Negotiating safety, belonging and agency in shared disability accommodation:

An Australian qualitative study

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ABSTRACT

This study explored the lived experiences of residents living in shared types of disability supported accommodation and investigates how such people negotiated their personal safety, belonging and agency. This study is shaped by a theoretical perspective strongly rooted within a social justice paradigm of critical feminist disability studies.

Seven people with disability took part in this study (representing a wide range of ages). Two lived in stand-alone group homes, 3 lived in clustered group homes and 2 lived in a hostel type setting. Participants shared their experiences through a range of mediums including semi structured traditional interviews, walking-and-talking conversations, drawing, collage and photos. The analysis extended on critical feminist disability studies by also drawing on new-materialist assemblage theory as a means to strengthen analysis and account for both the material and semiotic factors underscoring supported accommodation. These theories helped to shed light on the patterns of epistemic injustice experienced by residents in supported accommodation.

These narrative accounts collectively show that each person's experiences of safety, belonging and agency were profoundly changed when moving into supported accommodation settings. Participants saw structured routine and paid supports as crucial to their safety and survival. They saw supported accommodation as the only viable way to access these routine daily supports without being dependent on unpaid family or supports. Yet in these shared types of supported accommodation there was a climate of compromise. Residents felt safe because they had support and housing – yet were compromising on aspects of safety, belonging and agency in a range of personal ways. There were a plethora of examples where participants negotiated a multitude of issues of powerlessness, loneliness and abuse. This doctoral thesis documented these accounts solely from residents' perspectives. There were a range of insights and implications for policy and practice derived from the wisdom of these seven participants. This included the need for services to consider how they shift the power dynamics so that residents have decision making authority and are recognized as valuable contributors of knowledge. It also requires broader systemic and political reform to address the un-met need for housing and support in ways that do not rely on traditional group home models.

DECLARATION

I certify that this thesis:

1. does not incorporate without acknowledgment any material previously submitted for a degree or diploma in any university

2. and the research within will not be submitted for any other future degree or diploma without the permission of Flinders University; and

3. to the best of my knowledge and belief, does not contain any material previously published or written by another person except where due reference is made in the text.

Ellen Fraser-Barbour

Signed Ellen Fraser-Barbour

Date 21/09/2023

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With sincere thanks,

Ellen Fraser-Barbour

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GLOSSARY OF TERMS

	Working definition
Bodymind	This term is used to challenge the idea that the body and mind are experienced separately (Descartes). Written in various ways, Bodymind or Body-mind, this usage foregrounds the understanding that experiences of the bodymind are integrated. It also situates *ableism* as a concept that is important to consider in terms of experiences both of the body and the mind.
Critical theory	Critical theory refers to a field of research which serves to critique and analyse how power operates in discursive ways that render marginalized communities powerless, and asks vital questions about how and why some people are privileged while others are dismissed, marginalized and devalued.
Critical emancipatory research	Critical emancipatory research refers to research which seeks to not only understand the experience of marginalization, but also adopt a philosophical position that centres critique of what it takes to transform and promote social justice.
Embodiment	Refers to the ways bodyminds experience and interact with the material and social world around us, and recognizes that this is a valuable form of knowledge encoded and conceptualized. This means that there is no single truth – but rather multiple possibilities for understanding embodied knowledge.
Epistemic	To do with knowledge and ways of knowing.
Feminist Disability Studies	Theorizes identity categories as fluid, situated within historical and contemporary social, cultural and political contexts. Extends on feminist theory which questions the taken-for-granted categories of “women” and “men” and argues that these ideas are socially constructed identities situated within a range of historical and contemporary political contexts. Feminist Disability Studies refers to the work of scholars who take up a feminist disability studies approach, analysing why certain identity categories relevant to disability are devalued and seen as lesser, and paying particular attention to normative cultural, social, material or relational structures that compound powerlessness.
Inclusive Research	Refers to a range of research approaches that adopt specific methodological strategies to ensure inclusion of people with disability both in the design and in the implementation of research. These approaches are underscored by the shared belief that all people with disability should not be viewed only as valuable subjects to be researched *about* but rather should be research done *with* and *by* people with lived experience of disability.

Material factors	Pertains to elements of the material world (for example: the physical body, services, finances, resources, possessions, artefacts, physical infrastructure and architecture)
Narrative Inquiry	Is a qualitative research methodology which centres participants' experiences, and positions participants as experts. Narrative inquiry also recognizes that these experiences of negotiating with people or systems are often encoded in some form of narrative or dialogue. There are a range of different narrative inquiry approaches taken up in qualitative research.
New materialist assemblage theory	New materialist theory takes account of the material and semiotic flows affecting the way assemblages are produced (informed by the work of Deleuze and Guattari). Such an analysis explores how conditions are constantly in a state of change and evolvement depending on a range of assemblages at any given moment in time. In the present study, this theory was useful in analysing the social and material factors and the way these affect (either promote or constrain) negotiations of safety, belonging and personal agency.
National Disability Insurance Agency	National Disability Insurance Agency is Australia's federal agency managing the NDIS.
National Disability Insurance Scheme	Australia's National Disability Insurance Scheme (NDIS) provides individualized supports to people with disability who meet the eligibility criteria for funding.
Semiotic factors	Pertains to symbols, language and construction of meaning. Often related to human elements that are part of the social relational world around us. This might include people, relationships, language, symbolism, cognition, culture, beliefs, attitudes and a range of other human aspects.
Social-ecological theory	A model for understanding experiences of abuse. A social-ecological approach takes account of the different levels of interplay between the individual (and their wellbeing) and their micro, macro and mezzo environment.

CHAPTER 1: RESEARCH ISSUE, CONTEXT AND FOCUS FOR THE STUDY

1.1 Introduction

Whilst in the developed world the living standards for many people with disability have improved since the twentieth century, research data continues to show that many people with disability, particularly people with intellectual disability or complex support needs, are exposed to harm and neglect at a much higher rate compared to the general population (Krnjacki et al., 2016). This risk of harm significantly increases for those who live in disability service settings such as supported accommodation.

In Australia most people with intellectual or multiple disability may live at home with a family member well into middle adult years (Crinall et al., 2011). For those who do not live with family or unpaid carers the dominant model is what is termed *supported accommodation*, or *congregated living* settings, such as group homes (Bigby et al., 2017; McConkey, 2007; Walsh et al., 2010). Evidence also indicates that several young people with physical disability (sometimes progressive types of disability) are living in long term hospital care, respite or in aged care facilities due to lack of community living options available for people who require specialist support and nursing care (Disability Housing Futures Working Group, 2016). While the majority of people who live in shared types of disability accommodation in Australia may have intellectual disability, this study purposely chose not to focus on specific categories of disability – but rather chose to explore the experiences of residents (with any type of disability) who live in shared types of disability accommodation.

It is important to note that in this study, *disabled* and *people with disability* are terms used interchangeably. While some scholars and disability advocates ascribe to person-first language which is primarily concerned with the idea of recognizing disabled bodies as human beings worthy of dignity and human rights (Crow & Morris, 1996; Peers et al., 2014), other scholars ascribe to identity-first language arguing that disability should not be erased but rather embraced and seen as a valued aspect of human diversity and identity. Such scholars instead take up the understanding that when disabled *bodyminds* interact with normative material and social processes this then marginalizes and devalues those who are disabled. As Rice et al. (2021, p. 97) have argued, human embodiment should be understood as “fluid and indivisibly entangled with the world “.

The terminology of disabled *bodyminds* has been taken up at various points in this thesis in line with critical disability feminist and new materialist theoretical perspectives (see Chapter 3). The use of the term bodyminds sits in line with the work of critical feminist disability scholars who challenge the idea that the mind and body are two separate experiences or entities (Lewiecki-Wilson et al., 2011; Price, 2011, 2015), and who refer to bodyminds as an embodied and valuable site of knowledge – particularly when articulating how disabled bodyminds negotiate dominant social, material and structural factors (e.g., Burch, 2021a; Clare, 2017; Garland-Thomson, 2013; Sandahl, 2003).

This doctoral study explores how people living in shared types of disability supported accommodation negotiate a sense of *safety, agency* and *belonging* in their everyday lives. Specifically, this study challenges the separation and isolation of safety, belonging and agency often seen in literature and instead explores safety, belonging and personal agency as embodied and entangled experiences in everyday life (further detailed in Chapter 2). This first chapter provides an understanding of Australia’s approach to disability policy and concludes with an overview of the research question and rationale for this doctoral thesis.

1.2 Establishing the Australian context of supported accommodation

There is evidence to suggest that despite the shift towards in-community dwellings, quality of life varies significantly for people with disability depending on the type of supported accommodation they live in (Bigby et al., 2017; Bigby et al., 2018; Friedman, 2019; McConkey et al., 2018). Compared to the general population, adults with significant disability are more likely to stay and live in the family home into much later adult years (Bigby, 2022; Walker & Hutchinson, 2018). While some with significant disability may live in supported accommodation options such as an apartment or small unit, the majority live in group homes operated by disability service providers (NDIS Quality & Safeguarding Commission, 2023). These group homes may stand alone in the community or may include clustered groups of housing or hostels and motels. People living in supported accommodation represent a diverse mix of disability experiences ranging from a mild psychosocial disability through to profound physical, sensory or intellectual disability (NDIS Quality & Safeguarding Commission, 2023).

Research has demonstrated a wide range of outcomes for residents in these types of accommodation. Even when comparing a single type of accommodation, outcomes vary greatly depending on organisational cultures (Humphreys et al., 2022). However, research has consistently reported lower satisfaction overall and poorer wellbeing for those with disability living in larger congregated types of accommodation such as group homes, hostels or indeed in hospital or aged care settings (McConkey et al., 2016, 2018a; McIntyre et al., 2017; Oliver et al., 2020). Some scholars have argued that while smaller types of shared housing models may physically be embedded in the regular community, they still institutionalise residents and are seen as siloed – separate from community (Dearn et al., 2022). Nor do small community housing models necessarily improve inclusion either (Bos & Abma, 2022; Hall, 2010). At the same time, while traditional large scale disability institutions no longer exist in Australia, there remain a number of people living in institutional settings such as aged care settings, or living temporarily (but long term) in hospital settings due to lack of suitable community-based supported accommodation (Australian Institute of Health and Welfare, 2014; Wiesel, 2015). Often placement in these long-term nursing facilities happens due to the need for specialised equipment and/or nursing care which may not be available in supported accommodation (Wiesel, 2015). People with disability are also over-represented in out-of-home youth sectors, and in adult correctional facilities (Cadwallader et al., 2018). Taken together, these reports reinforce the existence of high levels of powerlessness and segregation in the lives of people with disability, many of whom have previous negative experiences with navigating complex and confusing disability service systems, and are still affected by these historical experiences today.

1.2.1 Residents in disability supported accommodation unaccounted for in Australian national data

The Australian Bureau of Statistics Personal Safety Survey conducted in 2016 (Australian Bureau of Statistics, 2017) disaggregated general disability data and consistently reported that such people experience a higher prevalence of violence and abuse across all areas compared to the general population. However, it is important to note that the dataset narrowly defined personal safety in terms only of well-recognized types of violence such as physical and sexual assault, harassment, stalking and general feelings of safety when out in public spaces (ABS, 2017). The more recently updated 2021-2022 personal safety data set (ABS, 2023) has since expanded its definition to also include emotional abuse and domestic and family violence’ however this updated dataset has not disaggregated data on personal safety among disability populations. Further to this, the Australian

Bureau of Statistics datasets exclude people from supported accommodation altogether which means that they are not counted (Araten-Bergman et al., 2017; Araten-Bergman & Bigby, 2020). This thesis adopts a broader approach to personal safety than that of the ABS and considers personal safety as multi-dimensional (explored in more detail in section 2.2).

1.2.2 Potential reasons for living in shared disability accommodation

Often the decision to move to disability service contexts is not an easy one for individuals with disability and/or their families, as shown in the many papers exploring future planning for career, housing, relationships (among other topics) in the context of the lives of people with disability. Such papers, however, tend to centre family perspectives and service provider priorities (Hart, 2022; Murphy, Clegg & Almack, 2010; Taylor, Cobigo & Oullette-Kuntz, 2019). While it is important for people with disability to have the support they need when making important decisions and when negotiating change throughout life, the broader research is heavily weighted towards family member views on future planning on behalf of, or when supporting, a person with disability (Brennan et al., 2020; Burke et al., 2018; Lee & Burke, 2021; Lindahl et al., 2019; Marsack-Topolewski & Graves, 2020; McCausland et al., 2019; Walker & Hutchinson, 2019). Few papers regarding the nature of future planning have focused on the views of people with disability.

The evidence on future planning from the perspective of family members demonstrates a universal concern and worry about the long-term safety of people with disability which underscores decisions about future planning and residential placements. At the core of many future planning discussions is an “uncertainty about what the future holds” including distrust and doubt about the quality of services (Burke & Heller, 2016; Casale et al., 2021; Innes et al., 2012; Lindahl et al., 2019; Marsack-Topolewski & Graves, 2020).

Such fears are not unfounded, as evidenced by media reports such as the story of Ann Marie Smith, an Australian woman with cerebral palsy who had been living alone in her own home with, supposedly, a support worker providing routine care and support. Instead Ann Marie Smith was subjected to financial, emotional and criminal abuse perpetrated by a single support worker. Anne Marie Smith died because of chronic neglect. After her death it became apparent that she had spent many months living in abhorrent conditions with no connection to anyone other than that one support worker (Henriques-Gomes, 2020; McGowan, 2020; Pestrin & Keane, 2021). The tragic story of Ann Marie Smith brings to light the concerns that many people with disability and family members have about what happens behind closed doors when people with disability live independently in private homes. Anne Marie Smith's case hit the disability community hard, highlighting what happens when such people no longer have natural safeguards, friends or family around to safeguard against abuse.

The independent review by the NDIS Quality & Safeguards Commission (Robertson, 2020) and a state level investigation led by South Australia's Safeguarding Taskforce (Vincent & Caudrey, 2020) both highlighted inconsistency in terms of screening workers and agencies and made several recommendations to improve screening processes. These reports both evidenced that Anne Marie Smith was failed by the disability service; they also highlighted grave concerns about people in similar situations to Anne Marie Smith isolated people with their only source of human connection stemming from paid disability workers, prompting the question: "who will know if something is wrong?". On this point, the report by Vincent & Caudrey (2020) noted that natural connections and a sense of belonging and value in community reduces the risks of abuse and exploitation. Such reports form part of the socio-political context for people with disability and their family members and it can be expected that concerns and worries about abuse in independent living situations do play a role in informing decisions to move to supported accommodation. While independent living is beyond the scope of this study, the case of Ann Marie Smith has brought to light dominant public discourses and beliefs about the vulnerability of people with disability living independently or in regular community. For every story published, there will be a sea of unspoken stories, and I believe an important counteraction to oppression and silence is individual and collective liberation to share stories and have these experiences listened to and validated.

1.2.3 Deinstitutionalization: From a medical to social-relational understanding of disability

The history of institutionalization can be traced across Britain, America and Australia (among other countries) back to the mid-19th century when people with certain characteristics were gathered up and incarcerated because their bodies and minds were seen as inferior and unsightly and a threat to society hygiene (Bostock et al., 2001, 2004; Mansell, 2006). Hallahan (2021) has diligently tracked the history of treatment towards disabled bodyminds in Australia and notes that those deemed "idiots", "lunatics", "mad", or "unfit for society" were generally looked after by family. Few had money to seek private care which often meant that disabled people were segregated in hospitals or asylums funded by benevolent charities or private funds or ended up incarcerated in prison systems. Globally during the 19th century there was increasing interest in medical science and intervention along with the rise of the eugenics movement, which compounded the growth of large scale facilities aimed to cure or “heal” (Roets et al., 2022). The growing interest in medicine and intervention meant an immense overcrowding in these systems (Cadwallader et al., 2018; Hallahan, 2021). Several Australian inquiries investigated these conditions and the poor treatment, and made recommendations which sought to change conditions, but not the model of housing or care itself (Hallahan, 2021). These reports consistently highlighted that living conditions were poor, with overcrowding, poor care and nutrition and lack of training for staff – all compounding maltreatment, abuse and violence. Hallahan reflects on the absence of disabled people’s stories and states that these voices were discounted “or squashed by administrators and attendants or attributed to the ravings of the idiots and lunatics” (Hallahan, 2021, p. 29).

The 20th century was an era of reform, with medicine taking hold as a means to cure and eradicate disability or illness. People with disability – particularly those with intellectual disability or significant physical disability – were relinquished long term into the care of hospitals and medical institutions on advice by medical practitioners. By the 1950s, it was common for both children and adults with intellectual or physical disability to live in institutions, often segregated on wards alongside those deemed lunatics or “mentally insane”. People with disability were subject to involuntary medical treatments, procedures and “cures” that were often unethical and inhumane (Mansell & Beadle-Brown, 2010). There are harrowing stories of routine violence and eradication of personhood and citizenship in accounts retold in projects such the Kew Cottages History project (Gleeson, 2010; Manning, 2009). In these institutions people were routinely exposed to violence, abuse, and neglect, further perpetuated by a sector that was under-funded, under-resourced and over-crowded (Hallahan, 2010). These systems and structures for housing disabled people in institutions were the antithesis of justice, and recognition of selfhood, self-determination and growth. This history has significance to this doctoral study – particularly given that relinquishment to institutions continued up until the 1980s in Australia (Hallahan, 2021). This means that some people with disability living today may still recall growing up in institutional settings.

The closure of institutions in Australia, which happened from the 1980s onwards was staggered and slow, and continues to this day (Hallahan, 2021). The deinstitutionalisation movement was a human rights uprising, with governments recognising that being segregated and isolated in institutionalized settings, subjected to harmful medical interventions that aimed to cure or eradicate disability, was an affront to the rights of the person. People with disability had been seen as objects of welfare and charity, to be cared for and treated as dependent on the state; they had not been seen as valued citizens worthy of rights, independence, choice and control (Hall, 2010). At the time of writing, there are very few remaining disability-specific institutions, with most of the residents currently in process of transitioning to community housing as small groups of residents (Altermark, 2017; Chowdhury & Benson, 2011; Steele, 2022; Wada et al., 2020). The institutionalization of people with disability is particularly relevant to consider in Australia, given that the major housing providers that still exist often have long histories – starting off as institutions and then becoming part of the deinstitutionalization movement (Hallahan 2021).

Linked to the deinstitutionalization movement is the shift from medical intervention, and the idea that people with disability need to be cured or eradicated, towards a social understanding of disability (Hallahan, 2021; Roets et al., 2022). The social model of disability contests the idea that the best way to deal with disability is to fix or cure bodily impairments and instead argues that each person's body and mind interacts in relation to the social and relational world around them and therefore society has a responsibility to address barriers for inclusion (Oliver, 2013; Shakespeare, 2016). While the idea of large scale institutions for people with disability may seem a distant history lesson for younger people with disability, many living older people with disability grew up in institutions and experienced moving from institutions to smaller types of shared accommodation or to independent supported living during the late 20th century and early 21st century (Altermark, 2017; Wada et al., 2020). These smaller community types of housing options have been proven to have better outcomes than larger institutions and have been a major step forward towards improving quality of life, health and wellbeing for people with disability (Altermark, 2017).

It is important to remember these historical accounts of institutional abuse and exploitation record what many people with disability experienced as part of the institutionalization era. Those whose bodies or minds were deemed deviant or "Other" were institutionalized and hidden away from mainstream community, reflective of dominant ideals and ableist values underpinning the rise of industrialism (Hallahan, 2021). The segregation and harm inflicted on children and adults with disability must be acknowledged as part of the cultural and social inter-generational narrative that influences people living with disability today.

1.3 The contemporary context of "home" in disability service settings

Regardless of ability, home is universally understood as a place of shelter, a place where fundamental human needs such as a roof over the head, water, food and sanitation can be fulfilled. It is also much more than this. Home is personal, and central to developing a sense of self-hood and identity; inextricably tied to our social, emotional and physical wellbeing (Beeckmans et al., 2022; Scott, 2009). Alain de Botton (2006, p. 3) describes home as a:

> sanctuary in a psychological sense as much as we need one in the physical: to compensate for a vulnerability. We need a refuge to shore up our states of mind, because so much of the world is opposed to our allegiances.

Research consistently highlights that people who experience unrest, violence, or discrimination fare poorer in health outcomes (Krnjacki et al., 2018). Not having a safe home has a ripple effect, impacting and shaping experiences of belonging in profound ways. In recent years in Australia there have been increasing issues of homelessness among the general population, and people with disability remain over-represented in such population groups (Beer et al, 2019). While much of this broader literature focuses on the need to develop safe housing in the context of homelessness, there are also issues of safety and denial of freedom when people with disability must navigate these same inadequate housing options, face waiting lists for support, and end up in residential situations that do not meet their needs and are insecure (People With Disability Australia, 2010). This would arguably have a significant impact on wellbeing and resilience over the life course and significantly influence how people negotiate issues of safety, belonging and agency in their lives.

Saunders and Williams (1998) saw home as political: as self-expression, choice and control, authority and realisation of independence; this involves constantly negotiating social ordering and power relations, particularly in terms of gender (Saunders & Williams, 1998). Sixsmith, one of the most well-known academics writing on the meaning of home to date, argued in one of her earliest well-cited works (1986) that home is multi-dimensional. She theorised that there were three primary features of home (Sixsmith, 1986, p. 292):

- the physical home as one that not only concerns the physical structure and architecture of home, but also concerns the interiors of “warmth, telephones and everyday modern conveniences”;
- the personal experience of home refers to experiences of self; a person with desires, needs and wants. Home is seen as central to the development of identity, self-expression and a space where people can “be themselves”;
- the social experience of home refers to the experiences of negotiating relationships with people within the home. These experiences significantly shape how people feel about the

> home. For some people relationships may mean love, enjoyment and entertainment; at other times it may be the base for stress, pain, anxiety and grief.

Sixsmith's theoretical model of home has strongly influenced a large body of research in a diverse range of fields such as anthropology, social geography, health, psychology and education. Many studies situated in health or disability borrowed Sixsmith's model of home in studies that explored (a) care and rehabilitation in the family home post-injury (Labbé et al., 2017) and/or (b) constructions of home for elderly and ageing populations transitioning to hospitals or elderly care facilities (Maersk et al., 2018; Sixsmith, 1986; Soilemezi et al., 2017). Many of these studies sought to explore meanings of home from the caring perspectives of paid healthcare professionals and/or informal family carers – tending to focus on elements of care (Sixsmith et al., 2014; Soilemezi et al., 2017). I posit that many of these studies adopted a medical pathologized understanding of disability, ageing and illness, and there was little recognition in these papers of how the context of living within institutionalised settings might perpetuate and increase social issues of powerlessness, harm or neglect.

1.4 The missing dialogue of "home" in disability service: An issue of social justice

There has been a mix of studies on congregated supported living situations, many of them using observational measures and survey data. Some studies included the perspectives and responses of people with intellectual or physical disability living in the accommodation setting, but often the studies represented the views of carers and support staff, managers and family members (Hart, 2022; Murphy, Clegg & Almack, 2010; Taylor, Cobigo & Oullette-Kuntz, 2019). These studies provide vital data and information on the needs of people with disability in congregated living situations and the issues they face; however I would argue that these second or third-hand observational accounts do not represent an authentic picture of congregated living as people with disability see and feel it.

Annison (2000) pointed out that people with intellectual disability, whilst counted in research, have rarely been consulted, or recognised by researchers as valued informants and sources of information. He sought to challenge this and conducted a landmark phenomenological study on the meanings of home from the perspectives of people with intellectual disability living in disability accommodation settings. This study critiqued the tendency to view such residential settings as businesses providing "service provision" and "supervision," considering it problematic when there is little recognition of those places being home to the people who live there. Annison's study further highlighted that the tendency to treat service provision as a business contributes to dehumanisation and de-personalisation of people with disability. This echoed concerns raised by earlier researchers who highlighted that many community houses still maintained rigid institutionalised cultures of supervision and business. O'Brien (1994, p.1) articulated this in the following way:

> …adults with developmental disabilities eat the bread of others and know only the way that goes up and down stairs that are never their own. Either they live in their parents' house or they occupy a bed in a place established to offer supervision and treatment. In most instance, opportunities to hold one's own lease require the ability to succeed with minimal assistance. Problems usually send a person with a life-long disability down the steps of the service continuum to a bed in a more restrictive facility. […] Today's service systems were developed around the unspoken assumption that people could not have both severe developmental disabilities and homes of their own.

O'Brien (1994) argued that people with disability did not have the same rights, freedoms or opportunities as their peers without disability and that there were a range of social, cultural and materialistic factors contributing to the social disadvantage of many with disability. Whilst O'Brien wrote this over two decades ago and there has been significant change since the 1990s, his words still hold power today and allude to deeply entrenched socio-cultural and political structures that deny the citizenship of people with disability. Indeed the majority of people with disability accessing government supports live at home with their parents, or in group homes, clustered housing and other residential dwellings (Crinall et al., 2011; National People with Disabilities and Carers Council, 2009)). When people with disability are seen as recipients of services, when there is little recognition of home in the lives of people with disability, and when there is systemic and systematic devaluation and silencing of the experiences of people with disability, this de-humanises people with disability.

If home is ideally a reprieve from public gaze and judgment, and a place of safety where we are free to make choices and self-express, then it seems relevant to investigate how people with disability who live in supported accommodation negotiate choice and control over what happens in their home life. If home is a space where the messiness and joy of relationships and intimacy can be enacted and negotiated with relative privacy, how do people living in supported housing negotiate and balance this need for relationships and social affinity with the people they live with, when historically they do not necessarily choose who to live with, or where to live, or who their staff are? If home is meant to be a safe place – a space that is “ours” and where we feel “at home”, how do people with disability negotiate belonging and feeling “at home” whilst simultaneously balancing the reality that this home is also a workplace for staff and workers governed by agencies, administrators and policies, all informing practices and cultures within the house. These questions underpin the rationale for investigating embodied experiences of safety, belonging and personal agency in supported accommodation settings.

Whilst in Australia and elsewhere in the developed world there has been significant policy reform and inroads made in terms of people with disability being included in society and living in the community (Altermark, 2017; Cadwallader et al., 2018; Roets et al., 2022), many disability advocates argue that in contemporary community housing institutionalized forms of abuse remain rife despite the shift towards community models of housing and supports (Disability Royal Commission, 2019a). There is an argument that community model type congregated settings are still underpinned by problematic cultures that devalue people with disability, restrict their personal agency and choices, and expose people to abuse and situations that harm (Cadwallader et al., 2018). Manthorpe (1999) raised such concerns in her book *Institutional abuse: Perspectives across the life course,* where she analysed the abuse experiences of children, people with disability and the elderly living in institutional settings in the United Kingdom. She argued that such people were frequently negotiating highly coercive settings of control, restriction and neglect. Despite Manthorpe’s work in 1999, these are not yet concerns of the past. Cadwallader et al. (2018) highlight similar concerns in their more recent essay titled *Institutional violence against people with disability: Recent legal and political developments* that people with disability were often in situations of powerlessness when navigating institutions such as disability accommodation institutions, aged care systems, psychiatric facilities and hospitals. People with disability are also over-represented in mainstream institutional settings, in out-of-home care, hospitals, psychiatric facilities and correctional facilities across Australia (Cadwallader, Spivakovsky & Steel, 2018). Institutional violence remains a pressing issue for people who live in community settings reliant on disability service systems. Whilst efforts have been made to close long-term disability-specific institutions since the 1980s and people with disability now tend to live in smaller community residences, the issues of powerlessness and the routine and systematic nature of violence, abuse and neglect have not diminished (Bigby, Bould, et al., 2018; Disability Royal Commission, 2019a; Holburn et al., 2008; Kåhlin et al., 2016).

1.5 International human rights agenda

The foregoing historical perspectives also shed light on how far we have come in Australia, and worldwide more generally, in terms of social progress and improved opportunities. In 2008 the United Nations implemented the Convention on the Rights of Persons with Disability (UNCRPD), recognizing that people with disability were at a significant disadvantage and were more likely to experience inequity and harm. This was the first binding instrument that consolidated existing international human rights obligations and spelled out obligations specific to all people with disability (Australian Law Reform Commission, 2014). The Convention served as a statement internationally that people with disability were and are valued human beings deserving of dignity and respect in policy and legislation, providing a comprehensive set of standards and principles. Australia was one of the first signatories to ratify the UNCRPD, accepting the obligations and putting forward various strategies and legislative reforms to address denial of these fundamental human rights and promote respect.

Many of the principles outlined in the UNCRPD are applicable to any and all people with disability. However for the purpose of this doctoral thesis, only the following two will be mentioned: Article 16: Freedom from exploitation, violence and abuse, and Article 19: Living independently and being included in the community. These are quoted in Figure 1.1 directly from the United Nations Enable web site.

Article 19 is a particularly important principle to cite here as it demonstrates that Australia has a commitment to ensuring that people with disability have the right, equal to that of non-disabled people, to choose their residence, as well as where and with whom they live. The Article also notes that people with disability should not be forced into certain types of living arrangements for disabled people that segregate them from community. It is important to note that while some in congregated disability settings want to "share" with others, the preference and will to share with others, with or without disability, should not then mean enforced segregation or restricted access to services, supports or community.

Article 16

- Freedom from exploitatoin, abuse and harm
- Article 16 - Freedom From Exploitation, Violence And Abuse

  1. States Parties shall take all appropriate legislative, administrative, social, educational and other measures to protect persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse, including their gender-based aspects.
  2. States Parties shall also take all appropriate measures to prevent all forms of exploitation, violence and abuse by ensuring, inter alia, appropriate forms of gender- and age-sensitive assistance and support for persons with disabilities and their families and caregivers, including through the provision of information and education on how to avoid, recognize and report instances of exploitation, violence and abuse. States Parties shall ensure that protection services are age-, gender- and disability-sensitive.
  3. In order to prevent the occurrence of all forms of exploitation, violence and abuse, States Parties shall ensure that all facilities and programmes designed to serve persons with disabilities are effectively monitored by independent authorities.
  4. States Parties shall take all appropriate measures to promote the physical, cognitive and psychological recovery, rehabilitation and social reintegration of persons with disabilities who become victims of any form of exploitation, violence or abuse, including through the provision of protection services. Such recovery and reintegration shall take place in an environment that fosters the health, welfare, self-respect, dignity and autonomy of the person and takes into account gender- and age-specific needs.
  5. States Parties shall put in place effective legislation and policies, including women- and child-focused legislation and policies, to ensure that instances of exploitation, violence and abuse against persons with disabilities are identified, investigated and, where appropriate, prosecuted.

Article 19

- Living independently in the community

- a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
- b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;
- c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs." (taken from UN website Article 19 – Living independently and being included in the community | United Nations Enable)

Figure 1.1: Articles 16 and 19 from the UNCRPD

1.6 Reports of deep rooted inequity among Australians with disability

In fulfilling the commitment Australia made by ratifying the UNCRPD in 2009 (see figure 1.1) Australia went on to establish its first National Disability Strategy78 2010-2020 (hereafter referred to as the original strategy). This Strategy was informed by extensive community consultations which resulted in the *Shut Out: Experiences of People with Disability and their Carers* report (NPDCC, 2009). This report emphasised "over-burdened and under-resourced" disability service systems which forced people to take what was on offer or do without support at all, even if these options for supports restricted choice and control. This report written over a decade ago acknowledged that people with disability were systematically denied rights to safe housing, education, employment and healthcare.

In Australia, there have been repeated calls from peak disability advocacy organisations for a Royal Commission into abuse in disability service contexts. These calls were answered in April 2019 with the establishment of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (hereafter referred to as the 'Disability Royal Commission' for brevity). Over the past four years from 2020-2023 the Disability Royal Commission heard from a range of stakeholders including people with disability, family and service providers, academics and others. There were thousands of submissions, 32 public hearings and over 1500 private sessions covering a wide range of issues of abuse, exploitation, neglect and violence across a range of community, disability, educational, work and other settings. The inquiry into *Abuse, Violence and Neglect in Institutional and Residential Facilities for People with Disability* (2015) noted that whilst some organisations were proactive in developing policies in line with zero-tolerance of abuse with reporting procedures, other organisations did not consistently report beyond the organisation. The inquiry also heard evidence that there was a conflict of interest when funding bodies were investigating organisations they funded, and a lack of clear avenues for disclosure or reporting within and external to organisations, particularly within residential and accommodation services. Such reports gave precedence to the voice of people with disability and their supporters, highlighting how reliance on inadequate supports led to conditions which caused harm.

1.7 Australia’s commitment to social progress

While the evidence reviewed suggests that people with disability continue to face significant disadvantage across all domains of life, there have also been a number of political and social reforms in line with the National Disability Strategy 2010-2020 informing all levels of government and guiding their responses to issues with political and practical actions. Some of these reforms such as the National Disability Insurance Scheme (NDIS) have been summarized in the below sections under policy reform (see section 1.8.1).

The original Strategy has now been superseded by Australia’s Disability Strategy (2021-2031). The updated Strategy prioritises targeted engagement and strategic actions, as well as improved measures to evaluate and report in relation to seven outcome areas: 1) employment, 2) inclusive homes and community, 3) safety and justice, 4) personal and community support, 5) education and learning, 6) health and wellbeing, and 7) community attitudes. The Strategy has a targeted Action Plan focused on Safety and Justice which outlines a number of objectives including:

- Improving how risk and protective factors relevant to harm are identified and responded to
- Ensuring mainstream and disability services’ understanding of appropriate and proportionate responses to protect people with disability at risk of harm
- Reducing or erasing the use of restrictive practice
- Focusing on natural safeguards (such as family members and community connections).

Perhaps most pressing to note was that at the time of writing there was **no** targeted action plan published which focused on addressing the need for action on the lack of inclusive housing, an area of desperate need particularly given the current rental and housing crisis in Australia more broadly.

1.7.1 National Disability Insurance Scheme (NDIS)

As part of ratifying the agreement of the UN Convention on the Rights of Persons with Disability and in accordance with Australia’s Disability Strategy 2010-2020, the implementation of the NDIS Australia which began in 2013 radically reformed the way services and goods related to disability supports were purchased and operationalized. In Australia as of June 2023 the National Disability Insurance Agency (2023) reported that across Australia there are 610,502 people with disability on the scheme with this number expected to grow over the coming decades (National Disability Insurance Agency, 2023). Additionally there are 31,509 people accessing ‘Supported Independent Living (SIL) options through the NDIS (which is the stream of funding that supports various supported living options) (National Disability Insurance Agency, 2023).

The Disability Housing Futures Working Group (2016) raised concerns about the eligibility criteria for specialist disability accommodation noting a significant number of people with disability (predicted to be between 35,000-55,000) were unable to access safe, affordable accessible housing that met their needs. At the same time housing has been in high demand across Australia more widely and there continues to be an increase in the number of people generally across Australia seeking help from homelessness services (Constantine, 2023).

Australia faces a chronic shortage of supports and adequate housing with long waiting lists of people asking to be placed (Disability Royal Commission, 2019b, 2020). While a relatively small sample of the NDIA population actually access specialist disability accommodation streams of funding, these people tended to have much higher additional expenses related to their supports compared to the average person accessing the NDIS (National Disability Insurance Agency, 2023) and therefore tended to have larger packages of funding. This Scheme fundamentally changed how disability services operated by moving away from block-funded “one-size-fits-all” services to instead provide individual funding packages allocated to individuals with disability. This ideally increases flexibility with more choice and control in how each person organizes their supports related to disability.

1.7.2 NDIS Home and Living Policy

Within the NDIA there has been significant effort to address the issue of housing with the introduction of a new Home and Living Framework. This framework was still in the development stage at the time of writing this thesis in September 2023 (Summer Foundation, 2023). The framework which is in the early phases of being rolled out aims to address the risk of people with disability ending up in inappropriate supported accommodation, aged care or hospital settings (NDIA, 2023). The NDIS Home and Living Policy aims to provide an overarching framework to guide how home and living supports are delivered and inform how decisions are made about the types of housing and supports people have. There are several potential sub-streams for funding through the NDIS which fall under the Home and Living Policy which assist people with disability with accessing and maintaining housing and supports (National Disability Insurance Agency, 2021). These are summarized and briefly defined in figure 1.2.

Funding type	**What supports are provided**
Individualized Living Options (ILO)	Support to help people with disability forward plan and make decisions about where they want to live, who they want to live with and what supports they need.
Supported Independent Living (SIL)	For people with higher support needs who require daily support with personal care or support/supervision with daily tasks. It may also include overnight support. SIL funding can be accessed by both those who live alone and those who share with other NDIS participants.
Specialist disability accommodation	Funding to help people access a range of housing that is specifically designed to be accessible for people who have been assessed as having an extreme functional impairment. These SDA dwellings vary and may include a range of individual or shared options.
Medium term accommodation	Enables people to have somewhere to stay in the interim while they are awaiting for supports to be arranged or set up. In order to access this support people must have a long-term home (e.g.. SDA) that they can move to. This is usually funded for 90 days. This may include individual or shared accommodation.
Short term accommodation	Enables people to stay in short term accommodation (e.g.. for respite or during emergencies). This covers the costs for short-stay accommodation of up to 14 days. This may be individual or shared.
Home modifications	Provides funding to make sure the home is customized to better suit individuals' needs and improve accessibility around their home.

Figure 1.2: Australia's National Disability Insurance Scheme Funding Streams Relating to Supported Accommodation

NDIS participants may also rent or own their residence privately, or via public or social types of housing. Currently it is increasingly difficult to access housing through social or public housing services as more and more Australians find themselves in strife, unable to meet the rising costs of living (Beer et al., 2019).

1.7.3 National oversight by the NDIS Quality and Safeguards Commission

The NDIS Quality and Safeguards Commission was set up as an independent national agency under the National Disability Insurance Scheme. The Quality and Safeguards Commission acts as a regulatory body with the primary aim of ensuring that services provided under the NDIS legislation are meeting the needs of individuals in a way that promotes human rights and personal safety (NDIS Quality and Safeguards Commission, 2021). It does this by:

- establishing an NDIS Quality and Safeguards Framework to standardize quality of practice and procedures across services
- delivering education and information across community
- responding to complaints as well as investigating and engaging in conciliation
- registering providers and ensuring background checks for workers
- providing oversight of provider practices and procedures.

It is worth noting that some people with disability receiving their personalised funding package may opt to buy or purchase goods, services or supports that are not specifically registered under the NDIS (NDIS Review, 2023). In these cases the NDIS Quality and Safeguards Commission does not provide oversight or responses.

There are a wide variety of regulatory bodies operating at a state and federal level that serve vital functions under various state/territory and federal standards and legislations. This means that there are also a variety of frameworks, roles and functions underpinning different agencies responsible for different aspects of community; for example the Office of the Public Advocate located in Victoria and the NSW Ombudsman in NSW are both state level agencies responsible for adult safeguarding oversight. There are also a range of state bodies responsible for mental health or mainstream community and health services. The wide variety of safeguarding structures and systems providing oversight means that the landscape for oversight varies depending on states and territories. Indeed the latest NDIS Review report (2023) on the Quality and Safeguarding Commission Framework highlights that many in the community were confused about where to complain or who to complain to when issues arose and were unsure which statutory body was best placed.

1.8 Summary and thesis outline

This first chapter has provided an overview of how the international and national landscape of disability and human rights have shifted over time, moving from the model of institutionalization to smaller community housing models. Additionally, funding has shifted from a welfare approach towards an ethos of personalized supports with the view that this will enable people to contribute to society as productive citizens. This has also meant shifting the perceived role of people with disability from that of a recipient of welfare towards a neo-liberalist agenda of consumers having choice and control over their supports. This in turn has meant that disability services (including supported accommodation services) have become market-driven providers.

The following chapter (Chapter 2) outlines the literature on personal safety, agency and belonging that has relevance to shared types of disability supported accommodation settings.

Chapter 3 first details my ontological assumptions underpinning the framing of this research including the centrality of lived experience and other inclusive research principles. It next details the qualitative methodology and range of methods taken up to ensure that I remained receptive and flexible to each participant's preferences in terms of how they wanted to partake in this research. The chapter concludes with an overview of who the participants were along with ethical considerations and safeguards that needed to be put in place.

Chapter 4 introduces readers to each of the participants by name (pseudonym) and provides a profile for each participant. Chapters 5 and 6 highlight the key findings that were heard from participants. Chapter 5 focuses on life prior to living in supported accommodation and explores how decisions were made. Chapter 6 delves into life in supported accommodation and reports on the factors participants felt were meaningful to them in regard to safety, belonging and agency.

Chapter 7 provides a discussion, linking these findings to the broader literature and applying a social justice lens to critique the ways people with disability in supported accommodation are silenced and impacted. Chapter 8 highlights some of the implications for policy and practice. Chapter 9 concludes with some final comments and call to action.

CHAPTER 2: REVIEW OF THE LITERATURE

2.1 Introduction

Chapter 2 presents an overview of the dominant issues identified in the literature in relation to disabled peoples' experiences of supported accommodation settings. These issues have been organized according to three dominant over-arching human needs of 'personal safety', 'personal agency' and 'belonging', since much of the disability studies literature has tended to focus on these three topics in isolation. Nevertheless, I acknowledge that, arguably, these three core values often overlap. For example, when people with disability have limited choice and control (whether it be due to attitudes of paternalism, or systemic constraints), this may lead to conditions that are abusive. Likewise, when people face significant discrimination and have few friendships this impacts on their level of resilience to negotiate issues of oppression or devaluing.

2.2 Personal safety

At the heart of "what helps people feel safe" in their home lies the range of situational factors that contribute to a sense of safety and resilience to deal with adversity, or conversely contributes to an environment where violence and neglect is prevalent in the lives of people with disability. In this thesis, "personal safety" has been taken to mean freedom from injury or harm. It is important to note that a person's disability does not inherently lead to them being vulnerable, rather there is a range of socio-political, cultural and material contexts that then create an environment where abuse or injury goes unchecked. The following section outlines the theoretical perspective on what constitutes 'personal safety' and then presents an overview of the multiple forms and types of harm and abuse that violate ones' personal safety.

2.2.1 Theoretical perspectives on personal safety

First, in order to conceptualize personal safety, it is important to address the issue of vulnerability of people with disability. While a person's individual characteristics of disability and impairment may increase the risk of abuse, research highlights that there are aspects of the human condition that are not caused purely by a person's bodily impairment, including a range of historical and contemporary material, social and political contexts that contribute to situational vulnerability

(Lid, 2015). For the purpose of this thesis, *vulnerability* is understood as both an inherent vulnerability that is an inevitable part of the human condition – situating disability as one aspect, but also inclusive of gender, race, class, and so on – as well as the social and relational experience of vulnerability – dependent on the situation and context (Mackenzie et al., 2014). This combination means that some people have less capacity and power to assert their interests, which is compounded when there are oppressive structural, material and environmental factors that also contribute to vulnerability. Conversely, some people have a greater degree of authority and privilege (again, dependent on both human condition and situational context), which may offer a degree of relative protection from harm. For people with disability, this definition has particular relevance as it shifts the focus away from the stigmatization of "vulnerable people" to instead understand how the interpersonal and systemic contexts form conditions which compound experiences of vulnerability and increase potential risk of abuse and harm (Araten-Bergman & Bigby, 2020).

Researchers highlight that the patterns of vulnerability and prevalence of abuse are better understood through a social-ecological lens which draws attention to the range of causes and factors at various levels of community and structure (Araten Bergman & Bigby 2020; Araten-Bergman et al., 2017; Hollomotz, 2009; Terry, 2014). This social-ecological perspective has been used in disability abuse research as a way to identify risk factors at different levels of community and illustrates that vulnerability is not "caused" by a person's disability, but rather by the interaction between the individual and their social and ecological environment (Terry, 2014). This emphasizes the need for approaches which address not only individual characteristics associated with disabled people which may compound risk of violence, but also pays attention to the range of strategies that may strengthen prevention and protection in the community and the structural environment surrounding the individual. Abuse may range from subtle, non-criminal (but nevertheless harmful) insults, humiliation or slights (Robinson, 2013) to criminal types of harm such as physical or sexual violence (McGilloway et al., 2020; Plummer & Findley, 2012).

In the context of this doctoral study, *personal safety* is understood to be multi-dimensional – a broad term that encompasses freedom from all types of physical and psychological types of abuse and the realization of physical and psychological wellbeing. Seemingly few studies have conceptualised what constitutes personal safety from a theoretical standpoint, while those studies that did explore personal safety tended to focus on personal safety from the point of view of prevention or protection strategies in an applied sense. Robinson et al. (2019) and Robinson and

Idle (2023) argue that personal safety is not just the absence of abuse, but also about what helps people to thrive. For example Robinson et al. (2019), in their report on promoting safe and respectful cultures in services, explored the way people in services understood prevention and safety and noted that the term was often understood by people with intellectual disability in concrete ways to mean physical safety or occupational health and safety. Robinson et al.'s (2019) report deepened these understandings of safety by inquiring about people's experiences of safety, care and support, decision making and choice, and ability to resolve problems that arose in service settings. From this report the key feature underscoring safe and respectful services was the importance of people with disability being socially connected, feeling valued, supported, listened to and respected as a human being with dignity.

An earlier study by Robinson (2014) explored how people with intellectual disability negotiated safety at home, notably in supported accommodation. This study found that while most participants understood personal safety in concrete ways, for example locking the door at night time or being safe around fire, it was more challenging to articulate experiences about harm in personal relationships. When harm is subtle, routine, or part of everyday interactions it can be difficult to identify and name these instances. Robinson (2014) supposed that some of these difficulties pertaining to the topic of interpersonal harm may be due to feelings of shame. Participants also talked about a range of practices and steps they took to feel safer such as:

- physical strategies: e.g., withdrawing from a bad situation; not going out at night time; locking the door
- relational strategies: e.g., spending time with family; choosing own workers; having a rapport with co-residents or neighbours
- help-seeking strategies: knowing where and how to complain, e.g., contacting emergency services on the phone or asking for help from someone within reach.

More recently, Robinson et al. (2018) conducted a similar study with young people with disability, exploring their perspectives on personal safety and finding that being safe for these younger participants meant being physically safe, being emotionally safe, having access needs met, and feeling capable (Robinson & Idle, 2023). This particular study also highlighted the importance of trusting relationships and building a sense of community as core to developing a sense of security and resilience to bounce back and deal with issues as they arose (Robinson & Idle, 2023). Taken together, the perspectives from these two studies provide insight into how people with intellectual disability conceptualize personal safety, often in very practical and concrete ways. Her work further highlights that there was no rule-book on how to self-protect personal safety. While some may withdraw and retreat to their bedroom, others may seek help or crack a joke to diffuse an uncomfortable situation. Some may alert staff or turn to family for help, whereas others may not feel comfortable to do so (Robinson, 2010; Robinson et al 2018). What is clear from this body of work by Robinson and her team is that personal safety was a personal embodied experience encompassing physical, emotional, social, spatial and other dimensions. Robinson has explored and researched personal safety for people with disability across a range of different contexts.

Much of the literature to date surrounding interpersonal experiences of violence against people with disability disaggregates the data by type of abuse and/or disability. While this is useful for providing an understanding of different typologies and patterns of abuse and correlations, in reality patterns and types of abuse may not happen in isolation. (For more detail about the prevalence and scope of abuse and harm in the lives of people with disability see sections 2.2.2 and 2.2.3.). Each person's own experience of safety will be strongly influenced by their experiences in community and by the broader social, political and economic structures (Robinson & Idle, 2023). This again reinforces the usefulness of taking account of both the material and the social factors constraining how personal safety may be strengthened or diminished. Here, I return to my earlier arguments to re-state that ableism and violence against people with disability are inextricably enmeshed. I posit that if we want to understand personal safety and what it takes for people with disability to thrive, then we also need to explore how people with disability resist in the midst of ableism and find ways to negotiate and counter negative experiences with more meaningful experiences where they feel valued, respected, recognized and seen. For the purpose of this thesis, personal safety is understood as multi-dimensional and relational, in this way expanding upon previous work which conceptualise it as a set of self-protective skills or prevention strategies.

The following sections will show that personal safety for people with disability means recognition and prevention from all forms of abuse. This must include recognition of the everyday nature of ableist microaggressions that many experience, which are highly important to consider alongside more recognized criminal types of abuse.

2.2.2 The everyday nature of ableism and the impact on *personal safety*

Over the past decade there has been a growth in theoretical work conceptualizing the everyday subtle nature of harm against marginalized identity groups (Delston, 2021; Freeman & Stewart, 2021; Friedlaender, 2018; Kattari, 2017, 2020; McClure & Rini, 2020; McTernan, 2018; Olkin et al., 2019; Perez Gomez, 2022; Rini, 2018; Schraub, 2023; Skinta & Torres-Harding, 2022; Williams, 2020). Subtle everyday interactions that cause hurt are increasingly recognized in critical social justice theory as forms of microaggression, particularly in relation to experiences of racism, sexism, homophobia, and ableism, as well as many other types of discrimination). Microaggressions refer to behaviour or words directed towards a targeted individual in ways that reproduce prejudice or stigma. Derald Wing (2010) organized these interactions into three categories:

1. micro-assaults (intentional actions and words that discriminate or abuse),
2. micro-insults (subtle and unintended segregation, devaluing, or insult), and
3. micro-invalidation (where a marginalized person's feelings are dismissed or invalidated as not true, base-less, or incorrect).

This theoretical body of work has specific relevance when considering how people with disability negotiate personal safety. Kattari (2020) conducted a survey of 311 adults with disability in the United States, reporting that microaggression for them was a routine part of everyday life and significantly impacted on their psychological and physical wellbeing (Kattari, 2020). The impact of microaggression on wellbeing is increasingly recognized across multiple fields including critical race, gender and queer studies (Ong & Burrow, 2017; Skinta & Torres-Harding, 2022; Williams, 2020)

Burch (2022) turns to using the term “everyday disability-hate” as a means to describe the wide spectrum of devaluing that people with disability may face (including microaggressions), situating “disability-hate” as part of the experience of everyday harm many people with disability may face. In her work, Burch (2020, 2022) notes that the favouring of able-bodiedness and the stigma seen towards disabled bodyminds inadvertently (and/or intentionally) devalues and communicates dislike, disfavour and devaluing of disabled people. These everyday “low-level” throw-away comments, slights and snubs are also examples of devaluing, dislike or hate towards disabled people (Burch, 2021b). In one study in the UK, Burch (2021b) spoke with 69 people with a range of disability about their experiences of “everyday hate” and reported that when people were repeatedly exposed to everyday interactions that communicated a degree of hate towards disability, this had an accumulative impact, leading people to internalize self-hatred in negative and harmful ways.

In Burch's (2021a) study she further notes that these experiences of hate are also interwoven with experiences of interacting with space and places in community (or indeed around home), and thus shape perceptions of feeling unwelcome and that these spaces are not for them. Such routine exposure to ableist encounters can reinforce the feeling of worthlessness, or not belonging. The impact is not only an emotional breaking of spirit, resolve and resilience, it is also felt viscerally in an embodied way. As Pullen (2017, p. 106) noted, these everyday experiences accumulate and continue to "live on in our flesh, layered as new events unfold that remind the body…" (Pullen, 2017, p. 106 as cited by Burch, 2021b). While Pullen was referring to the everyday nature of abuse against women, there are similar parallels when considering the way discrimination, abuse and harm affects disabled people, highlighting the point that even after each interaction has ended and goodbyes have been said, the underlying message of "not belonging" continues to linger – shaping sense of self and understanding of place and space in the world (Burch, 2021a). This leads to harmful negative interactions that inevitably communicate an underlying message of hate towards disability. Burch's (2022) work is contentious to some degree as the re-framing and adoption of the word "hate" may trigger defensiveness on the part of the offender with the argument that their actions were unintentional (similar criticisms have been made in relation to the term microaggressions).

While some authors such as Kattari (2020) refer to such everyday harms as ableist microaggressions, Robinson et al. (2022) refer to them as examples of mis-recognition and Burch (2022) refers to them as examples disability hate. Burch's (2020, 2022) framing of everyday disability hate, while contentious, situates the perspectives of people with disability in the UK and gives voice to the underlying message received by the targets each time they face devaluing encounters. Burch argues that these examples (however unintentional) communicate dislike, disfavour, devaluing and/or hate of disabled bodyminds. Burch (2022) makes the point that when people experience examples of devaluing each day this becomes an anticipated feature of everyday life, often treated as "mundane", which in turn means that the significant impact may be under-estimated and internalized as part of one's own understanding of self-identity and sense of place in the world around (Burch, 2022; Kattari, 2020). While there are different ways to frame subtle examples of violence and harm, all of these bodies of work highlight a wide spectrum of examples that carry underlying meaning of being ‘Other’ and devalued. This includes examples such as staring, jesting or banter, name-calling, comments and/or bullying. Furthermore, these works consistently highlight a tendency for such everyday forms of harm to be brushed off as minor and mundane despite causing significant harm (Burch, 2021b, 2021a; Kattari, 2017, 2020; Robinson et al., 2022).

Mueller et al. (2019) define violence as any type of force or power, threatened or actual (unintentional or intentional), used against another person or group, and which results in injury, death, psychological harm or deprivation. While their study was particularly focused on police brutality against people with disability in the US, it also offers a useful definition for the purpose of this doctoral thesis. The authors posit that violence can be perpetrated both by individuals at an interpersonal level, and structurally by systems and services that oppress and cause harm. Mueller et al. (2019) make the critical point that in order to understand the prevalence of violence and abuse against people with disability, it is vital to locate and analyse themes of ableism and racism more explicitly in research. Mueller et al. (2019) borrow from critical race and critical disabiity (DisCrit) theory and take the approach that when people are pathologized due to race and/or disability this leads to labelling and segregation which inevitably forms part of the experience of violence. Using DisCrit theory, the authors argue that there are two questions that should be asked when reviewing the literature on violence against disabled populations: (a) what practices, attitudes and behaviours are taken for granted as “normal” and how do these norms devalue disabled people? (b) how do the legal and historical contexts promote the conditions that then deny some people their human rights? Mueller et al. argue that these questions allow a more nuanced understanding of how experiences of disability intersect and also nuance the type and experience of violence (as well as the way violence is responded to).

More broadly, there appears to be little theoretical work critiquing or conceptualizing how experiences of ableism influence constructions of personal safety. The literature on microaggression and the subtle everyday nature of harm indicates that concepts of personal safety are informed by experiences of ableism (and other forms of marginalization). Campbell (2009) draws parallels between experiences of racism and ableism and draws on Critical Race Studies to argue her case for critical ableism studies. Campbell argues that if people understand racism as the alienation of people of colour who then must operate in a society where western values are taken for granted as natural, then ableism should similarly be understood as the devaluing of disabled people who must negotiate a society which takes for granted a range of values relating to ability, productivity and efficiency, which are entrenched at every layer of society.

In line with Campbell (2009) and others (Kattari et al., 2018; Wayland et al., 2020), I understand ableism as the taken-for-granted norms which value capacity, ability and productivity which then spiral into a spectrum of disability-specific devaluing, discrimination and harm1 (Wayland et al., 2022) . Ableism stems from the unconscious (and simultaneously conscious) belief that able-bodied people are natural, superior and whole, whereas disabled people are broken, tragic and in need of eradication or cure (Campbell, 2009; Goodley, 2014; Wayland et al., 2020). The everyday nature of confronting ableism indeed takes a toll on the body emotionally and physically, as evidenced above when discussing examples of microaggression and disability hate (Burch, 2021b, 2021a; Kattari, 2017; Keller & Galgay, 2010; McClure & Rini, 2020; McTernan, 2018 and others). It is important to understand that more widely recognized types of violence (such as physical, sexual or psychological abuse) are never separate from experiences of ableism. People with disability are always negotiating ableism. While not widely recognized in terms of ableism, there has been some recent theory discussing the impact of racism and the racial battle fatigue and burn out that may eventuate from negotiating racist interactions and systems (Quaye et al., 2019). Such theory has relevance here in terms of conceptualizing what it means for people with disability to develop and maintain personal safety and combat the fatigue of so doing. It then follows that anti-ableism (and other movements related to tackling marginalization) are central to understanding and conceptualizing what personal safety means.

2.2.3 Systemic types of harm

It is here that I turn to examine the literature on how systems at times may enable abuse to occur. While these are not criminal types of harm, examples of systemic types of harm raise some important questions about how much has changed in light of all of the current political and social reforms that have taken place in the Australian context.

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[1] I acknowledge that there are tensions in the use of the term *ableism* (Campbell, 2009; Kattari, 2017, 2020; Kattari et al., 2018; Wayland et al., 2020) and disablism (Goodley & Runswick-Cole, 2011; Watermeyer, 2012; Watermeyer & Swartz, 2016). Both terms are increasingly taken up by authors in differing ways which may cause confusion for readers. While some authors view disablism/ableism as a dichotomy and insist that these are distinct with different meanings, others seem to view disablism and ableism as synonymous. It is beyond the scope of this thesis to un-pack how varying authors describe or separate concepts of disablism and ableism. Campbell (2009) advises against taking a prescriptive definitional approach to ableism arguing that it can be reductionist but for the sake of clarity I have attempted to set out what I mean when I use the term ableism.

2.2.3.1 Chemical and physical restraint enabled by systems

There are a range of service practices which are enabled by organisational cultures, structures and systems, and some of these operate in ways that cause harm against the individual the system is trying to "protect". Relevant to institutional violence is the use of restrictive practices, particularly as a means to control behaviours of concern. These practices may at times appear to be supportive actions intended to foster safety (for example, using psychotropic medications to help behavioural issues) but in reality such practices may also cause harm when they are normalized as standard responses without appropriate positive behavioural planning or trauma-informed supports in place. Reports of such occurrences exist mainly in relation to the aged-care sector; however there is a growing body of literature highlighting particular concern about the restraint of people with disability living in group homes and other disability care settings, with some evidence to suggest that the type of living situation may impact on exposure and vulnerability to chemical or physical forms of restraint (Emerson et al., 2000; García-Domínguez et al., 2022; Matson & Boisjoli, 2009). There have been reports of administering, without diagnosis of mental health conditions, psychotropic medications and in some cases multiple forms of medication which in actual fact have aggravated and contributed significantly to health deterioration (Edwards et al., 2020; McGillivray & McCabe, 2006). Of those who were medicated, many were exposed to restraint over very long periods of time. Often these chemical restraint practices were favoured without investigation of underlying trauma or other issues (Kildahl et al., 2020; Matson & Boisjoli, 2009).

Globally there have been a number of studies disaggregating population data in various countries which have consistently highlighted that people with intellectual disability were more likely to experience co-occurring mental illness compared to those without disability (Lineberry et al., 2023; Mazza et al., 2020). It was not until recently that researchers and clinicians began to recognize that people with intellectual disability can and do experience mental health issues. Historically, clinicians and researchers tended to believe that "challenging behaviours" (behaviours which impacted on an individual or community safety) were directly caused by cognitive impairment or disability. In contrast, more researchers are recognizing that these so called "challenging behaviours" are actually conveying and communicating distress or discomfort (Friedman, 2021; García-Domínguez et al., 2022).

There is also substantial evidence indicating that people with disability living in accommodation settings have been more likely to be prescribed psychotropic medications compared to the rest of the disability population (Office of the Public Advocate Qld, 2016). From a social-ecological standpoint there has been a dearth of studies exploring prevalence of mental illness or psychological distress in relation to types of accommodation settings. More generally research on quality of life for those in supported accommodation has reported high rates of abuse, adversity and loss (in different forms), and found people also more likely to experience isolation with limited opportunities to experience meaningful work or educational opportunities (Mitra & Yap, 2021; Scheffers et al., 2020; Tuffrey-wijne & Rose, 2017). These experiences of adversity across a life time inevitably contribute to risk of co-occurring mental or physical ill-health over the life course (Krnjacki et al., 2018; Mithen et al., 2015; Scheffers et al., 2020). However, there appears to be very little recognition, acknowledgement or exploration of the link between psychological distress and / or mental illness related to experiences in supported accommodation.

2.2.3.2 Preventable deaths in disability accommodation

Recent Australian national reports have noted a high number of preventable deaths in supported disability accommodation settings, with many inquiries at state level highlighting similar issues (Troller & Salomon, 2019). In Queensland the Office of the Public Advocate Qld (2016) conducted a review of supported accommodation which found that people living in those settings were more vulnerable to illnesses such as pneumonia, heart disease, diabetes and cancer which often went undiagnosed and unaddressed. There were also significant issues with accidental causes such as choking and respiratory issues. Similar findings were highlighted in a recent report by the Disability Commissioner (2019) in Victoria which reviewed 59 deaths of people with disability (out of 103 total reports) and found the majority of these reports (83%) concerned people living in shared disability accommodation settings (40% of these reports were people with intellectual disability). The review highlighted that people with disability were dying significantly younger (age median 50-54 years of age) compared to a median lifespan of 80-85 years in the general population. These reports consistently highlight common causes of deaths in disability services related to respiratory disease, choking and aspiration risk, circulatory disease and neoplasms or epilepsy (Disability Services Commissioner, 2019; Office of the Public Advocate Qld, 2016; Troller & Salomon, 2019). The Disability Services Commissioner argued that many of these deaths would have been preventable had there been appropriate support planning, documentation and legible case notes to track health issues and respond in a timely way. These reports demonstrate that neglect can at times present as poor quality healthcare, poor training for support staff and general lack of responsive care. This neglect is compounded when there is not appropriate coordination between disability service providers and healthcare providers to address mental and/or physical health.

2.2.3.3 Policies and structures

Over the past ten years there has been radical change in the way services and systems work, linked to the introduction of the National Disability Insurance Scheme Act (Australian Government: Office of Parliamentary Counsel, 2013). This significant reform has meant that people with disability can now access personalised budgets and choose their own services. While the NDIS has been a positive change for many Australians with disability and has seen a tremendous growth in the disability service industry as a sector, it has not been without its challenges (Carey et al., 2021; Cortese et al., 2021). The relative newness of the scheme in Australia means a level of uncertainty, confusion, concern and complexity. Indeed this major policy reform has meant a steep learning curve both for citizens with disability and their families, and for service providers, politicians and other relevant stakeholders (Lakhani et al., 2018; Olney & Dickinson, 2019). Services needed to adapt their funding models and reform their businesses to meet the requirements of the NDIS while also managing the demands and needs of consumers. Politicians and policy makers were shouldered with the responsibility of building the new scheme and evaluating, monitoring and developing robust information and evidence to assist with making informed decisions (Olney & Dickinson, 2019).

There was also a significant impact on people with disability and their supporters. For example, there has been evidence demonstrating that people from marginalized socio-economic backgrounds struggled to access and engage with the NDIS and were systematically shut out due to the complexity and inaccessibility of information (Cortese et al., 2021). A participatory study by Warr et al. (2017) interviewed 42 NDIS participants and reported mixed experiences of NDIS. Some participants in that study found that access to the NDIS had a positive impact on their lives, enabling them to be more flexible and have a higher degree of choice and control when choosing which service providers suit them best. Whilst not stated explicitly, one could reason that this may also mean that people with disability have more opportunity to choose those services and providers they feel safe with. However, there have been issues with agreeing on what constitutes “reasonable and necessary” support to be covered by the NDIS. Often what people with disability felt was reasonable and necessary for them to live their lives was poorly understood by the NDIS planners or failed to be recognized due to policy gaps (NDIS Quality & Safeguarding Commission, 2023; Robertson, 2020; Warr et al., 2017; Wilson et al., 2022)

2.2.3.4 Negotiating service systems

The study by Warr et al. (2017) also highlighted that even when people had an individualised plan with budgets approved for services, the demand for these services and goods related to disability were high whereas supply was low. This meant that even if participants were given reasonable and necessary funding, some were still struggling to access services, therapies and goods that were necessary and reasonable. The outcome of this was that NDIS participants may have been going without services and supports. Further to this, research evidences that the administration required as part of navigating the NDIS – and subsequently, the services and goods required – has tended to fall on people with disability or their supporters (referred to as nominees) under the NDIS (Carey et al., 2021; Malbon et al., 2019). There is consequently a great deal of stress and anxiety placed on these individuals who are required to understand complex information and administrative procedures as part of successfully accessing services using their NDIS funding package(Carey et al., 2021). As Warr et al. (2017) note, often people were relying on informal networks for help with understanding the system and navigating and making decisions about their available options for organizing or changing supports and services. Those without informal supports were more likely to be disadvantaged, struggling to access information and tending to have poorer outcomes.

Olney & Dickinson (2019) highlighted that while the NDIS is an ambitious and positive step towards improving the lives of people with disability, the scheme poses an enormous web of intersecting and overlapping challenges for government, its agents, public and private service providers, community partners, people with disability, and their support networks. While some of the challenges have been outlined above, these challenges would represent the tip of the iceberg in terms of issues to do with personal safety. Given the broad all-encompassing nature of personal safety and the fact that safety is multifaceted, it is impossible to summarize the scale and breadth of issues in terms of systemic types of harm, especially for those with disability who live in disability service settings. Nevertheless, what is clear from such reports as the Own Motion Inquiry Report into Aspects of Supported Accommodation (NDIS Quality & Safeguarding Commission, 2023) is the complexity of these systems. This impacts on how people with cognitive or multiple disability negotiate and understand how these systems work.

Systemic structures wield a great deal of power over how people with disability manage their daily lives in all areas of the community, so when systems and services are not responsive to individual needs this compounds oppression, marginalization, violence and potential harm and neglect

(Mueller et al., 2019). People with disability and their family members may also be further disadvantaged by race, gender, age, location, sexuality and other aspects of intersectionality. First Nations people with disability in Australia face particular barriers compounded by experiences of intergenerational trauma - with many having experienced being ‘shuffled’ from system to system due to inaccessibility and limited availability of culturally safe Aboriginal led disability service options (Deloitte, 2023). Such experiences of social disadvantage, marginalization, exclusion and devaluation affect every aspect of life including wellbeing in the home, but also influence how people negotiate opportunities and build connections with the broader community beyond the disability sector in areas such as education, healthcare, employment and a range of others.

Much of the literature to date regarding consumer experiences of accessing and navigating the NDIS has tended to be small scale studies that were place-specific (for example a small city in Queensland) and have tended not to disaggregate the data by living situation (for examples see Collings et al., 2018; Dew et al., 2019). One paper by Fisher et al. (2021) explored the impact that individualized funding (pre-NDIS) had on the choices available to people with disability in terms of living independently or in a shared setting. Their research suggested that there were limited housing options on the market and that this in turn restricted choices for people with disability. This suggests that some people with disability have limited freedom to make choices about where and how they live and who they live with. While the NDIS has improved choice and control for some, others continue to have limited access to supports. This research aligns with research examining housing and supports within the NDIS context, echoing concerns that housing and support vacancies were limited and restricted (Callaway et al., 2021; Callaway & Tregloan, 2018).

There is a range of literature examining how people with disability broadly interact with the NDIS however very few studies examine perspectives directly from the viewpoint of people with disability living in supported accommodation services. There is consequently a need to explore how residents in supported accommodation (a) access and interact with their NDIS personalised budgets, (b) choose their services, and (c) negotiate the system to access supports they need to live life as they see fit. While there is a growing body of literature exploring the NDIS, there is a scarcity of literature exploring how the nature of individualized support packages funded via the NDIS makes a difference to personal safety. More research is needed to explore whether these policy reforms have had an impact at ground level for residents who are living in congregated disability accommodation settings in terms of improving personal authority in ways that mean people can make decisions that serve to promote their personal safety,

2.2.4 Interpersonal types of harm

Here it may be useful to look to the broader literature and framing around issues of domestic and family violence. Much of the literature on domestic and family violence focuses on how people with disability living in traditional family structures negotiate issues of abuse by a family member or intimate partner (Fanslow et al., 2021; García-Cuéllar et al., 2023; Harpur & Douglas, 2015; Pestka & Wendt, 2014; Robinson et al., 2021). This body of work is important as it explores the wide spectrum of violence that may be perpetrated within the domestic space (physical, sexual, psychological, financial and other) and highlights that for people with disability there may be additional layers of power abuse such as taking away a communication device, removing a wheelchair or controlling access to necessary accessibility tools and resources as a form of coercion, intimidation or threat (García-Cuéllar et al., 2023; Harpur & Douglas, 2015; Price-Kelly & Attard, 2010). The bulk of the literature found tended to explore domestic and family violence from the perspectives of women with disability who were not living in service settings. This raises questions about whether disability accommodation settings should also be considered a “domestic” context where violence occurs and thus should also be recognized as a form of domestic violence. These service contexts remain “home” to the residents who live there, and people with disability in these settings can be subject to multiple forms of domestic violence, whether it be by an intimate partner, a friend, housemate or co-resident, or others.

Data about the prevalence and scope of harm in supported accommodation tends to be fragmented in Australia and indeed globally across other nations. In Australia there is no national data reporting the prevalence or type or extent of abuse occurring for people in supported accommodation. Another factor that affects recognition of the complexity and nuance of domestic abuse specific to supported accommodation lies in lack of reporting. Service providers may often treat abuse and harm as an “incident” eliciting managerial procedural responses instead of viewing issues of violence as criminal in nature, or indicative of systemic cultural issues embedded in services (Coulson-Barr, 2012; Robinson & Chenoweth, 2011). Within organisations and in policy issues of abuse are not recognized or addressed as domestic violence in the context of supported accommodation. Instead, much of the literature which relates to people with disability in supported accommodation has tended to focus on specific types of abuse and correlation to specific types of cohorts. For example there is a growing body of international literature examining issues such as the prevalence of sexual assault and harassment against people with disability (Basile et al., 2016), or physical assault and behaviours of concern among people in supported accommodation (Emerson et al., 2000; Matson & Boisjoli, 2009; Vseteckova et al., 2022). In the following sections I provide a brief outline of some of the types of harm and abuse identified from the literature to date.

2.2.4.1 Physical and/or sexual violence

Research both internationally and in Australia has noted that people with disability are far more likely to experience physical or sexual violence compared to the general population (Krnjacki et al., 2016). Krnjacki et al. (2016) disaggregated the data from the 2012 Australian Bureau of Statistics survey on Personal Safety and found that women with disability were more likely to experience sexual violence and intimate partner violence than their counterparts without disability, whereas men with disability were more likely to experience physical violence than their counterparts. This is consistent with prior research both internationally and in Australia highlighting sexual violence as a prevalent issue for women with disability (Basile et al., 2016; Mailhot Amborski et al., 2022; McGilloway et al., 2020). However, Krnjacki et al. (2016) noted that of the small proportion of men reporting sexual violence, men with disability were at comparatively greater risk. Research further indicates that people with intellectual disability, those with complex communication needs or multiple types of disability were even more at risk compared to others with disability (Araten-Bergman & Bigby, 2020; Krnjacki et al., 2016).

At the time of writing, there has also been ongoing media attention regarding the care of people with disability, with investigative journalists in Australia reporting harrowing stories of abuse particularly focusing on institutional violence. One such example was a Four Corners report titled “Fighting the System” (ABC, 2017) which exposed a multitude of varying types and forms of abuse and violence behind closed doors of group homes concerning people with intellectual disability. These exposés were in line with investigative journalism headlines such as *Disability service providers referred to police after Victorian deaths in care* (SBS, Biwa Kwan, 20th December 2018); *Disability carer recorded saying “I just wanna f**ing beat these kids…”* (ABC, 27th September 2018), and *Head of Disability Safety Commission threatens penalties to providers* (ABC 17th August 2018). There have been a number of reports from statutory bodies, ombudsmen and other oversight bodies documenting poor investigation of complaints or reports of abuse. Arguably, reports were more likely to eventuate where there were fatal or physical signs of injury (NDIS Quality & Safeguarding Commission, 2023; Vincent & Caudrey, 2020).

Burch (2021b) observed that media in the United Kingdom often reported the more extreme cases of violence against disabled people where failures in protective services were overt and explicitly seen. Indeed similar trends have been observed in media reporting in the Australian context – as seen in Anne Marie Smith's case in Australia. Burch rightly observed that such media reports can perpetuate the myth that these occurrences were exceptional, unusual, and extraordinary. Yet these experiences represent the tip of the iceberg and neglect to recognize the mundane everyday experiences of exclusion and hostility that many disabled people experience in their day to day lives. Burch states (2021b, p. 15):

> Behind what we think we know about hate crime from large-scale statistical evidence, or media headlines, are a vast number of hate crimes that occur in the everyday lives of many disabled people. Hate crimes are not rare acts committed by extreme bigots, but, rather uncomfortably, are committed by 'ordinary people' in our ordinary, everyday lives.

Burch argues that many disabled people regularly and routinely encounter hate in many forms ranging from the subtle examples of ableist jokes or banter, through to more overt forms of verbal harassment, abuse or aggression. These acts of "hate" may not be intentional in the sense of causing harm, but still cause harm when they stem from prejudices which devalue disabled bodies and minds.

2.2.4.2 Hate, ableism and other forms of emotional and psychological abuse

Here I expand on my earlier comments on microaggression and everyday harm (mentioned in section 2.2.1) and argue that encounters involving microaggression form part of peoples' experiences of emotional and psychological abuse, including a long lasting impact on wellbeing.

In the context of this PhD it is vital to consider how everyday experiences of discrimination, abuse and harm impact on the lives of people with disability who live in shared types of supported accommodation, since inevitably everyday interactions of abuse accumulate and do have an impact on wellbeing. There has been a wide range of literature exploring the prevalence and nature of emotional and psychological types of abuse against people with disability, specifically in relation to recognizing issues of ableism and microaggression (Campbell, 2009; Kattari, 2020; Keller & Galgay, 2010; Robinson et al., 2022). Psychological and emotional abuse can be difficult to gather data on, particularly when it is least likely to be reported through services or counted in the data externally to adult safeguarding statutory bodies (Beadle-Brown et al., 2010). Robinson (2014) and Robinson & Chenoweth (2012) highlighted difficulties in recognizing and addressing emotional abuse in service settings given that it is often invisible and rarely acknowledged as harm that warrants explicit reporting. Robinson's (2013) study demonstrated that while humiliation, belittling, ignoring and insult were typically not criminal types of violence, they were interactions that caused significant harm and injury. She particularly noted a cumulative impact when these types of interactions tended to happen systematically in multiple forms over time. Robinson's (2013) research canvassed the perspectives of people with intellectual disability and family members who reported emotional abuse as a dominant issue in service contexts. While Robinson's study was specifically examining the experiences of psychological abuse against people with intellectual disability, her findings may also help understand how people with other types of disability in disability service settings encounter and deal with emotional abuse.

2.2.5 Section summary

Residents living in supported accommodation are at risk of experiencing multiple forms of abuse and harm in their home-contexts; however much of the literature does not refer to violence in supported accommodation as domestic violence (McCarthy et al., 2017; Nixon, 2009). It may be useful to contextualise supported accommodation first and foremost as a 'home' context for the residents who live there. This then situates an understanding of the multiple types of harm and abuse people with disability may be negotiating in their home context and pays attention to both the seemingly "mundane" experiences of everyday discrimination and abuse, as well as those overt types of violence that are recognized. Locating violence within the framework of *ableism* deepens understandings of how space and place of supported accommodation (both in a material and semiotic sense) contribute or corrode resilience and resistance to address abuse and violence. As mentioned by Burch (2021b), it is harder for people to report instances of abuse when constantly negotiating a society that devalues their existence on a daily basis. As Burch notes, people come to anticipate ableism as an "ordinary" part of life.

For those who live in disability services there are also a number of barriers that make reporting abuse difficult. For example, people with disability might fear reporting or addressing violence as it is not only about dealing with violence at the interpersonal level, but also the flow-on effect of consequences such as the loss or change of services or negative reactions from support workers, managers or others (Beadle-Brown, 2010). When services enact managerial responses and actions to manage "incidents" this communicates the message that it was an isolated "issue". When these incidents are treated as isolated it then masks the deeper issues of culture and systems that form part of the context in which abuse happens. There is a need for better recognition of the subtleties and impact of everyday harm on the lives of people with disability in supported accommodation. There is also limited research about how the transition to the NDIS has influenced issues of harm and abuse in disability service contexts, and it is not clear what actions have been taken when reports of abuse have been made to the Quality and Safeguarding Commission.

2.3 Personal agency: Identity, authority, choice and control

Personal agency is a concept widely debated in philosophical and sociological literature and there are several lenses and philosophical streams of thought about (a) how people develop a sense of self-identity and (b) what constitutes personal agency or having a sense of control over what happens day to day in life. The following section outlines some of the theory underpinning how 'personal agency' is understood in the context of this research in relation to disabled bodyminds. This literature highlights 'personal agency' as relationally produced depending on a range of social and material factors that either foster or disenfranchise individuals' sense of agency. This section also outlines some of the systemic and structural barriers impacting on how people with disability negotiate agency and express their will and preferences.

2.3.1 Theoretical perspectives on personal agency

Personal agency is sometimes referred to as psychological agency, human agency, or self-efficacy, among other terms (Tieu, 2022), and is multiply defined and widely debated in various disciplines. Rather than summarizing all of these different schools of thought, I attempt here to make clear my own theoretical position on personal agency for the purpose of this study. Tieu (2022) argues that each person has their own collective of embodied physical and psychological states of being that centre around their personal beliefs, values and desires and thus inform how people interact with the world around them, self-express and act. This is in line with Frie (2008) who posited that individuals have capacity to act in ways that align with their own preferences and decisions, arguing that the capacity people have is situated within a web of intersecting biophysical and sociocultural contexts in an ongoing interactive and developmental process. This work highlights that a sense of "self" in relation to the social and material world around one is inextricably entwined with concepts of personal agency (Frie, 2008). Indeed, Baumeister (1998) argued that having a sense of self is key to personal agency, and clearly articulated that personal agency (having a sense of control and choice) is the opposite of being a passive spectator:

> The self makes decisions, initiates actions, and in other ways exerts control over both self and environment. Common terms [agency, choice, control and decision-making]

> refer to this aspect of self. Without this function the self would be merely a passive spectator, aware of itself and related to others, but unable to do anything except perceive and interpret the flow of events (and experience emotions). (Baumeister, 1998, p. 712)

When examining the literature through a disability studies lens, personal agency rarely features in the discourse. However, the broader literature in sociology and psychology conceptualizes personal agency as having a sense of control over one's own decisions and actions in line with personal values and beliefs and embodied experiences (Frie, 2008; J. Martin, 2008; Modell, 2008; Sugarman, 2008; Sutterlüty & Tisdall, 2019). Specific to disability studies – much of the literature has tended to explore self-determination (Curryer et al., 2015; Shogren & Broussard, 2011; H. M. Walker et al., 2011; Wehmeyer, 2020; Wehmeyer & Abery, 2013). Arguably self-determination is related to personal agency in that both terms are used to describe a developing sense of self and expression of will and preferences. For example, Wehmeyer and Abery (2013) define self-determination as the process of being active contributors to, or authors of, their behaviour, which is self-regulated and goal-directed in action. Self-determined people are, in essence, actors or agents in their own lives, rather than being acted upon or against (Walker et al., 2011; Wehmeyer & Abery, 2013). While this is a useful framework for promoting a human rights agenda that sees people with disability as agent, it neglects to recognize the enmeshment and flow of contributing factors that shape a sense of self and their social and material world. It is helpful here to draw on Martin's (2008) relational approach to agency. He saw agency as a dynamic flow of factors that simultaneously constrain or foster and often overlap. Put simply, each person's experiences, beliefs and values influence their actions and understandings of the world, but simultaneously these actions are also products of interacting with the bio-physical, material and social world and are in a constant state of flow (Deleuze, 1994; Deleuze & Guattari, 1987; Goodley et al., 2018, 2019).

2.3.1.1 Self-determination in the context of disability services

While concepts of personal agency have not been widely adopted in disability studies literature, the concept of self-determination has been consistently referred to and embedded in practice and policy (Wehmeyer et al., 2013). Wehmeyer et al. (2013) noted that people with intellectual and developmental disabilities were often under decision making arrangements despite having demonstrated clear capacity to exercise control over their lives with the right supports in place. Overall this cohort also had fewer opportunities to express their preferences compared to people of a similar age and demographic without disability (Wehmeyer et al., 2013).

Here I draw on the words of Martin (2006) a self-advocate with intellectual disability who had lived in institutional settings prior to moving to his own home. He offers a compelling account of what it meant to be able to choose where he wanted to live. He described home as “freedom”: freedom to choose what to wear, or what to have for dinner, but also freedom to move freely and make his own relationships and associations with people in the local neighbourhood, workplace or other community areas. In essence, what Martin refers to, is a sense of being in control, an agent in his own life, able to make choices and act in accordance with his own preferences and will, and resist oppression (Shogren & Broussard, 2011).

The wider literature provides a stark contrast to Martin’s words and demonstrates that many people living within shared disability accommodation settings have reported fewer opportunities to express their will and preferences. This includes a broad span of frustrating and diminishing experiences for people with disability, ranging from small, but still important, choices such as not being allowed to choose the type of activities or pick their own routine for the day, through to major decisions such as where to live or who to live with (Shogren & Broussard, 2011). Similarly, Clement and Bigby (2009) conducted a research study which involved participant observations in five group homes in metropolitan and regional Victoria. Their field notes provided an observatory picture of day to day life inside of group homes from the perspective of researchers and documented how often the staff were key decision makers. Clement and Bigby (2009) noted that, while some staff prioritised responding to the will and preferences of the people they supported, often staff were making decisions to save time and increase efficiency. When staff prioritised time saving and efficiency, this compromised quality of support as residents had no say over everyday decisions such as what to have for lunch or when they would prefer to shower. Bigby et al (2012) were careful to say that not all residential group homes were the same, and that some houses were much more liberal and willing to engage in supportive decision making, but still were constrained by policies such as occupational health and safety. Robinson and Chenoweth (2011) observed similar practices in their paper exploring issues of psychological harm in group homes, noting that to some degree staff were recognizing the need to support decision-making and that opportunities to make small decisions and have choice in day-to-day matters such as what to wear or eat were improving. However this ideology of self-determination did not necessarily translate when it came to service providers supporting people with disability to have authorship over big life-changing decisions such as where to live, who to live with, or who to employ as staff.

Several studies have explored choice and control according to different housing and disability service arrangements. McConkey et al. (2016) compared the outcomes for residents in Ireland living in personalized arrangements, community group homes and congregated settings and found that those who lived in personalized housing reported better choice and control as well as better personal relationships. Jingree and Finlay (2008) found that whilst service providers seemed liberal in their views and cognisant of the ideals of promoting self-determination and choices of people they supported, they were often contradictory in action.

2.3.2 Accommodation type and relationship to personal agency

Research consistently highlights that those living in smaller institutional settings such as group homes were more likely to have choice and control compared to those in larger congregated accommodation options (Bigby et al., 2017; Pallisera et al., 2021; Šiška et al., 2017). Much of the literature on choice and control points to attitudinal barriers that prevent adequate support. For example it has been widely reported that people with intellectual disability and/or significant multiple disability were more likely to be viewed in negative ways as a burden, a hindrance, incapable, in need of help and protection (Pelleboer-Gunnink et al., 2021). Pelleboer-Bunnink et al. (2021) focused on stigma towards those with intellectual disability in the Netherlands and noted that often discrimination and stereotypes were subtle and pervasive, making it difficult to challenge with intervention. Similar trends in attitudes towards people with disability have been echoed elsewhere (Bollier et al., 2021; Ciurria, 2023; Wilson & Scior, 2015). Many studies internationally and in Australia report common themes about perceptions in disability service staff of incapability and vulnerability of residents, which translated to low expectations and assumptions about whether people can reliably express their will. When the dominant reaction and attitudes towards people with disability are negative, considered child-like, sick, deviant, damaged, broken and Other, this creates a power imbalance that shapes how people interact with those who have significant disability (Fyson & Patterson, 2020; Iriarte et al., 2016; Jingree et al., 2006; Mansell et al., 2008; Overmars-Marx et al., 2017).

In Global North countries there has been a shift at a political level over the past several decades, with increasing recognition that all people regardless of disability have fundamental human rights (McCallum, 2020). In the Australian context, this has translated into policy and practice in disability services framed around adopting a language and ethos of respecting dignity, independence and rights of people with disability (all components of personal agency). In practice, these values often collide with other values that also underscore disability services (Australian Institute of Health and

Welfare (AIHW), 2021; NDIS Quality and Safeguards Commission, 2019). For example Clement and Bigby (2009) and Humphreys et al. (2022) describe how values of efficiency and time may overtake values of personal agency. When practices do not adequately support the expression and will of individuals, this leads to a sense of disenfranchisement, boredom and exclusion from participation in home-life or indeed in community activities and social life (Talman et al., 2021). Some reports have also highlighted that, particularly when people have a significant disability, staff members may assume they know their clients well enough to know what they want and thus aim to save time by deciding on their behalf (Bigby et al., 2017; Curryer et al., 2015; Talman et al., 2021).

Services tend to prioritise a focus on building independent living skills, viewing this as an important measure of self-determination (Wehmeyer & Abery, 2013). While interventions may be useful for the development of certain skills such as making choices, decisions, setting goals, self-advocacy knowledge and self-awareness, Wehmeyer (2020) identified skills of self-reliance, self-awareness and self-dependence as core components of self-determination. Nevertheless, in my view, such definitions of self-determination fall short. Acting in line with one's own values, preferences and will should not be determined by how many functional skills have been mastered independently. The framing around development of individual capacity and skills has been further compounded by the structure and priorities set out by the NDIS where funds are allocated based on peoples identified personal goals such as "build independence" or "maintain social skills" (Carey et al., 2018; Olney & Dickinson, 2019; Warr et al., 2017 – see section 2.3.4 for more discussion about how NDIS amplifies the dominance of focusing on functional skill development). This understanding and framing of self-determination as synonymous with functional independence sets up those with significant disability to never meet able-bodied standards of functional independence. When self-determination is understood as a series of independent skills this reinforces attitudes and beliefs about how little capacity people have to make their preferences known or have authorship over what happens in their lives.

Here I return to the earlier argument at the start of this chapter noting personal agency as a relational concept and use this to make the argument that self-determination should not only be concerned with self-regulation, self-awareness or self-control (as seen in Wehmeyer, 2020; Wehmeyer & Abery, 2013). These conceptualizations run the risk of self-determination being understood as a deterministic set of skills in line with ableist measures of independence and self-reliance and thus reinforcing ableist attitudes and perceptions of those with disability who do require daily support.

2.3.3 Interdependence as a strength when negotiating personal agency

To be clear, skill development should not be discounted as part of supporting personal agency, but rather should be seen as one of many factors that facilitate. Research by Watson et al. (2019) drew attention to the supports and adjustments needed in order for all people to exercise agency over all aspects of their lives, which also applies to people with profound intellectual and multiple disability (see also Watson, 2016). As an example, Watson (2016) conducted a study with a small group of people with profound disability and their supporters and found that when people with profound types of disability have people around them who know them well and spend quality time with them, this enables expression of will and preferences. She argues that it is crucial that service providers adopt practices that focus on identifying key trusted people who know the individual well and are able to use their knowledge to observe, listen, acknowledge, interpret and respond:

> The role of a person with a disability in this dynamic is to express will and preference, either intentionally or unintentionally using a range of communication modalities including behaviour, vocalisation, vocal pitch, muscle tone, facial expression, eye movement and physiological reactions (eg. changes in breathing patterns). The role of the supporters within this dynamic is to respond to the expression of will and preference of those they support. (Watson, 2016, p. 4)

For Watson (2016) the characteristics and nature of best practice around supportive decision making with people who have significant communication disability fundamentally relies on forging connections with people who can then serve as key supports in that person’s life. These trusted relationships are vital as a point of familiarity and trust and for building familiarity with how each person may communicate their preferences and will using a range of modalities. Supportive Decision Making has received wide attention across a range of fields when working with people with disability and those who are elderly or aging. There are a range of different examples ranging from informal supportive decision making, which involves trusted people at an informal level, through to more formalized models of support instigated and facilitated by disability service providers (Beadle-Brown, 2015; Buhagiar & Azzopardi Lane, 2022; Devi et al., 2020; Peterson et al., 2021; Stainton, 2016). Whether the supportive decision making is informal or formal, Watson’s (2016) point holds true either way – supportive decision making is about relational support. This is important to note in the context of the present study as it demonstrates that even when people have profound types of disability, there are ways of facilitating personal agency. The research on supportive decision making centres the importance of meaningful relationships as a key component that then enables productions and expressions of personal agency. There may be a diverse range of people who may offer support in a variety of different ways and this may include both paid people (Robinson et al., 2020, 2022; Topping et al., 2022b, 2022c) and unpaid informal relationships (Duggan & Linehan, 2013; Emerson & McVilly, 2004; Mason et al., 2013; Sanderson et al., 2019, 2020; Therrien, 2019).

There is some research indicating that the nature of people's support networks may evolve and change over time, which in turn affects how people negotiate personal agency. Research by Sanderson (2019) reported that people with intellectual disability who were living at home with family seemed to have a higher degree of informal support networks to draw on and were more likely to be "known" by others in the community. Meanwhile those who lived in disability accommodation had the least number of informal relationships and the most number of paid professionals. Such research suggests that those who live in supported accommodation may not have as many meaningful connections, which in turn may mean missed opportunities to truly support personal agency and expression of will (the topic of 'belonging' will be discussed in more detail in section 2.4). I draw on this body of work to argue the point that concepts of "autonomy" and "self-determination" seem too heavily weighted towards a focus on functional skills. It is also important to note that personal agency cannot truly be understood as a social construct either. Taguchi (2012) instead posed the idea of the concept of agency using a DeleuzoGuattarian perspective to describe the multiplicity of components that co-constitute and create an entanglement of materiality and semiotics (Deleuze, 1994; Deleuze & Guattari, 1987). As Taguchi notes:

> we need to move, ontologically, from identifying bodies as separate entities with distinct borders to think in terms of processes of entanglements and interdependences in processes of an ongoing co-constitutive co-existence of different kinds of bodies (human as well as non-human or more-than-humans). Thinking diffractively, in short, means thinking as a process of co-constitution, investigating the entanglement of ideas and other materialities. (Taguchi, 2012, p. 271)

In the context of this study, personal perceptions of how one negotiates agency (as well as safety and belonging) can be understood as moments where a variety of material and semiotic factors affect and then shape the way people experience and understand safety, belonging and agency in embodied ways. By mapping the various factors that interplay, this enables a deeper understanding of what assemblages are fixed or rigid (territorialised) and where there may be emergence, change or new opportunities (Fox & Aldred, 2015). Deleuze and Gauttari introduced the idea of striated and smooth spaces to refer to the contrast between hierarchical, rule-bound and taken-for-granted norms (striated spaces) and those moments of movement, change, flexibility and progress (described as smooth spaces) (Goodley et al., 2014). Taking up this approach builds on the idea that personal agency is in a constant state of flux – a fluid process that must take account of the different components that assemble, disassemble and reassemble at various points to construct and produce moments for agency, safety and belonging. For Deleuze and Guattari it was more useful to understand assemblages as constantly "becoming" (Goodley et al., 2014). These components not only concern social constructs, but include all components of the living, the material and machinic. Together these factors constantly inform how one understands identity and sense of personal agency.

2.3.4 Disenfranchised by systems and structures

At a systemic level, people with disability must also interact with community structures and systems. While these systems are beneficial in that they enable access to health, disability support, welfare and other systems, they may simultaneously adversely impact wellbeing due to navigating inaccessible, difficult, complicated service systems (Krnjacki et al., 2018; Malbon et al., 2019; Mithen et al., 2015; Roos et al., 2022). In the Australian context, the NDIS has been a major shift towards individualized planning and support packages to shift the balance of power in favour of people with disability having choice and control. However, the reality is that the scheme is complicated, with many moving mechanisms and parts of the scheme operating at various levels of the community and aiding or hindering service delivery in different ways (Carey et al., 2018, 2021; Malbon et al., 2019; Nevile et al., 2019).

The NDIS and the personalization agenda aimed to give people with disability more control over their supports and was established in response to several reports noting that disability service sectors were under funded, under resourced and stretched to the limit (Community Affairs Reference Committee, 2015; National People with Disabilities and Carers Council, 2009; NDIS Quality & Safeguarding Commission, 2023; Royal Commission into Violence, 2021). While personalizing the market means that people with disability have choice and control over their services, they cannot directly control the availability or accessibility of providers. Evidence highlights several "market gaps" where people with disability are still unable to access services in a timely and efficient way. In short, people with disability continue to navigate disability service systems that are under-resourced and over-burdened (Carey et al., 2021; Malbon et al., 2019; Nevile et al., 2019).

Rayna Lamb (Community Affairs Reference Committee, 2015), an Australian disability activist, gave a testimony to the *Senate Inquiry into Violence, Abuse and Neglect against People with Disabilities in Institutional and Residential Settings* and eloquently expressed how systems excluded and devalued the voices of people with disability:

> Our disabilities do not inherently make us vulnerable. Attitudes towards us, and the value that is placed upon us by society is what makes us vulnerable. We are not seen as second-class citizens. That would be a step up. We are seen as third-, fourth- or fifth-class citizens. We are seen as less than human. We are seen as mistakes. We are seen as everybody's fears or nightmares. We are seen as fates worse than death. We are not seen as human. It is this that leaves us vulnerable, not our disabilities. We are left vulnerable because we have no power over our lives, because able-bodied people design and maintain the systems that control us, that keep us disempowered. All of the agencies and organizations—the nursing homes and the institutions—that we are dependent on are developed, staffed and managed by able-bodied people who do not have to live in our world. (Community Affairs Reference Committee, 2015, p. 20)

In her testimony Lamb argued that the very systems and services designed to support people with disability often disempower and silence. She described how the unquestioned norms and expectations of ability that are entrenched by default in the way society and systems operate, devalue the status of disabled people. In essence, she argued, as did Lid (2015) that disability is not inherently “causing” vulnerability – rather it is the way that society distributes relational resources and power that contributes to vulnerability. When people with disability are viewed as recipients of welfare systems and seen as a burden on welfare systems, this reinforces exploitation, marginalization, devaluation and violence.

2.3.5 Section summary

This section has demonstrated that there are many layers of systematic and systemic forms of devaluing that restrict how people with disability express their will and preferences and have a sense of control over their everyday life in supported accommodation. Much of the research to date focuses on self-determination by introducing measures of independence and autonomy, with many studies focusing on targeted skills around self-reliance, self-regulation and self-awareness. While some focus on skill-building is indeed useful when supporting people with disability to self-advocate and exercise choice and control in their lives, this framing can also prove problematic as people with disability are measured against able-bodied norms and constructions of autonomy. To counter this, it seems more useful to interrogate measures of self-determination to instead frame the expression of will, preference, choice and control as a relational task.

2.4 Belonging: Social connectedness and relational wellbeing

Much of the literature in disability studies and related disciplines has tended to discuss barriers for social inclusion outside the home, in areas such as work, education, leisure and sports (Jones & Gallus, 2021; Kaley et al., 2022). This speaks to the widespread issues of discrimination and exclusion experienced by people with disability across all domains of life and the impact this has on their health and wellbeing (Stancliffe & Hall, 2023). Stancliffe & Hall (2023) argue that each person will forge their own understanding of belonging and social inclusion depending on their own personal experiences of interacting with different contexts, people, spaces, time and places. Rather than a prescriptive recipe book for “social inclusion” Stancliffe and Hall (2023) argue that there is no single approach to social inclusion, but rather it is dependent on each person’s characteristics, desires, values and needs.

People with intellectual disability or multiple complex disability are significantly more likely to experience social stigma and prejudice than others when interacting within their community, and such experiences can also be compounded by multiple intersectional experiences of marginalization (for example, being queer, Aboriginal and so on). It seems fitting here to return to Burch’s (2021b) work on everyday harm in the lives of people with disability. Burch writes that when people discriminate or behave in ways that devalue or dismiss disabled bodyminds, this has an underlying core message of hate or dislike towards those bodyminds:

> Feelings, such as hate, are always negotiated in relation to the bodies that they move between, and the spaces within which this movement occurs. Such negotiations are experienced through the body and constitute a range of affects. For example, we can understand the ways in which the spatial and symbolic positioning of disabled people outside of particular spaces can affect their sense of belonging. From this perspective, hateful encounters are more than their discursive or physical nature; they exist (and are reinforced) through the relationality of bodies as together or against one another (Burch, 2021b, p. 76)

Burch’s work gives voice to the ways in which ableism and everyday experiences of abuse and discrimination intersect and inform how people feel about their own identity and sense of place and space in relation to the world around them. The following section presents the main issues seen in the literature relating to issues of belonging, social connection and isolation for people living in shared types of disability accommodation settings. The section also presents some of the sociological literature on belonging and related fields of social inclusion and integration, and lays out the key theoretical perspectives. This includes definitions of belonging along with a rationale for how belonging is different from social inclusion or integration, as well as an overview of what has been reported about the social networks of people with disability in relation to disability accommodation and belonging in their neighbourhood.

2.4.1 Theoretical perspectives on belonging

Belonging has been defined in varying ways across disciplines of geography, education, psychology, sociology and public health (Antonsich, 2010; Hall, 2010; Holt, 2008; May, 2011; Wright, 2015; Yuval-Davis, 2006). Many of these theoretical works have the common thread of referring to belonging as an emotional attachment to place – a psychological and embodied feeling of being "at home" in a familiar place with familiar people in the broadest sense (Antonsich, 2010), in other words, being at ease, with a feeling of affinity as well as safety and security in the sense of space, place and in relation to society (May, 2011). Belonging may also refer to attachment to place and people as well as memories (Block, 2018, cited in Strnadová & Nind, 2020). Belonging may also be understood as spaces, places, things or people that reinforce a sense of identity, dignity, value and respect.

Embodied belonging refers to the feeling of or desire for attachment to people or places, spaces or objects in ways that feel secure and affirming of our identity and place (Lähdesmäki et al., 2016; Morrison et al., 2020; Strnadová & Nind, 2020). Morrison et al. (2020, p. 2) in their article about (not) belonging in disability spaces aptly articulate how embodied experiences are not static, but rather constantly shifting depending on exclusionary or enabling contexts:

> It is impossible to separate the material from the discursive. Belonging and/or not belonging for disabled people is always personal and social, embodied and structural, individual and collective, and private and public. We aim to think about bodies, things and spaces as interacting in various ways to produce shifting exclusionary and/or enabling arrangements. A focus on embodied belonging can help add nuance to what it means for disabled people to feel in and/or out of place by drawing attention to lived, felt and spatial elements.

Morrison et al. (2020) argue that belonging is not only emotional, but rather an embodied belonging – a fluid experience that depends on a range of shifting forces and factors that are both material and semiotic. This is especially true for marginalized communities (whether because of race, religion, gender, disability or other) for whom experiences of belonging are often intertwined with politics and issues of power, and equally intertwined with the physical and material world and the ways in which these assemblages also marginalize certain bodies and minds (Wright, 2015).

In line with Wright (2015), rather than singling out a definition of belonging, it is perhaps more useful to be cognisant of the breadth of theoretical conceptualisations of belonging. Wright (2015) argues that it is more helpful to be open and flexible to different theoretical understandings and multiplicities. For Wright (2015), belonging needs to be seen not only as an emotional and subjective attachment to place or people, but also as a “process” and “performance” enacted and shaped by a wide variety of practices (not only human practices, but also those of animals, places, things and flows). The idea of the multiplicity of theoretical understandings of belonging has been used to inform the development of this literature review which weaves through varying schools of thought.

2.4.2 Distinguishing belonging from social inclusion and integration

Strnadová and Nind (2020, p. 198) argue that social inclusion and integration are problematic rhetoric, as this framing leads people to think of communities as “pre-existing entities that people with intellectual disabilities are inserted into in some way”. Much of the social policy and research to date has taken up the agenda of social inclusion as an anti-discrimination effort in line with the social model of disability, which identified barriers in mainstream community that devalued and excluded certain bodies while inherently privileging able-ness. The other common theme in this literature is participation and activities in community as a means to define social inclusion involving more than mere attendance and extending to quality of engagement across varying community activities.

This body of literature offers practical analysis and information about how people with disability interact with mainstream society (e.g., education, sports, employment). Social inclusion has a history that is rooted in assimilating people with disability into mainstream society, building on the strong belief that giving people with disability socially valued roles such as “student” or “employed” would facilitate a more positive image and therefore combat negative prejudice. There are remnants of this position reflected in contemporary policy. For example Cameron (2005) observes that in the UK social policy defines social inclusion as focusing on individual skills, engagement and participation in activities. Arguably, assimilation to able-bodied norms and values continues to devalue disabled bodies and minds unable to meet those expectations.

2.4.2.1 Anti-thesis of belonging: Loneliness, isolation and exclusion

It is important to also define the opposite of belonging to make clear what it means to “not” belong. This has tended to be described in a multitude of ways depending on personal circumstances. For example a recent systematic review by Mansfield et al. (2021) examined loneliness and isolation across various disciplines and found that studies about older people were more likely to refer to loneliness in terms of loss, detachment, and boredom whereas younger cohorts tended to associate loneliness with the need to escape from someone or something, and resignation or acceptance of negative feelings such as shame or stigma (Mansfield et al., 2021).

One study by Macdonald et al. (2018) compared non-disabled and disabled people's experiences of loneliness in the UK. This study indicated a high prevalence of loneliness and isolation reported by disabled people (74.4%). Correspondingly, disabled people spent far more time alone (60.5%) compared to non-disabled people (28%). Further to this, Macdonald et al.'s (2018) data demonstrated that, while disabled people reported far less contact with family or friends compared to non-disabled people, the majority also reported wanting to improve their social networks outside their home. Two factors that kept people in their home were difficulties with accessing community and communication barriers. More research like MacDonald et al.'s (2018) study is needed to explore the prevalence of loneliness and isolation among people with disability in shared supported accommodation.

There is a lack of evidence exploring how belonging or isolation are experienced by those living within service settings, although there is some research highlighting that residents in smaller models of housing situated in community (such as individual independent accommodation or smaller group homes of up to four people with disability) appear to have better social outcomes (Fisher, K. et al., 2008; S. Oliver et al., 2020; Stainton et al., 2011) compared to those living in larger institutions. For example they were more likely to be employed or have relationships. Meanwhile other studies highlighted that clustered accommodation provided a greater opportunity for social networks (mostly with other residents who had a disability (Mansell & Beadle-Brown, 2009). This suggests that the type of housing and support model may have some impact on how people interact and develop a sense of social connectedness. Nevertheless, it is hard to draw conclusions as to which type of accommodation or housing maximized social connectedness. Research that explored social connectedness of residents according to type of residential supported settings tended to yield a mix and range of outcomes and there was a distinct lack of studies exploring how residents in supported accommodation understood belonging. This may in part be due to varying cultures that exist within services at a local level, as well as different structures and policies underpinning services in each nation.

2.4.3 Social networks of people in supported accommodation

There has been a wide range of studies internationally exploring quantity and quality of networks by type of disability (Forrester-Jones et al., 2005; Harrison et al., 2021; Kamstra et al., 2015; McCausland et al., 2019; Simplican et al., 2015; Van Asselt-Goverts et al., 2015). Forrester-Jones et al. (2006) and Robertson et al. (2001) both analysed how people with intellectual disability living in small in-community residential facilities interacted with their social networks. Both studies found similar results, concluding that the majority of the social networks of people with intellectual disability were dominated by paid staff, service providers, and family members, with very few unpaid friends. Most of their association with friends happened in disability service settings (Forrester-Jones et al., 2002, 2005). An Australian study by Bigby (2008) showed similar trends. These findings suggest that people with disability can and do at times develop positive and affirming connections with other residents in meaningful ways. Residing in supported accommodation with house-mates they enjoy spending time with would significantly contribute to a sense of identity, value, recognition and respect.

Other studies have measured the choices people with disability make about how and with whom they associate, and/or or the correlation of participating in community versus actually developing meaningful community (Amado et al., 2013). Amado et al. (2013) make the point that it is the social preferences people have that determine their satisfaction. For example, one person may have one friend and feel satisfied, whereas another may have ten friends and feel loneliness. Notably, many of these studies focused on the development of social connections in terms of friendships, but did not necessarily explore how people negotiate relationships with intimate partners (Bigby, 2008; Forrester-Jones et al., 2005; Harrison et al., 2021; Kamstra et al., 2015). The studies that attempted to do so highlighted that few have a partner (Van Asselt-Goverts et al., 2015).

Research has highlighted a number of personal and contextual factors that seem to correlate with smaller social networks. For example:

- Older people with intellectual disability saw a marked decline in the quality of their social networks, with fewer connections to family or unpaid friends (Bigby, 2008). McCausland et al. (2019) found that older people with intellectual disability were more likely to rely on staff or co-residents for support because they no longer had family they could rely on.

- When people acquire a disability this may be a significant life change that results in a drastic change to social networks and a change in roles and relationships, particularly if the acquired disability impacts on traditional means of communication (Azios et al., 2022).
- Those with more significant profound levels of disability tended to have smaller social networks compared to those with mild or moderate types of disability (Kamstra et al., 2015).
- For people with complex communication needs there are additional factors that need to be considered such as the practicality of using various augmentative alternative communication methods across various aspects of community life (e.g., a communication device may not be used in the pool but may be useful in the home) as well as the familiarity of individuals to understand and communicate using AAC (Therrien, 2019).

These studies illustrate the importance of understanding the intersections of identity and recognizing that belonging and loneliness may take different forms and have different meanings for different people depending on their own background and circumstances.

2.4.4 Experiences of belonging (or not) among co-residents

The research is clear that people with disability living in shared types of accommodation (e.g., a group home or hostel) rarely have a say about who their co-residents are. Often these people are allocated accommodation at a service provider level (Disability Royal Commission, 2019a; Farmer et al., 2016; Mansell et al., 2003). The Royal Commission into Abuse in Disability Group Homes report (Disability Royal Commission, 2019b, 2020) heard evidence from a range of witnesses alluding to lack of choice and control over where or with whom people lived. They cited a range of issues such as shortage of housing supply which in turn meant that many were on waiting lists to be placed wherever there was a vacancy. Often these placements were allocated when people were in a state of crisis. These broader systemic issues created a climate of powerlessness and disenfranchisement where people with disability were forced to compromise and continue living in these situations even if they were uncomfortable, or felt actively unsafe around other residents. Witnesses in this hearing also pointed to a “clinical response” whereby behaviour support plans would be initiated by services instead of actively responding to the deeper issues of incompatibility and conflict among residents. This speaks volumes about some of the social complexities that people living in these settings must negotiate. Indeed, as discussed in earlier sections, there are people with disability in such settings experiencing all types of harm and abuse (physical, sexual, emotional and other). This broader literature alludes to some of the complex relational and social issues people may be negotiating in shared contexts; however there is scant research exploring the perspectives of residents in terms of how they navigate “belonging” in shared disability settings, as well as related experiences of belonging, isolation and disconnection. Consequently, disability services have a duty to ensure adequate responses to the nature of harm occurring within the confines of their services.

2.4.5 Quality of support underpinning embodied belonging in supported accommodation

As discussed in previous sections, there is a concerning prevalence of serious misconduct or criminal types of abuse that may occur in disability service settings. These types of harm are reportable and require immediate action. However Robinson et al. (2022) point out that, in reality, there may also be subtle types of interactions which cause harm and constitute “poor quality of support”. These types of interactions may be harder to address and are often unintentional, occurring on a day to day basis between people with disability and others around them. They include: offensive comments, slights, snubs and insults (relevant to emotional abuse as described in section 2.2.2.2). While these may seem like small interactions, they have the capacity to damage self-esteem and cause harm and trauma for people with disability, particularly when exposed to these subtle forms of misrecognition consistently over time. Given the high prevalence and presence of paid professionals in the lives of people with disability on a daily basis, it then follows that such interactions and the institutional structures that pertain to these interactions not only disrupt feelings of safety and security, but also impact on residents’ experiences of embodied belonging.

Support workers provide practical and transactional task support and often the front line of services. Their role is also inherently social and relational in nature. As Robinson’s (2022) work on recognition shows, even passive or subtle negative interactions can cause considerable hurt. This dyad between the individual(s) and their worker(s) is shaped by the service organizational operations, norms and culture. According to a review by Bigby et al. (2019, 2020) quality of supports consists of:

- low resident to staff ratio
- the quality and content of staff training (often reflective of organizational culture) as well as the length of time since Active Support has been adopted

- the level of engagement of staff and willingness to obtain qualifications, manage demands and take leadership
- active management and support from managers
- leadership on the front line to provide coaching and ensure development of support workers' skillsets.

The majority of the studies concerning quality of support have tended to (a) collate the views of service professionals and staff, relying on staff self-reporting (Beadle-Brown, 2015), and/or (b) rely on observational measures (Bigby et al., 2015, 2020; Humphreys et al., 2022a). Additionally Hutchison and Kroese (2016), who interviewed a small group of six support workers, highlighted that workers felt that quality of care was also linked to how support workers felt about the job. From their perspective they were more likely to see good quality of care when they had positive reciprocal relationships with the residents, other colleagues and managers in ways that made them feel valued and part of a team.

Notably, quality of support varies from organisation to organisation and there may be a range of social, cultural and economic factors and pressures that impact quality of support (Mansell et al., 2008). Further to this, Bigby et al. (2019) commented that the quality of leadership in organizations may be diminished due to pricing models associated with the shift towards the National Disability Insurance Scheme although there is little known as yet about how the NDIS impacts on cultures within organisations. While efficient delivery of services was key to reliability and presence of workers day to day, at a practice level, efficient "operations" actually had adverse impacts on people with disability and diminished the quality of personalised support (Bigby et al., 2019). This is supported by other studies which found that workers were less likely to take the time to listen, reciprocate and respond to what residents wanted support with (Löfgren-Mårtenson, 2013). While these studies provide a useful overview and framing of the multitude of institutional factors at play in delivering quality of support, at times direct support relationships may traverse the line between formal in nature and also informal in terms of reciprocity, humour and conversation. Conversely, support workers may also perpetrate or unintentionally cause harm (as discussed in previous sections).

Few studies have explored the subtle and nuanced social and relational experience between people with disability and their support workers. Of the studies that were found from the perspectives of people with disability having direct experience, there were common themes about the need to be recognized and treated as an individual and a human being capable of understanding and making choices about their needs. Topping (2022) canvassed the perspectives of people with neurological disability who articulated quality of support in more embodied terms as “being able to lead supports and live an ordinary life” (p. 8). Topping’s (2022) study re-iterated the importance of individualized person-centred practice as foundational to quality of support, rather than a one-size-fits-all approach. True quality of support depends on a respectful and reciprocal dyadic space between the individual and their support worker where the support worker recognizes that people with disability know their own body and can therefore make their own choices about what works best for them.

Robinson et al (2022) explored the views of young people with disability and their support workers and found that young people in their study tended to describe feeling shame, hurt, anger and frustration when they were “treated with throwaway comments, disregard, indifference, lack of attention and some mis-recognitive acts” (Robinson, 2022, p. 11). Mis-recognition is often routine and nuanced which makes it difficult to identify. It may also be a mis-recognitive act when people make assumptions about who someone is or what their preferences, qualities and needs are. Robinson et al. (2022) referred to these as everyday harms that constituted mis-recognition (disrespect, devaluing and disregard). Robinson (2022) suggested that often the resulting poor or harmful practices stem from people’s own worldview and experiences of mis-recognition in their own lives, or perhaps ignorance regarding the power of their words and actions and the impact these may have on people. At other times, their actions and words may in fact be wielded with intent to cause hurt (Robinson et al., 2022). Building on this argument, it is not only direct or overtly negative interactions that cause harm, but also passive lack of interest or the sense that workers did not want to be there and were just trying to fill employment or wanted the money (Topping, 2022).

2.4.6 Social connectedness beyond formal service structures

People with disability are vulnerable to loneliness and isolation (Gilmore & Cuskelly, 2014). However few studies have examined how people with disability negotiate direct support or mitigate and negotiate harmful interactions that may impact on confidence, wellbeing and disrupt the feeling of value and belonging. Family and unpaid carers feature strongly in the literature in relation to people who live in congregated types of care (see section 1.2.1 on why people live in congregated care). They play a significant role in making decisions about the future of people with disability particularly in terms of where to live or what services and supports people need

(Brennan et al., 2020; Casale et al., 2021; Lee & Burke, 2021b; Marsack-Topolewski & Graves, 2020; McCausland et al., 2019; Walker & Hutchinson, 2018). Many of these studies demonstrated common family concern and worry about the long-term safety of people with disability and vulnerability of people with disability in “ordinary society” (Marsack-Topolewski & Graves, 2020). This in turn, underscored family member decisions about future planning and placement in residential settings (Bredewold & van der Weele, 2022). At the core of many future planning discussions was an uncertainty about what the future held and fear of how people with disability might be neglected and uncared for in the general community (Curryer et al., 2015; Iriarte et al., 2021; Taylor et al., 2019; Tøssebro & Lundeby, 2006; Werner et al., 2009). This evidences a deep fear and distrust of the general community’s willingness to respond respectfully to people with disability.

While it is true that people with disability may experience discriminatory behaviour, abuse or hate in the general community (Emerson et al., 2016; Wayland et al., 2022), research has also indicated equally valid concerns about the quality of services for people with disability living in shared accommodation (Burke et al., 2018; Casale et al., 2021; Innes et al., 2012; Lee & Burke, 2021; Lindahl et al., 2019). The evidence is clear that even after people have moved to group homes and are no longer in the primary care of people they used to live with, family continue to provide a high degree of emotional and physical support (Burke & Heller, 2016; Casale et al., 2021; Lee & Burke, 2021b; Walker & Hutchinson, 2018). Conversely, those without family members (e.g. older people with disability) were less likely to have external sources of reciprocity or support to deal with difficulties as they arose.

2.4.7 Embodied experiences of belonging outside the home

While this thesis addresses how people with disability negotiate safety, belonging and agency in their home “space” in supported accommodation, it is critical to also understand the context of how people with disability fare in the broader community. As May (2011, p. 367) reasons, to understand how people embody and make meaning of self-identity and belonging in society it is necessary to also explore material and social structures that underpin everyday life “where the unofficial spheres of activities and thought intersect”.

In the 21st century, digital communication has a central role in facilitating social connectedness beyond the home (Gelfgren et al., 2022; Trevisan, 2017). A number of studies highlight the power of social media and mainstream technologies that have enabled people with complex communication needs to forge meaningful connections by using communication devices to engage with others. Digital communication has a different set of norms that do not require immediate responses, enabling people to take their time with communication and still build a meaningful reciprocal relationship (Dada et al., 2022; Paterson & Carpenter, 2015; Therrien, 2019), although some people with disability may find digital media challenging due to its reliance on literacy. Digital communication has provided meaningful ways for people with disability to engage with community and to confront ableist assumptions and stereotypes through advocacy and story-telling with wider audiences. Notably, however, both social media and mainstream media outlets tend to hear more from those with disability who are conventionally articulate. This in turn may obscure the weighting of 'who' is heard on disability issues. Society rarely sees people who live in supported types of accommodation with intellectual or multiple disability represented in such spaces (Anderson, 2022; Winterbotham et al., 2023).

2.4.7.1 Neighbourhood belonging

In Australia, as in much of western society, there has been significant reform and legislation over the past several decades to address overt discrimination and segregation of disabled bodies. These social reforms have seen many disabled people take up socially valued roles in society such as becoming a parent or engaging in employment, education, leisure and sports to a greater degree (Department of Families, 2011; Australian Institute of Health and Welfare (AIHW), 2021; Australian Law Reform Commission, 2014). There has been research indicating that the majority of those who live in disability service accommodation settings have been able to work in supported disability employment agencies, and to be more active in disability recreational, leisure, arts and sports groups (Bigby 2005; Forrester-Jones et al., 2002, 2005).

2.4.7.2 Power in affirmative Crip Spaces

The plethora of disability organizations, services, associations and networks that are specifically servicing the disabled community play a crucial role in individual support and systemic advocacy and campaigning for social change (Löfgren-Mårtenson, 2013; A. Scott & Doughty, 2012). While much of the social inclusion literature seeks to combat segregation of disabled people from mainstream society, it must be acknowledged that peer-to-peer connection and support among fellow disabled people can also serve as a form of resistance against exclusion, so long as it is consensual rather than enforced by services.

Organized disability-specific spaces do not always result in segregation and exclusion, but rather may enrich and build on the foundations of society. These peer to peer spaces – sometimes referred to as “crip” spaces – may often act as safe spaces where people can share knowledge, ideas, stories and foster a sense of mutuality (Beart et al., 2004; Clarke et al., 2015; Ryan & Griffiths, 2015). Peers can have a much more nuanced understanding of disability, reducing the taxing mental load of having to always explain “needs” to people who have very little exposure to disability.

There has been a considerable body of research about the value of self-advocacy networks for people with intellectual disability. From a self-advocacy point of view, the act of having conversations about routine day-to-day issues with peers in a peer-network setting can be a valuable way to seek external social feedback and information and assist people to move away from treating issues as an “incident” (in line with service-provider-speak) to instead understanding that such issues affect many people with disability in supported accommodation (Beart et al., 2004; Clarke et al., 2015). Such findings suggest that belonging to peer support networks facilitates the shift from individual self-advocacy to systemic and political advocacy. These sorts of affirming peer to peer interactions help people to confront stigma and take ownership in advocating for social change: “nothing about us without us”.

Some researchers highlight that opportunities for organic encounters with strangers and acquaintances in public spaces are an important part of fostering a sense of safety and belonging (Bigby & Wiesel, 2019; Bould et al., 2023). Boland et al. (2023) conducted a detailed systematic scoping review exploring how people with intellectual disability connect to place, and how they make connections to others in their locality. Their study demonstrated that experiences of belonging in neighbourhoods varied for people with intellectual disability due to:

- Location (e.g., living in an urban or city area enabling more opportunities for work or leisure)
- Familiarity with the area (e.g., those who grew up in the area were more likely to maintain relationships with acquaintances)
- Levels of safety and low crime rates
- Being understood and accepted (as opposed to being intimidated, stared at, name-called or avoided)

- Being known by name and recognised by members of the public as a familiar face in the neighbourhood.

Boland et al. (2023) argue that routine and regular neighbourhood participation in public spaces are vital in making connections even if these are just a greeting or short conversation.

2.4.7.3 Community attitudes and perceptions towards people with disability

People with disability face a range of negative perceptions, stigma and discrimination day to day in community. While some of these barriers may be environmental (e.g., buildings designed in ways that do not meet individual needs), many are constructed by implicit social and cultural marginalization of disabled people as lesser or incapable.

Bollier et al. (2021) conducted a national survey canvassing attitudes towards people with disability and found that, while explicit prejudice and overt discrimination may have declined, 78% of respondents surveyed still reported being uncertain about how to interact with people with disability, suggesting that there are still unconscious and conscious biases against disability (Bollier et al., 2021). Such prejudice can be both explicit and implicit in terms of interactions, and is often rooted in life-long learning and exposure to the idea that disability is a tragedy, along with ignorance and general lack of connection to anyone who has lived experience of disability (Fisher et al., 2022; Wilson & Scior, 2015). Consequently, when people with disability routinely encounter these attitudes, they may result in feelings of shame, hurt, anger and a sense of powerlessness (Logeswaran et al., 2019). Such negative experiences would significantly impact on how people make meaning of belonging.

2.4.8 Section summary

Research about belonging emphasizes belonging as a state of being human. To borrow from Weeks (1990, as cited in May, 2011, p. 368): “Identity is about belonging, about what you have in common with other people and what differentiates you from others.” In other words, for people in supported accommodation it is about all aspects of the individual being accepted – fully taking account of commonalities and shared moments as well as recognizing points of difference without fear, shame or retribution. Much of the literature to date has situated social connectedness of people with disability in terms of social inclusion, social participation and integration. While many studies have explored issues of belonging for people with disability more generally (e.g., in employment and sports among other aspects of community), very few studies have examined the embodied belonging of people living in supported accommodation and the inter-relationship with safety and agency.

2.5 Literature review summary

The review of literature across the three topics taken together has demonstrated the interwoven nature of safety belonging and agency. In order to understand the embodied nature of these experiences it was important to engage in a reflective discourse about exactly who defines justice and wellbeing. In social and political discourse, social justice is often framed in terms of economic problems that need to be addressed through policy and budget re-distribution. Whilst decisions about the budgets committed to disability services are absolutely crucial to quality of life of Australians with disability, the question of social justice is not only addressed through division of resources but is also concerned with social and cultural relations.

Inequality is deeply rooted in the lives of people with disability as a result of entrenched ableism, with inequalities being reported in all systems and structures at all levels of community. Such reports precipitate questions regarding quality of life and wellbeing and what these concepts mean to people with disability living in disability service contexts. If feeling and being safe and free of violence are foundational to wellbeing, then it makes sense to examine security, and safety of people with disability living within such situations where such people reportedly lack control, self-determination or a sense of social connectedness and belonging. It is increasingly clear that the culture and systems underpinning disability accommodation services have dominated the way people with disability live, and forced people to take up vacancies even if the housing and supports were not well matched to their values or needs (Disability Royal Commission, 2019a, 2019b). Reports have also indicated that the disability sector has been chronically under-funded with tight eligibility criteria governing who is eligible for supports. These broader contextual factors have impacted on choice and control and meant that people have been dependent on disability services that were ill-fitted to meet their needs appropriately. At the time of writing, the disability sector is undergoing intense change in Australia. The NDIS (see section 1.8.1) has seen the landscape of disability services rapidly changing, with the promise of more choice and control for people with disability. Whether this extends to those living in group homes or other forms of disability accommodation is yet to be seen and it is unclear whether the NDIS will impact on how supported accommodation is designed and provided for.

There is no doubt that the quality of life of people with disability has significantly improved in the post-de-institutionalisation era. However, research indicates that there are variations in levels of wellbeing when comparing the wellbeing scores of people living in various disability residential housing models. Several researchers have concluded that those living in group homes – the dominant model of housing in Australia –experienced a lower quality of life compared to those living independently or in other forms of supported living accommodations (Bigby et al., 2017; McConkey, 2007; Walsh et al., 2010). Research has also highlighted that people with disability experience a diverse range of pathways to housing, with a range of factors making it difficult to find, keep or maintain suitable housing options, including severity and type of disability, the changing nature of individuals' support needs, and adverse life circumstances (Mackie, 2012; Tually, Beer, & McLoughlin, 2011).

Inevitably, research about security and wellbeing in the home also concerns the degree to which people are respected, valued and recognised. Within such discourse, there are questions about how social structures and relations in structured accommodation settings facilitate the development of identity, social belonging and personal agency. Conversely, when people live in structured accommodation settings where their sense of authorship, choice and control are constrained, there are questions about how this impacts on experiences of personal safety. There is consequently a need to explore how people negotiate personal safety, belonging and agency in their everyday lives in accommodation settings. Secondary questions also emerge about how such people are heard and taken account of in policy, practice and in research. These questions need to be explored with particular attention to the voices of people with disability, particularly such people living in supported accommodation settings who are significantly under-represented in disability and social policy research.

There has been limited research exploring these questions by canvassing the perspectives of residents living in disability shared accommodation settings. The present study therefore aims to address this lacunae by directly exploring the lived experiences of people with disability in relation to their experiences of security, belonging and agency. Whilst the focus of this study is broad and open to the diversity of narratives and experiences, it has been vital to contextualise and acknowledge that participants' experiences may fall on a continuum, particularly given the range of information gained from recent abuse inquiries into institutional and disability residential accommodation settings. These inquiries have brought to light a multitude of situational, locational, social, cultural, political and structural factors which foster security, belonging and agency in the home, or adversely perpetuate harm and oppression (*Community Affairs Reference Committee*, 2015a). Thus the present study seeks to intentionally privilege the lived experiences of residents with disability living in shared types of accommodation and is shaped by a theoretical perspective strongly rooted within a social justice paradigm, drawing on elements of critical theory, feminist disability studies and inclusive research (Mattsson 2014; Nind & Vinha, 2014; Nkoane, 2012; Solnit, 2017).

2.6 Overarching research question

The literature review has provided an overview of some of the social issues people with disability face when living in shared types of disability accommodation and has made clear why this study focuses on identifying and analysing the ways people negotiate and embody safety, belonging and agency as inter-related experiences. This doctoral thesis sought to address the following research question:

> How do people with disability negotiate safety, belonging and agency in shared disability accommodation settings?

There were three main aims underscoring the study:

- To determine the factors contributing to or harming safety, belonging and agency in the context of shared accommodation
- To explore research methodologies that are accessible and inclusive to this cohort
- To discuss implications of these findings for systems, policy and practice.

In this research, disability was seen as a fluid concept, shaped by socio-political contexts, material and structural. I also posit that all aspects of being human – gender, sexuality, class, race, ethnicity, bodily difference – intersect in everyday experiences in ways that are not always easy to decipher when talking about how we negotiate our social world. I argue that the multiplicity of identities needs be taken account of, as all of these varying points of difference and continuity shape and constrain how people negotiate and access supports and services. The experience of middle class men with disability would vary from that of women with disability from poorer socio-economic status; the experience of an Aboriginal woman with disability would hold different meaning to that of an Indian woman with disability. I argue that how people make meaning of privilege, citizenship, power relations, divisions of labor and roles has less to do with type of disability, and more to do with how a person negotiates their own bodymind in relation to their material and social context.

For the purpose of this study, safety, belonging and personal agency are seen as inter-related concepts which have been drawn from the broader literature and core themes of security, safety, connection, agency, choice and control.

- ***Safety*** means being safe and protected from the threat or experience of violence, harm, neglect and oppression in all forms including physical, sexual, emotional, financial, and others.
- ***Belonging*** refers to a psychological and embodied sense of attachment and connection to people and places in the broadest sense. It is concerned with questions about what facilitates a sense of identity, belonging and value.
- ***Agency*** refers to a sense of authority to make decisions aligning with individual values in ways that control what happens in the home life wherever possible. This is not to be confused with self-reliance or self-assertiveness. People can sometimes need support to express their preference and will and to act accordingly.

These are working definitions based in the literature and offered to participants to help communicate the foundation of the study, acknowledging that, as working definitions, they may be subject to evolution and change over the course of the study.

2.7 Rationale for the current study

There is a dearth of literature exploring embodied experiences of safety, agency and belonging for people with disability who must also negotiate institutional structures that underscore shared types of accommodation settings. In this literature review, the evidence in relation to personal safety, belonging and agency has been presented in order to demonstrate how much the literature seems to focus on issues of personal safety, belonging and agency as separate entities. I believe that this is a timely doctoral study, given the current socio-political debate in Australia in relation to issues of safeguarding and prevention of harm against people with disability in disability care settings. It is also a time of intense political scrutiny for disability services with the introduction of the National Disability Insurance Scheme, a scheme which radically changes how people with disability access funding, with a transition to individualized funding packages to purchase and manage services, equipment and supports (Carey et al., 2018).

As this literature review has demonstrated, various reports in the media, government and academic literature continue to evidence that people with disability in congregated types of disability accommodation may face instances of harm in a multitude of ways and that this may be harm from a family member, housemate or co-residents, staff, management and others. Research also highlights that people with disability experience fraught and complex pathways to finding, keeping and maintaining secure housing. For those who are living in shared disability residential settings, there are still numerous factors contributing to experiences of insecurity, instability, isolation, violence and neglect. Stability in housing may be affected by issues such as a person's severity and type of disability and the increasingly higher care nature of individuals' support needs (Mackie, 2012; Tually, Beer, & McLoughlin, 2011). There are also several reports and inquiries highlighting a high prevalence of isolation and violence against people with disability who are negotiating life within these service systems. Such reports precipitate questions about what it takes for people with disability to negotiate and foster safety, belonging or agency in their lives and home. In order to address this question of prevention of harm, isolation and neglect, there is need for conversations about how people experience aspects of security, recognition and value. There are also secondary questions about how such people are heard and taken account of in policy, practice and in research.

CHAPTER 3: AXIOLOGY, ONTOLOGY, EPISTEMOLOGY AND METHODOLOGY

3.1 Introduction

As the literature demonstrates, housing is a significant human rights issue for people with disability. When options are limited and supports are tied to disability accommodation services this profoundly changes people's perceptions of personal safety, belonging and agency. The following chapter provides an overview of how this study was designed including:

- Reflexivity and personal axiology – values underpinning the justifications for doing this research (section 3.2)
- Ontological and epistemological assumptions underpinning this research and the rationale for a critical theory lens (section 3.3)
- Justification for the research methodology (section 3.4)
- Ethical considerations (section 3.7)
- Interview and creative tool kit methods (section 3.8)
- Rationale for new materialist assemblage analysis (section 3.9).

3.2 Reflexivity and personal axiology

Brown & Dueñas (2020) argue that the researcher's axiology should be explicitly identified as part of taking a reflexive approach to research. In this study axiology refers to my own values which underpin and inform my ontological and epistemological positioning as well as my choice of methodology. As Berger (2015, p. 220) highlighted: "Questions about reflexivity are part of a broader debate about ontological, epistemological and axiological components of the self, intersubjectivity and the colonisation of knowledge".

Here, it is important to acknowledge my own positionality as a disabled researcher, which impacts on the research in three ways. It impacts on the way I negotiate the processes in terms of my own communication needs (low vision and hearing); it has bearings on the data generation methods and analysis I chose; and it also influences the values I bring to the research. Nevertheless, I want to make it explicitly clear that I do not have lived experience of living in shared disability service contexts such as group homes or hostel type accommodation, and nor do I have a cognitive disability or physical disability requiring intensive day to day support. Thus, in my own research process, it was important to develop methods in ways that enabled the direction of this research to be guided by people with direct lived experience as much as possible.

As a disabled scholar, I have a long standing interest in critical feminist disability studies with values rooted in a social justice paradigm (Alvesson & Skoldberg, 2009; Lazard & McAvoy, 2020). Reading and learning about the disability rights movement and the shift from the medical to the social model of disability (Oliver, 2013; Shakespeare, 2016) helped me to understand my own internalized ableism from being embedded in a society where disability was seen as a tragedy – a medical problem or burden to be fixed, cured and eradicated . Learning about the social model of disability was particularly useful in helping me to re-frame my own identity when advocating for my own needs and negotiating prejudice and inaccessibility. Instead I began to argue that prejudice and barriers to accessibility and inclusion were a collective and social and civic responsibility to redress rather than a problem inherent to being me.

I situate this research within a broad critical feminist disability studies paradigm, recognizing that there are a swathe of different research theories and positionalities situated under this umbrella term (Brown & Strega, 2016; Campbell, 2009; K. Ellis et al., 2016; Goodley et al., 2014, 2018; Tregaskis & Goodley, 2005). Research in critical feminist disability studies engages in questions about how various identity categories such as “disabled”, “woman”, “queer” are embodied and affect power relations in intersectional ways (Brown & Strega, 2016; Denzin, 2017; Goodley et al., 2018, 2019; Kafer, 2013; Mog & Waggoner, 2020; Waldschmidt et al., 2017). Some scholars argue that marginalized identity categories such as (but not limited to) “disability” are an embodied experience that then produces power inequity when interacting with the majority world; this in turn causes those bodyminds to be seen as lesser (see Tremain, 2017, as an example). However other scholars primarily describe disability as the material experience of “misfitting” when negotiating dominant societal structures and norms underpinned by expectations of ability and productivity (see Garland-Thomson, 2011). While scholars have different ways of articulating marginalization through a critical feminist disability studies lens, the overarching paradigm has offered useful thoughts for ways to understand and articulate oppression, marginalisation and othering (Humphries et al., 2020; Mertens, 2017). In line with this overarching paradigm, my research aims to centre marginalized perspectives and aims to adopt an approach that aligns with the values of human rights, participation, citizenship and equity (Belle, 2022; Didi et al., 2016; Love & Fox, 2020; Nkoane, 2012; People with Disability Australia, 2010).

I draw on critical feminist disability theory in the sense that this research aimed to privilege the perspectives of residents living in disability accommodation in order to better understand the factors impacting, as well as the solutions, ideas and possibilities for social change and progress. It was through reading these scholarly works that I began to identify myself and all of us – regardless of disability – as people with human rights who are marginalized by structures and systems. To me, this does not mean ignoring individuality and difference between various states of embodiment, but recognising that all people deserve freedom from harm, equality, respect and dignity – regardless of intellectual disability, or autism, physical disability, deafness, blindness, or other. While my values align with critical disability feminist studies – I also build on this with the use of new materialist theory (Feely, 2020; Fox & Alldred, 2015) as a means to take account of both material and semiotic structures that impact on the experiences of people with disability in this study (see section 3.6 for discussion of new materialist assemblage analysis).

3.2.1 Navigating the research space as a disabled outsider and onlooker

In this research the lived experiences of people with disability are centred as essential valuable knowledge if we want to tackle issues of marginalization. In keeping with a critical disability feminist studies perspective, it was important for me to keep asking the question of who is marginalized and "difficult" to reach and why? When interrogating how research may be ethical and respectful towards people with disability and my role in this as a researcher, it was necessary to ensure the research goal was oriented towards an ethos of social justice and democratic citizenship which intentionally centred the voices of people with disability at all stages of the research process and kept my voice as a researcher to minimum (Nkoane, 2012). Arguably, power relations were not eliminated from the research process; however as a researcher I could at least recognize, attend to and reflect on status quo when interacting with advisory group members, people with disability and disability organisations (Karnieli-Miller et al., 2009; Råheim et al., 2016).

Many inclusive research scholars have discussed inclusive/emancipatory research in terms of non-disabled professional/academics working "with" disabled people in community. This presents a problematic binary discourse that separates the "professional" identity as distinct from that of the "disabled" identity (see Hollinrake et al., 2019). I was learning what strategies worked and did not work for me as a disabled researcher with my own accessibility and communication needs, while also learning how to work alongside people who had their own support needs. Together we had to navigate our needs and manage social stigma and marginalization in various and different ways. For this reason, my participation as researcher warrants some reflection given the influence my standpoint had in shaping the research process, the relationships that were built and the subsequent results and outcomes (Berger, 2015; Thoresen & Öhlén, 2015).

There were always power relations to be reflected on and navigated carefully within the various relationships I negotiated over the course of the research. This notably included the relationships with the “gate keeper” professionals within organisations I was liaising with and the people with disability who I was interviewing. There were also a number of incidental support people, other residents and staff who were often present. Interestingly, when entering accommodation services, both in the recruitment stages and during interviews, there were a number of occasions when support workers and staff approached me and asked if I had come to “join in the activities” (or similar). On such occasions I had to explain that I was a researcher here to speak with residents. This was often registered with what I think was confusion, then surprise and then embarrassment and a quick change of tack, sometimes exaggeratedly congratulating me on being a university student. Conversely, residents approached me more as a peer they could interact with, and tended to ask me lots of questions of about my disability, the role of my guide dog and what my own experiences were as a disabled person. These encounters led me to question whether I was perhaps more alert to observation of tone and non-verbal cues because of my own experience of being disabled in a social world where people with disability are routinely and systematically stigmatised and devalued. Has my disability afforded me some degree of insight or am I merely generalising my own experience given that I am an outsider? Even within the disability community there are levels of privilege and disadvantage.

Here I draw on the body of work done around reflexivity in qualitative research. Reflexivity as defined by Beck, Bonss and Lau (2003) concerns the disruption of taken-for-granted norms and social conventions that exist in language and discourse about disability. Reflexivity in the context of this study was not about being rid of privilege, but rather the conscious and intentional process of questioning and continually renegotiating norms and tensions in ways that reflect on power dynamics (Alvesson & Skoldberg, 2009). As Lumsden, Bradford and Goode (2019) note, reflexivity is the task of sitting with and explicitly reflecting on all the aspects of our research that failed or caused points of differences, discomfort, mess and confusion. I also experienced challenges as a disabled researcher with communication give-and-take and the disjointedness of interviews and resulting narratives. It was a give-and-take process of messy exploration, trial and error, and adjustment during interviews in order to figure out what modes of inquiry worked best for participants and for the researcher.

In addition to the data collected during meetings with participants. I also wrote field notes documenting progresses, challenges and my own thoughts, feelings, observations. These field notes were valuable in helping me to reflect on some of the difficult, awkward, messy interactions which took place between myself and staff who were incidental to the places I visited, and the people I was working alongside. The field notes also provided a degree of reflection on my own attitudes, values and observations as an outsider entering these home environments and meeting people (people with disability, family members and organisational staff) for the first time. Tensions and challenges that arose during the process of working with participants were also noted in the field notes. The notes provided a space to document and comment on contextual and environmental factors that were (a) shaping the course of recruiting and making contact with organisations and (b) affecting the interviewing and relationships. They provided some understanding and intuitive insight as to how people were relating and interacting at specific times, within specific places and with various people (Phillippi & Lauderdale, 2018). Some of the field notes were initiated during the interviews with key words; however most of the writing was done in the hours post interview. For some interviews, the notes were not completed for a few days due to the fatiguing and taxing nature of interviewing and the impact this had on me as a researcher. As Berger (2015) commented, field notes can be added to iteratively at any stage of the research process.

3.3 Ontology and epistemology

I believe that there are multiple realities and perspectives, shaped and understood within the social context and experiences we have when negotiating the world around us (Blaikie, 2010). I extend on this to also draw on Deleuze (1994) who argues that knowledge should not be seen as abstract, nor as universal entities such as soul, consciousness, reason, subject or object (Spindler, 2010). Instead, an event of thought is composed of “a relation between a certain idea of thinking, being and the self” (Spindler, 2010, p. 151). It is this interaction of nature and thought that enables meaning, understanding and ways in which to ask and address questions. Rather than viewing knowledge as singular and static, it is more useful to adopt a relational ontology, understanding reality as “a continuum and multiplicity in a constant state of becoming or differentiation in relation to each singular body (both material and social bodies)” (Deleuze, 1994, p. 163).

In the case of research *about* people with disability, the advocators of knowledge (informants) are more likely to be carers, family members and service professionals (Stack & McDonald, 2014). I do not wish to discount the knowledge and experience of carers, professionals and academics here, nor am I trying to undermine the impact of policies and systems; however it is not the direct experience of people who live in these accommodation settings every day. Historically people who have communication access needs or intellectual disability have been marginalized and excluded from much of the research (Dee-Price et al., 2021; Jones et al., 2020; Mey & van Hoven, 2019; Strnadová et al., 2016). There is consequently a need to build on the research which privileges the direct voices of people who have lived (or are living) in supported accommodation not only in the data, but also in the design of research and analysis (García Iriarte et al., 2023; Nind & Vinha, 2014; Schwartz et al., 2020).

3.3.1 Lived perspectives: The role of critical theory in tackling marginalization

Epistemologically, I take the view that knowledge is constructed and shaped by how we humans encounter and interpret the physical and social world and the people in it. Such an epistemological approach that draws on aspects of critical feminist disability studies allows for a robust analysis of the range of material and social factors people with disability negotiate when living in shared accommodation (Feely, 2020; Goodley et al., 2014). This thesis takes up the challenge of designing research in a way that it is flexible, inclusive and accessible to people who are not often heard in research. It aims to make a contribution to knowledge by canvassing the perspective of people with disability living in supported accommodation settings who are significantly under-represented in disability and social policy research. As Morris (cited by Watermeyer, 2012, p. 39) noted, people with disability are not necessarily angry about biological impairment or the physical or intellectual characteristics of disability:

> Our anger is not about having 'a chip on our shoulder', our grief is not a 'failure to come to terms with disability'. Our dissatisfaction with our lives is not a personality defect but a sane response to the oppression which we experience.

Morris articulates the frustration within the disability community which stems from dealing with social, cultural and political structures that discount them. There are power relations that must be negotiated and tensions that exist, on a continuum, between sites of oppression and liberation; colonization and decolonization, exclusion and inclusion, and privilege and disadvantage. Brown and Strega (2016) urged researchers to consider how research may be designed in ways that improve opportunities for people to participate and present themselves as agents with desires, dreams and hopes for future, thus disrupting power dynamics and the negative narrative of disempowerment.

It is here that I turn to the work of critical qualitative scholars calling for research to be founded on a human rights approach to practice (Denzin, 2017). Critical theory cannot be understood as a single theory; rather, it engages a diverse range of theories including feminist, post structural, decolonization, Marxist, queer, participatory and others still (Denzin, 2017; Farias et al., 2017; Goodley et al., 2018). These theories overlap in tackling the task of articulating, understanding and assisting researchers to use theoretical perspectives to understand experiences of marginalization and powerlessness and what constitutes social justice from the perspectives of people with lived experience.

3.3.2 Epistemic justice and injustice

Fricker (2008) argues that much of the knowledge we have comes from various testimonial sources (whether spoken, written, or through the arts). We depend on access to a variety of testimonies to inform our perspectives and make meaning of the world around us. For Fricker (2008) it was therefore important to examine whose testimonies were viewed as credible and expert, and conversely, why others' accounts of knowledge were devalued. Fricker argues that marginalized identities are less likely to be valued as credible sources of knowledge and refers to this as testimonial injustice, pointing out that testimonial injustices often stem from ignorance or prejudice on the part of the audience. Dotson (2011) provides the example of how Black women have been represented in public discourse in ways that perpetuate negative stereotypes of them as ignorant which in turn shape how audiences perceived testimonies from Black women. While Dotson (2011) used the example of racism to illustrate how Black women's knowledge may be devalued, there are useful parallels in draw in the context of this doctoral thesis in terms of exploring how ableism also informs and shapes the way audiences perceive the testimonies by people with disability.

The second type of epistemic injustice refers to hermeneutical injustice. This pertains to the broader social and material conditions that operate in ways that prevent disadvantaged people from having access to knowledge, which more deeply entrenches powerlessness and struggle for social meaning (Fricker, 2008). Dotson (2011) builds on Fricker's work by identifying different ways disadvantaged identities are silenced by hearers. Dotson (2011) emphasizes the role audiences have in recognizing the status quo and the impact this has when marginalized people give testimonies. She notes that audiences must recognize existing conditions of disadvantage and make an effort to hear and listen and respond in ways that communicate respect for different ways of knowing.

In Dotson's (2011) work epistemic quieting refers to the way marginalized groups are devalued and discounted as knowledgeable. Dotson reasons that this devaluing or undervaluing results from public discourse and stereotypical understandings of particular social identities. For example, she raises the point of Black women being stereotyped in media and public representation as welfare mum, whore (etc.), and how these images then underscore how audiences perceive and respond to their testimonies. Similar patterns of undervaluing and epistemic quieting are seen in the disability community, where "knowledge" is often associated with ability, capability and agency – a direct contrast to the ableist ideas of disability as involving tragedy, dependence, vulnerability, fragility and incapacity. . Epistemic quieting can also involve what Dotson (2011) calls testimonial smothering. This refers to the way speakers from marginalized backgrounds are constantly gauging the reciprocity and receptiveness of audiences and gathering a sense of the prejudices among their audience and thus minimising (smothering) their own testimonies to self-protect from epistemic harm. When the immediate audience seems unsafe or unwilling to listen due to their own bias or prejudices, this causes the testimony to be smothered. The concepts of epistemic injustice and epistemic quieting generate useful insight for this doctoral thesis by posing the question about whose knowledge we value and how those with significant disability who live in shared accommodation are recognized, perceived, and heard.

When examining the broader literature and background (see Chapters 1 and 2) it was clear that while some studies do canvas the views of those with direct lived experience of living in supported accommodation, these lived experience accounts were by far dominated by the prominence of perspectives from care-givers, guardians and service providers. This in turn means that much of the knowledge of what constitutes social justice for people in supported accommodation has depended on testimonies of parents, caregivers or service providers. The dominance of their views inevitably has a strong impact on public discourse and policy as these people are seen as knowledgeable experts. While government and society no longer supports mass institutionalization of disabled bodyminds (Chowdhury & Benson, 2011), some researchers continue to argue that contemporary in-community supported accommodation models still maintain institutionalized in terms of their practice, cultures and structures (Altermark, 2017; Cadwallader et al., 2018; Dearn et al., 2022; Roets et al., 2022; Sirotkin, 2019).

Such underscoring structures inherently privilege the views of professionals and institutions and may make it difficult for those with direct experience to challenge prevailing norms or offer alternative testimonials or ideas. As Ciurria (2023, p. 41) articulates:

> it is often a requirement upon oppressed people that we smile and be cheerful. If we comply, we signal our docility and our acquiescence in our situation ... On the other hand, anything but the sunniest countenance exposes us to being perceived as mean, bitter, angry or dangerous. If oppressed people refuse to smile in the face of adversity, they risk being punished by a battery of hostile attitudes.

Recognising the pattern of dismissal and devaluing that many marginalized identity groups experience when attempting to share their epistemic knowledge (Ciurria, 2023) may help to understand why people with disability struggle to share their knowledge in the context of disability services. If people were to challenge the norm of shared types of disability accommodation, they might risk being seen as ungrateful, unrealistic, irrational and bitter. (This is discussed in more detail in section 7.4.1: Identifying patterns of testimonial smothering and compulsory acquiescence.) Perhaps some of the under-valuing of the knowledge of people in supported accommodation stems from underlying perceptions of inherent vulnerability of those in disability settings and is reinforced by the dominant belief that professionals and support staff “keep these sorts of people safe”.

This thesis challenges the inherent under-valuing of lived experience by intentionally valuing the knowledge of those with direct experience of living in supported accommodation. Narratives and personal experiences are central to this thesis and contribute to new ways of knowing and understanding. Solnit, a feminist writer, argues that storytelling and the sharing of narratives are crucial to the “inclusion, recognition and rehumanisation that undoes dehumanisation” (Solnit, 2017, p. 20). Positioning lived experience as knowledge must be a precondition to changing dominant cultures, laws and policies that silence, harm and oppress. Solnit’s emphasis on spaces where people’s experiences are respected, and valued struck a chord with me. She writes:

> We are our stories. Stories that can be both prison and the crowbar to break open the door of that prison; we make stories to save ourselves or to trap ourselves or others, stories that lift us up or smash us against the stone wall of our own limits and fears. Liberation is always in part a storytelling process: breaking stories, breaking silences, making new stories. A free person tells her own stories. A valued person lives in a society in which her story has a place (Solnit, 2017, p. 30)

Solnit's words describe a response to the silencing and powerlessness perpetuated by systemic structures and systems which favour and respect some people over others. She articulates the emotional significance and political power of being able to have a say (voice) and a choice to be heard. This is pertinent to consider in the context of ableism, and the negative treatment of people with disability as Other. Solnit (2017, p. 19) defines *voice* as being free to "make choices – the choice to speak up, or be quiet – the choice to participate, or not participate". Her words certainly hold true for people with disability who have a long history of devaluation and segregation from mainstream society. This PhD study attempts to address the silencing and ableism entrenched in many traditional methods of qualitative research which have typically excluded people with disability from participation.

3.3.3 Inclusive research principles to guide and tackle marginalization

In line with, and in the spirit of, critical disability feminist studies, this project borrowed from some of the principles of inclusive research as a means to challenge research done "about" people with disability. As Nind & Vinha (2014) highlight, there are various ways to define inclusive and participatory research, so definitions are ambiguous. In the body of work found to date on inclusive research, there is a tendency to strongly critique the role of lead researchers (rightly so) and redefine power relations with a range of intentional strategies intended to bridge the gap and even out the authoritative voice of the researcher (Nind & Vinha, 2014). Researchers define the theory and process of inclusive research using words such as emancipatory, critical, feminist, co-produced and inclusive. It is increasingly common for inclusive research to have an advisory or reference group providing input at all stages of the research as well as paid co-researchers with disability as part of the research process. A number of papers were found to discuss how non-disabled people could strategically "include" disabled people in their research (Goodley et al., 2018; Puyalto et al., 2016; Tregaskis & Goodley, 2005). However, there were some elements in the inclusive research literature which seemed contradictory to my experience. I found the articulation of the binary non-disabled versus disabled researcher role in most of these papers complicated and unhelpful. The binary division between non-disabled researchers and disabled co-researchers also seems lacking in offering a lens through which to analyse the experience of being a disabled person researching within disability studies. Inclusive research principles enabled me to encompass a degree of trial and error, creativity and flexibility, which accommodated both the informants in my study and also me as researcher. Those principles also opened up opportunities for discussion about the extra resources, adaptations and accessibility issues which had to be negotiated for me to be *here* doing doctoral research.

For the purpose of this PhD, inclusive research was viewed as a range of overlapping approaches which centred the design and production of research in consultation with people with disability from the inception to the end of this project as much as feasibly possible within the context of a doctoral study. This allowed for discussion, agreement and disagreement and consensus on what constituted respectful research for people with disability (Nind & Vinha, 2014). Moreover, the involvement of people with disability as mentors, advisers and direct informants who had a say on the research design, methods and analysis strengthened the overall scope of the PhD project (Robinson et al., 2014; Walmsley, 2001),

3.4 Methodology

Within the critical feminist disability studies paradigm a narrative inquiry approach was developed to ensure that lived experience perspectives remained a central point of knowledge (see section 3.2). Principles of inclusive research were embedded to ensure that lived experiences not only informed the nature of findings, but were also woven through into the design and analysis of the study (see section 3.1). This meant that there were multiple layers of lived experience woven throughout at multiple points of the research process (see figure 3.1: Research process), not only in terms of the data itself (which was participant-led), but also in terms of advice on the research question, data collection methods and the analysis.

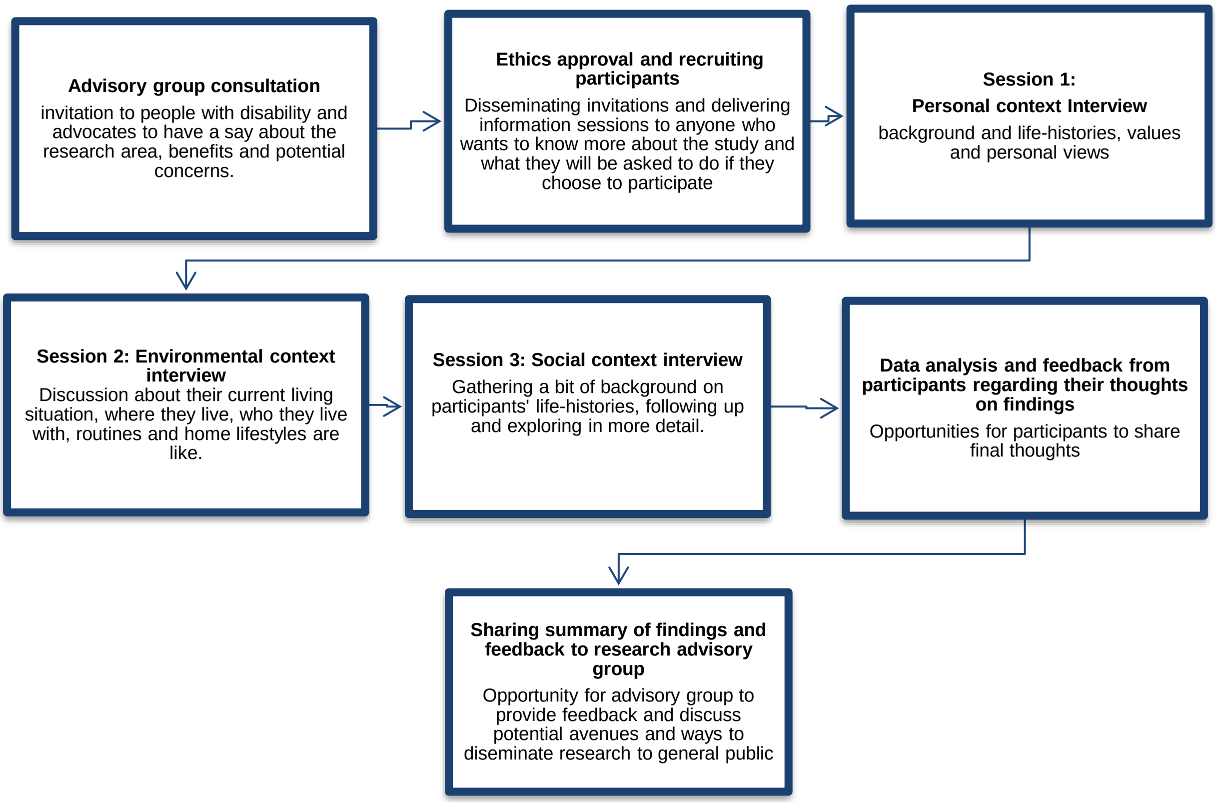


Figure 3.1: Research process

The following section first describes the role of the advisory group before describing the methodological approach and methods in more detail.

3.4.1 The role of the advisory group

Prior to ethical approval a research advisory group was established ensuring that this research maintained a respectful emancipatory focus privileging the voices of people with disability in the design of the research. During the early stages of forming the research question, there were several valuable people who provided input and it became clear through these conversations that this research was likely to include some people who may have experienced insecure, unstable or temporary housing arrangements and have histories that include the ripple-on effect of stress and uncertainty of relocation, as well as the ripple-on effect of secondary losses associated with insecure or temporary housing arrangements. The advisory group was established for the duration of this research, and included people with disability, as well as advocates. Membership of the group evolved over time and was also interrupted by COVID19.

This advisory group met three times over the course of this doctoral study. The first meeting was in 2018 and provided advice on the merit of the doctoral study research question, the design of the research data generation and analysis, and the presentation of findings. The advisory group's contributions were not collected as data, but served as part of an ongoing dialogue that was had throughout the development and analysis stages of the research, which assisted with my reflexive practice (Kramer-Roy, 2015). The second meeting, in 2019, focused on whether the methods for collection of data were accessible and inclusive. They also provided advice on ways to reach out to and connect with residents who lived in supported accommodation made available by various providers. The last meeting held in 2023 was for advisory members to provide advice on the findings and implications.

3.4.2 Participant-led narrative inquiry

The holistic nature of narrative inquiry means that people's experiences and knowledge constructs can be explored in context (Deleuze, 1994; Kohler Riessman, 2007; Riessman & Quinney, 2005). Exploring the contextual factors underpinning people's experiences allows for a greater degree of insight, not just at the individual level but also at a socio-ecological and political level. Adopting a narrative inquiry approach underpins the collection of data in a way that positions participants as epistemic knowers. Narrative inquiry thus fits well with exploring embodied experiences of supported accommodation. As Webster (2007, p. 21) notes: people "encode their experiences in some form of narrative, particularly those experiences of dealing with other people" or the world around them (Riessman, 2008). It follows that narrative inquiry honours the lived experiences of people with disability and also allowed for themes of safety, belonging and agency to emerge from conversations about negotiating people or environments in supported accommodation (Riessman, 2008). Traditionally narrative inquiry is often posited as a qualitative data method that enables people to talk in depth about an event or series of events with rich detail and reflective hindsight. For example, Riessman (2008) argues that narrative inquiry avoids ambiguous general statements and answers, and scaffolds interviews to elicit and draw out people's stories in ways that provide context and ample description of people, events and experiences.

However, this doctoral research needed to diverge from traditional narrative inquiry approaches. While narrative inquiry offered an overarching methodology for the design of interview questions and the techniques for data collection, the application of narrative inquiry as a strategy was not as simple as adopting a series of traditional interview formats. Such an approach might have excluded those who struggle to be articulate and coherent (for any number of reasons including disability, language, trauma, and so on). I refer here to the valuable work by Flynn (2019) who critiques narrative methodology orthodoxy. Flynn (2019) argues that it is problematic to assume that people's experiences are embodied and presented in a linear and detailed coherent narrative. He further argues that it can be difficult to de-construct and name practices and experiences if participants have not had opportunities to verbalise or articulate their own meanings. Certainly in this study, each individual responded differently to the narrative inquiry approach. As a researcher it was important to get to know each participant and to work with and support people with a range of diverse cognitive and communication styles.

Flynn (2019) argues that often narrative research is underpinned by ableist assumptions that only able neurotypical articulate people will benefit from narrative methods. Flynn interrogates how narrative inquiry can be an inclusive and receptive space for children with intellectual disability and urges researchers to be reflexive and cautious about how ableism shapes and steers the direction of research and excludes certain voices. Inclusivity is achieved not only by selectively focusing on specific voices, but also by presenting and disrupting the general acceptance of exclusionary findings in journal articles, and by presenting inclusive research findings in accessible ways in writing, over the airwaves, through video or online. The methodological design for this study was intentionally flexible and responsive to engaging in conversations in multiple ways not restricted to traditional qualitative interview formats.

To address the inadequacy of conventional narrative inquiry methods, I adopted the principles of narrative inquiry and developed a flexible toolkit of creative and visual tools and resources that could be integrated as part of working alongside people during our meetings, notably photo elicitation, collage and drawings. Participants were given the freedom to meet as many times as needed. The combination of narratives, observations, notes and other creative forms of data were valuable in being able to gather a broader range of data (Baker et al., 2016; Gladding, 2016).

The participatory creative mediums in my research toolkit provided accessible adjuncts that facilitated communication and made the project more inclusive of a range of people who would otherwise find it difficult to be heard in research. The rationale for using visual and creative mediums within interviews was informed by my own background in counselling and the arts. The principles and values a counsellor holds as central to their practice (such as adopting a non-expert stance, being person-centred and creating a reciprocal, safe, non-judgmental space) held true as guiding principles that were equally important to my qualitative research. However, while some of the counselling techniques were useful in generating conversation, there were key differences and it was made clear to participants that the use of visual and creative mediums was purely to gather information, not for therapeutic purposes. The visual based methods for engaging in conversations were offered as a way to disrupt the traditional and conventional formal interview style, which is often inaccessible for some with disability. Introducing possible creative mediums gave participants a wider variety of ways to share their testimonies in ways that felt comfortable and useful. The wider variety of ways to engage in conversations also helped participants to feel listened to, acknowledged, validated, respected and in control of the research process (Leavy, 2020). Visual artefacts strengthened the critical aims of this project by dismantling some of the inherent power imbalance between researcher and "researched" by providing participants with opportunities to have a say in how they wished to be involved in the research process and be in control of the data they produced and shared. This freedom allowed people to be flexible and in control of what they chose to portray and share of their realities (Chonody et al., 2013; Plunkett et al., 2013).

3.4.3 Ethical considerations and safeguards

This section addresses the following ethical considerations that were addressed prior to and during the duration of the study: informed consent (section 3.4.3.1), confidentiality (section 3.4.3.2), responding to psychological distress (section 3.4.3.3), and protocols for disclosure of abuse and harm (section 3.4.3.4). Approval was first sought and granted by the Social and Behavioural Research Ethics Committee at Flinders University in 2018 which ensured that the research was sensitive, respectful and justifiable, and that the benefits outweighed the risks as outlined by the National Statement of Ethical Conduct in Human Research (National Health and Medical Research Council, 2023). (See Appendix A.)

One organisation which was approached to share information had their own ethics review committee which agreed to the research on the proviso that names of participants were to be reported back to their organisation. However, this was a direct breach of ethical standards for anonymity as outlined by the National Health and Medical Research Council (2023). I responded to this with understanding whilst also reassuring managers that the organisations were all de-identified and the research was not focusing on investigating bad practices or 'catching bad people". I also outlined the protocol for when and where I would report, to whom, and under what circumstances if issues of abuse or harm emerged during the course of the research. Organisations were reassured that reporting and disclosure of abuse would be responded to appropriately in line with the Reporting Abuse Protocol (see Appendix L), which was developed by researchers Robinson and Vosz (2014) to address concerns of abuse that arose while they were interviewing young people with disability on experiences of safety and belonging. The authors have granted permission for their protocol to be used and adapted.

3.4.3.1 Informed consent

Historically, people with intellectual disability or those who have communication access needs have been routinely ruled out from participation in research due to concerns about capacity to make informed consent. This is particularly concerning when undertaking research of a sensitive nature which may trigger distress or result in reporting where there is a criminal disclosure. While my research was sensitive, I considered there were ways of being able to ensure that such people were fairly given access to information about the research topic and potential risks and benefits for participating in ways that were accessible. This included access to information sheets and consent forms in a variety of easy-read, plain text and pictorial formats (see Appendices C, D, E, H & I) as a way of ensuring that participants were provided reasonable access to information which then enabled them to make informed decisions about participating. (Appendices G, J and K provide additional consent forms.)

In line with the National Health Medical Research Council's National Statement on Ethical Conduct to Human Research (2023), as part of meeting people for the first time each potential participant was screened and assessed by me in terms of their level of understanding. The screening for each person involved a series of questions adapted from a questionnaire which had been specifically developed for those with intellectual disability by Arscott, Dagnan and Stenfert-Kroese in 1998 (as cited by Balandin et al., 2006, p. 471). Once we had been through the information sheet together, I then explained to participants that I would like to make sure they have understood by asking four questions to which they should answer just Yes or No (see also Appendix I). The questions were set in plain English as follows:

> Question: Do you have to take part in this study?
>
> > Correct answer: No
>
> Question: Can you change your mind and stop the interview?
>
> > Correct answer: Yes
>
> Question: Will your name be given out to others?

Correct answer: No

Questions: Will your answers be kept in a locked office?

Correct answer: Yes

All participants demonstrated informed consent and understanding and were able to sign their own consent forms. We were then able to make a time to meet to continue with further interviews. Prior to beginning each interview I again reminded people that they could change their mind and withdraw if they chose. Participants were also advised beforehand that, if they wished, they could have a support person of their choice present during the information and interview sessions.

3.4.3.2 Confidentiality

Due to the nature of recruitment (purposive sampling with a secondary method of snowball sampling – see section 4.2 for more details), it might have happened that people living within the same home were recruited to participate in this study. However, this would have breached confidentiality. To address this concern all possible precautions were taken to ensure that participants who were accommodated by the same organisation were from different houses and were note presently living together.

Ground rules were set at the beginning of each interview to ensure all participants were aware of confidentiality. I also ensured the removal of names, organisations and places during data collection, analysis and for storage. All data needed to be treated with respect and retained securely in a locked filing cabinet. This presented some challenges with large artifacts such as collages. These visual artefacts were scanned and saved to a secure university pass-coded desktop and originals destroyed. I also made sure to explain to participants that anonymity cannot always be guaranteed. Sometimes participants might still be identified accidentally even if names of people and places were anonymised.

3.4.3.3 Responding to psychological distress

Given the questions this research asks and the personal nature of this study, there was a probability that negative experiences of **not** feeling safe might emerge as part of people's experiences and understandings of what it means to feel secure. To avoid or minimise any experience of distress, a number of precautions were taken. Participants were reminded regularly that they did not have to participate if they did not wish to and were able to withdraw their consent at any time. Additionally, participants were provided with details of free counselling services they could access should they need to.

I paid particular attention to the potential for psychological distress in the design of the research. The series of interviews was designed loosely with intentional space for questions to be reframed, and with room to change tack and respond intuitively to however people were going in their interviews. I also drew on counselling theories and skills during the framing of interview questions and incorporated prompts people could use when taking photos, drawing or making collages. These counselling strategies were not embedded for the purpose of therapy, but were useful in ensuring that my interactions and questions were as non-confrontational as possible. There were two participants who seemed to be distressed during the process of an interview. When this happened, the interview was stopped for a break so that I could follow up to ensure the participant was okay. I then asked if they wanted to continue or change topics. Both participants wanted to continue talking about their experiences and made it clear they did not want the interview to stop, saying how "good" it was to talk. On these occasions I followed up with participants a few days after the interview to make sure they were okay and to ask if there was anything I could assist with. I also documented and relayed these interactions to my doctoral supervisors to check whether I had followed up with the appropriate responses.

3.4.3.4 Disclosure of abuse and criminal activity

Given the nature of this research, there were some disclosures of past or ongoing experiences of harm or neglect. The level, type and timing of these experiences dictated my response and obligations to report. During this study, all experiences that were talked about were historical in nature. One experience was current but had already been reported appropriately within the organisation. There were no disclosures of criminal offences during the study; however it is important to note that if criminal behaviours had come up, I was obligated to report. This obligation to report and make sure people were safe was explained to participants at the outset prior to interviews. I explained that if people talked about abuse or harm, I would ask their permission to speak to appropriate services should such experiences be disclosed, as outlined by protocols adapted from the Robinson and Vosz (2016) protocol for supporting young people with disability who disclose harm or abuse (see Appendix L).

3.4.4 Interview and creative toolkit methods

All interviews were underpinned by a semi-structured participant inquiry interview approach (see Appendix F for an overview of the interview guide). The purpose of meeting with participants over a series of weeks was to allow us to get to know each other and explore various ways of interacting for the purpose of gathering data. During initial meetings prior to starting interviews time was spent talking through the information sheet, answering questions about the project and checking consent to participate. These initial meetings were often a chance to talk about the different possibilities for sharing their experiences through “just having a chat” or photos, drawing or collage. Two participants chose to have support people in the room for our sessions. Matthew chose his dad to be his support person whereas Marie had a nurse with her at all times. For the other five participants, I had my own support worker with me during interviews to assist where there was possible communication breakdown on my part due to my own communication access needs (low vision and hearing).

Sometimes time was spent trialling some of the possible methods and working out which ones participants preferred. Participants were able to see some examples of visual mediums (collages, tree of life, drawing, photos) and talked about what interested them the most. For example both Marie and Sophia expressed a passion for creative mediums and loved the idea of doing a Tree of Life drawing or collage as a way of sharing information about their lives. Meanwhile Stewart preferred to walk, show and talk about his experiences. Given the semi-structured approach to interviews, there were some overlaps between the sessions and the inquiry approach really depended on the flow of conversations led by participants. After the initial meeting, participants and I worked together over a series of three sessions which gave us a chance to trial various methods and figure out and problem solve any access and communication issues. These three core research sessions were focused as follows:

3.4.4.1 Session 1: Personal context

The first stage of the research process specifically focused on getting to know each other. I asked questions about participants’ background, relationships in the past and present, and the people they had or had previously had in their lives who were important to them. This was done in one of two ways. For those participants who only wanted to talk (and not do any visual data this session consisted of a traditional interview following a semi-structured conversational approach. Others were keen to make their own “Tree of Life” using coloured papers and cut outs. The Tree of Life is a visual mapping tool developed as a non-confrontational method of talking with people about their lives in ways that reduce the risk of triggering distress (Farooq et al., 2021; Fleming et al., 2023; Hughes, 2014; Lock, 2016). While participants focused on the creative process of collaging – there were several guiding prompts about what was important to them growing up, the places they had lived, their family, the words they used to describe themselves and their interests, passions, hopes and dreams. We then talked about the people they now have in their lives who offer friendship, support and resources.

Often within Session 1 I would summarise and remind participants about what was going to happen "next" in the research process. Participants were also given opportunities to ask any follow up questions, add comments and provide feedback. Some participants willingly decided they would take photos around their home and environment prior to our next meeting – others were not keen on this.

3.4.4.2 Session 2: Environmental context

The second session involved questions about their home, things they liked and did not like, their routines and people they worked with. This session was a useful time to look at photographs participants had taken, if they had chosen this method, and to do some mind-mapping. The session also worked particularly well when taking a walk together, thus allowing the participant to point out things that had personal meaning and significance. The session was a way to gain an insiders' perspective on participants' everyday lives, homes and community.

3.4.4.3 Session 3: Social context

The third and final session built on the first and second with follow-up questions on participants' backgrounds, experiences, histories and worldviews. Some final questions delved deeper into the social context and who they lived with – housemates, friends, support workers – and ways they negotiated safety, belonging or choice and control. This meeting was often a chance to ask follow up questions based on photos or visual data participants had shared or spoken about. It was also an opportunity to summarize what had been talked about throughout.

3.4.4.4 Tool kit of creative prompts

Across the three sessions people could draw on the toolkit of creative and visual tools and resources to facilitate discussion and enhance data collection (Gladding, 2016; Neilsen, King, & Baker, 2015). Each of the methods taken up by particular participants is described below:

- **Photo elicitation**

  The act of photography allows people to make choices about photographing people, places, things, stories, and a range of other aspects of experience. The photos taken by participants in this study served as visual insight into their lives. Participants had opportunities to photograph over a few weeks, photographing in and around their home. One participant chose to take photos as he showed me around his home and neighbourhood while we did our interviews (King & Woodroffe, 2019). Alternatively, they could bring photo albums along with them to interviews. The photos served as prompts and enabled participants to lead the conversation as to what people, spaces, environments, routines were part of their lives and what they liked or disliked about these (Allen, 2012; Chonody & Armitrani-Walsh, 2014). Such methods may also make apparent social and cultural beliefs and world views of participants (Weiser, 2001). Papaloukas et al. (2017) further argue that photos are a useful way to gain sociological and cultural insight from insiders living such realities. This can be seen in studies such as Schleiena, Brake, et al. (2013) who demonstrated the effectiveness of photo methods in their study which canvassed the perspectives of seven people with intellectual disability using photo elicitation methods, finding that, through the use of photos, themes began to emerge about community participation, belonging and independence. Photo elicitation could extend beyond social and cultural experiences to also provide an insider's perspective on the environmental, structural and spatial natures of experiences (Copes et al., 2018; Rumpf, 2017; J. A. Smith et al., 2017). The flexible and visual nature of photography was considered particularly beneficial when interviewing people who have difficulty with communication, memory or information processing (Aldridge, 2007; Povee et al., 2014). In my study, some participants were reluctant about using photo voice and did not feel comfortable taking pictures around their home. Some did not want to share pictures of their current living circumstances or their bedroom, but were more comfortable sharing pictures taken outside the home, including family and pets, art, trees and footpaths or areas outdoors. It seemed to me that some participants did not feel a sense of ownership, connection, pride or comfort in their home; however this was not articulated directly.

- **Tree of life**

  The tree of life as a visual metaphor has been applied across a range of community and counselling projects around the world as a sensitive way to engage with children, young people and adults in non-confrontational discussion about their lives (Ncube, 2006). It is a particularly useful visual creative method in assisting people to map how they view themselves – their roots, their main characteristics, hopes and dreams, and resources, including people (Farooq et al., 2021; Hughes, 2014). It can also be further expanded as a way to externalise struggles and to map factors that are meaningful to an individual's personal sense of wellbeing, resilience and strength (Chow Oi, 2020; Fleming et al., 2023; Lock, 2016). The use of the tree of life metaphor has proven to be an exploratory narrative counselling tool which engages in sensitive discussions in a way that avoids re-traumatising people and also provides a framework for positive and supportive group therapy. For the purpose of this study, the tree of life concept was adapted as a sensitive and creative visual technique to elicit non-confrontational discussion and reflection from participants. Participants were guided to map their own tree of life by drawing or by using cut out templates which they were then able to use to draw or build their own tree of life. This was useful way to talk about people's overall life experiences, and to delve deeper into the social networks and important resources people draw on when the going gets tough. The tree of life map proved to be a particularly valuable tool in order to find out more about participants' background.

- **Collage**

  Collaging has been used by qualitative researchers in flexible and different ways, for example to create visual dream-boards, or as a tool for self-reflection and exploration of personal memories, others still have used collage to create self-portraits (Gerstenblatt, 2013; Stallings, 2010; Van Schalkwyk, 2010). Butler-Kisber and Poldma (2010) suggest that the strength of collage lies in aiding self-reflection, eliciting stories, experiences, memories and garnering meaning. In the context of this study participants who wanted to do a collage used cuttings from magazines, photos, newspapers and other snippets to create a theme-board centred around the question of what participants would like to see more of in their life and home. Collaging proved to be a versatile medium that enabled participants to take an imaginative approach – flicking through magazines from a variety of categories (home-architecture, home & lifestyle, popular media and social affairs, nature and science). The use of collage enabled a different visual way to generate conversations regarding material and environmental aspects that contributed to safety and belonging.

- **Drawing, maps, time-lines and other intuitive visual methods**
  Participants were also invited to draw as part of discussions with the researcher, providing opportunities to explain what they had drawn, even though this is an intuitive process for participants (Leavy, 2015). In the context of this study a range of intuitive visual strategies were useful during sessions to help participants collect their thoughts and articulate their experiences. These included strategies such as drawing a general timeline to allow the researcher to visually gain a better understanding of an individual's historical experiences and previous living circumstances; the process also prompted memory and helped participants to feel heard in terms of the prominent historical moments that held meaning to them (Bell, 2005; Lalanda Nico, 2016). Another strategy involved the use of visually brainstorming or concept mapping as a way to help participants visually track thoughts and connections and reduce the pressure some participants might have felt to rehearse what they were going to say, (Wheeldon, 2011; Wheeldon & Ahlberg, 2019; Wheeldon & Faubert, 2009).

For this researcher, the offering of various tools and flexibility in the research sessions meant following the lead of participants and adapting accordingly. When participants took the lead in sharing their perspectives it also meant that they communicated those perspectives in ways that played to their strengths and communication styles.

3.5 New Materialist Assemblage Analysis

Originally, at the beginning of this PhD it was assumed that the content of the data would lend itself to critical discourse analysis in line with critical feminist disability studies, with particular attention paid to themes relating to social constructions of identity, and power structures impacting on people with disability living in supported accommodation (Souto-Manning, 2014). As time wore on though, I realized that traditional narrative and discourse analytical techniques – which deconstruct interviews using social constructionist theories – were doing a disservice in this study. During analysis there were a range of material aspects noted by participants, or recorded in field notes and in photos – for example the architecture of buildings, or the materiality of services and resources – and it was clear that the data in this research was complex with a wide range of different components relevant to each person's negotiations of safety, belonging and agency. Rather than the data presenting as complete coherent narratives, there were snippets of experiences and stories woven through conversations, mind-maps, drawings, photos, collages, and in some cases physical gestures, key word signs or field notes. This meant the resulting dataset was fragmented and haphazardly pieced together. For example, when walking around the residential grounds with Stewart during our third meeting together; we came across a swing which he wanted to take a picture of. Through a series of gestures and key words, it emerged that this swing had originated from his parents' house, and when his parents passed away the house was passed to his brother, and he was given this lounge chair swing. The swing sits on the veranda. Stewart explained that he enjoyed sitting on the swing with some of his friends (other residents) with a cup of tea. Such a vignette also illustrates the vital significance of analysing participant experiences in context, taking account of environmental, material and social factors. Further to this, there times when people chose *not* to show some areas of their homes. Likewise there were moments of silence and re-direction of topics by participants, which were telling and useful to note.

The analysis of transcripts, field notes and visual artefacts was informed by an experimental new materialist analytical method outlined by Feely (2020). He argues that post structural and social constructivism privilege discourse and subjectivism in ways that discount materiality. Feely instead turns to assemblage analysis, informed by Deleuze and Guattari (1987), and uses assemblage theory to map a range of interdependent elements and flows, both human and non-human (see figure 3.2 on the next page).

Accordingly, as seen in figure 3.2, neither human nor non-human factors are seen as more important than each other (Fox & Alldred, 2015). Instead, the emphasis is on the nature of all the different components including individual characteristics of identity within broader contexts of material, social, environmental, institutional and political structures, referred to as "exteriorities" (Crowhurst & Faulkner, 2018; Deleuze & Guattari, 1987), and how they interplayed in ways that impacted on personal perspectives on safety, belonging and agency. Framing the analysis this way enabled me to map various assemblages simultaneously affecting safety, belonging and agency. This approach allowed multiple forms of data (interviews, pictures, collage, brain storming, mapping, etc.) to be interpreted in ways that were coherent. While each individual chunk of data merely appears as a fragment, when kept intact and analysed in connection to other pieces of data, this offers a greater degree of discovery.

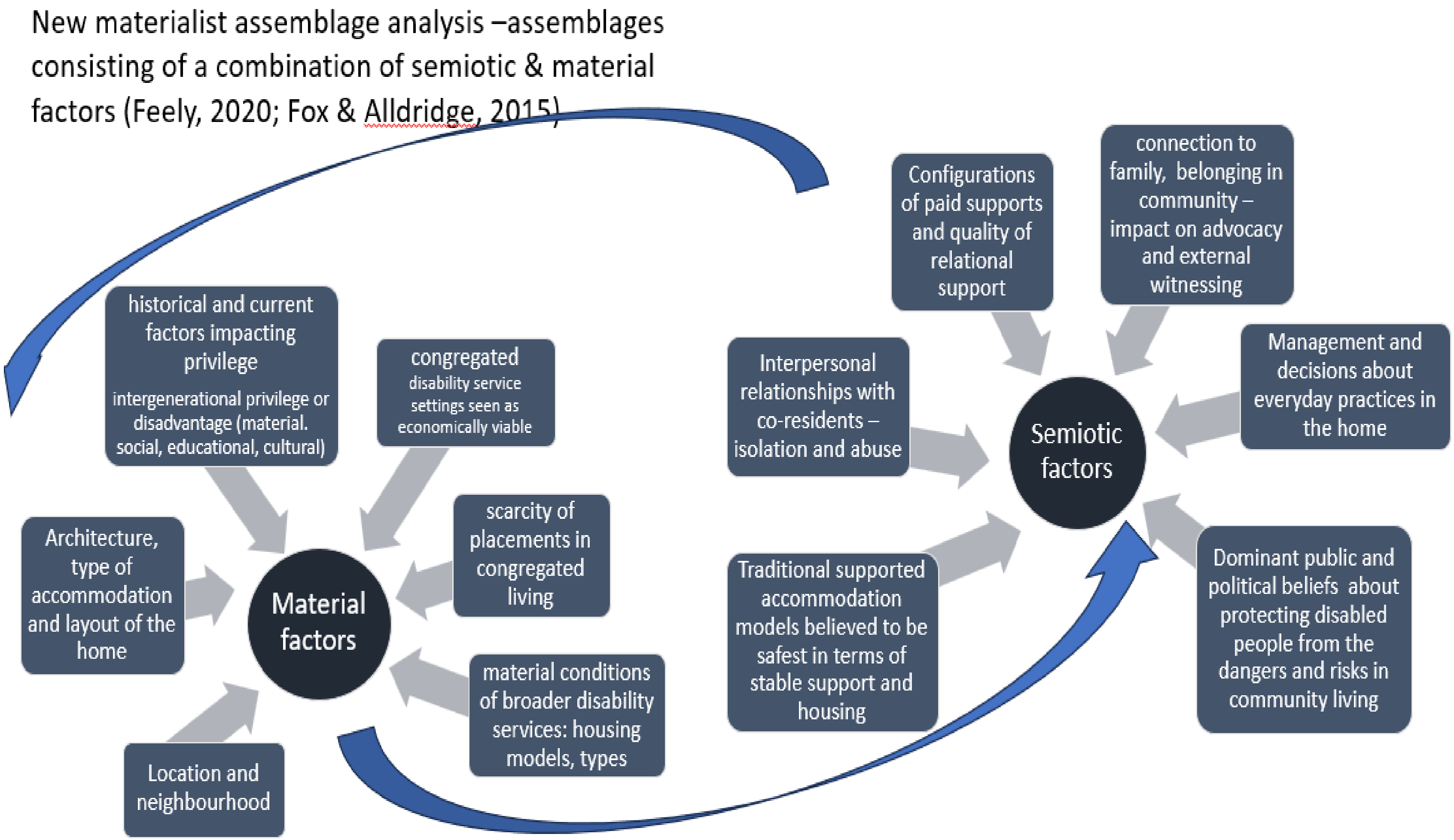


Figure 3.2: New materialist analysis of components identified by participants

Each assemblage consists of a series of components both material and structural, human and non-human, and together these affect the experiences people report in their day to day lives (DeLanda, 2016). Analysis of materialist and semiotic components aligns well within the critical qualitative paradigm of this doctoral study and the challenge of analysing how environmental and sociopolitical factors impact on people's experiences (Denzin, 2017). As suggested by Feely (2020) data coding and thematic analysis in this study needed to always address the question: "What material and /or semiotic forces are affecting this story?" (Feely, 2020, p. 7). This provided me with a starting point for analysis and added more depth to the mapping of various aspects impacting experiences of safety, belonging and agency.

In terms of compiling the variety of data sources for analysis – all of the data from all sessions were recorded and transcribed along with photocopies of visual images produced from drawings, photos, mind-maps and other sources. It became clear that these pieces of data needed to be grouped according to each participant's own story to produce a collage representing each individual's personal perspective. When analysing transcripts and visual data, the application of narrative assemblage analysis offered a useful alternative to discourse analysis by linking the personal and embodied experiences to contextual material and structural comments emerging from pictures, photos and field notes (Feely, 2020). To be clear, adopting a new materialist assemblage approach to analysis did not mean discounting analysis from a critical feminist disability studies perspective, with attention to structure and power see Fraser & Macdougall, 2017). Rather, the critical feminist disability studies perspective (outlined in section 3.2: Reflexivity and personal axiology) were seen as a useful critical lens to frame and understand how power relations (taking account of both semiotic and material factors) operated and flowed in ways that marginalized residents in supported accommodation.

Throughout the data sessions, it became clear that there were different types of silences and silencing happening that needed to be noted in response to the challenge outlined by Mazzei and Jackson (2012) who urge qualitative inquirers to look beyond the traditional multiplicity of voices and the taken-for-granted "spoken words" often chunked into coherent and simplified narratives. Mazzei & Jackson (2012) compel qualitative researchers to not only report what *is* said (the intentional communicated perspectives) but also what *is not* said. Mazzei & Jackson (2012) draw on the work of philosopher Deleuze to argue that the quality of inquiry may be deepened when we rise to the challenge of articulating not only what is spoken, written or shown, but also *what is not said or shown* in the data. For Mazzei & Jackson (2012) there is meaning and nuance in silences and absences. This was a challenge that I took up in the analysis of this doctoral study as I noticed that what participants said or shared was often done so with a sense of caution and diplomacy, particularly when interviews were taking place in people's homes or in places where many incidental people were within earshot, such as support workers, other residents or residential staff and management. This is where analysis of "out-of-field" voice may take account of the contextual, environmental or social power relations, structures and cultural aspects tied to what people do and do not share (Mazzei & Jackson, 2012). It is my considered view that adopting this approach does not undermine or devalue the authenticity of people's voices and does not take away from the value or truth of lived experiences. Rather it follows that:

> When the voice is not contained by a speaking subject, then we can further extend our hearing to the out-of-field voices that our participants "hear," and that we can access, should we seek the intertitles and silent speech-acts in ways that allow us to reconsider what constitutes voice. (…) spoken words and the discursive structures speak silently but forcefully". (Mazzei & Jackson, 2012, p. 149).

Querying nuances and out of field voices as part of the analysis enabled silences to be brought to the fore and integrated as another layer of richness and meaning in the data. This analytical approach provided a way of being able to also take account of feminist questions about human and social factors that contribute to powerlessness and silencing (Fraser & MacDougall, 2016).During the process of analysis, I used a range of practical approaches including manual coding (colour coding, highlights, sticky notes, brainstorming maps) along with data analysis using the digital data analytical software, NVivo. This approach fits in line with Maher et al. (2018) who note that the mix of both computer and manual data analysis may add rigor and improve the quality of findings. This approach seemed particularly useful for me given that a a third party transcription service was hired as an accessibility requirement. Due to this, I had not had the opportunity to initially engage with the transcripts in full (reading is a fairly passive activity, whereas transcription requires both intake and output of information). I was conscious that entering data straight into NVivo risked reducing the level of interaction and engagement necessary. Adopting a combination of both manual coding and digital coding offered a way for me to interact and think more deeply about the data and emerging content, particularly given the multiple sources of data (images and transcripts). Maher et al. (2018) note that analysis should be approached as a process rather than merely to achieve an outcome or output void of interaction, thought and engagement.

Photos and transcripts were grouped according to participant when imported to Nvivo as this helped with forming a more complete holistic understanding of each person's experiences. Images were particularly important to keep embedded and attached to transcripts, as often participants spoke to these images. The analysis of images also provided a deeper layer of insight as to some of the material aspects of a person's environment that proved meaningful to people in this study, which would not otherwise have captured during interviews. The combination of manual and digital coding was vital in allowing issues to percolate and emerge in relation to theory, philosophy and literature. This included coding images and transcripts according to any material or semiotic themes identified through reading and viewing the data. Once these themes were mapped in detail, a secondary reading and analysis of data was done with particular attention to Mazzei & Jackson's (2012) call to code not only voice, but also out-of-field voice. From this coding of various components, themes relevant to the overarching question of factors in negotiating safety, belonging or agency could be pulled together and analysed in greater depth (Guest, MacQueen & Namey, 2012)

3.6 Chapter summary

This study was shaped by a theoretical perspective strongly rooted within a social justice paradigm drawing on tenets of critical feminist disability which privilege embodiment as a valuable site of knowledge and raise critical questions about what constitutes epistemic justice (or injustice) (Clare, 2017; Dotson 2011; K. Ellis et al., 2016; Kafer 2013; Price 2011; Scully, 2020). With the knowledge that people with disability living in supported accommodation were often excluded from research (and with the aim of addressing this) it was important to adopt a narrative inquiry methodology that (a) recognized that people with disability were experts of their own lives, (b) was accessible and flexible to meet people's communication and access needs and (c) was ethical, respectful and sensitive. Participants chose to share their perspectives in a range of ways. Some chose traditional semi-structured interviews whereas others preferred to participate through a range of mediums such as walking-and-talking conversations, drawing, collage and photos. This resulted in a broad dataset consisting of transcripts from spoken interviews and an array of pictures, photos, drawings, collage and field notes. While the overarching framing of this study is rooted in critical feminist disability studies, with analysis and attention paid to power relations, the data analysis used a DeleuzoGauttarian approach to strengthen analysis by taking account of both the material and semiotic factors impacting on embodied experiences of safety, belonging and agency. The drawing together of both critical disability feminist perspectives with a new materialist lens helped to shed light on how material and social structures and systems existing in supported accommodation operated in ways that devalued residents and contributed to epistemic injustice.

CHAPTER 4: OVERVIEW OF THE PARTICIPANTS

4.1 Introduction

Chapter 4 first describes the recruitment strategies that were taken to reach out to potential participants living across a range of different types of shared disability accommodation settings, and then provides an introduction to each of the seven participants who took part.

4.2 Recruitment strategy and inclusion criteria

Participants were recruited using a purposeful sampling method via disability support providers and advocacy services (Campbell et al., 2020). Using a Purposive sampling enabled astrategic approach and ensured that participants were selected because of their lived experiences and knowledge, and because they were willing to share their valuable knowledge and insights (Etikan, 2016; Obilor, 2023). The number of participants who expressed an interest was very small, so all participants who met the criteria and demonstrated consent were recruited, in line with convenience sampling (Abrams, 2010; Obilor, 2023; Campbell et al., 2020).

When designing the inclusion and exclusion criteria for potential participants I intentionally did not focus on one specific type of disability. This study aimed to explore the combinations of material, social, environmental and political factors that were important to personal safety, belonging and agency from the perspectives of residents directly living in supported accommodation. The study was not about dividing and comparing or contrasting people based on biological differences. Invitations were extended across metropolitan South Australia to various disability accommodation settings and advocacy organisations. The inclusion criteria were also intentionally broad to encompass a range of different shared types of disability accommodation settings given the challenges of reaching out to participants who live in supported accommodation settings. The criteria thus included older participants who had previously lived in institutions and transitioned to community accommodation settings, as well as younger participants who had moved from private family homes into community accommodation settings. The specific inclusion criteria were:

- Resident of state where research was conducted, (name of city/state with-held to maintain privacy)

- Person with disability who lives in group home, clustered housing, small institutions or other supported congregate living arrangement
- (and/or) person with disability who has experienced insecure housing with multiple moves to various residential settings.
- Age 18 or over
- Able to provide consent.

The exclusion criteria were simply:

- People who are unable to indicate consent to participate
- Children and youth under the age of 18
- People living independently or in their family homes.
- No more than 3 participants from the same residential house or building

Information about the research project was initially disseminated in two ways: social media and through relevant organizations.

In terms of social media, I set up a Facebook page titled "PhD Project: Negotiating Safety, belonging and choice in shared disability accommodation settings", which included a flyer (see Appendix C). However the Facebook page proved mostly ineffective at reaching people living in supported accommodation. This was not surprising, particularly given the number of people living in such settings who have cognitive or communication access needs impacting on literacy and informational access. A study by Caton and Chapman (2016) indicated: (a) concerns of safety and restrictions placed on mobile devices to limit access to social media sites, and (b) lack of accessibility and use-ability of mobile devices, limited access to adaptive technology, and issues accessing and understanding cyber language. This situation meant that residents living in shared types of disability accommodation were more challenging to reach out to, being less likely to access research information via traditional recruitment methods such as information shared via email and through online platforms.

At this same point of time I also introduced myself and the research project (see Appendix B) to a number of accommodation and advocacy organisations across metropolitan South Australia to disseminate information to potential participants (see Appendices D & E). The majority of managers and CEOs of organisations were either non-responsive or were supportive off-record when they were kind enough to meet with me, but simultaneously indicating a high degree of pressure and stress in their current situation. Many disability accommodation services were experiencing an increase in their workload and a degree of organizational upheaval and change with residents transitioning to the NDIS (Williams, 2020). Professionals also described the stress intensified by new reporting protocols under the new Quality and Safeguarding Commission. The Disability Royal Commission into Abuse, Violence and Neglect may have also contributed to pressure on services. Similar constraints of time, pressure and increased workload were also reported by people working in advocacy organisations. Another barrier to recruitment lay with the safeguarding concerns of organizations who were in a position to share and support people with disability to make decisions about whether they would or would not take part in research. I suspect there were some understandable fears about stories which may have coloured their organisation in a negative light, particularly given the focus of this research on how people negotiated safety, belonging and choice and control in accommodation settings. To ensure a degree of distance and objectivity I did not approach organisations where I had had a previous affiliation as a member, board member and/or representative. This limited me from being able to approach a number of organisations who would have otherwise been interested.

Agreement to disseminate information about the research really depended on the willingness and interest of managers and top-level personnel within organizations: people who expressed a keen interest in the potential findings of the research project. As a researcher entering into these organizations and asking managers to share information, I was conscious of needing to build trust and develop a partnership that was mutually beneficial to the organizations, since connections to people living in accommodation services relied heavily on the organization's willingness to engage (Earle et al., 2020). In total six organizations (five accommodation organizations and two advocacy services) shared information with potential participants. These organizations sent general emails, flyers and made a note in their newsletters. However, like the social media attempt, there was very little interest.

Given these difficulties in connecting with people living in supported disability accommodation, the advisory group recommended a more direct approach involving a short information session face to face with small groups of people with disability where people could ask questions and trial arts methods. This proved to be the most useful way to reach potential participants. Two organisations allowed me (as the researcher) to present information face to face at events where people with disability were gathered, for example a shared meal or during a self-advocacy meeting. At these events I made a short 5-10 minute presentation to a large group of residents who were gathered. I explained briefly who I was, what I was researching, how they could be involved and asked them to contact me for more information. Information sheets and flyers were left on the table for people to pick up if they wished to (see Appendices C, D, E).

4.3 Who took part

In total, seven people took part in this study. Five identified as people with learning disability and/or psychosocial disability, while two identified as people with high support needs or physical disability. This reflects the distribution of people with disability living in accommodation services (Bigby et al., 2017; McConkey, 2007; Walsh et al., 2010). Participants were living in shared accommodation provided by two organizations, for which I am using the pseudonyms Cress Point Services and Midlands Services. These services differed in distinct ways. Notably, Cress Point Services had a cluster of 20 group houses and a block of hostel rooms grouped together on a piece of land referred to as “the campus”. Meanwhile, Midlands Services had an array of group homes across metropolitan areas embedded in community as individual stand-alone houses (see section 6.1 for more detail about these living environments).

Table 4.1 outlines each participant’s background and living context at the time of the study. Pseudonyms are used throughout to refer both to participants and the settings in which they lived.

Table 4.1: Participant demographics

	Age	Gender	Disability	Support needs	Current living arrangement & length of time	DESIGN	How many moves/transitions?	Occupation
Marie	25	F	High care/physical	AAC device (types words and speech output). - Some minor support needed to spell words - Marie's communication assistant (nurse)	Midland Group home A 2 years	9 residents (mixed gender & ages) Stand-alone house	Long term in hospital > home to family & respite > Moved when she was 21	Aus Disability Enterprise (ADE) at an organisation separate to accommodation service
Sophia	45	F	Intellectual disability	Fluent speech "but needs some help with reading and spelling" (her words) - Easy read English and some spelling - Ellen used hearing device (FM) but still needed comm assistance to repeat answers	Cress Point Group home B 10 years	3 residents (female) Complex of 80 people with disabilities (pwd)	Lived independently with support > was taken advantage of > moved to group home (shifted around 5 times)	ADE within a service providing both employment and accommodation
Caleb	36	M	High care/physical	Fluent speech & literacy No support needed with information communication. Ellen's FM used - no support needed by Ellen.	Midland Group home C 6 years	7 residents (Mixed) Stand alone	Sudden accident led to a year in hospital > rehab > supported accmm	None

Stewart	69	M	Intellectual disability	Few Key spoken words & gestures. Needs easy read & clear clarifying questions & summarizing FM used. Ellen had a communication assistant but found most of what was said was communicated via sign and gesture anyway.	Cress Point hostel 13 years	20 residents (Mixed) Complex of 80 pwd	Lived with family until parents elderly > then into motel	ADE at an organisation separate to accommodation service
Malcolm	38	M	Intellectual disability & psychosocial disability	Fluent speech & literacy Shorter meetings to accommodate fatigue & some reframing of questions to clarify. Not comfortable with FM devices (identified a fear of audio devices). Ellen asked for communication assistant to accompany	Cress Point Group home D 20 years	4 residents (male) Complex of 80 pwd	Family > group home > Motel > group home >motel > group home (4 or 5 times shifts)	ADE at an organisation separate to accommodation service
Stephen	51	M	Intellectual disability	Fluent speech with scattered sentences. Some clarifying questions needed. Needed easy read resources. Ellen used FM & also had communication assistance repeat where needed.	Cress Point hostel 6 months	20-40 residents (Mixed) Complex of 80 pwd	Family ageing > moved to motel	ADE at an organisation separate to accommodation service
Matthew	38	M	Intellectual disability	Speech: Needs simple words & clear explanations along with easy read resources. Ellen used FM (hearing devices). Family support person attended	Cress Point Group home E 12 years	3 residents (men) Complex of 80 pwd	Family > 5 transitions between group homes	ADE at an organisation separate to accommodation service

As table 4.1 indicates, no two participants had the same type of disability and among the seven participants each person had their own needs for support related to physical access, or information processing, literacy and/or communication. This in turn meant that each participant chose to partake and contribute to the study in different and diverse ways (see section 3.4.4).

In the following sub-sections, I briefly introduce each of the seven participants in the study. I provide an overview and build a picture of who each person is, as well as their living situation. When finding out more about peoples' life experiences across their life course, it became evident that the environment in which a person had grown up, along with the type of supports they had access to (both formal and informal) all significantly impacted on how people understood and made meaning of who they were today and what mattered most in their lives. For example, Marie had spent much of her childhood in the highly clinical setting of a hospital, which arguably presents a very different material set of experiences compared to others who grew up in the traditional family home. Ideally, these vignettes would have been co-created with participants. Unfortunately, the covid pandemic (in early 2020) caused significant disruptions to research activities for several months. While many researchers were able to adapt with the use of remote and online technologies- the participants in this study (and myself as a researcher with my own communication access needs) found online communications particularly inaccessible. These participant vignettes are drawn from my own impressions and knowledge from meeting with each individual. In follow up interviews, there were opportunities to summarise what had been heard to ensure accuracy – however it is important to note that these are my own reflections, and not that of participants. In this section, I provide an overview and build a picture of how I understand who each person is.

4.3.1 Marie

Marie, who had a physical disability and complex care needs, was in her mid-20s. When asked how she described herself, she said: "loud", "friendly" and "outgoing". Due to a tracheotomy she was unable to communicate by speech. Instead she used her iPhone and a stylus pen to communicate by typing words which were then converted to speech. Although it took time for Marie to type her messages and answer questions, she also communicated with gestures and facial expressions and was always able to steer our conversations by indicating that she still had something to say or that she had nothing further to add. Prior to moving, Marie spent much of her childhood in the local children’s hospital (across two states). Later, as an older teenager she spent her time between three respite accommodation services and also spent a little time at home with her family.

Marie lived in a house owned and operated by Midlands Service and integrated into the community, referred to in this thesis as “William House". William House was a large modern house with manicured rose gardens and modern interiors, situated in a very affluent suburb. At William House there was a mix of nurses, support workers and house managers rostered over a 24/7 period as permanent staff. Marie was the youngest in this house, with most residents being much older than her. There were nine residents at the time, varying widely in age, gender and disability, both physical and cognitive disability. All residents had the common need for intensive nursing care and a high level of physical support work 24 hours a day. Marie explained that she has 24 hour nursing support because of her specialised equipment and care needed for her to breathe using a machine. This was in addition to regular personal care and assistance with daily living tasks. At the time of interviewing, Marie had lived in William House for three years and worked two days a week at an Australian Disability Enterprise.

4.3.2 Caleb

Caleb was in his mid-30s.He acquired his disability as an adult as a result of a motorbike accident which happened within the last eight years. As a result of this accident Caleb has quadriplegia. Caleb is a quiet and gentle man who was keen to help with this research as he strongly believed in doing good for others in his community. He grew up in a “regular” family and mentioned that it was not until he was an adult that he turned to Christianity and the hand of God after a priest visited him in hospital. He was passionately involved in the work of the church and deeply committed to bible study groups. Caleb mentioned that prior to living at Samson House, which was also run by Midlands Service, he spent many months in hospital and in rehabilitation, essentially homeless. He used to live independently in a house with a group of friends but after the accident he was unable return there. A social worker then located a vacancy through Midlands Services. Caleb, like Marie, lived in a group house with ten residents who all had significant physical and high complex support needs. In contrast to Marie’s place, Samson House was styled as a rustic mansion/lodge with sweeping windows, maintained gardens, large gum trees and dark stone brick walls, as well as leather furnishings and fire places in the main communal areas.

4.3.3 Sophia

Sophia, in her 40s, identified as having an intellectual disability and hearing impairment. Sophia was an articulate communicator; however she mentioned that many people have trouble understanding her speech. Sophia lived at “House 9” operated and owned by Cress Point Services. Sophia also worked at Cress Point in their Australian Disability Employment service three days a week. In House 9 there were four women receiving daily support from support workers in the morning and in the evening. Sophia mentioned that life had been “bumpy” with the unexpected death of her brother as a teenager which had been hard on her and her family. As an adult she had lived in a rural area in her own home independently with a regular community support worker. When asked what words Sophia would use to describe herself (see Tree of Life) she chose: “stuck up for mum”, “caring” and “kind”. Sophia was particularly enthusiastic about using our time together doing some drawing, art and collage. Our conversations were easy-going, and Sophia occasionally asked how to spell some words she wanted to include in her drawings. Prior to living here Sophia had moved around between several states and had lived in several country towns as a child.

4.3.4 Steven

Steven was in his early 50s and had intellectual disability. He lived in Cress Point in one of the bedrooms located in the hostel – a large building with 40 rooms (20 rooms spread across each of two levels). Steven had lived in the hostel for over ten years. He was not sure how many were living in the hostel when I asked, but guessed it was about 20 people and that many rooms were unoccupied. Prior to living in the hostel he lived at home with his ageing parents. He experienced the traumatic passing of one of his parents from a heart attack one morning, which he says was really difficult. He remains close to his sister and brother-in-law who live locally but enjoy travelling. Steven worked for an Australian Disability Enterprise where he had worked for several years since being a young man. He worked full time and long hours. He loves the football and mentioned that he often watches this on the television with residents at Cress Point. He vouches for the home team. Steven was seemingly more introverted than most of the participants, preferring to sit together with me across the table and answer questions in a conversational way. He seemed to have a very quiet life going from work to home day to day. He tended to enjoy watching Foxtel on his iPad and mentioned watching British TV series such as Eastenders and Coronation Street (which was his Mum’s favourite), as well as the sports channel.

4.3.5 Stewart

Stewart was in his late 60s and also lived in what he called “the hostel” at Cress Point where Steven lived. Stewart had an intellectual disability and tended to use a combination of small sentences or broken spoken words combined with sign and gestures to communicate. Steven communicated using whatever means he could to get his point across. For example, rather than sitting across the table and having a conversation, he took me for a walk and pointed out important aspects around his home. He took pictures of the big gum trees outside his bedroom window, and talked about going for walks around his neighbourhood. Like Stewart, he preferred to stay home and had a large selection of musical DVDs he enjoyed watching, as well as watching the football. Despite Stewart being one of the older residents he was also one of the newer residents, having lived in Cress Point for just six months. Like Steven, he worked at an Australian Disability Enterprise (also run by Cress Point Services) where he had been working for 40 years.

4.3.6 Malcolm

Malcolm was in his late 30s and experienced mental illness and intellectual disability. Malcolm, like Steven, preferred to take part in interviews by sitting across the table and answering questions in a conversational way. He also lived at Cress Point and had been there since he was 18 years old. Malcom worked full time doing packaging at an Australian Disability Enterprise operated by Cress Point and had done so on and off since he was 18 years old. Outside of work he tended to “come home and watch TV or play a video game”. Malcolm had moved a handful of times back and forth between different group houses and the hostel due to repeated conflicts and issues with residents. Prior to moving to Cress Point he had lived with his dad who unfortunately got very sick, precipitating Malcolm’s move to shared accommodation.

4.3.7 Matthew

Matthew, in his late 30s with an intellectual disability and living at Cress Point, lived in a group house at Cress Point Services. Matthew chose to partake in interviews across the table in a conversational manner and, despite being an excellent communicator, he also chose to have his dad with him during interviews. His dad sometimes rephrased questions so that Matthew could understand. It is clear they had a close relationship. Before living at Cress Point Matthew lived with his family. He mentioned that things had changed recently as his mum had fallen sick. He has a large family and three sisters whom he also visits sometimes. Matthew described his current group house as “one of the newer builds” which he liked. He described himself as very sociable and loved to get out into the community and meet different people. Matthew is a sports person; he coaches the young ones and he plays in several teams and has been interstate on several occasions with his bowling team. He also described himself as very independent. Matthew worked full time in an Australian Disability Enterprise operated by Cress Point. Over the past 12 years prior to living in House 7 he moved around between six or seven different group houses.

4.4 Chapter summary

Chapter 4 has outlined how participants were recruited and has discussed some of the challenges that made reaching out to residents in disability services more difficult. In the event, seven participants took part, ranging from early adulthood all the way through to senior years. Five participants lived in clustered group houses or hostel accommodation managed by Cress Point Services while two lived in stand-alone group homes operated by Midlands Services (see section 6.1 for more information about each of these living environments). None of these participants lived with each other during the course of this study.

The following chapter (Chapter 5) provides more detail about how participants' personal histories, set within their social and political contexts, impacted and shaped the kinds of opportunities participants did or did not have in regard to making decisions about where to live or who to live with. Chapter 6 then presents an overview of the two service contexts for Midlands and Cress Points and describes a range of material and semiotic aspects that were identified as meaningful to participants' negotiations of safety, belonging and agency in this study.

CHAPTER 5: HISTORICAL, SOCIAL AND POLITICAL CONTEXTS OF DECISIONS TO MOVE TO SUPPORTED ACCOMMODATION

In order to understand experiences of people living in shared accommodation it is first important to map the range of interactions identified as part of the history people have prior to their current situation (section 5.1). These include:

- experiences of growing up (e.g., location, environment)
- family backgrounds and interpersonal relationships
- access to systems, people and places that influenced and shaped decisions about moving into supported accommodation.

The significance of these historical and social contexts in determining opportunities and possibilities will be discussed in relation to how participants' experiences influenced and shaped embodied safety, belonging and agency (section 5.2). I then explore in section 5.3 the ways in which participants understood how decisions were made about their move to shared accommodation (a hostel or group home).

5.1 Life prior to moving to supported accommodation

Many of the participants did not elaborate in detail about their experiences growing up and only briefly mentioned living at home with parents and siblings and attending school. Most of the participants were born with or acquired their disability very young. This meant that most had experienced a life time of interacting with disability service contexts and supports including segregated "special" schools or working in supported employment settings. Caleb was the only participant who did not have a life-long experience of disability having acquired his disability in his mid-30s. Most of the participants in this study had lived within their family home with a parent or parents well into their later adult years before moving to supported accommodation. Two participants relocated from hospital settings to their current home and only one participant had experienced living on their own with access to community support workers.

For most there was nothing “unusual” to talk about in relation to their earlier life experiences. Notably most grew up in the same city within a 10 to 30 minutes radius from where they were currently living. There were several examples of participants who witnessed their parents ageing, getting sick or passing away, which was often part of what prompted the move to supported accommodation (see section 5.2.2 for examples).

The data evidenced consistent themes about moving away from a house that was shared with informal carers (such as a parent) into supported accommodation, particularly among older participants. Often this was due to the changing needs and priorities of family members. Most participants when asked why they had moved to supported accommodation explained changing circumstances of the people around them – such as their mum or dad being unwell, or dying.

> Steven: Yeah, I moved here (to the hostel) because when they (parents) sold the house in Sommers (middle class hills suburb pseudonym) – the house too big for them so they moved me into here and - Yeah. They moved – then they moved further away South in a retirement home down there so… (silence).

The theme of ‘how’ and ‘who’ made decisions to move to supported accommodation is explored in more detail under section 5.3 (Decision to move).

In contrast, only one participant had lived independently in her own home in her younger adult years. She had lived in a rural small town and remembered her house, her neighbours and her town fondly. She was moved to a group home in the city after her mother discovered that Sophia’s support worker had been financially abusing Sophia. This was the catalyst for deciding that supported accommodation was a safer option:

> Ellen: If you could choose where you want to live and who you want to live with what would you like?
>
> Sophia: I’ll be on my own - do my own thing.
>
> Ellen: So you’d like to do your own thing. Live on your own.
>
> Sophia: Yes.
>
> Ellen: You don’t want to live with someone else.
>
> Sophia: No. I liked living on my own before.
>
> Ellen: Okay. Yeah. Because you’ve lived on your own once before didn’t you?
>
> Sophia: Yes.

Ellen: Were there things that worried you about living on your own?

Sophia: One carer used me. A carer used me

Ellen: In what way?

Sophia: She wanted my money.

Ellen: She was using your money?

Sophia: She wanted my money. Wanted me to buy her things all the time. My mum got mad.

Ellen: Is that part of the reason why you ended up living here?

Sophia: Wants me to buy her things all the time.

Ellen: I see. That’s not okay.

Sophia: No. She’s supposed to be helping me.

Despite her experience of being exploited by a support worker - Sophia remained adamant throughout all of our conversations about her desire to move to her own house with access to support. Notably she was one of the few participants in this study who had prior experience to draw on to inform her understanding and knowledge of what her ideal home would look like. When she was asked if she worried about being abused again if she were to live alone, Sophia replied: “I know what to look out for now”.

Caleb and Marie both had historical experiences of hospitalization over long stretches of time due to their need for high medical care, coupled with the limited options for accessible accommodation services in the community with capacity to provide highly specialised medical care. Caleb experienced 18 months in hospital “not wanting to live and not caring about much” dealing with adjusting to life after a motorbike accident. He described confusion and a deep intense depression and apathy when social workers raised questions about his future prospects. Caleb’s sudden experience of disability as an adult means he was new to accessing disability specific services, supports and funding schemes and had no prior experience before NDIS. As previously mentioned, Caleb’s situation was different from others in this study in that he previously lived in a share house with a group of friends until acquiring a spinal cord injury radically changed his needs and priorities around housing and access to support and care. He described how returning to the share house was not an option post-accident because it was inaccessible and he needed a high level of physical nursing care and support across the day and night. Due to the scarcity of supported accommodation offering 24 hour nursing care, there was nowhere to go – leaving him homeless and in hospital for 18 months.

In contrast, Marie spent several years in various hospitals having contracted a virus when she was a toddler which led to a lifelong need for medical and specialist nursing care and meant she was a long-term patient in hospital over several years. When her family moved interstate she also relocated with them, moving from one state children's hospital to another local children's hospital. She also attended school in hospital too. As she got to her late teenage years, she lived half the time at home with her family and half the time in a respite house.

> Ellen: Are there any other things that you would like to add to your tree of life about the roots and where you came from? In terms of where you grew up and who was important to you growing up?
>
> Marie: I grew up in two hospitals.
>
> Nurse: She says she grew up in two hospitals.
>
> Ellen: You grew up in hospital?
>
> Marie: (Nodding head) And Sydney.
>
> Ellen: How much time did you spend there when you were little?
>
> Marie: Lived there until I was 12 or 13 years old.
>
> Ellen: You spent quite a lot of time in hospital then. And when you were 12 or 13 did you go somewhere else?
>
> Marie: Half-home and half-respite house.
>
> Ellen: Half at home and then half at respite. Would you like to put hospital down on your tree of life? and then put home and respite? (Indicates.) Yes? Okay.
>
> Marie: (Indicates vehemently that she has more to say.) I still have my hospital nurses coming to see me. Some weekends.
>
> Ellen: I see, so you made good connections with the nurses.
>
> Marie: Yes. Some weekends they visit.
>
> Ellen: What did you think of these different places?
>
> Marie: I liked the respite house.
>
> Ellen: Do you miss any of these places?
>
> Marie: Hospital and 'respite house'. It is a respite house.

Ellen:	What do you miss about the 'House'
Nurse:	Carers. The carers, she misses.
Marie:	Carer. Support workers.

Her experiences of hospitals and of being sick – which can take a significant toll on bodily autonomy and wellbeing – arguably shaped Marie's perspective of safety. These prior experiences of hospitals no doubt offer her a comparison to her current situation which is a far smaller "ordinary" house in the community with specialised medical care. For both Marie and Caleb, access to nursing and specialist personal care teams was integral to their basic survival day to day in terms of assistance with basic daily tasks and functional movement. Caleb and Marie both expressed worry and concern about being at the mercy of support workers "who don't know what they're doing and are too inexperienced" as Caleb stated. Mistakes in personal care work may be seen as unintentional poor quality care, but for Marie and Caleb – mistakes in relation to their care had the potential to result in serious injury or death and both were very aware of this.

5.2 The centrality of historical context as part of safety, belonging and agency

Each participant had their own historical experiences of "home" and of the connections between things, people, places and spaces associated with home. Participants described the importance of maintaining connections to "home" in a variety of different ways. For example some participants noted that even when they moved to supported accommodation, they made a concerted effort to keep valued connections with people and places and appreciated when these places were accessible by public transport.

Steven and Malcolm both talked at length about the transport routes in the suburbs where they grew up and lived prior to moving into supported accommodation. Steven talked about his family moving house in response to change of transport routes. Even when participants had moved away from their family home to supported accommodation they maintained a degree of familiarity with trains, buses and trams in the area which enabled them to move freely around their neighbourhoods and continue to visit family. This was key to being able to have choice about coming and going from their supported accommodation as they pleased.

People also discussed the importance of being known by name and sight in the community, such as by GPs and hairdressers. Although Steven's parents had sold the family home and moved into a retirement village, he still travelled back to the suburb where he grew up regularly to maintain valued connections to people in the community whom he knew (and who knew him):

> Steven: Yeah. I still go to Sommers though to get my hair cut up there.
>
> Ellen: Yeah.
>
> Steven: Just – the one over the bridge there – up there just across the bridge there. I go up there, catch the train in the morning and go to visit.
>
> Ellen: So you are familiar with Sommers.
>
> Steven: Yeah, used to go up there often – yeah.

Participants' home (whether it was a family home, or a hospital) and the people they had grown up with were all pointed to as key aspects of embodied belonging. It was clear that participants found ways to hold onto these connections. For Steven, it was about maintaining connections with the neighbourhood; for Maria, it was about keeping in contact with the nurses who had looked after her at the children's hospital. These threads of belonging remained important when people moved on to supported accommodation in their adult lives.

5.2.1 Loss of connection to place, people or things

Some participants also talked about loss of familiarity and connection to people and places after moving to supported accommodation. Marie and Sophia both experienced relocation and moving across states and territories as children and young adults. It became clear during our conversations that their current understandings and feelings about their living situation were shaped by historical experiences of previous places where they had lived. For example, when Marie was asked about her roots and where she grew up (see Tree of Life image), she drew on her recollections of living long term in hospitals where she lived until she was twelve years old.

Figure 5.1: Tree of Life by Marie

Ellen: Were you in hospital for a long time?

Marie: I was in three different hospitals in two different states.

Ellen: I see. Was there – was it just that your family lived in different states or?

Marie: I was three hospitals – I was in three hospitals in Sydney where I'm from.

Ellen: Okay. Was there a reason why you were in hospital?

Marie: Because when I first got sick moved from two hospitals until I moved to the Sydney children hospital. When I came here (meaning relocating interstate to the current state she now resides in as an adult). I lived in the Women's and Children's Hospital.

As a teenager her living situation changed. Instead of being housed long term in the children's hospital, Marie lived part time with her parents and siblings and the rest of the time in respite care. When Marie was talking about respite as a place she had lived, her nurse was quick to correct that it was "only respite".

Ellen: And how many places have you lived in? Is this the first home you've had since hospital and family?

Marie: This place (Midlands) is my second place.

Ellen: So where did you live first of all?

Marie: I lived at Campbelltown (northern suburbs place)

Ellen: How long did you live in that place for?

Nurse: (Interjects) Respite. That was only respite.

Ellen: That was only respite. So you were going there occasionally? \

Marie: No. Every weekend.

Ellen: Over the weekend. So did you stay at your parents' place during the week and then you went to the respite place on the weekends?

Marie: (Marie nods her head in agreement). Thursday to Sunday. Respite.

While the nurse saw respite as insignificant, this respite place held significance to Marie as a place she had lived for a significant amount of time. Marie identified spending the majority of her time in Respite (4 days a week) and 3 days a week at home with her family. Marie described how she had shifted constantly between hospital, family home and respite care. She talked about missing the nurses and support workers who worked at this particular respite facility whom she had clearly gotten to know over several years. For Marie her living situation and sense of feeling safe relied on access to 24/7 specialised care and support, essential for keeping her alive and well. These sorts of historical experiences described by Marie of hospitals and living in institutionalised care systems from a very young age (with only some time spent at home with family) seemingly provide a stark contrast to the smaller community-based supported house she lives in now.

Meanwhile when asked about her earlier life experiences, Sophia described having attended many schools and having to "move around a lot" between the Northern Territory and South Australia. She had lived in various country towns as a child as her step-dad worked in the public sector. Prior to coming to the city to live in a group home in her mid-forties, as a younger adult in her thirties Sophia had lived independently in the community in a country town seven hours drive away from the nearest city. As previously mentioned, she was relocated to the city so that she could move into a group home. Sophia described how moving to the city was scary, as she didn't know anyone:

Sophia: I was scared when I first moved here.

Ellen: You were scared …?

Sophia: Yes.

Ellen: What were you scared of?

Sophia: I didn't know anyone.

Ellen: You didn't know anyone around here.

Sophia: No.

Ellen: Where you lived before, were there people you knew?

Sophia: Yes, I had friends there (in the country).

Ellen: So you had friends there.

Sophia: I had friends in Country Town

Ellen: So you left that place in Port Augusta and you moved to Residential here.

Sophia: Yes.

Ellen: And your mum was living in another country town two hours away.

Sophia: Yes.

For Sophia, being "placed" in a group home in the city several hours away came with compromises. Whilst there was increased support and more access to oversight of supports which her mother felt was important for Sophia's safety; there were also trade-offs, as she felt she had lost all the privileges that come with living independently in her own home such as privacy, freedom to do as she wanted on her own terms. Additionally, she described how she had lost connection to friends, people she knew in her neighbourhood as well as her country home. At the time of carrying out this research, Sophia had lived in the group home for many years however clearly still had an emotional attachment to her old home, her old neighbourhood and people she knew "up that way", and, as noted earlier, she held strong views about not wanting to live in a group home.

In each of these narratives participants talked about their own historical experiences of "home" (material and semiotic) and described how these histories impacted their own personal values and what held meaning to them in their current living situation. These previous historical contexts and experiences of belonging, feeling secure, safe – or not - served as a way for people to identify how their current living place compares in terms of feeling safe, having agency over what happens in your life and home, and being able to maintain and foster meaningful moments of connection and belonging. This raised critical questions about how people construct what safety, belonging and agency means when they have previously lived in highly institutionalized settings like a hospital.

5.2.2 Grief and loss of significant people

One further aspect emerging from participants' descriptions of their historical context and experiences was related to grief and loss. In this study participants often talked about losing people who had been important in their lives. These experiences needed to be acknowledged as significant and often emerged in discussions when talking about people they valued and liked spending time with, or sometimes the reverse. Contextual information about connections to family often opened up conversation about significant people who had died. Participants talked about maintaining a connection and remembering their loved ones in various ways.

For example, as Stewart went for a walk around Cress Point grounds and showed me his room he was able to point out various items, photos and objects that held meaning in his surroundings and often tied back to people whom he had lost. In his room he pointed out photos mounted on the wall of his dad who died some years ago as well as the wooden cabinet next to his bed which his dad (a wood-maker) had made for him. When walking around the campus grounds with Stewart during our third meeting together; we came across a swing which sat on the veranda which he wanted to take a picture of (see figure 5.2).

Figure 5.2: Swinging chair from Stewart's old place

Through a series of gestures and key words it emerged that this swing had been at his parents' house, and when his parents passed away the house was passed to his brother, who gave him this lounge chair swing to take with him to Cress Point. Stewart explained that he enjoyed sitting on the swing with some of his friends (other residents). This vignette illustrates the vital significance of belonging – not only in a material sense, but also in terms of remembering special people and moments of belonging. In contrast, most of the residents did not choose to take photos around their current residence, although they were happy to share photos of their family or friends.

For Sophia, the theme of belonging presented strongly through the Tree of Life drawing. The process of drawing her own tree of life prompted information about the important people in her life. For example, Sophia was definite and clear about wanting to include her brother in her drawing whom she said had died 20 years ago by suicide. She pointed to her drawing and said: "That's for when my brother died." She had put her brother's name in the leaves as someone who was important or helpful to her in her daily life. Later when completing her tree of life I again asked if there was anything she wanted to add to her tree:

> Sophia: Well, one thing important to me is my brother who died.
>
> Ellen: Yeah.
>
> Sophia: He's close to my heart.
>
> Ellen: Yeah. Would you like to represent this somehow?
>
> Sophia: Yes. (Draws a heart in the centre of the main trunk.) And my other one important to me is my nana.
>
> Ellen: Your nana?
>
> Sophia: Yes. She died too. She lived in a nursing home.
>
> Ellen: I see. She lived in a nursing home.
>
> Sophia: Yeah. In Tumby Bay. Up near Port Lincoln way.
>
> Ellen: In the country. So you would have done a lot of travelling out there to visit her.
>
> Sophia: Yes. There or there? (Asking where to place Nana's name).
>
> Ellen: It's up to you. This is your piece. There's no right or wrong.
>
> Sophia: N-A-N-A. I done art. I done art because my nana used to do art. My nana done art. So she hand it down to me.

It became apparent in the narratives that bereavement was integral to the participants' life experiences and deeply symbolic of their sense of belonging. The loss of important people had affected them deeply, particularly when, like Sophia, their social networks mostly existed around their supported employment or group home. It was also evident that participants drew resilience and support from their family or other people being supportive and present through moments of grief, shock, and sadness.

As an example of this, Steven's mother died unexpectedly while Steven was staying overnight (away from the group home). He recounted the awful moment of finding her in the morning on the floor and ringing the ambulance and police to try and revive her and being told that unfortunately she had died of a cardiac arrest.

> Steven: Mum was a bit – Mum was a bit of a shock because I was – on Saturday morning I was meant to do doctors, a blood test and – down at Happy Valley –and I just woke up and went to Mum's room and she was lying on the floor so ….
>
> Ellen: Oh. That would have been hard.
>
> Steven: Because I rang the ambulance and they came – they – but – then they all – and the police and ambulance. But then they told us she had a cardiac arrest that ….
>
> Ellen: Oh.
>
> Steven: Then I had to ring my sister and then I had to tell her … I think Mum's dead – and then – then they came down there.
>
> Ellen: It sounds like it wasn't expected. You had no idea that was going to happen. It couldn't have been predicted.
>
> Steven: No. She drove the day before – she was alright. It was a hot weekend, I think, and then… I heard something bang in the middle of the night but I didn't think anything of it. And then I was just getting ready to see – go for a blood test that morning and then she – then I saw her lying on the floor then …
>
> Ellen: That would have been very hard.
>
> Steven: Yeah. Yeah. Yeah, they're buried at a cemetery near me, both of them.

He described how much it meant to him when some of the staff who know Steven well from Cress Point attended his mother's funeral with him – which gave him much comfort and acknowledgement that he appreciated immensely. Steven emphasized how important it was to still be able to visit his parents at the cemetery not far from Cress Point. When loved ones such as parents, grandparents and siblings die, the grief and loss can be compounded for people with significant disability, as they not only deal with the death or absence of someone important but also loss, grief and change to their own life in terms of moving to supported accommodation or parting ways with belongings or places associated with belonging. It may also mean that the support network changes. Sometimes other family members or friends stepped in to be the key point of contact, although not usually as frequently and also to a lesser degree.

For those who had family still living, these connections served as a crucial reminder of value, love and respect beyond the supported accommodation setting. Often these family members or friends continued to support people to venture out beyond their supported accommodation such as going shopping or going to the doctors. When visiting, they functioned as outsiders to the service, observing the happenings within the home, and able to serve as independent informal advocates who pointed out issues or problems within the service. Participants in this study referred to family members who frequently spoke up, found information out about their service and negotiated administrative and service systems (particularly important in large organizations). Having outside connections and a sense of affinity and mutual value beyond the home made it easier for participants to negotiate aspects of safety in the home and service systems. Such supporters were allies and unofficial advocates who were able to say when things were not working, and could explain why or how the issue happened and what could be done to resolve the issue. It was clear from participants' accounts that when these allies died it meant there was no longer a person who could observe, communicate and explain the management of services, how they work, what might happen next and potentially ask or demand changes in the way things are done.

5.3 Decision to move to supported group accommodation

Everyone in this study described uncertainty, anxiety, stress, upheaval and worry when moving into shared accommodation for the first time. This next section explores how decisions about moving to supported shared accommodation were often made by others surrounding the person with disability. It was apparent that participants rarely had opportunities to talk about what they liked or preferred in regard to accommodation. Some participants, such as Matthew and Sophia, described being able to visit and see the place beforehand, but even in their case, both indicated that a vacancy was what ultimately led to them visiting and moving in quickly.

Some participants, notably Marie, were excited and optimistic about moving to their new home. Marie, the youngest participant in this study said that she had seen her siblings move out of the family home into their own places and wanted to experience this too.

> Marie: I moved in here in 2017. (Age 23)
>
> Ellen: Okay. So [you've lived here] two years then. What made you decide that it was time to move?
>
> Marie: Because my sister didn't live with us because she had just moved to live with her boyfriend and my brother, he was going to move to Melbourne, his university.

Marie saw the move as an opportunity for independence and as symbolic of maturing into adulthood. All of the other participants were in their mid-thirties to late forties by the time they had moved and usually their move to supported accommodation was precipitated by a crisis situation of some sort.

5.3.1 "They" made the decision

For some people the move to a group home was not their choice, but rather a decision made for them about where they should live. Often decisions were triggered by a family's changing needs and priorities. Most participants I spoke to within this study talked about other people making the decisions and explained these decisions were often due to changing circumstances of people around them, particularly parents who had had a primary role in providing daily support:

> Ellen: I'm wondering when you moved to the motel, who made that decision for you to move?
>
> Steven: My mum and dad, yeah, because they told me they were … they told me that I'm coming here, or decided to come here to look around here first because they were selling up [their house]. It was too big. The lawn was too big and all that. The yard was too – for my mum and dad to work and that. So I think they made a good decision to move. It was too hard to keep up with like the gardening and things like that.

As describe by Steven, the move was a decision *they* made (it was in *their* control). This spoke volumes about Steven's experiences of decisions made about him, for him. Steven's experience of moving because parents were downsizing to a retirement unit was not uncommon. Marie, for example, highlighted that the decision to move was based on her parents selling the family home and moving to a new house. This raises pertinent questions about how people with disability maintain or indeed establish authority and express their own will and preference for what happens in their future. If decision making stems from the priorities of family and supports who also need to plan their own future, these priorities may take carry the most weight, particularly if it means family members no longer have a residential place for their family member with disability.

For some participants in this study decisions were made due to crisis situations such as illness or sudden death within the family. When there was urgency because of an ageing or ill parent it meant there was even more pressure to take up available housing regardless of location. In these situations, anywhere where there was a vacancy with adequate 24/7 support became the priority.

For Malcolm the decision was made because his dad was very unwell which triggered moving into a group home:

Ellen: What about before you moved to supported accommodation?

Malcolm: I lived with my family.

Ellen: I know it's a long time ago, but can you remember how you made the decision to move?

Malcolm: Well it was hard. Dad had stuff going on, he had had enough. It was hard. It’s a bit embarrassing really. (Stops for a bit). I mean when I moved here it was all new and I worried about my dad. I couldn’t keep an eye on him. He was sick. But it’s alright here. (Said with a sense of resignation)

Ellen: That would have been tough.

Malcolm: Yeah.

Malcolm describes feeling worried about not able to take care of his dad while he was unwell. The decision making was impossible to disentangle from the politics of family. This study suggests that when decisions were triggered by carers’ changing life circumstances and decisions they needed to make about their own lives this compounded emotional distress, frustration and worry for everyone involved. In this study it was evident that participants had little power over decisions and that this powerlessness was an issue deserving of exploration in policy and service delivery; certainly in this study it was a strong theme. These issues of authority was particularly evident when participants were in the situation of relying on carers or family to explain and share information such as finding location and placement in accommodation, and to make the best decisions possible with the information known at that particular point in time. This lack of choice and authority was further compounded by limited availability in supported accommodation.

While participants acknowledged that decisions were often made by or with supporters, they were careful to reiterate that these supported accommodation options were the necessary and only choice. They saw their placement within group accommodation as the only way to have established the supports necessary for day to day functioning and survival (i.e. safety at its most basic). Stewart for example talked about receiving more support in the hostel compared to one of the group homes located on the premises. He felt that tasks like cooking were too much for him:

Ellen: So how long have you been living here for?

Stewart: Eight years. Yeah. Here.

Ellen: Before that were you living with your family?

Stewart: No. All my family put me in here.

Ellen: So you went from your family to here?

Stewart: Yeah.

Ellen: So you were living with your mum?

Stewart: My father

Ellen: Your father. Would you ever like to move to one of the houses?

Stewart: Not yet. See it first. When I had a look before ... The house. I had a look round. But not for me. Very hard to cook.

Ellen: So that was the reason why you decided to move here?

Stewart: Yeah.

Ellen: Because you don't want to do the cooking.

Stewart: Yeah. The motel good for me.

Steven saw moving to other types of supported accommodation (such as a shared house or independent house) as risky due to his need for functional support understanding. Stewart understood (or had been told) that in a shared or independent supported accommodation, he would not have access to the same support and thus the hostel was the best place for him as there were lower expectations on these residents. In a similar vein, Sophia was told that a shared type of supported accommodation was better for her as she was vulnerable to abuse living alone in community. These examples illustrated that participants understood that they had been moved to a hostel or group home specifically because they (a) did not have functional independent living skills such as being able to cook, and/or (b) needed to be protected and kept “safe” from exploitation.

As mentioned earlier (section 4.3.2), Caleb was essentially homeless and living in hospital waiting to be placed somewhere in community where there was access to nursing care. Caleb admits that after his accident and being in hospital for so long, he felt hopeless and thought his future was bleak. It was his social worker (allocated by the hospital) who helped him by stepping in to do the hard leg work of working through the system to explore different housing options:

Caleb: Well, we were talking to her (the spinal cord advocate) and I was saying, well, I don’t know where I’m going to go. I was just living with a friend in a townhouse and there's no way I'm going to return to it and, yeah, I don't know where I'm going to go and what I'm going to do. And then – so she started looking around for places and found this place. She then contacted the company and got on to the manager so that lady come out and met me and she talked about me and heard about my story and she said, yes, we'd like to have him come in to the facility. Then I had a guy from Disability SA who then had to come in and sorted it out and he was funding it so he had to then meet with – like the owners and work out funding. So he was a very good advocate too. And I had a social worker, another lady who was also organising things from Hospital's end. So yeah, those four all sort of come together like the peer support advocate from Para Quad, the social worker at the hospital, the owner – or the manager of this facility, and the funding body being Disability SA, they all sort of come together to make it work, yeah.

Ellen: It sounds like it was a bit of a complicated bureaucratic process …

Caleb: They had to, yeah, work out a few things I suppose as far as – yeah, funding, whether I'd fit into the place and all that sort of thing. They had other people that live here they had to worry about so yeah.

Ellen: You had people that could -

Caleb: Yeah, it was amazing really that they just took control and even though I was in a spot where I was too – too worried at the time it's turned out I've ended up in a great spot. Yeah.

As can be seen in this example, for Caleb, the social worker from the hospital was crucial in that she knew the system, understood his needs and drove the entire process. This included everything from finding an available placement, facilitating a meeting with the residential manager and organizing the transition to Midlands once a place had been found, as well as organizing the financial side through government services.

5.3.2 Finding a vacancy

The above examples of how decisions were made about where to live also demonstrate how much of the decision depended on sheer luck of timing and finding an availability (or somewhere to board temporarily while looking). When participants talked about getting lucky with locating a "vacancy" this signals just how difficult it was to negotiate service systems to find a place to live and call home. Often finding and locating these places relied on advocates (family/carers or paid) as illustrated by Caleb and others in the preceding quotes. Matthew and his father described their experience of securing a place in Cress Point as being down to several factors:

Ellen: Who made that decision and also how did you decide what to bring with you that was your stuff?

Jon (Dad): That’s a good question. I think Matt had been here for respite a couple of times.

Matt: Yeah, respite first and then I make the decision whether I like it or not.

Jon: And also my wife was on one of the committees and someone who was tied up with Cress Point said just out of the blue, “If there’s ever a vacancy let us know” and sure enough two weeks later and yeah we had to make a decision on the spot pretty much.

Ellen: So it was about whether there was a vacancy or not?

Jon: Yes. But Matthew loved it anyway when he was here on respite and he knew all the people because he’d worked with them (in supported employment), so it was a pretty easy decision.

As can be seen from the quotes above, for Matthew, finding a vacancy at Cress Point was advantageous given he was already familiar with the service as a result of his visits there for respite. His mother being involved with the service and sitting on a number of committees and boards, as well as Matthew’s job in supported employment through the same service, enabled her to have a direct link to the right people inside services to ask questions, seek information and thus enable Matthew to secure a place. It was not only about being “lucky” to find a place, but also relied on having an informal advocate to walk alongside, able to research information and navigate and build a rapport with managers within the relevant systems. In contrast, people like Stewart who did not have a carer to communicate his needs seemed to be more reliant on service system advocates or guardians.

This emphasis on “good luck” or having contacts to help in finding a vacancy potentially highlights a broader problematic in regard to socio political and economic structures governing the market for group homes, which creates a situation where opportunities to explore multiple sorts of housing and supports is difficult. When participants were asked if they had looked at multiple places before moving in, all of them said that they had only seen one place – the place they moved into.

Ellen: So when you moved to Cress Point did you look at other places as well or was the only place that you looked at?

Steven: This was the only place. Yeah.

Ellen: Yeah. And when you came to look at it for the first time what was that like for you?

Steven: I think it was pretty good to look at, yeah. Look around, it was fine, yeah.

It was difficult for Steven to define what it meant when a place was “good to look at” and one wonders how anyone in Steven’s situation could express disquiet or lack of will when faced with such a complicated maze of information and services as part of finding a place.

Marie was the only person in this study who had any semblance of choice around her eventual home, stating that she had actually looked at two places at two different services before moving . After her initial visit she described preferring Midlands because there were people who were more similar in age and she anticipated that there would be better opportunities to make friends.

Ellen: Yeah. And other places that you looked at as well?

Marie: One other.

Ellen: Okay. One other. Yeah. And what made you choose between this one and the other place?

Marie: I thought that I would be able to make more friends here.

Ellen: Yeah. So you thought you’d be able to make more friends here. And how do you feel about it now? How has it worked out?

Marie: I haven’t made any friends here at all.

Ellen: Does that upset you? (Aware of high emotion)

Marie: Yes. (Nodding head, teary)

Marie’s example of looking at two potential vacancies prior to moving to supported accommodation was the exception. As described above, most participants did not have any opportunities to explore nor discuss what they would like their home to be like, or indeed what their hopes were. Conversations about personal hopes and aspirations around organising or seeking alternative housing and support arrangements were non-existent.

5.4 Summary of historical social and political contexts

This chapter has focused on how people experienced and made meaning of belonging, safety and agency across their life course, as well as their experiences of transitioning to shared disability accommodation settings. It was clear that participants’ current housing arrangements (in shared disability accommodation) were essentially decisions about where and how they could be safe and well supported day to day. For some, this came about due to certain crises such as the death or ill health of a parent, or was related to complex physical support needs as in the case of Marie and

Caleb, for example. For Marie and other participants there were common experiences of compromising and putting up with features they did not like or found uncomfortable in their current housing so as not to cause issues and potentially lose their existing routine support.

Overall, participants' personal and historical contexts were shown to strongly influence how they came to be living in supported accommodation. These included a range of experiences across the life course affecting and shaping meanings of safety, belonging and agency (which will be further described in the next chapter). Some moved from home with a parent or family to a group home. Others moved from hospital to a group home. One moved from their own independent home to a group home. Relocation and change of neighbourhoods, as well as distance significantly shaped how participants maintained a sense of belonging and connection to family, friends and neighbourhoods. This included experiences of family, schooling, services and supports and housing.

Taking a new materialist analytical approach facilitated the identification of multiple material and semiotic factors interplaying. For example, disability service supports (e.g special schooling, or supported employment) may be seen as examples of material resources and supports, however, could also be understood as examples which are highly institutionalised and that in essence, provide a great deal of insight as to how people disability were treated in Australian policy, and the type of opportunities (or conversely, low expectations) that were placed on people with disability. Similarly, the adoption of a new materialist approach facilitated a deeper level of understanding of why participants in this study felt that the decision to move to a supported accommodation facility was necessary and in fact, their only viable choice. Often these decisions were made because participants needed access to routine daily paid supports (material resources) in their lives in order to survive and did not believe that this was achievable in community (prejudice, low expectations and/or lack of relationships – all of which can loosely be defined as semiotic).

There was an overall sense that finding a placement at all was "lucky" given the scarcity of placements available. Indeed it was clear that in these early decision making moments there were no conversations about the possibility of exploring different arrangements or having freedom to move on if the dynamics between residents were not working out (discussed further under 6.3: Semiotic aspects of home). The current land-scape of housing and support in Australia continues to enforce institutionalized and segregated ways of living for people with disability. The scarcity of supported accommodation compounds the sentiment that anyone who obtained a place was lucky. While it was not explicitly stated by participants, this in turn forced people with disability to constrain their own personal ideas for what “a good home is” and may have had a silencing effect, where participants’ values, preferences and views were not taken account of or valued.

CHAPTER 6: FACTORS AFFECTING SAFETY, BELONGING AND AGENCY IN THE EVERYDAY CONTEXT OF SHARED DISABILITY ACCOMMODATION

This chapter relates to participants' experiences in their current living situation of a shared disability accommodation setting. As previously described, all participants either lived in a disability hostel, a stand-alone group home or a clustered group home. The first part of this chapter focuses on providing an overall picture of what the various supported accommodation settings looked like. The chapter then moves on to present the material, social, cultural and emotional aspects that participants raised as meaningful to them. These factors have been organized in line with a new materialist narrative assemblage model (Feely, 2020) as described in Chapter 3. To be clear, the material and semiotic factors that participants talked about are not meant to be seen as hierarchical or separate, but rather they are all factors that interplay. Each of these factors strengthened or constrained personal safety, belonging and agency in and around the home. In an effort to resist the temptation to organise themes hierarchically in terms of prominence, the next section addresses the findings and organises their relevance according to whether they were material or semiotic. Despite this, it is worth noting that these factors could never truly be identified as only material or semiotic in nature. For the purpose of clarity, the following section presents themes according to material or semiotic flows with the view that the discussion section of this thesis then explores how these semiotic and material flows interplay in ways that shape how participants experience safety, belonging and agency in their daily lives.

6.1 Current living situation: Two residential disability services

Participants in this study lived in accommodation provided by one of two residential disability service providers. Each service offered a different range of residential accommodation ranging from supported independent options through to group homes and hostel accommodation. As previously mentioned, Marie and Caleb lived in two separate houses managed by a disability organisation here referred to as Midlands. In terms of location, Midlands Services manages eight to ten houses in various suburbs across the city, with each house having its own name. The houses

Marie and Caleb lived in both had sweeping modern designs with manicured rose gardens and polished interiors. Both houses were situated in middle class or high socio-economic suburbs. Within each house there was a small team of 12-15 nurses, support workers and house managers who were rostered 24/7 on a permanent basis. At the time, there were 8-10 residents in each house, varying widely in age, gender, race, ethnicity and type of disability (both physical and cognitive). All residents at Midlands' houses had a common need for a high degree of intensive nursing care across the day and night. Midlands also provided supports for people to live independently in their own home or with families (while this is not the focus of this study, it does indicate that Midlands' business model extended beyond residential accommodation settings).

Sophia, Matthew, Malcolm, Stewart and Steven all lived in various group houses or in the hostel rooms managed by Cress Point Services, which operated a different model of housing with a large cluster of 20 houses situated on a "campus". Sophia had taken photos outside her house to use as a talking focus with me during the interview (not included for reasons of confidentiality). These images portrayed the campus grounds, trees and the cluster of weatherboard houses lined around the carpark. She explained that the residents were typically grouped by gender across various houses with most being either men or women, and only a few of mixed gender.

> Ellen: So I can see there's lots of houses around. Lots of neighbours?
>
> Sophia: Yes.
>
> Ellen: Yeah. Okay. Right. So with your neighbours, do you -
>
> Sophia: They're all men next door.
>
> Ellen: Yeah.
>
> Sophia: Yeah. On the other side is house A6 …
>
> Ellen: Yeah.
>
> Sophia: It's all females.

Cress Point also ran a hostel - a block of 40 rooms for residents with disability. These rooms were lined down a long hallway which led to a large mess hall with dining tables and a cafeteria/kitchen and reception area and managers' offices. This long hallway is shown in the photo by Stewart taken outside the door of his room (figure 6.1).

Figure 6.1 Stewart's photo of home

The hostel was seen as housing for those with "more significant support" needs, for example elderly residents with intellectual disability. This hostel was at times also used to house people needing short term respite. Given the size and number of residents across the clustered site this also meant that Cress Point had a large pool of staff who tended to be rostered on 24 hours a day and allocated by management to the hostel or one of the houses. Some residents only needed support in the morning and evenings with the option to call staff for help if needed at night time. Others needed more intensive 24/7 support. Cress Point managed several services which extended beyond cluster group homes to also include supported independent living, supported employment and day option activity programs. Nearly all of Cress Point's residents I spoke with were also working for Cress Point in supported employment on subsidized wages estimated to be a few dollars an hour.

In each house, regardless of whether it was Cress Point or Midlands, there were four to nine people with disability living there as residents. There were also a number of other people who were all part of the social fabric and day to day routines. This often included a rotating roster of support workers and/or nurses, house manager(s) and/or team leader(s).

Both Midlands and Cress Point followed business models providing supports funded by the National Disability Insurance Scheme. From my observations most of the organizational structuring was invisible at a day to day routine level and therefore was not mentioned by residents. While not featuring as a strong theme for residents, but noted in my observations, there were also senior management and CEOs who were seemingly the main people in charge of decisions, managing budgets and organizing administrative tasks associated with running the organization. A major part of the social fabric and routine within each home was also the residents' family members, friends and other people who may visit.

6.2 Material aspects identified within disability service contexts of "home"

Similar to the general population when moving into shared housing for the first time, participants in this study reported a strong sense of hope for increased independence and opportunities to make new friends. Participants voiced similar hopes for getting to know other residents. However there were additional layers of complexity that residents had to negotiate in terms of systems and politics, as will be described in this chapter.

When asked what helped people to feel safe, connected to their community and in control of their lives and home, participants described a range of material aspects around their home and in their local neighbourhood that were important to them. These factors are here grouped loosely according to:

- features of location and surrounding neighbourhood
- exterior and interior design of the home
- personal possessions and belongings.

6.2.1 Location and surrounding neighbourhood access

In terms of social inclusion in their neighbourhood, at Cress Point there was a structured range of leisure and recreational activities hosted on a weekly basis both on and off site. Sophia, Steven and Matthew all said they enjoyed weekly activities such as bowling at the local bowling alley, art and drama classes, and sports (cricket, football, soccer). These activities tended to be disability-specific, i.e., some of the activities were set up by Cress Point as part of a regular weekly evening or weekend event, whereas others were disability events situated in community (e.g. mixed ability sports). This meant opportunities to interact with others in community; however all of these activities were with people with disability.

In contrast, Marie and Caleb who lived in accommodation run by a different disability service, were not part of structured leisure activities or social groups specifically for people with disability, nor did they spend time with other residents. This may have been because, unlike at Cress Point, Midlands did not offer structured residential activities. As Caleb and Marie indicated, on the rare occasion that each house would host a social event or celebrate a birthday, residents tended to stay distanced and did not spend much time together. Instead Marie tended to go out with her support workers or nurses on her own "to the cinema" or other community events, or to work.

Caleb went into the community without needing nurses in attendance and went to his local church group three times a week.

One of the key factors highlighted by all participants, irrespective of which service and type of accommodation they lived in, was that the location of their home and their neighbourhood was central to feeling safe. All participants spoke of the importance of their location and surrounding amenities and neighbourhood. The location mattered to participants for a range of reasons.

- Accessibility and familiarity with transport routes and surrounding amenities such as the local doctor, the shops and routes to work, church, sports and other activities.
- Opportunity and freedom to visit family or friends which in turn, strengthened a sense of belonging and connection and also meant that they had support networks who could support when issues arose in life, and vice versa, they could be a support (particularly in the case of ageing parents).
- A few participants talked about being ‘known’ in the local community among the hairdresser, or at their local shops, or by a friendly neighbour in the next street over.
- Feeling safe at the local shops and knowing which areas to avoid.

Participants stressed the importance of public transportation and familiarity with public amenities nearby as key to facilitating a sense of agency and freedom because it meant access to work, family or friends as well as to public spaces such as shops, hair-dressers, doctors, sports and other areas of community. Noticeably, those who had more bodily autonomy were able to move around their community and take public transport. For Matthew and Steven, this meant keeping a sense of connection to their family’s or friends’ houses, or their workplace or local precincts. Their relative independence and autonomous access to public transport meant that they had the means to do as they pleased, sometimes spontaneously and sometimes planned, without needing to rely on support workers’ availability. It was important to have familiar places in their neighbourhoods where they felt valued and respected and known by others. Sometimes this meant staying connected to neighbourhood, people or spaces that were important prior to relocating to supported accommodation. For example Matthew described being able to call a family member when he did occasionally get off at the wrong stop or got lost on the bus. Steven described knowing people in the local area whom he valued and appreciated as friends, neighbours, GPs and hairdressers.

Steven: Yeah, they're quite friendly up there. Yeah. The doctors were real friendly with – doctors – doctor – Dr Llewelyn we had up there.

Ellen: Yeah.

Steven: Knew our family – she was – he was our family doctor up there so -

Ellen: Do you still go to that doctor?

Steven: No. Another doctor – he – in this – in his practice anyway because Dr Llewelyn first time he – he just – he just shook my hand because he – he knew mum very well because she went there very often to the Dr – Dr Llewelyn, he was a family doctor so the first time I saw Dr Llewelyn after Mum died he shook my hand.

Having access to public transport meant participants could visit family, go to friends' places and go to work or organized activities. Freedom to move around the neighbourhood meant participants had choices about how and when they interacted with people and places in their community. In turn maintaining a sense of authority over their day to day life and interactions. Families were often key to social participation in community (e.g. Marie talked about visiting the shopping mall with her nana every week until her nana was too unwell to do so). Matthew was the only participant who expressed some hesitation about feeling safe, as he had prior experiences of being harassed and bullied by teenagers at his local shopping centre, who would try to pry money or valuable goods from him. Matthew still regularly got on the train to visit his family whenever he liked, but when attending the local shopping mall and precincts he now preferred to travel with other people rather than on his own.

In contrast, a few participants tended to rely on support workers or others to drive them and facilitate or initiate movement around the community which inevitably seemed to mean less freedom and choice and less spontaneity to respond to invitations for social outings moment to moment. When people did not have that freedom to move around their community as pleased, this in turn meant that they were unintentionally confined to their home and their bedroom more often and were unable to leave when the home environment was stressful or difficult to be around for various reasons. Stewart, the eldest member in this study (in his 70s), listed the fewest number of interests and daily pursuits when completing his collage tree of life. He tended to do very little with his days other than attend supported employment (full time) and then go back to his room (see figure 6.2). It could be suggested that the general neighbourhood and setting in which the supported accommodation was located was key to wellbeing and strengthening the safety, belonging and agency of its residents.

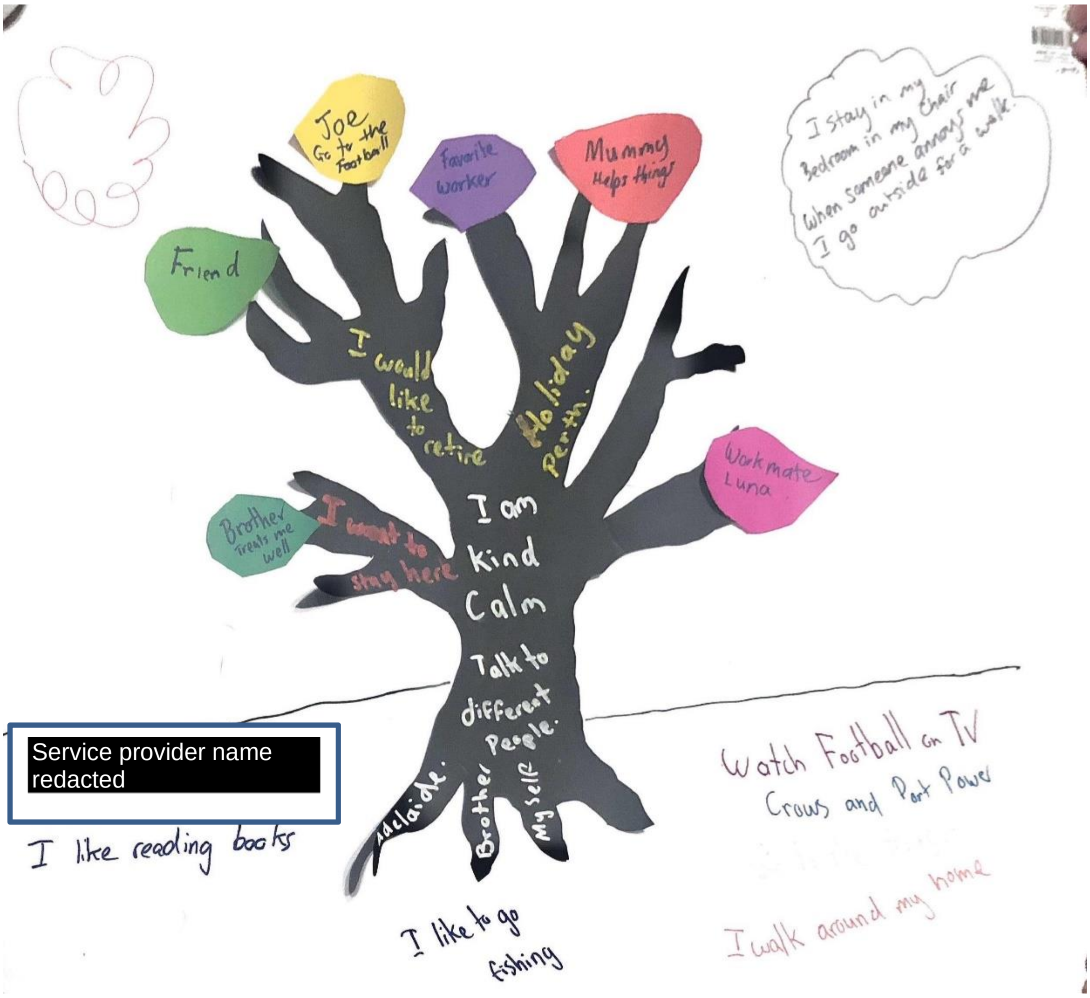


Figure 6.2: Stewart's Tree of Life

For those who did not have family, this meant fewer opportunities to naturally associate beyond the supported accommodation service. Some reminisced about their parents' houses being packed up after their passing and no longer having a place away from their own where they could go. For example Steven used to sleep over at his Mum's house regularly when he first moved into Cress Point, which gave him a space away from conflict or uncomfortable situations at his place. It is important to acknowledge these secondary losses that come with the grief of someone passing away, including no longer having those regular opportunities to leave and go "somewhere else" for a night or two.

As participants aged, their social networks and local connections to community and neighbourhood seemed to thin and become less of a priority. Stewart, who did not venture out much unless it was to attend his supported employment agency, preferred the quiet: watching musicals or the sports on television in his room or going for walks along the winding paths around the campus on his own. Notably, when Stewart was asked about who the key and important people were in his life, he had few people to mention (represented in the leaves on his tree of life). When significant people left, moved away or died this meant loss of people they could call on to help resolve issues, or offer mutual regard, support and advocacy.

6.2.2 Architectural design of the home

The design of housing and access to gardens and recreational areas were all highly valued, although in the Cress Point location participants tended to focus most on the gardens and surrounding trees and winding pathways around the campus. All participants (with the exception of Sophia) talked about the importance of outdoor spaces and access to gardens and green spaces and saw these spaces as central to wellbeing. Such outdoor spaces were treasured as quiet green spaces where people could sit outside and enjoy a cup of tea or chat to visitors, residents or staff.

Figure 6.3: Stewart's view of trees and birds from his bedroom

Participants at Cress Point described their rooms as small, allowing for a single bed, a TV and a few other possessions. They often had three to five other housemates living with them in each house or conversely were situated in one of the hostel rooms among a large group of temporary and permanent hostel residents.

At Midlands Service, Marie and Caleb both described the architecture of their home and its polished interior designs, the kitchen, the dining space and large rooms along with the hydrotherapy pool, manicured gardens and gym. The rooms were much larger at Midlands – and it certainly seemed that Marie and Caleb both had more opportunities to keep precious belongings and freedom to set up their room as they pleased.

> Ellen: There things that appealed to you about this place?
>
> Caleb: To come here? The thing that attracted me was definitely – well, firstly, I suppose, the place itself was very homely feel and the bedroom that they had available just catered for both – like a bedroom and a lounge room so it's plenty of room for people to come and visit so – yeah, so the house had a good feel to it. It was nice and big. It was easy to drive the wheelchair around so it was nice big open areas, had a good back yard with good outdoor area which is nice to have somewhere nice to sit around outside.
>
> Ellen: Yeah, It does look like nice. I can see you've got a beautiful view from your windows.
>
> Caleb: Yeah. So that was good. And the bedroom was great. I could have my bed and all the bed stuff on one side and it was big enough that I got like this lounge room area in the inside and I – yeah, can have friends and people in there and it's a good space.
>
> Ellen: Is this where most of your friends or family come and spend time?
>
> Caleb: Yeah, generally, yeah, because it gets hard for me to go out. But, yeah, there's people in and out of here all the time and it works well so – the place itself attracted me for that reason. Then there was a hydrotherapy pool which meant that I had – I was able to continue hydrotherapy which I was doing – like I was doing at the time at Hampstead so that was a big bonus. So they were things that attracted me to the place initially. The size was good because I didn't – there was only five other people living in there.

For those who resided at Cress Point, there were material aspects about their houses they wanted to see changed, including a disused pool which had been permanently closed for a few years, as well as a sports oval and barbeque area that multiple participants said was not used anymore.

> Matthew: No. I don't know. Maybe we could have a swimming pool again or something like that. Or even a – or even a cricket pitch …

Stewart similarly highlighted that the oval at Cress Point where people used to play sports is now dilapidated.

> Ellen: Another resident was telling me that around here on the oval they used to play cricket sometimes.
>
> Stewart: No. I don't think they play much these days. I don't think. Yeah.
>
> Ellen: Is that something that you would like to do sometimes?
>
> Stewart: I'm not sure – I haven't seen that happen very much these days. They – the oval – it's all – lot of ripped up and all that..

Ellen: They don’t do it much these days because the oval’s – the grass is all ripped up?

Stewart: Like it’s not in good condition. I’m not sure what's happening about the – managing. Yeah. I don’t know.

6.2.3 Possessions and belongings that have meaning

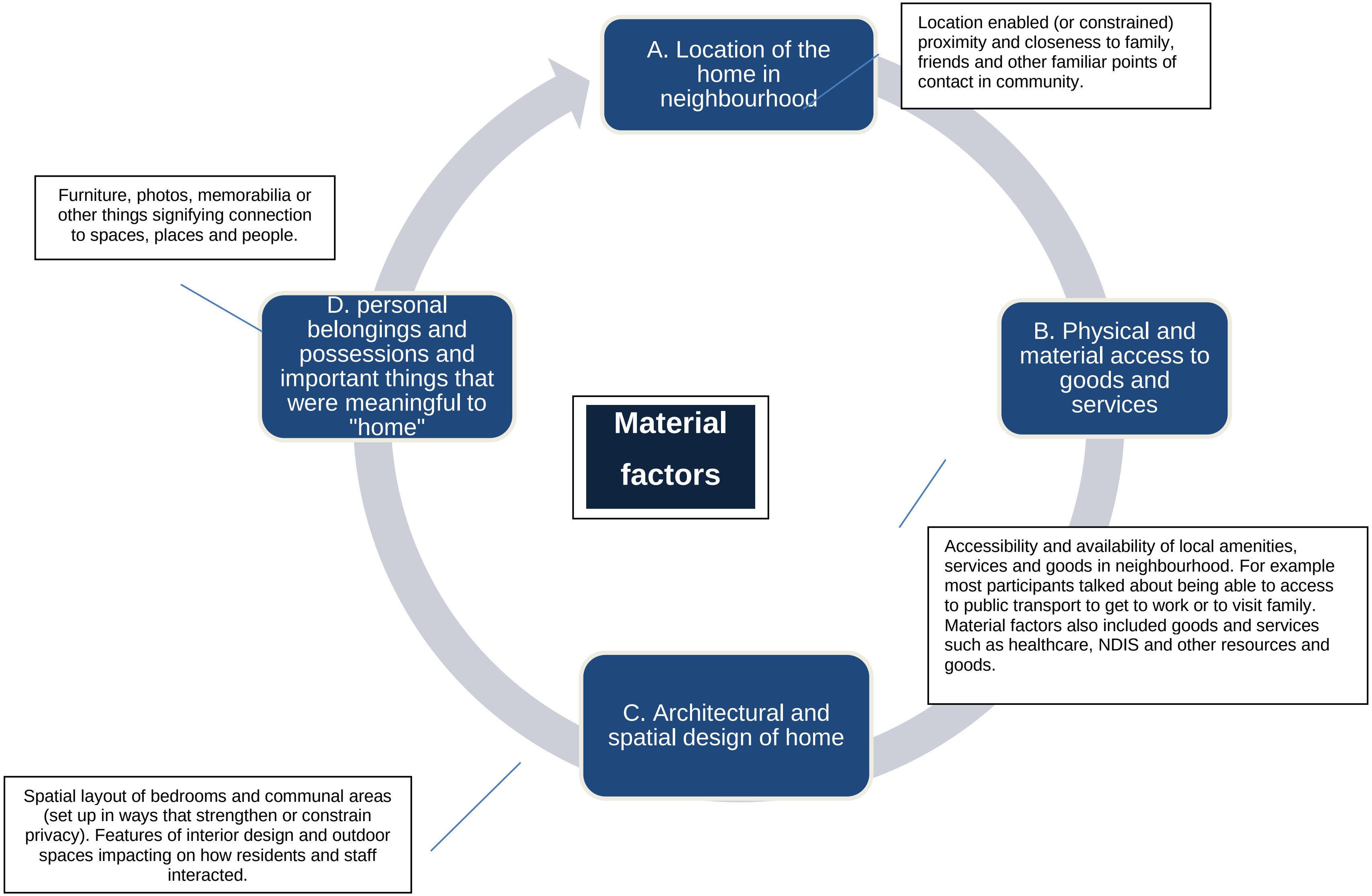
Moving into shared accommodation often meant participants had to make decisions about their belongings. For residents at Cress Point in particular this was an issue, as the rooms tended to be quite small and thus it was more difficult to fit their preferred belongings into the space; for example Sophia could not bring her double bed because it was too large for the small bedroom. In contrast Caleb was able to bring his sofa, desk, fish tank and a range or other furnishings from his old house and was able to create and decorate his bedroom as he pleased given that it was large enough to be a bedroom and a lounge room.

Regardless of which residential service they lived at, people pointed out a range of belongings which held significance for them, for example a TV which was given to Steven when his mother’s house was being cleared after her passing. Stewart treasured a bed-side cabinet and bookcase his dad made by hand, while Sophia cherished her nana’s Walkman and loved listening to music. Marie lined the walls of her bedroom with thousand-piece completed Disney jigsaws which she had completed over several weeks or months with particular support workers or nurses at Midlands. Sophia loved art “just like Nanna” and showed me pictures of herself doing art works. This was something her nanna and Sophia used to do together before her Nanna passed. For everyone in this study, belongings held personal significance, meaning and value in different ways. These were not just material possessions; they also represented a collective of memories and/or connections to people or spaces that were meaningful.

6.2.4 Summary of material factors

A range of material and non-human factors have been referred to in this section, with the note that, of course, these factors are simultaneously identified as potential semiotic factors too. As Feely’s (2020) framework indicates, it was important for the analysis to take account of both material and semiotic factors in order to gather a fuller understanding of how factors inter-related as part of people’s embodied experiences of supported accommodation. It is worth noting that at many points these factors overlapped and constrained and shaped each other. For example the location and neighbourhood where each participant was located had an impact on (a) how people made connections to their family or friends, and (b) their sense of freedom and autonomy to move around community accessing transport and amenities. The architectural design of housing also featured in different ways for participants; for example both Marie and Caleb commented on the outdoor spaces and interior designs of their respective houses. Likewise, participants discussed different types of belongings that were important to them in various ways. For example, Marie expressed her character and passion for Disney with lots of pictures and figurines that represented Disney. Steven on the other hand pointed out a book case his father had made for him and talked about objects that used to belong to his parents before they died which he now had with him.

In summary, material factors ranged from participant to participant including: (a) location and neighbourhood, (b) the architectural design of their home and outdoor spaces, (c) accessibility of services, goods and resources and (d) personal possessions and belongings (see figure 6.4).



Location enabled (or constrained) proximity and closeness to family, friends and other familiar points of contact in community.

Accessibility and availability of local amenities, services and goods in neighbourhood. For example most participants talked about being able to access to public transport to get to work or to visit family. Material factors also included goods and services such as healthcare, NDIS and other resources and goods.

Spatial layout of bedrooms and communal areas (set up in ways that strengthen or constrain privacy). Features of interior design and outdoor spaces impacting on how residents and staff interacted.

Furniture, photos, memorabilia or other things signifying connection to spaces, places and people.

Figure 6.4: Summary of material factors participants identified

The use of assemblage analysis enabled a deeper degree of reflection and critique about all of the varied factors that assembled in different ways for participants. It enabled a deeper analysis which not only focused on the socio-cultural discourses, but also took account of material factors that had relevance and meaning to each participant in their narratives. The next section focuses on the equally important semiotic factors that were identified by residents.

6.3 Semiotic aspects of "home"

Participants highlighted a range of semiotic factors being negotiated day to day in their supported accommodation. Some of the consistent factors which were relevant to most or all participants were:

- stability of housing and displacement
- interpersonal relationships and relational belonging
- configurations of paid support
- management of finances, rules and policies
- opportunities for change

Notably, there were also some differing factors for residents at Midlands compared to Cress Point. Specifically, given the nature of clustered housing at Cress Point, residents were often observed congregating between houses visiting other residents and friends, and there was a much larger visible presence of staff members and support workers as well. In contrast, Midlands' houses appeared to be much quieter with far fewer people seen, other than the residents and the core support staff for the day. This quietness was in part due to the model of individual houses nestled within neighbourhoods. It meant that there were fewer residents with disability and fewer staff. Caleb also indicated that managers and head office were off site. The differing physical design and set up of the two housing models at Cress Point and Midlands Service inevitably influenced the sheer number of people who were on site and influenced the style and nature of relationships between residents and others around them.

Nevertheless, all residents regardless of location negotiated with many professionals across their days at home, whereas in the general population the home tends to be a much more private space. For these residents in supported accommodation, their "private home" also represented a "public workplace" for support workers and others. Arguably residents had no choice but to negotiate their home as a public space as well as a private space.

Participants mentioned having mixed feelings when moving for the first time to a share house within disability accommodation. Some expressed common experiences of uncertainty, worry and stress and a sense of not knowing what to expect. Other participants talked about the excitement of moving out of the family home, as well as nervousness, and saw the move to disability accommodation as symbolic and as a mark of independence and adulthood. As mentioned in section 5.3) Marie, in particular, talked about her siblings all moving out of home and starting their lives and how excited she was to move out of home into her own place too. Residents understood that moving to supported accommodation meant a roof over head that was not dependent on parents or family. None of the participants had experiences of switching service providers or exploring housing or support arrangements beyond their current situation. Some residents did however report experiences of regularly being displaced and rotated between houses at Cress Point in an attempt to resolve issues as discussed below.

6.3.1 Stability and displacement among people in group homes

While disability accommodation providers offered security in terms of permanence, a roof overhead and daily access to support workers, this did not mean that residents felt secure. Many at Cress Point listed several places they had relocated to across the one campus). It was commonplace to move between houses on campus. Sophia, who lived in House 9, described being shifted repeatedly between five or six houses over the past ten years, within this same cluster of group housing. Matthew described the numerous houses he had moved between at Cress Point along with several combinations of housemates, some of whom he got along better with than others.

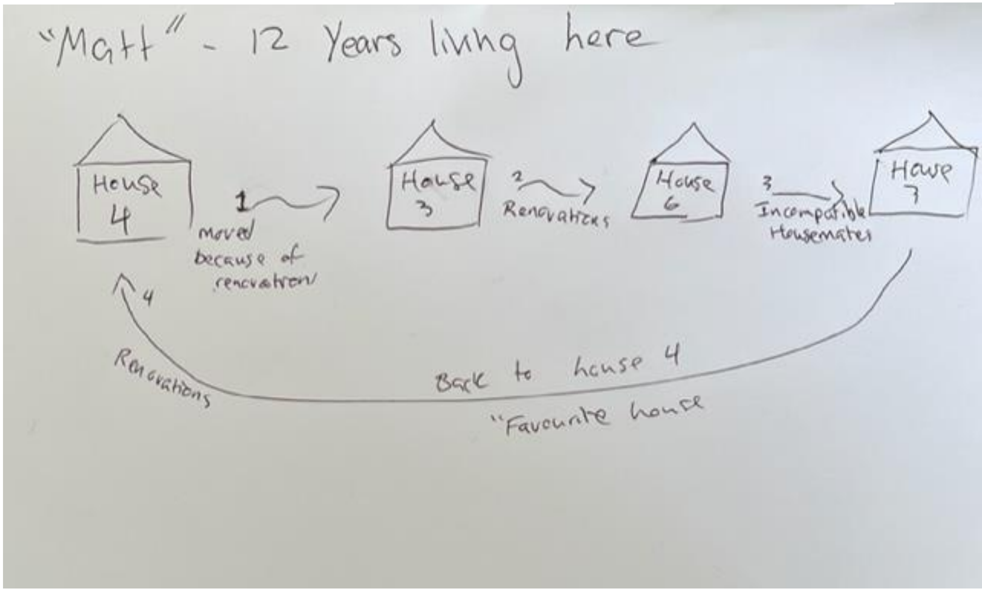


Figure 6.5: Relocation between group homes for Matthew

Matthew and his dad mentioned that people were often relocated to different houses due to renovations and upgrades in each house or in the motel, or as a way of trying to resolve conflicts and incompatibility. It was common for residents at Cress Point to be rearranged and moved between houses within the service.

Steven and Stewart, who both lived in the hostel at Cress Point, described a constant stream of people coming and going from the hostel. Both were uncertain about how many people were living in the hostel and said that it varied greatly. Some people stayed in the hostel for respite, some were there temporarily while organizing a new or different placement in one of the houses, and a few (about 24 from Steven's guess) were permanent residents.

> Steven: Probably, yeah. Well, there's three – more than three – three floors – it goes – rooms go up to – over 50, yeah so 50 rooms. Yeah, yeah, probably more than 24 people I think in the hostel 24 in the hostel –
>
> Ellen: So there's 50 rooms and 24 people you know who live there-
>
> Steven: Might be a few empty rooms, yeah.
>
> Ellen: Okay. Do you know if the people who live here are permanent or whether people move around?
>
> Steven: Sometimes they – sometimes they fill rooms up when they're – when someone goes out and someone comes in but I'm not sure when – there's a few – someone there moves out and then it's empty for a while and then someone moves in from the house for a while. Then they move back.
>
> Ellen: Yeah. It sounds like that people come and go a little bit.
>
> Steven: Yeah, some people use the motel while they're doing the houses up I think or if there's problems. So like a few weeks ago they were using the houses – using the motel because the house was getting renovated.
>
> Ellen: Oh. So for some people it might be temporary.
>
> Steven: Yeah. Yeah.

Steven highlighted here the unpredictable nature of clustered housing and the constant stream of people coming and going between the houses and hostel. Sometimes this move may be because of unknown factors, or private factors not shared with participants such as issues with compatibility, abuse, etc., or alternatively due to repairs and renovations in the houses.

In contrast, at Midlands Services where houses stand alone, nestled in the neighbourhood, neither Marie nor Caleb had histories of being relocated between different houses. While each house owned by Midlands accommodated 8-10 people, the places were limited and selection of residents was the remit of the Midlands manager; there also seemed to be much less tendency to move residents between houses. If there were issues with incompatibility or lack of reciprocity among residents – in Marie's case this seemed to be prominent issue – there were no efforts to change or move around housemates; rather it was seen as a privilege to even have a room in one of these houses.

6.3.2 Interpersonal belonging and relationships

Within each house it was evident that there were varying dynamics between residents, sometimes regarded as "mates" and friends and at other times not. Interestingly, participants described belonging and friendship in different ways. At Cress Point there seemed to be a unifying passion for Australian Rules Football. Nearly all the participants at Cress Point spoke about the football season finals on television and described decorating their bedroom doors with their local football team colours as part of a friendly rivalry between residents. These moments signified elements of belonging and mutual reciprocity. Matthew meanwhile made friends with neighbours down the street on his way home after work:

> Matthew: I get to know my neighbours. Yeah.
>
> Dad: That was – yes, at house up in the hills - but here – with all the friends here, I mean, you don't really meet the neighbours here, do you?
>
> Matthew: I have down the road, yes, near work, yes. I know some people that live near work. They're ... I've know this guy called Josh for a while. Me and him are best friends.
>
> Ellen: Okay.
>
> Matthew: He is a really nice guy. Dad and mum haven't met him yet but –
>
> Dad: I think I've met Josh.
>
> Matthew: Yeah, you have once or twice. Yeah, he's a really nice guy.
>
> Ellen: How did you meet him?
>
> Matthew: Just ... because I walked past his house every day probably.
>
> Dad: And say hello.

Seemingly, participants at Cress Point Services had a greater degree of familiarity and comradeship among residents, not only within their own houses but also in the neighbouring houses and hostel. Many residents at Cress Point knew each other through attending disability programs, social clubs and/or through disability employment options. On the other hand, Sophia, having lived rurally in a small town several hours away, was somewhat of an outsider. She mentioned being scared when first arriving in Adelaide:

> Ellen: What were you scared of? People or just not knowing?
>
> Sophia: I didn’t know anyone.
>
> Ellen: You didn’t know anyone around here.
>
> Sophia: No.
>
> Ellen: Yeah. Whereas in the old place that you used to live in, did you know anyone?
>
> Sophia: Yes, I had friends there.
>
> Ellen: So you had a friend there.
>
> Sophia: I had friends in Port Augusta.
>
> Ellen: Yeah. I see. So you had friends in Port Augusta …
>
> Sophia: Yeah.
>
> Ellen: … that you could get to know people in the neighbourhood?
>
> Sophia: Yeah.

While Sophia did not have any previous connection with any of the residents, she had since made several friends through participating in arts groups or recreation activities organised by Cress Point and through her disability employment. She mentioned also being close to her mum who had recently relocated to the city to be closer to her. Sophia also has a boyfriend who lives at Cress Point who wanted her to move in with him, but she wasn’t keen. While Sophia enjoyed going to the movies and going out on outings with her boyfriend, she also liked having her own space. These findings suggest that shared types of supported accommodation offer some benefit in terms of opportunities to develop some authentic and meaningful connections with others who share similar interests. What remained important in this study was that participants got to choose when and how they associated, who they associated with, and were able to find mutual points for connection over shared interests.

6.3.3 Conflict, abuse and isolation as a result of “incompatibility” between residents

There were multiple examples of conflict and abuse described by participants in this study. It seemed that the material aspects such as the clustered nature of supported accommodation seemed to correlate with increased risk of abuse. Participants who lived at Cress Point described arguments as common between residents. Such arguments were also witnessed by the researcher when visiting. These moments of conflict were often in communal or shared spaces. Sophia for example described arguments about “who hogs the TV” and said that it wasn’t fair that her housemate got to control what was on the TV while Sophia had to hang out in her room to avoid conflict. Sometimes participants were themselves targets of abuse and sometimes they were witness to conflict between other residents or between residents and support workers.

Sophia had several stories about one house mate whom she felt unsafe with and threatened by. Sophia did not like it when her housemate mocked her by talking about Sophia’s nanna as this was a painful topic. Sophia had made herself clear and yet her housemate continued to deliberately harass and upset Sophia with comments about her Nanna and family, or insults about her weight and teasing or “jokingly” behaving in ways that were intimidating and disrespectful such as continually spraying cleaning products at Sophia even after she had asked the housemate to stop.

> Ellen: You have to watch what you're doing or saying?
>
> Sophia: Yes. She gets upset.
>
> Ellen: Yeah. Does that happen often?
>
> Sophia: Yes.
>
> Ellen: That must be really hard for you.
>
> Sophia: Yeah because I have to live with her.
>
> Ellen: Yeah. And do you think that will change in the future?
>
> Sophia: Well, I would like to – no, she’s moving to a different house on Friday so I’ll be more happier then.

Figure 6.6 Sophia's Collage

While Sophia was not keen on taking photos around her home or bedroom, she enjoyed making a collage (figure 6.6) choosing a range of magazine pictures that represented what she would "like" to see in her home. She talked about how important her bedroom was to her because that was where she spent most of her time, especially when she was struggling with her housemates. She coped with difficult adverse situations by retreating to her room and listening to music or watching television.

At Matthew's place, he described dreading dinner times as he knew that one particular resident found meal times triggering. Dinner time, usually a shared time of day, was a stressful experience as his housemate regularly fought with support workers over dinner time and refused to help clear up the dishes or do chores. As Matthew said: "I can't even eat dinner when he's like that":

Ellen: So tell me about the people that you live with at the moment. What are they like?

Matthew: The people that I live with they're okay to talk to …

Dad: You can be honest. This isn't going to have your name on it.

Matthew: I know.

Dad: Okay.

Matthew: They can get a little bit narky sometimes.

Ellen: Okay. Yeah.

Matthew: Not with .. it's just .. sometimes they say silly things.

Ellen: Yeah. So what do you mean by silly things?

Matthew: They argue with the staff a lot.

Ellen: Okay.

Dad: But it’s not everybody though, is it?

Matthew: No. But sometimes (name) can go over the top, literally over the top, it is so annoying.

Ellen: Yeah. It is frustrating.

Matthew: Yeah. It just ... I can't even eat dinner while he’s like that.

Dad: He can be a bit extreme.

Matthew: Extreme. He ... he just doesn’t like the staff telling him to cook or, you know, he just refuses.

Malcolm also had difficulties with a particular person in his accommodation?

Ellen: Can you tell me about the people that you live with at the moment, what is it like to share?

Malcolm: Well, it’s up and down. With him, he’s got split personality, one minute he’s good and next minute he’s not. You never know what’s going to happen. I could say or do something and he’s off.

Ellen: So you have to watch what you say around this person?

Malcolm: Yes, I stay away.

Certainly as a researcher visiting Cress Point to interview various participants, it was clear that residents were routinely witnessing and observing a lot of commotion, shouting and arguments between residents, and at times between staff and residents in the corridors and in communal areas. It was often chaotic and difficult to tell who was shouting at whom. Sometimes it was merely loud and interfering laughter, jostling and friendly interruptions, while at other times it was confrontational, angry and volatile. For example one evening after completing an interview, I saw one of the other residents at Cress Point burst out the front doors of the reception, highly agitated and stressed, running after two people who appeared to be family members, walking to the car park. This is recorded in my field notes as follows:

> Finished visiting Matthew – finished by 7.30 pm. I was sitting outside in the carpark waiting for an Uber directly by the main entrance (which leads to staff reception area, the mess hall and motel) and there was a lot of commotion. An older man and woman who appeared to be relatives or carers were leaving the property after a visit with someone. They headed towards their car. A woman came running out after the couple screaming and shouting, distressed about them leaving. The support workers closely following behind.

> They grabbed the woman by the arms, got a hold of her before she could follow further and pinned her to the brick wall by the doors to hold her in place so that they could face her. She struggled a little but didn't resist strongly. She kept yelling. The support workers kept intervening with raised voices: "Calm down, they'll be back. They'll be back. Okay? Hey. Okay. Calm down, HEY! Let's go inside, let's play a game?! Yeah? Play a game? Come on, let's play a board game. Let's go inside. Come on" the support workers kept repeating "Come on, come inside now, they've gone, they've said goodbye, they'll visit you soon. Come on now, time to go inside" until she turned around and headed back through the sliding doors.

These notes documented the complex and emotional work that goes with living in supported accommodation and the significance of connection and belonging with loved ones. Connection to people beyond the group home (whether it be family members, friends or others) can offer a sense of security and safety.

While "home" should be a refuge and safe place, it was clear that housemates were in a frequent state of conflict which caused a high level of tension and stress for all residents. Overt types of conflicts were most noticeable at Cress Point where there were many more people naturally congregating and mingling in the carpark, communal areas, the gardens or the mess hall or in the houses.

6.3.4 "Staying out of it" when there's conflict at home

Where there were overt confrontational arguments, or bullying and abuse within their place of residence, participants had to find ways to deal with it and keep themselves safe. When asked how they dealt with conflict, there was a common refrain of "staying out of it". Most participants said they went to their room – this was their escape:

> Malcolm: Yes, I stay away. I can go to my room and walk away. I don't pick the fights. He's the one that does.
> Ellen: Yes and your way of managing the situation is to stay away in your room.
> Malcolm: Yes, I watch tv or do something else.
> Ellen: It must be stressful, walking on egg shells not knowing what will trigger?
> Malcolm: Yes, I have to watch what I say.
> Ellen: Are there other things you can do to get away from the situation when it happens?

Malcolm: I can talk to the guys (staff) and let them know what's going on and they help.

For many, as well as the habitual mention of staying in their room to avoid conflict, it was even more important to keep going to work or recreational activities as this was an accessible routine way to have space and time. It is telling that when talking about what their hopes for the future were, many said they wanted to go away on a trip interstate or overseas.

When participants were asked how they resolved issues with other residents some said that they contacted management for help, but there was a general reluctance to do this unless it was absolutely necessary, particularly if the complaint concerned a resident or an issue to do with services, perhaps due to concerns about retribution or backlash. Participants who had family members often called on these people for informal support and advocacy. These family members served as key points of information and a source of advocacy when needing an action to resolve an issue. Participants seemed to think it was more effective when family members had conversations with management as they were able to find out information and communicate this directly back to residents. For example Matthew's dad kept making comments in our interviews such as "I'm not supposed to tell you Matthew, but I have had a chat to (manager) and there's going to be some changes happening soon about that housemate…" It was clear that residents were often left out or were the last to know about decisions or communications relating to their home.

6.3.5 Isolation and detachment

Interestingly, the two participants living at Midlands did not discuss overt confrontation and conflict between residents, but rather tended to refer to an environment where there was an overall lack of warmth and interaction between residents which led to a sense of detachment and isolation. As previously mentioned, both Caleb and Marie identified a culture of solitariness among residents who tended to stay in their own rooms and rarely interacted. Both said they did not have much interaction day to day with the other seven to nine residents in their home. When asked "why", both Caleb and Marie explained that the residents rarely strayed from their rooms or interacted due to the severity of their physical or/and intellectual disability and their minimal access to communication.

When Marie first moved to her current home she was excited as she thought she would be among people with disability who were like her and she would make some new friends. Now three years later, she maintains that she has not made friends:

Ellen: Were there things that made you feel nervous?

Marie: I wouldn’t know anyone from here.

Ellen: You didn’t know anyone here, what they would be like and that worried you? (Marie nods). So did you get to come and visit the place before you moved in or how did it work?

Marie: Yes. I got to visit. I thought that I would be able to make more friends here.

Ellen: Yeah. And how do you feel about it now, you’ve been here for a while now? How has it worked out?

Marie: I haven’t made any friends here at all.

Ellen: Does that upset you?

Marie: Yes (Nodding head, teary and drawn expression)

Ellen: I’m sorry. I can see it upsets you. Yeah. Are there things that could be done to make friendships easier?

Marie: No. Not everyone wants to come out of their room.

Ellen: Yeah. You can't control what they do which makes it hard. That would be very hard.

Marie: And we are different ages too.

Nurse: Age.

Ellen: Oh age. Different ages. Yeah. So what kind of age ranges are there?

Nurse: Some people are quite old like 50 or 60.

Ellen: Okay. Yeah. So quite a bit older than you.

Nurse: Yeah. The younger are probably thirties. That’s the thing you feel that other people are older, right?

Ellen: You’re the youngest one living here. Yeah.

Marie: (Nodding head)

Ellen: Yeah, you would like to get to know people better. So what do you think would make a difference in terms of getting to know people or making friends here?

Marie: But here is a very high care place and most of the people here not want to come out of their room. You can't make them to come out of their rooms if they not want to.

While Marie did not make friends with other residents she did feel close to the nurses and support staff and loved playing games, or doing puzzles with them. Marie took photos of her 500 piece puzzles (pictured on the wall) as well as a picture of herself with a card game spread out in front of her. These were clearly shared moments that meant a lot to Marie and her support workers were not only providing practical assistance but also a sense of reciprocity and mutual enjoyment seen in the pictures.

Figure 6.7: Marie loves doing puzzles with support workers

Ellen: (Looking at photos taken by Marie.) Are these puzzles?

Marie: It’s over 500 pieces.

Ellen: Yeah.

Marie: All Disney ones.

Ellen: They're amazing. Yeah, of course they were Disney ones. That was the other thing that you mentioned that they're Disney ones. How long does it normally take to do one of those?

Marie: I have a support worker help.

Ellen: Okay.

Marie: So sometimes say two months. Two months to like finish.

Ellen: Yeah. Wow. Where do you tend to do them?

Nurse: The bedroom.

Ellen: Yeah.

Marie: I don’t do them anymore. Because he was getting more busy.

Ellen: Sorry, can you repeat that?

Marie: Because was getting more busy.

Nurse: We got more new clients.

Ellen: Okay.

Nurse: And the support worker is busy helping other people.

Ellen: I see.

Nurse: It’s hard to make time to do a puzzle now.

The pictures of the puzzle and Marie playing games were symbolic of quality time Marie spent together with paid workers, which she loved. She also recalled her favourite memory of doing a Harry Potter Movie Marathon with her support workers when she moved into Midlands and how much both she and her workers had enjoyed it.

Figure 6.7: Marie loves doing puzzles with support workers

Unfortunately, such memories also represented loss and change, as staff were under increasing pressure to work efficiently and spread their time across multiple clients. This meant fewer opportunities to spend time with her workers unless it was transactional care tasks. Despite these fond memories and good moments with support workers and nurses, the nurse who was with her during interviews quipped that they didn’t have much time any more to do puzzles or play games like we used to” due to increase of clients placing a higher demand on the staff to work efficiently.

For Marie, time with paid people was even more important because there was no reciprocity or sense of connection with other residents. Caleb shared similar views, saying that residents stayed in their room and didn’t tend to spend time together unless it was for meal times. Caleb however, did not seek out friendships:

Ellen: Can you tell me about the people you live with?

Caleb: I only know them since they’ve come in.

Ellen: Yep.

Caleb: Yeah.

Caleb: I wouldn’t know them personally outside of here.

Ellen: Do you try to get to know them?

Caleb: Yeah. Yeah, I get to know them a bit (non-committal). Yeah. I don’t spend a lot of time hanging out with anyone here. I know them and I know a bit about them and we have chats at dinner time -

Ellen: Yeah.

Caleb: Yeah. That’s about it though really. I don’t really have a lot more to do with many people here.

Ellen: Yeah. So people tend to stay – stick to themselves?

Caleb: Yeah. Yeah, people stick to themselves.

Ellen: Would you like to get to know people more here?

Caleb: My life is busy enough I don’t need to. Yeah. So no, I’m happy the way things are.

Ellen: Yeah.

Caleb: Yeah. If I choose to in a way but most of them stick to themselves and have got brain injuries so it’s hard to have too much of a connection or friendship with them in a way.

Caleb, like Marie, did not attach any value or meaning to relationships with other residents and felt that the nature and severity of disability and limited means to communicate made building rapport a challenge. Unlike Marie though, Caleb spent the majority of his time with friends and family, most of whom knew him prior to acquiring disability (hence, his social circle is larger than most who live within Midlands). Caleb was also closely connected with his local church and his faith in God which has also enabled friendships beyond Midlands.

This solitariness in both houses run by Midlands provided the illusion of peace and quiet (a stark contrast noted when reflecting on differences between Cress Point and Midlands, when visiting as a researcher). However the solitariness may also mean that issues of incompatibility and acquiescence are masked and go unrecognized. Certainly at Midlands there was no history of shifting participants or other residents around between houses. Instead there was a culture where residents tended to cope as best they could with the circumstances.

6.3.6 Configuration of paid support in the home

The managers of the residential accommodation sites in both Cress Point and Midlands were named by participants as the person who had power to decide where or in which house residents were placed in. When participants were asked: “who makes the decisions” most stated: “the big boss” or “the managers”.

Further to this, when participants were asked about their experiences of accessing the National Disability Insurance Scheme and managing their personalized budgets, all the participants again deferred and said: “You’d have to talk to the manager about that”. It was clear that most participants did not feel any sense of personal authority over when or how their personalized budgets were used to organize support. Residents in this study seemed to have little opportunity to express their opinions or preferences for where they would like to live or who they would like to live with, or what their supports should look like. The fact that participants did not recall any personalized planning does not mean it did not happen; it merely reflects that during the research sessions residents indicated that managers “dealt with that” in terms of decisions about their needs, goals and supports.

The reality was that none of the residents had a choice about which workers they had entering and exiting their home and lives. Support workers were allocated to residents at a management level. None of the participants had a choice about who their workers were for the day. At Cress Point, the support workers were assigned to a house for the day and their roster displayed with pictures of each staff member alongside house numbers:

> Malcolm: Well sometimes it’s Marjorie (pseudonyms), sometimes it’s Mali, sometimes it’s Abdul, sometimes it’s Lina, sometimes it’s Tayla.

Ellen: So you don’t know who it’s going to be?

Malcolm: Well, they have a notice board with pictures for the roster which tells us who it’s going to be for the day…

This rostering board was seen near the administration office. At Midlands services there were no rosters displayed around the houses but Caleb confirmed that support workers and nurses were hired and managed at an operational level and residents were allocated whoever was rostered on for the day. This was seen as standard practice. In short none of the participants in this study were able to choose their support workers for the day or week or had opportunities to be part of interviewing or screening support workers before they were hired. The nature of shared support between residents meant that individual choice and personal preferences were constrained. For example, when residents wanted to go out but needed support to do so, this needed to be negotiated and was often complicated because the staff had to distribute their time efficiently among other residents as well rather than individually supporting residents one to one.

Being allocated staff made it difficult for participants to build any sense of affinity or warmth with particular people. There were also limited opportunities to voice preferences about which workers participants’ personally liked or enjoyed working with. Conversely, it was difficult for participants to raise issues or concerns about workers they did not like or feel safe with. Caleb was able to voice some of the ramifications of speaking up about workers, which he constantly weighed up when deciding whether or not to speak up about poor quality care or discomfort with certain workers. He explained that residents had to negotiate and be careful not to “upset” the organization or their support workers because of the fear of subsequent poorer quality service as retribution:

Ellen: What about in terms of being able to hire or choose your own supports? You mentioned that some support workers have a knack and others don’t – are you able to ask or choose them and avoid the ones you’re not as comfortable with?

Caleb: Okay. I try not to go down that road because you can start feeling a bit demanding. What I’ve done is I have brought up with the manager – with the manager – there’s a manager in the facility so she’s usually here working on the floor so if there’s anyone that I’m not particularly happy about I’ll go and see her and generally she does what she can to steer that person away from my care.

Ellen: Okay.

Caleb: So there is a bit of that. I try not to just go and pick and choose when the shift starts who I want because it almost makes it not fair on the others. If they're not very good with me generally they're not going to be as good with others.

Ellen: Yeah, that must be tricky.

Caleb: I just tell the manager a bit of feedback as to who, yeah, might be a bit of a – bit of a problem or a struggle and generally she'll sort it -

Ellen: So you've worked out ways of being diplomatic?

Caleb: I suppose, yeah.

Ellen: Yeah. It must be quite a balance sometimes.

Caleb: Yeah. Big time.

Ellen: Especially because you depend on their care as well.

Caleb: Yeah. Yeah, you don't want to bite the hand that feeds you in a sense.

Caleb raised many examples of practices he did not like, such as his laundry being washed with other residents' laundry which then resulted in his clothes smelling of faeces. While he found it unpleasant and had raised the issue with management, he also talked about how difficult it was to keep following up repeatedly when issues were not resolved.

When participants were asked in the research interview what a "good support worker" does they struggled to talk about specific staff or examples. Marie was the only person in this study who drew on specific examples and referred to staff with a sense of mutual regard and warmth. It was clear that for Marie, staff were a source of social connectedness and meaning-making. It seemed as though these positive interactions were key to Marie's emotional resilience and contributed to her feeling safe at home.

Ellen: Yeah. What about in terms of the support people?

Marie: I like when the support workers get to know me.

Ellen: They get to know you. What are some of the things that make it easier for you to get to know them?

Marie: They spend lots of time with me. And they play games with me.
They take me out to different places that I want to go to.

Ellen: Whereabouts do you go when you go out?

Marie: Movies.

Given that Marie had spent such a long time in hospital and in respite care before moving to Midlands, she also named support workers and nurses from these previous places where she lived who she felt were important to her and whom she loved staying in touch with. Marie's experience was different to others in this study in that she seemed to have a much closer relationship with her support workers and nurses. In part this was due to the intensive 24 hour care she required from nurses and paid staff. It may also be due to her history of growing up in a hospital environment for several years prior to moving to a smaller in-community housing option.

In contrast, the majority of participants tended to describe assistance with daily tasks as transactional. For example, helping people get up in the morning and ready for work, or assisting with tasks such as cooking, cleaning and other executive planning and organization tasks.

> Ellen: You have your brother in law outside of home. What about here – do you have people here who support you?
>
> Stewart: Yeah, the staff.
>
> Ellen: So the staff give you support?
>
> Stewart: Yes.
>
> Ellen: What kind of things do you find most helpful about them?
>
> Stewart: I like them helping me with cooking.
>
> Ellen: They help with the meals and cooking?
>
> Stewart: Yes. Like – like they help me out of bed and check my room clean and ..
>
> Ellen: Okay. Yeah. So they help you with the practical things. The cooking. The cleaning.
>
> Stewart: Yeah. I let the staff help me sometimes.

Most participants were non-committal and disengaged when asked about key paid staff. They shrugged or made general comments about support workers being "good" and "helpful" but did not share specific memories or examples of what *really* made the difference with a good support worker:

> Malcolm: Nah, these guys are fine. I didn't like Tom (pseudonym) at first, but I got used to him and now we get on fine. It just takes a while.
>
> Ellen: What do you think makes the difference for you? What does good support mean?

Malcolm: Well… They're helpful. They have a good attitude.

Ellen: What are some of the things they help you with?

Malcolm: (long silence)…. they talk. They just help.

The absence of discussion about particular workers they liked or got along well with was a key finding within itself. Participants seemed to accept and comply with management decisions about whichever staff were rostered on and were used to being told who they would be allocated. This sense of acquiescence seemed noticeable among older participants in particular, which was not surprising given that many had had decades of services which were block-funded and where allocation was the norm.

For Caleb and Marie, their own personal safety was highly dependent on the quality of personal care support workers and nurses provided. Both had negative experiences where nurses or support workers had misunderstood or did not have the appropriate skills or had caused physical injuries. Notably however, quality of care was noted as a broad spectrum. For example, Caleb described how some nurses treated his body roughly during personal care tasks due to poor training and lack of insight. In another incident a nurse who did not have good English misunderstood an instruction which left Caleb with severe burns due to an over-heated heat pack. This experience required admission to emergency department as well as multiple follow up surgeries and skin grafts and weeks of medical treatment and rehabilitation.

Marie, when asked about what helps her feel safe in her home, took a picture of the red emergency call button situated by her bed (figure 6.9). Conversely, she expressed deep anxiety and fear about workers or nurses not knowing what to do if she stopped breathing or if there were a medical crisis – a genuine risk for Marie. For her, the red emergency button represented a symbol of safety and urgent support when and as needed for her to survive.

Figure 4.9: Marie's picture of what helps her feel safe at home

Ellen: In this picture. Are you able to tell me more about what in this picture makes you feel safe?

Marie: Because if I need someone in an emergency they have to come in very quick if I have an emergency.

Ellen: I see. Okay. Has that happened ever before?

Nurse: So far not happened.

Ellen: Yeah. Thankfully it hasn't happened. But it – it is something that worries you Marie?

Marie: Yes. (nodding head emphatically)

Ellen: Can you tell me more?

Marie: Yes. I never know what people will act like.

Ellen: Okay. Yeah. You never knew what people would react like. What does that mean?

Marie Some people not like to see someone turning blue.

Ellen: Yeah. Some people wouldn't like to see someone turning blue. Is that … do you mean here that some people may not respond ...

Marie: They get scared.

Ellen: They may freak out?

Marie: In an emergency situation they might not know what to do. (…) One of my nurses asked for the emergency one.

Ellen: Yeah. Okay. So with the emergency button, are there ...

Nurse: (interjects.) We haven't used it.

Ellen: No.

Nurse: But we practice with one that just makes a different sound.

Ellen: Yeah.

Nurse: People have to come running quickly.

Ellen: Yeah. Okay.

Nurse: Because you know, at other times just, you know, they might helping other people but they have to wait.

Ellen: Yeah.

Nurse: But if she press emergency call someone have to come quickly.

Ellen: Okay. So in an emergency you (referring to Marie) reach for the bell to ask for help?

Marie: No. The nurses do.

Ellen: Okay.

Nurse: Marie can't press the button.

Ellen: Yeah. Okay. So it's more the nurses that call for help.

Nurse: Yeah. Always have to be with her 24/7 anyway

Ellen: Okay. So you have someone with you 24/7 (referring to Marie). Yeah. And has that always been the case or has that been more recent? … It's always been the case.

Marie: Always. Since I was 18 months old after I got sick. At school. At work.

For Marie, there is a real sense of anxiety and fear associated with having inexperienced staff on duty who might not know how to respond in the situation of a crisis. It was difficult to question Marie further about whether there had been quality of support issues because the nurse was present in the room and was interjecting, trying to reassure Marie by stating that staff did know what to do when the red emergency button was pressed.

Quality of support takes on a whole different level of meaning when relying on other people for the basics of personal care and necessary life-sustaining medical and bodily support. This reliance on workers for physical care and safety may compound the reluctance residents have towards raising issues. Caleb articulates this as:

Caleb: You don't want to bite the hand that feeds you in a sense.

Ellen : Yeah.

Caleb: But on the other hand you want to be looked after yourself so -

Ellen: Definitely.

Caleb: Yeah, it is a bit of a tough juggling act. Some people really make your life a bit harder. Not that they've done it on purpose but if they are rough I've got to say something. Yeah.

For Marie and Caleb, there were fears about the consequences of speaking up, or retribution that may translate to dangerously poor quality of care and neglectful or hurtful practice. For others in this study who mostly had intellectual disability, it was still difficult to raise issues. Even if the response was merely awkwardness or discomfort between resident and worker, this no doubt would arguably been seen to have a damaging effect on quality of support.

6.3.7 "Managers deal with that": Management as key point of contact

As has been previously mentioned, resolving issues or making changes to the operations in each participant's house was often seen as an issue for the manager to deal with. For example Steven wanted internet access in his hostel room so he could watch sports channels, however was unable to because staff were still deciding whether it was "safe" to allow internet access in private spaces. When asked what Steven thought of this, he deferred and said it was management's decision.

None of the residents at Cress Point or Midlands seemed to have regular house meetings or regular get togethers between residents, support staff or managers and there were no informal ways to provide feedback. Instead participants approached staff or management on their own initiative if there were issues that needed addressing. While Midlands' services did not seem to host house-meetings between residents at all, Cress Point occasionally held meetings for the hostel residents; however these were mentioned by residents with distinct lack of interest and they certainly were not a space where they felt free to raise issues, share ideas or comments or take an active role in decisions. Instead they referred to these meetings as a way for managers to provide residents with information. There was no sense of collective authority or peer support or leadership in terms of making decisions for residents by residents. Nor were there processes for raising feedback, questions or issues with staff in ways that protected them from retribution.

Many of the socio-political aspects underscoring group accommodation, which includes management of NDIS plans, securing of funding, decisions about staff and so on, operated behind the scenes and were not well understood by the residents. When asked about how or who made decisions about aspects such as rostering support workers, or placement or relocation of residents participants would frequently say: “You need to talk to the manager about that”. None of the participants felt that their NDIS plan gave them more choice or freedom – instead they would defer or say: “The manager deals with the NDIS”. Most residents in disability accommodation were newly transitioned to the NDIS which meant a degree of uncertainty and unfamiliarity with how the NDIS worked and what it would mean to them personally. It was not surprising that most participants said that their supported accommodation provider manager “dealt with that”. Such responses suggest a lack of involvement of residents in terms of planning their supports. More broadly there was also a lack of authority to influence management decisions in their favour in relation to housing or support, as illustrated by the conversation between Matthew and his dad about re-housing another resident. The manager willingly disclosed information to his dad about relocating a co-resident Matthew was struggling with but had not disclosed it to Matthew. This conversation clearly demonstrates a hierarchical approach to decisions. In some circumstances where participants had a family member or close outsider advocate in their corner, this was an advantage as they had an advocate to help them navigate the hierarchy of service administration.

6.3.8 Future sense

As stated in section 5.3 (Decision to move to supported group accommodation), it was common for others to have actively made decisions about where the person with disability was to live or who s/he would live with. Sometimes it was a family member, at other times a social worker or disability professional. Some participants like Malcolm, Stewart and Steven had moved to supported accommodation as a result of crisis (due to carer circumstances changing, such as illness or death). Meanwhile for Caleb and Marie, the alternative was a hospital setting. All of these varying reasons made it hard in different ways for people to have any sense of authority over their future planning. There was a common thread of powerlessness and inevitability of ending up in supported accommodation.

The participants who had existing connections to family members or friends beyond their supported accommodation seemed more likely to have at least some semblance of authority and power to change or resolve issues as they arose. These social connections afforded them a greater sense of voice, with family members able to advocate for changes when things were not working well within supported accommodation.

One participant, Matthew, said that when making decisions he relied on his dad and mum to help manage. During this conversation Matthew's dad interjected to point out that staff were also there to help with decisions:

> Matthew: I've had Dad to help me (make decisions and advocate – e.g not getting along with a house mate) because I wouldn't be able to on my own. If I'm really struggling or something I can ask Dad for help.
>
> Dad: You can always ask the staff too.
>
> Matthew: Yeah I know (reluctantly)
>
> Ellen: Do you feel there's a difference between asking a paid support person compared to asking your dad, or a family member?
>
> Matthew: Well, to be quite honest, they do help a lot but if I really want to make a decision about something else then I would rather ask my dad.
>
> Ellen: I'm just wondering what the difference is between the two people and how they support you, what is that difference?
>
> Dad: It's probably history I think because we've always done it, but in the process we're trying to encourage Matthew to talk to the staff and take his questions to the staff because we're not going to be around forever so you need someone there to reassure you and guide you along the way.

This interaction between Matthew and his dad highlights how much Matthew values and draws on his dad as a trusted, familiar, close person in his life. He valued the reciprocal bond and felt that his dad had a good understanding of how to support Matthew with processing information and making decisions. His dad however was keen to remind Matthew to also call on support workers, with the view that in the future he may not be around to help. For Matthew, it was clear that staff members did not provide the same quality of support and probably did not have the same deep understanding or knowledge of how to support Matthew in the way that he wanted to be supported with decisions. This study suggests that relationships between people with disability and significant others in their lives (whether it be a carer, family member, sibling, friend) are very different to those with their support staff, as it is much harder to build trust, particularly if there is no preference in terms of choosing workers rather than having them allocated. In short, for Matthew the closeness he felt with his dad enabled him to feel heard, listened to and in control of decisions. Others in this study who had lost the trusted people in their lives as they had aged and died also seemed to lose those moments of support and advocacy which in turn meant that people had less opportunity to resolve issues or make changes to their lives.

When asked about whether they wanted to live somewhere else or with different people it was difficult for participants to conceptualise this as an option, despite a common sense of disquiet and frustration about who they lived with. While participants were able to express frustration or dislike, there was a typical sense of accepting and acquiescing to conditions as people believed that their current supported accommodation was their only option for safe, stable housing and supports.

No two participants were the same in terms of their values, preferences and needs, with the sample representing a wide range of characteristics, qualities, needs, interests, lifestyles and different priorities that were meaningful to their daily lives. Marie described many hopes and dreams for her future including travelling to Disneyland, the Gold Coast and Broadway, New York, and also talked about wanting to go nightclubbing as many other 20 year olds her age were doing. Similarly Matthew also talked about wanting to travel.

Tellingly, only one participant, Sophia had a clear vision and emphatic view about changing her living circumstances and wanting to try somewhere different. She was clear about her desire to leave the current residence (a group home) as she wanted to live in a different suburb. She was also explicit about who she did not want to live with. For example, she made it clear that while her boyfriend wanted her to move in with him, this was not in her future plan. Sophia’s prior experience of living alone with support had given her insight as to what “home” meant and felt like to her and what she hoped and aspired for. While Sophia was incredibly articulate and had told her family and staff this, there did not seem to be any support to help her with her goal. Most of the other residents in this study struggled to even express their views on what they would like in their own futures. Instead questions about their future were met with silence, non-committal shrugs, or confusion. Evidently, many had not been asked about where they saw themselves in their future, or what they would like their home to look and feel like. It was clear that many participants in this research had not had opportunities to question or explore what their aspirations were for their future, including where and how they would like to live.

6.3.9 Summary of semiotic factors

In summary, there were a range of semiotic (human) factors identified in these findings as seen in figure (6.11) which highlights four aspects: (a) the level of support people had when making decisions, (b) interpersonal interactions with residents, (c) relationships and access to support workers and staff, and (d) role of management and facilitation.

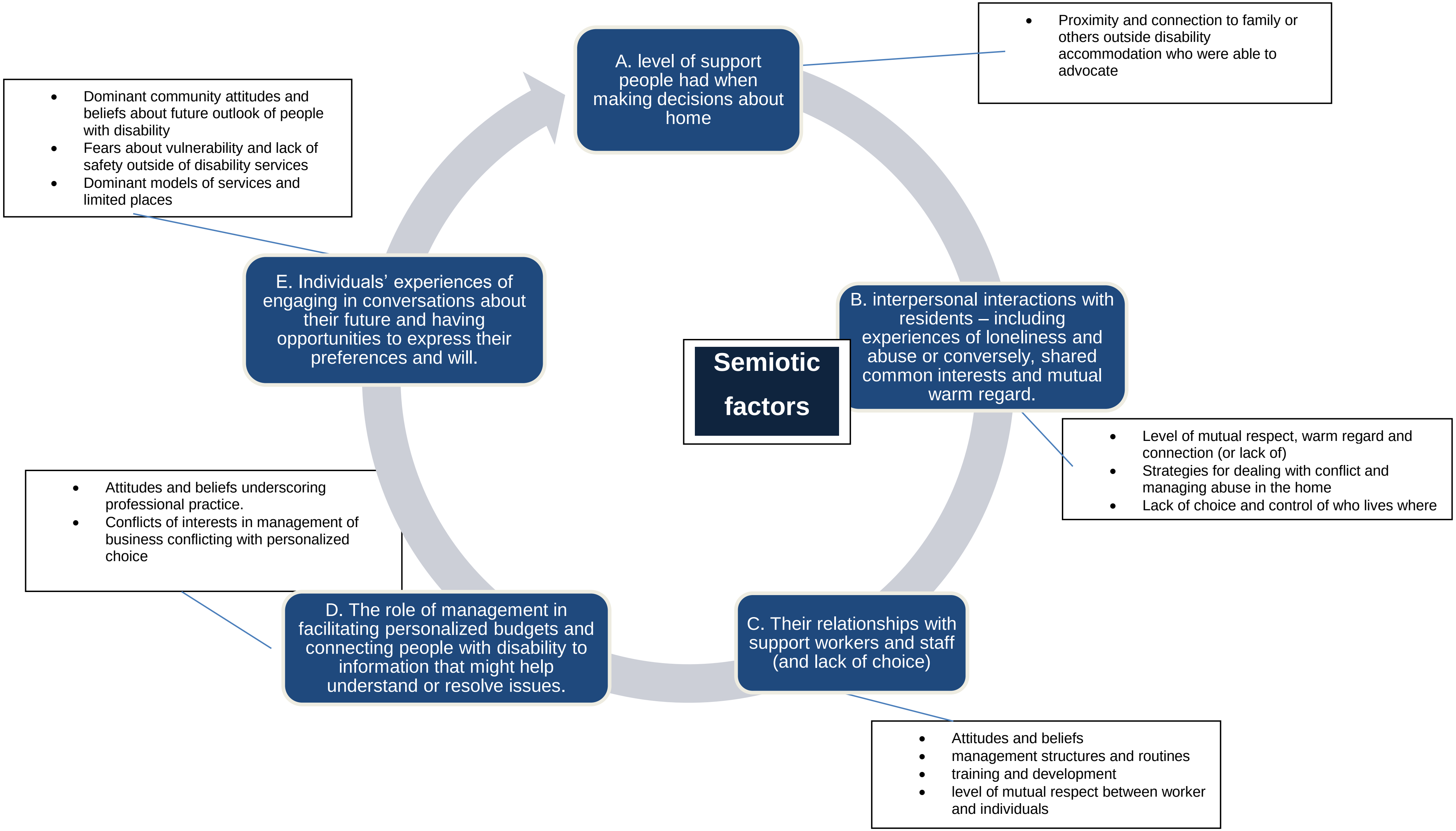


Figure 6.10: Summary of semiotic factors underlying belonging, safety and agency

As noted earlier, these human factors operate as flows in connection with material factors (outlined in section 6.2). The use of New Materialist analysis deepened understanding and assisted in identifying the wide range of material and semiotic factors participants spoke of regarding what impacted on safety, belonging and agency. From the findings it was clear that distribution of resources impacted significantly on the opportunities people with disability had to explore housing, their relationships within housing and the supports they needed to do daily life.

CHAPTER 7: DISCUSSION

7.1 Introduction

This chapter explores the results of the study in more detail. The first part of the discussion (Section 7.2) discusses the conditions that impact decisions to move to supported accommodation and relates this to the existing literature. The next section (7.3) provides an overview of the various material and semiotic factors that were meaningful to participants and the ways that this affected their embodied experiences of safety, belonging and agency in shared disability accommodation settings. Section 7.4 explores the usefulness of applying a social justice lens, arguing that, in order to understand why those with significant support needs were routinely treated in ways that devalued their authority, it is important to acknowledge the distribution of resources and material aspects as well as the social conditions impacting on how personal safety, belonging and agency are embodied in the home for people with disability in congregated settings. I also take up ideas of epistemic injustice (and justice) as a way of shifting the focus away from individualized forms of harm and protective response, to instead argue that part of the issue lies in how lived experiences of people in supported accommodation are valued or devalued. To conclude, section 7.5 focuses on key learnings from the study and identifies the implications for policy and practice.

7.2 Conditions that constrained decisions about where or who to live with

This first part of the discussion analyses some of the factors identified by participants in relation to decisions to move to shared accommodation, and demonstrates how these semiotic and material, cultural and natural, human and non-human – constantly interplay in ways that disrupt personal authority as demonstrated in figure 7.1. The interplay between these factors are described in more detail in the following sections.

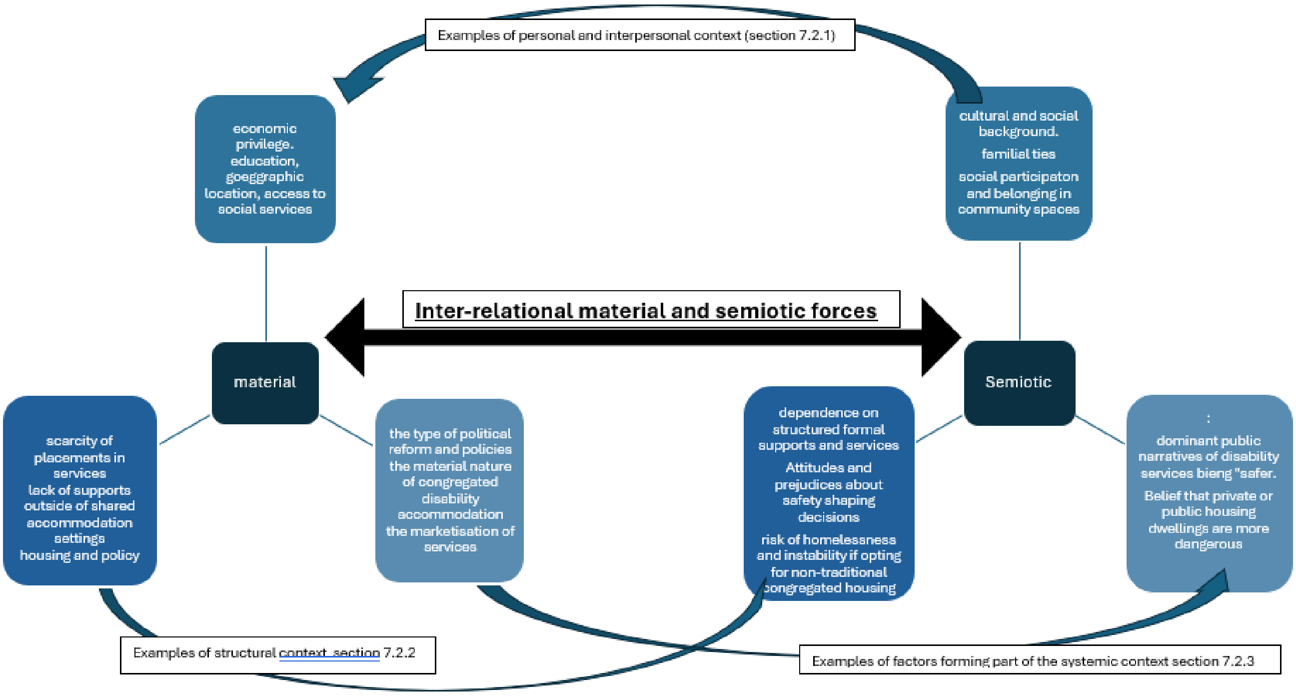


Figure 7.1: Factors negotiated when decisions were made to move to shared accommodation

7.2.1 Personal historical factors influencing how participants understood safety, belonging and agency in their everyday lives

Moving out of the family home as an adult was widely seen as a rite of passage and a typical milestone of Australian society – a milestone that participants in this study strove for too (Leiter & Waugh, 2009). Indeed, some participants were excited and optimistic about moving to their new home, viewing the move as an opportunity for independence and symbolic of maturing into adulthood. For participants in this study perceptions of the future and decisions about where or how to live were socially and relationally constructed. Understanding individual experiences of interactions with social services through a historical lens from childhood onward helps with understanding the disillusionment and lack of engagement many seemed to embody. From a historical perspective, most participants had spent much of their lives engaged with disability service contexts in various ways, through school, employment, recreation and sports, home support and accommodation (National People with Disabilities and Carers Council, 2009). It is also important to note that most had grown up in an era prior to Australia's National Disability Insurance Scheme where disability programs and supports tended to be block-funded with a one-size-fits-all approach. It may also be that many had historical experiences of not being in control of their supports or services and thus did not have experiences to draw on in terms of knowing what their rights were or how supports could be changed to better meet their values, needs, life style and goals (Bigby, Douglas et al., 2018). Their histories of interacting with professionals and social services were not strongly represented through direct conversation yet underscore participants' reflections at a sub-conscious level (Bigby, Douglas, et al., 2018). Particularly apparent among the older participants in this study who still recalled the era of disability institutions was awareness that people with disability have been embedded within service cultures where there are strong narratives about accepting help "offered" or go without supports (Altermark, 2017; Steele, 2022). This narrative is now amplified by socio economic debates about the costs of disability services. Such a policy context inevitably shapes how people with disability perceive disability services, and influences how people perceive, whether consciously or unconsciously, their own future and place in society. When people move to disability service contexts full-time each individual brings their own "learning" in terms of how they interact with disability services.

As Mason et al. (2004) argue, an individual's understanding and expression of personal agency is dependent on relationships and their social environment around them. In the same vein, Swartz (2008) emphasizes that each person's life opportunities and experiences across the life course are shaped by experiences of their family and intergenerational privilege and/or disadvantage. Likewise in this study it was clear that intergenerational privilege affected how people with disability accessed services and resources across their life course. Swartz (2008) contends that family are key to personal agency, resilience and access to supports and resources. While Swartz (2008) was referring to how family capital operates in a way that transfers privilege across generations, there were parallels in this current study in that some participants also benefited from family capital while others who did not have family struggled to speak or have their perspectives heard in services. It is important to note that each family assemblage represented a different collection of material and semiotic factors and impacted on participants' perceptions of safety, belonging and agency in different ways.

While family were seen as key sources of support and advocacy, there were also many other assemblages influencing personal agency. Notably, within service structures, there were also a range of assemblages operating in ways that systematically and systemically devalued residents' perspectives. As seen in this study, participants found it hard to articulate their own values and needs and were often tentative about sharing criticisms for fear of backlash. While disability may contribute to difficulties in understanding information and articulating needs, it does not negate the systematic devaluing of residents living in disability accommodation. Such people are often deemed vulnerable and in need of protection (particularly evidenced in service provider views

(Pelleboer-Gunnink et al., 2021). This influences how service providers, policy makers and others in positions of power and decision making listen to or dismiss residents' knowledge.

Tieu (2022) argues that each person has their own collective of embodied physical and psychological states of being that centre around their personal beliefs, values and desires which inform the decisions and actions people take; however these human semiotic aspects are also in a constant state of interaction with the material world. People with disability who live in congregated settings have a wealth of insight and knowledge, which provides a strong basis for application of the theoretical body of work on what constitutes epistemic justice. Situating epistemic justice in the context of supported accommodation shifts attention away from the idea of personal agency as a functional set of skills. Arguably, it is more useful to understand how the material and social environments may produce moments for personal agency or conversely constrain them (Mazzei & Jackson, 2017; McFarlane & Anderson, 2011).

Adopting a new materialist perspective situates personal agency as a fluid state of "becoming" in ways that enable power imbalances in this study to be considered from the perspectives of participants. As Barad (###"cited in Dolphjin and van der Tuin, 2012, p. 55) argue:

> The notion of agency I am suggesting does not go against the crucial point of power imbalances. On the contrary. The specificity of intra-actions speaks to the particularities of the power imbalances of the complexity of a field of forces. I know that some people are very nervous about not having agency localized in the human subject, but I think that is the first step—recognizing that there is not this kind of localization or particular characterization of the human subject is the first step in taking account of power imbalances, not an undoing of it.

If personal agency is always "becoming" and never static, then it is understood as an ever-evolving collection of embodied experiences and interactions of material and semiotics that continue to assemble in ways that produce a continuum of experiences of authority, choice and control, or conversely of oppression, marginalization and harm (Fox & Alldred, 2023; Mazzei & Jackson, 2017; McFarlane & Anderson, 2011).

When personal agency is understood as relational and contextual, it allows us to move away from a reductionist view, which is often taken up within services with the goal and focus on independent living skills and proving capacity to make decisions independently. Instead, it involves understanding personal agency as a fluid relational embodied experience that relies on a combination of ever-developing personal skills, knowledge and beliefs **as well as** the environment and people surrounding (Wehmeyer & Abery, 2013). While Wehmeyer and Abery (2013) offer a basis for understanding how one's capacity to exert control over decisions and actions may be influenced by people and the environment, as well as one's personal skills and attributes, this study highlights the importance of recognizing that each person with disability has the capacity to express their preferences and forge a sense of belonging in ways that are meaningful to them.

These findings highlight a significant gap in the current body of research about future planning *with* and *by* people with disability. Very little of the prior literature seems to pay attention to the development of personal agency – authority over decisions and actions – from a socio-relational stand point with a focus on how people forge and establish belonging in new and different ways as relationships with family members change and support roles are re-negotiated. Further to this, the findings raise questions about how people with disability express their desires for belonging in their home and in their community when negotiating disability service settings where residents have no authority over how their housing or supports are arranged. Instead much of the prior literature tends to position disabled people as "in need of care" and focuses on parents relinquishing care and setting up systems for ongoing support. Many papers exploring future planning in the context of the lives of people with disability (in career, housing, relationships etc.) have tended to centre family perspectives and service provider priorities (e.g., Hart, 2022; E. Murphy et al., 2011; Taylor et al., 2019). This in turn has meant that family member and service provider definitions of safety have been prioritised. The broader literature and evidence around future planning from the perspective of family members has demonstrated a universal concern and worry about the long-term safety of people with disability and vulnerability of people with disability in "ordinary society" which underscores decisions about future planning and residential placements (Bredewold & van der Weele, 2022). At the core of many future planning discussions is an "uncertainty about what the future holds" and fear of how people with disability might be neglected and uncared for in the general community (Bredewold & van de Weele, 2022).

Political and economic issues such as the availability and scarcity of housing and underfunded and under-resourced support systems adds fuel to fire, adding pressure to families who urgently worry about future security for people with disability whom they love or know. Literature on future planning from the perspective of family members mentions the need to "relinquish care" in order to secure placements in congregated living situations (Grey et al., 2015; Nankervis et al., 2011; Werner et al., 2009). Much of the literature concerned with future planning has tended to discuss the burden of care on parents or caregivers who in turn have poorer health and economic outcomes (Brennan et al., 2020; Burke & Heller, 2016; R. Walker & Hutchinson, 2019).

In this study there was a notable tension that all participants had to negotiate in terms of how they established and maintained supports in their life while also maintaining a sense of personal authority, choice and control over their day to day experience. There was complete silence from participants when asked about exploring choice of location, housing, house mates or support arrangements; this silence and lack of any response holds meaning, speaking volumes about the underlying power tensions that exist. It is therefore vital to consider future planning with people with disability as an iterative ever-evolving process rather than a once-off event that is sorted after one has relocated to supported accommodation. Future planning is not only about the material set-up of stable housing and structured paid supports; it also needs to take account of what helps people to maintain a sense of identity and belonging. This means that future planning should also be about opportunities to build meaningful relationships within the home and broader neighbourhoods. More work needs to be done to challenge the dominant social norms, trajectories and expectations that people with significant disability experience in supported accommodation.

7.2.2 Factors constraining aspirational goals for the future: Housing and support

In contrast to family member perspectives, the participants in this study did not talk about their vulnerability or concerns for their safety; rather they saw moving to a group home as a marker of independence and growth, moving away from family. Participants voiced a sense of hope for greater independence. In broader research it is clear that many people with disability share similar aspirations, viewing the prospect of moving as an opportunity to live independently or to leave their family or another unhelpful situation, such as a group home not working out (Hole et al., 2015), or, as seen in this study for Sophia, an independent living situation where she had experienced exploitation. Congregated living options were considered the only “safer” option given the need for high level care. In short, most participants saw the move to congregated living as a positive step towards safety and stability in adulthood. This is consistent with the broader literature highlighting independence and self-determination as key markers of adulthood for those both with and without disability (Mannino, 2015; E. Murphy et al., 2011).

Mannino (2015) conducted qualitative interviews and focus groups with 28 individuals with disability aged between 18-26 years of age. Participants in their study defined adulthood as (i) being able to freely make decisions based on one’s own personal preferences, ideas, values and dreams instead of being told what to do by others; (ii) forging meaning and creating value in life through career, relationships and other aspects of meaning; and (iii) imparting learning, knowledge and life experience and learned wisdom in ways that benefit the community. Using this definition of adulthood, it is easy to see why participants in this current study saw moving away from the family home as a marker of adulthood.

In this study participants had not had opportunities to talk about their ideal housing and support situations and none of them were able to choose who to live with or who supported them in the home and/or community. In fact, opportunities for participants to choose where to live and who to live with were very limited as they contended with residential services that were over-stretched, scarce and limited (Callaway et al., 2021; Nankervis et al., 2011; Skipsey et al., 2022; Verseghy et al., 2019). This made it difficult for participants to explore what *could be different* as they had limited examples to draw on in terms of options for organizing housing, people and supports. When their disabled peers and friends all seemed to be in traditional group home models of shared disability accommodation this further perpetuated the idea that group homes were the “only” safer option and may also have reinforced distrust and fear about making un-traditional decisions beyond traditional supported accommodation.

This study demonstrates the need for future planning to diversify by including the voices of people with disability. Very little in the literature focuses on future planning from the perspective of people with disability, instead the majority focuses on perspectives of family members and service providers (Nankervis et al., 2011). An examination of the literature indicates that for family members and service providers their first priority in taking up accommodation placements was to ensure stable housing and reliable supports (for safety). Certainly these dominant views were seen in this study: participants seemed to view congregated living options as the “only option” where they could receive stable support and housing. This doctoral thesis demonstrates the need to actively combat power imbalance by intentionally and strategically involving people with disability in decisions about their future. It is vital for people with disability to make their preferences known and to have a sense of ownership and belonging in the place where they live. There is a dearth of research exploring how policy and community structures influence and shape or constrain future expectations and aspirations of people with disability. However, since the National Disability Insurance Scheme there has been an increasing focus within service provision on goal setting, and person-centred planning and decision making (Curryer et al., 2015). When people have ample support through NDIS (and good independent advocacy supports from family or formal advocates) this is likely to significantly improve how people with disability perceive their future.

Johnson and Hitlin (2017) posit that how a person perceives their future is entwined with their own core beliefs and appraisal of their own identity. Adopting the view that identity is socially constructed, I postulate that people with disability are obliged to negotiate additional societal barriers that compound and constrain the development of agentic beliefs (the core belief that a person has authority, control and choice over their goals and is capable of personal growth and development). Agentic beliefs are highly striated over the course of a life of negotiating material conditions consisting of under-resourced and underfunded systems while also repeatedly encountering dominant attitudes which position people with significant disability as dependent, in need of care and protection, while conversely costing too much, asking for too much.

As Hart (2022) noted, agentic experiences of taking part in decision making were key for the young people with disability in her study, and facilitated a sense of dignity. When people with disability are faced with challenging and complicated systems that they must negotiate day to day, this would likely impact on how they articulate a sense of what they would “like” in their future lives. Baillergeau and Duyvendak (2022) argue that adversity significantly influences how much control (or lack of control) people may feel over their own circumstances when they are in survival mode responding to what is happening in their current daily lives and unable to even think about change or future aspirations. The findings of this study demonstrate the need to re-think how aspirations are developed, explored and then taken account of in service provision contexts.

7.2.3 Systemic and cultural norms in disability service contexts

Participants in this study all desired and hoped for stable housing and supports that would enable them to live their lives as adults, but all experienced a sense of powerlessness to change aspects of their living circumstances once already located in the supported accommodation system. For all participants in this study there was a shared belief that the level of support they had access to was only possible in their current supported accommodation place. Often the alternatives to taking the vacancy were all equally unpleasant – being stuck in hospital, for example, or homeless and/or alone without support from a family member due to illness or death. These were the types of choice people were faced with – living in hospital, or in a group home? being vulnerable and alone in community with no or little supervision over staff, or living in clustered housing with ample oversight and on-staffed supports?

The findings suggest that there was a level of felt safety that came with knowing there were organizational structures in place to oversee the management and reliability of day to day support and a stable roof overhead both for participants and for their families and service providers. The subtext underscoring this was the belief that they were not safe in the community in independent housing, or in alternate share-housing and support arrangements. These sorts of choices underscore the valid concerns and worries many have about the safety of people with disability and confirms and extends on the bulk of the literature illustrating that future planning was about safety (Marsack-Topolewski & Graves, 2020; Walker & Hutchinson, 2018). This accords with some researchers who argue that the social inclusion agenda of an "ordinary life in community" at times seems an impossibility, believing that people with disability are more at risk in community and more likely to be taken advantage of (Bredewold & van der Weele, 2022). Bredewold and van der Weele (2022) argue that a "good life" for people who need daily support is better achieved in disability accommodation contexts where life can be ordered and organized to "accommodate" the needs of people with disability, which means needing to find reliable systemic daily formal support in shared disability accommodation.

While concerns about safety are valid, a larger body of research demonstrates that living within disability service contexts does not necessarily prevent abuse, harm or neglect either. There have equally been concerns about the quality of services for people with disability living IN disability accommodation (Burke et al., 2018; Casale et al., 2021; Innes et al., 2012; Lee & Burke, 2021; Lindahl et al., 2019). While most people in the general community may regularly make decisions about where and who to live with, and can later either maintain or abandon the decision, people with disability rarely have opportunities to explore or change their mind about housing and support arrangements, despite the widely held view that mistakes are part of learning. Perhaps part of the issue is that usually future planning conversations are concerned with ways to minimise and avoid risk or harm, and there are concerns that there will not be anyone around to help pick up the pieces when mistakes have been made or change is needed. Indeed, this supports the research highlighting that those who have meaningful connections to unpaid others are more able to address issues as they arise which, in turn, contributes to personal safety and resilience when dealing with adversity.

7.2.4 Structural factors: Scarcity of housing and support

This study has shown that service providers held power and authority, particularly when deciding on placements, and were constrained by availability of housing and by funding arrangements. This meant that the focus was on the logistics of a stable roof overhead and organized support rather than individual experiences of psychological and physical safety, belonging or agency in the home.

When participants were asked if they were able to look at varied options for different housing locations and support types prior to moving, most had not. Marie was the only one who had seen two options for residential placements (having done respite at one place and been to visit the other place in person when looking at options). This was the exception. None of the other participants had opportunities – rather, they were "placed" where there was availability due to the scarcity of disability accommodation with access to round the clock support.

There was a noted silence in terms of whether NDIS meant that participants had opportunities to examine alternatives beyond the dominant congregated living model of housing in Australia. This may indicate a sense of risk and uncertainty with trialling alternative models of organizing supports and housing. People feared that supports and management structures were unreliable if living in a non-disability-specific housing situation. The NDIA seems to be operating in a way that advantages "old legacy stock" (disability organisations with long histories of residential shared accommodation) and preferences congregated living options.

While there is a scarcity of research exploring availability and flexibility of housing and support arrangements for people with disability in the Australian context (or indeed internationally), research by Callaway, Tregloan, Moore and Bould (2021) audited how many supported housing vacancies were available and found very few. Even with people transitioning to NDIS, information about housing and support arrangements (and vacancies) and coordination was not easily accessible to people with disability and their families. The audit demonstrated that of the 504 SDA dwellings advertised at the time of their analysis, the majority were owned by non-government, non-profit providers (80.6 per cent) and government providers (17.4 per cent). In contrast, only 2 % were private developers. Callaway et al. (2020) noted that of the few vacancies available, most were "old legacy stock", meaning disability accommodation providers with long histories of providing housing and support, some dating back to the institutionalization era. This research demonstrates the need for information and central coordination of supported housing. As the public begin to understand the potential for NDIS to promote housing growth, the distribution may change as private developers take up the challenge.

There have been several submissions and reports made to the Disability Royal Commission (Public Hearing 3) about group homes (Disability Royal Commission, 2019). Several reported that the shortage of placements in group homes meant that the focus was on "finding a vacancy" regardless of whether people were compatible with other residents:

> the shortage of supply of housing and the desperate situation of people being offered a place meant that there were compromises about who they lived with and the compatibility of residents in those homes. (Disability Royal Commission, 2019a, p. 68)

While it may seem more practical and economical to share supports and funding within the context of group homes, the reality is that congregation means that people with disability must compromise. In the literature there has been commentary about people with disability under more surveillance from other residents, paid staff and others (Bigby et al., 2017; Farmer et al., 2016; Holburn et al., 2008; Humphreys et al., 2022; Kåhlin et al., 2016; Mansell et al., 2003).

Over the course of writing this doctoral thesis a very strong sentiment has emerged both within government and the broader public about the "cost blow out" of the NDIS. In Australia the political shift to personalized supports and funding packages also means a shift towards viewing disabled people as consumers buying and purchasing their services. While personalized support budgets were meant to enable choice and control, the reality for participants in this study was that residential managers and guardians or support people were often the ones managing services and negotiating marketized services and this was in part due to the complicated systems and structures that had to be negotiated to locate and find the right supports (Roet, 2022).

The shortage of vacancies and placements for people with disability has come to mean that policy is working in such a way that the NDIA encourages and fosters the building of more group homes where people with disability are required to share in order to receive funding and organize their supports. This in turn makes it harder for people to explore alternative models for organizing housing and supports in a way that promotes individual agency, belonging and safety (Disability Royal Commission 2019a). This has a ripple-on effect to people with disability and family members who must negotiate complicated systems and structures with limited options for supporting individuals' wishes and preferences (McCausland et al., 2019).

This dominant discourse of "finding a placement" means that people with disability are "allocated" based on what works well from an operational and systemic perspective within the confines of what is available, which then becomes the measure of "suitability". This reinforces and more deeply entrenches language about "looking after" disabled clients as a body, rather than as individuals, and it compromises the NDIA's focus on individualized goals and personal plans. Callaway et al. (2021) called for the NDIA to put more focus on stimulating supply in line with the NDIA's stated Innovation Plan. These scholars urge NDIA to examine the ways that industry can re-imagine the housing situation for people with disability. With support, industry can transform a sector of traditional group homes to buildings that are both indistinguishable from and intermingled with housing in the neighbourhood. This is a timely call to action.

There is a need to recognize that humans are inherently interdependent, and that for people with significant disability, interdependence and relational support strengthens personal authority. Adopting a socio-relational approach would enable us to explore ways to enable and support personal authority. Stability of a roof overhead and arranged support structures should absolutely be a priority; however it should not mean compromising psychological safety, belonging or agency in the home – key factors that promote quality of life, growth and wellbeing long term.

Much of the literature has explored family member perspectives of care-giving and making decisions about future placement of people with disability. While family members or caregivers have everyone's best interests at heart, there can be issues with contrasting or competing priorities and needs, between what caregivers need and what the person with disability needs (Burke & Heller, 2016). It was clear in this study that for those with significant support needs who had spent their lifetime reliant on block-funded, one-size-fits-all service accommodations, it was much harder to realize the potential to use individualised funding packages to their advantage in future planning. This, coupled with a lifetime of low expectations from professionals, family members and others, and dominant narratives about scarcity of resources makes it harder to aspire to different ways of living and being.

7.2.5 Section summary: How decisions are made about where to live

Decisions about future planning and aspirations tend to centre on the immediate need to find stable secure housing and support. This may be particularly difficult to negotiate if family members have their own concerns, perspectives and priorities as they age and prepare for end of life. It was evident from the findings that people with disability in this study had very few opportunities to be part of the decision making. Systems and structures continued to reinforce the message that supported accommodation was their only choice for secure and stable housing and support. Participants experienced a collection of compounding factors influencing the kinds of opportunities available to them which prevented them from being able to explore a variety of different housing and support arrangements to suit their life, their preferences and values.

7.3 Negotiating safety, belonging and agency in supported accommodation

The next section of this discussion outlines the factors that impacted how participants negotiated safety, belonging, and agency in their shared disability accommodation settings. As demonstrated in the findings sections, there was a range of material or semiotic factors (often overlapping) which were identified in the lived experiences participants shared. Figure 7.2 offers a diagrammatic representation of the interplay of material and semiotic factors highlighted by participants as key to negotiating their life in shared accommodation.

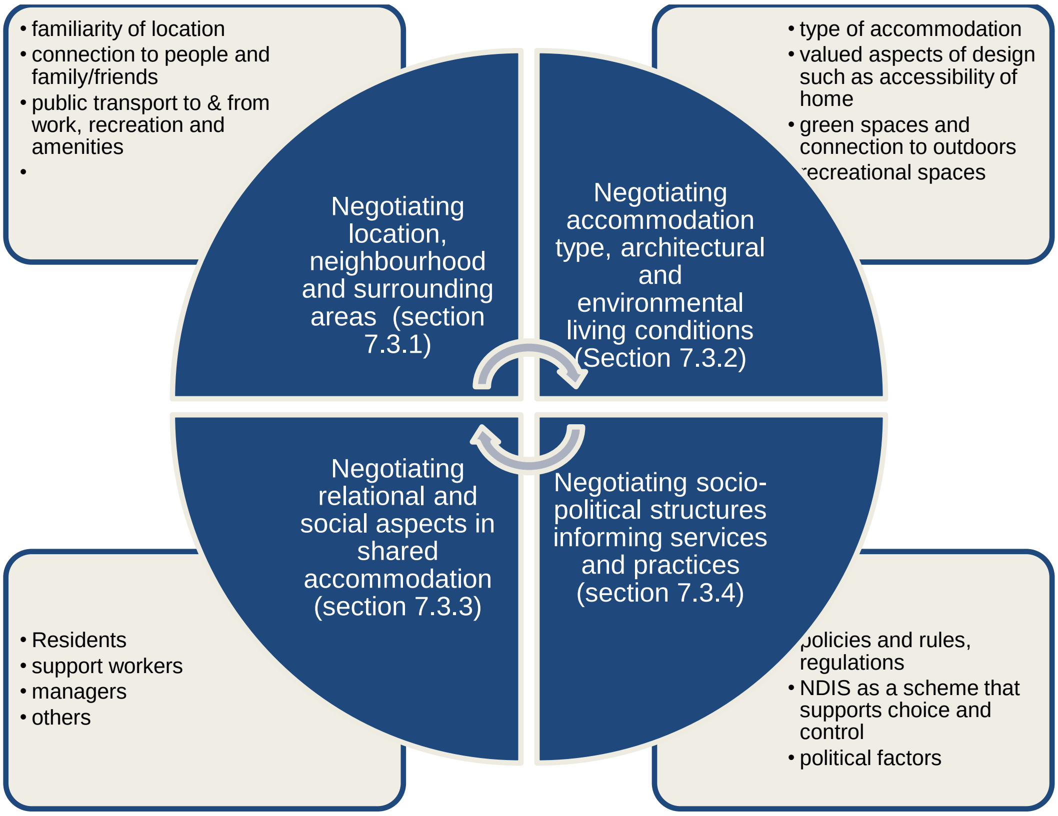


Figure 7.2: Range of overlapping factors important to negotiating life in supported accommodation

Figure 7.2 demonstrates the importance of taking account of the range of factors related not only to the person, but also to the environment, community and social-political structures. The analysis from a New Materialist perspective provided insight as to how different factors impinged, as well as the necessity to negotiate them (Atkinson, 2023; DeLanda, 2016; Feely, 2020; McFarlane & Anderson, 2011; Patton, 2000; Youdell & McGimpsey, 2015), which no doubt has an impact on wellbeing and health. In what follows, these factors are discussed in detail and related to the literature.

7.3.1 Accommodation type, architectural and environmental living conditions

7.3.1.1 Type of accommodation and living environment

Individual group homes operated by Midlands Services throughout the community tended to have groups of 5-10 people with disability living in each residence without any interaction with neighbouring houses. In contrast, Cress Point, with its clustered set of homes, had a culture where it was common for neighbours to be interacting with each other, particularly when residents all had disability and often attended the same community activities, disability sports groups, or places of employment. Thus, there were some differences in the social and cultural aspects of Midlands and Cress Point. Specifically, given the nature of clustered housing at Cress Point, residents were often observed congregating between houses, and visiting other residents and friends, and there was a much larger visible presence of staff members and support workers as well. In contrast, Midlands' houses appeared to be much quieter with far fewer people seen (other than the residents and the core support staff for the day). This quietness was in part due to the model of individual houses scattered across the state and nestled within neighbourhoods. It meant that there were far fewer people congregating. Caleb also indicated that managers and head office were off site. The differing physical design and set up of housing models inevitably influences the sheer number of people on site and influences the style and nature of relationships between residents and others around them.

These findings are consistent with other research studies highlighting that clustered housing can increase social interactions with residents and can also mean a sense of support, not just in their own residence but also with their neighbours (L. Ellis, Munoz et al., 2020). In contrast Midlands (with their houses dispersed across the community) tended to feel quieter with far less social movement or incidental interactions between residents, even within the one house. Residents tended to stay in their room at the residence they were assigned to. This ambivalence and lack of willingness among residents to interact, confirmed by both Marie and Caleb, indicate an environment that lacks warmth or reciprocity between residents.

There were also issues that needed to be navigated that seemed more prone to occur in clustered settings; these included the increased risk of conflict in their own home, as well as observing and witnessing conflict among other residents when they were having a bad day or got into a fight. There also seemed to be a pattern among residents at Cress Point of being moved between houses within the clustered compound as managers attended to issues and attempted to resolve conflict. While it was useful to have the option to move houses when things were not going well, it may also have led to a sense of precariousness for residents and a lack of ownership over their own home. There appears to be very little research about the phenomena of "movement between group homes" in clustered group settings and the impact this has on a sense of belonging, agency and safety.

7.3.1.2 Architectural elements of what "home" looks like

Many residential disability accommodation services across Australia have come from roots of institutionalization. While Australia now has a strong policy position against institutionalization, there are still institutionalized practices built into the way organizations operate, despite the shift towards community types of disability accommodation. Cress Point, which has a long history that stretches back to the institutionalization era, continues to operate as a cluster of group homes and hostel despite the shift to community style living. In contrast, Midlands, a newer organization set up in the early 2020s resembles modern houses dispersed through the community, while still maintaining some sterile features that resemble medical care. Roets et al. (2022) argue that despite the shift in disability policy and practice internationally towards "community living" many professionals and organizations continue to subconsciously embody paradigms rooted in medical and pathologized ways of thinking about disability, and struggle to question and innovate different and new ways of providing support. This occurs even though residential institutions have closed and disability policy has embedded ideals of "living in community like ordinary people".

As Roet et al. (2022, p. 9) write:

> societies continue to reproduce architectural and spatial approaches conceived as hospital models or isolated care environments even when we renovate or build new care settings. Also, powerful marginalization, othering and exclusion dynamics in all different domains and societal interactions in societies continue to be at stake.

Roet et al. (2022) go on to argue that despite the shifting times and multiple types of residential accommodation now offered in community, policies and practices remain disablist, leading to experiences of segregation and marginalization.

The architectural design and layout of residences varied between participants: two lived in the hostel (which had 40 bedrooms, only half in use); two lived in group homes for people with high physical and/or intellectual care needs, with 8-10 residents; and four lived in clustered group home settings (with a mix of 2-5 housemates). Regardless of the type of accommodation, participants all consistently had their own bedroom and access to "shared communal spaces" which included the living room, bathroom, kitchen and outdoor areas. There was also consistency in the elements participants valued and found important for their wellbeing around their home irrespective of which type of accommodation they lived in. These included:

- physical accessibility of the build: which was key to safety and also increased independence, particularly for Caleb and Marie who were wheelchair users
- outdoor spaces and green areas to sit or wander the garden or socialize
- access to recreational and physical therapy areas around the home, such as the pool, sports oval and general green spaces, gardens and outdoor areas.

For all participants, green spaces and access to outdoor areas in the garden were vitally important to psychological wellbeing. One of Stewart's favourite things about his room in the hostel was that his window overlooked a grassland with old gum trees and he could enjoy listening to the birds. Kaplan and Kaplan (1989) suggested that gardens provide a space for recovery from stress and anxiety and that being present in nature with fauna, birds and nature provides an immersive experience that is restful, particularly needed when people are in situations that require a lot of emotional or physical energy and stress. For participants in this study their home also meant negotiating institutional structures with staff and workplace cultures and regulations. These additional dimensions added to participants' stressors and therefore it was particularly important to have spaces and places to retreat to for quiet and escape (including gardens and outdoor areas). More research is needed to explore how architecture impacts on the ways people living in congregated disability accommodation settings negotiate and resolve relational issues.

7.3.2 Location, neighbourhood and surrounding areas

7.3.2.1 Freedom and safety in the local neighbourhood

All participants talked about the location of their home and how it impacted them in various ways, for example in regard to proximity to workplaces and recreation, to family and friends, or with regards to accessing public goods and services. For participants in this study, familiarity with their neighbourhood strengthened a sense of safety, particularly in terms of access to public spaces such as church and local shopping precincts, and also in terms of confidence to use public transport to travel to work or to visit family and friends. These findings are consistent with the broader literature highlighting the importance of familiarity with the local neighbourhood (Boland & Guerin, 2022a, 2022c, 2022b).

Most participants in this study were participating in social programs and employment specific to people with disability. It was difficult to know whether participation in disability-specific programs strengthened a sense of belonging in meaningful ways or whether it indicated a lack of opportunity to explore mainstream neighbourhood connections. While people in the general community may connect to neighbours through interests and association in community, participants in this study did not have these opportunities. Only one participant talked about knowing their neighbours “down the street” and spoke of how he was known by sight and name in the community because he regularly stopped to talk to people. In contrast, most participants in this study felt a sense of loss when they moved into disability accommodation as they lost connection to people and places they had nurtured previously. The broader literature supports the importance of familiarity and affirms that nurturing attachment to place impacts on a sense of belonging and positive wellbeing (L. Ellis et al., 2020; Wilkinson & Ortega-Alcázar, 2019). With this in mind, it could also be said that loss of such attachments and connections as spoken about by participants in this study adversely impacted wellbeing and reinforced a sense of isolation when participants were moved to disability service contexts.

As Boland and Guerin (2022a) noted, there is a gap in service provider policy positions which in turn means that service providers may not actively support residents to make connections in their immediate local community; instead they understand and support social inclusion in terms of supporting people with disability to actively participate in valued social roles, access to public goods and nurturing their family and friendship networks. Boland and Guerin (2022a) argue that service providers need to support their residents to foster incidental interactions that happen in everyday life when in the local community interacting and engaging in mutual interests such as the arts, sports, gardening. Boland and Guerin (2022a) point out that when service providers do not support and facilitate connection to local community and neighbourhood, residents in turn miss out on convivial encounters that reinforce a sense of being known by sight or name and being positively regarded in their neighbourhood. Such encounters are equally important in developing attachment to place and a sense of belonging.

7.3.2.2 Public transport enabled freedom

Participants at Cress Point spoke highly about their location because it was close to trains, buses and other means of public transport. This meant greater independence and freedom to leave and come as they pleased from their residence. They had the means to get to work, to visit family and friends and head to the shops. This sense of movement and freedom increased personal agency by allowing participants to choose when and how they affiliated and associated with people around them, and enabled them to participate in parts of the community that had meaning to them. This in turn, strengthened a sense of control and personal agency as it meant participants were not reliant on support workers and were empowered to connect with people outside the home on their own terms. These opportunities to seek positive encounters in their local neighbourhood also counteracted powerlessness and contributed to a sense of safety and dignity in that participants could move freely through their community without necessarily relying on others (Chapman et al., 2023).

7.3.2.3 Freedom to associate with family or friends

Participants in this study who had family living nearby in close proximity seemed to have frequent and regular contact with them and to have their support and informal advocacy, in the sense that these people could help negotiate systems and prompt quality of care. Those who are distant from their family (whether it be emotionally and/or spatially) may not have people they can fall back on to explain and negotiate the ways systems work and may be less likely to speak up or have support to resolve issues, instead acquiescing. Family members in this study were seen as a strength and contributor to feeling safe and secure and able to cope with adversity and change, as in a previous study by Marsack-Topolewski and Graves (2020). Across the life course experiences of relational support from family (and others) impacted on how participants connected to resources and systems. These relational supports became even more important once people moved to shared accommodation. It was noted that people with disability who remained connected and surrounded by family even after they had relocated to shared accommodation tended to have outside supporters who were observing, prompting and communicating with management about issues as they arose.

7.3.2.4 Public harassment in the local community as an issue of safety

Participants described certain places they knew in their neighbourhood where they would not go on their own (such as their local shopping centre) or the nearby bus interchange, as they had previously been harassed and taken advantage of. The evidence in the literature highlights that people with intellectual disability were more likely to experience abuse, hate or harassment in public spaces (Emerson et al., 2016; Wayland et al., 2022). Exploitation and abuse may be particularly hard to distinguish, especially if one has a disability that impacts on cognition, decision making or social behaviours.

The broader experiences and encounters that participants had in their local neighbourhood are significant to consider. While harassment, exploitation and abuse may occur outside the home, it is vitally important to consider how those living in disability service contexts are supported to feel safe in their neighbourhood. In this study, participants experienced marginalization, discrimination and abuse outside the home, this also had a significant impact on stress, resilience and wellbeing. When negotiating negative circumstances beyond the home, it seems even more important that people with disability have a safe haven that they can retreat to where they can access meaningful relationships and support, are reminded of their value, and feel recognized.

7.3.3 Life inside supported accommodation: Social-relational contexts

It was clear in this study that wellbeing and self-understandings of safety, belonging and agency in relation to where participants lived depended not only on the physical and material conditions, but also on affective, emotional and social conditions (Tarvainen, 2021). None of the participants had a say in who they lived with, being instead allocated a room in a group house or in the hostel, decided by management in relation to their assessed level of support needs. The practice of allocating or “arranging” placements goes directly against Article 19 of the United Nations Convention on the Rights of Persons with Disability, which urges countries to put in place legislations and supports to enable people with disability to have an opportunity to choose where and who to live with (Murphy & Bantry-White, 2021). The right to choose where to live or who to live with remains unrealized when set within a climate of austerity in terms of housing and government resources. Such conditions make it hard to bring up conversations about alternatives, particularly when people with disability are told consistently that they should be grateful for what they currently have in terms of service supports.

Regardless of whether participants had choice about their housemates, some still reported positive experiences of getting to know those they lived with. Participants identified moving to shared residential accommodation as an opportunity to build social relationship and also saw the move as a way to feel safe – knowing that one was not alone, but surrounded by residents or with a staff member nearby. There were mixed experiences of socio-relational dynamics. Participants talked about positive experiences of shared mutual interests such as doing puzzles, football or art which cemented a sense of positive regard, reciprocity and recognition. Connection to others who shared similar life experiences aided a sense of emotional reciprocity, support and political identity.

7.3.3.1 Psychological and physical abuse by other residents in shared accommodation

There is a dearth of research exploring how residents relate to their co-residents and negotiate shared accommodation settings with them. Many studies about the prevalence of abuse in institutionalized settings or group homes have centred the experiences of abuse and misuse of power against people with disability by service providers or the reverse – clients directing abuse towards support workers (Banks et al., 2021; Matson & Rivet, 2008; Nankervis et al., 2020). In this study it was clear that participants experienced numerous issues with other residents and that these experiences tended to be on a continuum from subtle behaviours such as ignoring or making comments through to more extreme forms of verbal, psychological and/or physical abuse. This aligns with work by Robinson (2014) and by Robinson and Chenoweth (2012) highlighting the prevalence and range of psychological abuse and harm for people with intellectual disability, along with the difficulties in recognizing and addressing these types of harm given that it is often invisible unless reported explicitly. The nature of such negative interactions varied for each person in this study. Marie and Caleb both described an unwillingness to engage or spend time with their respective house mates and, while Caleb was happy not to engage, for Marie the lack of affinity among her and other residents she lived with was hurtful.

All the participants at Midlands Services talked about a breadth of experiences of bullying which included repeated hurtful comments despite being repeatedly asked to stop, mocking or cruel joking, and physical assaults. Participants also talked about witnessing abuse or issues of questionable practice among residents, within their own home and sometimes from neighbouring homes as well.

While broader research has noted an impact on staff members when dealing with what is often termed in the literature “challenging behaviour” (Banks et al., 2021; Friedman, 2021) there appears to be a lack of literature exploring the impact from co-residents’ perspectives. One could argue that if the impact is significant for staff members, then it follows that people with disability who live in these contexts will also be experiencing the psychological impact of burn out, trauma and adverse outcomes. Additionally, residents may not have clear avenues for escape or separation between work and home like most workers do.

While there appears to be little literature reporting on how people with disability manage relationships with co-residents, there has been a number of recent media reports across the western world consistently highlighting abuse in shared types of disability accommodation among residents (Davies, 2019; Edmonds, 2021; Harris, 2023; Henriques-Gomes, 2020, 2021a, 2021b; Hill, 2012). Certainly, the data from the recent Disability Royal Commission along with the NDIS *Own Motion Inquiry into Supported Accommodation* adds to the evidence indicating residents' potential risk of exposure to violence and abuse. Notably these reports have still tended to focus on overt incidents, for example a report may be made about restrictive practice being used, or a behavioural incident. The incident-based reports represented in the data signify the tip of the iceberg given the everyday issues of psychological and emotional abuse happening as well, even if not clearly identified and reported. Arguably, the datasets underpinning official reports do not take account of the subtle nature of psychological and emotional abuse which is harder to complain about. Certainly in this study, none of the participants talked about formal complaint mechanisms, tending rather to negotiate situations informally with residents, staff or management. This also means that the everyday encounters of microaggression, psychological and other types of subtle abuse in their everyday lives go unrecognized in policy and practice despite the impact on health and wellbeing (Freeman & Stewart, 2021; Friedlaender, 2018; Kattari, 2020; Keller & Galgay, 2010; Williams, 2020).

7.3.3.2 Isolation and detachment from place and people

Caleb and Marie reported that they rarely interacted with other residents in other rooms. They had far more interaction with staff and paid supports. What Caleb and Marie experienced is not an isolated case. In one study of adults with cerebral palsy who used augmentative alternative communication devices, Balandin et al. (2006) found that these residents in shared accommodation were more likely to experience isolation and loneliness compared to those with other types of disability.

While for many people home may be a relative safe haven away from prying eyes or the public gaze (and the social norms and expectations that come with this), for participants in this study, their private space was also a workplace for employees and mediated by the nature of shared spaces. It is important to note that the variety of people coming in and out of the home daily and sometimes hourly (such as residents, workers, managers, visitors) adds to the social energy required to deal with day to day life in the home. This was a particularly prominent theme in different ways. For residents at Cress Point there was a high volume of social traffic given its nature as clustered housing and hostel type accommodation grouped together. This meant that participants were often interacting with neighbours (sometimes in a positive way, sometimes in a negative way dealing with conflict), and were more frequently crossing paths with support workers, staff and family members from other houses on a regular basis, increasing the social demands on participants. In contrast, within the houses owned by Midlands Services, residents were rarely seen interacting with each other (see section 6.3.5 for findings related to isolation and detachment). Instead the majority of the interactions tended to occur when residents were interacting with staff. This was in part due to the high level of physical care needed 24 hours a day which meant that there was more time spent one to one with staff in the semi-privacy of their own rooms. At Midlands services, there was a stronger presence of support workers and nurses busy "on the floor" – a phrase heard used by a worker. Often staff were seen in communal areas such as in the kitchen preparing meals or doing a range of other personal care or medical related tasks. While these practical tasks were vitally important from a safety and health perspective, what Marie valued were the moments spent with her workers playing card games, or completing puzzles (which often took weeks to complete). It was these shared moments of reciprocity and enjoyment that strengthened a sense of connection and belonging. Unfortunately for Marie and her staff, the workload on staff had recently increased due to more residents moving in. This meant that interactions with staff were increasingly focused on completing tasks which, while important to Marie's health, were not fulfilling, affirmative or positive experiences.

7.3.3.3 Formal care: Support workers foundational for physical and psychological safety

Participants in this study prioritised ongoing support and saw this as core to their wellbeing and survival, since all required a high level of daily support albeit to varying degrees. Support workers' roles varied from person to person. Some people identified a variety of health and medical needs that were crucial to bodily autonomy and physical safety and wellbeing. Others needed assistance with domestic chores, finances, transport and executive planning/organizing such as getting up and organized for work – all essential in order for participants to feel secure. As Bigby et al. (2017) highlighted in their study, people with disability need the guarantee and assurance that when help is needed, it can be accessed. Likewise, in this study it was clear that a stable permanent residence and reliable supports were essential. Without this assurance participants felt more vulnerable and at risk.

It was clear from this study that organizational structures underpinned congregated living, with a pool of workers and management/oversight and policies in place to protect human rights and standardize risk aversive practices. When there were four to nine people with disability living in each house (and 15-20 residents in the hostel at any given time) this meant that it was a logistical task to sort out a rotating roster of support workers and/or nurses, house manager(s) and/or team leader(s) that matched individuals' needs. There were also senior management, boards and chief executive officers in charge of decisions, managing budgets and organizing administrative tasks associated with running a large organization. Participants did not get to choose their support workers and were not involved in determining the quality of their supports. Rather recruitment was done by senior management and participants were assigned their workers by managers. This may reinforce the view that support workers do transactional tasks such as personal care, cleaning and so on, and make it harder for people with disability to develop a rapport or any sense of affinity with these workers.

While efficient delivery of services was key to reliability and presence of workers day to day, prioritising efficiency diminished the quality of support and personalized planning (Löfgren-Mårtenson, 2013). Participants shrugged or gave non-committal responses when asked about their favourite support workers or the workers they preferred to have. This may suggest a reluctance to show favouritism for fear of this impacting on their relationships. Certainly Caleb described being very careful in raising concerns for fear of retribution or decline in quality of care. This was a particularly vulnerable position to be in when relying on care day to day. It may also be that participants were so used to the rostering of multiple support workers that they had come to see it as a "revolving door" and thus did not feel a sense of connection with any specific workers.

In one study by Friedman and VanPuymbrouck (2019) those people with disability least likely to have choice over their workers were those requiring a high volume of hours per day, those who lived in provider operated group homes, or those who had a guardian or informal advocate assisting with decision making. Friedman and VanPuymbrouck (2019) argue that this restricted choice was less to do with individuals' decision making capacity and more often than not a reflection of unchecked bias and attitudes towards people with disability as "the eternal child," "incompetent," "dependent". While this may in part explain some of the data in the present study, I argue that there were also conflicts of interest that needed to be acknowledged for participants who were receiving supports and housing by the same provider while these providers were also seen as "the person to talk to" about individuals' personalized NDIS plans and decisions related to budgets. While providers may deem it simpler to keep the budgets in-house and hire their own pool of workers, this may also prevent choice and control on the part of participants and restrict their opportunities to connect to support workers beyond those of the housing provider and who may better suit individual personality and goals.

The broader literature highlights a clear link between quality of life for people with disability and hiring and recruiting their own workers (Friedman & VanPuymbrouck, 2019), as well as measures of personal safety and reduction of abuse and harm. It also aligns with an increased likelihood of a romantic relationship, more organic friendships and opportunities for social inclusion generally. This suggests that the process of matching workers with individuals and enabling participants to recruit their own worker has a profound multidimensional impact on personal perceptions of safety, agency and belonging.

Most participants did not talk negatively about their experiences of support workers, but, rather, had little to say in general, neither positive nor negative. Marie raised fears about new workers who may not know how to respond to medical emergencies, while Caleb said that the quality of nursing and personal care varied significantly from worker to worker with some being more gentle and respectful of his body whilst others were rough which sometimes resulted in mis-step, injury and physical harm.

Such experiences of poor quality care corrode trust and increase hypervigilance, particularly when past experiences resulted in injury or harm. Caleb in particular described severe burns as a result of a heat pack that had been over-cooked in the microwave and had not been checked. He also mentioned witnessing questionable quality of support from a support worker who was working with another resident who was unable to speak up. These experiences were difficult to report due to fears of retribution and backlash from those workers on their next shifts. Often this led to a climate where issues were not addressed or reported unless they were blatant or serious enough to result in injury.

7.3.3.4 Coping with adversity in the context of supported accommodation

When participants were asked about how they resolve conflict with other residents the response was that they “tell someone – tell a support worker”. This seemed to be a common strategy advised and coached by management and by family members. When asked if people ever did tell a worker, there seemed to be a common sense of resignation and acquiescence. As discussed above, participants in this study did not tend to see support workers (or other paid staff) as key people they could turn to for support to resolve issues in their home. This suggests a level of distrust and lack of confidence in the way staff may respond; for example they may fear dismissal or think they will not be believed, or may fear repercussions or backlash.

Participants all mentioned “staying out of it” when asked how they dealt with conflict or abuse among residents. “Staying out of it” occurred in different ways. Sometimes it meant participants withdrawing to their bedroom to remove themselves from abusive situations they were in or were witnessing. For Marie, who reported feeling isolated and disconnected from other residents, it meant that she accepted that other residents did not want to engage, and put up with it. All participants described their room as their safe space where they could decompress in ways that worked for them, such as watching their favourite musical DVDs, or listening to the radio or their favourite songs.

Also part of the social fabric and routine were the residents’ family members, friends and other people who might visit and advocate or agitate behind the scenes. This supports evidence from the literature review noting that often family members played a key role in supporting or making decisions, and in administrative tasks such as with NDIS, finances, management or practical administration (Hart, 2022; E. Murphy et al., 2011; Taylor et al., 2019). Some participants in this study who still had family continued to rely on these people to help “talk up” through chains of management whenever issues were needing to be addressed. This is consistent with literature highlighting that family members were often responsible for legal guardianship, finances and administration (Lindahl et al., 2019) even after a person with disability was moved to congregated care settings (Engwall, 2017; Grey et al., 2015). While these supports were valued and essential to supporting personal agency, belonging and safety – there remain some substantial power dynamics at play.

Evidently, one of the advantages of congregated living was the overall sense of reassurance that there would always be people on site to assist and help out if needed, also ensuring a degree of oversight and security. There was a common sense of reassurance and guarantee that came with structured supports and housing which contributed to a sense of stability and security, key aspects of safety (Bigby et al., 2017). During times when home was rife with conflict and an uncomfortable space to be, it was even more vital for participants to have a sense of worth, value and security outside the home in terms of work, family ties and/or social connections beyond paid support. Participants established a sense of connection and belonging through their supported disability place of employment or through recreational programs or through their residential organization. Caleb was the only participant who did not associate with disability programs but instead was deeply involved with the church.

Belonging meant different things to different people but was always forged by quality of time spent with people, whether this was friends, family at church, or with a house mate watching the football and engaging in friendly rivalry over opposing football teams. It was these moments of reciprocity that reinforced and strengthened a sense of being “recognised, valued, welcomed and understood in everyday places” (Kaley et al., 2022, p. 308). Kaley et al. (2022, p. 311) defined belonging “as an emotional or embodied attachment to place, of feeling secure, accepted or at home in familiar surroundings.” Kaley et al. (2022) and other authors have tended to situate “belonging” in terms of public spaces such as work, education, leisure & sports, in line with broader social inclusion and human rights agendas. However, I argue that Kaley et al.’s (2020) definition of belonging in relation to “being in community” would also be useful to consider in the home context. If we consider the flip side of Kaley et al.’s (2020) definition, it is clear that participants in this study all had experiences of exclusion, unwelcome-ness, ambivalence, devaluing, bullying, abuse and neglect in their home environment which no doubt harmed and reinforced a sense of powerlessness to change the situation when dependent on the systems and structures that provided support to live day to day. I believe this must have a direct impact on psychological safety and wellbeing and physical health outcomes long term.

7.3.4 Negotiating organisational culture and management

While organizations may vouch for person centred supports and write choice and control into policy and organizational aims – a catch phrase of the NDIS – it was clear in this study that participants had had few conversations about choice and control over their own NDIS plans and had limited support to make their own decisions about their personal goals and subsequent services and supports. Although one participant identified that NDIS had improved their options for creative activities, the majority saw the NDIS as a way of maintaining the daily living supports they had in place prior to NDIS, which included support work and access to housing.

Participants talked about addressing issues to do with choice and control over belongings or access to certain goods and services being denied or ignored, for example being denied access to Wi-Fi in the bedroom because of online safety concerns. One participant wanted to watch sports channels of Foxtel but was told that these were “being looked into”. The broader literature highlights principles of “choice”, “independence”, “self-determination” and “human rights” as key to all service provision, yet the research by Hawkins et al. (2011) indicates that in practice there were more nuances and complexities that have to be managed from a service provider perspective.

Fullana et al. (2019) argue that while residential organizations align their policies and philosophies in ways that couch human rights and personal choice, these services work in subtle ways to disempower people with disability from exercising their right to agency and freedom to choose how they live day to day. Certainly in this study, participants were supported by others who made decisions about living circumstances. This raises pertinent questions about how people with significant level disability are ever able to exercise the right to choose where and with whom to live. These rights are problematized by institutional structures and beliefs about capability.

Culturally and historically within disability services there has been a dominant shift towards enabling independence, choice and control. These values may mean that people with significant disability constantly fall short of abled measures and norms of independence. Fullana et al. (2019) argue that there are dominant beliefs that independence must be “proved”, particularly in service contexts and thus, until people with disability have “proved” abled norms of independence, they are not supported with dignity or respect as equal. Instead they are seen as “other” and “in need of support”. Notably, services have been heavily focused on developing individual capacity and skills, and while this can be useful for building personal agency, it can also create problematic discourse where people with disability are in a perpetual state of never performing to able-bodied standards of autonomy and independence. Independence and having control should not depend on one’s ability to perform tasks alone, independent of assistance (White et al., 2010).

Svanelöv (2020) observed power practices and the impact these had on residents in group homes in Sweden and found that staff in group homes were still operating in institutionalized ways whereby people with disability were viewed and treated as less capable, incapable, or dependent, and often the focus was on “teaching” disabled people in order to integrate into community and meet able-bodied standards and norms. He posits that when staff in organisations deemed certain skills “necessary” in order to be seen as a valued citizen and community member, this shifted the organizational focus to evaluating group home residents based on their functional independence and participation skills. This deeply entrenched mentality in group home settings more deeply entrenches ideas about needing to acquire a certain level of independence as a pre-requisite to inclusion in every day community life.

Certainly in the present study, there was little evidence of an exploratory approach to future planning which took account of personal values, perspectives and ideas. Nor was there evidence of conversations about options and possibilities for housing and supports and assisting participants to make their preferences known. Sometimes, like all humans, people with disability may make mistakes or change their mind about their living situation, and this should also be supported. For participants in this study, managers from residential accommodation settings seemed to be the authority in terms of expert knowledge and power. These were the people participants turned to, in order to help them work out what their individualized funding packages meant in terms of day to day functioning, support and inclusion. Managers attached to the residential organizations were seen as responsible for organizing support workers, housing and infrastructure and other administrative tasks as well. They had a significant role to play in the smooth running of services, key to survival of people with disability.

Normative ableist assumptions form part of the social feedback internalized by people with disability and inform their understanding of where and how they live and what constitutes secure housing (Roets et al., 2022). In the present study, this was seen when Malcolm stated that he did not want to move out of the hostel because he did not want to cook or clean and needs help with these sorts of tasks. In Malcolm's mind, moving to a house in the community meant no longer having the high level of support he felt was necessary for his security. These public discourses about what types of accommodation are "safer" needs to be acknowledged here as these attitudes and beliefs about the safety ensured by congregated living options form part of the rationale for people moving to shared disability accommodation. In this study it was clear that people with disability were being grouped by type of disability and support needs, and participants were not given freedom to choose where to live or who to live with, or indeed change their mind about their living situation down the track.

7.3.5 Negotiating broader socio-political dynamics

From participants' perspectives, there were two main benefits of shared accommodation: a stable home and access to reliable supports to live day to day. This required funding, budgets and personalized planning, yet when participants were asked about their experiences of using their NDIS plan they suggested that their residential manager would be the better person to talk to, being the one in charge of their NDIS plan. This deference suggests a lack of engagement and authority in decision-making. This may in part be due to the relative newness of the scheme, as, at the time of interviewing, many adults with disability in supported accommodation had spent a life time dependent on block funded services that were restricted in what they offered. They were used to professionals coming in and out of their life and being told what their needs were, and what supports they were allowed to have.

Murphy and Bantry-White (2020) state that disability-specific forms of deprivation of liberty are a human rights issue; yet in this study there was routine deprivation of liberty, complicated by finite distribution of resources as evidenced by Callaway et al. (2021) and Callaway and Tregloan (2018). Services are obliged to support self-determination and choice while also mitigating risks or issues of harm, and sometimes these are contradictory to each other – for example supporting someone's choice not to take medication versus mitigating risk of self-harm, or supporting someone's choice to access Wi-Fi from their bedroom versus mitigating the risk of accessing illegal or inappropriate content, or supporting a choice to eat unhealthy foods versus mitigating the risk of poor health outcomes due to poor diet (Curryer et al., 2015; Hawkins et al., 2011; Leiter & Waugh, 2009; White et al., 2010). Many of these decisions seemed to be made on behalf of residents for the benefit of all residents, suggesting that residents were treated as heterogenous instead of being seen as individuals with their own preferences for supports. Bigby et al (2019) who explored the factors underpinning quality of support, reasoned that these types of approaches may be reflective of difficulties tailoring support when residents are viewed as heterogenous in terms of their grouping by type of disability.

In this study, when issues were serious (for example Caleb's example of serious burns as a result of a mistake on the part of the worker) actions were taken by service managers to address the report both internally within the service and externally through the NDIS Quality & Safeguards Commission. The majority of the factors that confronted participants related to every-day interactions and experiences that caused discomfort, distress, harm or hurt, such as an upsetting comment or bullying from another resident, laundry that continually got mixed in with the other residents and smelled of faeces or the fact that residents were not allowed internet in their room. These sorts of issues tended to be addressed in-house as "incidents" to be dealt with and reacted to at an individual level case by case. While these internal processes for feedback and response were important, such processes may also perpetuate the view that the issues were isolated incidents, rather than routine and systemic – affecting multiple residents not one alone. Addressing incidents only at an individual level denies their ubiquity and further silences and isolates residents.

Residents who had family members advocating for or with them were more likely to have advocacy and support to make changes when issues arose. At times it appeared that management, rather than directly informing residents, was more likely to share information with a family member or advocate about how issues were being dealt with – for example, moving a difficult resident on, or promising to look into a concern. This was noted in interview when a family member said, “I’m not supposed to tell you this, but the manager has said they’re going to move X in the next few weeks”. Notably, participants seemed far less likely to know what the decision making processes and hold-ups were at a systemic level and they tended to rely heavily on family members or guardians to help with navigating management issues. A return to the literature indicates a lacunae with few studies exploring how decisions regarding services, housing or other aspects were communicated in shared disability settings. In this current study there was a flow of information sharing among family members of residents in shared accommodation which at times seemed to be kept from residents themselves.

7.3.5.1 NDIS de-personalized: Ambivalence and silence in decision making

The NDIS Practice Standards and Quality Indicators highlight that each individual should be supported by providers to make informed choice, exercise control and maximise independence relating to supports (NDIS Quality and Safeguards Commission, 2021, p. 6). This should include indicators such as:

- Active decision making and individual choice supported for each participant including the timely provision of information
- Everyone’s right to dignity of risk in decision making is supported and people with disability are able to make choices about the benefits and risks of such decisions
- Each person’s autonomy is respected including the right to have personal relationships
- Individuals have sufficient time to review their options and seek advice
- Individuals have the right to access an advocate of their own choosing.

While these indicators exist in principle, the NDIS proved to be a difficult topic to broach. Participants reported that an NDIS plan to their name did not seem to change their day-to-day decision making or choice of services. One participant talked about the NDIS being good because the organization had increased their rostered staff; another talked about using her NDIS plan for a range of activities from dancing classes to drama. When asked who made decisions about how their budget was spent and managed they said “talk to management about that”, referring to residential service managers (NDIS Quality & Safeguards Commission, 2021). This suggests a lack of clarity about who has the authority over decision making and a distinct lack of ownership or sense of influence over decisions related to their own NDIS budgets.

When examining the NDIS Guidelines there were clear processes and steps in place to ensure individuals were allocated a certain bracket of funding based on their needs with a personalized set of goals up front identified as part of guiding connection to services and supports. These could include goals such as “improve independent living” or “maintain friendships” (NDIS, 2022). Interestingly, none of the participants in this study identified their NDIS planner (or mentioned a support coordinator who could help with linking and coordinating services) as a key player in their life. Instead they referred to their residential manager and/or their family members as key decision makers. This may have been in part be due to the barriers of accessing and understanding systems which in turn makes it difficult to understand the information that is needed to make informed decisions. In short, once people were in the accommodation setting, the view was that this was their permanent place of residence. There was limited support to help participants change their mind about their living situation or support arrangements. From a quality of services point of view, there is a risk of service providers guiding participants towards services that fit within the interests of the organization financially and in terms of efficacy; while this was not an issue considered by participants in this study, it would warrant future research.

The absence of NDIS planners in the lives of participants in this study may indicate a lack of familiarity with the roles of people they have spoken with or a lack of understanding of roles and functions different professionals may serve in terms of helping them to identify goals and supports. There appears to be a missed opportunity to support residents’ understanding and ownership of decision making in new and innovative ways that extend beyond the usual block-funded approach to services. Even if support was needed with making decisions, one could argue that there are ways to ensure that individuals maintain a sense of authority over decisions.

Most participants undertaking the NDIS planning process had irregular contact with their planner and may have experienced their planning meeting as more of a transactional relationship, seeking and securing budgets, rather than it being person-centred with time and space to work through necessary supports and plans for the future. While the transactional planning process serves a practical purpose, such practices are exclusionary, disadvantaging those with communication access needs or cognitive disability. The planning process needs to be adapted to meet these needs. This includes the planner having intentional presence and regular contact with a focus on developing an ongoing rapport enabling them to collate a more detailed and useful understanding of individuals' goals and needs over time (Collings et al., 2018).

7.3.6 The impact of compromise on people in supported accommodation

It was clear also that, while residents had moments of joy, reciprocity and a sense of community through shared accommodation (for example, an afternoon spent with residents or workers, bonding over a marathon movie session, or watching football), these settings were also potential sites of dehumanization and disrespect, as found in other studies (Ciurria, 2023; May Schott, 2016). Certainly in this study residents experienced a range of abuse, violence and harm from residents they shared with and had little say over who they lived with. They also appeared to have limited authority over their daily lives and did not have a choice of who their workers were. From the point of view of participants in this study, discontent was regular and innate – a part of living in shared accommodation and seen as a necessary compromise for regular support structures and systemic oversight seen as essential to safety. Compromise occurred in varying forms for different residents and families, ranging from being treated with indifference or lack of regard – but nevertheless degrading, dehumanizing and emotionally damaging – to more serious examples of physical harm and injury. For Caleb it meant coping with his laundry being mixed up with that of other residents and smelling of incontinence which he hated but had not yet been able to resolve or address. For Marie, it was about loneliness and isolation because other residents she lived with all had profound physical and intellectual disability which meant that they did not conventionally communicate by speech or through use of assistive technology or sign. For others, it was about the revolving door of support workers allocated, or the disharmony, abuse or bullying they experienced from other residents on a daily basis.

Across all these examples, there was a common response from residents of "putting up with it" as best they could as they needed continuity of formal supports and accessible housing. There was also the sense that "it could be worse" (e.g., living in a hospital). There was a consistent belief that the current living environment was "the safer" place to be given the high level of support required. Issues that arose tended to be dealt with on an individual basis between the resident and their manager or support workers. This confirmed prior research by Robinson (2013) and Hollomotz (2009) who argued that when issues were addressed as an individual complaint or incident it tended to be responded to as an isolated incident. Such service management responses may fail to recognize the routine, systematic and structurally embedded factors that precipitate harm reoccurring to others in similar situations.

While formal support and housing arrangements for people with significant disability are indeed necessary, practical and needed, there were some tensions that needed to be addressed related to NDIS still funding traditional models of supported accommodation in the form of group homes, hostels or other shared group accommodation. This suggests that the trajectory of those with significant support needs moving into shared accommodation settings may be seen as common sense by those in policy or administrative positions. From a social justice stand point the funnelling of people with particular support needs into a placement in shared supported accommodation options devalues and denies personhood. The economic and administrative costs involved in managing the operation of supports, housing and appropriate oversight should not then force people with disability into compulsory silence about discontent and uncomfortable conditions they live within. This has immense consequences in terms of the harm on physical and psychological health and wellbeing, which have been largely kept silent and undocumented at least until the advent of the Disability Royal Commission.

The resources and funding allocated at a national and state political level did not feature strongly for participants in their accounts of direct lived experience. Often such people who require significant support have grown up within a society where there was a common trajectory to group housing, supports or relationships, and consequently they may not be fully aware of how these wider public discourses influence their own self-conceptions of what it means to feel safe, in control and valued in their daily life. These public discourses are pervasive, particularly when policy continues to preference and privilege “old legacy” accommodation options.

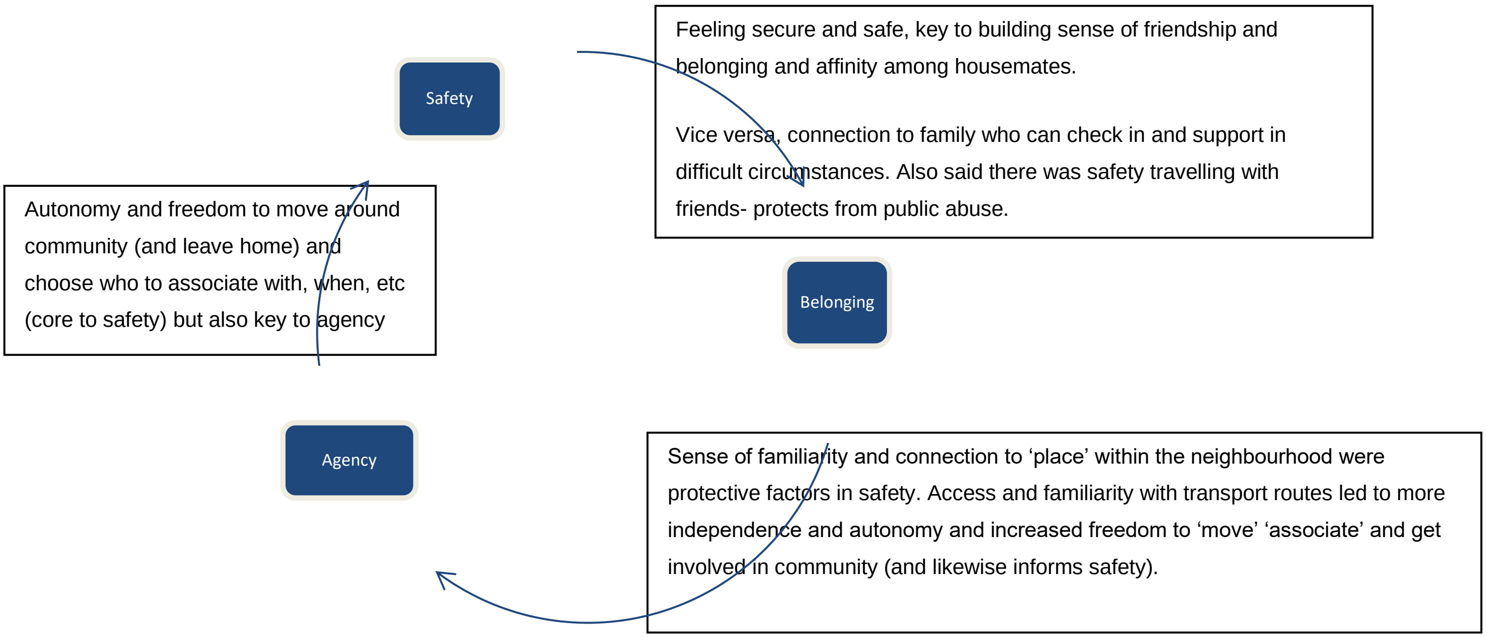
7.3.7 Summary of how participants negotiated safety, belonging and agency

In order to address the over-arching research question of how people negotiate safety, belonging and agency in shared disability accommodation, it has been useful to understand that each participant’s experience and understanding of safety, belonging and agency was informed by their home environment, their neighbourhood environment and the broader systems governing how disability services operate in community.

Participants in this study saw four themes as critical to embodied safety, belonging and agency:

- the accommodation type (small residence, number of staff, etc.)
- architectural and environmental conditions (comfort, style and accessible design)
- location and neighbourhood (social connections, feeling safe in community, accessibility of public transport)
- relational and social conditions in their supported accommodation (with residents, staff and others)
- broader socio-political and economic conditions (organizational structures and impact of public policy).

In this study, participants described their lived experiences of living in supported accommodation in deeply embodied ways. Often themes of safety, belonging and personal agency were inter-woven together as three mutually embodied core needs. While personal safety and freedom from abuse and harm may be the primary reason people with disability choose to live in disability shared supported accommodation, these settings were operating in such a way that residents had limited authority or control over their life or their interpersonal or material conditions. Arguably, personal perceptions of safety are fundamentally shaped by their experiences of having choice and control over their life and a sense of value and belonging among peers they choose to associate with. There needs to be a better social-ecological understanding of how these types of housing and support arrangements promote or disrupt individual agency, belonging and safety in tandem. Rather than viewing safety, belonging and agency as hierarchical, these themes were seen as intertwined as part of people's lived experiences. To illustrate this approach, Figures 7.3 to 7.5 map, for three participants, how aspects of their social and material lives together influence safety, belonging and agency.



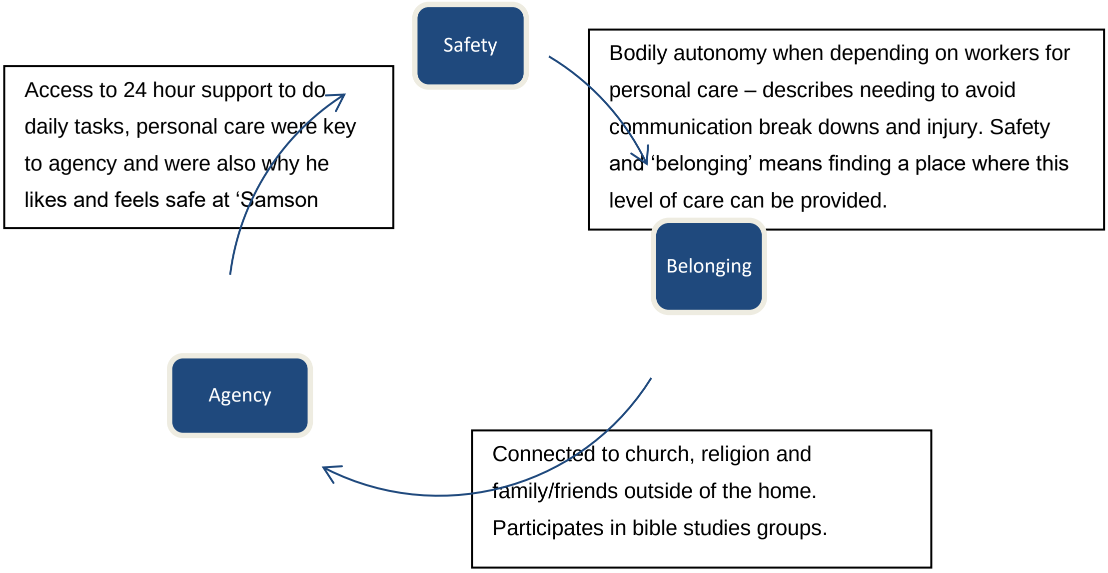
Feeling secure and safe, key to building sense of friendship and belonging and affinity among housemates.

Vice versa, connection to family who can check in and support in difficult circumstances. Also said there was safety travelling with friends- protects from public abuse.

Autonomy and freedom to move around community (and leave home) and choose who to associate with, when, etc (core to safety) but also key to agency

Sense of familiarity and connection to ‘place’ within the neighbourhood were protective factors in safety. Access and familiarity with transport routes led to more independence and autonomy and increased freedom to ‘move’ ‘associate’ and get involved in community (and likewise informs safety).

Figure 7.3: Example of how aspects of safety, belonging and agency overlap for Matthew

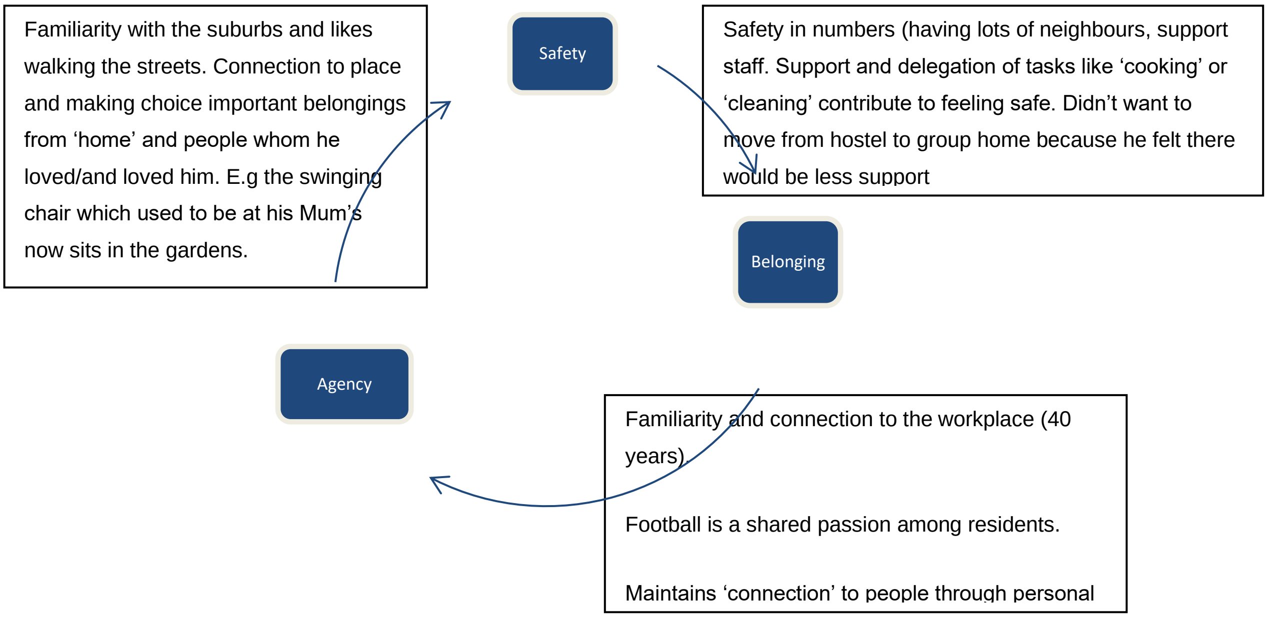


Access to 24 hour support to do daily tasks, personal care were key to agency and were also why he likes and feels safe at 'Samson

Bodily autonomy when depending on workers for personal care – describes needing to avoid communication break downs and injury. Safety and 'belonging' means finding a place where this level of care can be provided.

Connected to church, religion and family/friends outside of the home. Participates in bible studies groups.

Figure 7.4: Example of how aspects of safety, belonging and agency overlap for Caleb



Familiarity with the suburbs and likes walking the streets. Connection to place and making choice important belongings from 'home' and people whom he loved/and loved him. E.g the swinging chair which used to be at his Mum's now sits in the gardens.

Safety in numbers (having lots of neighbours, support staff. Support and delegation of tasks like 'cooking' or 'cleaning' contribute to feeling safe. Didn't want to move from hostel to group home because he felt there would be less support

Familiarity and connection to the workplace (40 years)

Football is a shared passion among residents.

Maintains 'connection' to people through personal

Figure 7.5: Example of how aspects of safety, belonging and agency overlap for Stewart

Across all the narrative experiences participants shared there were three common messages about what helped people to belong, feel safe and in control:

1. authority over where they live, who they live with and who supports them
2. feeling physically safe from threat (including the threat of homelessness) and free from psychological or other types of abuse and harm in their home, and
3. feeling valued both within the home and by their peers and others they choose to associate with outside the home.

These three core values may offer a starting point for reviewing the range of factors that facilitate or disrupt embodied value, safety or personal agency. Together, these form an overarching understanding from which to work through the question of what social justice looks like for people living in supported accommodation.

7.4 Situating the findings as social justice issues

Bell (2022, p. 1) defined the goal of social justice as:

> a vision of society in which the distribution of resources is equitable and ecologically sustainable and all members are physically and psychologically safe and secure, recognized and treated with respect...

Bell (2022) addresses the question of what is socially just by arguing that it is about opportunities for a fair and decent life. Social injustice on the other hand refers to: (a) resources being distributed in ways that privilege some and devalue or harm others, and (b) lack of recognition and exclusion from decision making processes that affect how people live their lives (Bell, 2022). For the context of this doctoral thesis, social justice is situated as a relational process. Within these relations there are constant flows of differing social and material status, power and authority operating in ways that marginalize and exclude. Sometimes discrimination may be overt and sometimes it may be subtle and pervasive. I borrow from Fricker (2008) and other scholars who have influentially argued that anyone concerned with social justice needs to reflect on how we individually and collectively listen, learn and respond to knowledge shared by those who experience devaluation and marginalization. The following section discusses the patterns of epistemic injustice seen for participants, the ways they are silenced and the consequences.

7.4.1 Identifying patterns of testimonial injustice (or quieting)

The seven participants in this study demonstrated a willingness and capacity to share their insights and experiential knowledge and also their embodied experiences, using words, pictures, photos, creative mediums. Yet their evident knowledge did not mean they got to participate in decisions about their housing or supports at a personal level, let alone in broader political conversations. Here I return to Fricker's (2008) work on epistemic injustice (see section 3.3.2) and her argument that the audience has a key role to play in listening. In this study, the necessity for routine and structured daily support as paramount to personal safety meant that managers within service providers held a great deal of responsibility for oversight of resources, and in turn, authority and power in terms of their own testimonies and decision making. Indeed, participants in this study reported limited authority over their day to day lives at a personal level.

Scully (2020) questions why disabled people do not feature widely in broader social and public discourse and points out that often non-disabled people tend to be viewed as more credible in public spaces and in turn this silences embodied knowledges. Scully (2020, p. 299) points to power relations as a key feature that must be reflected on:

> Social and material power therefore equate to some people have more voice than others because they own the authority to establish and enforce. Through being able to decide which accounts to receive, from whom, in what form, whether they are legitimate and credible, the routes through which they are fed into public discourse or policy decisions, and so on, some people exert a disproportionate influence on the collectively available epistemic resources that enable people to make sense of their world and lives […] Power consists of having authority to establish and enforce epistemic practices. It means being able to decide which and whose accounts are valid and credible.

Scully (2020) defines testimonial injustice as the injustices which occur when people with lived experience of marginalization are perceived as epistemically lesser. She argues that "whomever" has "expert knowledge" exerts a degree of authority and credibility. Dotson (2011) meanwhile reasons that the undervaluing and dismissal of testimonies contributes to a form of silencing in practice which she refers to as epistemic quieting that happens as a result of audience's unchecked prejudice and ignorance. In this study, elements of testimonial injustice were seen in various ways; for example, when participants did not have a choice about where to live, or who to live with, or when their preferences were not considered in terms of their support workers. Participants tended to defer to managers and supporters as the experts.

Further to this, patterns of hermeneutic injustice can be seen in the way systems and structures operated in this study in ways that excluded participants. For example, NDIS plays a key function in their lives. The NDIS operates as a highly specialised epistemological structure of health and social care with the potential to significantly dominate and either constrain everyday access to resources and supports or aid and facilitate daily life in a positive way. As part of this, there are operationalized forms of power embedded in the structure of how NDIS works, its policies and language, which people with disability need to have a specialized epistemological knowledge about, despite being epistemically excluded, sheltered or shielded from supported decision making or goal setting in relation to their needs to live day to day and under-represented in political spaces. The expert knowledge required to navigate the individualized funding scheme (NDIS) inherently positions service providers and coordinators as the "experts" and reinforces the view that participants were "recipients" of services. Combatting these dominant models in future planning around support to live life well requires knowledge of how systems are funded and operated within the confines of the legislation, the UNCRPD and other policies. As Scully (2020, p. 305) articulates:

> Disabled people are therefore potentially exposed to unique forms of lifelong epistemic exclusion because the highly specialized epistemological structures of health and social care expertise often dominate their everyday lives. Whether a one-to-one encounter with a healthcare professional or a confrontation with an aspect of policy, healthcare operates with implicit expectations about the forms of language, narrative construction, or evidence that will be used.

I argue that, in turn, residential organizations wield a great deal of social and material power in the lives of their residents with disability and at times may operate with a conflict of interest relating to what works at a business level. The decisions at varying levels of the system work in ways that may not be directly understood by people with intellectual disability or those who have highly complex support needs, which in turn may contribute to a sense of powerlessness to change their current living circumstances. Discussions about what constitutes social justice tend to occur in public domains beyond disability service settings, including through popular media, social media and in other mediums. Notably these mediums may be inaccessible for people with intellectual disability. While participants in this study needed support from key people in their lives to help access knowledge and make decisions (as we all do, remembering that social justice is a relational task not a solitary one), this should not prevent intentional privileging of direct experience. The expert knowledge and lived experience of residents who live in group accommodation has rarely been heard or documented widely in political or public discourse. Indeed those with significant disability living in supported accommodation were also least likely to be heard in research.

7.4.2 Testimonial smothering and compulsory acquiescence

Participants in this study were also at risk of being silenced and smothered in their testimonies, deeming it risky to detail experiences of abuse, loneliness or poor quality care, particularly when reliant on their service providers for care and support.

Scully (2020) reinforces the importance of reflecting on privilege, prejudice and bias as a listener and the need to intentionally privilege and account for testimonies rarely heard. As Solnit (2015, p. 50) writes, "who is heard and who is not, defines the status quo". All seven participants in this study had the potential to provide testimonies whether it was through walking tour conversations, sign, speech, photos or drawing (or a combination of all means available). Researchers argue that even those with profound disability have the capacity to express their will and preferences, and it is dependent on the skill of the listener/reader in terms of being able to determine accurately. The real challenge lies in how to confront bias and prejudice in the wider audience so that these testimonies can be heard and respected as valued forms of embodied knowledge. That is the true question.

It was difficult for participants in this study to explore what safety, belonging and personal agency meant to them personally. There was also a risk of backlash or repercussions when expressing disquiet. If participants resisted or named dominant negative forms of oppression (for example expressed discontent and a desire to leave a particular service provider), they ran the risk of repercussions as illustrated by Caleb who aptly said: "You don't want to bite the hand that feeds you". The structural and systemic oppression on individuals no doubt has an impact at a personal level for residents in this study. Ciurria (2023) noted the "double bind" that marginalized people find themselves in where those experiencing systemic discrimination, abuse and harm were often expected to be compliant and grateful in the face of oppression, particularly when their testimonies were more likely to be discounted or devalued. As Ciurria (2023) argues, when people are routinely entrenched in oppressive structures, part of surviving means to acquiesce and accept in order to avoid further repercussions. For participants in this study, elements of this were evident, for example when participants were hesitant about speaking openly about what they did not like in their home (e.g., abusive residents or issues to do with quality of support). Participants felt a need to mitigate conflict and acquiesce so as to keep the peace. The sense conveyed was that to say anything negative or critical came at the risk of being seen as ungrateful "mean, bitter, angry or dangerous" (Ciurria, 2023, p. 41).

Each participant ascribed meaning to different factors that were important and personal to them in feeling a sense of safety, belonging and control in their life. Each participant had their own life experiences and individual characteristics which informed their values and shaped the different factors and aspects that held meaning for them. Central for all participants was their common need for reliable routine support and a stable roof overhead, as well as oversight. Yet this research highlights a tension between what is right for individual residents versus what works well for all residents. This meant compromises for all participants in their own individual ways, as is common for all people who share their lives with others. However there were additional tensions for participants in this study given that it was not only their home or personal relationships they were negotiating, but also a service context that they were reliant on. This in turn brought to light questions of how much to negotiate and how much to acquiesce. How to negotiate and how to maintain the peace? When to say there are issues and when to let the issues lie? There is no single answer for this, as each person will have a different answer on what feels comfortable and sits well with them. However, this study illustrates the importance of thinking beyond isolated goals of safety, independence or social inclusion as a set of functional skills that needs to be "developed" and coached. Rather social justice occurs as a relational process. The systematic and systemic devaluing of residents' knowledge seen in this study goes to the heart of implications for policy and practice.

7.4.3 Summary of epistemic injustice in supported accommodation

It was evident in this study that the knowledge and expertise of people with disability living in their service settings was rarely sought out or listened to. This absence was further compounded when residents were reluctant to provide feedback to services in which they live. As previous scholars (such as Dotson, 2011, and Scully, 2020) have argued: epistemic justice depends on the relationship between the individual and the audience's willingness to adapt and listen.

The next chapter outlines some of these potential 'audiences' and considers some implications for policy and practice.

CHAPTER 8: IMPLICATIONS FOR POLICY AND PRACTICE

This research reinforces the fundamental principle of taking time to get to know each individual, their values, their relational context and their aspirations and goals, as well as their dislikes, fears and worries. This in turn facilitates an understanding of what helps people to maintain a sense of belonging, authority and control over their life, and in turn feel safe. This is certainly not a new contribution to knowledge, it merely echoes and reiterates what many philosophers and disability studies scholars across the decades have been arguing for since the de-institutionalization movement: personalized planning in human service delivery.

Resident safety should always be paramount; however it should not compromise freedom, choice and control over services and relationships. Consciously privileging experiential knowledges of people living in supported accommodation requires change at multiple levels of systems from the service level to the broader political level. This means subverting “old legacy” power relations where service providers have been seen as authoritative experts. This is where the body of work on epistemic justice may strengthen approaches to person centred planning by (a) critiquing how and why disabled people seem to have less credibility and (b) and offer some useful principles that focus on how audiences position themselves as listeners and learners. Scholars argue that epistemic justice depends on the relationship between the individual and the audience’s willingness to adapt and listen. Dotson (2011) notes that epistemic justice happens when audiences:

- intentionally reflect on how we relate to those who are epistemically marginalized
- recognize and take account of the way systems and structures privilege some while devaluing others and also working in ways that prevent access to knowledge and resources.
- work to address these conditions and adapt to meet the needs of those who are marginalized so that their testimonies can be heard.

For the sake of clarity, it is important to note that “audience” in the context of this study may mean different people. It could be the immediate audiences of house-mates, service providers, family members and others, or it could be beyond the immediate environment extending to advocates, policy makers and others. This next section outlines some of these potential audiences and some of the implications for policy and practice both in supported accommodation and more broadly.

8.1 Implications for policy and practice in supported accommodation

8.1.1 Conversations with residents about where they live and who they live with

This study has shown that participants did not have many planning conversations or conversations about their preferences, desires and goals. It was unclear whether participants were disengaged and did not understand the nature of planning sessions, or whether they were absent from these conversations altogether. Whatever the reason, it is vital to ensure that residents in supported accommodation are supported to express their preferences and will in ways that have meaning for them.

Participants felt that they would not survive without their daily supports and therefore saw compromise in their living situation as necessary. This in turn made it difficult for them to discuss issues or problems for fear of repercussions. They also had limited opportunities to explore alternative arrangements for housing and supports. Participants highlighted further barriers to engaging in future planning, particularly when decisions were made due to family crisis or housing instability. Residents with disability living in service contexts need to have opportunities to explore their current situation, what is working, what is not, as well as aspirations for their own future, which may at times mean freedom to explore housing and support opportunities beyond the current service they rely on.

Participants in this study all saw their relationships with others around them, such as parents, siblings or in-laws, as key to making decisions and getting support to deal with any issues that might arise. These people were critical resources for support and often knew the participants best, as well as observing, witnessing and listening to them and responding in supportive ways (for example talking to a manager to try and resolve issues). However there was also evidence that family members’ priorities and goals tended to outweigh those of the individual, as found in some previous studies (Curryer, 2015; Perry, 2019). This is where independent support may be useful within a planning meeting to ensure that decision making processes about supports and housing are centred on the perspectives of the person with disability, whilst simultaneously recognising that supporters also have key insights to share.

Historically, services have long been shaped by a culture of under-resourcing and rationing by service providers. While there has been a radical shift to individualized planning in Australia with the introduction of the NDIS, this study suggests that work still needs to be done to counteract traditions and entrenched service norms that privilege “old legacy” group home stock (Callaway et al., 2021). NDIS plans should be the cornerstone for choice and control, centred on developing an iterative planning process that enables people to personalize supports in ways that match their values and goals in life. This requires capacity building initiatives focused on developing walk-alongside independent advocacy/support to offer individuals and their families opportunities to explore the range of potential ways to maximise their plans, and explore possibilities for living a good life. Where people have chosen to house-share with others who do or do not have a disability, there should be collaborative models of practice put in place to support people to make collective decisions where possible and also help people to move on should their priorities change. Ordinarily, all of us make decisions, some of which we come to regret, and some of which we are happy with. What matters is that there are supports in place to help us pick up the pieces when we have experienced insecurity, abuse or harm and to help with finding different housing and support arrangements.

8.1.2 Freedom to choose who provides support

In this present study participants demonstrated an unwillingness to discuss which support workers they valued or preferred to work with in their home. None of the participants in this study were able to choose their workers day to day. This may be in part due to the revolving door of workers scheduled as part of managing a large accommodation service with multiple residents. Participants also expressed reluctance to disclose issues they had with their workers due to fears that this might lead to trouble.

While there may be practical challenges in supported accommodation, broader research consistently highlights that the effectiveness of support depends on the quality of relationships between people with disability and their workers (K. R. Fisher et al., 2021; Laragy et al., 2015; Topping et al., 2022b, 2022c, 2022a). On this point, the present study suggests that more work needs to be done to honour the epistemic knowledge of residents and ensure choice of preferred supports in their life and home. Participants highlighted qualities they liked in support workers, including (a) general knowledge, training and experience, particularly for those working with people who have high physical support needs, and (b) qualities such as listening and friendliness. These findings confirm prior research such as that by Topping et al. (2022a) who similarly found that people with disability valued workers who demonstrated warmth, positive regard and respect. Topping et al. (2022a) argue that this preference is not only about skill level or universally valued character traits such as being respectful and friendly, but also the “personal chemistry” between individuals and their support worker.

In this study residents were not privy to discussions about recruitment of direct line staff. However, with the introduction of the NDIS there is an opportunity to develop organizational recruitment practices that collaborate with people with disability to ensure that the selection process centres appropriately on personal values that each resident has. Clearly, this may disrupt “business as usual” given that organizations are not accustomed to allocating support hours and support workers accordingly. However, while supporting residents to choose their own support workers may be more labour intensive for organizations, it would significantly increase wellbeing and personal authority of residents. This study confirms and supports prior research which highlights the need to consider how workers are recruited and matched with individuals. The findings highlight the need for flexible recruitment of workers whereby participants could meet potential workers and could change workers as needed.

While experiences of support workers was not the focus of this study, it is important to acknowledge broader contextual factors impacting on quality of support. At times quality of support and reciprocity were hindered due to the limited time workers had to complete their work and the number of residents they were supporting. Broader literature also notes a shortage of workers, high turn-over rate and casualized workforce conditions further impacting on recruitment and choice of workers (Dowse, et al., 2016). These issues affect the type of workers attracted to the industry as well as continuity of care, and may result in instability long term for people with disability. When workers have better working conditions and feel valued and secure in their own work this benefits both the individual and their workers (Dowse et al., 2016). Providing residents with choices about who their support workers are would enable residents to choose workers they feel comfortable and safe with for different tasks and support needs. It would also enable residents to choose workers who provide relational support, warmth and safety beyond just completing practical support tasks in a transactional way (Araten-Bergman et al., 2017; Bigby et al., 2017; Topping et al., 2022b, 2022a).

8.1.3 Need for independent advocates to manage conflicts of interest in these conversations

Participants in this study believed that shared disability accommodation was the “only” way that they could stay safe in a physical and tangible way, given their level of need for support. This immediately positions residents in the vulnerable position of being dependent on the service provider in order to access basic supports. As the study suggests, managers in disability residential contexts are key players in the lives of such people with disability. They largely provide reliable standards of routine care and quality assurance, and fulfil tasks such as organising budgets, rostering, training and supporting their staff, and managing the dwelling and infrastructure. Managers may also be responsible for the practical and interpersonal issues that arise when there are multiple residents across multiple houses. According to the interview data, managers were seen to “manage residents” by making decisions such as which resident was moving on and which residents were being matched together, with residents generally excluded from such service provider conversations. Participants identified “house meetings every now and then” as a meeting held by a manager who would lead the meeting as a way to “give information” such as building work, update on safety in carparks, and so on. Participants indicated a tendency for management to deal with interpersonal issues in-house, including subtle emotional and ongoing abuse or bullying, by moving residents around to different houses. It was clear that while person-centred planning has been a central principle for many decades in service provision, participants in this study did not see themselves as authority figures in decision making. Instead it was “the manager makes decisions”.

While it is true that some people may not have the cognitive capacity to engage in abstract conversations, all of the participants in this study absolutely demonstrated capacity to contribute to conversations about important things in their lives. Yet they did not see themselves as having a key role to play in decisions about their housing or supports. Perhaps part of this was due to many of these participants having spent a life time in disability service contexts where service providers were positioned as experts and themselves as recipients (Curryer et al., 2015). This raises pertinent questions about conflicts of interests for providers who may prevent residents from looking for better housing and support arrangements beyond the service they currently reside in. To counteract the power differential between manager and residents it is important to invest time and effort in building relationships between residents and independent coordinators or advocates who get to know the individual, their environment, the people in their life and their goals, needs and values underpinning formal support. In other words, what is needed is an independent advocate or supporter outside the residential service who has the time to walk alongside the resident. While for some of the participants, family members or guardians tended to assume this role, not all participants had these connections. It is therefore vital to ensure that people with disability have natural supports around them to help in navigating services, as well as the NDIS process. Research has previously shown that supporters such as a family member, a friend, an advocate or peer-led support organization can significantly help with communication and understanding (Perry et al., 2019). Older participants in this study notably did not have strong ties to family and were disadvantaged as they had very few or no independent people who knew them well, and understood their needs and communication style. This meant they did not have anyone to walk alongside and help to negotiate issues as they arose (Collings et al., 2019), and were at risk of getting lost in the system.

The National Disability Insurance scheme attempts to provide some level of independence separate from service providers by allowing for NDIS planners to engage in unbiased planning sessions in ways that support representation of individual interests. Ideally NDIS planners take the time to get to know the individual and build an active relationship. However, none of the participants in this study identified an NDIS planner or relevant support coordinator when asked about who they would speak to about their future plans or goals or things they wanted to change about their housing or supports. This lack of continuity has been echoed in earlier studies such as Perry (2019), who noted that it was common for people to only have met their NDIS planner once for “once off reviews” when developing their personal budget and support plan. Often there was a high turnover rate among NDIS planners and there was limited time spent building a detailed understanding of the individual, their needs and goals and their supports and community, with planners rarely spending time getting to know the individual or their broader context. Consequently, the implementation of the intended role of NDIS planners has fallen short in regard to the anticipated assessment of personal needs and goals (Perry, 2019). Such a lack of reciprocity was seen among participants in this current study, as their NDIS planner had very little presence in their life. Instead, when participants were asked about their experience of putting their personalized support plan into action, they nearly all said that it was the residential managers who were dealing with “that”. At times supported accommodation managers may in fact have the most accurate understanding of residents given their proximity and time spent getting to know residents, as well as witnessing and being present in their home environment. Their management and oversight provides a critic al point of information. However, they also have a conflict of interest which may hinder true exploration. Meanwhile, there was an absence of independent support to help with planning. NDIS planners or support coordinators did not seem to be building a rapport with residents and/or their supporters and were not engaging in iterative conversations either.

Further to the challenges identified within the NDIS, there are also issues in accessing broader community services such as community and mental health services (Productivity Commission Australian Government, 2019). Further, many independent and systemic disability advocacy services were facing increasing demand for their services across all states and territories in Australia, at the same time as funding has ceased in many areas (Productivity Commission, 2017). These broader community sector issues further compound residents' reliance on service providers to help negotiate and advocate for supports.

8.1.4 Resident expertise informing top levels in organisations

Linked to the lack of residents' authority in decision making on accommodation identified in this study is the lack of avenues for residents to have authority over what happens at a service level. One particular way of dismantling service providers' inherent status as experts and decision makers may be through deliberate representation of people with disability on boards or in reference groups for supported accommodation services. A report by the Disability Royal Commission in 2021, Public Hearing 13, appropriately highlighted that disability service organizations were not mandated to have people on their board with lived experiences of negotiating disability services, and that the lack of board directors with lived experience profoundly "impeded the board's ability to discharge its responsibilities effectively" (p. 7). The Royal Commission further described the lack of representation of people with cognitive disability on the board of directors as a sign of prevailing attitudes about disabled people as incapable, dependent, and objects of policy.

There is a need for governance models within services that enable people with lived experience to be in control and themselves defining values that underpin appropriate housing and models of support. Inclusion of board directors who are self-advocates with lived experience may provide a critical step forward in ensuring that issues are raised at a systemic level where decisions may effect change more broadly across the organization, rather than perpetuating a purely reactive individual response to issues. Such a change would flatten the hierarchy and counteract some of the power that traditionally sits with management and boards of directors in organizations.

8.2 Implications for broader community sectors

8.2.1 Address un-met need for housing and support

This study highlights a desperate need for the service sector and housing market to diversify and create a flexible range of options for stable housing and supports that are specific for the disability community. There is no single “correct” model of housing and support. While some residents may enjoy or prefer shared housing and supports, others may not. What was clear, however, was that placement of individuals who have similar “support needs” was not benefitting the residents, only the service providers. Enforced sharing of housing and supports adds to discomfort, conflict and abuse. Consequently, there must be innovative and new ways to negotiate collective decision making on the part of residents who have chosen to share (Cumella & Lyons, 2018; Fahey et al., 2010) and freedom to try housing and supports with the view that residents can be supported to express discontent and change their circumstances as needed. This requires leadership at the highest level of government. These issues of housing must be negotiated not only in terms of private Specialist Disability Accommodation options, but also through public housing and other avenues (Callaway et al., 2021; Callaway & Tregloan, 2018).

Politicians need to take up the challenge of addressing the shortage of housing and support options for people with disability. This may mean supporting businesses to develop alternative and creative arrangements for organizing secure long-term housing and structured reliable supports which enable a degree of safety and oversight. People with disability need support to explore broader futures that move beyond what the market currently offers in terms of the dominant form of group homes, which is an economically viable system for realtors. People with disability need opportunities to explore ways of talking about making decisions about where to live and who to live with that move beyond the language of “availability” and “vacancies”. People with disability need multiple possibilities.

People with disability and their families need practical resources and exposure to a range of examples in order to make informed decisions about possibilities and potential ways of arranging their supports. Resources are important in enabling a range of options and allowing people to make decisions knowing that some might be good, some may not work out, but they have flexibility to choose and know that they will be okay if things do not work with particular people/services/housemates/etc. Such moments of decision make for learning and power and enable future decision making if done safely without risk of homelessness or, worse, abuse and neglect.

8.2.2 Recognizing absence of embodied knowledge in public discourse

The lack of participation and representation of people with direct lived experience in broad service provider, public or political spheres may more deeply entrench the norm of dealing with issues in-house behind the scenes at a management level. This limits opportunities for residents to combat systemic injustice and fight for attitude change that is meaningful to them. It also reinforces the view that issues are isolated, one-off issues to be responded to as an incident, rather than being epistemic and systemic. It is rare for the general public to hear from people with direct lived experiences of living in disability service operated homes or shared disability service contexts. Currently it is more common to hear from parents or caregivers or service providers about their understandings and experiences of supporting a person with disability, rather than hearing from people with disability themselves about their lived experiences and perspectives and how they negotiate their material, political and social environment. One study by Winterbotham (2023) exploring representation of people with intellectual disability in Australian media found that most media sources centred perspectives of family members, politicians, government officials or representatives from organizations. This study also found that issues of housing, and mistreatment or abuse of people with disability were the dominant issues picked up by media. However, the lack of media representation of people with direct lived experience of these issues makes it hard to counteract the deeply entrenched belief that people with disability are “objects of policy” (Winterbotham et al., 2023). There is consequently a need for a more diverse range of media examples and stories to raise public awareness and understanding of the critical issues people with disability negotiate in their daily lives, specific to disability support and housing.

The experiential knowledges and opinions of people who live in these settings need to be prioritised, privileged and woven through all levels of governance and policy. Scully (2020) argues that collective epistemic justice depends on people in privileged positions, such as service providers, policy makers and supporters, making conscious efforts to ensure that people with lived experience are at the forefront in terms of governance and deliberations about social policy concerning housing and support.

8.2.3 Self-advocacy and collective advocacy

In this study it was difficult for participants to engage in conversations about the broader political and structural issues that were often underpinning and influencing access to information about possible ways to use their NDIS plan to realize their goals and explore alternative ways of managing support or housing. They were also less likely to access information about the current political debates and discourses happening in media about contemporary social issues that are directly relevant to them, such as abuse in disability services, the Quality and Safeguarding Commission and other mechanisms. There were dominant social and historical power relations existing in their service provision which prevented epistemic agency, especially when residents with significant disability could not access information or resources. This had an impact on how residents could self-advocate and share their own knowledge.

While part of self-advocacy depends on skill building (such as developing access to assistive communication devices where possible), applying an epistemic justice lens shifts the focus to instead examine how audiences such as policy makers, service providers, families, and other supporters recognize embodied experience as a valued form of knowledge.

There are multiple levels of community services and public sector (such as service providers, independent and systemic advocacy services, state-level safeguarding units or ombudsman as well as the NDIS Quality & Safeguarding Commission) that play a key role in collating testimonies and providing resources and supports. All of these sectors contribute knowledge of key issues faced by people with disability across the sector (including residents in supported accommodation). Yet access to these resources and information from various layers of the community sector remains fragmented and difficult to make sense of – particularly for those with significant disability who may not have a high level of literacy or have access to the internet. While there has been some effort by state and federal departments to ensure that their reports are in easyread, this still places the onus on individuals to seek out information and research. It does not address the epistemic injustice residents faced in this study when they relied on service providers, who had a conflict of interest, to help negotiate systems. As mentioned earlier, this reliance on service providers may be a strength when they know the individual well; however it may also reinforce resident issues as “incidents” to be dealt with rather than as social justice issues.

While participants in this study had not experienced self-advocacy or peer networks, the research literature demonstrates that establishing self-advocacy and/or peer networks can be a fundamental way to subvert social and historical power relations which have traditionally sat with service providers and policy makers (Carey, 2011; Smith & Mueller 2022). There has been considerable work done to ensure that Australian policy spaces diversify their submission processes to reach out to peer networks and self-advocacy groups led by people with intellectual disability. These approaches have enabled a wider variety of testimonies (for example by using videos, pictures, photos or drawings). Such examples provide a starting point for thinking about how services, organizations and public sector reach out and seek knowledge and start to be creative and reflective in the way they hear testimonies.

8.3 Chapter summary

This doctoral thesis set out to canvas the direct experiences of residents living in shared types of supported accommodation in relation to their experiences of safety, belonging and agency. Notably, these three concepts were not easily separated or distinguished in participant narratives. Rather, these three core needs and values were intertwined and understood as embodied. Themes of safety, belonging and personal authority, choice and control were inter-connected and woven through participants' experiences in personal ways.

It is important to note that while the literature review highlighted several key issues such as medical and physical restraint, as well as issues around the shorter life expectancy and higher death rates in supported accommodation, these did not feature strongly or at all in participants' conversations. There is likely a general lack of awareness of what the broader statistics show and the impact of what this data means at an individual level. For participants, their understandings of safety, belonging and agency (or lack of these) tended to relate to personal interactions within their immediate home environment. In this study, participants raised several features of negotiating safety, belonging and agency which were not widely reported in the literature.

Each participant ascribed meaning to different factors that were important and personal to them in feeling a sense of safety, belonging and authority in their life. Each participant had their own life experiences and individual characteristics which informed their values and shaped the different factors and aspects that held meaning to them. Central for all participants was their common need for independence away from unpaid care-givers and access to reliable routine support and a stable roof over head. This meant their home environment was also a service context and a workplace governed by legislation, policies and service structure and organisational culture. All participants reported no choice of who they lived with. Instead the norm was to “find a vacancy” among a group of residents by disability type or support need. Arguably this increased the risk of abuse, loneliness and isolation for residents who shared very little in common with the people they lived with other than their need for support. Each participant had to negotiate and compromise in their own personal ways. For example, some participants were ill-matched with other residents resulting in isolation and apathy between residents. For others it was about exposure to repeated conflict, abuse or bullying. Still others talked about poor quality support from staff. These sorts of experiences tended to be seen as the norm for supported accommodation and were, in part, accepted as necessary to negotiate in order to maintain their necessary support. As a result of all these compounding material and semiotic factors, people were routinely subjected to decisions made about them for them in terms of where they lived or who they lived with. This in turn had a flow on effect of exposure to isolation, loneliness and/or abuse and harm. Where participants raised issues with management – for example an upsetting comment by a resident, or laundry that smelled of faeces – they tended to be “resolved” in-house as “incidents” that were addressed, or sometimes simply left unresolved. In other cases action would be taken, for example shuffling residents between houses, which led to more significant upheaval. Dealing with incidents as individual problems perpetuated the view that such issues were isolated, rather than routine and systemic.

While shared and/or clustered types of supported accommodation may be economically viable from a service provider point of view, these traditional models (compounded by chronic shortage of places) force people with disability to take up vacancies as they come up. Such a climate also makes it much harder for people with disability living in these settings to move on or try different types of housing or support arrangements It was clear in this study that the common need binding all participants together was their need for structured support and oversight to avoid potential occupational risks or overt types of harm. Yet this fundamental need forced each of the participants into a position of powerlessness to change their circumstance, forcing them to compromise personal values of safety, belonging or personal agency.

The findings in this study suggest that filling vacancies in supported accommodation options set up a climate where people were exposed to oppressive conditions that harm and damage wellbeing. Yet the alternatives of not having structured routine support or stable housing were equally damaging. The under-resourcing and chronic shortage of placements in disability service contexts seemed to enforce a system whereby people with disability were placed in a bedroom in a designated house or hostel (or other congregated model) wherever a vacancy could be found. Residents had no choice of where or with whom they lived. Nor did they report any sense of personal agency or control over who their support workers were. While moving to supported accommodation meant having a home in the sense of a stable permanent place to live and routine regular support, supported accommodation continues to predominantly operate in prescriptive ways that devalue the inherent dignity and individual values and preferences each person has.

CHAPTER 9: CONCLUSION

This chapter revisits the aims for this research and summarizes the original contribution to knowledge, including theoretical and methodological contributions. It also offers some reflections on some of the limitations of the study along with future directions. The chapter ends with final comments and a call to action.

9.1 Original contribution to knowledge

This was an exploratory qualitative study investigating how people living in shared types of supported accommodation negotiated their safety, belonging and agency. The study brought to light how important reliable routine support was for people to live their lives safely. Most participants in this study had wanted to be less dependent on unpaid care-givers or less confined to hospital, and therefore saw their move to supported accommodation as a means to attain some sense of human dignity and independence. Access to reliable and routine support was foundational to personal safety, yet these organizational structures simultaneously operated in ways which seemed to precipitate harmful conditions that corroded personal safety, belonging and agency.

In this study participants did not describe criminal types of abuse although their narratives included a range of everyday examples of apathy, bullying, abuse and/or harm, yet these instances were treated as mundane and ordinary. Even though participants found these interactions frustrating, distressing or damaging, they also commonly seemed to acquiesce, anticipating such encounters as part of ordinary life when living in supported accommodation. These compromises were different for each participant. For example, some participants were ill-matched with other residents resulting in isolation and apathy between residents. For others it was about exposure to repeated conflict, abuse or bullying. Still others talked about poor quality support from staff. Living in supported accommodation added extra layers of complexity to the notion of home, as it was not only a resident's own personal space – symbolising independence from unpaid care-givers – it was also a shared space with other residents, as well as a workspace and disability service context with its own culture, rules and norms that would not normally be seen in a regular private home.

This research has detailed several examples of epistemic injustices where residents' embodied experiences and knowledge were silenced or discounted, overlooked or dismissed both within service systems and within broader political conversations. This contributes to testimonial and hermeneutical injustices. Very little research has sought to hear the testimonies of those who directly live in shared supported accommodation and there are few opportunities for residents to have their views and perspectives heard both within service provision structures and decisions, and more broadly in political spaces. Inevitably supporter knowledges shape public discourses, definitions and values ascribed to "home" – sometimes in helpful ways, yet unwittingly suppressing and devaluing the embodied knowledge and wisdom of residents.

This current study establishes the firm entanglement of safety, belonging and personal agency as three core personal experiences that are always inter-relational and embodied as part of people's experiences and overall sense of wellbeing. Each research participant had their own understanding of what constituted and helped them to (a) feel safe in their home; (b) have a sense of being valued by (as well as valuing) people they live with, and (c) personal agency and authority over what happens in their day to day life. The use of new materialist theory offered a nuanced level of analysis by taking account of the material practices as well as the cultural and semiotic constructs that contribute to everyday experiences of harm, isolation and powerlessness. The approach in this study also extends on new materialist theory by taking a critical disability feminist perspective in order to take account of power dynamics entangled in structural and social systems of oppression impacting on everyday lives of the participants. Further to this, theoretical work on epistemic injustice offered a means to articulate which voices are more often heard from in research, policy and practice in relation to what constitutes social justice; it also highlights the multitude of ways in which the valuable knowledge of people living in disability supported accommodation may be undermined, discounted or disregarded.

This study highlights the importance of resisting a prescriptive traditional interview approach when undertaking inquiry. In this study each individual chose their own range of participatory methods. While some chose to do a traditional talking interview, for others it was supplemented by a variety of photos, drawing, collage, or walk-and-talk activities. The flexibility enabled participants to take the lead. The process of interviewing was often haphazard, intuitive and messy; consisting of fragments of perspectives (some coherent, some less so) along with visual artefacts and field notes. Here, I turn to researchers such as Strawson (2004, p. 429), who argued that standardized approaches “close down important avenues of thought, needlessly and wrongly distressing those who do not fit”. In contrast, the flexible and intuitive approach used in this study enabled avenues of inquiry that would have remained invisible through conventional talk-based interviews. This generated novel and different insights and focused on working to participants’ strengths and interests.

9.2 Limitations of this study

In keeping with my methodology, I take a reflective approach to this study, acknowledging that there are some limitations that need to be considered, notably the power dynamics between researcher and researched, the small sample size and the absence of voices who could have brought an intersectional understanding. While elements of inclusive research were embedded as part of the overall design of this PhD study, there were limitations in terms of shifting the power from researcher to participants (Puyalto et al., 2016; Råheim et al., 2016). The nature of a doctoral thesis involved meeting certain requirements and being completed within a certain time frame. The design, research findings and analysis may have been different had there been paid co-researchers with lived experiences of shared accommodation working alongside during the design, collection and analysis (Hollinrake et al., 2019; Puyalto et al., 2016; Thoresen & Öhlén, 2015).

At the time of data collection (2019-2020) there were several social and political factors that made recruitment difficult. First, it was a challenging time to recruit within disability accommodation providers (a main point of contact for sharing information about this research with potential participants), as many providers were under pressure to bring their businesses and staff up to date with changes in policy due to the introduction of the National Disability Insurance Scheme and the NDIS Quality and Safeguarding Commission. At an organizational level these structural changes added considerable pressure. Secondly, the COVID19 pandemic took hold in Australia in early 2020. This had ongoing ramifications in terms of interactions with residents with disability in supported accommodation settings. Nevertheless the richness of examples provided by the seven participants who came forward suggests that there are some important contributions that residents can make towards theoretical understandings of safety, belonging and agency.

The small sample size also meant that this research did not canvas the perspectives of residents with disability who represent other aspects of marginalization such as those from cultural and linguistically diverse backgrounds or Aboriginal and Torres Strait Islanders. In addition, it is difficult to know how the creative and flexible research methods adopted would have worked had the participant sample been considerably larger or more culturally diverse. However, there is certainly scope to explore how these methodologies could be used to canvas a larger range of perspectives.

9.3 Future research

Research is needed to explore the factors that protect and strengthen how residents living in supported accommodation participate in decision making at all levels of systems that affect them, both in the organization and in broader policy landscapes. While the nature of individualized funding packages aims to improve equity to resources and supports, there is a need for research exploring how residents in supported accommodation engage in personalized planning for their immediate day to day life and their future. Further to this, the present study also highlights a need for research examining potential conflicts of interest that exist when accommodation service providers provide support and housing (as well as other services) which may impinge on the personal authority of residents relying on these supports.

Notably, data about the lives of people in supported accommodation is fragmented and difficult to garner. It depends on service provider reporting, as well as data collection through various statutory bodies. The absence of residents’ perspectives needs to be countered by researchers. This means developing research methodologies that flexibly meet the needs of people with intellectual disability or high complex support needs and enable them to share their embodied knowledge. There is also a need to continue building on the small but growing body of research which intentionally canvasses the perspectives of people with disability who directly live (or previously lived) in shared types of supported accommodation. There is a need to examine how the personal authority of residents with disability is constrained, taking account of how the broader environment operates in ways that devalue and compromise quality of life for people with disability in supported accommodation. There is also a need for future research exploring how individuals’ social backgrounds and intersectional aspects of privilege and disadvantage impact on everyday experiences of supported accommodation. There is a need for critical reflection about how people experience privilege and social disadvantage due to interrelationships between factors including race, sexuality, gender, ability, class, age (Crenshaw, 1991; Mattsson, 2014).

9.4 Final comments

This study illustrates the importance of thinking beyond isolated goals of safety, self-determination and social inclusion as a set of functional skills that needs to be "developed" and coached. Rather, social justice occurs as a relational process. The systematic and systemic devaluing of residents' knowledge seen in this study goes to the heart of implications for policy and practice.

Participants in this study were not only navigating their immediate home environment – which encompassed a range of material and semiotic relations and power dynamics underlying people's experiences of space, place and people – they were also contending with broader systemic and political issues which were forcing people with significant disability into difficult situations due to the scarcity of housing and support models. There was a sense of silencing and powerlessness among these seven participants who were constantly negotiating a system that had its own competing priorities and demands.

This silencing becomes more deeply entrenched when research and policy predominantly hears the perspectives of service providers and support people. While such supporter perspectives have a certain degree of credibility and expertise, the flow-on effect is that knowledge constructs about what meaningfully contributes to personal safety, belonging and agency in the context of supported accommodation are informed predominantly by second and third hand accounts from family members, advocates, politicians, supporters and allies, and not by the people with disability themselves.

Participants in this study were contending with deep un-named questions about how much to speak up and ask, and how much to acquiesce and accept conditions as they stood. More specifically, there were fundamental questions about when or how to speak up, when and how to follow up when issues were persisting (for example being bullied and harassed by another resident), and when to let issues lie for the sake of keeping the peace. In the context of this study, keeping the peace meant safety in terms of stable housing, stable support, stable routines and stable structured oversight to manage these systems. Each of the seven participants in this study had their own ideas for what helped them to feel at ease, valued, and in control. Likewise, each person had varying levels of tolerance for coping with and resisting harmful conditions.

It is vital to reflect on who we predominantly hear from in the disability sector, and that we intentionally find ways to gather a wide collection of testimonies from people with direct lived experience. As Solnit (2017, p. 21) averred in her essay entitled *Silence*, the stories and perspectives we hear from are the tip of the iceberg.

> If libraries hold all the stories that have been told, there are ghost libraries of all the stories that have not. The ghosts outnumber the books by some unimaginably vast sum. Even those who have been audible have often earned the privilege through strategic silences or the inability to hear certain voices including their own.

This study attempts in some small way to disrupt the hierarchy of whose stories have been valued, whose stories have been heard, and whose stories have influenced the sway of decision making. People who spoke in this study are credible, they all have knowledge to share and ideas for change and yet were rarely sought as experts either within service provision or beyond. This reinforces the implied devaluing of valuable knowledge.

The hope of this work is that by listening to the direct personal experiences of people in supported accommodation we can pave the way for better understanding the level of compromise residents have had to make and continue to make, and which are part of the silencing elucidated in the notion of testimonial smothering (see section 7.4.2) Once housed with a vacancy in disability accommodation one’s chances of leaving or changing is rare. There is a sense of compulsory obligation and gratitude for having a roof over one’s head.

At the end of the day I am left with the uncomfortable truth that residents are left to negotiate issues related to their wellbeing by compromise. The causes of these compromises are less to do with disability and more to do with the intersection of both material and structural factors which are inseparably embodied in people’s lives and inform the way they interact with the world. When there are opportunities to share one’s truth to a receptive audience this opens up new avenues to explore what constitutes social justice from the perspectives of residents who live in these settings. We are missing out on valuable knowledge because we have not sought out these voices. This thesis ends therefore with a question aimed both at institutions and people in the general community: “Are you prepared to take the time to value, listen and take action in your respective spheres of influence?” Who better to make meaning of what constitutes social justice than those who live in these residential settings?

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APPENDICES

Appendix A: Ethics approval

Appendix B: Introduction letter for organizations

Appendix C: Flyer for social media

Appendix D: Plain text information sheet

Appendix E: Easy English information sheet

Appendix F: Semi-structured interview prompt sessions

Appendix G: Support person consent form

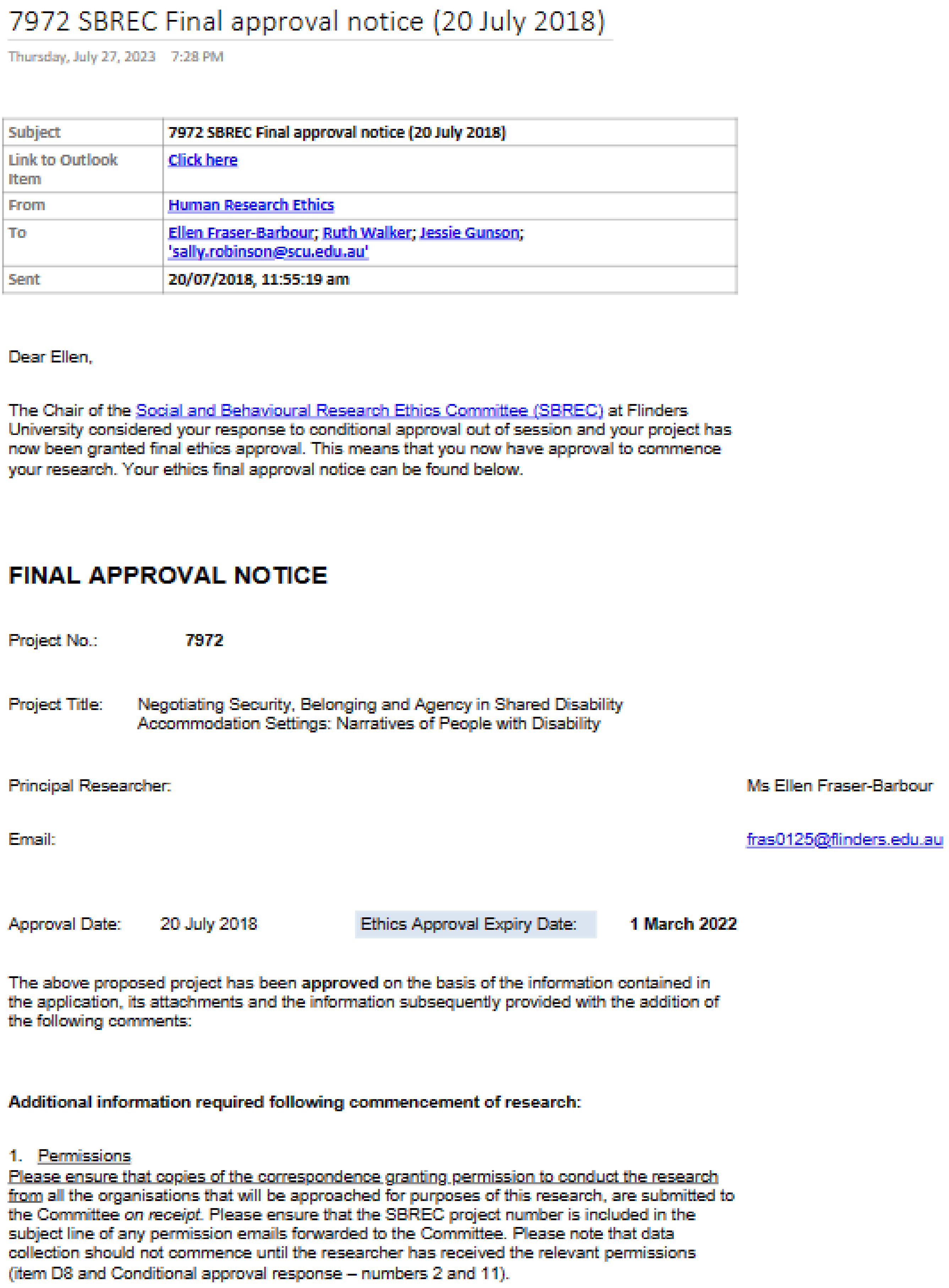
Appendix H: Person with disability consent form

Appendix I: Easy-read consent form

Appendix J: Visual data consent form

Appendix K: Legal guardian consent form

Appendix L: Reporting abuse response protocol



7972 SBREC Final approval notice (20 July 2018)

Thursday, July 27, 2023 7:28 PM

Subject	**7972 SBREC Final approval notice (20 July 2018)**
Link to Outlook Item	Click here
From	Human Research Ethics
To	Ellen Fraser-Barbour; Ruth Walker; Jessie Gunson; 'sally.robinson@scu.edu.au'
Sent	**20/07/2018, 11:55:19 am**

Dear Ellen,

The Chair of the Social and Behavioural Research Ethics Committee (SBREC) at Flinders University considered your response to conditional approval out of session and your project has now been granted final ethics approval. This means that you now have approval to commence your research. Your ethics final approval notice can be found below.

FINAL APPROVAL NOTICE

Project No.: **7972**

Project Title: Negotiating Security, Belonging and Agency in Shared Disability Accommodation Settings: Narratives of People with Disability

Principal Researcher: Ms Ellen Fraser-Barbour

Email: fras0125@flinders.edu.au

Approval Date: 20 July 2018 Ethics Approval Expiry Date: **1 March 2022**

The above proposed project has been **approved** on the basis of the information contained in the application, its attachments and the information subsequently provided with the addition of the following comments:

Additional information required following commencement of research:

1. Permissions

Please ensure that copies of the correspondence granting permission to conduct the research from all the organisations that will be approached for purposes of this research, are submitted to the Committee *on receipt*. Please ensure that the SBREC project number is included in the subject line of any permission emails forwarded to the Committee. Please note that data collection should not commence until the researcher has received the relevant permissions (item D8 and Conditional approval response – numbers 2 and 11).

Appendix A: Ethics Approval

2. Permissions – attached items - request

The permission correspondence from the following organisations: (1) Health and Community Services Complaints Commissioner's office; (2) Advocacy for Disability Access and Inclusion; (3) DEAI; which were stated to be attached to your conditional approval response (numbers 2 and 11) do not appear to have been attached. Please send these by reply email, and so that these may be added to your ethics project file.

RESPONSIBILITIES OF RESEARCHERS AND SUPERVISORS

1. Participant Documentation

Please note that it is the responsibility of researchers and supervisors, in the case of student projects, to ensure that:

- all participant documents are checked for spelling, grammatical, numbering and formatting errors. The Committee does not accept any responsibility for the above mentioned errors.
- the Flinders University logo is included on all participant documentation (e.g., letters of Introduction, information Sheets, consent forms, debriefing information and questionnaires – with the exception of purchased research tools) and the current Flinders University letterhead is included in the header of all letters of introduction. The Flinders University international logo/letterhead should be used and documentation should contain international dialling codes for all telephone and fax numbers listed for all research to be conducted overseas.
- the SBREC contact details, listed below, are included in the footer of all letters of introduction and information sheets.

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project Number 'INSERT PROJECT No. here following approval'). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email *human.researchethics@flinders.edu.au*.

2. Annual Progress / Final Reports

In order to comply with the monitoring requirements of the *National Statement on Ethical Conduct in Human Research (March 2007)* an annual progress report must be submitted each year on the **20 July** (approval anniversary date) for the duration of the ethics approval using the report template available from the Managing Your Ethics Approval SBREC web page. *Please retain this notice for reference when completing annual progress or final reports.*

If the project is completed *before* ethics approval has expired please ensure a final report is submitted immediately. If ethics approval for your project expires please submit either (1) a final report; or (2) an extension of time request and an annual report.

Student Projects

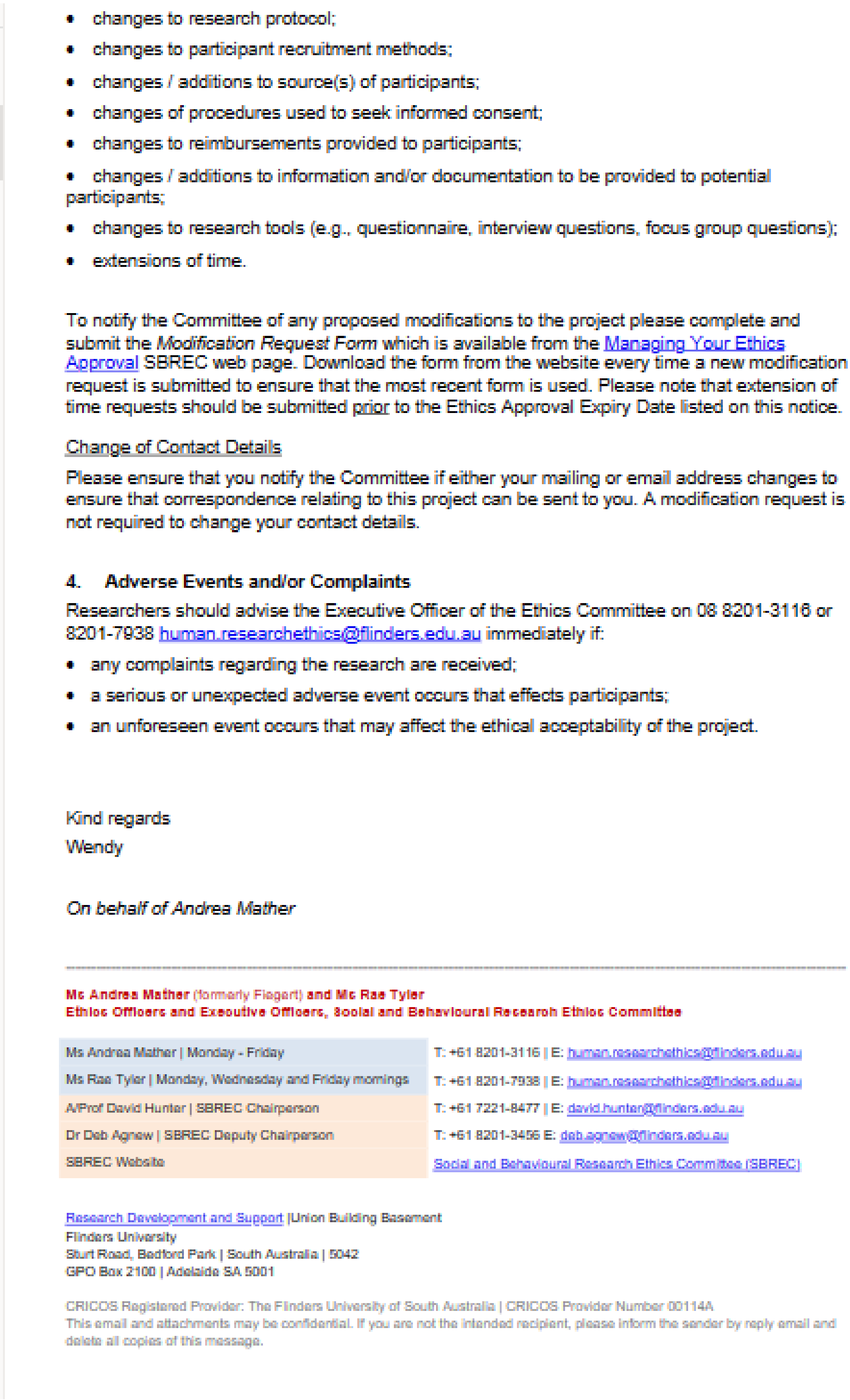
The SBREC recommends that current ethics approval is maintained until a student's thesis has been submitted, reviewed and approved. This is to protect the student in the event that reviewers recommend some changes that may include the collection of additional participant data.

Your first report is due on **20 July 2019** or on completion of the project, whichever is the earliest.

3. Modifications to Project

Modifications to the project must not proceed until approval has been obtained from the Ethics Committee. Such proposed changes / modifications include:

- change of project title;
- change to research team (e.g., additions, removals, principal researcher or supervisor change);
- changes to research objectives;



- changes to research protocol;
- changes to participant recruitment methods;
- changes / additions to source(s) of participants;
- changes of procedures used to seek informed consent;
- changes to reimbursements provided to participants;
- changes / additions to information and/or documentation to be provided to potential participants;
- changes to research tools (e.g., questionnaire, interview questions, focus group questions);
- extensions of time.

To notify the Committee of any proposed modifications to the project please complete and submit the *Modification Request Form* which is available from the Managing Your Ethics Approval SBREC web page. Download the form from the website every time a new modification request is submitted to ensure that the most recent form is used. Please note that extension of time requests should be submitted prior to the Ethics Approval Expiry Date listed on this notice.

Change of Contact Details

Please ensure that you notify the Committee if either your mailing or email address changes to ensure that correspondence relating to this project can be sent to you. A modification request is not required to change your contact details.

4. Adverse Events and/or Complaints

Researchers should advise the Executive Officer of the Ethics Committee on 08 8201-3116 or 8201-7938 human.researchethics@flinders.edu.au immediately if:

- any complaints regarding the research are received;
- a serious or unexpected adverse event occurs that effects participants;
- an unforeseen event occurs that may affect the ethical acceptability of the project.

Kind regards

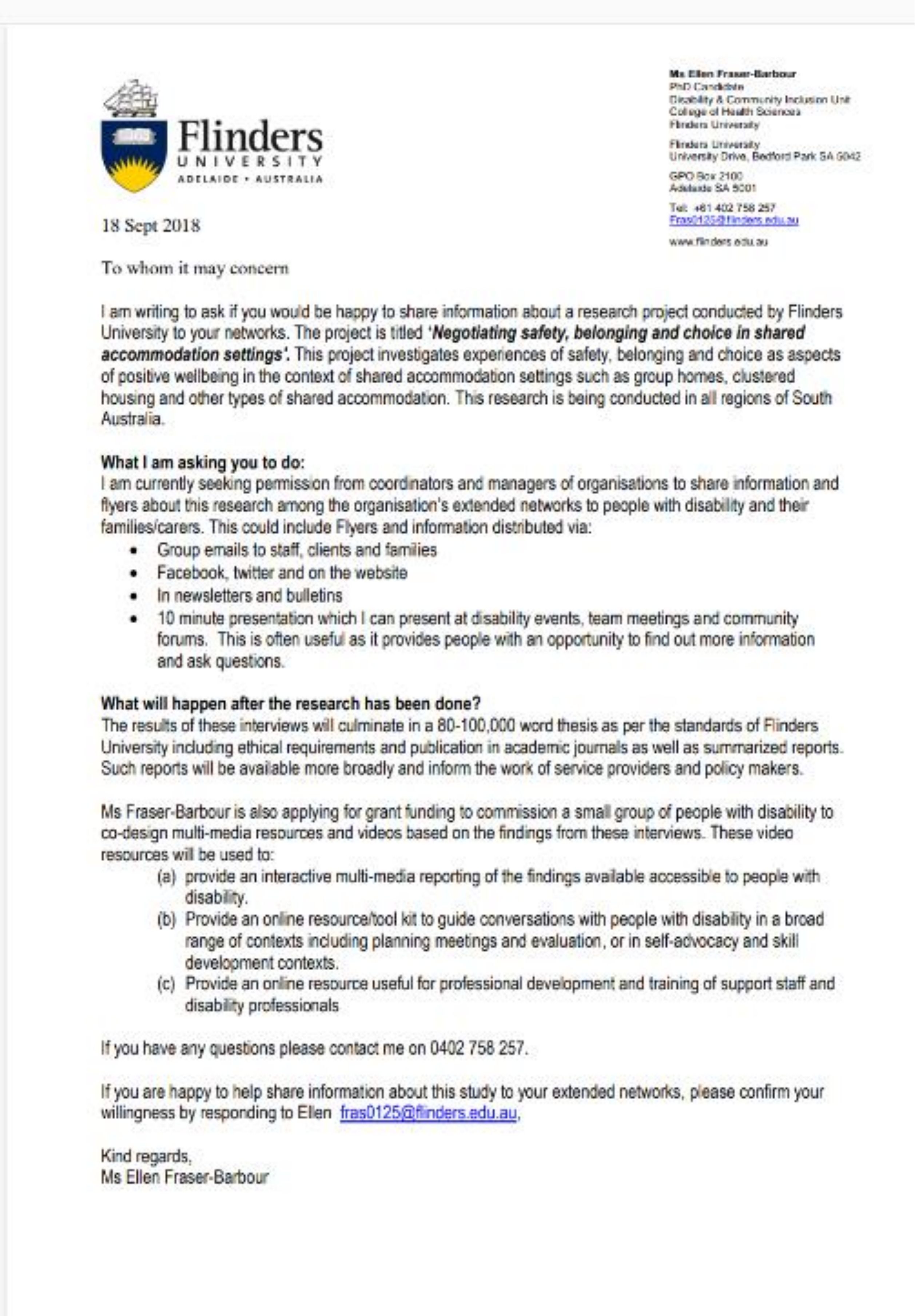
Wendy

On behalf of Andrea Mather

Ms Andrea Mather (formerly Fiegert) **and Ms Rae Tyler**
Ethics Officers and Executive Officers, Social and Behavioural Research Ethics Committee

Ms Andrea Mather | Monday - Friday	T: +61 8201-3116 | E: human.researchethics@flinders.edu.au
Ms Rae Tyler | Monday, Wednesday and Friday mornings	T: +61 8201-7938 | E: human.researchethics@flinders.edu.au
A/Prof David Hunter | SBREC Chairperson	T: +61 7221-8477 | E: david.hunter@flinders.edu.au
Dr Deb Agnew | SBREC Deputy Chairperson	T: +61 8201-3456 E: deb.agnew@flinders.edu.au
SBREC Website	Social and Behavioural Research Ethics Committee (SBREC)

Research Development and Support |Union Building Basement
Flinders University
Sturt Road, Bedford Park | South Australia | 5042
GPO Box 2100 | Adelaide SA 5001



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Ms Ellen Fraser-Barbour
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18 Sept 2018

To whom it may concern

I am writing to ask if you would be happy to share information about a research project conducted by Flinders University to your networks. The project is titled ***'Negotiating safety, belonging and choice in shared accommodation settings'.*** This project investigates experiences of safety, belonging and choice as aspects of positive wellbeing in the context of shared accommodation settings such as group homes, clustered housing and other types of shared accommodation. This research is being conducted in all regions of South Australia.

What I am asking you to do:
I am currently seeking permission from coordinators and managers of organisations to share information and flyers about this research among the organisation's extended networks to people with disability and their families/carers. This could include Flyers and information distributed via:

- Group emails to staff, clients and families
- Facebook, twitter and on the website
- In newsletters and bulletins
- 10 minute presentation which I can present at disability events, team meetings and community forums. This is often useful as it provides people with an opportunity to find out more information and ask questions.

What will happen after the research has been done?
The results of these interviews will culminate in a 80-100,000 word thesis as per the standards of Flinders University including ethical requirements and publication in academic journals as well as summarized reports. Such reports will be available more broadly and inform the work of service providers and policy makers.

Ms Fraser-Barbour is also applying for grant funding to commission a small group of people with disability to co-design multi-media resources and videos based on the findings from these interviews. These video resources will be used to:

(a) provide an interactive multi-media reporting of the findings available accessible to people with disability.
(b) Provide an online resource/tool kit to guide conversations with people with disability in a broad range of contexts including planning meetings and evaluation, or in self-advocacy and skill development contexts.
(c) Provide an online resource useful for professional development and training of support staff and disability professionals

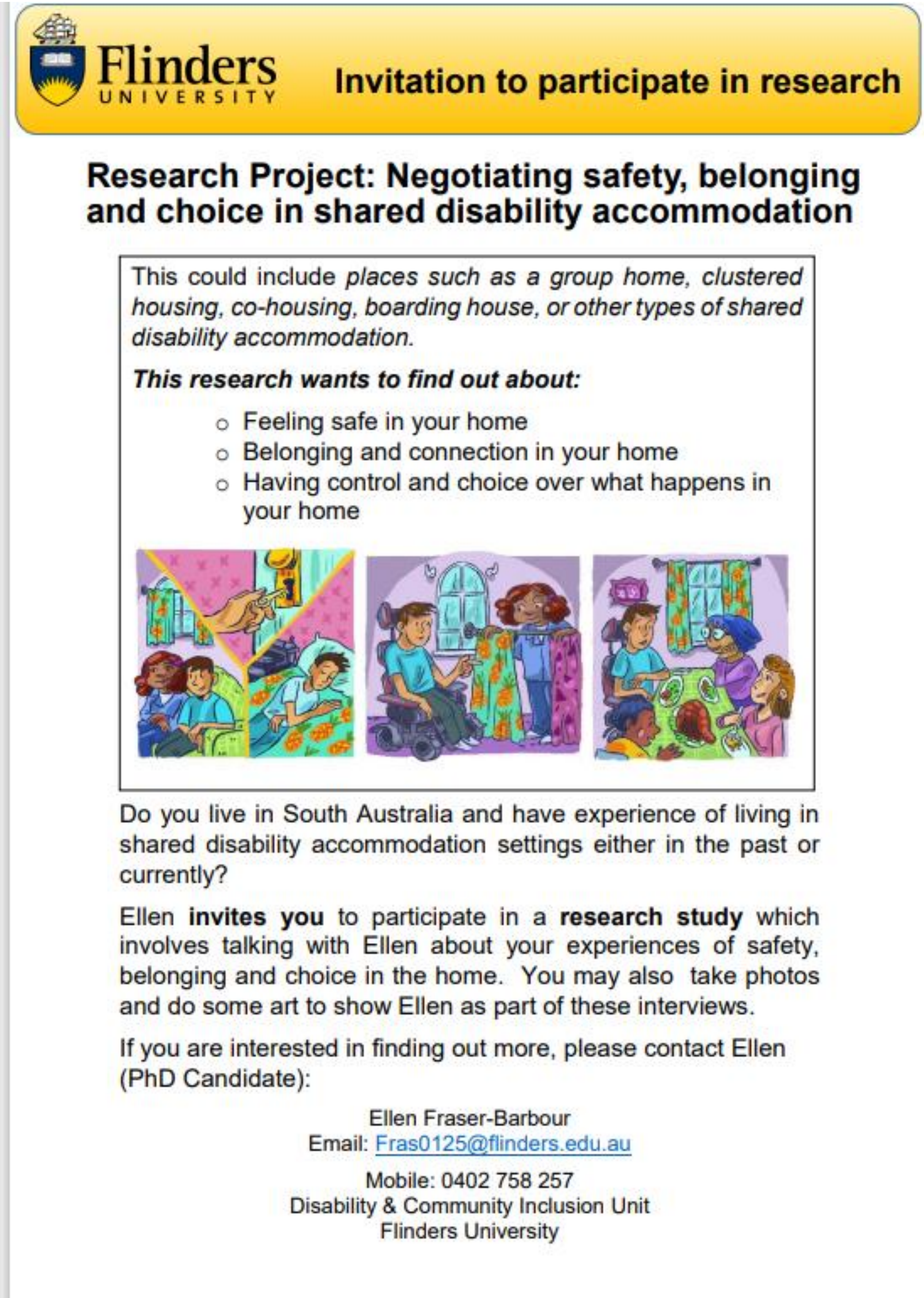
If you have any questions please contact me on 0402 758 257.

If you are happy to help share information about this study to your extended networks, please confirm your willingness by responding to Ellen fras0125@flinders.edu.au,

Kind regards,
Ms Ellen Fraser-Barbour

Appendix B: Introduction letter for organizations

Appendix C: Flyer for social media



Flinders UNIVERSITY

Invitation to participate in research

Research Project: Negotiating safety, belonging and choice in shared disability accommodation

This could include *places such as a group home, clustered housing, co-housing, boarding house, or other types of shared disability accommodation.*

This research wants to find out about:

- Feeling safe in your home
- Belonging and connection in your home
- Having control and choice over what happens in your home

Do you live in South Australia and have experience of living in shared disability accommodation settings either in the past or currently?

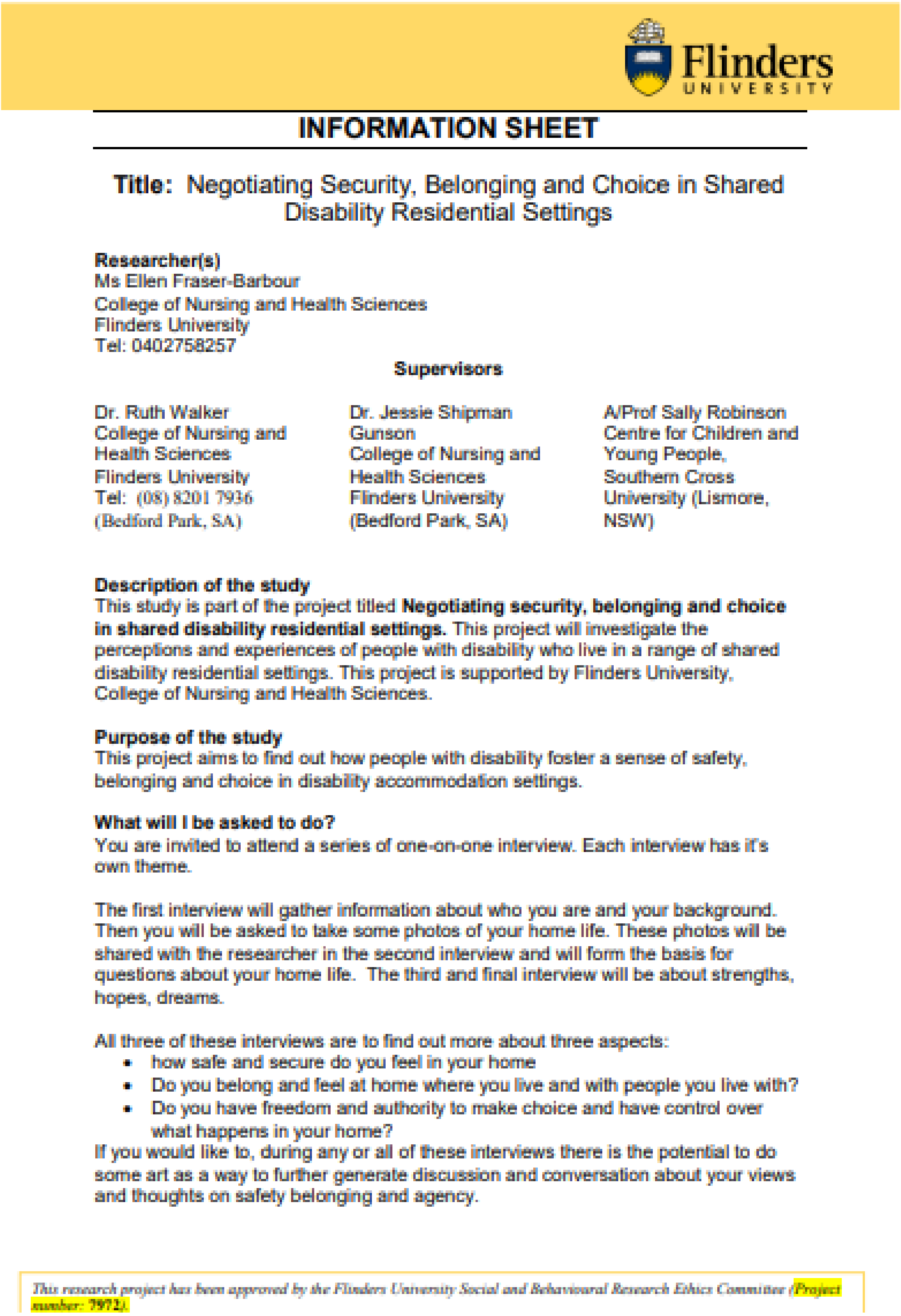
Ellen **invites you** to participate in a **research study** which involves talking with Ellen about your experiences of safety, belonging and choice in the home. You may also take photos and do some art to show Ellen as part of these interviews.

If you are interested in finding out more, please contact Ellen (PhD Candidate):

Ellen Fraser-Barbour
Email: Fras0125@flinders.edu.au

Mobile: 0402 758 257
Disability & Community Inclusion Unit
Flinders University

Appendix D: Plain text information sheet



Flinders UNIVERSITY

INFORMATION SHEET

Title: Negotiating Security, Belonging and Choice in Shared Disability Residential Settings

Researcher(s)
Ms Ellen Fraser-Barbour
College of Nursing and Health Sciences
Flinders University
Tel: 0402758257

Supervisors

Dr. Ruth Walker
College of Nursing and Health Sciences
Flinders University
Tel: (08) 8201 7936
(Bedford Park, SA)

Dr. Jessie Shipman Gunson
College of Nursing and Health Sciences
Flinders University
(Bedford Park, SA)

A/Prof Sally Robinson
Centre for Children and Young People,
Southern Cross University (Lismore, NSW)

Description of the study
This study is part of the project titled **Negotiating security, belonging and choice in shared disability residential settings.** This project will investigate the perceptions and experiences of people with disability who live in a range of shared disability residential settings. This project is supported by Flinders University, College of Nursing and Health Sciences.

Purpose of the study
This project aims to find out how people with disability foster a sense of safety, belonging and choice in disability accommodation settings.

What will I be asked to do?
You are invited to attend a series of one-on-one interview. Each interview has it's own theme.

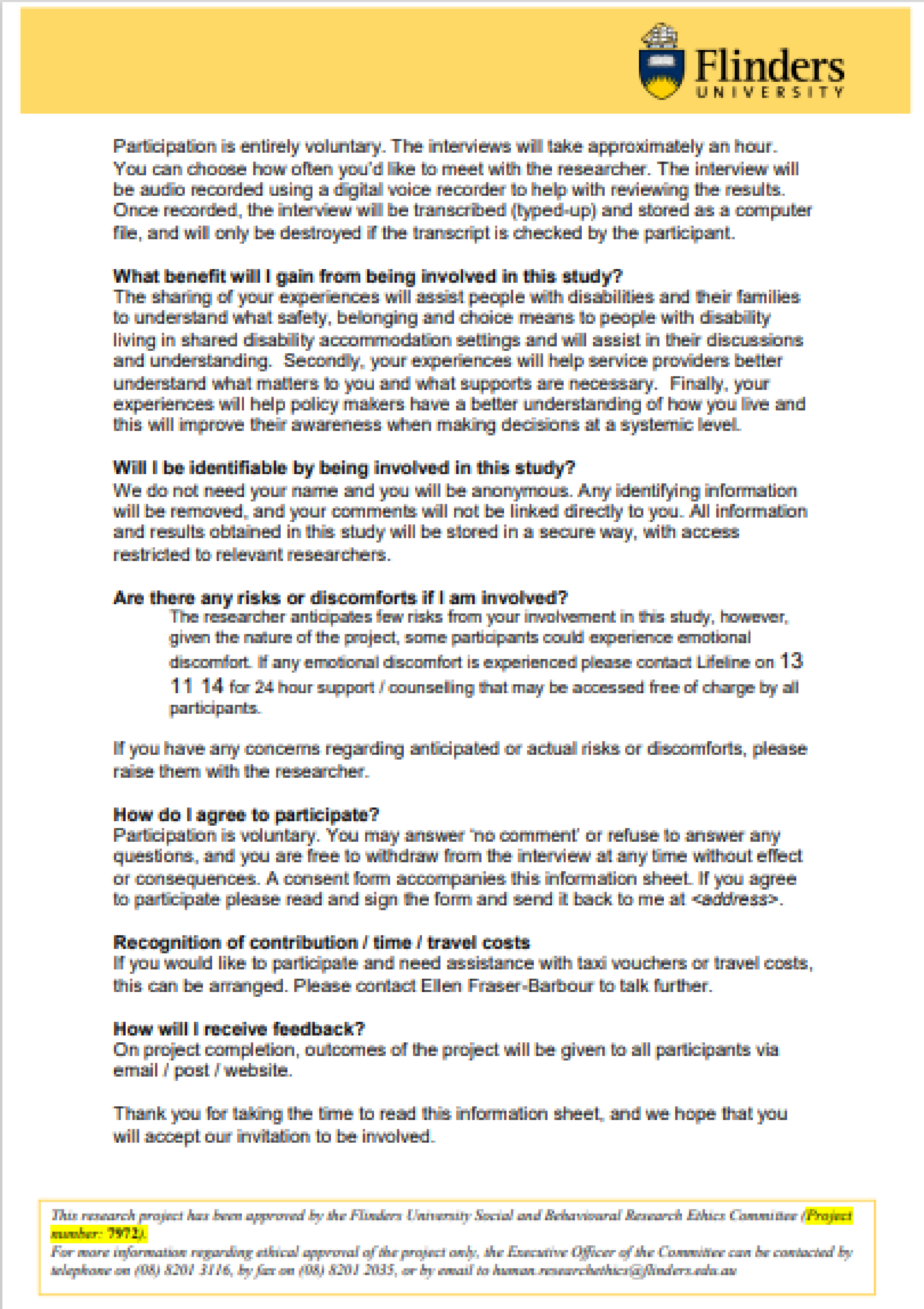
The first interview will gather information about who you are and your background. Then you will be asked to take some photos of your home life. These photos will be shared with the researcher in the second interview and will form the basis for questions about your home life. The third and final interview will be about strengths, hopes, dreams.

All three of these interviews are to find out more about three aspects:

- how safe and secure do you feel in your home
- Do you belong and feel at home where you live and with people you live with?
- Do you have freedom and authority to make choice and have control over what happens in your home?

If you would like to, during any or all of these interviews there is the potential to do some art as a way to further generate discussion and conversation about your views and thoughts on safety belonging and agency.

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project number: 7972).



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Participation is entirely voluntary. The interviews will take approximately an hour. You can choose how often you'd like to meet with the researcher. The interview will be audio recorded using a digital voice recorder to help with reviewing the results. Once recorded, the interview will be transcribed (typed-up) and stored as a computer file, and will only be destroyed if the transcript is checked by the participant.

What benefit will I gain from being involved in this study?
The sharing of your experiences will assist people with disabilities and their families to understand what safety, belonging and choice means to people with disability living in shared disability accommodation settings and will assist in their discussions and understanding. Secondly, your experiences will help service providers better understand what matters to you and what supports are necessary. Finally, your experiences will help policy makers have a better understanding of how you live and this will improve their awareness when making decisions at a systemic level.

Will I be identifiable by being involved in this study?
We do not need your name and you will be anonymous. Any identifying information will be removed, and your comments will not be linked directly to you. All information and results obtained in this study will be stored in a secure way, with access restricted to relevant researchers.

Are there any risks or discomforts if I am involved?
The researcher anticipates few risks from your involvement in this study, however, given the nature of the project, some participants could experience emotional discomfort. If any emotional discomfort is experienced please contact Lifeline on 13 11 14 for 24 hour support / counselling that may be accessed free of charge by all participants.

If you have any concerns regarding anticipated or actual risks or discomforts, please raise them with the researcher.

How do I agree to participate?
Participation is voluntary. You may answer 'no comment' or refuse to answer any questions, and you are free to withdraw from the interview at any time without effect or consequences. A consent form accompanies this information sheet. If you agree to participate please read and sign the form and send it back to me at <address>.

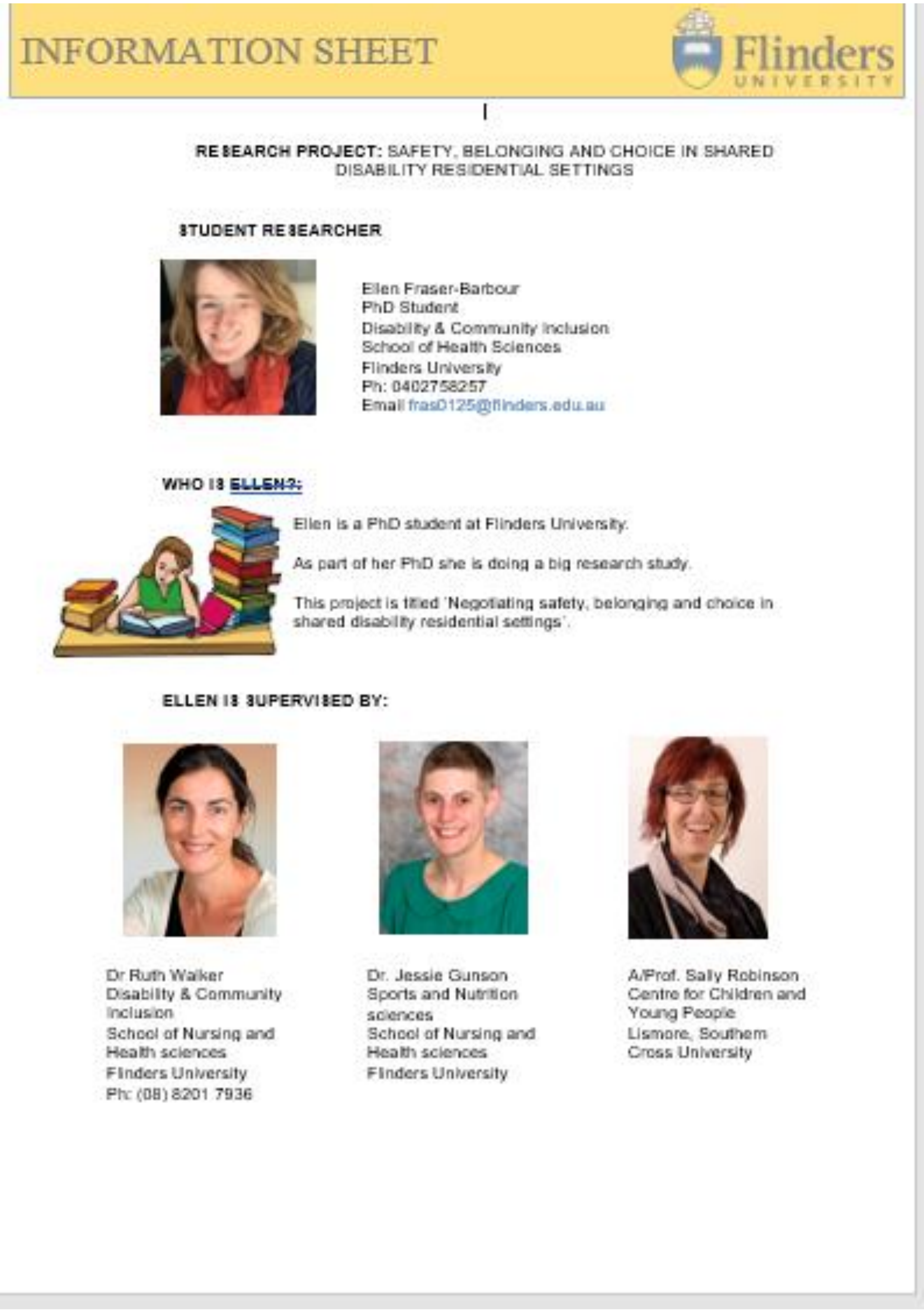
Recognition of contribution / time / travel costs
If you would like to participate and need assistance with taxi vouchers or travel costs, this can be arranged. Please contact Ellen Fraser-Barbour to talk further.

How will I receive feedback?
On project completion, outcomes of the project will be given to all participants via email / post / website.

Thank you for taking the time to read this information sheet, and we hope that you will accept our invitation to be involved.

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project number: 7972).
For more information regarding ethical approval of the project only, the Executive Officer of the Committee can be contacted by telephone on (08) 8201 3116, by fax on (08) 8201 2035, or by email to human.researchethics@flinders.edu.au

Appendix E: Easy-read information sheet



INFORMATION SHEET

Flinders UNIVERSITY

RESEARCH PROJECT: SAFETY, BELONGING AND CHOICE IN SHARED DISABILITY RESIDENTIAL SETTINGS

STUDENT RESEARCHER

Ellen Fraser-Barbour
PhD Student
Disability & Community Inclusion
School of Health Sciences
Flinders University
Ph: 0402758257
Email fras0125@flinders.edu.au

WHO IS ELLEN?:

Ellen is a PhD student at Flinders University.

As part of her PhD she is doing a big research study.

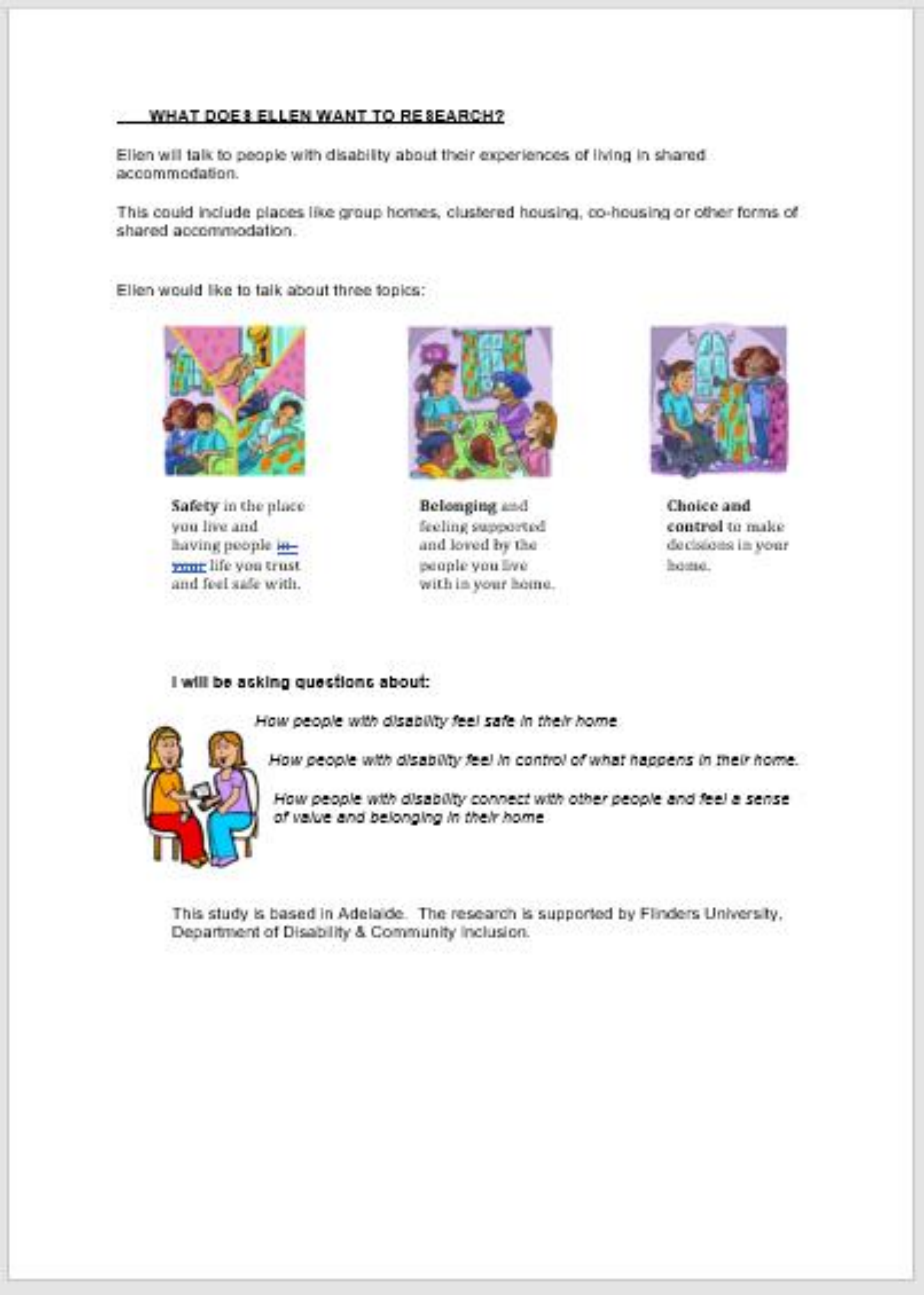
This project is titled 'Negotiating safety, belonging and choice in shared disability residential settings'.

ELLEN IS SUPERVISED BY:

Dr Ruth Walker
Disability & Community Inclusion
School of Nursing and Health sciences
Flinders University
Ph: (08) 8201 7936

Dr. Jessie Gunson
Sports and Nutrition sciences
School of Nursing and Health sciences
Flinders University

A/Prof. Sally Robinson
Centre for Children and Young People
Lismore, Southern Cross University



WHAT DOES ELLEN WANT TO RESEARCH?

Ellen will talk to people with disability about their experiences of living in shared accommodation.

This could include places like group homes, clustered housing, co-housing or other forms of shared accommodation.

Ellen would like to talk about three topics:

Safety in the place you live and having people ~~in~~ your life you trust and feel safe with.

Belonging and feeling supported and loved by the people you live with in your home.

Choice and control to make decisions in your home.

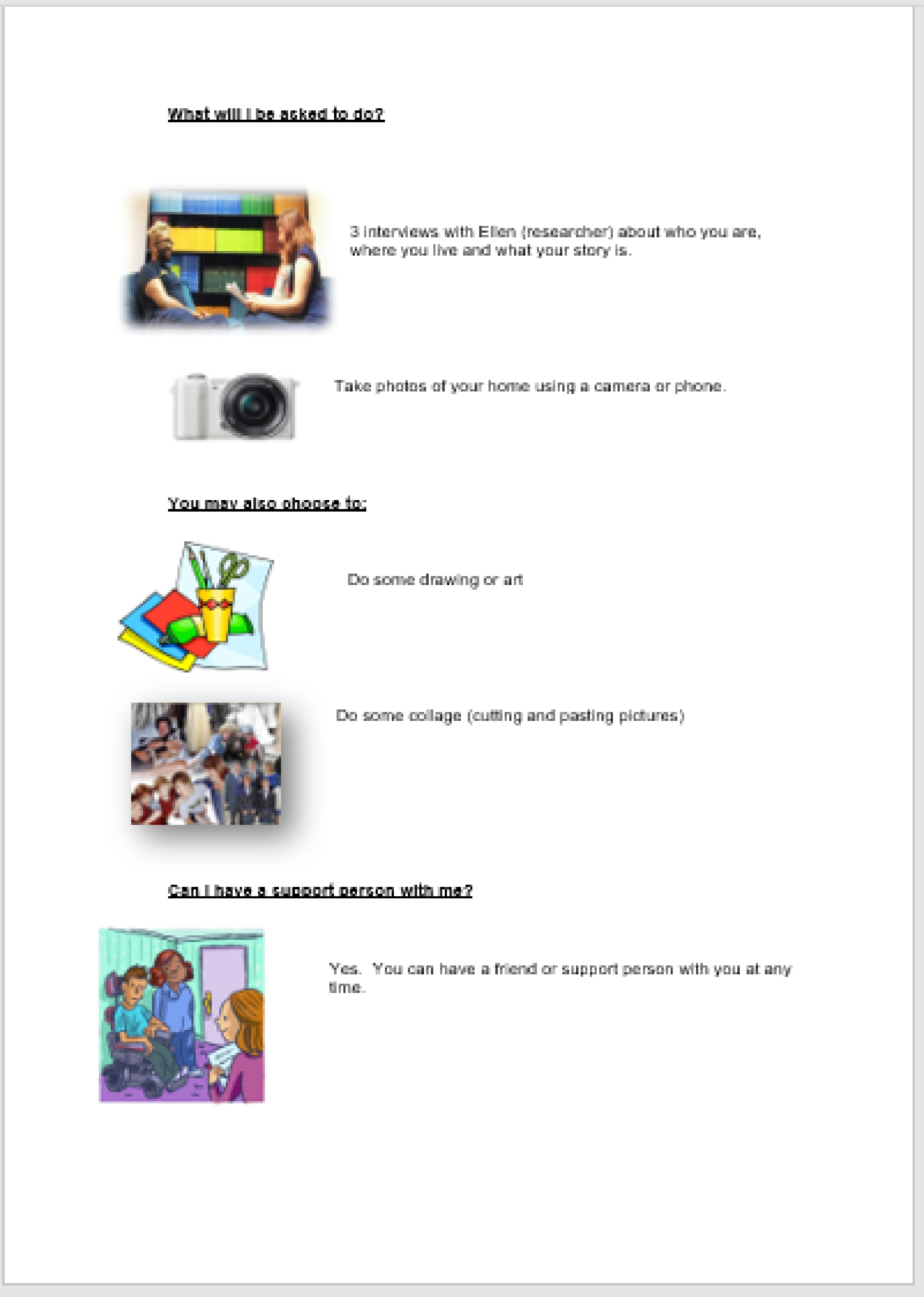
I will be asking questions about:

How people with disability feel safe in their home

How people with disability feel in control of what happens in their home.

How people with disability connect with other people and feel a sense of value and belonging in their home

This study is based in Adelaide. The research is supported by Flinders University, Department of Disability & Community Inclusion.



What will I be asked to do?

3 interviews with Ellen (researcher) about who you are, where you live and what your story is.

Take photos of your home using a camera or phone.

You may also choose to:

Do some drawing or art

Do some collage (cutting and pasting pictures)

Can I have a support person with me?

Yes. You can have a friend or support person with you at any time.

What will you do with the information I give you?

If it's okay with you, what you say will be recorded on audio-tape. This is to make sure we don't forget anything you've said.

After Ellen has interviewed everyone, she will write a report which Will be online for all to read.

WHAT DO I GET OUT OF BEING PART OF THIS PROJECT?

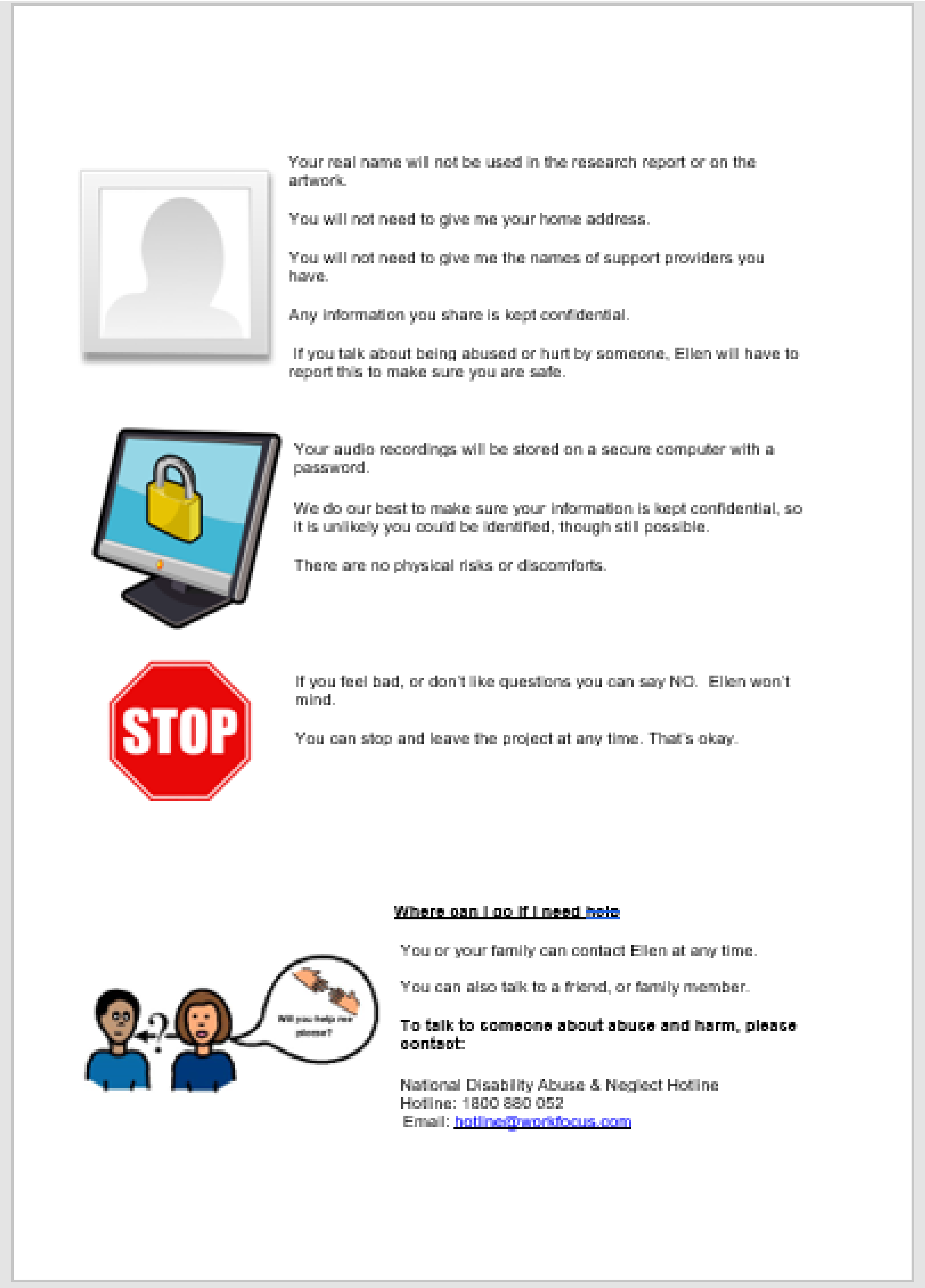
Your stories, photos and art can help in many ways.

It will help other people with disability.

It will help disability service providers.

It will also help policy makers.

Will I get in trouble if I do this study?



Your real name will not be used in the research report or on the artwork.

You will not need to give me your home address.

You will not need to give me the names of support providers you have.

Any information you share is kept confidential.

If you talk about being abused or hurt by someone, Ellen will have to report this to make sure you are safe.

Your audio recordings will be stored on a secure computer with a password.

We do our best to make sure your information is kept confidential, so it is unlikely you could be identified, though still possible.

There are no physical risks or discomforts.

If you feel bad, or don't like questions you can say NO. Ellen won't mind.

You can stop and leave the project at any time. That's okay.

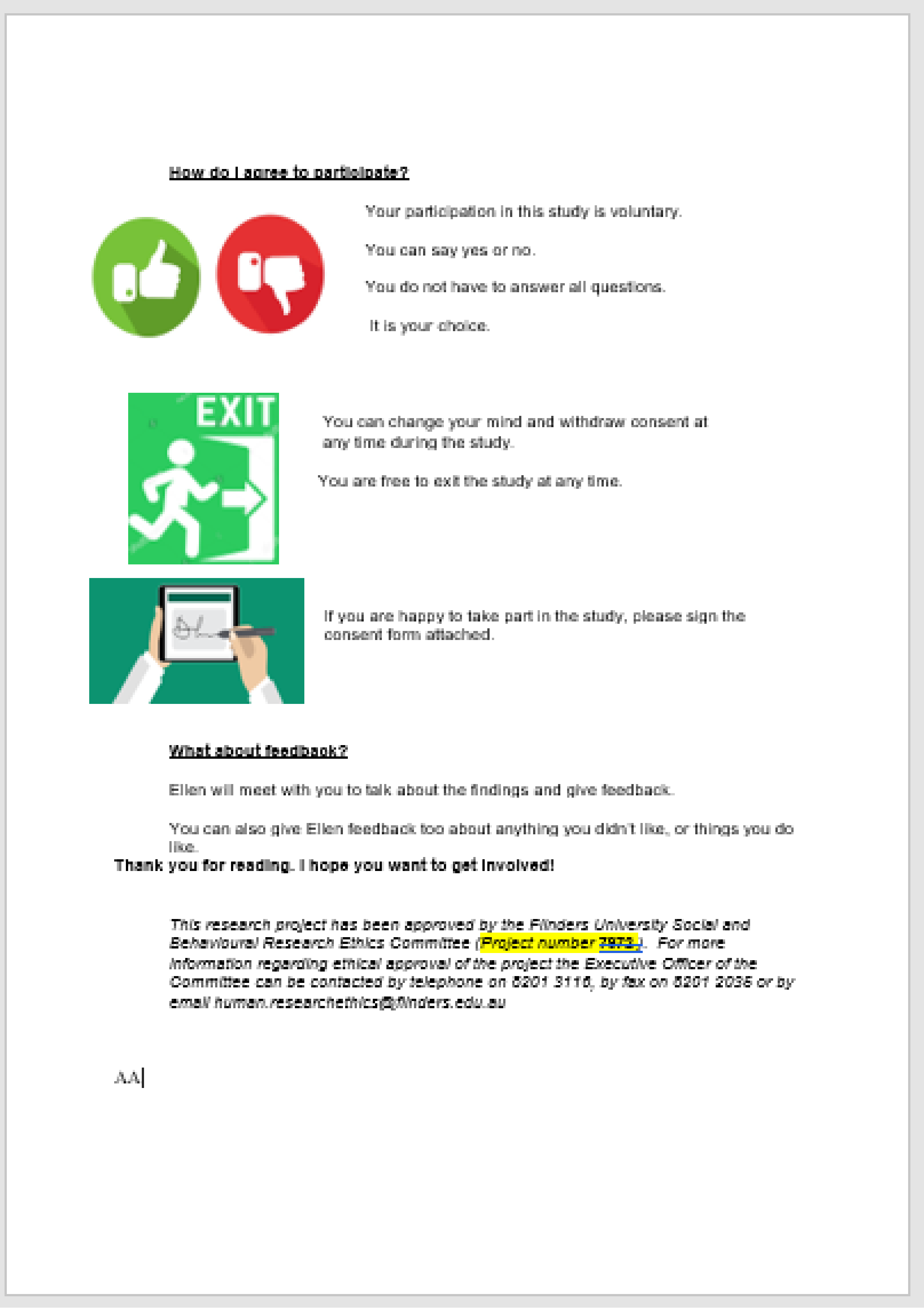
Where can I go if I need help

You or your family can contact Ellen at any time.

You can also talk to a friend, or family member.

To talk to someone about abuse and harm, please contact:

National Disability Abuse & Neglect Hotline
Hotline: 1800 880 052
Email: hotline@workfocus.com



How do I agree to participate?

Your participation in this study is voluntary.

You can say yes or no.

You do not have to answer all questions.

It is your choice.

You can change your mind and withdraw consent at any time during the study.

You are free to exit the study at any time.

If you are happy to take part in the study, please sign the consent form attached.

What about feedback?

Ellen will meet with you to talk about the findings and give feedback.

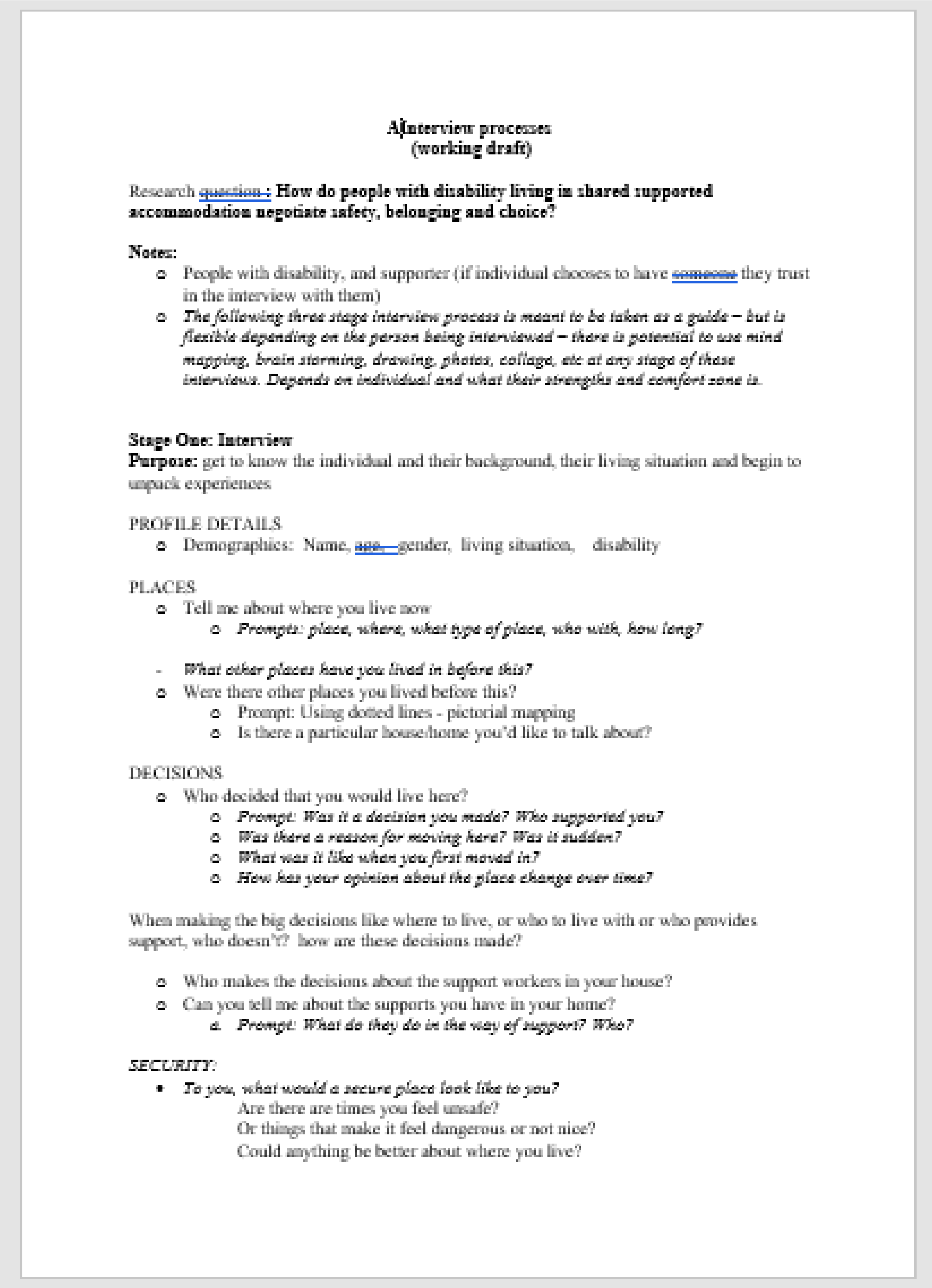
You can also give Ellen feedback too about anything you didn't like, or things you do like.

Thank you for reading. I hope you want to get involved!

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project number 7972). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au

AA

Appendix F: Semi-structured interview prompt sessions



AInterview processes
(working draft)

Research ~~question :~~ **How do people with disability living in shared supported accommodation negotiate safety, belonging and choice?**

Notes:

- People with disability, and supporter (if individual chooses to have ~~someone~~ they trust in the interview with them)
- *The following three stage interview process is meant to be taken as a guide – but is flexible depending on the person being interviewed – there is potential to use mind mapping, brain storming, drawing, photos, collage, etc at any stage of these interviews. Depends on individual and what their strengths and comfort zone is.*

Stage One: Interview
Purpose: get to know the individual and their background, their living situation and begin to unpack experiences

PROFILE DETAILS

- Demographics: Name, ~~age,~~ gender, living situation, disability

PLACES

- Tell me about where you live now
    - *Prompts: place, where, what type of place, who with, how long?*

- *What other places have you lived in before this?*
- Were there other places you lived before this?
    - Prompt: Using dotted lines - pictorial mapping
    - Is there a particular house/home you'd like to talk about?

DECISIONS

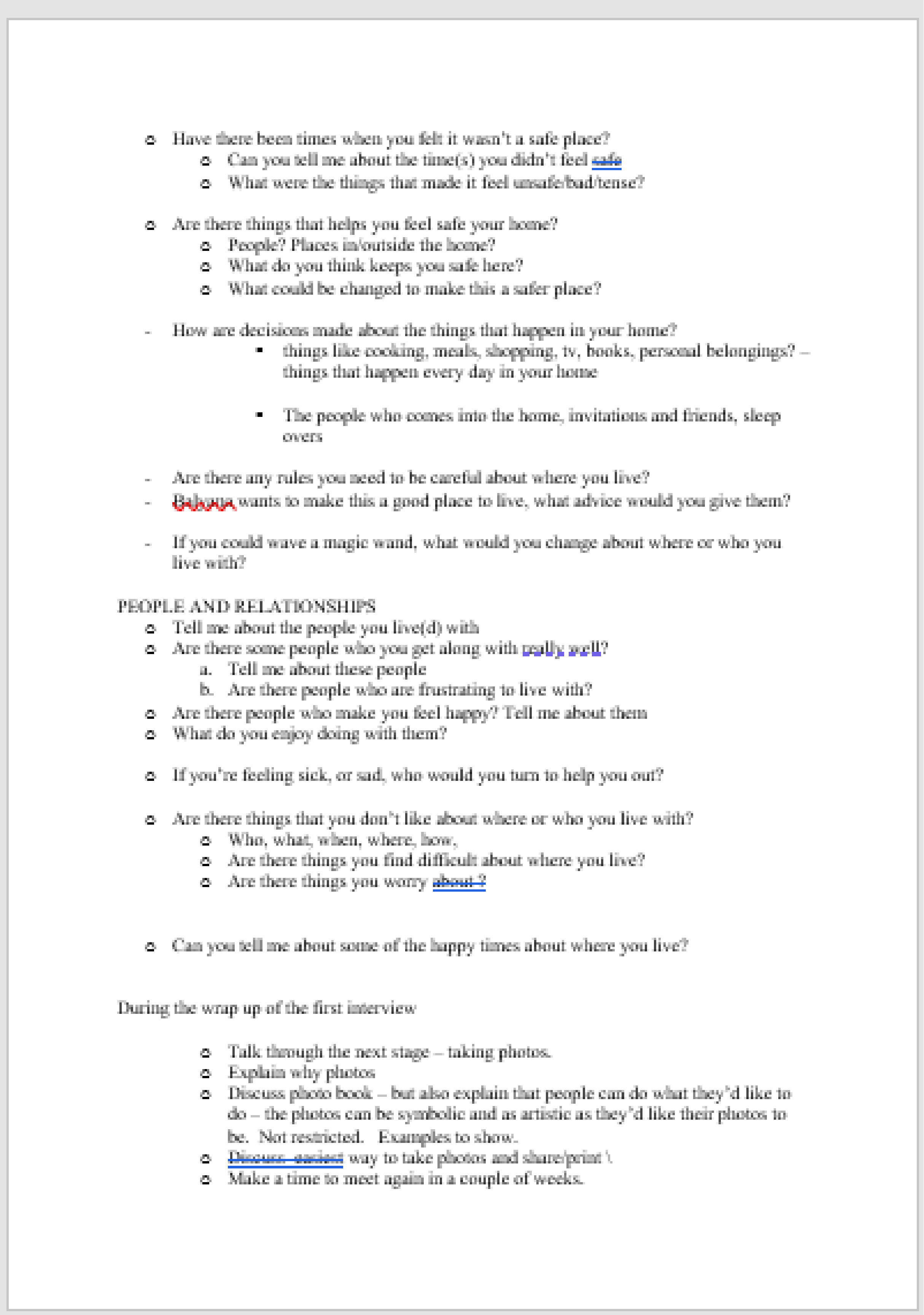
- Who decided that you would live here?
    - *Prompt: Was it a decision you made? Who supported you?*
    - *Was there a reason for moving here? Was it sudden?*
    - *What was it like when you first moved in?*
    - *How has your opinion about the place change over time?*

When making the big decisions like where to live, or who to live with or who provides support, who doesn't? how are these decisions made?

- Who makes the decisions about the support workers in your house?
- Can you tell me about the supports you have in your home?
    a. *Prompt: What do they do in the way of support? Who?*

SECURITY:

- *To you, what would a secure place look like to you?*
  Are there are times you feel unsafe?
  Or things that make it feel dangerous or not nice?
  Could anything be better about where you live?



- Have there been times when you felt it wasn't a safe place?
    - Can you tell me about the time(s) you didn't feel safe
    - What were the things that made it feel unsafe/bad/tense?

- Are there things that helps you feel safe your home?
    - People? Places in/outside the home?
    - What do you think keeps you safe here?
    - What could be changed to make this a safer place?

- How are decisions made about the things that happen in your home?
    - things like cooking, meals, shopping, tv, books, personal belongings? – things that happen every day in your home

    - The people who comes into the home, invitations and friends, sleep overs

- Are there any rules you need to be careful about where you live?
- Bahoua wants to make this a good place to live, what advice would you give them?

- If you could wave a magic wand, what would you change about where or who you live with?

PEOPLE AND RELATIONSHIPS

- Tell me about the people you live(d) with
- Are there some people who you get along with really well?
    a. Tell me about these people
    b. Are there people who are frustrating to live with?
- Are there people who make you feel happy? Tell me about them
- What do you enjoy doing with them?

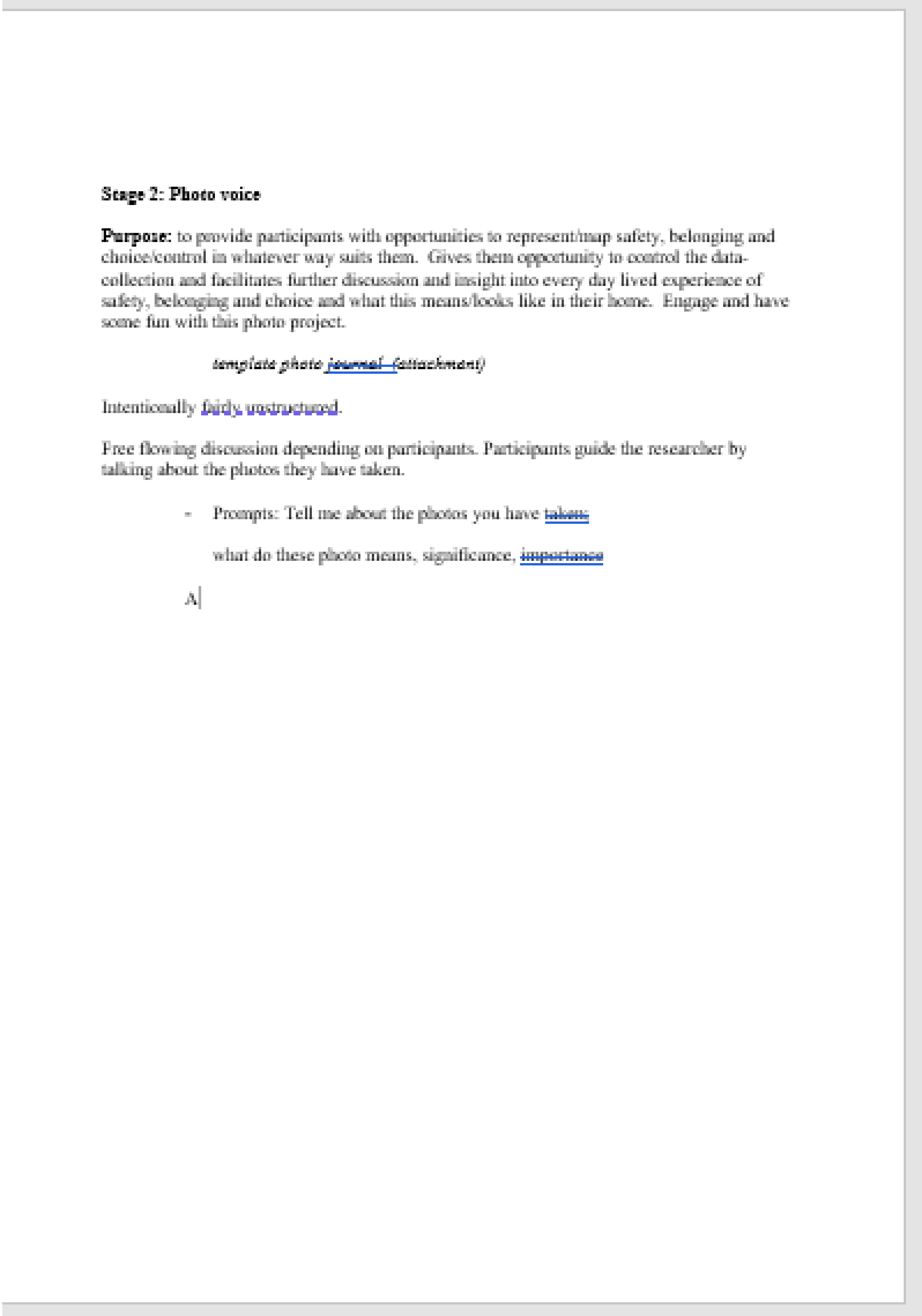
- If you're feeling sick, or sad, who would you turn to help you out?

- Are there things that you don't like about where or who you live with?
    - Who, what, when, where, how,
    - Are there things you find difficult about where you live?
    - Are there things you worry about ?

- Can you tell me about some of the happy times about where you live?

During the wrap up of the first interview

- Talk through the next stage – taking photos.
- Explain why photos
- Discuss photo book – but also explain that people can do what they'd like to do – the photos can be symbolic and as artistic as they'd like their photos to be. Not restricted. Examples to show.
- Discuss easiest way to take photos and share/print \
- Make a time to meet again in a couple of weeks.



Stage 2: Photo voice

Purpose: to provide participants with opportunities to represent/map safety, belonging and choice/control in whatever way suits them. Gives them opportunity to control the data-collection and facilitates further discussion and insight into every day lived experience of safety, belonging and choice and what this means/looks like in their home. Engage and have some fun with this photo project.

template photo ~~journal -~~ (attachment)

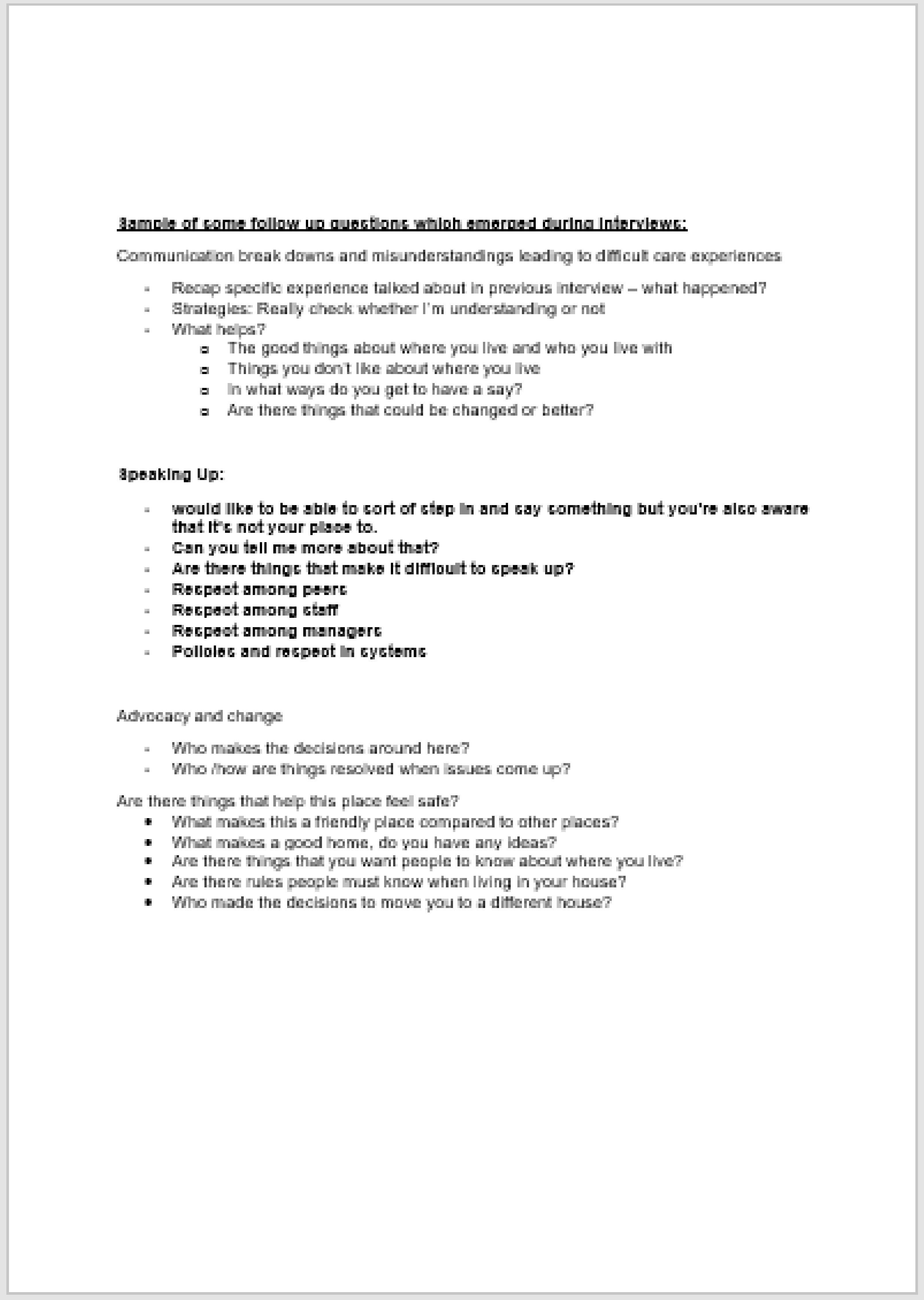
Intentionally fairly unstructured.

Free flowing discussion depending on participants. Participants guide the researcher by talking about the photos they have taken.

- Prompts: Tell me about the photos you have ~~taken:~~

  what do these photo means, significance, ~~importance~~

A



<u>Sample of some follow up questions which emerged during interviews:</u>

Communication break downs and misunderstandings leading to difficult care experiences

- Recap specific experience talked about in previous interview – what happened?
- Strategies: Really check whether I'm understanding or not
- What helps?
    - The good things about where you live and who you live with
    - Things you don't like about where you live
    - In what ways do you get to have a say?
    - Are there things that could be changed or better?

Speaking Up:

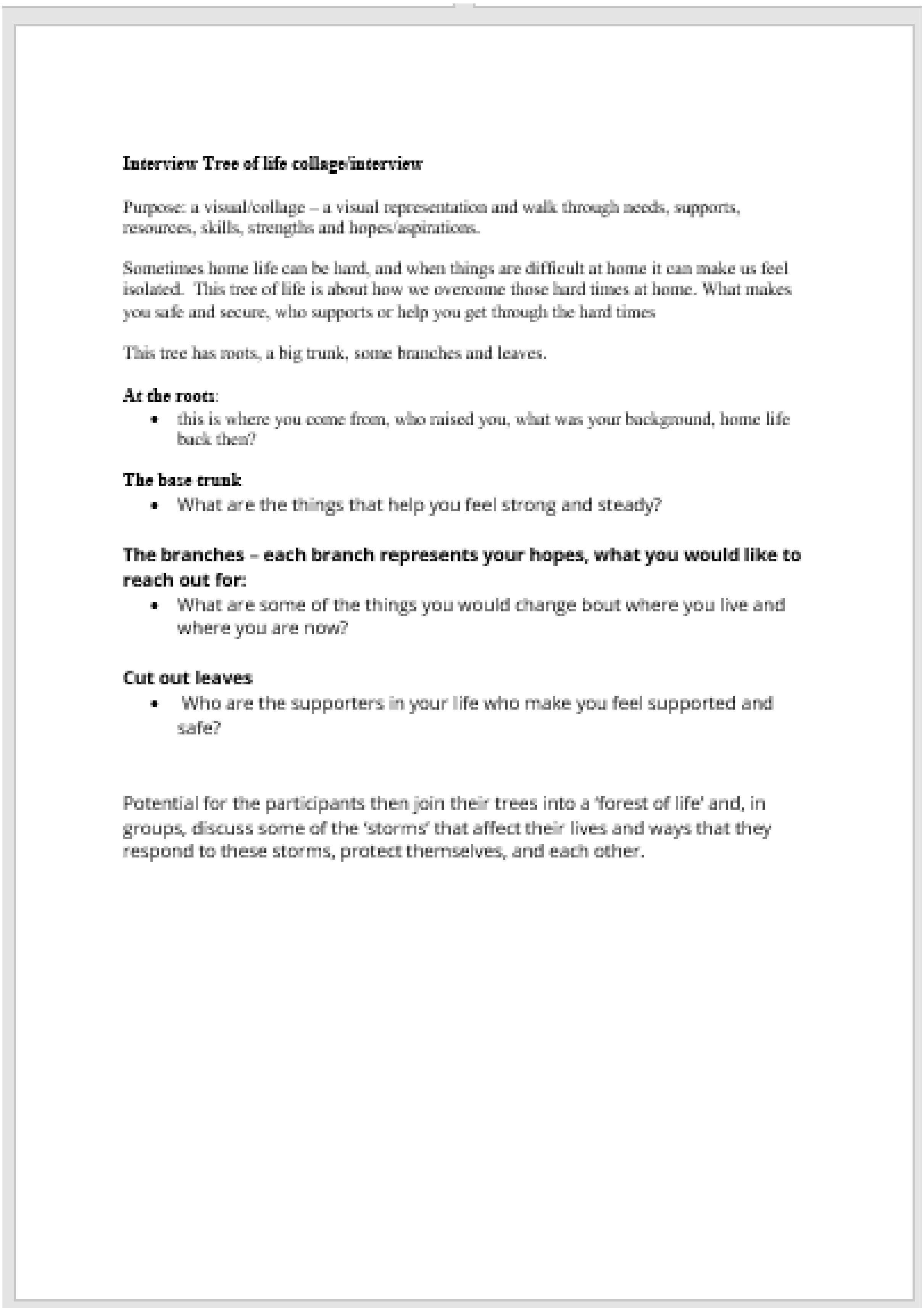
- **would like to be able to sort of step in and say something but you're also aware that it's not your place to.**
- **Can you tell me more about that?**
- **Are there things that make it difficult to speak up?**
- **Respect among peers**
- **Respect among staff**
- **Respect among managers**
- **Policies and respect in systems**

Advocacy and change

- Who makes the decisions around here?
- Who /how are things resolved when issues come up?

Are there things that help this place feel safe?

- What makes this a friendly place compared to other places?
- What makes a good home, do you have any ideas?
- Are there things that you want people to know about where you live?
- Are there rules people must know when living in your house?
- Who made the decisions to move you to a different house?



Interview Tree of life collage/interview

Purpose: a visual/collage – a visual representation and walk through needs, supports, resources, skills, strengths and hopes/aspirations.

Sometimes home life can be hard, and when things are difficult at home it can make us feel isolated. This tree of life is about how we overcome those hard times at home. What makes you safe and secure, who supports or help you get through the hard times

This tree has roots, a big trunk, some branches and leaves.

At the roots:

- this is where you come from, who raised you, what was your background, home life back then?

The base trunk

- What are the things that help you feel strong and steady?

The branches – each branch represents your hopes, what you would like to reach out for:

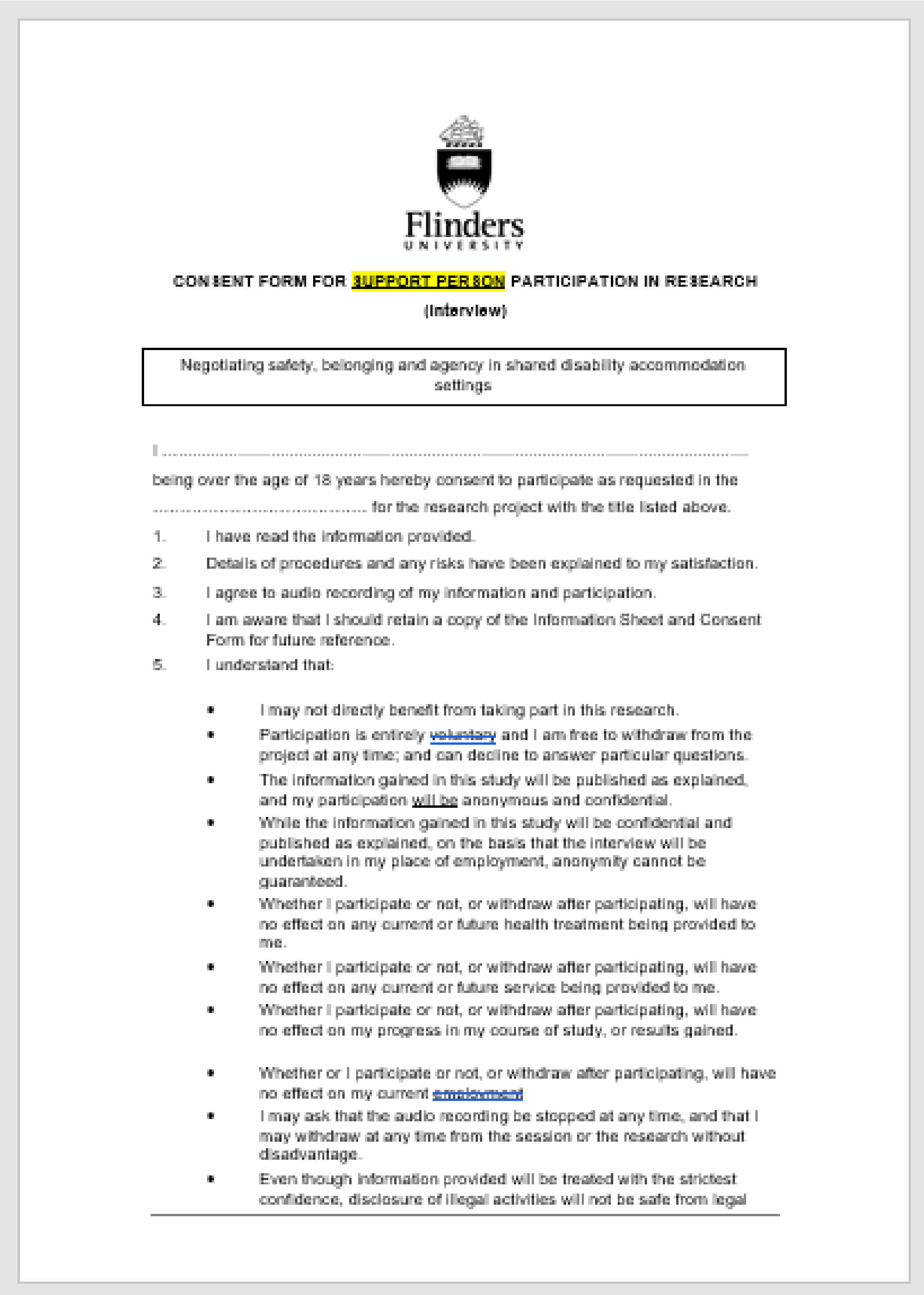
- What are some of the things you would change bout where you live and where you are now?

Cut out leaves

- Who are the supporters in your life who make you feel supported and safe?

Potential for the participants then join their trees into a 'forest of life' and, in groups, discuss some of the 'storms' that affect their lives and ways that they respond to these storms, protect themselves, and each other.

Appendix G: Support person consent form



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CONSENT FORM FOR SUPPORT PERSON PARTICIPATION IN RESEARCH

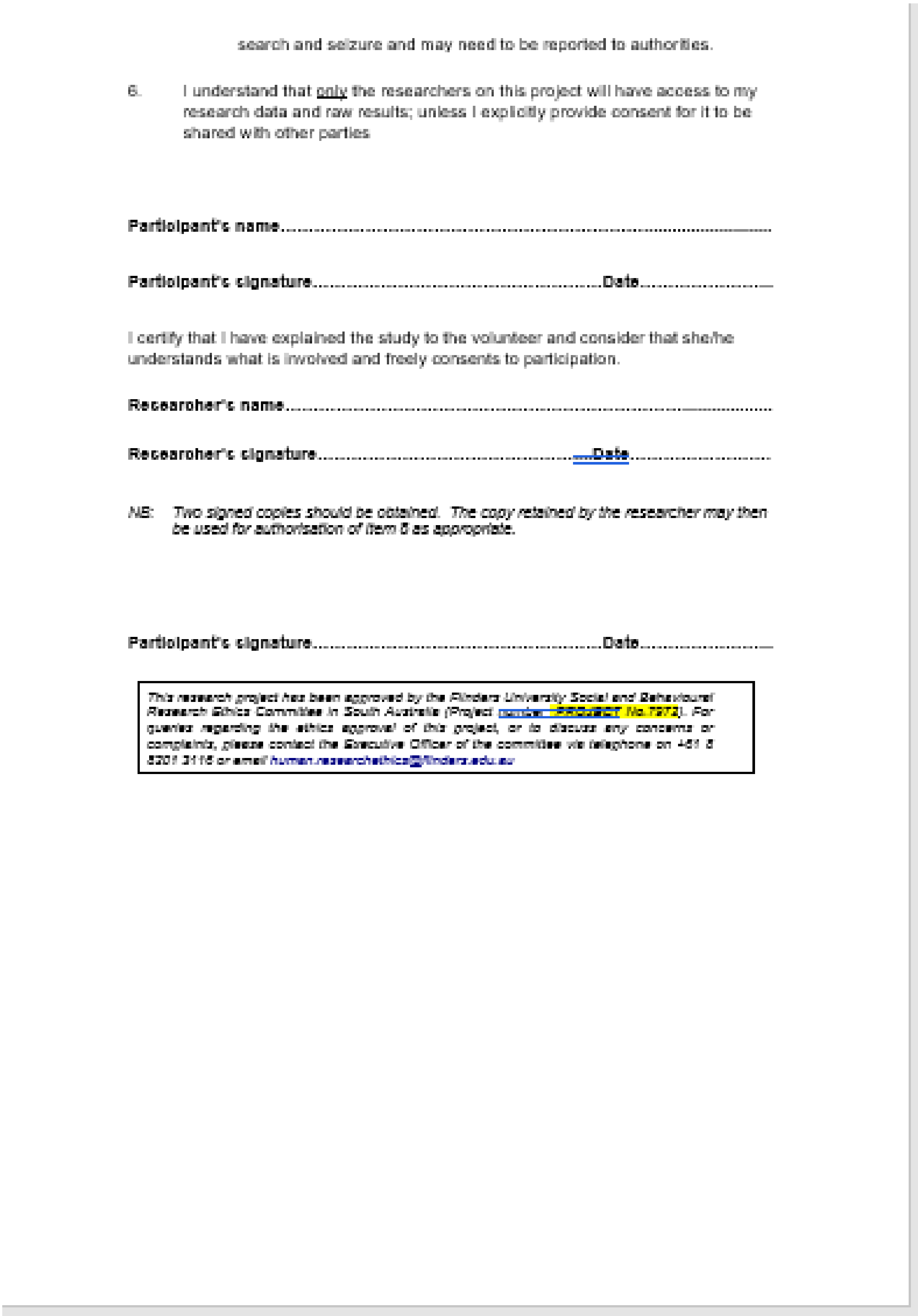
(Interview)

Negotiating safety, belonging and agency in shared disability accommodation settings

I ....

being over the age of 18 years hereby consent to participate as requested in the .... for the research project with the title listed above.

1. I have read the information provided.
2. Details of procedures and any risks have been explained to my satisfaction.
3. I agree to audio recording of my information and participation.
4. I am aware that I should retain a copy of the Information Sheet and Consent Form for future reference.
5. I understand that:
    - I may not directly benefit from taking part in this research.
    - Participation is entirely voluntary and I am free to withdraw from the project at any time; and can decline to answer particular questions.
    - The information gained in this study will be published as explained, and my participation will be anonymous and confidential.
    - While the information gained in this study will be confidential and published as explained, on the basis that the interview will be undertaken in my place of employment, anonymity cannot be guaranteed.
    - Whether I participate or not, or withdraw after participating, will have no effect on any current or future health treatment being provided to me.
    - Whether I participate or not, or withdraw after participating, will have no effect on any current or future service being provided to me.
    - Whether I participate or not, or withdraw after participating, will have no effect on my progress in my course of study, or results gained.
    - Whether or I participate or not, or withdraw after participating, will have no effect on my current employment
    - I may ask that the audio recording be stopped at any time, and that I may withdraw at any time from the session or the research without disadvantage.
    - Even though information provided will be treated with the strictest confidence, disclosure of illegal activities will not be safe from legal



search and seizure and may need to be reported to authorities.

6. I understand that <u>only</u> the researchers on this project will have access to my research data and raw results; unless I explicitly provide consent for it to be shared with other parties

Participant's name...

Participant's signature...**Date**.......................

I certify that I have explained the study to the volunteer and consider that she/he understands what is involved and freely consents to participation.

Researcher's name...

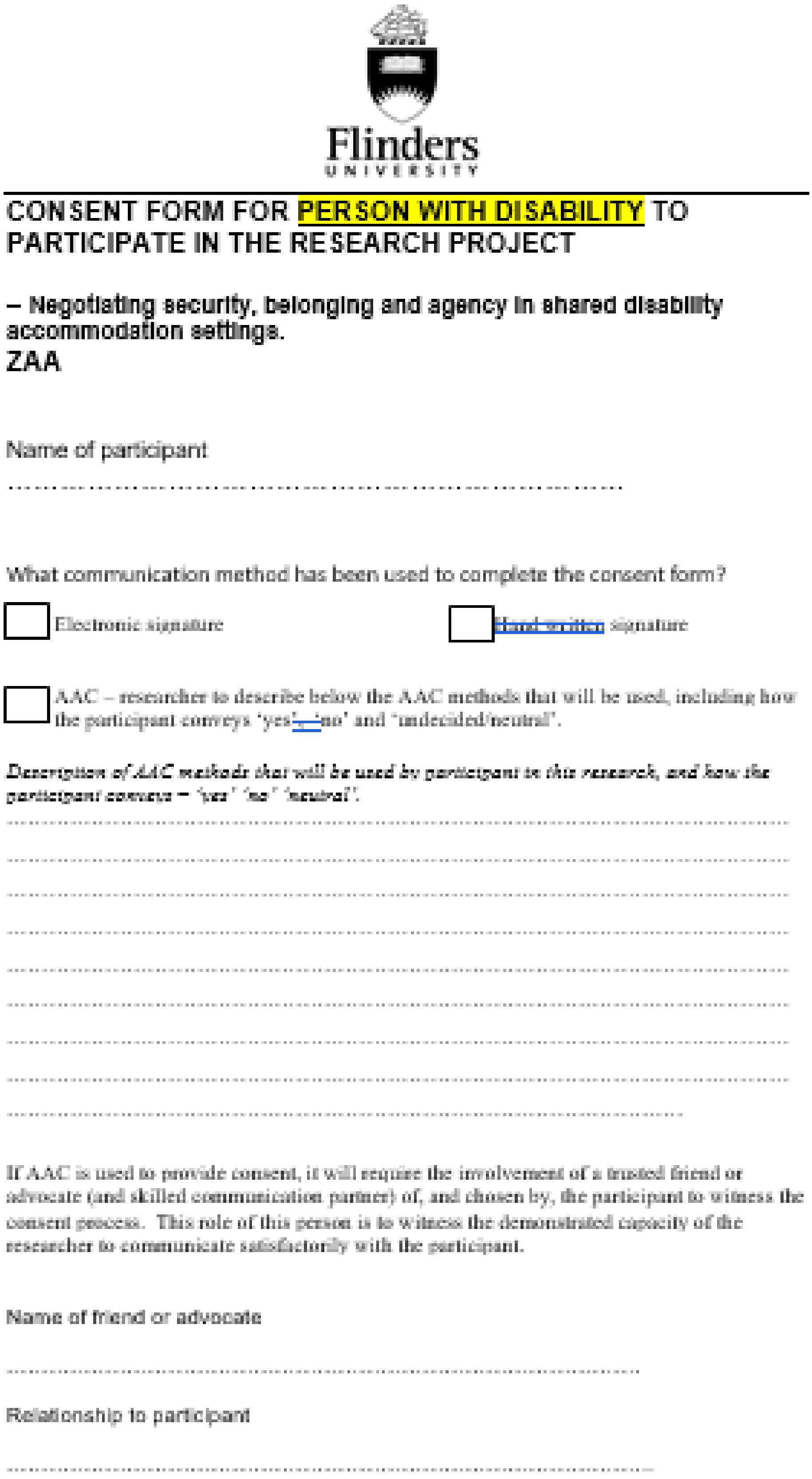
Researcher's signature...**Date**.......................

NB: Two signed copies should be obtained. The copy retained by the researcher may then be used for authorisation of item 5 as appropriate.

Participant's signature...**Date**.......................

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee in South Australia (Project ~~number 'PROJECT~~ No.7272). For queries regarding the ethics approval of this project, or to discuss any concerns or complaints, please contact the Executive Officer of the committee via telephone on +61 8 8201 3116 or email human.researchethics@flinders.edu.au

Appendix H: Person with disability consent form



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CONSENT FORM FOR PERSON WITH DISABILITY TO PARTICIPATE IN THE RESEARCH PROJECT

– Negotiating security, belonging and agency in shared disability accommodation settings.

ZAA

Name of participant

…………………………………………………………………………

What communication method has been used to complete the consent form?

☐ Electronic signature ☐ ~~Hand written~~ signature

☐ AAC – researcher to describe below the AAC methods that will be used, including how the participant conveys 'yes', 'no' and 'undecided/neutral'.

Description of AAC methods that will be used by participant in this research, and how the participant conveys – 'yes' 'no' 'neutral'.

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If AAC is used to provide consent, it will require the involvement of a trusted friend or advocate (and skilled communication partner) of, and chosen by, the participant to witness the consent process. This role of this person is to witness the demonstrated capacity of the researcher to communicate satisfactorily with the participant.

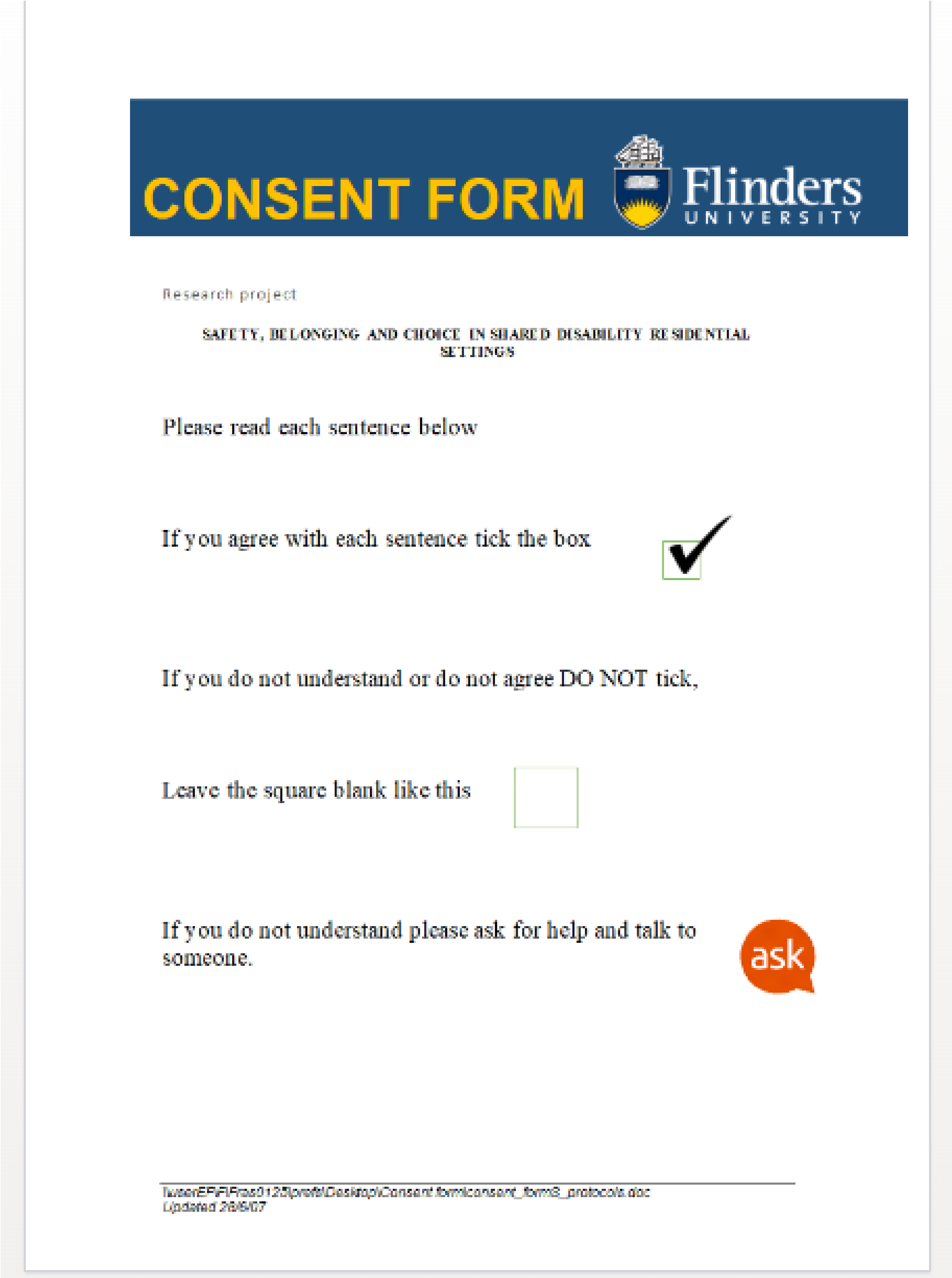
Name of friend or advocate

…………………………………………………………………………………

Relationship to participant

…………………………………………………………………………………

Appendix I: Easy-read consent form



CONSENT FORM

Flinders UNIVERSITY

Research project

SAFETY, BELONGING AND CHOICE IN SHARED DISABILITY RESIDENTIAL SETTINGS

Please read each sentence below

If you agree with each sentence tick the box ☑

If you do not understand or do not agree DO NOT tick,

Leave the square blank like this ☐

If you do not understand please ask for help and talk to someone. ask

PLEASE TICK IF THE ANSWER IF YES.

If the answer is NO, leave the square blank.

I have read the information sheet about the project. ☐

I understand the project is about my experience of living in disability shared housing. ☐

I know that Ellen wants to find out about three things: 1) safety, 2) belonging
and 3) choices in the home.

I would like to talk about these things with researcher Ellen ☐

I know this project is voluntary. ☐

I know I can stop and change my mind if I don't want to help with the project any more. ☐

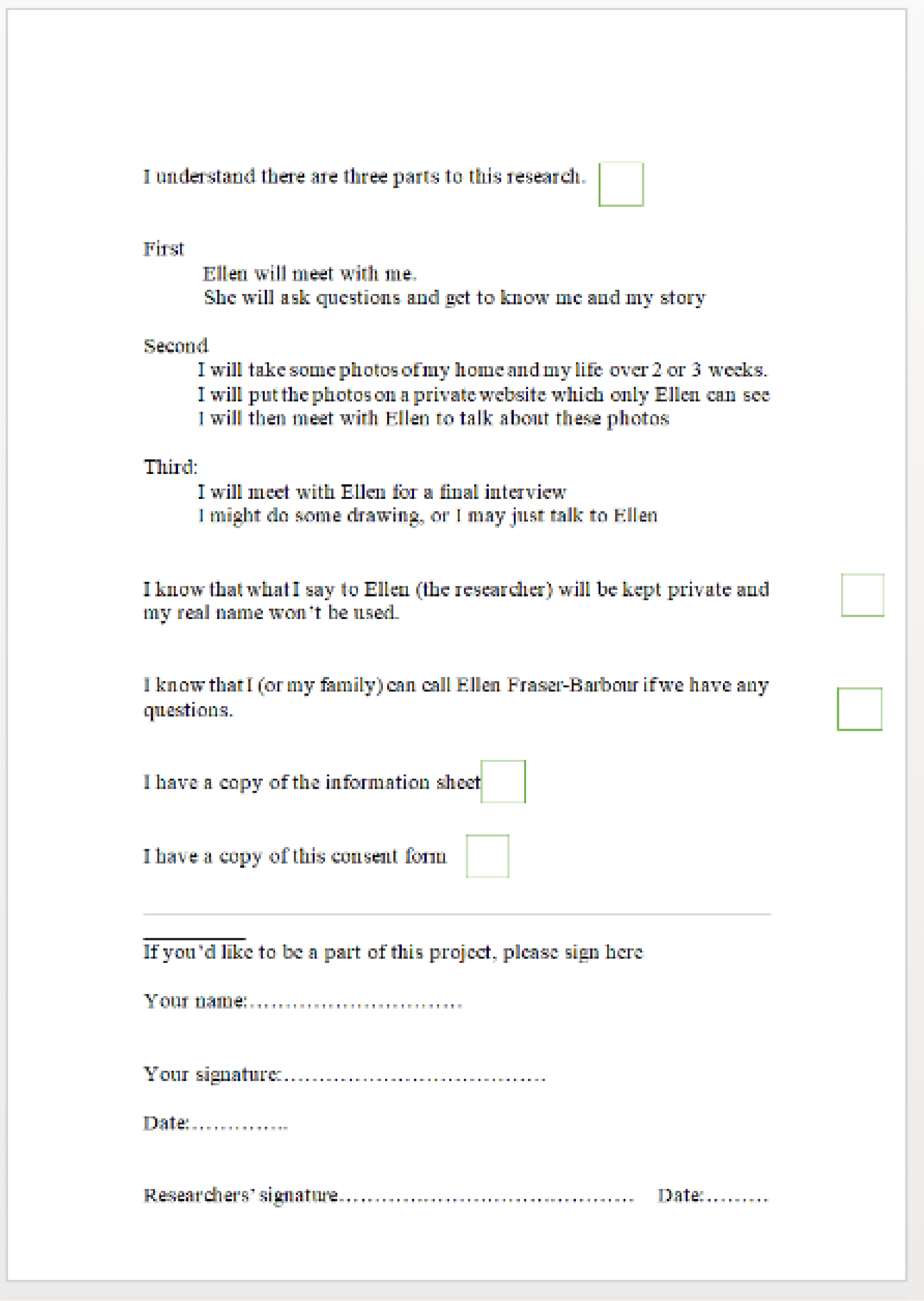
The project involves taking photos of the things in my home. ☐

I know Ellen will talk to me about my experiences. ☐

I know that I can have a friend or support person with me at any time. ☐

I understand that our interviews will be recorded. ☐

I say it is okay for the researchers to listen to the tapes. ☐



I understand there are three parts to this research. ☐

First

Ellen will meet with me.
She will ask questions and get to know me and my story

Second

I will take some photos of my home and my life over 2 or 3 weeks.
I will put the photos on a private website which only Ellen can see
I will then meet with Ellen to talk about these photos

Third:

I will meet with Ellen for a final interview
I might do some drawing, or I may just talk to Ellen

I know that what I say to Ellen (the researcher) will be kept private and my real name won't be used. ☐

I know that I (or my family) can call Ellen Fraser-Barbour if we have any questions. ☐

I have a copy of the information sheet ☐

I have a copy of this consent form ☐

If you'd like to be a part of this project, please sign here

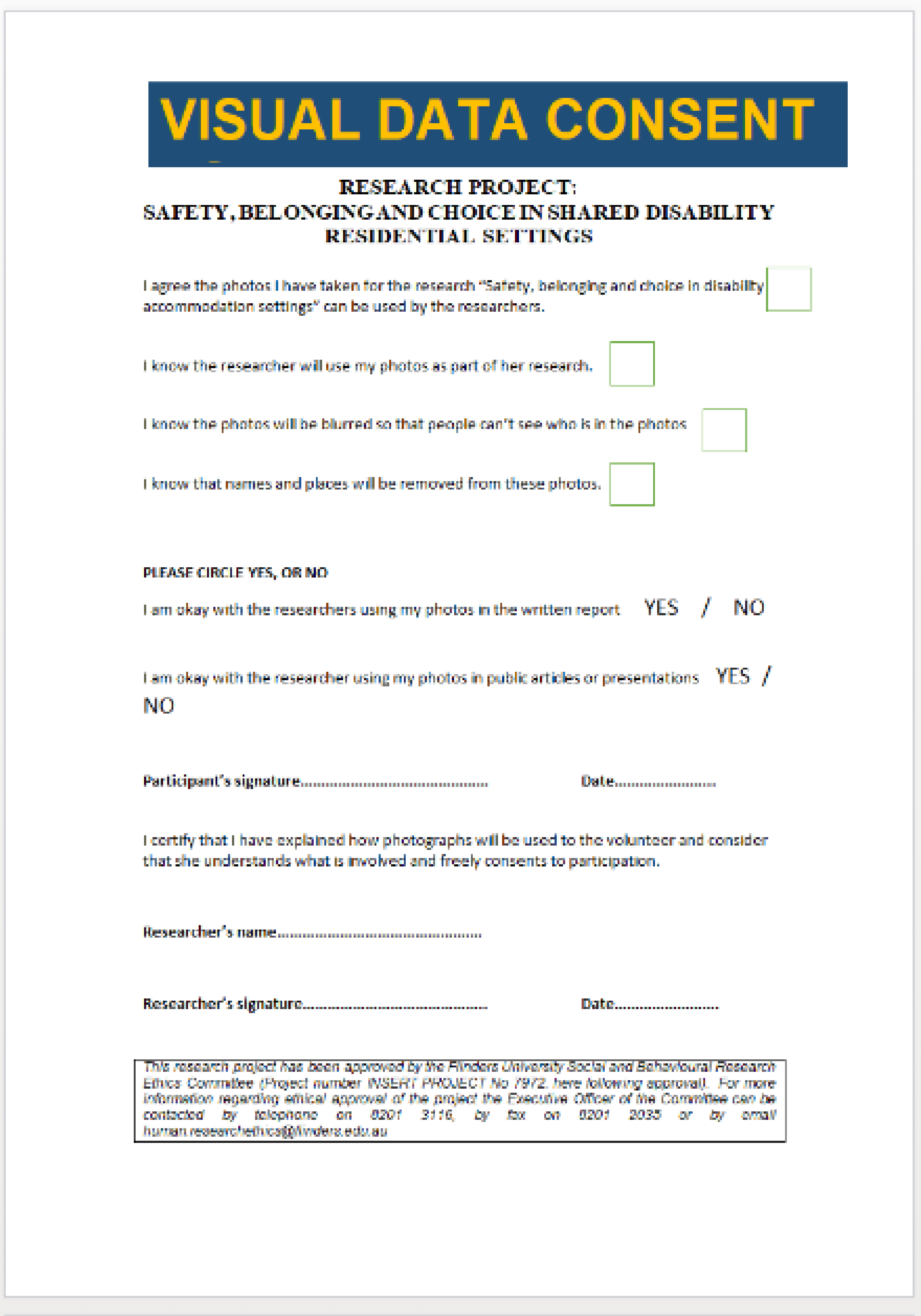
Your name:…………………………

Your signature:…………………………………

Date:…………..

Researchers' signature…………………………………… Date:………

Appendix J: Visual data consent form



VISUAL DATA CONSENT

RESEARCH PROJECT:
SAFETY, BELONGING AND CHOICE IN SHARED DISABILITY RESIDENTIAL SETTINGS

I agree the photos I have taken for the research "Safety, belonging and choice in disability accommodation settings" can be used by the researchers. ☐

I know the researcher will use my photos as part of her research. ☐

I know the photos will be blurred so that people can't see who is in the photos ☐

I know that names and places will be removed from these photos. ☐

PLEASE CIRCLE YES, OR NO

I am okay with the researchers using my photos in the written report YES / NO

I am okay with the researcher using my photos in public articles or presentations YES / NO

Participant's signature.. **Date**.........................

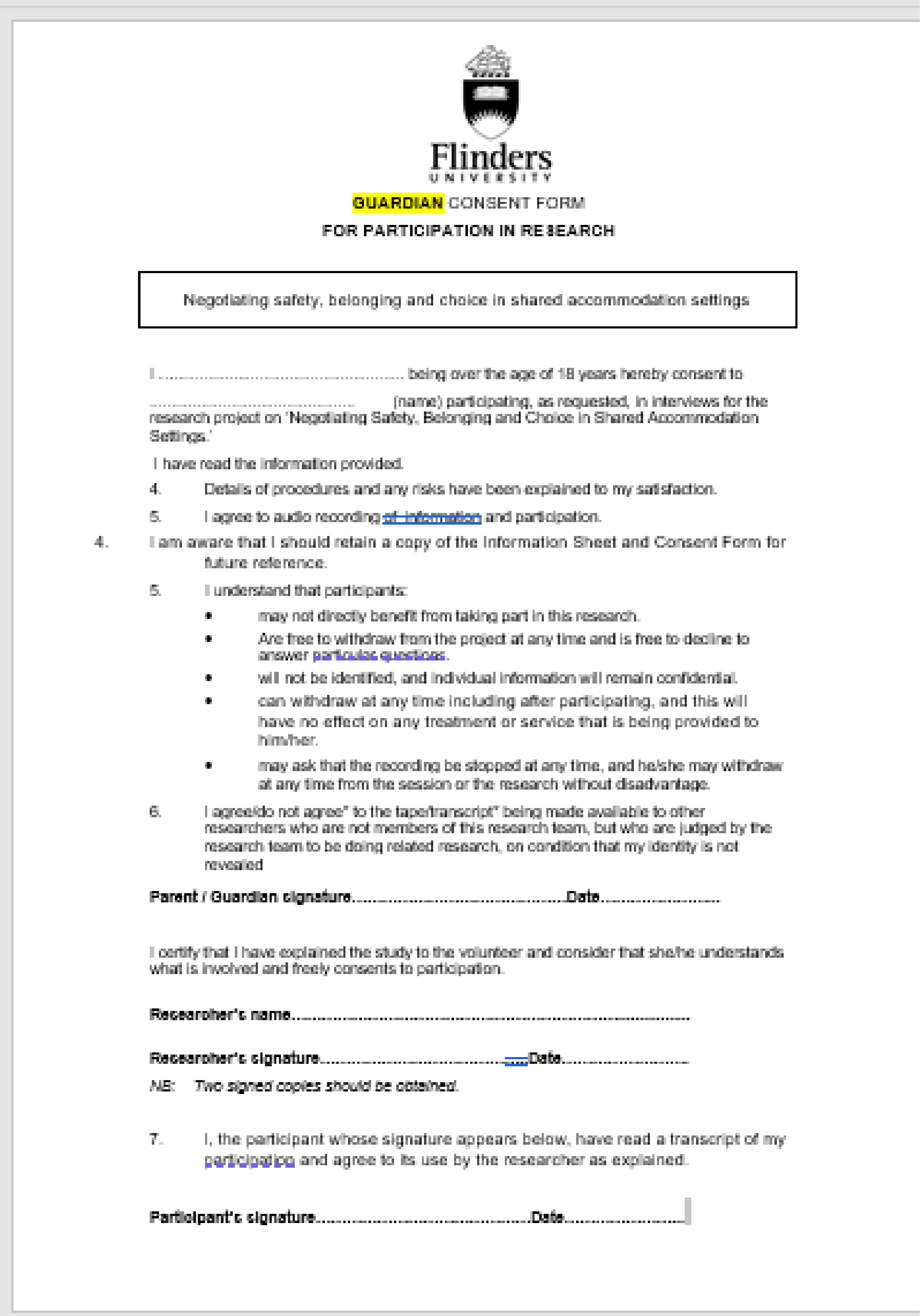
I certify that I have explained how photographs will be used to the volunteer and consider that she understands what is involved and freely consents to participation.

Researcher's name..

Researcher's signature.. **Date**.........................

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project number INSERT PROJECT No 7972. here following approval). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au

Appendix K: Legal guardian consent form



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GUARDIAN CONSENT FORM

FOR PARTICIPATION IN RESEARCH

Negotiating safety, belonging and choice in shared accommodation settings

I ………………………………………… being over the age of 18 years hereby consent to ………………………………… (name) participating, as requested, in interviews for the research project on 'Negotiating Safety, Belonging and Choice in Shared Accommodation Settings.'

I have read the information provided.

4. Details of procedures and any risks have been explained to my satisfaction.

5. I agree to audio recording ~~of information~~ and participation.

4. I am aware that I should retain a copy of the Information Sheet and Consent Form for future reference.

5. I understand that participants:
   - may not directly benefit from taking part in this research.
   - Are free to withdraw from the project at any time and is free to decline to answer particular questions.
   - will not be identified, and individual information will remain confidential.
   - can withdraw at any time including after participating, and this will have no effect on any treatment or service that is being provided to him/her.
   - may ask that the recording be stopped at any time, and he/she may withdraw at any time from the session or the research without disadvantage.

6. I agree/do not agree* to the tape/transcript* being made available to other researchers who are not members of this research team, but who are judged by the research team to be doing related research, on condition that my identity is not revealed

Parent / Guardian signature……………………………………**Date**…………………

I certify that I have explained the study to the volunteer and consider that she/he understands what is involved and freely consents to participation.

Researcher's name……………………………………………………………………

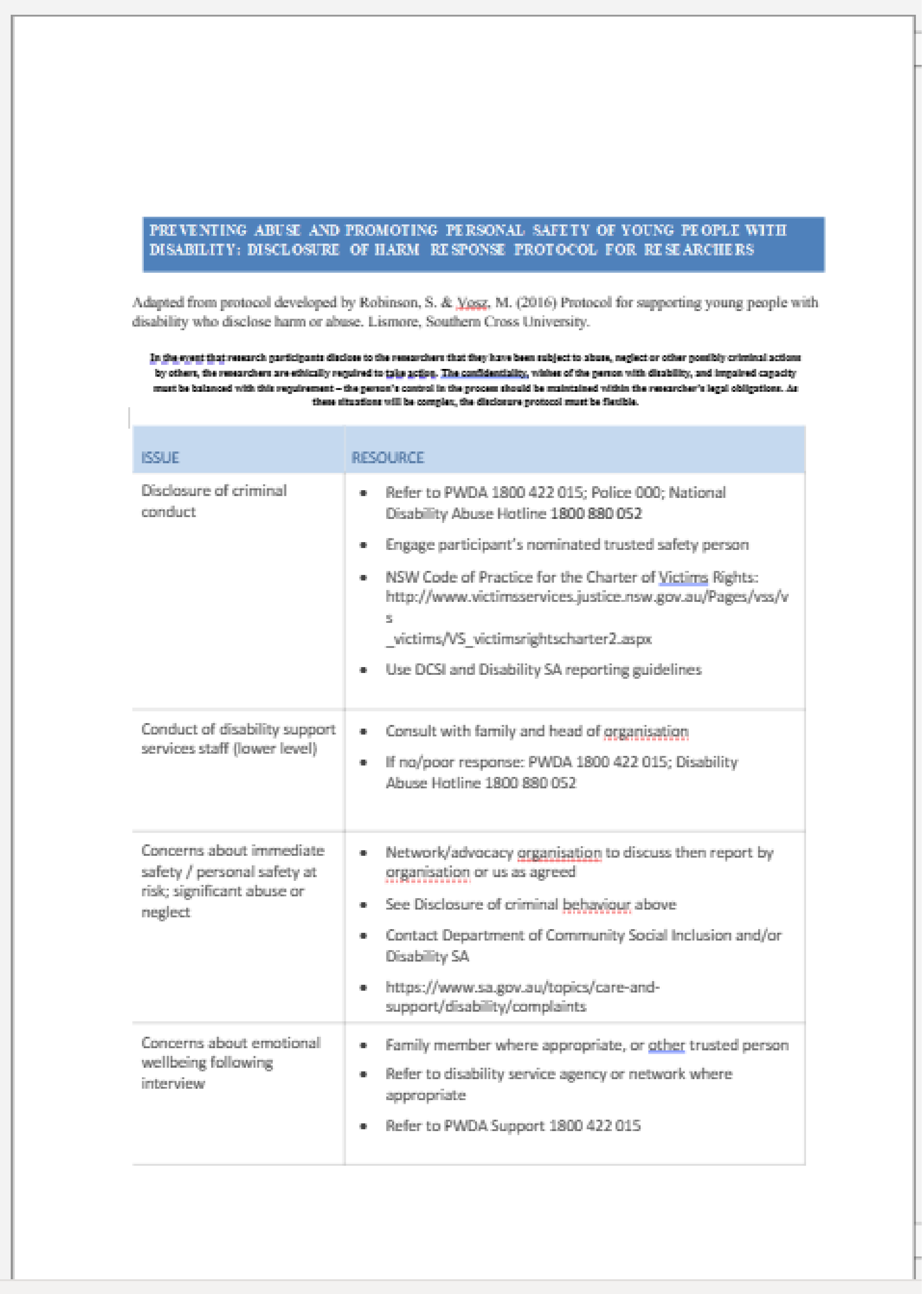
Researcher's signature…………………………………**Date**…………………

NB: Two signed copies should be obtained.

7. I, the participant whose signature appears below, have read a transcript of my participation and agree to its use by the researcher as explained.

Participant's signature……………………………………**Date**…………………

Appendix L: Reporting abuse response protocol

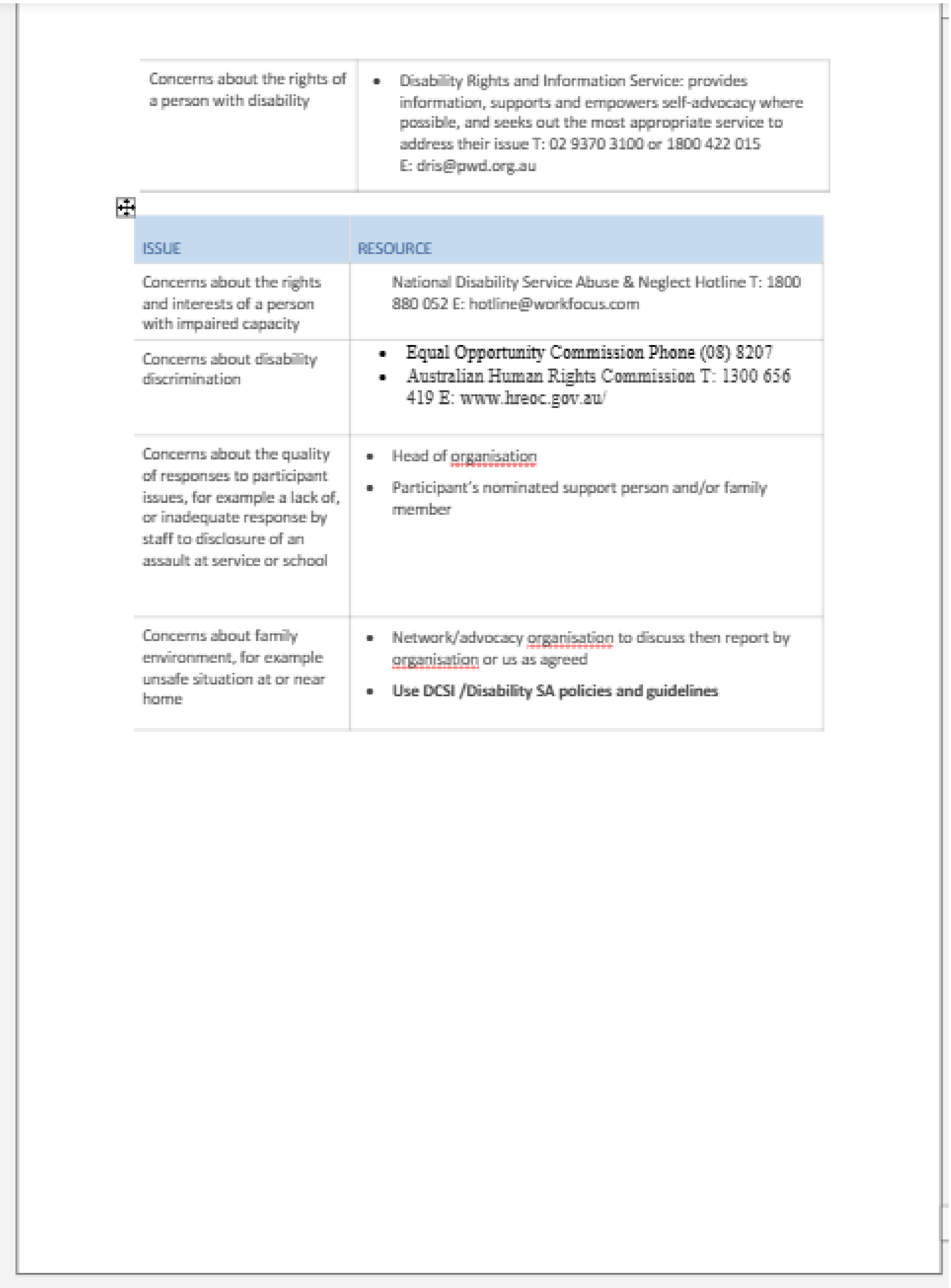


PREVENTING ABUSE AND PROMOTING PERSONAL SAFETY OF YOUNG PEOPLE WITH DISABILITY: DISCLOSURE OF HARM RESPONSE PROTOCOL FOR RESEARCHERS

Adapted from protocol developed by Robinson, S. & Yoez, M. (2016) Protocol for supporting young people with disability who disclose harm or abuse. Lismore, Southern Cross University.

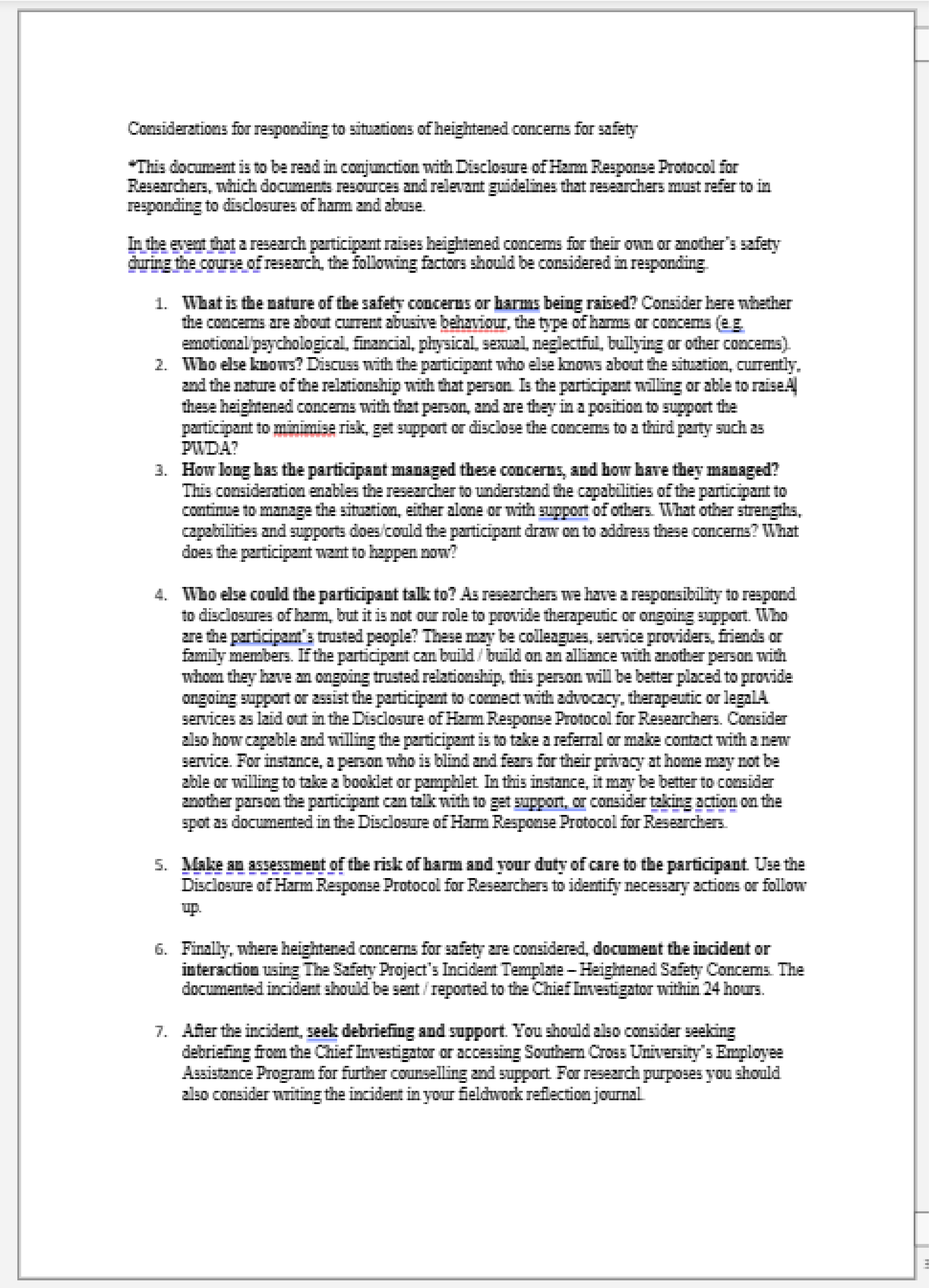
In the event that research participants disclose to the researchers that they have been subject to abuse, neglect or other possibly criminal actions by others, the researchers are ethically required to take action. The confidentiality, wishes of the person with disability, and impaired capacity must be balanced with this requirement – the person's control in the process should be maintained within the researcher's legal obligations. As these situations will be complex, the disclosure protocol must be flexible.

ISSUE	RESOURCE
Disclosure of criminal conduct	• Refer to PWDA 1800 422 015; Police 000; National Disability Abuse Hotline 1800 880 052 • Engage participant's nominated trusted safety person • NSW Code of Practice for the Charter of Victims Rights: http://www.victimsservices.justice.nsw.gov.au/Pages/vss/vs_victims/VS_victimsrightscharter2.aspx • Use DCSI and Disability SA reporting guidelines
Conduct of disability support services staff (lower level)	• Consult with family and head of organisation • If no/poor response: PWDA 1800 422 015; Disability Abuse Hotline 1800 880 052
Concerns about immediate safety / personal safety at risk; significant abuse or neglect	• Network/advocacy organisation to discuss then report by organisation or us as agreed • See Disclosure of criminal behaviour above • Contact Department of Community Social Inclusion and/or Disability SA • https://www.sa.gov.au/topics/care-and-support/disability/complaints
Concerns about emotional wellbeing following interview	• Family member where appropriate, or other trusted person • Refer to disability service agency or network where appropriate • Refer to PWDA Support 1800 422 015



Concerns about the rights of a person with disability	- Disability Rights and Information Service: provides information, supports and empowers self-advocacy where possible, and seeks out the most appropriate service to address their issue T: 02 9370 3100 or 1800 422 015 E: dris@pwd.org.au

ISSUE	RESOURCE
Concerns about the rights and interests of a person with impaired capacity	National Disability Service Abuse & Neglect Hotline T: 1800 880 052 E: hotline@workfocus.com
Concerns about disability discrimination	- **Equal Opportunity Commission Phone (08) 8207** - Australian Human Rights Commission T: 1300 656 419 E: www.hreoc.gov.au/
Concerns about the quality of responses to participant issues, for example a lack of, or inadequate response by staff to disclosure of an assault at service or school	- Head of organisation - Participant's nominated support person and/or family member
Concerns about family environment, for example unsafe situation at or near home	- Network/advocacy organisation to discuss then report by organisation or us as agreed - **Use DCSI /Disability SA policies and guidelines**



Considerations for responding to situations of heightened concerns for safety

*This document is to be read in conjunction with Disclosure of Harm Response Protocol for Researchers, which documents resources and relevant guidelines that researchers must refer to in responding to disclosures of harm and abuse.

In the event that a research participant raises heightened concerns for their own or another's safety during the course of research, the following factors should be considered in responding.

1. **What is the nature of the safety concerns or harms being raised?** Consider here whether the concerns are about current abusive behaviour, the type of harms or concerns (e.g. emotional/psychological, financial, physical, sexual, neglectful, bullying or other concerns).
2. **Who else knows?** Discuss with the participant who else knows about the situation, currently, and the nature of the relationship with that person. Is the participant willing or able to raiseA these heightened concerns with that person, and are they in a position to support the participant to minimise risk, get support or disclose the concerns to a third party such as PWDA?
3. **How long has the participant managed these concerns, and how have they managed?** This consideration enables the researcher to understand the capabilities of the participant to continue to manage the situation, either alone or with support of others. What other strengths, capabilities and supports does/could the participant draw on to address these concerns? What does the participant want to happen now?

4. **Who else could the participant talk to?** As researchers we have a responsibility to respond to disclosures of harm, but it is not our role to provide therapeutic or ongoing support. Who are the participant's trusted people? These may be colleagues, service providers, friends or family members. If the participant can build / build on an alliance with another person with whom they have an ongoing trusted relationship, this person will be better placed to provide ongoing support or assist the participant to connect with advocacy, therapeutic or legalA services as laid out in the Disclosure of Harm Response Protocol for Researchers. Consider also how capable and willing the participant is to take a referral or make contact with a new service. For instance, a person who is blind and fears for their privacy at home may not be able or willing to take a booklet or pamphlet. In this instance, it may be better to consider another person the participant can talk with to get support, or consider taking action on the spot as documented in the Disclosure of Harm Response Protocol for Researchers.

5. **Make an assessment of the risk of harm and your duty of care to the participant**. Use the Disclosure of Harm Response Protocol for Researchers to identify necessary actions or follow up.

6. Finally, where heightened concerns for safety are considered, **document the incident or interaction** using The Safety Project's Incident Template – Heightened Safety Concerns. The documented incident should be sent / reported to the Chief Investigator within 24 hours.

7. After the incident, **seek debriefing and support**. You should also consider seeking debriefing from the Chief Investigator or accessing Southern Cross University's Employee Assistance Program for further counselling and support. For research purposes you should also consider writing the incident in your fieldwork reflection journal.

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