adults With a Learning Disability in Long-Term Social Care Residential Settings in the United Kingdom: A Systematic Literature Review. *Journal of Long-Term Care*, 187 – 209. https://doi.org/10.31389/jltc.189

Mansell, J., & Beadle-Brown, J. (2012). *Active support: Enabling and empowering people with intellectual disabilities*. London: Jessica Kingsley Publishers.

Mansell, J., Knapp, M., Beadle-Brown, J., & Beecham, J. (2007). *Deinstitutionalisation and community living–outcomes and costs: report of a European Study - Volume 2, main report*. Retrieved December 17, 2024, from

https://eprints.lse.ac.uk/3460/1/Deinstitutionalisation_and_community_living_%E2%80%93_outcomes_and_costs_vol_2(lsero).pdf

Mansell, J., Elliott, T., Beadle-Brown, J., Ashman, B., & Macdonald, S. (2002). Engagement in meaningful activity and "active support" of people with intellectual disabilities in residential care. *Research in Developmental Disabilities*, *23*(5), 342–352. https://doi.org/10.1016/S0891-4222(02)00135-X

Manthorpe, J., Martineau, S., Moriarty, J., & Hussein, S. (2010). Support workers in social care in England: a scoping study. *Health and Social Care in the Community*, *18*(3), 316–324. https://doi.org/10.1111/j.1365-2524.2010.00910.x

Marx, K. (1859). *Preface to a Contribution to the Critique of Political Economy*. Retrieved December 21, 2024, from https://www.marxists.org/archive/marx/works/1859/critique-pol-economy/preface.htm

McArthur, A., Klugarova, J., Yan, H., & Florescu, S. (2015). Innovations in the systematic review of text and opinion. *International Journal of Evidence-based Healthcare*, *13*(3), 188–195.

McCormack, B., & McCance, T. (Eds.). (2016). *Person-centred practice in nursing and health care: theory and practice*. John Wiley & Sons.

McCormack, B., Roberts, T., Meyer, J., Morgan, D., & Boscart, V. (2012). Appreciating the 'person' in long-term care. *International Journal of Older People Nursing*, *7*(4), 284-294. https://doi.org/10.1111/j.1748-3743.2012.00342.x

McGill, P., Vanono, L., Clover, W., Smyth, E., Cooper, V., Hopkins, L., Barratt, N., Joyce, C., Henderson, K., Sekasi, S., Davis, S., & Deveau, R. (2018). Reducing challenging

behaviour of adults with intellectual disabilities in supported accommodation: a cluster randomized controlled trial of setting-wide positive behaviour support. *Research in Developmental Disabilities*, *81*, 143–154. https://doi.org/10.1016/j.ridd.2018.04.020

McGrath, C., Palmgren, P. J., & Liljedahl, M. (2018). Twelve tips for conducting qualitative research interviews. *Medical Teacher*, *41*(9), 1002–1006. https://doi.org/10.1080/0142159X.2018.1497149

Mencap. (n.d.*a*). *How common is learning disability*? Retrieved October 17, 2024, from https://www.mencap.org.uk/learning-disability-explained/research-and-statistics/how-common-learning-disability

Mencap. (n.d.*b*). *What is a learning disability*? Retrieved October 17, 2024, from https://www.mencap.org.uk/learning-disability-explained/what-learning-disability

Nagra, M. K., White, R., Appiah, A., & Rayner, K. (2017). Intensive Interaction Training for Paid Carers: 'Looking, Looking and Find Out When They Want to Relate to You'. *Journal of Applied Research in Intellectual Disabilities*, *30*(4), 648–660. doi: 10.1111/jar.12259

National Health Service England. (n.d.). *Making information and the words we use accessible*. Retrieved December 10, 2024, from https://www.england.nhs.uk/learning-disabilities/about/get-involved/involving-people/making-information-and-the-words-we-use-accessible/

National Institute for Health and Care Excellence. (2015). *Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges.* Retrieved December 19, 2024, from http://edr-

behaviour.co.uk/wp-content/uploads/2020/03/challenging-behaviour-and-learning-disabilities-prevention-and-interventions-for-people-with-learning-disabilities-whose behaviour-challenges-1837266392005.pdf#:~:text=It%20is%20relatively%20common%20for%20people%20with%20a,care%20services%20for%20people%20with%20a%20learning%20disability

National Institute for Health and Care Research. (2022). *Payment guidance for members of the public considering involvement in research.* Retrieved November 25, 2024, from https://www.nihr.ac.uk/payment-guidance-members-public-considering-involvement-research

National Institute for Health and Care Research, School for Social Care. (2020). *A cluster randomised controlled trial to test Who's Challenging Who*. Retrieved July 20, 2021, from https://www.sscr.nihr.ac.uk/wp-content/uploads/RF64.pdf

National Association of Care and Support Workers. (n.d.). *About NACAS*. Retrieved October 25, 2024, from https://nacas.org.uk/about-nacas

Norah Fry Research Centre. (2010). *"It's about respect": people with learning difficulties and personal assistants*. Retrieved July 20, 2021, from http://www.bristol.ac.uk/norahfry/research/completed-projects/itsaboutrespect.pdf

Oliver, D. G., Serovich, J. M., & Mason, T. L. (2005). Constraints and Opportunities with Interview Transcription: Towards Reflection in Qualitative Research. *Social Forces*, *84*(2), 1273–1289. https://doi.org/10.1353/sof.2006.0023

Ouzzani, M., Hammady, H., Fedorowicz, Z., & Elmagarmid, A. (2016). Rayyan—a web and mobile app for systematic reviews. *Systematic reviews*, *5*(1), 1-10. https://doi.org/10.1186/s13643-016-0384-4

Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D., Shamseer, L., Tetzlaff, J. M., Akl, E. A., Brennan, S. E., Chou, R., Glanville, J., Grimshaw, J. M., Hróbjartsson, A., Lalu, M. M., Li, T., Loder, E. W., Mayo-Wilson, E., McDonald, S., … Moher, D. (2021). The PRISMA 2020 statement: An updated guideline for reporting systematic reviews. *The BMJ*, *372*(71). https://doi.org/10.1136/bmj.n71

PBS Academy. (2015). *Positive Behavioural Support - A Competence Framework*. Retrieved December 19, 2024, from http://pbsacademy.org.uk/wp-content/uploads/2016/11/Positive-Behavioural-Support-Competence-Framework-May-2015.pdf

Penninga, W., Nijs, S. L. P., van Bakel, H. J. A., & Embregts, P. J. C. M. (2022). Meaningful moments of interaction with people with profound intellectual disabilities: Reflections from direct support staff. *Journal of Applied Research in Intellectual Disabilities*, 1–10. https://doi.org/10.1111/jar.13019

Peplau, H. (1952). *Interpersonal relations in nursing: A conceptual frame of reference for psychodynamic nursing*. G. P. Putnam's Sons, New York.

Phillips, N., & Rose, J. (2010). Predicting placement breakdown: individual and environmental factors associated with the success or failure of community residential placements for adults with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, *23*(3), 201–213. https://doi.org/10.1111/j.1468-3148.2009.00530.x

Pink, S. (2012). *Situating Everyday Life: Practices and Places*. London: Sage.

Pockney, R. (2006). Friendship or facilitation: People with learning disabilities and their paid carers. *Sociological Research Online*, *11*(3), 1–9. https://doi.org/10.5153/sro.1382

Polacsek, M., Boardman, G., & Mccann, T.V. (2017) Paying patient and caregiver research participants: putting theory into practice. *Journal of Advanced Nursing*, *73*(4), 847–856. doi: 10.1111/jan.13222

Popay, J., Roberts, H., Sowden, A., Petticrew, M., Arai, L., Rodgers, M., Britten, N., Roen, K., & Duffy, S. (2006). *Guidance on the Conduct of Narrative Synthesis in Systematic Reviews.* Retrieved July 20, 2021, from https://www.lancaster.ac.uk/media/lancaster-university/content-assets/documents/fhm/dhr/chir/NSsynthesisguidanceVersion1-April2006.pdf?msclkid=ca623d07d06311ecb4d991d9c4ba8ea4

Probst, B., & Berenson, L. (2014). The double arrow: How qualitative social work researchers use reflexivity. *Qualitative Social Work*, *13*(6), 813–827. https://doi.org/10.1177/1473325013506248

Quilliam, C., Bigby, C., & Douglas, J. (2017). Staff perspectives on paperwork in group homes for people with intellectual disability. *Journal of Intellectual & Developmental Disability*, *43*(3), 264–273. https://doi.org/10.3109/13668250.2017.1378315

Randell, M., & Cumella, S. (2009). People with an intellectual disability living in an intentional community. *Journal of Intellectual Disability Research*, *53*(8), 716–726. doi: 10.1111/j.1365-2788.2009.01181.x

Rashid, M., Hodgson, C. S., & Luig, T. (2019). Ten tips for conducting focused ethnography in medical education research. *Medical Education Online*, *24*(1). https://doi.org/10.1080/10872981.2019.1624133

Reis, H. T., Collins, W. A., & Berscheid, E. (2000). The relationship context of human behavior and development. *Psychological Bulletin*, *126*(6), 844–872.

Riviere, M., Dufoort, H., Van Hecke, A., Vandecasteele, T., Beeckman, D., & Verhaeghe, S. (2019). Core elements of the interpersonal care relationship between nurses and older patients without cognitive impairment during their stay at the hospital: A mixed-methods systematic review. *International Journal of Nursing Studies*, *92*, 154–172. https://doi.org/10.1016/j.ijnurstu.2019.02.004

Rogers, C. (2016). *Intellectual Disability and Being Human: A Care Ethics Model.* (1st ed.). London, UK: Routledge. https://doi.org/https://doi.org/10.4324/9781315638713

Rogers, C. R. (1957). The necessary and sufficient conditions of therapeutic personality change. *Journal of Consulting Psychology*, *21*(2), 95–103. https://doi.org/10.1037/h0045357

Rose, D., & Rose, J. (2005). Staff in services for people with intellectual disabilities: the impact of stress on attributions of challenging behaviour. *Journal of Intellectual Disability Research*, *49*, 827–838. https://doi.org/10.1111/j.1365-2788.2005.00758.x

Rose, J., Jones, F., & Fletcher, B. (1998). Investigating the relationship between stress and worker behaviour. *Journal of Intellectual Disability Research*, *42*, 163–172. https://doi.org/10.1046/j.1365-2788.1998.00115.x

Rubery, J., Grimshaw, D., Hebson, G., & Ugarte, S. M. (2015). “It's all about time”: time as contested terrain in the management and experience of domiciliary care work in England. *Human Resource Management*, *54*(5), 753-772. https://doi.org/10.1002/hrm.21685

Rycroft-Malone, J., Burton, C., Hall, B., McCormack, B., Nutley, S., & Seddon, D., & Williams, L. (2014). Improving skills and care standards in the support workforce for older people : a realist review. *BMJ Open*, *4*(5). https://doi.org/10.1136/bmjopen-2014-005356

Saks, M. (2020a). Introduction: Support Workers and the Health Professions. In Saks, M. (Ed.), *Support Workers and the Health Professions in International Perspective. The Invisible Providers of Health Care* (pp. 1–11). Policy Press. https://doi.org/10.1332/policypress/9781447352105.001.0001

Saks, M. (Ed.). (2020b). *Support Workers and the Health Professions in International Perspective: The Invisible Providers of Health Care*. Policy Press.

Samuel, J., Nind, M., Volans, A., & Maudsley, S. I. (2008). An evaluation of Intensive Interaction in community living settings for adults with profound intellectual disabilities. *Journal of Intellectual Disabilities*, *12*(2), 111–126. doi: 10.1177/1744629508090983

Sandhu, B. (2017). *The Value of Lived Experience in Social Change: The Need for Leadership and Organisational Development in the Social Sector*. Retrieved November 1, 2024, from https://www.knowledgeequity.org/wp-content/uploads/2021/06/The-Value-of-Lived-Experience-in-Social-Change.pdf

Saunders, M. N., & Townsend, K. (2016). Reporting and justifying the number of interview participants in organization and workplace research. *British Journal of Management*, *27*(4), 836-852. https://doi.org/10.1111/1467-8551.12182

Schalock, R. L., Brown, I., Brown, R., Cummins, R. A., Felce, D., Matikka, L., Keith, K. D., & Parmenter, T. (2002). Conceptualization, Measurement, and Application of Quality of

Life for Persons With Intellectual Disabilities: Report of an International Panel of Experts. *Mental Retardation*, *40*(6), 457–470.

Scheffelaar, A., Hendriks, M., Bos, N. Luijkx, K., & Van Dulmen, S. (2019). Determinants of the quality of care relationships in long-term care - a participatory study. *BMC Health Services Research*, *19*, 1–14. https://doi.org/10.1186/s12913-019-4195-x

Scior, K., Hamid, A., Hastings, R., Werner, S., Belton, C., Laniyan, A., Patel, M., & Kett, M. (2020). Intellectual disability stigma and initiatives to challenge it and promote inclusion around the globe. *Journal of Policy and Practice in Intellectual Disabilities*, *17*(2), 165–175. https://doi.org/10.1111/jppi.12330

Skills for Care. (2018). *The adult social care workforce supporting people with learning disabilities and /or autism*. Retrieved January 20, 2022, from https://www.skillsforcare.org.uk/resources/documents/Developing-your-workforce/Care-topics/Learning-disability/The-workforce-supporting-people-with-learning-disabilities-andor-autism.pdf

Skills for Care. (2021). *The state of the adult social care sector and workforce in England*. Retrieved January 20, 2022, from https://careengland.org.uk/wp-content/uploads/2020/11/The-state-of-the-adult-social-care-sector-and-workforce-2020.pdf

Smith, C., Felce, D., Jones, E., & Lowe, K. (2002). Responsiveness to staff support: evaluating the impact of individual characteristics on the effectiveness of active support training using a conditional probability approach. *Journal of Intellectual Disability Research*, *46*(8), 594–604. https://doi.org/10.1046/j.1365-2788.2002.00433.x

Stahlke Wall, S. (2015). Focused Ethnography: A methodological adaptation for social research in emerging contexts. *Forum Qualitative Sozialforschung Forum: Qualitative Social Research*, *16*(1).

Strandås, M., Wackerhausen, S., & Bondas, T. (2019). The nurse–patient relationship in the New Public Management era, in public home care: A focused ethnography. *Journal of advanced nursing*, *75*(2), 400-411. https://doi.org/10.1111/jan.13850

Sundberg, T., & Taylor-Gooby, P. (2013). A systematic review of comparative studies of attitudes to social policy. *Social Policy & Administration*, *47*(4), 416–433. https://doi.org/10.1111/spol.12027

Thomas, C., & Rose, J. (2009). The relationship between reciprocity and the emotional and behavioural responses of staff. *Journal of Applied Research in Intellectual Disabilities*, *23*(2), 167–178. https://doi.org/10.1111/j.1468-3148.2009.00524.x

Thurman, S., Jones, J., & Tarleton, B. (2005). Without words – meaningful information for people with high individual communication needs. *British Journal of Learning Disabilities*, *33*(2), 83–89. https://doi.org/10.1111/j.1468-3156.2005.00342.x

Totsika, V., Toogood, S., Hastings, R. P., & Nash, S. (2008). Interactive training for active support: Perspectives from staff. *Journal of Intellectual & Developmental Disability*, *33*(3), 225–238. https://doi.org/10.1080/13668250802283348

Toogood, S., Drury, G., Gilsenan, K., Parry, D., Roberts, K., & Sherriff, S. (2009). Establishing a context to reduce challenging behaviour using procedures from active support: a clinical case example. *Tizard Learning Disability Review*, *14*(4), 29–36. https://doi.org/10.1108/13595474200900036

Tronto, J. C. (1998). An ethic of care. *Generations: Journal of the American society on Aging*, *22*(3), 15-20.

Trundle, C., & Phillips, T. (2023). Defining focused ethnography: Disciplinary boundary-work and the imagined divisions between 'focused' and 'traditional' ethnography in health research – A critical review. *Social Science & Medicine*, *332*. https://doi.org/10.1016/j.socscimed.2023.116108

Tyndall, J. (2010). *AACODS checklist*. Retrieved July 20, 2021, from https://fac.flinders.edu.au/dspace/api/core/bitstreams/e94a96eb-0334-4300-8880-c836d4d9a676/content

Waggett, N. (2012). Ghosts in the care home: the nature of relationships in a home for people with learning disabilities. *Journal of Social Work Practice: Psychotherapeutic Approaches in Health*, *26*(4), 443–457. https://doi.org/10.1080/02650533.2012.678819

Walton, C., Antaki, C., & Finlay, W. M. L. (2020). Orienting to affect in services for people with severe or profound intellectual disabilities: A UK-based investigation. *Journal of Applied Research in Intellectual Disabilities*, *33*(5), 876–886. https://doi.org/10.1111/jar.12707

Wehmeyer, M., Bersani, H., & Gagne, R. (2000). Riding the Third Wave: Self-Determination and Self-Advocacy in the 21st Century. *Focus on Autism and Other Developmental Disabilities*, *15*(2), 106–115. https://doi.org/10.1177/108835760001500206

Wenger E. (1998). *Communities of Practice: Learning, Meaning and Identity*. Cambridge University Press, Cambridge.

Wilberforce, M., Abendstern, M., Tucker, S., Ahmed, S., Jasper, R., & Challis, D. (2017). Support workers in community mental health teams for older people: roles, boundaries, supervision and training. *Journal of Advanced Nursing*, *73*(7), 1657–1666. https://doi.org/10.1111/jan.13264

Wilkinson, S. (1988). The role of reflexivity in feminist psychology. *Women's Studies International Forum*, *11*(5), 493–502. https://doi.org/10.1016/0277-5395(88)90024-6

Williams, S., Dagnan, D., Rodgers, J., & Freeston, M. (2015). Exploring Carers' Judgements of Responsibility and Control in Response to the Challenging Behaviour of People with Intellectual Disabilities. *Journal of Applied Research in Intellectual Disabilities*, *28*(6), 589–593. https://doi.org/10.1111/jar.12146

Williams, V., Ponting, L., & Ford, K. (2009a). "I do like the subtle touch": Interactions between people with learning difficulties and their personal assistants. *Disability and Society*, *24*(7), 815–828. https://doi.org/10.1080/09687590903283407

Williams, V., Ponting, L., Ford, K., & Rudge, P. (2009b). Skills for support: Personal assistants and people with learning disabilities. *British Journal of Learning Disabilities*, *38*(1), 59–67. https://doi.org/10.1111/j.1468-3156.2009.00570.x

Willis, M. E. H. (2022). Critical realism and qualitative research in psychology. *Qualitative Research in Psychology*, *20*(2), 265–288. https://doi.org/10.1080/14780887.2022.2157782

Windley, D., & Chapman, M. (2010). Support workers within learning/intellectual disability services perception of their role, training and support needs. *British Journal of Learning Disabilities*, *38*(4), 310–318. https://doi.org/10.1111/j.1468-3156.2010.00610.x

Appendices

Appendix 1: List of publications and relationship with thesis chapters

An article version of **Chapter 3** was published in the open-access Journal of Long-Term Care in May 2024: Mamolis, G., Triantafyllopoulou, P., & Jones, K. (2024). Care Relationships Between Support Staff and Adults With a Learning Disability in Long-Term Social Care Residential Settings in the United Kingdom: A Systematic Literature Review. *Journal of Long-Term Care*, 187 – 209. https://doi.org/10.31389/jltc.189

To access the article in KAR please use the following link: https://kar.kent.ac.uk/106050/ (KAR id:106050).

Appendix 2: Materials and Documents for Study 2

Demographics & Eligibility Questionnaire

Hello and thank you for your interest in this study!

The information gathered from this short questionnaire will be used to describe the characteristics of participants as a group and to check whether you are eligible to attend the interview.

Completing the survey is expected to take around 5 minutes or so. Before data analysis starts, the questionnaire will be fully anonymised to protect your identity and there will be no way for your answers to be traced back to you.

Your first name:

_____

Your middle name:

Please leave this box blank if you don't have a middle name

_____

Your surname:

_____

Your official work email as a support member of staff:

(*This is the official work email that your employer has provided you as part of your professional care role*)

_____

Today's date:

_____

Demographics

*Kindly note that you must answer all questions

Which gender do you identify as?

(You may choose more than one option)

- ☐ Woman (including trans women)
- ☐ Man (including trans men)
- ☐ Non binary person
- ☐ Agender
- ☐ An identity not listed here, please describe:

_____

- ☐ I would prefer not to say

Which ethnicity do you identify with?

(You may choose more than one option)

- ☐ White British
- ☐ White Other
- ☐ Mixed British
- ☐ Mixed Other
- ☐ Asian British
- ☐ Asian Other
- ☐ Black British
- ☐ Black Other
- ☐ An identity not listed here, please describe:

_____

- ☐ I would prefer not to say

Which category best describes your age group?

- ○ 18-24
- ○ 25-34
- ○ 35-44
- ○ 45-54
- ○ 55-64
- ○ 65+

What best describes your highest academic qualification?

- ○ I do not currently hold any qualifications
- ○ GCSE
- ○ A-Levels
- ○ National Vocational Qualification (NVQ), specify subject: _____
- ○ Undergraduate degree, specify subject: _____
- ○ Postgraduate degree, specify subject: _____
- ○ Doctorate degree, specify subject: _____
- ○ My qualification is not listed here, please describe and specify subject: _____
- ○ I would prefer not to say

Eligibility (staff characteristics)

*Kindly note that you must answer all questions

Are you currently a paid (formal) support staff providing direct care to adults with a learning (intellectual) disability?

Learning disabilities entail 'a reduced intellectual ability and difficulty with everyday activities – for example, household tasks, socialising or managing money – which affects someone for their whole life' (Mencap)

- ○ Yes
- ○ No

You support adults with:

(You may choose more than one option)

- [ ] Mild learning (intellectual) disability
- [ ] Moderate learning (intellectual) disability
- [ ] Severe or profound learning (intellectual) disability
- [ ] I am not sure about their level of learning (intellectual) disability

What is your job title?

- ○ Support worker
- ○ Care worker
- ○ Personal assistant
- ○ Team leader
- ○ Manager
- ○ Not listed here, please describe:

_____

Are you:

- ○ Full time
- ○ Part time
- ○ On a zero hours contract
- ○ Agency/Bank staff

- ○ Not listed here, please describe:

_____

In your current role, how many hours a week you spend providing direct support to adults with a learning (intellectual) disability?

- ○ I do not work directly with adults with a learning (intellectual) disability
- ○ Approximately 7 to 14 hours a week
- ○ Approximately 15 to 29 hours a week
- ○ 30+ hours
- ○ Not listed here, please describe:

_____

Have you worked as paid support staff with adults with a learning (intellectual) disability before your current role?

- ○ Yes
- ○ No

If yes, how long was this for?

- ○ For less than three months, please specify:

_____

- ○ For three months or more, please specify:

_____

- ○ Not applicable

Eligibility (service characteristics)

*Kindly note that you must answer all questions

What best describes the social care residential setting(s) you are currently based at?

(You may choose more than one option)

- ☐ Care home
- ☐ Supported living
- ☐ Domiciliary care (people's own homes)
- ☐ Not listed here, please describe:

_____

Is the residential setting a long term one?

A long term residential setting can be described as a person's home and is of more permanent nature in contrast to short term residential settings such as a respite service. For example, a care home or supported living setting would be expected to be long term.

- ○ Yes
- ○ No, please describe:

_____

- ○ It's complicated, please explain:

_____

How long have you been working in your current setting(s) for?

- ○ For less than three months, please specify:
  _____
- ○ For three months or more, please specify:
  _____

What best describes the organisation that manages the service you are currently based at?

- ○ Local authority/Council
- ○ Independent/Voluntary/Charity/Third sector
- ○ Private sector
- ○ I am employed by the person I support or their family
- ○ Not listed here, please describe:
  _____

Which region in England best describes the location of the service you are currently based at?

- ○ South West
- ○ South East
- ○ Greater London
- ○ East of England
- ○ West of England
- ○ East Midlands
- ○ West Midlands

- ○ Yorkshire and Humber
- ○ North West
- ○ North East
- ○ Not listed here, please describe:

_____

- ○ I am not based in a service in England

Interview Protocol

Opening

I will now do a quick introduction and then we can proceed to the actual interview:

-Introduce myself and briefly talk about my work and academic background.

-This study is about...

-Quick reminder, everything we discuss today will remain confidential unless concerns of abuse, harm, illegal activity

-No right or wrong answers.

-During the interview feel free to ask any questions.

-This interview explores six areas of relationships. Expected to last about one hour.

PRESS RECORD

Okay just so you know I am now recording this, alright?

Interview

In your online form you've mentioned that you support adults with [levels of learning disability], so my first question is:

<u>1. Definitions</u>

How do you understand your relationship with the people you support?

Prompts (if necessary):

What does it look like?

What does it involve?

If you were to define it, what would your definition be?

If I was there, what would I see?

Is this understanding applicable to your current and also your previous relationships (if applicable)

What makes your relationship with the people you support a positive one?

Prompts (if necessary):

Would you say that you have or have had positive relationships with the people you support?

Can you think of any positive relationships you have with the people you support?

What do they look like?

If I was there, what would I see?

Is this applicable to your current and also your previous relationships? (if applicable)

If you were to define positive relationships with the people you support, what would your definition be?

Prompts (if necessary):

***The United Kingdom** is defined as "the country that consists of England, Scotland, Wales, and Northern Ireland"*

2. Processes and practices

You support people in their daily lives, what role does this play in building a relationship with your people?

Prompts (if necessary)

Are there advantages and/or disadvantages for building relationships in the context of everyday life support in comparison to other more defined contexts (e.g., day centres)? What are they?

What do you do as a member of staff to build positive relationships with the people you support?

Prompts (if necessary):

What do you do to make it happen? Examples

*What practices/processes do you employ to foster positive relationships? What are the **main actions** that you take?*

What would I see you do if I was there?

Is this applicable to your current and also your previous relationships? (if applicable)

Once established, what do you do as a member of staff to maintain positive relationships?

Prompts (if necessary):

What do you do to make it happen? Examples

*What practices/processes do you employ to maintain positive relationships? What are the **main actions** that you take?*

What would I see you do if I was there?

Is this applicable to your current and also your previous relationships? (if applicable)

---

3. Facilitators

What enables/helps you build good relationships with the people you support?

Prompts (if necessary):

Provide example to participant to clarify if unclear (e.g., training)

*Factors **can be** **personal, organisational, or social** and **situated in staff or residents***

Is this applicable to your current and also your previous relationships? (if applicable)

---

4. Barriers

What makes it difficult to build good relationships with the people you support?

Prompts (if necessary):

*What **prevents** you from building positive relationships with the people you support?*

Provide example to participant to clarify if unclear (e.g., training)

*Factors **can be** **personal, organisational, or social and situated in staff or residents***

Is this applicable to your current and also your previous relationships? (if applicable)

---

5. Impact

What impact do positive relationships have on you as support staff?

Prompts (if necessary):

How do positive relationships affect your general experience as staff or your practice?

What impact does lack of positive relationships have on you as support staff?

Is this applicable to your current and also your previous relationships? (if applicable)

What impact do positive relationships have on the people you support?

What impact does lack of good relationships have on them?

Is this applicable to your current and also your previous relationships? (if applicable)

---

6. Restoration

This is a 'yes' or 'no' question. In the context of supporting adults with a learning disability, have you ever had a positive relationship with a person you support that has been disrupted or challenged?

Prompts (if necessary):

By disruption/challenge, I mean *something that happened within the relationship (e.g., challenging behaviour) that changed previously positive dynamics.*

If yes: can you tell me more?

If no: can you use examples from your colleagues' experiences?

How would you make a relationship like that, a relationship that has been challenged, positive again? *Prompts (if necessary):*

What strategies could staff use?

What strategies could the people who receive support use?

Is this applicable to your current and also your previous relationships? (if applicable)

End of interview

Overall, is there anything else you would like to add?

-Copy of transcript? Means?

-Summary of findings? Means?

-Payment form (all participants receive payment for their time)

Favourable Ethical Opinion from the Tizard Centre Ethics Committee

29/06/2022

Application 677

Dear Mr Mamolis

Favourable Ethical Opinion for Care relationships between support staff and adults with a learning disability in social care residential settings in England.

Your research project has now been granted a favourable ethical opinion from the Tizard Centre Ethics committee.

Please notify the committee about any ethical problems or questions that arise during the project using the email lssjethics@kent.ac.uk

Yours sincerely

[signature omitted for data protection purposes]

Professor [name omitted for data protection purposes]

Acting Chair of Research Ethics Committee

Tizard Centre

University of Kent

University of Kent sponsorship

[name omitted for data protection purposes]

Research Ethics and Governance Manager

Dialling code for Canterbury:

01227 (UK) or +44 1227 (International)

Tel: [number omitted for data protection purposes] direct line

Fax: [number omitted for data protection purposes]

Email: [email address omitted for data protection purposes]

URL : http://www.kent.ac.uk/research

22 July, 2022

Ref: ResGov 455

To whom it may concern

Dear Sir / Madam

RE: Georgios Mamolis – research project: Care relationships between support staff and adults with a learning disability in social care residential settings in England

This is to confirm that the University of Kent will accept the role of Sponsor for the above project, according to the requirements of the UK Policy Framework for Health & Social Care

Research, following confirmation of a favourable opinion from the Tizard Centre research ethics committee.

If you have any questions about this letter or arrangements for the research governance, please do not hesitate to contact me.

Yours sincerely

[name omitted for data protection purposes]

Research Ethics and Governance Manager

Flyer for advertising the study

Information Sheet for Participants

Study title

Care relationships between support staff and adults with a learning disability (intellectual disability) in social care residential settings in England

Lead researcher

Georgios Mamolis, former support worker and current PhD Candidate in Applied Psychology, Tizard Centre, University of Kent, E: gm518@kent.ac.uk link to academic profile: Georgios Mamolis - University of Kent

Supervisors

Dr Paraskevi (Vivi) Triantafyllopoulou, Tizard Centre, University of Kent, E: P.Triantafyllopoulou@kent.ac.uk

T: 01227 824784, link to academic profile: Dr Paraskevi Triantafyllopoulou - University of Kent

Professor Karen Jones, PSSRU, University of Kent

E: k.c.jones@kent.ac.uk T: 01227 827953, link to academic profile: Professor Karen Jones | PSSRU

What is this study about?

This study is part of a PhD project exploring care relationships between support staff and adults with a learning disability (intellectual disability) in long term social care residential settings in England. In this study, we are interested in hearing support staff's thoughts on what makes their relationships with the people they support positive, how positive relationships are established and what impact they have on people's lives, what factors can facilitate or hinder good care relationships, and other related topics.

Why is this important?

Little is known about care relationships between support staff and adults with a learning disability (intellectual disability) in social care residential settings. This is quite surprising, considering that staff and residents spend so much time together and that support takes place in everyday life which admittedly involves so many different things. This study will hopefully help people understand staff-resident care relationships better and will inform care practice and outcomes for those who receive and those who provide support.

Do I have to take part in the study?

This study has received ethical approval from the Tizard Centre Research Ethics Committee, University of Kent. Your participation is completely voluntary and you do not have to take part if you do not want to. Even if you agree to participate, you may withdraw at any time without giving a reason. If you decide to participate and we collect data from you, you can still withdraw up until data analysis has been finalised without giving a reason. The information you provided to us will be deleted and not included in the analysis. Taking part, withdrawing from, or refusing to participate in the study will not affect your employment in any way. Your participation or otherwise will not be revealed to your employer.

Who can take part?*

- ✓ You must be **paid support staff** in **social care**, for example a support or care worker, personal assistant etc, providing direct care to **adults with a learning disability** (intellectual disability) in **England**.
- ✓ You must be based in a **long-term residential setting**, for example a care home, a supported living setting etc, or in **domiciliary care**, namely providing support in people's own homes.
- ✓ Your **social care** organisation must be managed by **local authorities** (council), or the **independent/voluntary/charity/third** sector, or the **private** sector.

- ✓ You must be **18 years** of age or over and able to **communicate in English**. All genders and cultural backgrounds are welcome.
- ✓ You may be a **full time** or **part time** staff. **Agency/bank** or **zero hours** contract staff may also be eligible.
- ✓ You must have been working for **three months or more** in your current learning disability service.
- ✓ If you are a **senior** or **management staff**, for example a team leader, a home manager etc, you may also be eligible.

**Although this is a carefully devised list of inclusion criteria, we understand that people's work circumstances may vary, and this does not necessarily mean that you will not be able to take part in the study. If in doubt, please contact Georgios to discuss.*

Who cannot take part?*

- ⊗ Practitioners **other than** support staff (e.g., nurses, psychologists), employed as such.
- ⊗ Support staff based in **short term** residential settings (respite), or **Shared Lives scheme** settings, or community **palliative** settings, or social care services managed by the **National Health Service (NHS)**.
- ⊗ Support staff based in **day centres** or **healthcare settings**, for example hospitals.
- ⊗ Staff **below the age of 18**, not working in **England**, or not able to **communicate in English**.

**Although this is a carefully devised list of exclusion criteria, we understand that people's work circumstances may vary, and this does not necessarily mean that you will not be able to take part in the study. If in doubt, please contact Georgios to discuss.*

What will I be asked to do?

You will receive an online link and you will be asked to use this to sign the consent form and to complete a short multiple-choice Demographics & Eligibility Questionnaire (around five minutes) gathering basic demographic information and double-checking that you are eligible to participate. You will also be asked to enter your official work email address in the questionnaire. This is yet another measure to ensure that only eligible participants take part. If you are not eligible, you will be informed of this and thanked for your time and interest. If you are eligible, an interview with Georgios will be arranged to discuss your thoughts and experiences on the study topic. The interview is expected to last around one hour and fifteen minutes and could take place either in person or online, depending on circumstances. The interview will be audio recorded as this will allow Georgios to transcribe the audio and analyse the information you provided. Once the interview transcript is ready, you will have the opportunity to see it and comment on it, if you wish so.

What if I get distressed?

Even though we do not anticipate that this study will cause distress, should you experience any unpleasant feelings or thoughts, we would suggest contacting the following mental health organisations:

- *Samaritans* for support over the phone: T: 116 123 for free, 24 hours a day, 365 days a year, E: jo@samaritans.org (response time: 24 hours), Post: Freepost SAMARITANS LETTERS, Website: How we can help | Samaritans
- *Mind* for information and signposting: T: 0300 123 3393, open 9am to 6pm, Monday to Friday, E: info@mind.org.uk, Post: Mind Infoline, PO Box 75225, London, E15 9FS, Website: Helplines - Mind

Will I get paid?

You will receive £10 for taking the time to be interviewed and you will also get a certificate of participation confirming that you fully took part in the study. Kindly note that if you are in receipt of benefits, it is your responsibility to find out if the £10 payment will affect your benefits entitlement. Moreover, if any costs incur (e.g., travel costs etc) as part of your participation in the study, those will be reimbursed to you. Once the interview has started, withdrawing from it will not affect your payment or reimbursement. Unfortunately, participants who have completed the consent form and the Demographics & Eligibility Questionnaire and are deemed not eligible to participate in the interview, will not receive any payment or a certificate of participation.

What about confidentiality?

All the information you provide will be kept confidential. However, confidentiality may be breached when there are serious safeguarding concerns. For example, disclosing information about risk of or actual abuse taking place, danger to self or others, or illegal activity, would justify breaching confidentiality. In such circumstances, Georgios will first seek advice from his supervisors prior to potentially contacting the appropriate authorities/services.

What will happen to the information I provide?

Overall, your information will be treated in compliance with the General Data Protection Regulation (GDPR, 2018). The Demographics & Eligibility Questionnaire will be fully anonymised, and, in interview transcripts, pseudonyms will replace real names. Additionally, any potential description of people, services, or conditions will be omitted. There will be no way for the information you provided to be traced back to you or other people and services. Georgios will be using a password protected computer and all data will be stored securely in an online password protected drive managed by the University of Kent. Only the research team will have access to the online drive. The University of Kent GDPR policy can be found here: Data Protection Policy (kent.ac.uk). Additionally, the University's privacy notice in relation to

how the institution is handling the data of researchers can be found here: Privacy Notice - Research at Kent

How the findings of the study will be shared more widely?

Georgios will report the findings in his PhD thesis which will be made available to the public upon completion. Finding may also be published in academic journals or in relevant organisations and may be presented in conferences, seminars, or public events. As stated above, all data will be anonymous or pseudonymised, with any description of people, services, or conditions omitted. If you wish, you can receive a summary of the findings and/or links to publications (if applicable). Please note that generating findings is a lengthy process and may take a while.

Can I provide feedback?

You will receive a comments form as part of your participant package with all relevant information, should you wish to provide feedback. Feedback may include comments on what went well but also suggestions and complaints.

How do I join?

If you wish to participate in the study or for any questions, clarifications, etc., please contact Georgios or his supervisors. Contact details can be found at the top of this sheet.

Thank you for taking the time to read this information sheet.

TIZARD
University of Kent

Cornwallis North East, Canterbury, Kent, CT2 7NF

Comments Form

Thank you for taking the time to speak to Georgios and for contributing to research on care relationships between support staff and adults with a learning disability in social care residential settings. We hope that everything went well!

We would be interested in any comments you would like to make, positive or negative. When things go well, we like to encourage researchers by giving them good feedback. But if things don't go well, it will help us to know this.

If you wish to send any comments please contact the Tizard Centre Ethics Committee.

Post:

Tizard Ethics Committee

Tizard Centre

Cornwallis North East

University of Kent

Canterbury, CT2 7NF

Email: lssjethics@kent.ac.uk

Alternatively, you can contact the research team directly at:

Georgios Mamolis: **E**: gm518@kent.ac.uk or his supervisors:

Dr Paraskevi (Vivi) Triantafyllopoulou: **E**: P.Triantafyllopoulou@kent.ac.uk **Tel**: 01227 824784

Professor Karen Jones: **E**: K.C.Jones@kent.ac.uk **Tel**: 01227 827953

Thank you once again for your time and contribution.

Tizard Centre Research Ethics Committee

Consent Form

If you have any questions, please contact the lead researcher or his supervisors before completing this form. Our contact details can be found in the Information Sheet you received via email.

*Kindly note that you must answer all questions in this form

I have read and understood the information provided in the Information Sheet for participants.

- ○ Yes
- ○ No

I understand that my participation is voluntary and I am free to withdraw at any time (up to the finalisation of analysis) without giving any reason.

- ○ Yes
- ○ No

I understand that my interview will be audio recorded.

- ○ Yes
- ○ No

I understand that the information I provide will be kept confidential unless the researchers feel that there is risk of harm, abuse, or illegal activity.

- ○ Yes
- ○ No

I understand that the information I provide may be shared within the research team and that it will be stored securely and deleted when appropriate.

- ○ Yes
- ○ No

I agree for the research team to use anonymous or pseudonymised data that cannot be traced back to me, my service, or other people, in publications, conferences, or presentations.

- ○ Yes
- ○ No

I confirm that I have received a comments form.

- ○ Yes
- ○ No

All of my questions have been answered to my satisfaction.

- ○ Yes
- ○ No

Q9 9) I agree to take part in this study.

- ○ Yes
- ○ No

Your first name:

_____

Your middle name:

If you don't have a middle name, please leave this box blank

_____

Your surname:

_____

Today's date:

_____

Certificate of Participation

Public Advisor Payment Form

Project title*: Care relationships between support staff and adults with a learning (intellectual) disability in residential settings in England*

This payment claim form is in relation to the project: 5270 400 17636 C1.

The research contact is: Georgios Mamolis.

I confirm the following work/attendance at a meeting on (detail work undertaken and date)**:**	**I will receive the following fee as payment** (insert amount)**:**
Semi-structured interview with lead researcher (Georgios Mamolis).	£10 (ten pounds)

Date:	
The total fee for work/meeting attendance is £10 (ten pounds)	

I acknowledge that this payment does not make me an employee of the University of Kent and that I remain responsible for the payment of all relevant taxes and responsible for declaring the income to any relevant authorities. I am aware that receiving this payment might affect my entitlement to certain benefits.

I am aware that this form, including my bank details, will be passed to colleagues in the University of Kent's Divisional Finance Team, Research and Innovation Accounts Team and the Payments Office. It is also possible that funding auditors may ask to see this form.

Please allow 4-6 weeks for the payment to be made.
If you have not received the payment within this time, please do let us know.

Total amount claimed* (work/meeting attendance plus any expenses): **£10 (ten pounds)

*Cheques not available during the pandemic

Public Advisor Name:	**Bank account details** Bank account name:
Public Advisor Address:	Sort code: Account number:

GDPR Certificate

Appendix 3: Materials and Documents for Study 3

Demographics & Eligibility Questionnaire for Support Staff

Please complete this questionnaire only if you agreed to take part in this study.

Georgios will use the information collected here to describe the characteristics of participants as a group and to double-check that you can take part in this study.

Before data analysis starts, Georgios will anonymise the questionnaire and there will be no way for your answers to be traced back to you, your care service, other people, or specific locations.

Please answer all questions.

Your first name:

Your middle name (*leave blank if you don't have one*):

Your surname:

Today's date:

1. **What is your gender?** (*you can choose more than one options*)
    - Woman (including trans women)
    - Man (including trans men)
    - Agender
    - Non-binary
    - An identity not listed here, please describe:
    - I would prefer not to say

2. **What is your ethnicity?** (*you can choose more than one options*)
    - White British
    - White Other
    - Mixed British
    - Mixed Other
    - Asian British
    - Asian Other
    - Black British
    - Black Other
    - An identity not listed here, please describe:
    - I would prefer not to say

3. **What is your age group?**

- 18-24
- 25-34
- 35-44
- 45-54
- 55-64
- 65+

4. What is your highest academic qualification?

- I do not currently hold an academic qualification
- GCSE
- A- Levels
- National Vocational Qualification (NVQ), specify subject:
- Undergraduate degree, specify subject:
- Postgraduate degree, specify subject:
- Doctoral degree, specify subject:
- My qualification is not listed here, please describe and specify subject:
- I would prefer not to say

5. Are you currently a paid (formal) support staff providing direct care to residents with a learning (intellectual) disability in [name of service]?

- Yes
- No

6. What is your job title?

- Support worker

- Care worker
- Senior support worker
- Senior care worker
- Team leader
- Manager
- Not listed here, please describe:

7. **Are you:**
   - Full time
   - Part time
   - Zero hours contract
   - Agency/Bank staff
   - Not listed here, please describe:

8. **As a support staff, how many hours a week do you spend working directly with residents with a learning (intellectual) disability in [name of service]?**
   - Approximately 7 to 14 hours a week
   - Approximately 15 to 29 hours a week
   - 30+ hours
   - Not listed here, please describe:

9. **Have you worked as paid support staff with adults with a learning (intellectual) disability before your current role?**
   - Yes
   - No

10. If yes, how long was this for?

- For less than three months
- For three months or more, please specify:
- Not applicable

11. How long have you been working in [name of service] for?

- For less than three months
- For three months or more, please specify:

Demographics & Eligibility Questionnaire for Residents

Please fill out this questionnaire only if you agreed to take part in this study

Georgios will use this information to describe the participants as a group and to double-check that you can take part in this study.

Georgios will make the questionnaire anonymous and there will be no way for your answers to go back to you, the house you live in, other people, or locations.

Please answer all questions.

Your name & surname:

Today's date:

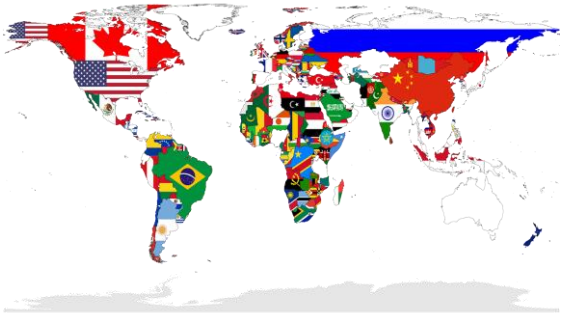
1. **What is your gender?** (*you can choose more than one*)

- Woman (including trans women)

- Man (including trans men)
- Agender
- Non-binary
- Other, please describe:
- I would prefer not to say

2. What is your ethnicity?

(*you can choose more than one*)



- White British
- White Other
- Mixed British
- Mixed Other
- Asian British
- Asian Other
- Black British
- Black Other
- Other, please describe:
- I would prefer not to say

3. What is your age group?

- 18-24
- 25-34
- 35-44

- 45-54
- 55-64
- 65+

4. **How do you describe your learning disability, sometimes also called intellectual disability?**

- Mild
- Moderate
- Severe or profound
- I do not use these words to describe my learning disability
- Other, please describe:
- I would prefer not to say

5. **Is [name of service] your permanent home?**

- Yes
- No, please describe:

6. **How long have you been living in [name of service]?**

- For less than three months

- For three months or more, please describe:

7. Where did you live before [name of service]?

(*you can choose more than one*)

- With family
- With friends
- With my partner
- On my own
- In a different home like [name of service]
- In a long-term hospital
- Other, please describe:
- I would prefer not to say

8. If someone helped you fill out this questionnaire, what was their role?

- I did it by myself without help
- Staff in [name of service]
- A family member
- A friend
- A partner
- Georgios, the researcher
- Other, please describe:

Demographics & Eligibility Questionnaire for Significant Others

Please complete this questionnaire only if you agreed to take part in this study.

Georgios will use the information collected here to describe the characteristics of participants as a group and to double-check that you can take part in this study.

Before data analysis starts, Georgios will anonymise the questionnaire and there will be no way for your answers to be traced back to you, the care service, other people, or specific locations.

Please answer all questions.

Your first name:

Your middle name (*leave blank if you don't have one*):

Your surname:

Today's date:

1. **What is your gender?** (*you can choose more than one options*)

- Woman (including trans women)
- Man (including trans men)
- Agender
- Non-binary
- An identity not listed here, please describe:
- I would prefer not to say

2. **What is your ethnicity?** (*you can choose more than one options*)

- White British
- White Other
- Mixed British
- Mixed Other
- Asian British

- Asian Other
- Black British
- Black Other
- An identity not listed here, please describe:
- I would prefer not to say

3. What is your age group?

- 18-24
- 25-34
- 35-44
- 45-54
- 55-64
- 65+

4. What is your highest academic qualification?

- I do not currently hold an academic qualification
- GCSE
- A- Levels
- National Vocational Qualification (NVQ), specify subject:
- Undergraduate degree, specify subject:
- Postgraduate degree, specify subject:
- Doctoral degree, specify subject:
- My qualification is not listed here, please describe and specify subject:
- I would prefer not to say

5. Are you a family member, partner, or a friend of a resident in [name of service]?

- Yes
- No

6. What is the resident's name?

Please write the resident's name here:

7. What is your relationship with the resident?

- Parent
- Sibling
- Partner
- Friend
- Not listed here, please describe:

8. How long have you known the resident for?

- For less than three months
- For three months or more, please specify:
- All my life

9. How often do you get in touch with the resident?

- Daily
- Weekly
- Monthly
- Every six months or so
- Annually

- Not listed here, please describe:

Demographics & Eligibility Questionnaire for Consultees

Please complete this questionnaire only if you agreed for your family member, partner, or friend to take part in this study.

Georgios will use the information collected here to describe the participants as a group and to double-check that they can take part in this study.

Before we start analysing all information, Georgios will anonymise the questionnaire and there will be no way for people's answers to be traced back to them, the care service, other people, or specific locations.

In this form, I use the term 'resident' to refer to your family member/partner/friend living in [service].

Please answer all questions.

Your name & surname:

Name & surname of the resident you are acting as a consultee for:

Today's date:

1. To your knowledge, what is the resident's gender? (*you can choose more than one*)

- Woman (including trans women)
- Man (including trans men)
- Agender
- Non-binary

- A gender not listed here, please describe:
- I do not know
- I would prefer not to say

2. **To your knowledge, what is the resident's ethnicity?** (*you can choose more than one*)

- White British
- White Other
- Mixed British
- Mixed Other
- Asian British
- Asian Other
- Black British
- Black Other
- An ethnicity not listed here, please describe:
- I do not know
- I would prefer not to say

3. **To your knowledge, what is the resident's age group?**

- 18-24
- 25-34
- 35-44
- 45-54
- 55-64
- 65+

4. **To your knowledge, what best describes the resident's learning disability, sometimes also called intellectual disability?**

- Mild learning disability
- Moderate learning disability
- Severe or profound learning disability
- These labels are not relevant to describing the resident's learning disability, please share your thoughts:
- Not listed here, please describe:
- I do not know
- I would prefer not to say

5. **To your knowledge, is [name of service] the resident's permanent home?**

- Yes
- No, for example, they are there as respite or emergency, please describe:

6. **To your knowledge, how long has the resident been living in [name of service]?**

- For less than three months
- For three months or more, please specify:

7. **Where did the resident live before [name of service]?** (*you can choose more than one*)

- With family

- With friends
- With their partner
- On their own
- In a different home like [name of service]
- In a long-term hospital
- Not listed here, please describe:
- I do not know
- I would prefer not to say

Participant Observation Schedule

**The participant observation schedule is a dynamic, rather than a static, document and it may be revisited/modified/updated once observations begin.*

1. Definitions

Observe how staff and residents discourse (positive) care relationships in daily practice.

Observe how such discourses and meanings influence daily interactions/care practices/relationships between staff and residents.

Observe how staff and residents discourse themselves in the care relationship.

---

2. Processes & practices

Observe interactions between staff and residents as well as how the whole relationship flows.

Observe the language used, tone of voice, non-verbal cues (body language), and facial expressions.

Observe the actions that staff and residents take to build, establish, and maintain good care relationships.

Observe the skills, strategies, and techniques, used by staff and residents to build, establish, and maintain good care relationships.

Observe whether specific models of care practice are used during interactions and to build relationships.

Observe the role that delivering and receiving care in daily life plays in the formation of good care relationships.

Observe the emotions (e.g., empathy, enthusiasm, happiness, boredom, fear, uncertainty, anxiety) displayed by staff and residents during their interactions and within their care relationships.

---

3. Facilitators

Observe what micro (e.g., situated in staff or resident -attitudes, motivation, attributions, challenging behaviour, level of learning disability, health issues, communication issues-), meso (e.g., organisational support, training & supervision, service culture, MDT, activities, physical environment), and macro (e.g., funding/resources, salaries, staff turnover, regulation/inspections, policies) factors can help staff and residents build and maintain good care relationships.

---

4. Barriers

Observe what micro (e.g., situated in staff or resident -attitudes, motivation, attributions, challenging behaviour, level of learning disability, health issues, communication issues-), meso (e.g., organisational support, training & supervision, service culture, MDT, activities, physical environment), and macro (e.g., funding/resources, salaries, staff turnover, regulation/inspections, policies) factors can prevent staff and residents from building and maintaining good care relationships.

---

5. Impact

Observe how positive interactions and positive care relationships (or lack thereof) impact the lives of staff and residents. Include impact on daily care practices and life in the service.

Observe the impact on emotional reactions (e.g., empathy, enthusiasm, happiness, boredom, fear, uncertainty, anxiety) of staff and residents.

Observe the impact on motivation to deliver and receive care and support.

---

6. Relationship restoration

Observe how often challenges in care relationships occur. Observe the kind of challenges.

Observe how such challenges are being discoursed.

Observe the main actions, skills, strategies, techniques, and care practice models, that are used by staff and residents to restore care relationships that have been challenged.

Interview Protocol for Support Staff

Opening

I will now do a quick introduction and then we can proceed to the actual interview:

- Former support worker, currently PhD researcher in Applied Psychology
- This study is about… (summarise topic)
- Quick reminder, everything we discuss today will remain confidential unless there are concerns of abuse, harm, illegal activity
- There are no right or wrong answers, I just want to hear your thoughts
- During the interview feel free to ask any questions
- This interview explores 6 areas of relationships. Expected to last about one hour
- Any questions before we move on?

START RECORDING

Okay just so you know I am now recording this, alright?

1. Definitions

How do you understand your relationship with the people you support?

Prompts (if necessary):

What does it look like? What does it involve? If I was there, what would I see?

What makes your relationship with the people you support a positive one?

Prompts (if necessary):

Can you think of any positive relationships you have with the people you support? If I was there, what would I see?

If you were to define positive relationships with the people you support, what would your definition be?

Prompts (if necessary):

The United Kingdom *is defined as '' the country that consists of England, Scotland, Wales, and Northern Ireland''*

---

2. Processes & practices

You support people in their daily lives, what role does this play in building a relationship with your people?

Prompts (if necessary)

Are there pros and cons in comparison to other more defined contexts (e.g., day centres)?

What do you do as a member of staff to build positive relationships with the people you support?

Prompts (if necessary):

What are the ***main*** ***actions*** *that you take? What would I see you do if I was there?*

Once established, what do you do as a member of staff to maintain positive relationships?

Prompts (if necessary):

What are the ***main*** ***actions*** *that you take? What would I see you do if I was there?*

---

3. Facilitators

What helps you build good relationships with the people you support?

Prompts (if necessary):

Provide example to participant to clarify if unclear (e.g., training)

*Factors **can be** **personal, organisational, or social** and **situated in staff or residents***

---

4. Barriers

What makes it hard/prevents you from building good relationships with the people you support?

Prompts (if necessary):

Provide example to participant to clarify if unclear (e.g., training). Factors can be as above.

---

5. Impact

What impact do positive relationships have on you as support staff?

What impact does a lack of positive relationships have on you as support staff?

What impact do positive relationships have on the people you support?

What impact does a lack of good relationships have on them?

---

6. Restoring relationships

This is a 'yes' or 'no' question. In the context of supporting adults with a learning disability, have you ever had a positive relationship with a person you support that has been disrupted or challenged? By disruption/challenge, I mean something that happened within the relationship that changed previously positive dynamics.

If not: can you think of any examples from your colleagues' experiences?

How would you make a relationship like that, a relationship that has been challenged, positive again? *Prompts (if necessary):*

What are the main actions that you take?

End of interview

Is there anything else you would like to add?

STOP RECORDING

-Would you like to receive a copy of the transcript? Means?

-Would you like to receive a summary of the findings? Means?

-Information about payment form and certificate of participation

Interview Protocol for Residents

Opening

I will now do a quick introduction and then we can proceed to the actual interview:

- I used to be a support worker, now I am a researcher at the University
- This study is about… (summarise topic)
- Everything we discuss today will remain confidential unless there are concerns of abuse, harm, illegal activity
- There are no right or wrong answers, just want to hear your thoughts
- During the interview feel free to ask any questions
- This interview explores 6 topics around care relationships. Expected to last about one hour

- Any questions before we move on?

START RECORDING

Okay just so you know I am now recording this, alright?

1. Definitions

What's your relationship with staff like?

Prompts (if necessary):

What does it look like? How would you describe it?

What does it involve?

If I was there, what would I see?

What makes your relationship with staff positive/good?

Prompts (if necessary):

Can you think of any positive relationships you have with staff? What does it look like?

If I was there, what would I see?

Can you give me your definition of a positive relationship with the staff? Just put it in a sentence (a good relationship with staff is…)

Prompts (if necessary):

***The United Kingdom** is defined as '' the country that consists of England, Scotland, Wales, and Northern Ireland''*

2. Processes & practices

You work with staff in daily life to go out and about, to prepare meals, sometimes they support you when you are unwell or sad, etc. What role does this play in building a relationship with them?

Prompts (if necessary)

Are there pros and cons compared to other environments (e.g., day centres)?

What do you do to build a good relationship with staff?

Prompts (if necessary):

*What are the **main actions** that you take?*

What would I see you do if I was there?

What do you do to make sure that this good relationship remains in place as time goes by?

Prompts (if necessary):

*What are the **main actions** that you take?*

What would I see you do if I was there?

---

3. Facilitators

What helps you build good relationships with staff?

Prompts (if necessary):

Provide example to participant to clarify if unclear (e.g., similar interests, competent/empathic staff)

---

4. Barriers

What makes it hard to build good relationships with staff?

Prompts (if necessary):

Provide example to participant to clarify if unclear (e.g., not enough staff who are always busy, not enough money to go out with staff, not giving staff a chance)

---

5. Impact

When you have a good relationship with staff, how does that make you feel?

When you do not have a good relationship with staff, how does that make you feel?

When you have a good relationship with staff, how does that make staff feel?

When you do not have a good relationship with staff, how does that make staff feel?

---

6. Restoring relationships

Have you ever had a good relationship with staff that stopped being that good because you guys had a falling out/disagreement/etc?

If no: can you think of any examples from other people's experiences?

What would you do to make that relationship positive/good again?

Prompts (if necessary):

What are the main actions that you would take?

End of interview

Is there anything else you would like to say?

STOP RECORDING

-Would you like to receive a copy of the transcript? Means?

-Would you like to receive a summary of the findings? Means?

-Information about payment form and certificate of participation

Interview Protocol for Significant Others

Opening

I will now do a quick introduction and then we can proceed to the actual interview:

- Former support worker, currently PhD researcher in Applied Psychology
- This study is about… (summarise topic)
- Quick reminder, everything we discuss today will remain confidential unless there are concerns of abuse, harm, illegal activity
- There are no right or wrong answers, I just want to hear your thoughts
- During the interview feel free to ask any questions
- This interview explores 6 areas of relationships. Expected to last about one hour
- Any questions before we move on?

START RECORDING

Okay just so you know I am now recording this, alright?

1. Definitions

How do you understand the relationship between staff (S) and residents (R)?

Prompts (if necessary):

What does it look like? What does it involve?

What makes it a positive/good relationship?

Can you perhaps give me a definition?

Prompts (if necessary):

***The United Kingdom** is defined as '' the country that consists of England, Scotland, Wales, and Northern Ireland''*

---

2. Processes & practices

In your view, what role does providing support in daily life play in building a relationship between S and R?

Prompts (if necessary)

Are there pros and cons?

What do S do to build positive relationships with R?

Prompts (if necessary):

*What are the **main actions** that they take?*

What do R do to build positive relationships with S?

Prompts (if necessary):

*What are the **main actions** that they take?*

How do both parties maintain those positive relationships?

Prompts (if necessary):

*What are the **main actions** that they take?*

Any suggestions about other things that S or R could do to build and/or maintain good relationships?

---

3. Facilitators

In your view, what helps S build good relationships with R?

In your view, what helps R build good relationships with S?

Prompts (if necessary):

Provide example to participant to clarify if unclear (e.g., training)

*Factors **can be personal, organisational, or social** and **situated in staff or residents***

---

4. Barriers

In your view, what prevents S from building good relationships with R?

In your view, what prevents R from building good relationships with S?

Prompts (if necessary):

Provide example to participant to clarify if unclear (e.g., training). Factors as above.

---

5. Impact

What impact do positive relationships have on S?

What impact does a lack of positive relationships have on S?

What impact do positive relationships have on R?

What impact does a lack of good relationships have on R?

---

6. Restoring relationships

Sometimes the relationship between S and R can go through hard times for various reasons and relationships that were initially positive can be challenged.

How can S make a relationship like that, positive again?

How can R make a relationship like that, positive again?

Prompts (if necessary):

What are the main actions that they could take?

End of interview

Do you have any other thoughts, suggestions, things you would like to add?

STOP RECORDING

-Would you like to receive a copy of the transcript? Means?

-Would you like to receive a summary of the findings? Means?

-Information about payment form and certificate of participation

University of Kent sponsorship

26 June, 2023
Ref: ResGov 472

Dear Sir / Madam

RE: Georgios Mamolis – research project: Care relationships between support staff and adults with a learning (intellectual) disability in long-term social care residential settings in England: An ethnographic study

This is to confirm that the University of Kent will accept the role of Sponsor for the above project, according to the requirements of the Research Governance Framework for Health & Social Care, (RGF), subject to confirmation of a favourable opinion from the National Research Ethics Service.

If you have any questions about this letter or arrangements for the research governance please do not hesitate to contact me.

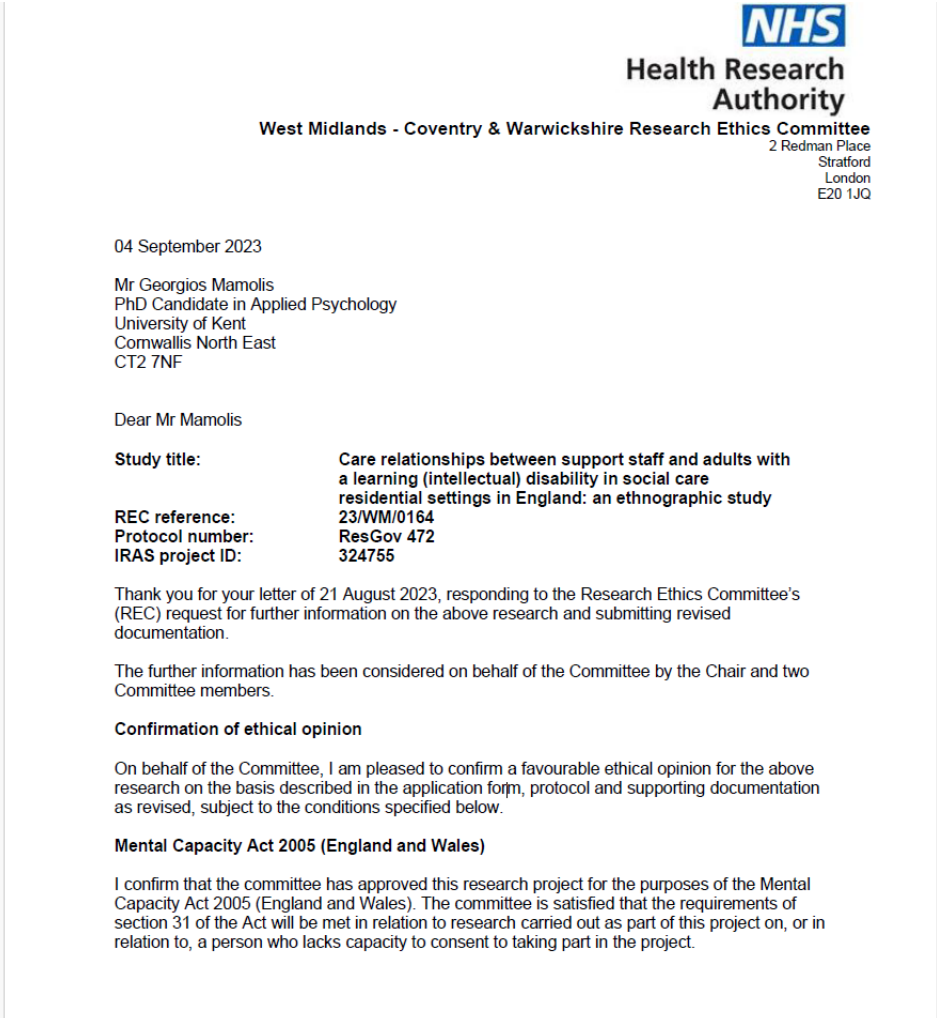
Yours sincerely

[signature omitted for data protection purposes]

[name omitted for data protection purposes]

Research Ethics and Governance Manager

Favourable ethical opinion from HRA West Midlands - Coventry & Warwickshire Research Ethics Committee[69]



NHS
Health Research Authority

West Midlands - Coventry & Warwickshire Research Ethics Committee
2 Redman Place
Stratford
London
E20 1JQ

04 September 2023

Mr Georgios Mamolis
PhD Candidate in Applied Psychology
University of Kent
Cornwallis North East
CT2 7NF

Dear Mr Mamolis

Study title:	**Care relationships between support staff and adults with a learning (intellectual) disability in social care residential settings in England: an ethnographic study**
REC reference:	**23/WM/0164**
Protocol number:	**ResGov 472**
IRAS project ID:	**324755**

Thank you for your letter of 21 August 2023, responding to the Research Ethics Committee's (REC) request for further information on the above research and submitting revised documentation.

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

Confirmation of ethical opinion

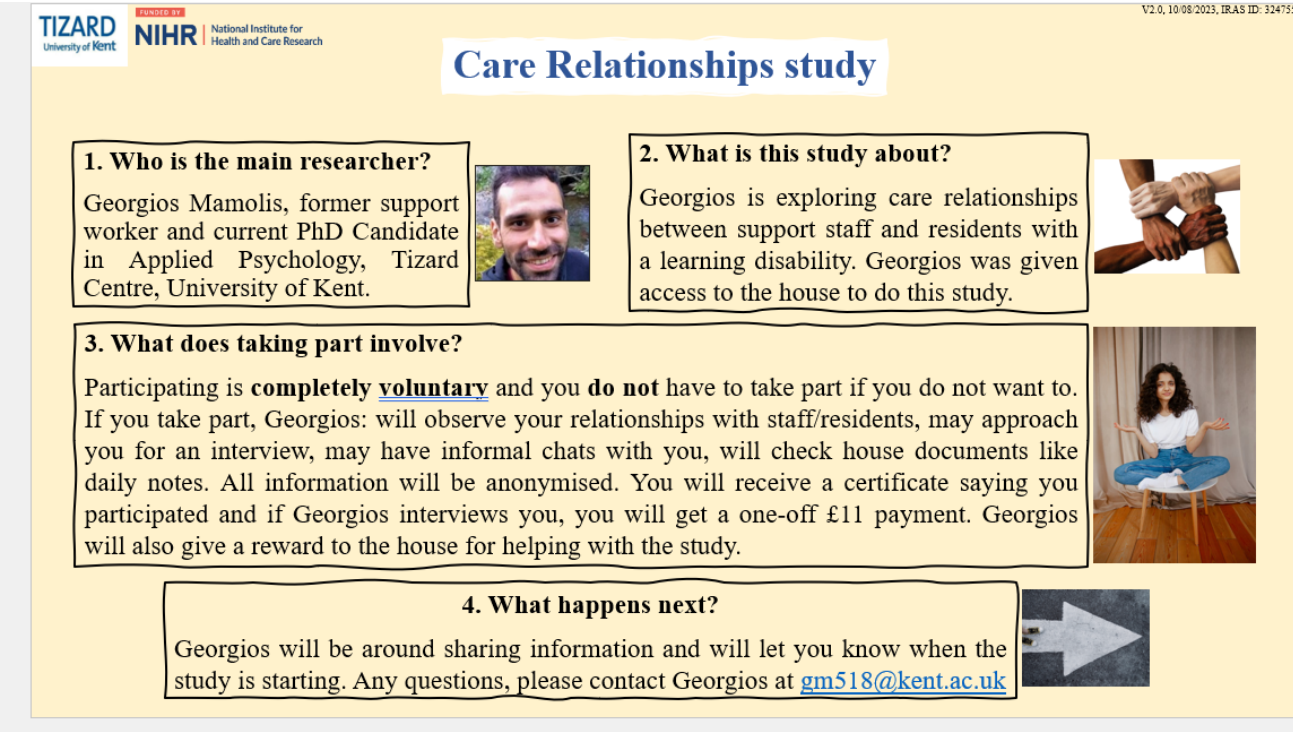
On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Mental Capacity Act 2005 (England and Wales)

I confirm that the committee has approved this research project for the purposes of the Mental Capacity Act 2005 (England and Wales). The committee is satisfied that the requirements of section 31 of the Act will be met in relation to research carried out as part of this project on, or in relation to, a person who lacks capacity to consent to taking part in the project.

[69] Due to the length of the letter, I am only attaching the first page of the letter to evidence favourable ethical opinion.

Flyer for advertising the study



Information Sheet for Support Staff

Study title: Care relationships between support staff and adults with a learning (intellectual) disability in long-term social care residential settings in England: An ethnographic study

Lead researcher
Georgios Mamolis, former support worker and current PhD Candidate in Applied Psychology, Tizard Centre, University of Kent, E: gm518@kent.ac.uk link to academic profile: Georgios Mamolis - University of Kent.

Supervisors

- Dr Paraskevi (Vivi) Triantafyllopoulou, Tizard Centre, University of Kent, E: P.Triantafyllopoulou@kent.ac.uk T: 01227 824784, link to academic profile: Dr Paraskevi Triantafyllopoulou - University of Kent
- Professor Karen Jones, PSSRU, University of Kent
  E: k.c.jones@kent.ac.uk T: 01227 827953, link to academic profile: Professor Karen Jones | PSSRU

Funder
National Institute for Health and Care Research (NIHR), School for Social Care Research (SSCR)

What is this study about?

Georgios is exploring care relationships between support staff and adults with a learning (intellectual) disability by using ethnography. Ethnography is a method to describe people's way of life, beliefs, and practices. [service] agreed to facilitate this study and Georgios is planning to carry out the study in [service].

Why is this study important?

We do not know much about care relationships between support staff and residents with a learning disability in residential settings. This study will try and help people understand those relationships better. We also hope to inform care practice and outcomes.

Do you have to take part in this study?

Your participation is completely voluntary and you do not have to take part if you do not want to. Even if you agree to participate, you can withdraw from the study at any time up to the finalisation of analysis without giving any reason. Simply let Georgios know and Georgios will ask you to complete a very short 'Withdrawal Form'. If you withdraw, Georgios will aim to keep and use the data he collected from you up until you opted out, but if you are not happy with this, your data will be deleted. If you initially said that you don't want to participate in the study and you then changed your mind, you can always opt in. Taking part, withdrawing, or not participating, will not affect your employment in any way. If you decide not to participate, Georgios will still be present in the service collecting data from other people, but not from you.

Who can take part?

Paid support staff or senior support staff, for example, support workers, team leaders, or managers, delivering direct care to residents.

18 years of age and over and able to communicate in English.

Who cannot take part?

Practitioners other than support staff (e.g., nurses, psychologists, etc), employed as such in the service.

People below the age of 18.

What will happen during this study?

This study is expected to last about 4 weeks. Georgios will be doing the following research activities with the people who agreed to participate:

- Georgios will ask staff and residents to complete a short 'demographics & eligibility' questionnaire, collecting demographic information and checking people's eligibility to participate in this study.
- Georgios will observe interactions and relationships between support staff and residents inside and outside the service. Inside the service, Georgios will aim to observe in communal and non-communal areas. Non-communal areas may include resident bedrooms or bathrooms with Georgios observing interactions when staff and residents spend time together or during personal care. Georgios will **only** observe as long as staff and the resident are happy to be observed.
- Georgios may approach support staff and residents to do an interview lasting about one hour (online or in person). Interviews will be audio recorded, but if you are not happy with this, we will find alternatives.
- Georgios will have relaxed chats with staff and residents.
- Georgios will look at relevant documents, for example, daily notes.

Will you get paid?

Everyone who participates in the study will receive a certificate to say they participated.

If you take part in the interview, you will receive a one-off payment of £11 to your bank and if any other costs (e.g., travel costs) come up as part of your participation to the interview, those will be reimbursed to you. Kindly note that if you are receiving benefits, it is your responsibility to find out if the £11 payment will affect your benefits.

The service as a whole will also receive a reward as a 'thank you' for helping with this study.

What about data protection?

All data will be treated in compliance with the General Data Protection Regulation (GDPR, 2018) and the University of Kent's research privacy policy. Georgios will anonymise all data and any descriptions of people, services, locations, or conditions will be deleted. There will be no way for the information gathered to be traced back to you or other people, locations, and services.

What about confidentiality?

Your participation or otherwise will not be revealed to your employer. Georgios may just provide some numbers to the service manager to describe the level of participation as a whole. All the information you provide will be kept confidential unless there are serious safeguarding concerns, for example, risk of or actual abuse taking place, danger to self or others, or illegal activity. Such concerns could justify breaking confidentiality. Breaking confidentiality could range from discussing the issue with the home manager to notifying relevant authorities. Georgios has developed a guidance to help him handle such situations, however, Georgios expects that the likelihood of such issues arising is low.

What if you get distressed?

Even though we do not expect that this study will cause you distress, should you have any unpleasant feelings or thoughts, we would suggest contacting your service manager and/or the following mental health organisations:

- *Samaritans* for support over the phone: T: 116 123 for free, 24 hours a day, 365 days a year, E: jo@samaritans.org (response time: 24 hours), Post: Freepost SAMARITANS LETTERS, Website: How we can help | Samaritans
- *Mind* for information and signposting: T: 0300 123 3393, open 9am to 6pm, Monday to Friday, E: info@mind.org.uk, Post: Mind Infoline, PO Box 75225, London, E15 9FS, Website: Helplines - Mind

Can you provide feedback if you want to?

Yes! You are receiving a comments form. Feedback may include comments on what went well but also suggestions and complaints. You do not have to provide feedback if you do not want to.

What are the next steps?

To tell Georgios whether you wish or do not wish to participate in this study, please complete the short forms that you got with this sheet.

For any questions, please contact Georgios.

Consent Form for Support Staff

Short Title: Care relationships: an ethnographic study
Investigators: Georgios Mamolis (lead researcher)
Dr Paraskevi (Vivi) Triantafyllopoulou (supervisor), Professor Karen Jones (supervisor)

Please answer <u>all</u> questions

I have read and understood the information provided in the information sheet for support staff.	Yes. No.
I understand that my participation is voluntary and I can withdraw at any time (up to the finalisation of analysis) without giving any reason.	Yes. No.
I agree for Georgios to observe my interactions and relationships with residents and I understand he will be present in the house observing life in the service. I understand that observations may take place during different activities, in different parts of the house, inside or outside the service.	Yes. No.
I agree for Georgios to approach me for an interview. If I am interviewed, I understand that my interview will be audio recorded. If I don't wish to be audio recorded, I will notify Georgios and alternatives will be found.	Yes. No.
I agree for Georgios to approach me for unstructured conversations (informal/relaxed chats) and for him to observe or participate when I am informally chatting to my colleagues or residents.	Yes. No.
I agree for Georgios to check service documents, for example daily notes, care plans, or practice policies.	Yes. No.
I agree for Georgios and his team to use anonymised information that cannot be traced back to me, my service, other people, or specific locations, in the PhD dissertation, reports, publications, conferences, or presentations.	Yes. No.
I understand that all information collected will be kept confidential unless there is risk of harm, abuse, or illegal activity.	Yes. No.
I understand that Georgios may share with his team the information collected and that the information will be stored securely and deleted when appropriate.	Yes. No.
I confirm that I have received a comments form.	Yes. No.
All of my questions have been answered to my satisfaction.	Yes. No.

I agree to take part in this study. Yes. No.

Your name & surname:

Your signature:

Today's date:

FOR RESEARCHER ONLY

Name & surname of the researcher taking consent:

Researcher's signature:

Today's date:

Consultee Information Sheet[70]

Why are we contacting you?

[service] agreed to facilitate this study and Georgios is planning to carry out the study in [service]. As your family member/partner/ friend who lives in [service] has difficulties around providing consent Georgios is contacting you, as an appropriate consultee, to see whether you agree or disagree that your family member/partner/friend in [service] participates in the study. All residents will receive their own information sheet and consent form to say whether they want to take part in the study or not. However, given the residents' capacity status, an appropriate consultee for each resident must also say whether they agree or disagree with study participation. You may feel unsure about your role as a consultee in the context of this study and this is very understandable. You can always contact Georgios to discuss this further or you could speak to [service] or an independent advisor about this. More information about this study can be found below.

[70] The Consultee Information Sheet contained, for the most part, the same information as the Information Sheet for Support Staff. To avoid repetition, here I am only including the sections that were relevant to consultees.

Does your family member/partner/friend in [name of service] have to take part in this study?

No they do not, participation is completely voluntary. As discussed above, all residents will be informed about the study and asked to indicate whether they wish to take part or not. Even if you agree that your family member/partner/ friend participates, you can change this at any time up to the finalisation of analysis without giving any reason. Simply let Georgios know and Georgios will ask you to complete a very short 'Withdrawal Form'. If you withdraw Georgios will aim to keep and use the information he collected from the resident up until the opt out, but if you are not happy with this, Georgios will not use the information and will delete it. If you said that you don't want your family member/partner/friend to participate and you then changed your mind, you can always opt in. Taking part, withdrawing, or not participating, will not affect your family member's, partner's, or friend's placement in the house in any way. If you do not agree that your family member/partner/friend participates in the study, Georgios will still be around the house collecting information from other people, but not from your family member/partner/friend.

What about confidentiality?

Your family member's, partner's, or friend's participation may have to be revealed to staff or the service manager. Georgios will not reveal your family member's, partner's, or friend's participation to other residents.

All the information collected will be kept confidential unless there are serious safeguarding concerns, for example, abuse, danger to the resident or others, or illegal activity. Those concerns could mean that Georgios may have to break confidentiality. Breaking confidentiality could range from discussing the issue with the home manager to notifying relevant authorities. Georgios has developed a guidance to help him handle such situations, however, Georgios expects that the likelihood of such issues arising is low.

Will the participants get paid?

Everyone who participates in the study will receive a certificate to say they participated.

If a participant is interviewed, they will receive a one-off £11 payment to their bank and if any other costs (e.g., travel costs) come up as part of their participation to the interview, those will be paid back to them. If the participant is on benefits, the participant or Georgios will have to see if this payment will affect their benefits. If it does, we will have to find alternatives.

The house will also receive a reward as a 'thank you' for helping out with this study.

What if your family member/partner/friend gets anxious?

We do not expect that this study will cause distress. However, if the resident becomes distressed, Georgios will stop data collection immediately and give the resident time and space. If the resident is consistently becoming distressed in the presence of Georgios, he may consider removing the resident from the study to ensure that their wellbeing is not affected and their wishes are respected. In any case, Georgios will speak to the resident, you, and the service manager about this first.

What are the next steps?

To tell Georgios whether you agree or disagree that your family member, partner, or friend participates in this study, please complete the short forms that you got with this sheet.

For any questions or if you want to discuss the study further, please contact Georgios, his details can be found at the top of this sheet.

Declaration Form for Consultees

Short Title: Care relationships: an ethnographic study
Investigators: Georgios Mamolis (lead researcher)
Dr Paraskevi (Vivi) Triantafyllopoulou (supervisor), Professor Karen Jones (supervisor)

Please note that all residents will receive their own information sheet and consent form to get more information about the study and indicate whether they wish to take part or not.

*Your family member/partner/friend who lives in [service] is referred to as *the resident* in this form.

Please answer <u>all</u> questions

I have read and understood the information provided in the consultee information sheet.	Yes. No.
I understand that the resident's participation is voluntary and an opt out can take place at any time (up to the finalisation of analysis).	Yes. No.
I agree for Georgios to observe the resident's interactions and relationships with support staff and I understand that Georgios will be present in the house observing life in the house. I understand that observations may take place during different activities, in different parts of the house, inside or outside the house.	Yes. No.
I agree for Georgios to approach the resident for an accessible interview, if possible. I understand that the interview may be audio recorded or Georgios will take notes. If I don't agree with the interview being audio recorded, I will let Georgios know and he will only take notes.	Yes. No.
I agree for Georgios to approach the resident for informal/relaxed chats and for him to observe or participate when the resident is chatting to staff or fellow residents.	Yes. No.
I agree for Georgios to check house documents, for example the resident's daily notes, care plan, or practice policies.	Yes. No.
I agree for Georgios and his team to use anonymised information that cannot be traced back to the resident, the care service, other people, or specific locations, in the PhD dissertation, reports, publications, conferences, or presentations.	Yes. No.
I understand that all information collected by Georgios will be kept confidential unless there is risk of harm, abuse, or illegal activity.	Yes. No.

I understand that Georgios may share with his team the information collected and that the information will be kept secure and deleted when appropriate.	Yes. No.
I confirm that I have received a comments form.	Yes. No.
All of my questions have been answered to my satisfaction.	Yes. No.
I agree for the resident to take part in this study.	Yes. No.

Your name & surname:

Your signature:

The name & surname of the resident you are acting as a consultee for:

Your relationship with the resident (e.g., parent, sibling, friend, etc):

Today's date:

FOR RESEARCHER ONLY

Name & surname of the researcher taking consent:

Researcher's signature:

Today's date:

Information Sheet for Significant Others[71]

Why are we contacting you?

[service] agreed to facilitate this study and Georgios is planning to carry out observations in the service, speak to support staff and residents, and look at service documents. As you have a family member, a partner, or a friend living in [service], Georgios would also like to hear your views on staff-resident care relationships. Your participation is completely voluntary and you do not have to take part if you do not want to. Even if you agree to participate, you can withdraw from the study at any time up to the finalisation of analysis without giving any reason. Simply let Georgios know and Georgios will ask you to complete a very short 'Withdrawal Form'. Taking part, withdrawing, or not participating, will not affect your family member's, partner's, or friend's placement in [name of service].

Who can take part?

Family member, partner, or friend of a resident in [service] who is keeping in touch with the resident.

18 years of age and over and able to communicate in English.

What will you be asked to do?

If you take part, you will be asked to complete a short multiple-choice Demographics & Eligibility Questionnaire gathering basic demographic information and double-checking that you are eligible to participate. This can be provided to you online or in a paper format. If you are not eligible, you will be informed of this and thanked for your time and interest. If you are eligible, an interview with Georgios will be arranged to discuss your thoughts on support staff-resident care relationships. The interview is expected to last around one hour and could take place either online or in person. The interview will be audio recorded but if you are not happy with this, we will find alternatives.

[71] The Information Sheet for Significant Others contained, for the most part, the same information as the previous information sheets for this study. To avoid repetition, here I am only including the sections that were relevant to significant others.

Will you get paid?

If you are interviewed, you will receive a one-off payment of £11 (bank transfer) and a certificate of participation in the study. If any other costs (e.g., travel costs) come up as part of your participation to the interview, those will be reimbursed to you. Kindly note that if you are receiving benefits, it is your responsibility to find out if the £11 payment will affect your benefits. Unfortunately, if you completed the Demographics & Eligibility Questionnaire and you are deemed not eligible to participate in the interview, you will not receive any payment or a certificate of participation.

What about confidentiality?

Your participation or otherwise will not be revealed to the care service or your family member/partner/friend who lives in [service]. All the information you provide will be kept confidential unless there are serious safeguarding concerns, for example, risk of or actual abuse taking place, danger to self or others, or illegal activity. Such concerns could justify breaking confidentiality. Breaking confidentiality could range from discussing the issue with the home manager to notifying relevant authorities. Georgios has developed a guidance to help him handle such situations, however, Georgios expects that the likelihood of such issues arising is low.

Consent Form for Significant Others

Short Title: Care relationships: an ethnographic study
Investigators: Georgios Mamolis (lead researcher)
Dr Paraskevi (Vivi) Triantafyllopoulou (supervisor), Professor Karen Jones (supervisor)

Please answer <u>all</u> questions

I have read and understood the information provided in the information sheet for significant others.	Yes. No.
I understand that my participation is voluntary and I can withdraw at any time (up to the finalisation of analysis) without giving any reason.	Yes. No.
If I am interviewed, I understand that my interview will be audio recorded. If I don't wish to be audio recorded, I will notify Georgios and alternatives will be found.	Yes. No.
I agree for the research team to use anonymised information that cannot be traced back to me, the care service, other people, or specific locations, in the PhD dissertation, reports, publications, conferences, or presentations.	Yes. No.
I understand that all information collected will be kept confidential unless there is risk of harm, abuse, or illegal activity.	Yes. No.
I understand that Georgios may share with his team the information collected and that the information will be stored securely and deleted when appropriate.	Yes. No.
I confirm that I have received a comments form.	Yes. No.
All of my questions have been answered to my satisfaction.	Yes. No.
I agree to take part in this study.	Yes. No.

Your name & surname:

Your signature:

Today's date:

FOR RESEARCHER ONLY

Name & surname of the researcher taking consent:
Researcher's signature:
Today's date:

Comments Form

Thank you for taking part in this study! We hope that everything went well!

Any feedback, positive or negative, is welcome.

When things go well, we like to share this with researchers by giving them good feedback.

But if things don't go well, it will help us to know this.

If you want to give feedback, you can:

Contact Georgios Mamolis (lead researcher): **E**: gm518@kent.ac.uk
Or speak to him directly!

Or contact Georgios' supervisors at:

Dr Paraskevi (Vivi) Triantafyllopoulou: **E**: P.Triantafyllopoulou@kent.ac.uk **Tel**: 01227 824784
Professor Karen Jones: **E**: K.C.Jones@kent.ac.uk **Tel**: 01227 827953

Thank you once again for taking part in this study!

TIZARD
University of Kent

Certificate of Participation

Guidance for raising concerns & breaking confidentiality

Study title: Care relationships between support staff and adults with a learning (intellectual) disability in long-term social care residential settings in England: An ethnographic study

Lead researcher
Georgios Mamolis, PhD Candidate in Applied Psychology, Tizard Centre, University of Kent, E: gm518@kent.ac.uk link to academic profile: Georgios Mamolis - University of Kent.

Supervisors

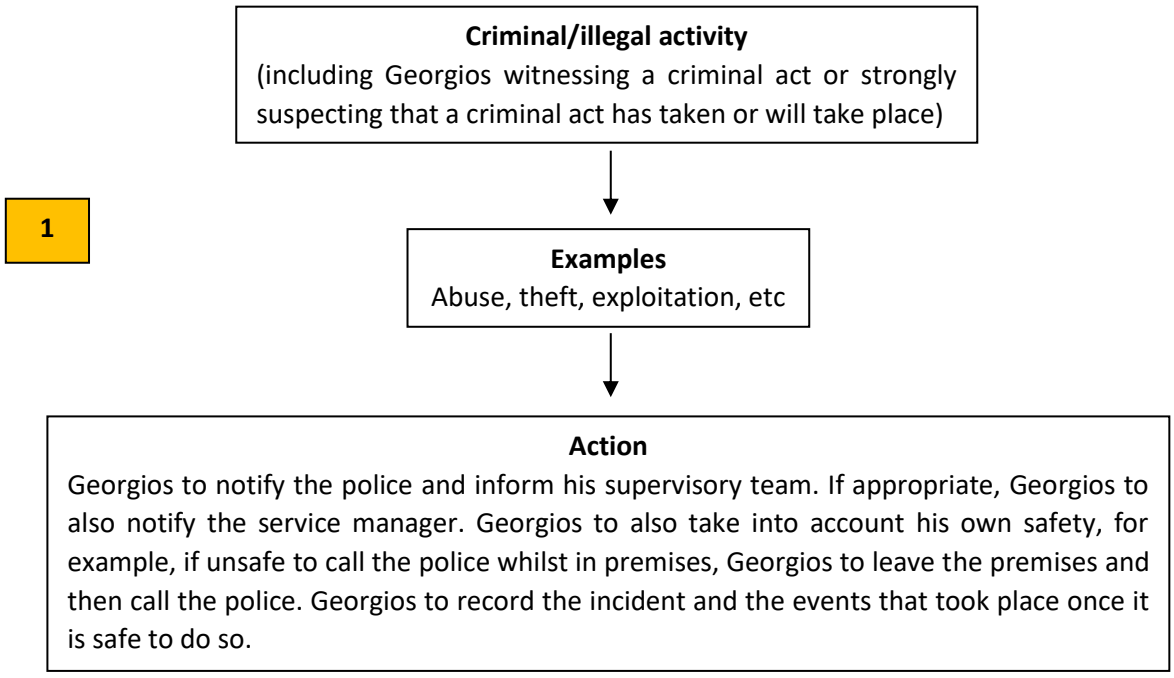
- Dr Paraskevi (Vivi) Triantafyllopoulou, Tizard Centre, University of Kent, E: P.Triantafyllopoulou@kent.ac.uk
  T: 01227 824784, link to academic profile: Dr Paraskevi Triantafyllopoulou - University of Kent
- Professor Karen Jones, PSSRU, University of Kent
  E: k.c.jones@kent.ac.uk T: 01227 827953, link to academic profile: Professor Karen Jones | PSSRU

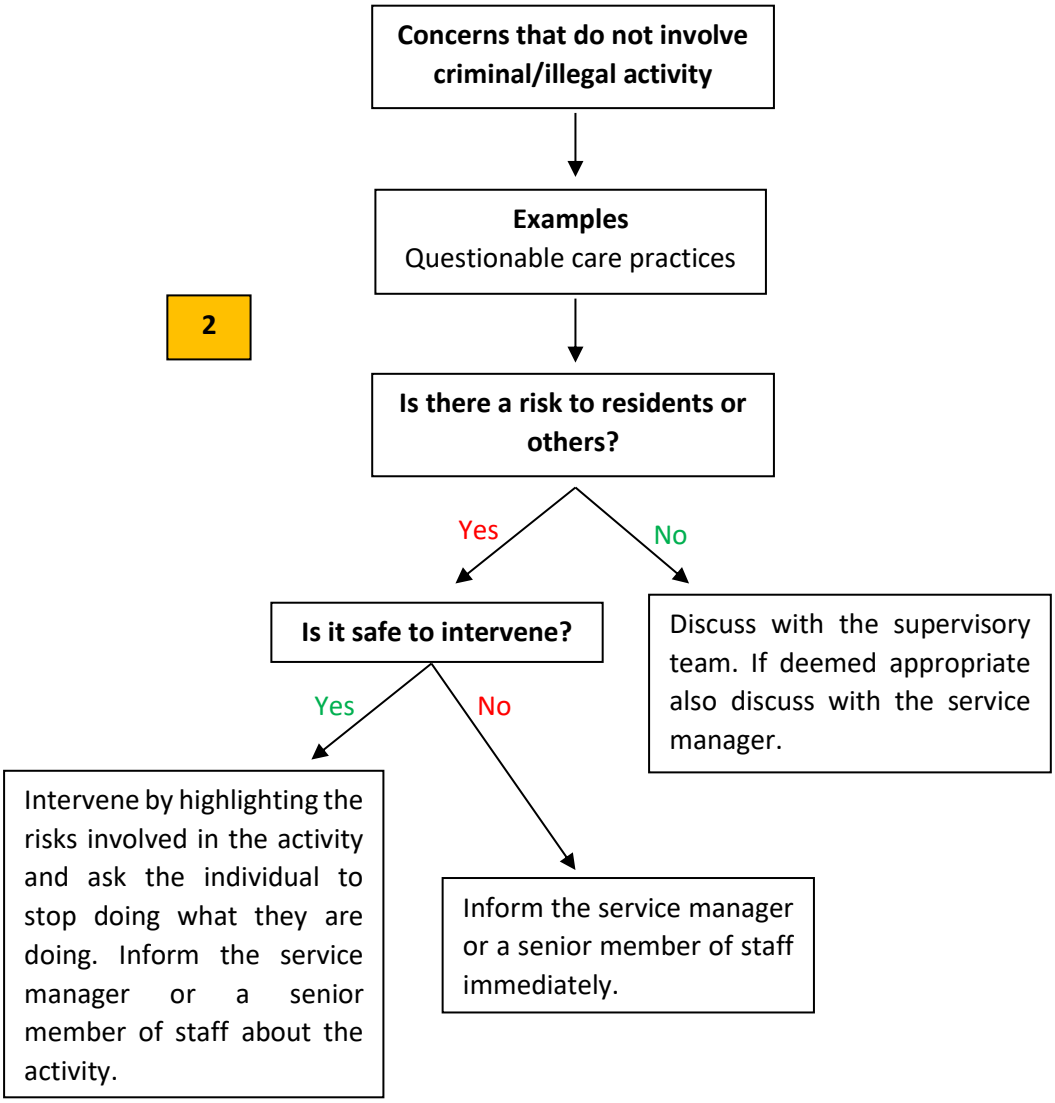
Funder
National Institute for Health and Care Research (NIHR), School for Social Care Research (SSCR)

* * *

In this document, Georgios describes the procedures to be followed when raising concerns during the study and breaking confidentiality is deemed necessary to ensure that everyone is safe and protected. Even though Georgios is hoping that such circumstances will not occur, it is important to be proactive and have relevant procedures in place. Please note that these procedures should not be viewed as linear and that room for proportionality, subjectivity, and flexibility must be allowed to assess whether the situation is calling for raising concerns and breaking confidentiality. As ever, effective and proactive communication with the service to understand the context where care is delivered and received is key.

The procedures are described schematically below:





Contacting other organisations

Depending on the circumstances, Georgios may have to contact other organisations to raise concerns. This decision will be made following reflection and discussion with the supervisory team and, if appropriate, with the service manager. The following organisations may have to be contacted to raise concerns:

1) Local council Adult Social Care Team.
2) Local Council Safeguarding Team.
3) The Care Quality Commission (CQC).

Withdrawal Form[72]

Please answer <u>all</u> questions

I wish to withdraw from the study '*Care relationships: an ethnographic study*' and I do not wish Georgios to collect data from me any longer.	Yes	No
I am happy for Georgios to keep and use the data he collected from me before I withdrew from the study.	Yes	No
I understand that Georgios will still be around the house collecting data from other people, but not from me.	Yes	No

Your name & surname:

Your signature:

Today's date:

FOR RESEARCHER ONLY

Name & surname of the researcher receiving the form:

Researcher's signature:

Today's date:

[72] As the Withdrawal Form was not utilised in this study, here I am only sharing the Withdrawal Form - Support Staff so the reader gets a sense of what the form entailed. The Withdrawal Form for residents, significant others, and consultees was very similar to the form presented here.