WITHIN THESE WALLS: AN ETHNOGRAPHY OF HOME AT LAKE HOUSE

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Abstract

Home is an abstract concept, difficult to describe and define, deeply personal yet, at the same time, home is a fundamental part of our shared humanity. Home for people with intellectual disability has had a problematic historical relationship. Emerging from a history of deinstitutionalisation, group homes are the dominant model of contemporary accommodation and support for adults with intellectual disability. By the same token, knowledge about group homes has been dominated by service provider points of view and the voices of people who live in group homes have been largely absent. This study asked, how do people with intellectual disability who live in a group home understand and experience home? Six housemates with intellectual disability participated in the study. The housemates lived together in a group home called Lake House. Using an ethnographic methodology, the housemates and I collaborated to understand how meanings of home were constructed within the group home environment. My findings illustrated a complex, nuanced, contradictory space of home. On the surface, institutional elements such as block treatment, congregation and segregation from the community pervaded the space. In this way, Lake House was not homely or home-like. Yet, these constructions were outsider perspectives. My findings illustrated the ways in which the housemates of Lake House negotiated the strictures of everyday life within the group home and, in so doing, constructed meanings of home within this institutional frame. My findings show how the housemates of Lake House were not passive recipients of care, rather, they demonstrated agency, creativity and tenacity in their home-making.

The group home, then, was somewhat of a virtual chimera with a paradox of service delivery. The more service providers tried to create home for the people they serve the more service-like home became. My study found that home was a space that was always being produced through a complex intersection of service provision and active home-making by the housemates. Findings from my study have implications for service provision, particularly in the contemporary era of increased choice and control offered through the Australian National Disability Insurance Scheme. My study provides insight into possible approaches for supporting the inclusion of people with intellectual disability who live in group homes in future research, policy and program development but the question remains, who will listen?

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List of Abbreviations

CRU	Community residential unit
HREC	Human research ethics committee
IQ	Intelligence quotient
NDIS	National Disability Insurance Scheme
QUT	Queensland University of Technology

Statement of Original Authorship

The work contained in this thesis has not been previously submitted to meet requirements for an award at this or any other higher education institution. To the best of my knowledge and belief, the thesis contains no material previously published or written by another person except where due reference is made.

Signature: QUT Verified Signature

Date: September 2018

Dedication

This work is dedicated to my parents, Marie and Peter Hamilton, with thanks for their love, kindness and generosity. Thank you for your many sacrifices over the years to support all my endeavours, including this one. My father died just days before I was due to submit my thesis. He was an important part of this work and is dearly missed and always loved. Thank you, Dad, for showing me the butterflies in winter.

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The long and winding road of this research endeavour has been filled with twists and turns and many good people who helped me along the way. Firstly, my sincere thanks to the generous and compassionate housemates of Lake House for allowing me into your home and for sharing your lives with me. Thank you for our adventures and for inviting me to stay a while.

Growing up in a small rural town, part of our community was a group home called Campaspe House, a new, innovative model of its time. Campaspe House was home to a group of young people with intellectual disability of similar age to me. I began volunteering at Campaspe House and we became good friends. As I went to the local high school, my friends went to a special school in another town. As I picked tomatoes over the summer holidays, earning my first pay check, my friends were placed on waiting lists. As I wondered what to do with my life, my friends had individual program plans and general service plans developed for them. When I went to university, preparing for a career, my friends were taken together by bus to their adult day programme. Our paths took us in different directions, but I will always be very grateful for your friendship and all that you taught me, so many years ago. Thank you.

This thesis was inspired by the work of Dr John Annison and his own scholarship on home. John has been a wonderful mentor over many years and he was a significant influence on this work. Thank you for all you have done, John, and for your unwavering compassion and dedication to improving the lives of people with intellectual disability and the service systems which can learn from them.

This thesis would not have been possible without my wonderful supervisors, who formed a team par excellence. I am indebted to my Principal Supervisor, Professor Mark Brough who has given so generously of his knowledge, wisdom, good humour and time. Always creative, Mark constantly challenged me; again and again. Mark's commitment to and enthusiasm for the ethnographic methodology lifted my work beyond anything I could have envisaged. Thank you, Mark, for your conceptual thinking, your intellect and scholarship and our memorable conversations. Thank you

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Finally, I would like to thank a remarkable man I met some two decades ago. You will meet Jerry[1], and his mother, later in this thesis but it is to them that I owe an enormous debt of gratitude. Having lived in many, many group homes over the years, Jerry challenged me to try to understand what life was like from his perspective. I listened to you Jerry and I heeded your advice. Although you will never read the words printed here, thank you, Jerry. This work is for you.

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[1] Jerry is a pseudonym.

Chapter 1: Introduction

Welcome to the Cottages

As a young student nurse[2], a mental retardation nurse, one of my early university placements was at Kew Cottages where I was placed in Unit 31. My first morning shift commenced at 7am and I was taken by an older staff member to the shower block and told to pick my station. Standing in single file were thirty naked men, some shivering, all waiting in line for their morning shower. Two male staff members stood dressed in 'wet gear', enormous plastic white aprons, with white gumboots. They stood in front of two shower stations, holding long shower hoses, ready, waiting for the unit manager to give the signal to commence.

A whistle sounded and the staff members, in unison, turned on the showers, with an accompanying deafening sound of the water gushing out. The staff members began shouting at the naked men, "Move forward! Quickly! Quickly! Move forward!" The men hurried under the water, automatically putting their arms in the air as they were hosed down then ordered to turn around as their backs and bottoms were hosed. The staff members shouted at them, "Go! Move! Next!" and the man next in line was pushed forward into the water. After the hosing's the men moved to the stations for towelling, where a staff member used a single towel to dry them, changing towels every five men or so. Those waiting to be towelled down were obviously cold, lips tinged purple from the icy water lingering, goose bumps on their flesh.

The next station was shaving, where a single disposable razor was scratched over the men's faces, nicks and cuts causing bright red blood spots to pool on their faces, occasionally dropping to the floor. Then, the men were pushed to the next station; talcum powder and deodorant. The stench of deodorant was unpleasant but, for me, the fear and anxiety in the men's eyes as they hurried along the line, as per the instructions shouted at them by the staff, was more distressing. After the deodorant station the men were pushed into one room and clothes were thrown at them by another

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[2] A mental retardation nurse was an official category of nurse as per the Victorian Nurses Board in the 1990s. The specialisation of this qualification was in mental retardation (now called intellectual disability in Australia). This classification is now closed to new applicants.

staff member who retrieved items from a large pile in the middle of the room. Throughout, the unit manager hovered, pacing backwards and forwards between stations, holding a stopwatch and at intervals making recordings on her clipboard. As the last man was showered, number thirty, the silence of the shower room almost echoed as the water was turned off. The unit manager shouted, "7 minutes! A new record! Good work everybody!" to which the staff members cheered and slapped each other on the back, myself included. As the men, now showered and dressed, filed into the common room to wait for breakfast, one staff member turned to me and said, "Welcome to the Cottages!"

~ Kew Cottages, 1992

BACKGROUND TO THE RESEARCH

This chapter outlines the background and context of my thesis. My aim in this thesis is to explore and understand how people with intellectual disability experience life within a group home setting. *Welcome to the Cottages* illustrates the ways in which the quest to understand the experiences of people with intellectual disability has often been overshadowed by the more dominant, hegemonic voice of the disability service system which surrounds them. *Welcome to the Cottages* introduces my aim within this thesis, which is to develop ways of listening to people with intellectual disability who live in group homes and understanding their experiences. *Welcome to the Cottages* illustrates the ways in which the voices of the men in Unit 31 were ignored, or overlooked, when the staff who supported them focused on their own work routines and priorities. My challenge in this thesis, then, is to develop ways of understanding what home is like within a group home from the perspectives of the people who live there. This chapter defines key terms and concepts used in the thesis and provides an overview of the scope of the research and its significance. I also provide an outline of the structure of the thesis and the chapters that follow.

THE RESEARCH PROBLEM

Kew Cottages[3], where I worked in the early 1990s, was Victoria's largest institution for people with intellectual disability (Fox, 2003). Tragically, on the 8th April 1996 nine of the men who lived in Unit 31 died in a fire which consumed the locked unit (Feigan, 2011, p.14). At the time, policies of deinstitutionalisation[4] had slowly been implemented at the Cottages, however, the fire hastened this process. After the fire, residents began to move into new models of community-based, accommodation and support; group homes. In Victoria, at the time, these new models of accommodation and support were called Community Residential Units (CRUs). Dispersed throughout community neighbourhoods, these group homes were smaller than the large units and wards of the institutions and offered opportunities for residents to be included within society. Although there was strong resistance and opposition to deinstitutionalisation, particularly from some parents and family members of residents, Kew Cottages was finally closed in 2008 (Manning, 2009). However, despite the heralding of an official milestone of closure, large sections of the Cottages were in fact re-developed on the grounds. The Kew Cottages experience of closure of a large, congregate care facility, its re-development and relocation of residents, is only one of many institutional closures both within Australia and internationally. Much more than an operational process, deinstitutionalisation has been described as "…one of the most significant policies in the history of human services" (Chenoweth, 2000, p. 80). Deinstitutionalisation transformed the provision of support to people with disability (Bigby & Fyffe, 2006; Stancliffe & Abery, 1997) and group homes for people with intellectual disability emerged from deinstitutionalisation (Stancliffe, 1997) as an alternative model of accommodation and support.

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[3] Built on a hill outside of the city of Melbourne city, Kew Cottages, formally known as Kew Residential Services, was an institution for people with intellectual disability. Established in 1887 as "an Institution for the care and training of feeble-minded children" (La Trobe University, 2010, "Kew Cottages History, 1887-1912", para 1) the institution was first called the 'Kew Idiot Asylum'. By the end of its first year, the institution was home to 54 patients (La Trobe University, 2010, "Kew Cottages History, 1887 – 1912" para 2). Ten years later, the population of the institution rose to 203. Later, colloquially known as Kew Cottages, the institution for people with mental retardation grew and in 1968, records indicate that 948 residents called the Cottages home (La Trobe University, 2010, "Kew Cottages History". In the early 1980s, residents began moving out of Kew Cottages as a result of deinstitutionalisation policies (La Trobe University, 2010, "Kew Cottages History, 1976-2008", para 3.) In 2001, the Victorian Government announced the closure of Kew Cottages and its redevelopment (La Trobe University, "Kew Cottages History, 1976-2008", para 3).

[4] Deinstitutionalisation is a complex concept that is discussed in more detail in section 2.2.

In Australia, more than half a million people have an intellectual disability and 61% of this population require support with daily living activities (Australian Institute of Health and Welfare (AIHW), 2008). Intellectual disability is a permanent condition that affects an individual's cognitive, social and adaptive functioning, manifesting in the developmental period. Group homes are the dominant form of contemporary accommodation and support for people with intellectual disability (Clement & Bigby, 2010). Characterised by rostered staff support, often twenty-four hours per day, group homes are provided by government and non-government service providers. Group homes typically resemble suburban homes and residents generally have their own bedroom and share common areas such as the lounge room, dining room, bathrooms and kitchen. Group homes are designed to look like ordinary homes, in ordinary streets (Department of Health UK, 2001). Although group homes are the dominant model of accommodation and support for adults with intellectual disability, there is a continuum of options available, with four distinct streams (Wiesel, 2015); institutions (large residential centres), group homes, living at home beyond the age when people would usually leave (often living with ageing carers) and living in the community with support where appropriate (adapted from Connellan, 2015, p. 57). However, are group homes genuine homes?

Home for people with intellectual disability has been conceptualised very differently to home for people without intellectual disability. In the disability service sector, the language used to describe home is dominated by service-centric terminology. People with intellectual disability who live in group homes may be described as service users, residents, clients or consumers. Different housing supports may be described as cluster housing, short term accommodation, outreach, drop-in support, shared supported living, or community-based residential services. In 2018, many of these settings look homelier or more home-like than the large-scale, long-stay institutions of old, such as the wards and units of Kew Cottages. But are these models of accommodation and support genuine homes? And from whose perspective is this question to be answered?

In the early days of deinstitutionalisation, experimental units were established (Tizard, 1964) to evaluate quality of life outcomes for residents living in smaller abodes compared to residents living in large-scale, congregate care institutions such as Kew Cottages. In 1976, the American Journal of Mental Deficiency, as it was called at the time, published a review of the literature examining the relationship of institution size and quality of care for 'retarded individuals[5]' (Balla, 1976). This review of the literature found significant variation in quality of care, with greater outcomes identified in smaller residences, which were defined as ranging from 9 to 100 residents. Balla (1976) found that these types of arrangements could be labelled as a home but Annison (2000) has disputed this, arguing that such labelling had led to a mis-use of the notion of home for people with intellectual disability.

In my excerpt, *Welcome to the Cottages*, I explored a typical morning from my experience as a trainee mental retardation nursing working in Unit 31. In this unit, people with intellectual disability were congregated together and segregated from society behind the walls of the institution. Yet, when I compared the experiences of the men who lived in Unit 31 with my own experience of home, I found several disparities. Where I was free to shower at leisure, to choose my own routines and lived in an environment where no one shouted at me to be quicker and faster in order to break a bureaucratic record, the men in Unit 31 had very different experiences. But, more importantly, what did the men of Unit 31 think? How did they define home? What was important to them about home? Did they consider Unit 31 to be their home? It was clear to me that no one had asked.

RATIONALE FOR THE RESEARCH

> Je suis l'espace où je suis
> I am the space where I am
> ~ Noël Arnaud (1950) (quoted in Bachelard, 1964, p. 137).

An abstract notion, difficult to describe and articulate, home is a fundamental aspect of our shared humanity, our "…corner of the world" (Bachelard, 1964, p. 4). Much more than bricks and mortar, home is constructed through personal meaning, built through individual experiences, memories and knowledge, which are cumulative and built over time (Lyra, 2007). Home is understood as a space which is produced

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[5] In 1976, the terminology used to describe intellectual disability was most commonly mental retardation. This language is no longer appropriate. In Australia, intellectual disability is used and, in the UK, learning disability is used.

(Lefebvre, 1991), where meanings of home are dynamic. Multidimensional in nature (Mallett, 2004), home contributes significantly to quality of life (Sixsmith, 1986) and home has both material and affective elements (Gorman-Murray, 2007, p. 229). Home has social meaning (Saegert, 1985, p. 287), where it is a place to raise a family or is a refuge, a sanctuary from the outside world (Sixsmith, 1986). Yet, home is difficult to define, and home is variously described in the literature as a place (Peled & Muzicant, 2008), a space (Heidegger, 1971) and as "…one of the most basic daily-life experiences (van der Klis and Karsten, 2009, p. 235). Bachelard (1964) evocatively described home thus:

> [I]f I were asked to name the chief benefit of the house, I should say: the house shelters day-dreaming, the house protects the dreamer, the house allows one to dream in peace… (p. 6).

In contrast, far from Bachelard's (1964) romantic ideals, home for people with intellectual disability has been described and understood very differently. For people with intellectual disability, home has often been conflated with service provision. Home is a service model, a configuration of rostered staffing, and an accommodation option on a continuum of services. With deinstitutionalisation, service providers and policy makers have focused on the physical and material aspects of home, ensuring that community-based residential units, group homes, look like ordinary homes in ordinary streets (Towell, 1988). However, are group homes genuine homes? Annison (2000) argued that '(t)he term "home" has been liberally (mis-)applied to a wide range of residential service settings for people with an intellectual disability over many years" (p. 251).

A large number of studies have found that community-based living provides better outcomes for people with intellectual disability than institutional living (see, for example, Young, Sigafoos, Suttie, Ashman, & Grevell, 1998; Kozma, Mansell & Beadle-Brown, 2009; Clement & Bigby, 2008; Wiesel & Bigby, 2015). However, is this a reasonable comparison? Balla (1976), for example, labelled large, congregate care facilities as home. Would the people who lived in these facilities have shared Balla's (1976) conceptualisation of home? And if so, what are the impacts of individual histories and experiences on understandings of home? What is the sociocultural context within which home is located? These are aspects of home that I consider in my study. In contrast to knowledge about home for people without intellectual disability, the disability specific literature has largely ignored the social and affective elements of home, focusing instead on staff practices and physical design, emphasising the homeliness or home-like-ness of group homes. Despite the emergence of a significant body of knowledge about group homes over the last two decades, this knowledge is predominantly from a service provider and service delivery perspective. There is a paucity of knowledge about group homes from the perspectives of the people who live in these community-based models of accommodation and support. The experiences of people who live in group homes remains poorly understood.

RESEARCH QUESTIONS AND OBJECTIVES

My study aimed to explore and understand the group home from the perspectives of the people who live there, and my primary research question asked:

> *How do people with intellectual disability who live in a group home understand and experience home?*

To assist in answering my primary research question, I asked some further questions:

- How do people with intellectual disability who live in a group home construct meanings of home?
- What are the attributes that they identify as essential to home?
- What influences enhance and detract from achieving these ideals?

The research questions supported my exploration of Lake House, my field site, a group home for people with intellectual disability. As an ethnographic journey, the research process was also informed by my own life experiences, perspectives, and background and my own positioning in the research (Bird, 2013).

THE SETTING AND MY APPROACH

Over the course of eighteen months, using an ethnographic methodology, I immersed myself in everyday life at a group home called Lake House. Home to eight people with intellectual disability, six of whom agreed to participate in my study, Lake House is owned and operated by a disability service organisation. Occupants of group homes are often referred to as residents, service users or clients and in contemporary times the term consumer is becoming more prominent. In my study, the participants referred to one another as housemates and I have honoured their language by also using the term housemates.

Lake House has a roster of paid disability support workers who are supervised and managed by a hierarchy of personnel from the disability service organisation. At Lake House, the housemates referred to the disability support workers as "the supervisors[6]." Again, I have honoured the housemates' language and use this terminology throughout the thesis. I conducted my fieldwork at Lake House where I immersed myself in the daily activities and tasks that are part of everyday life. As part of my fieldwork, I also accompanied the housemates on shopping trips, outings to restaurants or cafes and walks in the park or the nearby lake to immerse myself in these settings. In Chapter 4, I acquaint the reader with Lake House in more detail and I introduce the housemates through a series of individual portraits which the housemates and I developed together throughout fieldwork.

REFLEXIVITY

The research process in ethnographic inquiry is informed by the research questions and the positioning of the researcher. In ethnography, the researcher is the primary instrument for data collection and analysis (Madden, 2010) and should, therefore, be acknowledged as participating in the research (Bird, 2013, p. 16). It is important for the researcher to be reflexive and to acknowledge the ways in which her own experiences, thoughts, feelings, values, and biases and influence the data she collects and how she interprets the data through analysis. Bird (2013) posits that by

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[6] Throughout the thesis, I have used the pronoun he when referring to the supervisors to avoid inadvertently identifying any one staff member.

acknowledging the researchers' own biography, epistemology and ontology, then the research and its findings and conclusions can be better understood (p. 8).

My own story begins when, as a young person, I volunteered at a group home in my small, rural community, called Campaspe House. Five young people of similar age to me lived at Campaspe House in an era where group homes had just emerged as an alternative to institutional living. At the time, Campaspe House was an innovative model of community-based accommodation and support yet the young people who lived at Campaspe House lived a very different life to my own. Our burgeoning friendship kindled my interest in working with people with intellectual disability, an interest which has proved enduring and now spans some two decades.

After I left my home town, and moved to the city to go to university, I continued working in group homes. Through one of my casual jobs, I received a call late at night, an emergency I was told, and the rostering co-ordinator told me she was at her wits end as she had been unable to find anyone to fill the shift. I took the shift, happy for the opportunity and the additional money, and arrived at the group home. It was here that I met Jerry[7] and where, later, I would also meet his mother. After living at home with his mother for most of his life, Jerry had moved into the disability service system as his mother's health deteriorated and she was no longer able to care for him on a full-time basis. Since this time, Jerry had lived in many different group homes. Due to his intellectual disability, autism, echolalic speech and a stubborn personality, he had a reputation of being difficult to work with. Over time, Jerry and I began to understand one another. Jerry and his mother, a tight-knit pair, influenced the way I saw the world and Jerry taught me to consider what life in a group home might be like from his perspective.

At the same time as I met Jerry and his mother, I began studying at university where I met Dr John Annison, who was Principal Lecturer in Disability Studies at Deakin University. Dr Annison's lectures in my undergraduate career inspired me and motivated me and my work with Jerry and his fellow group home residents confirmed

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[7] Jerry is a pseudonym. Jerry and I first met when I came to work in his home, a group home that had been labelled a "challenging behaviour house" largely because of the number of incidents that occurred within the group home. When I first met Jerry, he was generally disliked by the staff because of his physical aggression and his consistent refusal to comply with staff directions. Jerry had grown up in the family home with his mother, who cared for him for many years until her own health deteriorated. Jerry and his mother then embarked on a long, emotional journey through many different group homes on a quest to try and find Jerry the perfect home.

that this was the career for me. Dr Annison's scholarship on home and Jerry's experience of group home life were the inspirations for my Masters' work and then, much later, for my PhD work as well. While I was studying at Deakin University, I also began working at Kew Cottages, Victoria's largest institution for people with intellectual disability. Although I only worked at Kew Cottages for a short time, I found the conditions there confronting and the staff culture intractable and I worried about the futures of the people who lived there. The fire at Kew Cottages in 1996, which killed nine of the men who lived in the unit where I had worked the most, was a tragedy of unimaginable proportions and deeply affected me personally, even though I was no longer working at the Cottages at the time. This tragedy further motivated me to study the group home model as an alternative to institutional living.

As I finished university, I worked in a range of roles in the disability sector from support worker to case manager to team leader to project manager and later in policy. At one point in my career, I took a diversion and worked in strategic planning for the State government for some time and then, in another diversion, I worked in child protection and youth justice for a while. However, these different career paths seemed to me to be diversions from the work I was most interested in and I began my PhD in 2009 with the Queensland University of Technology (QUT). I was clear from the start that I wanted to explore the group home further and I wanted to further my knowledge and understandings of what life was like within group homes from the perspectives of the people who lived there. After a move interstate, I found my PhD Supervisors who supported my idea for this study but enhanced it greatly through their own experiences and perspectives. It was here that I was first introduced to the quixotic journey of ethnography.

As my PhD scholarship ran out, I again moved interstate and began teaching disability studies at TAFE and later at university. Significantly, I also worked at the Centre for Disability Studies (CDS) in Sydney for a time, where I was introduced to the CDS inclusive research network. This group of outstanding researchers, with and without intellectual disability, had an incredible influence on my life and my passion for inclusive and collaborative research remains to this day.

Since Dr Annison's scholarship on home I have been interested in this abstract, complex, notion of home and how home is experienced for people with intellectual disability. Dr Annison's work in this area has served as my inspiration and motivation.

Jerry’s challenge to me, all those years ago, to consider his perspective and what life might be like for him in a group home has also guided and influenced my PhD journey.

SIGNIFICANCE OF THE RESEARCH

My study aims to contribute to knowledge about home by supporting the voices of people who live in one group home, a place called Lake House, to be heard. Despite the dominance of the group home model of accommodation and support, there is a paucity of knowledge about what it is like to live in a group home and how everyday life is experienced within these settings. This paucity of knowledge is significant because group homes likely to continue to remain the dominant model of accommodation and support for the foreseeable future.

The voices of people with intellectual disability who live in group homes are rarely heard. Instead, this cohort are often positioned as passive service users or recipients of care rather than as home owners, tenants or citizens. My study also aims to make a methodological contribution to knowledge by illustrating how ethnography can be used to support the voices of people with intellectual disability to be heard. In this thesis, I adopt the position that people with intellectual disability who live in group homes have much to say about home and researchers, policymakers and service providers need to find ways to listen. My study aims to illustrate ways in which people with intellectual disability can be included in discussion and policy about home, and why it is important to do so.

Conceptualising home for people with intellectual disability as the antithesis of institutional living is no longer sufficient. In the current service context, housing and support is an area of significant growth and development. However, if home continues to be conceptualised and operationalised by service providers and funding bodies without people with intellectual disability, or on their behalf, then home risks being reduced to a commodity to be purchased. New and innovative service models may be produced that are home-like, or homelier, but can such models be genuine homes if the very notion is constructed and imposed by others? The literature on home for people without intellectual disability conceptualises home as a dynamic space where home is produced not merely received or purchased. The notion of home extends beyond bricks and mortar, or a model of service delivery, rather, home is understood as a way of being in the world (Lefebvre, 1991).

THESIS OUTLINE

My exploration of the problematic of home for people with intellectual disability begins with an examination of the cultural and historical contexts which have led to the emergence of the group home as the dominant model of contemporary accommodation and support for people with intellectual disability. In Chapter 1, I have outlined the background and the setting, and I have outlined the rationale for the research.

In Chapter 2, I use a historical portrait of home to understand the ideological foundations from which group homes have been forged. In Chapter 2, I review the literature on home for people with and without intellectual disability and identify an immediate disparity between the two. The label of home has been applied to a range of settings which would not be considered home for people without intellectual disability. In Chapter 2, I use the literature to explore this problematic. Chapter 2 also outlines the contemporary context of disability support which, in Australia, is experiencing unprecedented reform with the introduction of the National Disability Insurance Scheme (NDIS). Using the literature on home for people without intellectual disability, I consider the fundamental elements of home and theoretical understandings of home as a space that is continually being produced. Chapter 2 emphasises the importance of including people with intellectual disability in group home research where, to date, their voices have been largely absent.

Chapter 3 provides the conceptual framework of the study and the research design. Drawing upon Crotty's (1998) schema, I describe the epistemological, theoretical and methodological aspects of the study. Chapter 3 emphasises the importance of a collaborative research approach and the absence of the voices of people with intellectual disability in group home research provides a rationale for the ethnographic methodology used in this study.

In conducting a study in home, a deeply private and personal space, with people with intellectual disability, a cohort identified as vulnerable in research, there are significant ethical implications arising. I discuss the ethical issues associated with the study and in Chapter 4 I outline my process for informed voluntary consent and further detail inclusive and collaborative research as the frame for my methods. In Chapter 4, I detail participant recruitment and highlight the challenges I faced in gaining access to participants and the complex web of negotiations that surround group home research. In this chapter, I outline the methods used in the study; participant observation, ethnographic conversations and visual methods. In Chapter 4, I describe the ways in which the housemates and I collaborated to make these methods our own. This chapter also discusses the iterative, recursive nature of ethnographic data analysis. I conclude Chapter 4 by providing a brief introduction to Lake House. I then introduce the housemates of Lake House through a series of individual portraits which we developed together throughout the course of fieldwork.

Chapter 5 is the first of two findings chapters and introduces Lake House and the housemates in more detail, exploring aspects of the group home from different perspectives. Chapter 5 illustrates the ways in which the physical and material culture of Lake House try to reproduce home, positioning Lake House as an ordinary home in an ordinary street. In this chapter, I use my findings to delve beneath this superficial construction of home and find that features which look like everyday items can be conduits for the routinisation of life. Using ethnographic material which the housemates and I produced collaboratively, I illustrate the ways in which the housemates construct home within an institutional frame.

Chapter 6 highlights the ways in which everyday life at Lake House is constructed, through a routines and regimes, signs and symbols and a culture where the housemates are positioned as docile and compliant. Through layers of surveillance and complex power relations, an institutional culture pervades. Chapter 6 emphasises that the housemates are not passive within this institutional frame, rather, the housemates demonstrate agency, creativity and tenacity in their home-making.

Chapter 7 begins with an allegorical piece, using an ethnographic voice, which is an assemblage of ethnographic material used to wander through a typical day at Lake House. In this chapter, I consider the way in which space is socially produced at Lake House and I explore in detail the home-making practices of the housemates. Demonstrating agency and resistance, the housemates used various techniques to construct home for themselves. In this chapter, I explore the complex grid of power relations at Lake House, using a theoretical lens to consider how the housemates negotiate the institutional frame of the group home. I examine technologies and apparatuses for government and the ways in which the housemates experience this governmentality. I also examine technologies of the self. In this chapter, I consider the ways in which the group home model of accommodation and support has been constructed by the disability sector to be ‘just like’ genuine, ordinary homes yet, in doing so, the less like home they become. Thus, I consider the group home as a type of other space; a heterotopian space. Chapter 7 explores the co-production of home at Lake House and uses creative, literary devices to illustrate everyday life. I consider the contribution of ethnography, and ethnographic writing, and how significance of collaborative and inclusive research methods.

Chapter 8 concludes the study by revisiting the research questions and articulating the argument of my thesis. I outline the broad significance of the research. My study also had limitations and I use this chapter to outline and discuss these. In Chapter 8, I make recommendations for future research and emphasise the importance of including people with intellectual disability in future research about group homes. In this chapter, I argue that group home residents have always had a voice about home and that the voices of the housemates of Lake House did not emerge as a result of my study. Rather, I emphasise the role of policy makers, service providers, governments and scholars in finding new ways to listen.

I conclude the thesis by exploring my vulnerabilities as a researcher through a short ethnographic piece that considers the ways in which this ethnographic journey of home never really finishes and that the memories of the research endeavour remain.

Chapter 2: Home and the experiences of home for people with intellectual disability: A review of the literature

In this chapter, I use a historical portrait to explore how the label of home has been placed over a range of residential settings for people with intellectual disability that have been distinctly un-home-like and almost unrecognisable compared to notions of home for people without intellectual disability. The group home model of accommodation and support emerged from an institutional history and this legacy is never far from the surface. This section leads to an exploration of the problematic relationship of home and intellectual disability service delivery. In this chapter, I discuss the ways in which the group home has gained prominence, as the antithesis of institutional living, with its ideals of community-based social inclusion. The next section reviews the contemporary context of support, characterised by human rights frameworks and consumer purchasing power. In Australia, the National Disability Insurance Scheme (NDIS) has changed the paradigm of support, and in this review of the literature I consider what this new paradigm may mean for home for people with intellectual disability. In the next section, I examine the literature on home more broadly, using the literature to understand the fundamental elements of home. These elements are rarely considered in group home research. Specifically, I draw on Lefebvre (1991) to extend understandings of home beyond bricks and mortar and beyond service delivery. Instead, the group home can be understood as a space which is being produced through home-making practices. In this section, I compare and contrast these understandings with conceptualisations of the group home as a model of service delivery. I conclude this chapter by highlighting the paucity of knowledge about what group homes are like from the experiences of the people who live there. The voices of people with intellectual disability who live in group homes have been noticeably absent in group home research. The significance of this gap in the literature, and this gap in knowledge, has led to the research design for my study and the conceptual framework.

INTRODUCTION

Throughout different epochs of care, home for people with intellectual disability has come to be conflated with the provision of support by service organisations in their various guises. Home, and the experiences of home for people with intellectual disability, has been a problematic historical relationship. Scholarship about group homes has been largely preoccupied with aspects of service delivery and service culture. From a history of institutionalisation, group homes, the focus of my study, have emerged as the dominant form of contemporary accommodation and support (Clement & Bigby, 2010) yet this model continues to perpetuate the sociospatial exclusion of people with intellectual disability from society.

The ideals of the group home, conceived of as the antithesis to institutional living, have not been fully realised. In many ways, the group home has become an artificial production, or reproduction, of home. The othering of people with intellectual disability can be found in the ways in which group homes are considered. Notions of homeliness and home-like-ness are examples which advocate for approximations of homely features to be included within group homes. Homely décor and home-like productions of privacy, such as individual bedrooms, have been considered as constitutive of home. Yet, these are somewhat superficial approximations of home if group home residents are not able to choose with whom to live or if they are must live their lives according to staff routines, rosters and priorities. Such facades of home perpetuate the deceptive language of home which has been a hallmark of the problematic relationship between home and intellectual disability service provision which I explore in detail in this chapter.

AN HISTORICAL PORTRAIT OF HOME FOR PEOPLE WITH INTELLECTUAL DISABILITY

The following section provides an historical portrait of home for people with intellectual disability which has been characterised by different epochs of care, each with their own history of ideas and perspectives about home and about people with intellectual disability. An historical portrait provides a picture of the problematic relationship between home and intellectual disability service provision. Home, a shared aspect of our humanity, has been considered very differently for people with intellectual disability and a range of residential settings have been labelled, and mislabelled, as home. This historical context has important implications for the emergence of the group home model of accommodation and support, which is the setting for my study. Contemporary ideas of home for people with intellectual disability are inextricably interwoven with historical ideas and perspectives of home.

Institutionalisation. The institutionalisation of people with intellectual disability has a long, sad history. Established as state of the art, centres of excellence, institutions were based on societal values towards intellectual disability as a type of ‘deviancy’ and a condition to be treated and cured. The institutions were repositories of medical knowledge and power. Characterised by the congregation of people with intellectual disability together in large numbers on the basis of shared diagnosis, the institutions were large physical structures, often with enormous perimeter walls to separate those within the walls from society. Overcrowding, decrepit living conditions, abuse and neglect are other characteristics that came to be associated with institutionalisation as successive governments the world over neglected these spaces.

Institutionalisation is often thought of in terms of the material environment, however, institutionalisation is also a process whereby people with intellectual disability were admitted for curation or medical intervention and became subjects within the institutional system. Other characteristics of institutionalisation, such as the block treatment of residents (Goffman, 1961/1991), high levels of surveillance (Foucault, 1977) and structured, regimented daily routines, had a profound effect on ideas of home for people with intellectual disability. Power relations within institutions were complex, staff were the enforcers of rules and regulations and were also institutionalised through strict, often poor, working conditions and onerous bureaucracies. In turn, staff influenced the ways in which people lived within the institutions.

The neglect and abandonment of institutions around the world by governments also led to insular practices within the walls of the institutions, as they became places of sociospatial exclusion for both residents and staff. Institutionalisation has had an everlasting effect on ideas of home for people with intellectual disability and these historical perspectives continue to exert a significant influence on contemporary conceptualisations of home.

Institutions as places of medical intervention, treatment and training. Historically, home for people with intellectual disability was within the family home. However, in the 18th century families were increasingly encouraged to relinquish the care of their family member with intellectual disability to the expertise and specialised treatment offered by the institutions. At this time, religion and medical knowledge were the forms of knowledge associated with power (Foucault, 1963/2012), rather than families or people with intellectual disability themselves. Institutions were constructed, in Australia and internationally, designed as physically imposing structures, often with large external walls to separate those inside the institution from those outside. As symbolic structures, the institutions were emblematic of the episteme that expertise for the residential care and training of people with intellectual disability lay with medical professionals and, "(p)hysicians explained to parents that "nothing could be done" for their disabled children but provide custodial care…" (Levinson, 2010, p. 19).

In 1847, England's first institution for people with intellectual disability was established, the 'Royal Earlswood Asylum for Idiots' which was designed as a centre of excellence. In 1887, in Melbourne, Australia, the 'Kew Idiot Asylum' (colloquially referred to as 'the Cottages') was established for the care and training of "feeble-minded children" (Manning, 2008). Residents of the institutions were congregated together on the basis of disability, for specialised medical treatment, care and training. In 1887, when Kew Cottages was established, it was "…regarded as a world-leading facility as it offered both residential care and educational opportunities." (Manning, 2009, p.151). Later, there was a separation of 'idiocy' from 'lunacy' (Trent, 1994) and people with intellectual disability were classified as distinct from people with a psychiatric history (Reaume, 2002). Thus, children and adults with intellectual disability were moved from the lunatic asylums and psychiatric hospitals within which they had lived (Marshall & Tilley, 2013, p. 401) to institutions devoted specifically to people with intellectual disability.

Foucault's (1961) work in *Madness and Civilization: A history of insanity in the age of reason* focused on the ways in which 18th century society confined and segregated people through processes of alterity. Anyone seen as different, or, as other, were placed in facilities designed for their containment. Thus, people with intellectual disability, were congregated together on the basis of diagnosis and segregated from society for their own good and for the good of society (Simmons, 1982). Such sociospatial exclusion was considered therapeutic (Gleeson, 1997) and protective and people with intellectual disability were classified, and measured, according to medico-psychological criteria (The Royal Medico-Psychological Association, 1938). The pathologisation of people with intellectual disability in this way meant that individuals within the institutions were measured as deficient against the norm (Rose, 1986). This era was characterised by the medical gaze (Foucault, 1963/2012) and Foucault (1977) identified the institution, in its many variants including the asylum, the prison, and the clinic, as a site of disciplinary practice where subjects were produced (Burrell & Trip, 2011) and contained as patients or inmates of the institution.

In the Czech Republic, and other Central and East European countries, institutionalisation was sustained by the "(o)fficial government policy of placing people with intellectual disability (ID) into institutions was premised on the discipline of defectology coming out of Russia's Institute of Defectology, established in 1929." (Vann & Siska, 2006, p. 426). Such social policies, ensured that people with intellectual disability remained hidden, invisible (Mental Disability Rights International, 1999) and "…(b)y maintaining children with disabilities in separate, segregated facilities, Soviet society was able to exist as if there were no people with disabilities." (Vann & Siska, 2006, p. 426). Further, in some countries, such as Austria, the end of World War II led to the realisation of Nazi policies which saw the genocide of people with intellectual disability in institutions and across the country, which resulted in the death of "almost all people with intellectual disabilities in Austria" (Neugebauer, 1990, cited in Buchner, 2009, p. 5).

For people with disability, the medical model of disability, which counted and classified human bodies and compared them to norms of functionality and utility, positioned individuals as 'deviant' if they differed to the perceived norm. Deviancy was thought to be able to be cured through medical and pharmacological intervention.

At the same time that institutions were being built for a range of people society desired to keep separate, including people with intellectual disability, the 18th century saw home emerge as a space of privacy and domesticity separate and distinct from public life (Vickery, 1993). In particular, during this time, public life came to be considered as dangerous, risky and children, for example, began to be considered as safer at home, behind closed doors. Home, then, was a refuge from a dangerous, world which lay outside, and home was ideologically positioned as separate from public life (Rybczynski, 1987). The inner world of home evolved as a space for self-expression, household negotiations, and a space to choose décor and furnishings were no longer just practical, useful items. The separation of the outside world from the inside world saw control of the hearth of the home as important in terms of who was permitted inside the home and who was kept out. During this era, Saunders and Williams (1998) note that home became based on familial ties and home was the base from which people would leave and return. In an almost parallel fashion, the institutions were expanding and people with intellectual disability continued to be segregated from society within the walls of the institutions.

Deinstitutionalisation. As the institutions grew to capacity, and then exceeded such limits, the once grand, stately structures began to crumble, deteriorating from neglect, overcrowding and severe underfunding. Life within the walls of the institutions, kept hidden and out of sight for so long, was gradually exposed accompanied by public outrage and demands for closure of the institutions.

Parents, who had long raised concerns about deteriorating conditions and endemic underfunding, were instrumental in both advocating (Tøssebro et al., 2016) and resisting institutional closure (Wiesel & Bigby, 2015). Using the media to expose the appalling conditions of the institutions, parents advocated and campaigned, and applying political pressure. In Australia and the Nordic countries, parents were instrumental in government policy supportive of deinstitutionalisation and the relocation of residents to group homes (Wiesel & Bigby, 2015, p. 186). In 1995, the Kew Cottages Parents' Association sued the Victorian government for the chronic underfunding and reduction in programmes for residents at the institution (Manning, 2008, p. 155).

At the same time, some parent groups campaigned for the redevelopment of institutions, resisting government plans to move residents into group homes. The Kew Cottages Parents' Association, for example, campaigned against redevelopment plans for the institution and successfully lobbied for the development of new group homes for one hundred residents on the institutional grounds (Wiesel & Bigby, 2015, p. 188). Similarly, parents successfully lobbied the Victorian State government who eventually abandoned plans to fully devolve Janefield and Kingsbury Training Centres. Instead, the government developed a new 100-bed facility on the institutional grounds (NCA, 1996).

With such pressures, governments searched for alternatives. Scholars conceived of smaller residences, dispersed within communities, where people with intellectual disability could live together and receive support. These new models of accommodation and support, called group homes, provided a better quality of life than the institutions. However, remnants of institutionalisation remained in the ways in which people with intellectual disability were congregated together, albeit in smaller numbers, and subject to the routinisation of everyday life. Support provided within group homes was better than the conditions of the institution, however, people with intellectual disability were still disengaged, spending large amounts of their time waiting, watching and hoping for something to happen. As staff prioritised personal care tasks, social inclusion was often deemed as less important, or staffing ratios made it difficult to access the community or to support the development of friendships through community activities.

Group homes were like ordinary homes in ordinary streets, but they were also vastly different. While the physical and material elements of home looked nicer and were more aesthetically pleasing than the institutions, little attention was paid to the affective elements of home. Group homes became parallel, artificial reproductions of home, spaces which looked like home on the surface, but spaces which were constructed for people with intellectual disability by others.

Exposés and the development of a continuum of care. Deinstitutionalisation, described as one of the most significant policies in the history of human services (Chenoweth, 2000, p. 80), was both an ideological movement (Bank-Mikkelson, 1969; Nirje, 1969; Wolfensberger, 1972; 2000) and a physical closure of the institutions. Post-war influences on home for people with intellectual disability included exposés of abuses and squalid conditions within the institutions. Blatt and Kaplan (1966) published a photographic essay titled Christmas in Purgatory: A photographic essay on mental retardation which exposed the abuses of people with intellectual disability who lived in state institutions within the United States. While exposés such as Blatt and Kaplan's (1966) served to reveal the abuse and neglect of people with intellectual disability, such reporting also held a voyeuristic element, and was in itself another form of othering. Photographs were used to objectify people with intellectual disability in distress and to present them to the public as objects of pity.

In Australia, in 1967, the population of people with intellectual disability living at Kew Cottages peaked at 946 residents (Manning, 2009) and residents were found living in squalor and appalling conditions (Manning, 2009, p. 162). In 1986 in Austria, conditions within the institutions were condemned (Buchner, 2009) and in 1998, UNICEF reported that children with intellectual disability in Russia were confined to their beds all day within the institutions they visited (Mental Disability Rights International, 1999, p. 20). In 1995, the Basil Stafford Centre, an institution for people with intellectual disability in Queensland, Australia, was investigated and significant abuses were found, including that "…an insidious institutional culture existed at the Centre. This culture promoted the occurrence of client abuse and gross neglect…" (Queensland Criminal Justice Commission, 1995, p. xii). The report concluded:

> …it is more probable than not that further acts of official misconduct will continue to occur at the Centre until such time as it is closed." (p. xiii).

Inconsistent with human rights frameworks, institutional life was restrictive, characterised by block treatment where residents were treated homogenously, grouped together, treated and controlled. Levinson (2010) argued that such exposés had a revelatory impact (p.20) and that institutionalisation came to symbolise the extreme neglect and abuse of people with intellectual disability. However, while these reports and investigations occurred, often taking many years, very little was heard from people with intellectual disability themselves. Hidden behind the walls of institutions, their voices were largely unheard by society at large.

After the Second World War, the principle of normalisation began to be conceptualised (Bank-Mikkelson, 1969; Nirje, 1969; Wolfensberger, 1972), which positioned people with intellectual disabilities as individuals with the right to the everyday functions and activities of life that people without intellectual disabilities usually freely experienced. Nirje (1969) described the principle of normalisation as:

> Making available to the mentally retarded patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society. (p. 181).

The principle of normalisation which Nirje (1969) espoused was the right for people with intellectual disability to the normal rhythm of everyday life, to normal routines and opportunities and normal economic standards. This was in stark contrast to the block treatment and regimentation of the institution's (Goffman, 1961/1991; Nirje, 1994). Described by Wolfensberger and Thomas (1983) as a "megatheory of human service" (p.42), the principle of normalisation had a profound impact on the philosophical foundations of deinstitutionalisation. Wolfensberger's (1972) scholarship on the devaluation of people with intellectual disability was also influential, adding to Nirje's (1969) principle of normalisation, suggesting that normality was attained when value was ascribed to one's role within society.

Nirje's (1969) principle of normalisation and Wolfensberger's (1972) concept of social role valorisation was influential in changing social policy and moving towards deinstitutionalisation. Nonetheless, the principle of normalisation has been criticised, or misconstrued, as trying to force people with intellectual disabilities to become 'normal' (Perrin and Nirje, 1985), thus reinforcing the dualism between the aberrant and the norm. Oliver (1996) criticised the principle of normalisation for reinforcing the distinction of normal and abnormal. Oliver (1996) contends that this dualism perpetuates the distinction of the 'able' and the 'disabled'. Oliver's (1996) critique is also especially relevant in considering changing epochs of care, which moved away from the medical model of disability towards the social model of disability. Further, social role valorisation has been criticised for diverging from the original principles of normalisation and creating a different value base for judging the 'normalcy' of people with intellectual disabilities (Perrin and Nirje, 1985).

In addition to these theoretical frameworks, with deinstitutionalisation, came consideration of alternatives to institutional living. Levinson (2010) emphasised that, "(p)reviously, only one form of service was on offer after a diagnosis: institutionalization" (p. 42). In the late 1960s and early 1970s, alternatives for institutional living began to emerge. Group homes were established as community-based models of accommodation and support, designed as ordinary homes in ordinary neighbourhoods (Department of Health UK, 2001). Early research which measured outcomes for people with intellectual disability who left the institutions and moved to group homes found more individualised and personalised support within group homes

(King, Raynes & Tizard, 1971). In the UK, Tizard (1964) established an ‘experimental unit’ where 16 children with intellectual disability were relocated from a “mental deficiency hospital” (Balla, 1976, p. 121). After 2 years, the children showed improvements on measures of ‘mental age’. Tizard (1964) emphasised that the staff practices in the experimental unit were focused on educational practices rather than the clinical approach of the institutions.

As the institutions began to close, suburban housing was becoming popular in the post-war period as a place to raise a family and populations began to move out of the central hubs of the cities (Blunt & Dowling, 2014). Suburban homes became sites of personal expression and the great Australian dream was described as a detached house with a backyard, located near schools and shops in the suburbs. The suburban home was replicated for people with intellectual disability in the guise of the group home model of accommodation and support, where people lived in smaller, dispersed housing. However, with its characteristic rosters of paid support staff, routinisation of everyday life and bureaucratic organisation, the group home approximated home based on middle-class, heteronormative, conservative ideals.

In the post-war era, the medical model of disability also began to be contested (Oliver, 1990). Disability began to be conceptualised as socially constructed, determined by an individual’s social and physical environment (Oliver, 1990). Disability, rather than being positioned as a type of sub-normality, or deviancy, was reconsidered as part of the human condition. At the same time, civil rights movements contested the medical model as reductive and proposed the social model of disability. The changing social and cultural construction of intellectual disability influenced notions of home and became part of social change in housing and support arising from deinstitutionalisation. In some countries, such as the United States of America, deinstitutionalisation became mandatory, enacted through legislation[8], however many people with intellectual disability remain living in institutions due to high waiting lists for community-based accommodation.

Emerging from deinstitutionalisation, the group home model became the dominant form of contemporary housing and support for people with intellectual disability, however, there were other models being developed as part of a continuum

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[8] Americans with Disabilities Act (US Supreme Court’s Omstead decision)

of care (Taylor, 2005). The continuum of care was a way of considering residential settings from the most restrictive to the least restrictive alternatives. At one end of the continuum were the most restrictive models such as institutions and nursing homes. In the middle of the continuum were transitional houses, group homes, cluster housing, foster care and semi-independent living (Taylor, 2005). At the other end of the continuum was supported living where the person with disability owned their own home with disability support provided. Other alternatives on the continuum of care included lead tenancy, a model of social inclusion whereby the lead tenant was a person without an intellectual disability who would live with a small group of people with intellectual disability in their home. In return, the lead tenant would receive free or low-cost board and lodging and amenities paid. Back up support may be provided by a disability service provider. There is very little research to evaluate the effectiveness of this model and it is difficult to determine how many of these arrangements were available.

The continuum of care was conceptualised as dynamic, rather than a static model, and designed for people with intellectual disability to move through the continuum from most restrictive to least restrictive options. As individuals developed, and demonstrated, independent living skills in the institution they were envisaged to transition to an independent living unit, sometimes called a cottage, on the grounds of the institutions. Then, once success was demonstrated in the cottage, the individual would transition to small, community-based group homes in the community, perhaps eventually graduating to a more independent unit with less staffing support (Hitzing, 1980, p. 80, cited in Taylor, 2005, p. 99). However, for people with more severe and profound intellectual disability, it might never be possible for them to transition from a more restrictive housing model as they may never be able to develop increased independence. In this way, the continuum was a fallacy.

The continuum of care did not always effectively support people who fell outside of strict eligibility requirements, based on a classification system of an intelligent quotient score of less than 75. If a person was assessed as having an IQ of greater than 75, they were referred away from disability support services to mainstream services, which were often ill-equipped to meet the needs of this group. People with intellectual disability and more complex needs were also ill-served by the continuum of care. Service systems often operated in service silos and were unable to provide the flexibility required to meet the needs of this group. People with multiple, complex needs were vulnerable to marginalisation and exclusion. The Australian Productivity Commission identified this group as vulnerable to falling between the silos of service provision (Productivity Commission, 2011). People with complex medical needs were often unable to be served in the community and were moved to nursing homes. Homelessness remained a significant issue for many people with intellectual disability. People who were transient or itinerant often received ad hoc services. People with multiple, complex needs such as drug and alcohol issues, homelessness, mental health needs, or contact with the criminal justice system were often ill-served by the multiple support systems that surrounded them (Hamilton, 2016).

Many people with intellectual disability remained living at home with their families. A range of augmentative services supported these living arrangements. Facility-based respite was a way for families to have a break while their family member with disability went to a group home for a weekend, a few days or longer. In Australia, under the NDIS, respite is now referred to as short term accommodation (NDIS, 2017) to emphasise the short-term nature of the arrangement. Other types of respite were also developed to further support families, such as leisure-based activities, holiday camps or regular attendance at a day programme or day centre. In-home respite was also an option developed for families, where a support worker would engage with, and care for, the family member with a disability within their own home. When family care arrangements are no longer possible, perhaps due to ageing parents or to increasing complexity of needs of the person with disability, the individual would then enter the continuum of care. In these times, crisis accommodation was required, or temporary arrangements cobbled together, until a more permanent and stable option on the continuum was found.

Post-deinstitutionalisation. Although deinstitutionalisation was envisaged as a bright new future of community and social inclusion for people with intellectual disability, with a range of housing and support options, in reality the continuum of care was a false idol. Economies of scale, unprecedented demand and unmet need and emergent neoliberal ideologies meant that people remained in group homes after the institutions closed and were not able to move along the continuum to more independent living. Reflecting upon the first wave of deinstitutionalisation with its rehousing of people with intellectual disability from large-scale institutions into smaller, community-based residences, Wiesel and Bigby (2015) posit that the second wave of deinstitutionalisation was consolidated through legislation and an emphasis on community participation (Bigby & Frawley, 2010).

Yet, confined by its historical roots, disability policy failed to ensure a commitment to deinstitutionalisation and its continuation (Wiesel & Bigby, 2015) and the monumental early gains of deinstitutionalisation stagnated. The third wave of deinstitutionalisation, which I have called post-deinstitutionalisation, emerged as an epoch characterised by dissatisfaction and frustration with the inadequate progress of deinstitutionalisation. Stagnant policy reform and a disability support system overburdened with the task of implementation brought forth a fragmented, rigid, complex service system unable to meet demand (Buckmaster & Tomaras, 2013a, p. 5).

In their examination of Nordic experiences of deinstitutionalisation, Tøssebro et al. (2012) identified two phases which I paraphrase as the closure of institutions and a move toward generic services (p. 136). In the third phase, post-normalisation/post-deinstitutionalisation, the authors note a strengthening ideological position with an increased emphasis on self-determination, empowerment and individualisation of services (p. 138). Yet, in contrast to its ideological roots, post-deinstitutionalisation experienced a focus on uniformity of service provision and standardisation under the guise of quality service provision. Emerging in an era of neoliberalism, under notions of marketisation and contestability for services (Tøssebro et al., 2012), post-deinstitutionalisation emphasised free market and consumer choice. Increased choice and control, the hallmark of post-deinstitutionalisation, was realised through neoliberal paradigms where consumers have purchasing power and choice of providers is emphasised (Purcal, Fisher & Laragy, 2014).

The group home, although reformed and rectified, was never abandoned in its multiple iterations. In this third wave of deinstitutionalisation, traditional labels of welfare recipient or client were categorically rejected and people with intellectual disability, and their families, re-positioned as consumers with purchasing power. Nevertheless, post-deinstitutionalisation was also based on erroneous assumptions that the first and second waves of deinstitutionalisation had been completed. Addressing this point, Altermark (2017) used the term 'post-institutionalisation' (p. 1316) to describe contemporary times where "traits of institutionalisation both have continued and been reshaped into new technologies of government." (p. 1316). Disrupting the common understanding of deinstitutionalisation as beginning with the "dark past of state institutionalisation that has been replaced by policies of community living and societal inclusion" (p. 1316), Altermark (2017) posits that such narratives erroneously portray a simplified view of both history and present circumstances for people with intellectual disability.

Indeed, post-deinstitutionalisation has created somewhat of a paradox. Contemporary, insurance-based schemes such as the NDIS emphasised the increased opportunities for individuals to choose their own supports, called self-directed support, notions which have been "…couched in terms of social norms such as self-determination and human rights." (Marston, Cowling & Bielefeld, 2016, p. 399). Yet, Australia's National Disability Strategy 2010-2020 (NDS, 2010) made "no commitment to the continuation of the deinstitutionalisation project" (Wiesel & Bigby, 2015, p. 183) assuming its implementation as fait accompli. While post-deinstitutionalisation gave rise to other possibilities of home, refusing to be wedded any longer to the fallacious continuum of care, real alternatives to group homes have remained elusive for many people with intellectual disability.

The reshaping of new technologies of governmentality, at the essence of Altermark's (2017) argument, continues to construct narratives of home for people with intellectual disability that remain very different to home for people without intellectual disability. In this post-institutional landscape, Altermark (2017) summarises thus:

> *In parallel, people with intellectual disabilities are today provided with services that shall serve for their independence and self-determination, whilst, in practice, these services often continue to constrain how members of this group are allowed to live their lives. (p. 1316)*

Home as the antithesis of institutional living is no longer adequate. The demonstrable benefits of group home living, compared to institutional living, have been documented extensively in the literature. At the same time, variable outcomes achieved in the group home model required a greater focus on such aspects as staff ratio's and staff skills (Mansell & Beasley, 1993). Staff turnover and waxing and waning management support were also identified as factors contributing to variable outcomes in the group home model (Landesman, 1988). Mansell, Felce, Jenkins, de Kock and Toogood (1987) found that providing ‘ordinary’ environments for people with intellectual disabilities did not automatically equate to community inclusion or increased community participation. So, while people may have resided in the community, they often failed to become part of the community they lived in. Emerson et al., (2001) found that people sharing their homes with between one and three people had greater choice in their lives and in particular had more choice in co-residents and where they wanted to live than people living in larger group homes of six people or more. Robertson, Frawley and Bigby (2008) found that people living in smaller group homes of up to three were more likely to live in a house that was home-like in design and they had more opportunities for self-determination than people living in larger group homes of up to eight residents.

In the early 2000s, many countries, including Australia, had almost completed deinstitutionalisation (Chou, Lin, Pu, Lee, & Chang, 2008) in the sense that most people with intellectual disabilities were no longer living in large, congregate care facilities or long-stay hospitals and had, instead, moved into group homes based in the community. Kozma, Mansell and Beadle-Brown (2009) observed that (deinstitutionalisation) “…has been one of the most important shifts in adult social services in some Western countries in the past 30 years.” (p. 193). The post-deinstitutionalisation phase was characterised by a focus on life in the community for people with intellectual disabilities, rather than closure of institutions and Bigby (2004) notes:

> With the exception of a few ill-informed journalists, who still argue for institutional renovation and additional building on the grounds as a way of addressing waiting lists for accommodation (Davidson, 2003), the debate is no longer whether institutions should be closed. Emerson’s[9] paper illustrates that the focus has become the types of housing and support options that should replace institutions. (p. 202).

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[9] Bigby (2004) is referring to the paper by Emerson (2004).

Bigby's (2004) quote encapsulates post-deinstitutionalisation well. Yet, post-deinstitutionalisation could be conceptualised further; as an epoch in which the very essence of housing and support could be reconsidered. Kozma, Mansell and Beadle-Brown (2009) argued that in the post-deinstitutionalisation era it was no longer sufficient to compare outcomes for people with intellectual disabilities living in group homes, with outcomes for people with intellectual disabilities who lived in institutions. Instead, the authors argued, that comparisons should be made with outcomes for people without intellectual disabilities, stating:

> As large institutions disappear, the policy problem will become one of sustaining good outcomes for everyone in the community…a further trend is the shift from comparison with the past to comparison with the life experience of individuals in the general community… (p. 216-217).

Bigby and Fyffe (2006) note that despite the physical closure of some institutions, and relocation of residents to community-based group homes, that institutional practices re-emerged. Community-based group homes, in and of themselves, did not automatically create community inclusion for people with intellectual disabilities nor ensure improvements for all individuals who left institutions.

Sixsmith's (1986) phenomenological study of home has been used as a way of thinking about home in a small number of studies of group homes for people with intellectual disability (Clement & Bigby, 2010). The utility of the model is attractive, with Sixsmith's (1986) tripartite dimensions of home; the physical, social and personal dimensions of home. However, Sixsmith's (1986) work is now over three decades old and a significant body of knowledge has been developed about home, and meanings of home, since this time. Sixsmith's (1986) study also had a small sample size of 22 postgraduate students who were living on campus at a university and thus the experiences of participants may not be generalisable to other populations, for example, older people or people with disability. Nonetheless, Sixsmith's (1986) model continues to provide ways of thinking about how a place, such as a group home, is not, in and of itself, a home. Rather, bricks and mortar or a service model can be conceptualised as an abode, a physical dimension, but home is a more subjective experience (Sixsmith, 1986). In the post-institutionalisation era, disability scholarship and disability service provision would benefit from drawing on literature about home for people without intellectual disability and thus expanding conceptualisations of home beyond service models or the physical and material elements of home.

Evolving yet static; Ideas of home and the group home. In the post-institutionalisation era, where is the place of the group home? Emerging from a history of institutionalisation, the group home model offered an alternative to institutional living. Yet, the model is now some three decades old. Is the group home still a viable model of accommodation and support? Will quality of life continue to be measured against institutional living? Are group homes genuine homes? And from whose perspectives will these questions be answered? The voices of people who live in group homes are rarely heard.

Ideas of home and intellectual disability have had a problematic historical relationship. Evolution has occurred through exposés and public outrage rather than through intellectual thinking or a contestation of ideas. Rather, models for funding and service provision are refined, given a new paint of coat, and re-labelled as genuine homes.

HOME WITHIN THE GROUP HOME

Described as emblematic of community care, group homes are typically suburban houses based in communities where small groups of people with intellectual disability reside (Tøssebro et al., 2012). Compared to institutional living, group homes have demonstrably better outcomes for residents. However, in the post-deinstitutionalisation era, this comparison is no longer adequate. The very nature of group homes means that they are automatically different to home for people without intellectual disability. The pervasive presence of staff (Clement & Bigby, 2010), the routinsation of everyday life, the limits on self-determination, choice and control, are features of the group home model that are not found in definitions and descriptions of home. Simultaneously, group homes are both a workplace for the staff and a home for the residents. Thus, a tension arises; are group homes genuine homes? People with intellectual disability are rarely asked.

Tensions within group homes: A workplace or a home? While not the only service model of housing and support, the group home has emerged from deinstitutionalisation as the dominant form of contemporary accommodation and support for people with intellectual disability (Clement & Bigby, 2010). While group homes may take many different forms, typically in Australia, they are suburban homes, dispersed throughout neighbourhoods, with an ideal maximum of five to six people with intellectual disability living together. Group homes are characterised by the provision of paid staff, sometimes referred to as disability support workers, who are recruited, trained and employed to provide support to residents with activities of daily living. Rostered staffing support varies from residence to residence but can commonly include twenty-four-hour support with active night shifts or sleepover shifts. Staffing support may be configured at key times, such as mornings and afternoons, to meet the needs of group home residents. Thus, the very nature of this type of service delivery creates challenges for policy makers, service providers and for people with intellectual disabilities with the frequent tensions between the same physical spaces being on the one hand, an individual's home and on the other a staff work place (Levinson, 2005).

A substantial number of studies have examined the group home from a work place or staff or organisational perspective (Felce, Lowe & Jones, 2002; Todd & Shearn, 1999; McGhee, 2014; Deveau & McGill, 2014; 2016; Bigby & Beadle-Brown, 2016; Quilliam, Bigby & Douglas, 2017a; 2017b). This significant focus on staff or organisational perspectives is warranted given the key role that staff have within group homes and their ability to enhance or detract from quality of life outcomes for the people they support. Yet, in contrast, few studies have explored the group home from the perspectives of the people who live there. In 2000, Annison argued that further research was required to examine the notion of home and the way in which it is experienced by people with intellectual disability. In 2018, few studies have emerged to support such an examination.

Group homes are a source of significant government expenditure (Department of Communities, Queensland, 2009). In Australia, for example, in 2008-09 the Queensland Government provided or funded accommodation services for 6,355 people with disabilities. In 2008-09 the Disability Services Department of the Queensland Government directly provided services for accommodation support and respite services for people with disabilities for the sum of $108.9M. This represents a significant economic and social investment. The literature provides convincing evidence that group homes provide better outcomes for people with intellectual disabilities than institutions, however, Mansell (2009) argued that group homes retained institutional practices because the model was organisationally conceived and operationalised, and thus institutional practices are inevitably recreated. Mansell (2009) questioned whether group homes could be genuine homes given that, "…group homes…are themselves necessarily institutional." (p.11). Kozma, Mansell and Beadle-Brown (2009) noted that while quality of life for people with intellectual disability who left institutions and moved to group homes was demonstrably improved, the expected dramatic improvements were not evident. Hamlin and Oakes (2008) found that contemporary models of accommodation and support for people with intellectual disabilities, including but not limited to group homes, retained elements of institutional discourse.

Despite the significant body of evidence supporting deinstitutionalisation and the demonstrable improvements in quality of life for people who moved from the institutions to community-based group homes, knowledge of the experiences of home for people with intellectual disability living in group homes remains limited (Clement & Bigby, 2008). Outcomes in group homes are typically measured through positivistic approaches (Clement & Bigby, 2009), with measures focusing on resident numbers, group home size, staffing levels, environmental structures and staff activity. Felce, Lowe and Jones (2002) classified resident outcomes under 'other influences' in their study on possible associations between factors in group homes and outcomes. People with intellectual disability are rarely directly asked about their experiences or directly involved in research about group homes. Kozma, Mansell and Beadle-Brown (2009) found that only two papers from sixty-eight studies reviewed from 1997-2007 included some participation by people with intellectual disabilities. Further, Kozma, Mansell and Beadle-Brown (2009) found that these two papers emerged from the one study.

While the concept of home for people without intellectual disability has been extensively explored in the literature, little is known about how home is experienced by people with intellectual disability. Annison (2000) identified that relatively little was known about what makes a group home a genuine home. Annison's (2000) premise was extended some years later by the work of Clement & Bigby (2009) who used an ethnographic and action research methodology to explore the experiences of people with intellectual disability living in group homes.

Home is a complex, multi-dimensional concept (Sixsmith, 1986), fundamental to an individual's quality of life, multifaceted and socially constructed. However, the literature on home for people with intellectual disability conceptualises the phenomenon of home as a form of service delivery. The culture of group homes is necessarily influenced by the presence of paid staff and organisational routines and operational policies and procedures. In this way, the literature on home for people with intellectual disability is distinct, occurring almost in a segregated way from the literature on home for people without intellectual disability. With the exception of Annison's (2000) work, few studies, to date, have attempted to bridge this gap.

Group homes have been explored, measured and examined from multiple perspectives. In a study by McConkey and Collins (2010a) about support worker practices, the authors found that staff rated care tasks, that is tasks of daily living such as managing meals, supporting clients to get dressed, washing clothes, were prioritised over social inclusion tasks. Social inclusion tasks were defined as improving clients' social skills, supporting clients to make choices about their day to day activities and supporting clients to have contact with friends and family. The authors found that support workers rated care tasks as the priority. Clement and Bigby (2009) found that support workers spent most of their time on direct care tasks and administration, rather than social inclusion. People with intellectual disability, in particular people with more severe and profound intellectual disability, are less likely to have strong social networks, instead, their social networks are small and mostly include family and paid staff (Johnson, Douglas, Bigby & Iacono, 2011; Iacono, 2006).

Within the group home model, then, there is an immediate disparity with the social exclusion experienced by people with intellectual disability who live in group homes and the prioritisation of personal care tasks over social inclusion tasks by the people who support them. Social relationships, then, are more likely to be with co-residents, paid support staff and family members. People who live in group homes have little, or no choice as to who they live with and they may have minimal involvement in recruitment or choosing who supports them. If support workers prioritise personal care tasks over social inclusion tasks, then these influences direct how home is experienced, rather than home being a notion that is personal and self-determined. Organisational priorities also influence things like rosters, which determine when support will be provided, or organisational cultures where ‘doing for’ the person is emphasised over ‘doing with’ the person (Bigby et al., 2012), all impact on how home is both experienced and constructed.

Due to the significant influence that staff have in influencing an individual’s quality of life, many studies have focused on staff practices within group homes (Bigby, Bould & Beadle-Brown, 2017a; 2017b; 2017c; Bigby, Bould & Beadle-Brown, 2017c), practice leadership (Bould, Beadle-Brown, Bigby & Iacono, 2018) and, more recently, staff culture within group homes (Bigby et al., 2012; Bigby & Beadle-Brown, 2016). In their study, Bigby et al. (2012) found that in underperforming group homes these cultures were more likely to be staff-centred rather than person-centred, staff practice was oriented towards ‘doing for’ rather than ‘doing with’ and there was a misalignment of power-holder values with the values espoused by the organisation (p. 452). Further, the authors found that staff culture in underperforming group homes were more likely to other people with intellectual disability and staff were more resistant to new ideas and change (p. 452). In contrast, Bigby and Beadle-Brown (2016) studied ‘better performing’ group homes and found these cultures were characterised as cohesive with good team work, shared power, strong practice leadership (Bould et al., 2018) and shared values of inclusion, dignity, respect, attentiveness to difference and openness to new ideas (p. 324).

THE CONTEMPORARY CONTEXT OF HOME FOR PEOPLE WITH INTELLECTUAL DISABILITY

Group homes must be considered within the political and economic context of changing disability support paradigms. Human rights frameworks and new paradigms of disability funding and support are influential on the ways in which people with intellectual disability are positioned within society. No longer positioned as recipients of welfare (Soldatic, van Toorn, Dowse & Muir, 2014, p. 7), people with intellectual disability are now recognised as rights holders and as consumers with purchasing power. Yet, how can home be purchased? In this contemporary context how will home be considered and constructed? Where will people with intellectual disability be in this construction and how will their voices be heard? The literature suggests that, at least for the short to medium term, group homes will remain the dominant model of accommodation and support. Thus, there is potential for the new veneer to continue to perpetuate the deceptive language of home seen throughout historical epochs of care. Further, there is a paucity of knowledge about what people with intellectual disability consider to be important about home and the voices of people with intellectual disability in this space are largely absent.

Human rights frameworks, new paradigms of disability support and home. In 2008, Australia ratified the United Nations' Convention on the Rights of Persons with Disabilities (2006) (UNCRPD). Firkowska-Mankiewicz and Szeroczynska (2009) note that self-determination has become one of the most important human rights for people with intellectual disabilities. Article 19 of the UNCRPD (United Nations, 2006) specifically addresses the rights of people with disabilities to be able to live independently and to be included in the community (pp. 13-14).

Prior to the UNCRPD, studies have shown that people with intellectual disability, in particular, had little choice of whom they would like to live with or choice of housing and support (Braddock et al., 2001; Stancliffe, 2002; Bigby, 2004). In this way, scholars have argued that the ability of the group home model, in its current form, to meet the rights of persons with disabilities is inadequate (Clement & Bigby, 2009). The service system which provides group home support is restrictive and heavily bureaucratised thus significantly complicating choice and control. Group homes, for example, by their very definition, automatically preclude people with intellectual disability from choosing to live alone, with support, if they so desired. Long waiting lists and unmet needs have led to a shortage of group home places, reducing choice and control even further, and people are often reluctant and unable to move from group homes due to short supply and high competition. Declarations of human rights, alone, do not ensure that people with intellectual disabilities have the right to a home, or to their own home, or to a home of their choosing. The intent of human rights declarations, associated legislation and notions of citizenship is to ensure that people with intellectual disabilities have the same rights as every other citizen and have access to appropriate supports to realise these rights. However, Mansell (2009) noted that group homes, and the organisations that manage group homes, classify people with disabilities as residents of the group home (and the organisation) rather than as citizens living in their own homes.

In Australia, the National Disability Strategy (NDS) establishes a policy framework to guide government activity for community development and for the disability sector (NDS, p. 9). This policy framework supports the UNCRPD to be incorporated across government departments and provides reporting mechanisms for the UNCRPD. In relation to home, the NDS focuses on improving the provision of accessible housing through inclusive housing design thus providing greater choice for people with disability about where to live and with whom. The identification of inclusive housing design in a national policy framework is significant however the literature on home for people without disabilities also emphasises the affective and emotional elements of home. Such elements are not considered within the NDS.

Despite the UNCRPD and the NDS, in Australia the group home model itself remains a model of segregation, where people with intellectual disability are congregated together on the basis of diagnosis and required supports. Although group homes are physically based in the community they remain a form of segregated service, with a focus on functional deficits associated with intellectual disability from which support needs emerge. Studies have shown that it is the provision of this support which is a determinant in whether people who live in group homes are genuinely included within their communities or a merely present within them (McConkey & Collins, 2010a). The variability found amongst staff support in facilitating, and valuing, social inclusion for people who live in group homes (McConkey, Abbott, Walsh, Linehan & Emerson, 2007) reinforces the presupposition that inclusive housing design must also acknowledge the inherent challenges of a disability support system in supporting or hindering social inclusion.

The Shut Out Report (Department of Social Services (DSS), 2012) found that while group homes were an improvement, compared to institutional living, the model continued to congregate and segregate people with intellectual disability (p.27). Further, the report found:

> It is reasonable to argue that very few people living in group homes would choose to live in such a setting if they had a realistic choice. It is a compromise brought about by necessity, as they do not have enough support through funding for paid support, even augmented by their family and informal support networks, to live in their own home. (p. 27)

However, the voices of people with intellectual disability who live in group homes are absent in such debates. A lack of alternatives has also created a dependence on group homes or a perception that group homes are the only model available. The Shut Out Report (DSS, 2012) found that ageing parents are unable to plan for their adult son or daughter to leave home because of long waiting lists and a lack of housing and support options. Thus, people with intellectual disability may continue to live at home with their parents well past the age when their siblings may have moved out of home (Wiesel, 2015). Parents and families may also only be familiar with a small range of models available, such as the group home or other shared supported accommodation arrangements. Shaw, Cartwright, & Craig, (2011) found that parents did not want their family member to live in an institution and were more comfortable with the group home model of care. However, the study was limited in that it only presented parents with already existing, distinct housing and support models from which to choose. In this way, the study did not provide more flexible or innovative options that parents may have been able to construct with their family member. For example, transitioning to independent living was conceived of as through a residential program in a group home. However, another way of providing this support for independent living could be to have a group of friends' trialling independent living through a series of stays at an Air B&B, with a support worker, to gain a sense of daily living activities such as shopping, setting house rules or to experience sharing a bathroom.

While principles of human rights, equality and citizenship led to deinstitutionalisation these rights have become conflated with distinct models of service delivery. Shaw et al. (2011) found that parents had a strong preference for their family member to live in close proximity to their peers with disability. This is in contrast to the aims of community-based living, which are intended to decrease the congregation and segregation of people with intellectual disability by encouraging greater social inclusion. In the study by Shaw et al. (2011) parents indicated a strong preference for more segregated settings.

New paradigms of disability support: contemporary debates. In Australia, the disability sector has experienced unprecedented reform with the implementation of the NDIS. A review of Australia's disability system by the Australian

Productivity Commission (2011) found a fragmented, complex disability support system unable to meet demand (Buckmaster & Tomaras, 2013a, p. 5). Moreover, people with disability continued to experience significant barriers to full participation in economic and social life (DSS, 2012) with little choice and control or individualisation of services available. These findings were well known to people with disability, their families and advocates who had long called for change within an inflexible, bureaucratic disability system with substantial unmet need (Productivity Commission, 2011) In 2011, grassroots campaigning mobilised in an unprecedented way, culminating in a high profile public media campaign *Every Australian Counts* (http://www.everyaustraliancounts.com.au/) which fought for the introduction of the NDIS (para 1). Effective campaigning and the findings from the Productivity Commission (2011) led to the establishment of the NDIS in Australia, enacted through the *National Disability Insurance Scheme Act 2013.*

Aiming to reform the traditional disability sector, the NDIS was challenged by an overburdened system, characterised by traditional, block-funded services, long waiting lists, systemic inequities, and constructs of self-determination that were inherently limited (Productivity Commission, 2011). The NDIS recognised that a disability support system alone could not meet all the needs of participants and concurrently focused on building community capacity and community services[10].

Aligned with the UNCRPD (United Nations, 2006), individual choice and control was emphasised within the NDIS, which recognised the ways in which "…impairment is situated in relation to environmental barriers" (Soldatic et al., 2014, p. 8). As an insurance-based scheme, the NDIS moved away from short to medium term funding based on budget cycles (Bonyhady, 2016). Replacing a traditional welfare system, where people with disability were recipients of welfare, an insurance scheme was positioned to have the ability to calculate the future costs of scheme participants, encouraging "short-term investments that maximise lifetime opportunities and reduce long-term costs." (Bonyhady, 2016, p. 117). As former Chair of the National Disability Insurance Agency (NDIA), Bonyhady (2016) argued that funds that were traditionally vulnerable to economic and revenue pressures, cost blow-outs and "the vagaries of government" (Productivity Commission, 2011, p. 404)

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[10] Sometimes referred to as mainstream services.

are able to be forecast within an insurance-based scheme. Future expenditure, then, was "…factored in over the life of an individual" (Buckmaster, 2017, p. 5).

Terminology, too, has been contested under the NDIS with traditional labels of client or welfare recipient rejected. So, too, the more modern terms of customer, consumer or service user were replaced by the term 'participant'. The rhetoric of choice and control was foundational within the NDIS, with an emphasis on the self-direction of support and choice of providers within a free and contestable market (Purcal, Fisher & Laragy, 2014).

Criticism of the NDIS has been levelled at the competitive marketisation aspect, where larger disability organisations hold a competitive advantage over smaller organisations (Gibbs, 2013). Implications for the group home model have been significant. If smaller organisations are to be gradually subsumed by larger organisations, then what will become of group homes? With providers seeking more market share, in order to survive or to produce profits, group homes and their staffing contingents become the commodities of trade. People with intellectual disability, then, are positioned as consumers, with responsibility for choosing services, with the support of family. But what are the choices? How do consumers assess the marketplace? How do consumers choose a provider? How do providers advertise, brand and market and maintain and expand market share? For people with intellectual disability who have multiple, complex needs or require specialised support, the marketplace may not yet be sufficiently mature to support a range of providers from which to choose. Fawcett and Plath (2014) argued that the market "…is under no obligation to respond to the wants and needs of individuals and will only do so if it is economically worth the effort." (p. 754).

The individualisation of funding and supports has emerged from a broader social policy focus on human rights (Dean, 2008) and not just a neoliberal paradigm, with its drive towards increased marketisation of social services (Davis & Weller, 1996). In relation to accommodation and support for people with intellectual disability, these factors have driven a move towards more individualised housing and support (Da Roit & Le Bihan, 2010). Internationally, there has been great variability within individual funding policies (Fisher et al, 2010). Purcal, Fisher & Laragy (2014) provided an informed critique of individual funding social policies noting concerns with viability of service providers, equity of access and quality of support (p. 90).

One of the hallmarks of individualised funding approaches has been an increased emphasis on individual choice and control yet Purcal, Fisher & Laragy (2014) raise the matter that choice can be difficult to define or categorise. If a person with intellectual disability has choice between three different group homes, is this a genuine choice when the individual would really rather live alone? Or if a person would like to go to work but their funding package does not provide for transport or employment support, is this genuine choice? Marston, Cowling and Bielefeld (2015) emphasise the potential for choice to be contained to what the market is willing to offer, arguing that "(n)otions of 'choice' can quickly become empty rhetoric in the absence of evidence-based information to inform choice and supporting people with disability and their families to exercise meaningful choice" (p. 408).

Another key feature of the NDIS are the planning processes (Dowse, Wiese, Dew, Smith, Collings & Didi, 2016, p. 81) where people with disability articulate goals and aspirations tied to individualised budgets. In this way, people with disability are positioned as consumers and as rights holders rather than as recipients of welfare (Soldatic et al., 2014, p. 7). Planning and individualised support budgets aim to increase consumer choice and control and purchasing power. In relation to home, anecdotal evidence has suggested that housing markets are responding to consumer demands for more accessible housing options. Property developers, for example, are increasingly providing accessible housing stock such as apartments with full modifications and adaptations and smart homes using technological advances to enhance independence. Governments have also provided incentives for developers or local councils to work with developers, thus emphasising strong collaborations as housing options become more flexible and more tailored to meet the demands of consumers seeking more innovative housing options.

While marketplaces may be effective at responding to consumer demand for physical and material elements of home such as ramps, apartment lifts, specially designed kitchens or smart home technologies, social and affective elements of home are less tangible and more difficult for a market to meet. Nonetheless, a more flexible funding and purchasing scheme, offered by the NDIS, has contributed to increased opportunities for individuals to choose where they would like to live, and with whom, thus creating a sense of belonging. Such elements of home, identified as fundamental in the literature on home for people without intellectual disability, have previously received scant attention in a disability support system focused on protection and care. Increased consumer demand has perhaps begun to influence the ways in which housing and support will be considered. Rather than conceptualised as a need, for which a service response is required, people with disability can be positioned as consumers in a marketplace that supplies options to meet demand.

Other housing and support options for people with intellectual disability are emerging. Home sharing is one such option, where an adult with intellectual disability shares a home with another person (or multiple people) who is typically not related and who is paid to provide support. Home share providers are established to facilitate such arrangements. Hole, Robinson, Stainton, Lige and Crawford (2015), in their qualitative study of home share arrangements in British Columbia interviewed 68 participants which included people with intellectual disability, family members and home share providers. The authors found that home sharing was successful when there was a good relationship amongst all stakeholders and effective support to maintain the home share arrangement. Although the authors found positive and encouraging outcomes from home sharing, further research about this emerging option for housing and support is required.

The NDIS has begun to transform the way support workers are conceptualised, and paid, with many NDIS participants choosing to recruit and employ their own workers. The implementation of the NDIS has provoked debate across the disability service sector about pricing with many organisations concerned about levels of funding to employ support workers but a lack of infrastructure to ensure ongoing professional development and training or formal supervision or team meetings or practice leadership. The lack of a clear job description and inconsistent (or non-existent) access to supports such as formal supervision has been found to lead to support worker burnout (Vassos, Nankervis, Skerry & Lante, 2013). However, with the relatively recent implementation of the NDIS, it remains uncertain what impact the scheme will have on support worker recruitment, ongoing development and retention. Disability support workers are a critical, and integral, part of the group home model and studies have shown the importance of support staff in facilitating social inclusion (McConkey & Collins 2010a; McConkey & Collins, 2010b). Changes in employment conditions and wages may prove to have a significant impact for people who live in group homes and for the organisations who deliver disability specific accommodation and support.

The NDIS provides opportunities for people with disability, families and carers, the disability sector and the community to conceptualise home beyond physical and material dimensions. Historical epochs of care have influenced the ways in which home for people with intellectual disability has been conceptualised, and operationalised, over time. Preoccupied with home as a type of service model on a continuum of care (Levinson, 2010), the disability service sector has focused on the physical and material elements of home and a consideration of the affective elements of home has been largely absent. Significantly, there is also a paucity of knowledge about home from the perspectives of people with intellectual disability themselves.

WHEN IS A HOME A HOME?

Home is an abstract concept which is difficult to define and describe. What constitutes home for people with intellectual disability has been a problematic throughout various epochs of care. The label of home has been applied to residential settings that were not genuine homes and, therefore, the use of home has been a deceptive use of the language. Although the contemporary context of home for people with intellectual disability is influenced by human rights frameworks and unprecedented sector reform, home remains a concept that is not well understood. In contrast, the literature on home has been extensively studied for people without intellectual disability and an emerging body of knowledge has consistently grown over the past two decades. Yet, disability scholarship and disability service providers have made little use of this emergent knowledge. Contemporary ideas about home for people with intellectual disability remain preoccupied with service models, bed numbers, staffing configurations and staff practices and organisational cultures. It is not that these ideas about home are unimportant or insignificant, on the contrary, they are necessary in improving quality of life outcomes for people who are supported in group homes. Yet, these ideas about home remain one-dimensional. In this section, I explore how the broader literature on home can extend knowledge and offer new understandings and new ideas about home for people with intellectual disability.

Home is a place, a space, a bundle of feelings. Imbued with meaning, home forms part of one's identity (Marcus, 1995) and has been recognised as fundamental part of being human (Bachelard, 1964). Home is not a static concept, it is dynamic and fluid. In her study of homelessness among institutionalised older people, Carboni (1990) sought to define home and found that home was "…the experience of a fluid and dynamic intimate relationship between the individual and the environment" (p. 32). Home is not a homogenous concept. Multi-dimensional in nature (Blunt & Dowling, 2014) home has been conceptualised as having physical, material, emotional and spiritual elements (Sixsmith, 1986). Dimensional aspects of home include psychological dimensions such as security, emotional attachment (Newton, 2008) and belonging, physical dimensions such as the built environment (Tanner, Tilse & de Jong, 2008), home ownership (Dupuis & Thorns, 1998) and the ways in which space is appropriated within the home (Lyra, 2007). Social dimensions of home include relationships, choice of whom to live with and interactions within the home (Annison, 2000). Giorgi, Padiglione and Pontecorvo (2007) described the multidimensional nature of home and the ways in which home is intertwined with our own experiences, customs, histories and expectations (p.147).

In the literature, home is understood as more than just a dwelling or an abode, home is an affective space, steeped in emotion and personal meaning (Gorman-Murray, 2007). Home has been explored as a way of being-in-the-world (Heidegger, 1971) and a space that is produced (Lefebvre, 1991). The concept of home has been studied across disciplines from multiple perspectives using a variety of methodologies, however, Mallett (2004) critiqued the lack of intersection between the disciplines about home. Somerville (1992) argued that a multidisciplinary approach to home is required in order to fully explore the phenomenon.

Socioculturally situated and interpreted, home does not sit in isolation. A significant body of knowledge has been developed about home, identifying the fundamental elements of home. Annison (2000) argued that the absence of any of these fundamental elements of home could render the home a "non-home" (p. 251).

Drawing upon the work of Sixsmith (1986), Despres (1991), Somerville (1992) and Smith (1994) are the following fundamental elements of home:

- Personal and self-determined; meaningful to the occupants
- Spatial and material structures
- Social including relationships and choice of relationships in the home
- Activities and events, including critical and formative experiences
- Personal privacy and freedom; a refuge from the outside world and freedom from surveillance
- Permanence, security, continuity and stability

Complex, abstract and imbued with meaning, home extends beyond bricks and mortar. The literature on home is multidisciplinary, heterogeneous, exploring a variety of aspects of home. Never neutral, home provides an insight into the complex representations of the inhabitants (Giorgi, Padiglione & Pontecorvo, 2007). Price (2002) posited that the spaces of home are generated intersubjectively.

Home has been considered from a range of theoretical perspectives. Marxist perspectives position home as a space where labour power is reproduced, and home ownership is seen to encourage an identification with, and commitment to, capitalist ideals. Bachelard (1964) wrote about home from a phenomenological perspective, emphasising the centrality of the notion of home to human life. Sociocultural perspectives on home are examined in detail in the literature on home.

The fundamental elements of home may be experienced differently by people with intellectual disability who live in group homes. Having a space that is personal and self-determined, for example, is challenged when group home residents have little to no choice over where to live, or with whom. Self-determination may also be constrained by the needs of other housemates, limits to staff availability or priorities, and a lack of funding and resources which means people live in group homes because of a lack of alternatives.

In contrast, some people with intellectual disability who live in group homes may have genuine friendships with the people they share their home with. For some people, the group home may in fact be a genuine home, depending on how the fundamental elements of home are interpreted and experienced. The central tenet, however, is that a group home is not, in and of itself, a home. The group home is transformed into a genuine home, or not, by how home is created and constructed within the space. No model of accommodation and support will ever fulfil all the fundamental elements of home identified in the literature without considering the transactional nature of home, the ways in which home is constructed as meaningful to the occupants, and the ways in which home is experienced within the setting.

THE PROBLEMATIC OF HOME AMONGST INTELLECTUAL DISABILITY SERVICE DELIVERY

Within group homes, the setting for study, there are intrinsic power struggles about home, which is at once a home and a workplace. The literature on home for people without intellectual disability identifies fundamental elements of home however there are inherent assumptions within this literature that people have agency in their own home-making. People with intellectual disability live in group homes primarily because they require support with the tasks of daily living and individuals may have limited cognitive skills. Understanding home within this context is complex. The literature has not adequately explored people's understandings of home. In many ways, two parallel streams of knowledge about home have been developed; one for people with intellectual disability and one for people without intellectual disability. The question, then, of who does the home-making in the space of the group home, is a problematic which I explore in the following section.

Homeliness and home-like-ness. If the label of home has been mis-applied to a range of residential settings (Annison, 2000), what does home mean? When is a group home a genuine home? One way of trying to grapple with this problematic has been to examine whether group homes are homely or home-like. However, in the very act of doing so, there is an inherent assumption that, perhaps, group homes are similar to genuine homes but are not quite there yet.

The label of home has been (mis-)applied to the residential settings for people with intellectual disability in a range of ways (Annison, 2000). Balla (1976) found that a congregate care facility, where people with intellectual disability were segregated from society, could be called home. Contemporary notions of homeliness (Robertson et al., 2008; Clement & Bigby, 2010) for people with intellectual disability would not extend to places of large-scale congregation and segregation. Yet, Balla's (1976) study is an example of how an outsider's perspective could be used to apply the label of home to a setting that would not be considered as home for people without intellectual disability.

In the very language and terminology of the model, the group home model has the label of home applied after the word group, which is a somewhat contrary pairing. Considering the elements of home for people without intellectual disability, home is a space that is created by its occupants, imbued with meaning. In a group home, however, home is a space that is also a workplace, thus, a shared space with paid staff, and group home residents typically have little to no choice as to where to live and who to live with. Group homes are also characterised by high levels of routines and structures with competing residents' needs and limited staff availability. Resident routines are often conflated with staff routines. Felce, Lowe and Jones (2002) found that staff routines govern group home routines and, as a result, there was limited community inclusion. In contrast, home, for people without intellectual disability, is conceptualised as a space to express one's identity, to be able to choose one's activities within the home, to be able to enter and leave the home as one desires, and home as a place to create and to dream (Bachelard, 1964).

In their study, *Making life good in the community: When is a house a home?* Robertson et al., (2008) examined the 'homeliness' of a sample of community residential units in Victoria following deinstitutionalisation. A distinctive feature of their study was the role of the first author, a self-advocate and person with an intellectual disability as co-researcher. Based on Annison's (2000) work on meanings of home, Robertson et al., (2008) developed a framework that identified three elements that made a house a home and the authors explored the interconnectedness of the elements. The three elements of the framework identified in the study were; physical, social and atmospheric which focused on the mood of the house, and what the house felt like. These elements are consistent with the literature on the meanings of home for people without intellectual disabilities, particularly Sixsmith's (1986) framework on home, and the elements were applied as a research tool in the group home environment. Examining five group homes, Robertson et al., (2008) examined made comparisons as to whether the group homes in the study were 'homelier' than institutional accommodation. Homeliness was subjectively defined, based on the experiences, perceptions and assessments of the group home units. Robertson et al., (2008) concluded:

> The houses we saw didn't really look homely, they didn't really feel homely and they were not places where social things happened. (p.28).

The authors identified features of group homes that were not homely, such as large bathrooms or wide hallways, designed for accessibility but which "…give them a different look and feel from some other houses." (p. iii). These types of judgments could be considered as surface level; focusing only on the physical and material elements of home. Does the group home look homely? The authors were outsiders to the homes they examined, thus, their judgments about homeliness were subjective and influenced by their own experiences and preferences for home. An insider perspective, for example, may have found that the 'un-homely' elements, such as wider hallways or large, stark bathrooms, actually contributed to a sense of belonging for the residents, where space was tailored and designed to suit an individual who uses a wheelchair. If the accessibility of the rooms of the group home enhance independence for the occupants, or provide opportunities for self-determination, then these features may contribute positively to a sense of home. Thus, the individual can use the space more productively than an exclusionary space that may be considered by outsiders as appearing more 'homely'. Further, I argue there is an ablest bias in non-wheelchair users making judgements about the homeliness of accessible spaces. People living in the home may have different experiences of the same space.

The study by Robertson et al. (2008) makes a contribution to the literature on group homes, and group home environments through a consideration of homeliness and home-like-ness. Thus, the authors have attempted to create a fusion between the intellectual disability specific knowledge of group homes with knowledge of home for the population without intellectual disability. This bridge has been missing in much of the literature on home. This bridge between the two streams of ideas in relation to home for people with and without intellectual disability is also consistent with Kozma, Mansell and Beadle-Brown (2009) recommendation that comparisons on home with the past must now shift to comparisons on home with "…the life experiences of individuals in the general community" (p. 216-217).

In Robertson et al., (2008) the inclusion of a person with an intellectual disability as a co-researcher is innovative and brought a depth of perception and lived experience of disability to the research that was valuable. However, the study remained focused on what 'outsiders' perceived the home to be, that is, people who lived outside the home undertook assessments of how 'homely' the group homes were, even though one of the 'outsiders' was someone with an intellectual disability.

In Australia, in order to make group homes homelier or more home-like, the disability sector has based the group home model on the average suburban home (Blunt & Dowling, 2014) built for the heteronormative nuclear family (Gorman-Murray, 2007). Yet, in Australia, the ideals of the suburban home, conceived of as a place for raising a family (Gorman-Murray, 2007) are not realised for group home residents who are not a family group. Contemporary understandings of family are no longer confined to a narrow definition of the heterosexual nuclear family, however, Blunt and Dowling (2014) argue that this definition of home continues to be espoused as the ideal (p. 100).

The disability sector has modelled the group home on this "ideal" of what home should look like, which has conflated home with the heteronormative nuclear family (Gorman-Murray, 2007). Even as understandings of home and family continue to evolve, and to be contested, the dominant ideology of home remains conflated with the nuclear family (Gorman-Murray, 2007). It is not surprising, then, that the group home model is designed to replicate the typical Australian suburban home designed for the nuclear family. Yet, group home residents are not family, they may not choose to live together, and they may or may not consider their co-residents as 'like family'. Dupuis and Thorns (1998) found that the rites and rituals of family life are strongly associated with home (p. 34) but these may be absent within group homes or they may be replicated by staff for the residents, but they are not organically produced by the residents themselves.

Thus, approaches by the disability sector to make group homes look like ordinary homes in ordinary neighbourhoods focus largely on the physical and material elements of home. Further, attempts to make the group home environment homelier or to replicate the idealised heteronormative nuclear family, are artificial productions of home. Fundamental elements of home, identified in the literature on home for people without intellectual disability, such as privacy, identity, hearth and heart (Gorman-Murray, 2007, p. 231) are constructed by others. Privacy, for example, may be interpreted to be the provision of an individual bedroom within the group home yet, concomitantly, how is privacy experienced in a group home where the presence of paid support staff is pervasive (Clement & Bigby, 2010) and perhaps also necessary? Privacy is construed in the literature on home as having a safe, secure, space, a refuge from the outside world, a space where the individual is able to control access as to who crosses the threshold. Yet, in the group home model, control of the threshold is, at best, shared with staff, other personnel of the organisation, auditors, health and safety inspectors and the like. In some group homes, control of the threshold is entirely the domain of direct support workers. Privacy, as a fundamental element of home, may also mean freedom, or at least control, of surveillance (Gorman-Murray, 2007, p. 230). Yet, the group home model provides high levels of surveillance through the direct support workers but also through the supervision of tasks and activities undertaken by group home residents.

Notions of homeliness or home-like-ness are constructs which have attempted to make group homes more like genuine homes. Such notions build a bridge between the parallel streams of literature on home in this space. Yet, such notions also serve to reinforce the separateness of ideas of home. In the context of intellectual disability service provision, home is a concept which remains cloudy and ill-defined and home continues to be constructed for group home residents by others.

GROUP HOMES, POWER AND DISCOURSES

Although the doors of the institutions have ostensibly closed (or continue to close) and group homes have been developed to look nicer than the wards and units of old, it can be argued that institutionalisation, in many ways, remains. And although group homes may be homelier and more home-like than institutional living, they remain somewhat artificial constructs. Almost genuine homes but not quite, the absence of many of the fundamental elements of home perhaps, as Annison (2000) argued, renders them “non-home” spaces. However, group homes are homes for the people who live in them and although they may not be ideal homes, or homes conceptualised a romantically as Bachelard (1964), they do, nonetheless, hold meaning for their occupants. Another way of thinking of group homes may be to consider them as in-between spaces.

Paradoxically, the group home setting is both a home for the occupants and a workplace for the staff who provide support to the occupants. At times, these roles conflict. Thus, power relations in this space are intricate, intertwined and complex. The historical legacy of institutionalisation remains, pervading the group home space through the routinisation of space, the structuring of time according to staff rosters and routines and the block treatment of residents. Power relations and discourses within group homes hold great utility for better understanding the contradictory environment of the group home.

An intricate grid of power relations and the group home. Group homes may be delivered directly by government or non-government organisations which are contracted to provide accommodation and support services through funding and service agreements. Such systemic frameworks, and discourses, emphasises the group home as a contractual arrangement and a site of service provision. The group home is also subject to annual audits against disability service standards to ensure compliance and the provision of ongoing funding. Within Organisations which manage and operate group homes, there may be a hierarchy of staff, with direct support workers at the group home reporting to team leaders and co-ordinators and managers. Such bureaucratic structures provide role descriptions, and identities, for each staff member, thus, distinguishing them from people who live in the group home, the residents.

Goffman's (1961/1991) work *Asylum*, explored the ways in which the total institution stripped an individual of their identity, in order to treat, cure and rehabilitate thus positioning them as a patient or inmate. The total institution was a space where a "…number of like-situated individuals, cut off from the wider society for an appreciable period of time, lead an enclosed, formally administered round of life." (Goffman, 1961/1991, p. xii). Characteristics of the total institution included binary roles of staff and inmates where each group adjusted their actions to conform to their expected roles. Nunkoosing & Haydon-Laurelut (2011), however, observed that, within group homes for people with intellectual disability, staff held the power to change and re-adjust their roles whereas residents did not. If residents were labelled as difficult or challenging this may result in a referral to a specialist behaviour support to have such aberrant behaviour corrected and reformed. When inmates arrived at the asylum, there was a process of mortification (Goffman's (1961/1991) whereby inmates were dispossessed of their former roles and identities. Upon admission, and during institutionalisation, the individual was "shaped and coded into an object" (Goffman, 1961/1991, p.26). Nunkoosing & Haydon-Laurelut (2011) argue that the group home model's historical roots in institutionalisation have continued to influence contemporary group home culture with the binary positioning of roles; staff and resident. However, this binary understanding has been criticised for creating "hostile stereotypes" (Bengtsson & Bülow, 2016, p. 60) and for limiting understandings of power relations.

Foucault's (1980) writings on power and knowledge identify how power produces dominant discourses and this is useful to consider in the group home context (Nunkoosing & Haydon-Laurelut, 2011). The group home as a producer of intellectual disability discourse (Nunkoosing & Haydon-Laurelut, 2011) is reflected in the service language used to describe people who live in group homes where they are referred to as service users, service recipients, consumers, clients and residents. People with intellectual disability who live in group homes are positioned as passive recipients of care (Annison, 2000). Mansell (2009) argued that disability service organisations label people with intellectual disability as group home residents living in a setting owned and operated by the organisation rather than as citizens living in their own home with support. Thus, within the group home model, there is multiple-labelling. What are the consequences of such labelling? How is labelling experienced by people who live in group homes? To date, these are questions that remain unexamined in the literature on group homes.

In Foucault's (1977) *Discipline and Punish*, the ways in which institutional systems work to construct docile, compliant bodies is examined. Foucault (1977) uses Jeremy Bentham's concept of the panopticon as a metaphor with which to explore power and surveillance in modern society. Designed as a circular watchtower, located in the middle of the prison, the panopticon gave inmates the impression that they were always being watched. Guards in the watchtower were hidden from the inmates' view, thus inmates were never sure if they were being watched, or not, and therefore disciplined themselves, acting as if they were under constant surveillance. Foucault's (1977) concept of *panopticism,* derived from Bentham's prison designs, has been used to consider how society came to be organised in the 19th century through increasing levels of surveillance. The panopticon has been used metaphorically, as an all-seeing inspector which influenced the ways in which citizens behaved and checked and monitored their own behaviour to act accordingly (Brunon-Ernst, 2012). Foucault's (1977) interpretation of Bentham's panopticon has been widely adopted by scholars in examining and understanding surveillance and its influence on human behaviour and societies.

In group homes, pervasive surveillance is combined with the authority and control of the disability support staff, and the hierarchy of team leaders and managers. Group homes are characterised by rosters, client routines, and other technologies designed to control and order the behaviour of group home residents. Hockey (1986) argued in his ethnographic study of British Army life, that the strictures of a highly regulated and hierarchical institution demand conformity and obedience. The panoptic systems of group homes aim to produce docile, compliant bodies and, there are parallels with the strictures of British Army life examined by Hockey (1986), as uncomfortable as it may be to compare group home life to aspects of army life. Bentham's panopticon has come to be understood as "…an emblem of modern power" (Semple, 1992, p. 108). However, O'Farrell (2012), cautions against the "easy and widespread equation: Bentham = Panopticon = oppressive totalising society of surveillance" (p.xi) as populist and reductionist.

A Foucauldian analysis of power is increasingly being used in disability studies as Tremain (2005) notes:

> [A Foucauldian] conception of power as government ("the conduct of conduct") is in stark contrast to the "jurdico-discursive" (to use Foucault's term) conceptions of power that much disability theory takes for granted (p.9).

Foucault (1977; 1988) argues that power is not merely repressive, however, and that power is productive. Foucault (1977) examines power as a relation. Discipline is conceptualised as a mechanism of power which controls and regulates individual behaviour, enacted through a complex grid of surveillance. Foucault's (1977) theoretical perspectives are useful to consider the ways in which power operates within group homes. Foucault has not been widely used in disability scholarship, with some scholars questioning its usefulness (Hughes, 2005), while other scholars have argued that attempts to engage with Foucault and disability studies have been "largely rudimentary" (Tremain, 2005, p. 2). However, Drinkwater (2005), in the volume edited by Tremain (2005), argued for greater engagement with Foucault in considering supported living for people with intellectual disability. In particular, Drinkwater (2005) contests the simplistic assumption that deinstitutionalisation has led to community inclusion, without consideration of the ways in which new types of power, governmentality, have been transformed. Drawing upon Foucault's (1977) panopticism, Drinkwater (2005) considers the ways in which supported living arrangements use disciplinary techniques within the post deinstitutionalisation era to govern resident behaviours.

Power has been understood as the ability of an individual or social group to control the activities and behaviours of others (Renbald, 2000, p. 55). In her study of social networks, Renbald (2000) found that people with intellectual disability had few opportunities to choose their social networks and were subjected to the power, and control, of support staff, who ultimately approved or denied individual social networks. Gilbert (2003) used a Foucauldian analysis of care planning for people with intellectual disability. Using Foucault's notion of governmentality, Gilbert (2003) examined power relationships between stakeholders and found that people with intellectual disability were subject to powers exerted over them by the organisations that provided their support. In turn, these organisations were subject to powers exerted over them by regulators and funding bodies and contracting processes.

Agency and resistance. Although little is known about residents' agency amongst people who live in group home, agency is an important concept for this study. Defined as the ability of individuals to make choices and to operationalise their choices (Petesch, Smulovitz & Walton, 2005), agency may be constrained within the group home context for several reasons. Group homes have the potential to diminish individual agency through tightly controlled and administered bureaucratic regimes, based on historical notions of protection and care. Such notions infantilise people with intellectual disability (Wolfensberger, 1975) which can lead to the denial of adult rights (Wardhaugh & Wilding, 1993). Institutionalisation inherently includes the separation and exclusion of a group of individuals from larger society (Foucault, 1961;

1977) thus marginalised individuals are subjected to disciplinary techniques which can make resistance difficult and subject to punitive measures (Goffman, 1961). The group home model of accommodation and support is also constitutive of such institutional regimes (Tøssebro et al, 2012). Further, the infantilisation of people with intellectual disability positions them as children to be cared for and protected from harm rather than as adults with decision making capacity.

The concept "agency within constraint" has been used by Bell (2012) to refer to the ways in which individuals find agency within complex, constrained environments. In his study of young people's sexual agency in rural Uganda, Bell (2012) articulates a continuum of agency (Klocker, 2007) where at one end, young people are able to act within a broad range of options (thick agency) and at the other end of the continuum, young people are constrained by "moral, gender and age-based ideologies and beliefs" (p. 284). This is an interesting lens through which to consider the agency of people with intellectual disability who live in group homes. Goodley (2001) argues that the labelling of people with intellectual disability or learning disability frames a perception of individuals as impaired, which can lead to a separation of people as "'irrational' (impaired) and the 'rational' (non-impaired)" (p. 210). Within the group home such a binary division was also evident between residents and staff, with implications for power relations as I have discussed previously. Thus, agency for group home residents is further constrained.

Resistance, then, within the group home environment becomes risky. In their study of referrals of group home residents to disability specialist behaviour teams, Nunkoosing and Haydon-Laurelut (2011) found that residents were positioned as "a problem to be solved, as in need of surveillance" (p. 405) and treatment. Residents received a label of challenging behaviour that positioned them as clients to be referred and treated in order to control the individual and their behaviour (p. 406). These realities add to Klocker's (2007) notion of 'thin agency'.

There are, however, support practices which aim to support group home residents to maximise choice and control. Person-centred active support, for example, focuses on disability support worker practice, aiming to provide just the right amount of support to increase the engagement of people with intellectual disability in everyday tasks (Mansell & Beadle-Brown, 2012). Person-centred active support is an evidence-based approached which has been shown to increase the amount of choice given to residents by direct support staff during activities (Beadle-Brown, Hutchinson & Whelton, 2012). Such staff practices can enhance opportunities for people with intellectual disability to make choices, yet little is known about whether they can create 'thicker agency' (Klocker, 2007) or to what extent they can ameliorate more systemic constraints surrounding agency within group homes.

HOME AS A SPACE THAT IS BEING-PRODUCED

The group home is often considered a model of service delivery, a type of accommodation and support that is delivered by one group to another. While the disability service sector, and disability scholarship, has been preoccupied with home as a type of service model and creating environments that are homelier and more homelike than the institutions, consideration of the ways in which home is socially produced has been largely ignored. The fluidity and dynamism of home-making is an important part of producing home and this can be considered as a contested role within the group home. In many ways, staff are employed to home-make for group home residents. Many of the activities of daily living, with which people with intellectual disability require support, are opportunities to home-make. Preparing a meal, making a bed, choosing how to spend one's leisure time, choosing who to invite into the home and a range of social interactions and experiences are all constitutive of home. The group home has temporal and spatial dimensions which are experienced differently according to whether one occupies the position of staff or resident. Lefebvre's (1991) theoretical perspectives on space and time are useful in developing a more nuanced and sophisticated understanding of home within the group home.

Home-making. Scholars such as Blunt and Dowling (2014) have argued that home, particularly in Australia, has become conflated with an owner-occupied domicile in a suburban location with a detached suburban house designed for a nuclear family (p. 100-101). Government funding for group homes is also often conceptualised along these lines with four to five (sometimes more) people with intellectual disability living together in dispersed housing stock in suburban areas. In more traditional, block-funded disability service systems, economic influences meant that individuals typically could not afford to live alone or with only one other person.

In doing so, the level of support they required would not be able to be provided, without the sharing of staffing costs, rosters, household expenditures and the like. More individualised funding schemes, such as the NDIS, may provide more flexible funding options and, thus, more flexible models of housing and support. Yet, even more contemporary approaches consider the group home, and its variants, as a model of housing and staff support, rather than home as a site of social production or a space that is being-produced.

In his seminal work, *The Production of Space*, Lefebvre (1991) argued that every society produces its own space and such productions of space can be understood through everyday life. Home as a space where one's identity is constructed, and re-constructed, is discussed widely in the literature on home (Gorman-Murray, 2007) but rarely at all in literature on home for people with intellectual disability. The process of home-making facilitates self-expression; in choice of décor, in social relationships within the home, in changing models of home. A young person leaving the family home for the first time, for example, may live in a share house with other young people but after getting a job and a steady income, this same young person may choose to live alone or with a partner or in a share house in a preferred neighbourhood which they could not previously afford. Thus, home-making can include identity construction within the house where one resides, but home-making also extends beyond the walls of the house. A family home in the suburbs, for example, may be exchanged for some inner-city unit once adult children leave the home, thus home-making has both geographic and temporal dimensions. However, home-making is not static, it is a process of changing and cumulative identities (Blunt & Dowling, 2014) where experiences are accumulated over time (Lyra, 2007).

Heidegger (1971) posited that home is fundamental to an individual's experience of being-in-the-world. Much more than just a physical space, Heidegger (1971) conceptualised home as a state of being. A participant in Gorman-Murray's (2007) study of meanings of home for gay men and lesbians spoke of how home represented her identity, her being:

> Home probably reflects my identity as an artist more than anything, but a queer feminist artist definitely. (Angela, 50s, apartment/tenant, regional NSW). (p. 234).

Thus, there is a fluidity, a dynamism to home-making that is not recognised in the literature on group homes for people with intellectual disability. This group are not recognised as active agents in their lives, rather, they are positioned as passive recipients of service, where a model of home has been constructed, and delivered, by others. A group home resident's identity, for example, is assumed by the disability service sector to be a person with disability requiring support with daily living activities. This is a stark contrast to the rich, self-determined way Angela interprets her identity as a queer feminist artist in Gorman-Murray's (2007) study, where her home reflects her identity.

Lefebvre's (1991) notion that space is socially produced is an important theoretical perspective for this thesis. Lefebvre (1991) developed a three-part schema to understand the social production of space. The first part, spatial practices, understands how everyday life, with its patterns and rhythms and social activity can produce space. Through a Marxist perspective, space is produced and then utilised by capitalism for its goal of production. Spatial practices include the home, office, public space where everyday activities occur such as commuting, purchasing items, working, recreating or cooking a meal. Home-making is full of various spatial practices, which add up to the construction of home, transforming a physical space (the house) into a site which may be personally constructed as comforting, safe, secure, a place of belonging and a range of other personal meanings which constitute home. In the group home model, spatial practices also include the ways in which the staff use the site as a workplace, writing file notes, completing administrative paperwork, locking cupboards and retaining access to resources such as money and technology in the staff office. Although the staff office is part of the house, only the staff and the Organisation for whom they work, control this space, it is a space from which group home residents are generally excluded. Yet, the rules and regulations and policies and procedures that emanate from the staff office significantly affect the group home residents.

The second part of Lefebvre's (1991) schema is representations of space, which include how space is designed and intended to be organised, through maps or architectural designs or plans, rosters and timetables. The third part of Lefebvre's (1991) schema is representational spaces, alternative spaces, abstract spaces of imagination, dreams, romantic ideals and social movements and where space is contested such as when resistance ideals are conceived. Bachelard's (1964) conceptualisation of home as a space where dreaming can occur may be a type of representational space. Dreaming can also change the space or appropriate the space, such as dreaming of a home by the seaside which may lead to purchasing a home in a seaside location.

Lefebvre's (1991) work has not been widely used in group home research, to date. Gleeson (1997) considered the ways in which the social production of space is influenced by a range of sociocultural and structural dynamics (p. 202), thus, leading to the potential for "…human service agencies and state bodies to produce the social space of community care." (p. 202). Gleeson's (1997) point has relevance for this thesis and the ways in which a range of influences determine how the space of the group home is produced. The historical sociospatial exclusion of people with intellectual disability within institutions has been one way that space has been produced for this group. The congregation and segregation of people with intellectual disability into more aesthetically pleasing and a higher quality of life in physical and material domains is another way in which space has been produced for people with intellectual disability.

Lefebvre's (1991) theory of social space has received little attention in group home research. Housing studies more broadly have increasingly used Lefebvre's (1991) conceptual framework. Petersen and Minnery (2013) used Lefebvre's theory of social space to understand daily life of older people living in a residential complex. Described as somewhat of a hybrid space (p. 824), residential complexes for older people can provide a range of supports with care facilities and more independent units sometimes within the same space. Like group homes, although on a much larger scale, residential complexes are a type of separated space, where people are congregated together on the basis of age and support needs, living in dedicated spaces somewhat separate from the community. In their study with 22 participants living within a residential complex, the Petersen and Minnery (2013) found that spatial practices were diverse and complex. The authors explored how spatial practices imbued space with meaning, finding tensions in the production of one space, the residential complex, and the heterogeneity of older people living in such complexes (p. 838). The residential complex both hindered and enabled spatial practices through "…a complex set of social, political and cultural dynamics that surround residential complexes as spaces for older people." (p. 840). Using Lefebvre as a conceptual framework (p. 823), the authors asked how space "…is conceived, perceived, and lived…" (p. 840).

The relationship between individuals and the social context within which they are located is a key tenet of Lefebvre's (1991) analysis of space and time. Within the group home, space is produced differently by support workers than it is by residents. Time is also influential within the group home. Staff rosters are governed by specific time allocations which are influenced by industrial relations and labour awards. Group home residents, then, are influenced by the staff rosters and adjust their activities according to staff availability or rotas. Breakfast time, within the group home, for example, can be experienced differently depending on whether one is a staff member of a resident. As a support worker, breakfast time may signal the beginning of a shift and shift duties may include support with the morning meal, dispensing medications, ensuring residents are ready for the day ahead and prepared for activities or appointments. For a group home resident, however, breakfast time may signal time to eat a favourite cereal or to get ready for a busy day ahead. Or, breakfast time may signal waiting for staff to get breakfast ready and served, waiting to have medication, waiting for the bus to arrive, waiting to be picked up and waiting to go out.

Time within the group home is often considered in the literature in terms of staff practices, such as the ways in which staff can be allocated and organised to support person-centred active support (Beadle-Brown, Bigby, & Bould, 2015). Time within the group home has been written about extensively and comprehensively in terms of levels of disengagement of group home residents (Bigby, Bould & Beadle-Brown, 2017a; 2017b; 2017c; Bigby & Beadle-Brown, 2016) with studies developing measures of engagement and disengagement. Yet, there is a paucity of knowledge about how group home residents would like to use time, or where they would like support time to be focused. Spatial practices receive little consideration in group home research.

The preoccupation of disability scholarship and the disability service sector with group homes as sites of service provision, perhaps reflects the one-dimensional consideration of home-making within this space. Studies of staff practices within group homes are essentially examining the ways in which staff produce space. Using Lefebvre's (1991) theoretical suppositions about how space is produced, staff practices can be considered as types of home-making, which staff produce for the people they support. This has not been explored in group home research to date. Further, while knowledge about group homes recognises the setting as a site of service provision, the literature on home for people with intellectual disability has largely ignored the ways in which home is a socially produced space. There is a significant gap in the literature about how people who live in group homes construct meanings of home and how they home-make within the group home context. Lefebvre (1991) argued that productions of space can be understood through everyday life. Further, the agency of people with intellectual disability who live in group homes to construct their own meanings of home and to actively home-make is under-examined in the literature. The paucity of knowledge in this area provides a rationale and an argument for the focus of this study.

THE VOICES OF PEOPLE WITH INTELLECTUAL DISABILITY ON HOME

The voices of people with intellectual disability have been largely absent throughout the history of ideas about home and intellectual disability service provision. More often, people have spoken on their behalf, through surveys, questionnaires or via third-party and proxy respondents. It remains to be seen within new paradigms of disability support, experienced in Australia through the NDIS, where there is an increased emphasis on choice and control and positioning people as rights holders, how the voices of people with intellectual disability will be heard. How will policymakers, funding bodies, and service providers know if people wish to continue to live in group homes or if they would like to construct other models of home? Too often, the severity of intellectual disability or cognitive impairment, or the individual's complex language, have been used as excuses to exclude their voices about home. Or to turn to staff and family members to speak on their behalf.

Few studies have explored what home is like within a group home from the perspectives of the people who live there. However, the contribution of those studies which have are significant and pave the way for future research. Without the voices of people with intellectual disability, understandings of home will continue to be dominated by service-centric perspectives. Debates and conversations about home will be one-dimensional and unbalanced and self-serving. Inclusive and collaborative research approaches have emerged in recent years (Walmsley & Johnson, 2003; Johnson, 2009) and provide a guide for future researchers as to how to include people with intellectual disability in research about home and group homes. Service providers, too, could utilise inclusive and collaborative approaches to better hear the people they support.

Oral histories of home. The devolution of large scale, segregated, congregate care facilities for people with intellectual disability has been one of the most significant policy developments to have occurred in the disability services field (Mansell and Ericsson, 1996; I-ASSID, 2009). Yet, the voices of people who lived in institutions were often overshadowed by exposés constructed and presented on their behalf, positioning people as objects of pity. Oral historians have contributed to knowledge about what life was like lived within the walls of the institutions by supporting people to share their stories and oral histories. In *Bye-Bye Charlie: Stories from the Vanishing World of Kew Cottages* (Manning, 2008), Ted Rowe shared his experiences of life at the Cottages. Ted lived at the Cottages in the 1920s[11].

> Ted Rowe was not fond of the close supervision or showering en masse. He recalled that in the, 'big shower room…eight goes in a time and they time you. They say 'Righto, time to get out of the shower and dry yourself…Go to your dormitory [and]…get your clothes on.' (Manning, 2009, p. 162).

In the following account, Ted shares personal insight into meal times at the Cottages;

> Due to budgetary restrictions, residents were often deprived of a nutritional diet. The majority of residents ate in large groups assembled in a central dining area or in the wards. Ted Rowe thought that the food 'Wasn't bad. Could have had better, but they don't give you much.' At times the small serves were a blessing, particularly in regards to morning porridge. Ted recalled that breakfast was, 'always porridge…We always used to say "Oh you got this glue out again! (Manning, 2009, p. 164).

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[11] For further information about Ted Rowe's experiences at Kew Cottages, visit *kewcottageshistory.com.au*

Oral histories provide an important counter hegemony to service-centric perspectives. Where Balla's (1976) review of the literature found that congregate care, at least institutions of a size less than 100 people, could be labelled home, Ted Rowe's oral history of his life at the Cottages provides a counter perspective. Ted's rich account of home illustrates how home within an institution was lived and experienced, rather than merely conceptualised or considered or labelled as home from a detached, outsider perspective.

Atkinson (2004) emphasised the power of oral and life history research, in particular, with its potential for empowering people with learning disability through the co-production of knowledge. Atkinson (2004) notes the powerful process of sharing one's story and life experiences through oral and life histories and being able to share using one's own words and not the words of others speaking on one's behalf.

Drawing upon her experiences with oral/life history research Atkinson (2004) also emphasised the empowering aspects of groups of like-minded members coming together to share their experiences and stories. Atkinson (2004) illustrates how these empowering aspects burgeoned through her researcher-established six-week 'history group' (p. 693) with members with learning disability, which morphed into a participant-led group focused on writing and documenting people's stories which lasted for two years.

Walmsley and Johnson (2003) argue that participants with learning disability can benefit from the research process, developing new skills and learning about research. Reflecting on her experiences leading an inclusive research project with people with intellectual disabilities from the Republic of Ireland, Johnson (2009) found that participants developed skills in self-advocacy through the research process (p. 250). Such skills are also beneficial to participants outside of the research process in everyday life.

Developing insider perspectives: Learning from Edgerton. The importance of hearing from people with intellectual disability is illustrated through Robert B. Edgerton's (1967) seminal work, *The Cloak of Competence: Stigma in the Lives of the*

Mentally Retarded[12], which provided inspiration for my study. Although not specifically exploring the notion of home, Edgerton's (1967) ethnography of the experiences of people after they a left long-stay hospital, an institution, was a significant study, illustrating ways of developing insider perspectives and ways of hearing the voices of people with intellectual disability. Edgerton describes his rationale for using an ethnographic methodology:

> This study has proceeded upon the belief that in order to understand the behavioural features of the everyday lives of these retarded persons, as well as their own feelings about themselves and their lives, it would be necessary to establish prolonged and direct personal contact with them. Insofar as possible, it would be necessary to see these people through their own eyes and to hear them in their own words. (p. 7).

In his study, Edgerton (1967) contacted 53 people with intellectual disabilities who had been discharged from the Pacific State Hospital in California, a long-stay hospital where people with intellectual disabilities lived and received training and treatment. Patients were discharged on the basis of successful completion of a program that required them to demonstrate that "…they were competent to manage their own lives without the aid or control of the institution." (p.10). Edgerton (1967) provides detailed case studies of four people with intellectual disabilities who left the Pacific State Hospital and each story reveals how the individual's life changed upon leaving the hospital. One participant provides valuable insight into way life 'inside' and 'outside' the institution is considered. Edgerton (1967) writes:

> The receipt and display of mail is something else which concerns these former patients. Very few send or receive mail, and when they do send it, they usually need help. All, however, love to receive mail, because receiving mail is "what outside people do all the time." (p. 159).

In this excerpt, the participant refers to 'outside people' as those people who live outside the institution or long-stay hospital. The experience of this participant on the 'inside' (that is, living in the Pacific State Hospital) formed his expectations of life on

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[12] Edgerton uses the language of the time to describe intellectual disability. Mental retardation is no longer an acceptable term to use.

the ‘outside’, including what elements of daily life he identified as important in order to live a successful life and avoid being reinstitutionalised. Critically, Edgerton (1967) used methods to speak and work directly with people with intellectual disabilities themselves, using interviews and participant observation to achieve this aim. At the time, few studies took this approach with most studies interviewing parents and/or staff rather than people with intellectual disabilities themselves.

Edgerton’s (1967) approach yielded valuable information about the actual experiences of people with intellectual disabilities who had left a long-stay hospital. Edgerton’s (1967) inclusive approach enabled rich data to be presented, ethnographically, provided evocative illustrations of everyday life. Edgerton’s (1967) study challenged previous perceptions and ideas about people with intellectual disabilities and provided vignettes, case studies and real-life examples to demonstrate that people with intellectual disabilities were, in fact, hiding their struggle to cope living in the outside world through their ‘cloaks of competence’.

Edgerton (1967) argued that people with intellectual disabilities were able to hide their struggles, in part, because society did not want to look or to really see them, or to acknowledge their real experiences. Fundamental to Edgerton’s (1967) ethnographic approach was the deep, rich, exploration of experiences. For example, the four case studies presented provide detailed and in-depth accounts of the real-life experiences of participants; this knowledge had not been available previously.

Edgerton’s (1967) approach was built on the premise that what ‘others’ (such as family, staff, governments, society, community) see, or choose to see, about their reality, and their lives, may be vastly different from the lived experience of people with intellectual disability. Ted Rowe’s oral history of his life lived at the Cottages (Manning, 2008) provides a powerful perspective, and a counter, to outsider perspectives of institutional living. Thus, emphasising the importance of including people with intellectual disability. Edgerton (1967) found that society overlooked the real struggles that people with intellectual disabilities experienced with the closure of institutions and long-stay hospitals. Edgerton’s (1967) study illustrates the importance and value of exploring and understanding perspectives directly from people with intellectual disabilities and his work was a significant inspiration for my own study.

Hearing the voices of people with intellectual disability who live in group homes. The inclusion of people with intellectual disability who live in group homes is challenging. There is also a dearth of literature about how to include people who live in group homes in research about home, housing and support, or broader policy debates. Clement and Bigby (2008) in their study of life in group homes following the closure of a large-scale institution in Victoria, state:

> One important measure of service quality is missing from this research – the subjective views of people with intellectual disabilities themselves, which were inaccessible to us. The residents could not tell us how the (sic) they perceived their lives or the goals that had been set on their behalf. They could not advise the staff how they wanted to be supported. Unlike customers in other service industries they certainly could not 'walk away' and take their 'custom' to another group home if they were dissatisfied. (p.25).

Clement and Bigby (2009) raise an important point, which is relevant in the contemporary context of disability service sector reform occurring in Australia with the implementation of the NDIS. In the new paradigm of disability support, how can people who live in group homes take their 'custom' to another group home or, indeed, to another model of accommodation and support altogether. There is a paucity of research in this area. Very few studies have examined the group home from the perspective of the people who live there. Annison (2000) argues:

> Further research is required to identify and describe the manner in which people who have intellectual disability experience and conceptualise home or indeed, whether the concept is meaningful or useful (or both) to them, and if so, in what way. (p. 261)

Previous positivistic and experimental research approaches are also limited in contributing to knowledge about the group home experience, and the outcomes that people with intellectual disabilities themselves identify as important to improving group home living. Clement and Bigby (2009) define past research on group homes as largely 'quasi-experimental' and argue that such research has failed to provide an understanding of the day-to-day experience of life within group homes. More often, people have spoken on behalf of people with intellectual disability, through surveys and as third-party proxy respondents. In reviewing the literature on home, the voices of people with intellectual disability are largely missing. In particular, the voices of people with more severe or profound intellectual disability are rarely heard.

REFLECTION AND SUMMARY

Home is a product of the sociocultural context within which it is constructed. Therefore, the context of the society that produces home needs to be understood, in order to understand home. Explorations of home for people with intellectual disability frequently neglect this sociocultural context, and the historical influences of home, charging straight towards examinations of home as a service model on a continuum of care (Levinson, 2010). In this chapter, I located the dominant model of contemporary accommodation and support for people with intellectual disability, the group home, through a historical portrait of different epochs of care. Socioculturally positioned, the group home is reflective of a culmination of a history of ideas about home for people with intellectual disability service provision. Throughout this chapter, I have emphasised a parallel construction of ideas about home for people with intellectual disability which is different to ideas about home for other community members. These different conceptualisations, based on notions of alterity, have created binary understandings of home and a separate, artificial accommodation and support system has been developed for people with intellectual disability. Thus, the dominant hegemony of home is one of service provider perspectives. In this way, home has been a concept constructed for group home residents by others.

The paucity of knowledge about how meanings of home are constructed by people with intellectual disability who live in group homes provides a rationale and an argument for the focus of my own research. The individual experiences of people who live in group homes are often subsumed by a service system preoccupied with models of service delivery. Human rights frameworks and new paradigms of disability support present opportunities to consider group homes differently yet without new ideas about home, new perspectives, the disability field risks reinventing the same old models with a fresh coat of paint. Without the voices of people who live in group homes, the dominant hegemony will persist.

Chapter 3: Conceptual Framework

This chapter describes the conceptual framework of the study. Using Crotty's (1998, p. 2) schema, I describe the philosophical stance of the study and the methodology. My choice of each was based on the ability to support the research questions and I was also influenced by the maxim of the self-advocacy movement, *nothing about us, without us* (Charlton, 1998). This maxim seeks to actively and meaningfully include people with intellectual disability in research which is about them and influenced the design of my study and my methodological choices. In the previous chapter, I argued that the voices of people with intellectual disability have been largely absent in debates and policy about home. In particular, people who live in group homes and people with more severe and profound intellectual disability continue to be excluded from research, with the more dominant use of third party, proxy respondents or positivistic research approaches in this space.

I begin by revisiting the research purpose and research questions and I outline how I have used Crotty's (1998) schema in my study to guide the conceptual framework. Then, I discuss social constructionism, which is the epistemological approach of my study. In the next section, I outline my use of interpretivism and why this perspective was relevant in my study. Following this, I describe in detail my methodological choice and I discuss why ethnography has particular utility in understanding how meanings of home are constructed by people with intellectual disability who live in group homes. In Chapter 4, I discuss ethical implications for the research and outline in detail each of the methods used in the study.

REVISITING THE RESEARCH PURPOSE AND RESEARCH QUESTIONS

My study aims to explore and understand the group home from the perspectives of the people who live there, with my primary research question asking:

> *How do people with intellectual disability who live in a group home understand and experience home?*

To assist in answering my primary research question, I asked:

- How do people with intellectual disability who live in a group home construct meanings of home?
- What are the attributes that they identify as essential to home?
- What influences enhance and detract from achieving these ideals?

In the development of a research proposal, Crotty (1998) argues that researchers must answer two questions:

> First, what methodologies and methods will we be employing in the research we propose to do? Second, how do we justify this choice and use of the methodologies and methods? (p. 2).

In order to answer the research questions, and to guide the development of the conceptual framework for my study, I used Crotty’s (1998) schema, Figure 1, to support the development of knowledge about group home life from the perspectives of the people who live there. In the next sections of this chapter, I discuss each part of the schema in more detail and emphasise the interrelatedness of each.

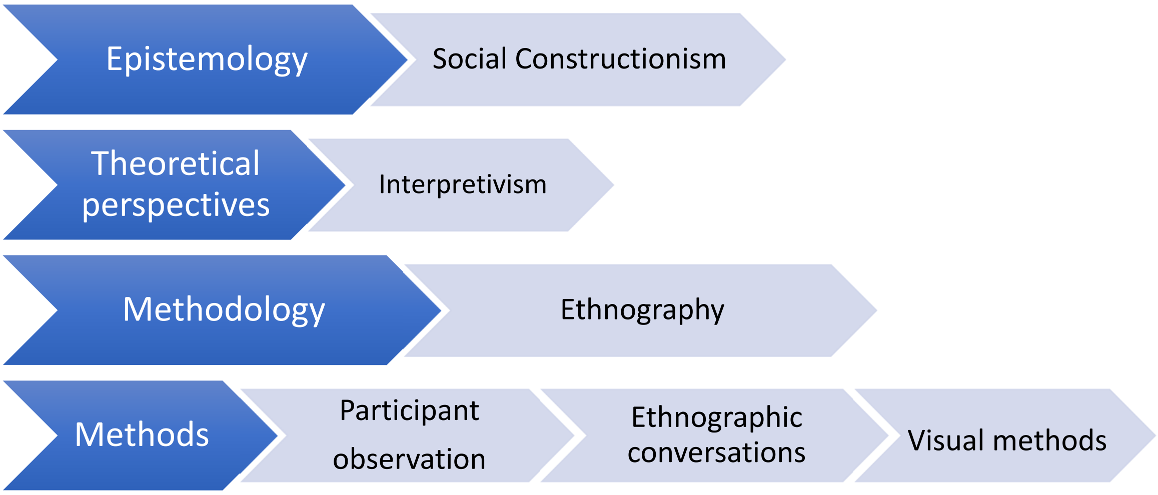

Figure 1. The conceptual framework for the study is based on Crotty's (1998) schema.

SOCIAL CONSTRUCTIONISM

A branch of philosophy, epistemology is described as the theory of knowledge (Greckhamer and Koro-Ljungberg, 2005). Epistemology is described as, "…a continuously unfolding conversation about the nature of knowledge and our understanding of the world" (Gergen & Gergen, 2003, p. 183). Bachelard (1964) declared that nothing is given, all is constructed. In my study, I used social constructionism as a way of understanding Lake House and the ways in which the housemates constructed meanings of home. Crotty (1998) points out that an epistemological stance is required in research studies in order to make sense of the knowledge gained through the methodology and methods. Constructionism's stance is that there is no objective truth waiting to be discovered (Crotty, 1998, p. 8), rather, meaning and knowledge are socially constructed and arise from our engagement with the world (Charmaz, 2006). Heidegger (1971) emphasised that the world is already there, it is not waiting for us to happen across it in order for it to be discovered. In my study, I wanted to know what life was like within a group home by entering into it (Charmaz, 2006).

Socioculturally positioned, home is a concept that is continuously constructed and negotiated, where individuals produce home by using space and time to create spaces which reflect their identity and sense of self. Home is actively produced, it is not a concept waiting to be discovered. Home is culturally represented so it is important to understand the political, economic, cultural context within which home is situated. I have used the metaphor of the hearth of the home to further understand the ways in which home is socially constructed. By 'crossing the hearth' of Lake House, the setting for my study and my fieldwork, by entering within, I am able to understand the phenomena of home, within a group home environment, using emic perspectives but also my own etic perspectives.

As I discussed in the previous section on reflexivity, my own personal histories of home, my values, feelings, perspectives and my own career working in group homes for many years are influential in my quest to understand home within the group home environment. My foundational argument, and rationale for this study, is that I cannot expect to understand home at Lake House by standing outside on the footpath looking inside through closed windows or doors. For no matter how loud I speak from the footpath those living inside the group home cannot share their perspectives with me unless I entered into the setting. The conceptual framework for this study is designed to enable me to cross the hearth of Lake House, to enter within, and to stay a while.

The following excerpt, Jerry's[13] writing, is an allegory for how I approached the research strategy for my study, seeking to understand the different ways knowledge is constructed and understood and how the space of home is produced by its occupants. When I met Jerry, I was a support worker in his home, a group home he shared with four other people with intellectual disability. Jerry was considered by other staff to be challenging and he was often referred to as stubborn and determined. I have used the allegory to illustrate the ways in which there are multiple constructs of reality (Raines, 2013, p. 425) and that meaning needs to come to be understood.

Jerry taught me to think (and listen) differently when asking the question, "How do we know the world?" In coming to know the world, and the place of Lake House and the housemates within the world, the notion that "reality is socially constructed" (Berger & Luckmann, 1966, p. 7) underpinned my approach for this study. Making sense of the world, constructing meaning, is a process that occurs through social actors' engagement with the social world (Neimeyer & Torres, 2015). The pursuit of a universal truth of home was not the goal (Crotty, 1998). Thus, I needed to find collaborative methods of inquiry, to extend my capacity to flex and bend, to understand group home life and how meanings of home were constructed by the housemates of Lake House.

Jerry's Writing: Teaching me to flex and bend

Although his reputation preceded him, I first met Jerry in the early 1990s when I accepted a casual shift to work in his home, Edenvale[14]. The group home had many ways of producing knowledge about Jerry; his manila client file, thick and blemished, chief among them. At first, Jerry was not easy to understand. He spoke in the third person, sometimes cryptically, and I found him reserved, abrupt and often confusing. A series of support workers in and out of his life had led Jerry to distrust most and he was stand-offish with me for quite some time. My quiet, gentle, perseverance proved

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[13] All names in this allegory are pseudonyms.

[14] Edenvale is a pseudonym for a community-based group home for five people with intellectual disability where Jerry lived for many years.

effective and, eventually, Jerry and I developed a strong rapport. I began to realise that if I listened differently, Jerry could be heard. If I sat beside him, I could learn. In the many years that have passed since we first met, I have often thought of Jerry. The following excerpt, *Jerry's Writing* captures a moment in time that significantly influenced my life, and, in extension, exemplifies my research approach to understanding home at Lake House in this thesis.

Jerry's Writing

> A large pile of papers lay on top of the outdoor rubbish bin when I arrived for my shift on a spring day in September. A light breeze lifted one of the sheets and blew it towards me and I noticed the neat cursive handwriting. The papers were Jerry's. Reading his words, I recalled an anecdote from his mother as she reflected on Jerry's childhood when doctors first diagnosed him with autism. The doctor, she said, had sat behind his large oak desk and emphasised Jerry's limited prospects. Certainly, he told her, reaching over to pat her hand, Jerry would never read nor write. Showing her to the door, he gently admonished her, "It is just not realistic to expect mental retardants to do so. No, Mrs Goldblume, one must always be realistic."
>
> Now Jerry was in his late 50s and his elegant handwriting sat discarded atop the rubbish bin. These papers were his history, evidence of his mother's long hours of patient perseverance. These papers were expressions of events that Jerry wanted to record, his thoughts and feelings throughout his lifetime. Retrieving the papers, I brought them inside, feeling perplexed. Asking my colleague why Jerry's writing had been discarded, he replied, "Oh. Well. It's just rubbish. It's nothing important, just his usual ramblings. You know how he loves to go on and on." I rifled through the papers, noting the measured spacing of the written words. "Besides", said my colleague, taking the papers out of my hands and placing them in the kitchen bin, "They were cluttering up his bedroom, making it look messy. So, today, I took the opportunity, while Jerry was away at day placement, to go through his room and clean it up. It looks so much better now I've cleared away all this rubbish."

Edenvale had many ways of producing knowledge about Jerry yet his own perspectives, detailed in voluminous pages of writing, were dismissed by my colleague as ramblings and literally discarded as ‘rubbish’. Asking Jerry directly about his own perspectives would also have been ineffective; talking with words was not his strong suit. However, as I learned to listen differently, I came closer to understanding him. Jerry taught me to flex and bend in order to understand his perspectives, rather than to insist he make himself understood to me or demand of him to change. My colleague viewed Jerry’s writing from his own perspective. Jerry offered another perspective. And Mrs Goldblume too.

In their seminal work *The social construction of reality: A treatise in the sociology of knowledge,* Berger and Luckmann (1966) emphasise:

> Everyday life presents itself as a reality interpreted by men and subjectively meaningful to them as a coherent world. As sociologists we take this reality as the object of our analyses. (p. 19)

Keeping in mind Gergen and Gergen’s (2003) description of epistemology as the knowledge of knowing, as a continuously unfolding conversation (p. 183), I will use social constructionism in this study to support my understanding of how meanings of home are constructed by the housemates of Lake House through processes of engagement with the social world (Neimeyer & Torres, 2015). Meanings of home for the housemates have not simply arisen; they have been constructed through experiences and knowledge and in a social context. Lyra (2007) argues that meanings of home are cumulative, built over time, thus, the housemates are already in the world (Ram, 2015, p. 33) prior to my arrival. The social world and, in particular, the everyday interactions, routines, activities, relationships, conversations, signs and symbols of the group home are of great interest from a social constructionist perspective (Burr, 2015 p. 4). In his seminal work, anthropologist Clifford Geertz (1973) famously described the social world as, “webs of significance” (p. 5) which the researcher seeks to understand, where meaning is not discovered, or found, but constructed. A social constructionist approach to developing knowledge of group home life provides opportunities for me to flex and bend in order to understand multiple constructs of reality (Raines, 2013, p. 425).

INTERPRETIVISM

The philosophical stance behind a methodology is what Crotty (1998) calls theoretical perspectives (p. 7). Theoretical perspectives provide a lens with which to view the world to make sense of the world. The theoretical perspectives of a research study form the philosophical stance which, Crotty (1998) posits, lie "behind the methodology" (p. 66). Seibold (2002) notes that theory both underpins the methodological choices of a study and also provides guidance in relation to data analysis.

Interpretivism is one theoretical perspective, which will guide how I immerse myself in the field, how I participate in and observed group home life at Lake House, how I collected and interpret and analyse data. Blaikie (1993) describes the interpretivist approach as one of seeking to understand the social world within which the research is situated. In contrast, the dominant positivistic approaches to understanding group homes have sought to test and measure phenomena (Liamputtong and Ezzy, 2005) across a large number of group homes, seeking replication and generalisation. Key assumptions of interpretivism are that reality is socially constructed and that there are multiple social realities, as my allegory of Jerry's writing attempts to illustrate. As the researcher, I must also be reflexive about my own ways of seeing the world and how my own history and experiences influence the way I see the world of the group home and how I come to understand how meanings of home are constructed by the participants.

ETHNOGRAPHY

From Malinowski's fieldwork in the Trobriand Islands (Malinowski, 1922/2014) to Boellstorff's (2015) cyber-ethnography to Hockey's (1986) study of the infantry body in the British Army, ethnography is a descriptive methodology for exploring and understanding culture. Although certain touchstones are evident, ethnography can be used in many different contexts and in many different ways. Ethnography can be used in different ways depending on the epistemological approach of the researcher and their theoretical perspectives (Denzin and Lincoln, 2013).

In the present study, I used ethnography within a social constructivist paradigm, where I sought to understand how home was socially constructed within a group home environment. Ethnography is a methodology ideally suited to the group home environment, which is rich, activity-filled, and full of interactions, engagements, interrelationships, routines, rituals and significant moments, and at times, it can be utterly chaotic. Flick (2006) emphasises the usefulness of ethnography in contexts where research sites would be poorly controlled and especially, where it would be undesirable to do so. As naturalistic inquiry, ethnography is inextricably linked to anthropology (Harrison, 2014, p. 90) with its hallmark method of participant observation. Ethnography requires the researcher to locate herself within the culture under study through prolonged immersion in the field (Van Maanen, 2011), in order to observe, participate, interpret, reflect and re-interpret that which surrounds her. By experiencing what life was like within Lake House, I will be able to more fully understand the points of view of the insiders, the participants (Denscombe, 2014). Lambert, Glacken and McCarron (2011) define the essence of ethnography as, "(e)ssentially, ethnography is a field-orientated activity that has cultural interpretations at its core, although the levels of those interpretations vary." (p.17)

There are limitations, also, with the ethnographic methodology. Rashid, Caine & Goez (2015), for example, in their examination of ethnographic studies in health research, found studies tended to focus on specific health issues, rather than drawing upon a broader frame and cultural perspective. The authors found that published ethnographies failed to articulate their ontological and epistemological stance in sufficient detail (Rashid et al., 2015, p. 12). This creates a tension when scholars such as O'Byrne (2012) highlight the critical importance of contemporary ethnography as a "disciplinary and bio-political tool" (p. 866).

Ethnography holds the potential to capture meanings from everyday life (Hammersley & Atkinson, 1995), visual ethnography in particular holds potential to understand life from the participant's point of view (Given, 2008). However, there are also criticisms of visual ethnography such as its unstructured and unsystematic nature which is not objective (Brewer, 2000; Pink, 2013).

Ethnographies may represent journeys to unfamiliar lands such as Malinowski and Mead, and other early ethnographers, who intentionally took themselves away from their homelands to unfamiliar cultures for months and years at a time. In my case, however, my *a priori* knowledge of group homes served as my motivation for undertaking ethnographic research in a site familiar to me. While Hammersley and

Atkinson (1995) caution against familiarity in the ethnographic field, highlighting the temptation for researchers to keep seeing what is already known, contemporary ethnographers may intentionally seek to study their own communities (Madden, 2010). Sanders (1988) in *Marks of Mischief: Becoming and Being Tattooed* undertook his ethnographic research as a result of his own experience with tattooing and his desire to learn more about the culture surrounding this art. Czerniawski (2011) in *Disciplining Corpulence: The case of plus-size fashion models* was herself a plus-size fashion model who chose to research her own professional community ethnographically. Although ethnography remains an uncommon methodological choice in relation to group homes for people with intellectual disability, there is an emergent body of knowledge (see, for example, Levinson, 2005; Croft, 1999; Clement & Bigby, 2010; McGhee, 2014).

Reid-Cunningham (2009) argues "(a)n ethnographic lens continues to provide a valuable perspective for understanding disability, especially the experiences of people who are different from the researcher" (p. 108). Denscombe (2014) notes that ethnography is useful when seeking to understand experiences from the point of view of participants. This approach has been noticeably absent in previous research on supported accommodation, which has traditionally used the views of residential staff, families, case managers, program managers and other third-party or proxy respondents (Emerson & Hatton, 1994). Clement and Bigby (2008), in the only ethnographic study found to date in relation to people with intellectual disability living in supported accommodation, identified how ethnography assisted them:

> …to explain how different factors in the ecology of a group home for people with intellectual disabilities work together to produce outcomes for its residents (p. 7).

Ethnography is ideally suited to building knowledge of group homes and for studying meanings of home. Prolonged immersion in the field, a hallmark of ethnography, provides the ethnographer with opportunities to do as the participants do, to experience their significant moments, challenging events, everyday routines and activities of daily life. As an abstract notion, home can be difficult to define and describe. Illustrated through my allegory, *Jerry's Writing,* meaning can be difficult to understand and interpret 'on the surface, and ethnography permitted me to dive beneath the surface, to discover that was initially appeared, perhaps, to be ‘rubbish’, was of great value to Jerry, his mother and even the group home. An ethnographic methodology supports the co-production of knowledge where both the researcher and participant are interpreting and making sense of the world around them (Rabinow, 1996).

REFLECTION AND SUMMARY

In this chapter, I outlined the research design and conceptual framework for the study. The epistemological and theoretical assumptions of the study underpin my methodological choice. In this chapter, I highlighted the ways in which an ethnographic methodology can support the co-production of knowledge. My review of the literature in Chapter 2 emphasises why this co-production of knowledge about group homes is important. Ethnography can support a counter-balance to the dominant hegemony of group homes which is one of service provision and service delivery. Ethnography can support the voices of people who live in group homes to be heard and to provide a deeper understanding of what group homes are like from the perspectives of the people who live in these models of accommodation and support.

Chapter 4: Methods

Chapter 4 details my research approach and ethical implications associated with my study. I begin this chapter by discussing the ways in which the sad and difficult historical legacy of research on people with intellectual disability has continued to influence the ways in which researchers must work today, including my own study. In this section, I also discuss the specific ethical implications of conducting research with people with intellectual disability within the group home environment. Next, I outline my sampling framework and explain the challenges associated with gaining access to the group home as a research site. Participant recruitment within a group home presents its own set of unique challenges. In this chapter, I highlight the multiple levels of gatekeeping which the researcher is required to navigate. In the next section, I discuss informed voluntary consent and my approach and associated considerations.

Then, in the next section, I discuss in detail the methods used in the study; participant observation, ethnographic conversations and a range of visual methods. I conducted fieldwork over the course of 18-months and there were challenges associated with maintaining and sustaining access to the field. In the next section, I discuss the iterative nature of data analysis in ethnographic research where data was collected and analysed in an iterative way. Next, I provide a brief introduction to Lake House, introducing the research setting. I conclude this chapter with a detailed introduction to the housemates of Lake House through a series of individual portraits that we developed together.

THE METAPHORIC BUSH TRACK

Ethnographic research within a group home environment, over an extended period of time, is a somewhat unusual and challenging endeavour that requires the full adoption of the elements of 'fluidity and flexibility' posited by O'Reilly (2012, p. 27). Before embarking on any journey, it is beneficial to map out the intended path prior to commencement of the journey and it is always useful to heed the advice of other travellers who have gone before. The literature with regards to the methodological skills, knowledge, techniques and strategies of ethnographic research are well documented within the ethnographic tradition (Geertz, 1973; 1988; Clifford & Marcus, 1986). However, ethnographic studies of group homes for people with intellectual disability are scarce, with a dearth of knowledge about the specific methodological approaches, opportunities and challenges that arise within this context. To support my conceptualisation of the route ahead, I used the metaphor of a curving, meandering bush track. The metaphor of a bush track, with its fallen debris, dips and curves, and large boulders on the path was useful in order to plan and prepare my own ethnographic journey at Lake House. As with any voyage, the journey often benefits from hindsight, and I diligently reviewed the bush track as I went along, working reflexively. However, it was not until I left the bush track, once I took off my walking shoes, sat down and had a drink of water and reflected on my journey with the benefit of distance, that I began to more fully reflect on the challenges and opportunities of ethnographic research within the group home environment.

BEGINNING THE BUSH WALK

Embarking upon an ethnographic journey with people with intellectual disability who live in group homes first requires careful consideration of the ethical implications of such an endeavour. Moreover, the researcher must constantly and continuously consider such implications throughout the entire research cycle. In my study, I was faced with a tension between protecting vulnerable participants and genuinely and meaningfully including people with intellectual disability in research which directly affects them.

Ethical issues associated with the study. Contemporary research with people with intellectual disability is conducted within an historical context where this vulnerable cohort have been manipulated, exploited and abused at the hands of researchers. This tragic legacy must serve to inform the work of contemporary researchers (Iacono, 2006). In 1947, the Nuremberg Code was established in response to human research abuses which occurred during the Second World War and, together with the Universal Declaration of Human Rights 1948, prompted a post-war examination of human research. People with intellectual disability have been subject to many abuses under the guise of research. One significant instance was the study conducted at Willowbrook State School for the Retarded between 1956 and 1972. In this study, children with intellectual disability were intentionally infected with hepatitis (Wedeen, 2000, p. 231). Further, this study proceeded with questionable processes for obtaining informed consent from the children's parents (Iacono, 2006), under the guise of beneficence. The Nuremberg Code 1947, Universal Declaration of Human Rights 1948, and the Declaration of Helsinki 1964, have influenced the ways researchers consider and approach informed consent, a key principle in human research (NHMRC, 2015). Contemporary research must incorporate appropriate safeguards to protect participants while at the same time supporting the rights of people with intellectual disability to participate in research, especially in research which is about them or directly affects them. This tension was at the heart of my own approach to this study, which I will discuss in latter sections of this chapter.

People with intellectual disability have been identified as a vulnerable cohort in research and the NHMRC developed the National Statement on Ethical Conduct in Human Research (National Statement) (2007, updated May 2015) to provide ethical guidelines for conducting research in Australia. The National Statement dedicates a specific section to people with intellectual disability because of the nature of their vulnerabilities, which was relevant to this study.

Such vulnerabilities may include the impact of intellectual disability on decision-making capacity, a compromised ability to provide informed consent (Iacono and Murray, 2003, p. 41) and the consideration that people with intellectual disability "…may be more-than-usually vulnerable to various forms of discomfort and distress" (NHMRC, 2015, p. 58). The National Statement (2015) establishes principles and values for ethical conduct which guided this study, encouraging researchers to empower individuals with 'diminished capacity' (p. 13) where possible while, at the same time, providing safeguards. Thus, the vulnerabilities of people with intellectual disability in research must also be balanced with the rights of individuals to participate in research, articulated in the National Statement (2015) which specifies the entitlement of people with intellectual disability to participate in research "…and to do so for altruistic reasons." (p. 58).

Ethical issues associated with research in group homes. Home, by its very nature, is an intimate, private, deeply personal space. Home is a place where people seek sanctuary from the outside world, where people go home to relax, shedding the layers they may wrap themselves in to face the outside world. Therefore, the introduction of another person within this space with unavoidably creates a change to the dynamics of the space. Research, then, within the home necessarily involves residents being more vulnerable. People with intellectual disability who live in group homes face additional, specific vulnerabilities where group home residents are in dependent relationships with their service providers. Hamlin and Oakes (2008) identity that staff have power over group home residents and that this is more than the power afforded them in their role. For example, people living in a group home may be afraid of a staff member's disapproval or may actively seek to do things to please a staff member. These power dynamics can be transferred to other people who are in perceived positions of authority, such as a university researcher.

In a position statement for the International Association for the Scientific Study of Intellectual Disabilities (IASSID), Dalton and McVilly (2004) identified that this cohort can be vulnerable to exploitation and abuse when participating in research. The authors identify specifically the power imbalances between participants and researchers and unequal power relationships between people with intellectual disability and the settings within which they live and work. Dalton and McVilly (2004) specifically identify congregate care or institutional facilities (p. 58) as settings where people with intellectual disability are especially vulnerable to "coercion and exploitation" (p. 58). Group home residents may also share such vulnerabilities. Within the group home, service providers are positioned as powerholders, having the authority and capacity to influence a residents' placement within a group home. As a result, residents may be reluctant or fearful to criticise the powerholder due to perceived consequences. Similarly, group home residents may be vulnerable to being encouraged to participate in research, relying on the trust and confidence they place in group home staff or people in positions of authority such as people from universities.

In identifying these vulnerabilities, the onus is on the researcher and her considered and diligent approach to research design and Coleman, Menikoff, Goldner and Dubler (2005) argue that researchers must address research-relevant vulnerabilities. In my study, I took particular steps to address vulnerabilities in relation to participant recruitment, informed consent and the provision of support to make decisions in relation to participating in the research. I discuss the steps I took in detail in the following section.

Ethical approval. The study received approval from the QUT Human Research Ethics Committee (HREC) and the Human Ethics Approval Certificate (Approval Number 1000000154) can be found in (Appendix A).

Inclusive and collaborative research with people with intellectual disability. The genuine inclusion of people with intellectual disability in research recognises both the importance of including this vulnerable cohort in research which directly affects their lives and the challenges in doing so. As discussed, researcher work in the shadow of the tragic legacy of research being conducted on people with intellectual disability, conducted about them without them (Iacono, 2006). Ward and Simons (1998) note that prior to the 1980s, "user views" (p. 128) were commonly conceptualised as parental or professional views rather than the views of people with intellectual disability themselves. Erroneous assumptions about capacity and a lack of methodological skills to include people with more complex communication or people with more severe and profound intellectual disability has perpetuated the exclusion of this group from directly participating in research. Indeed, group home research continues to use proxy and third-party respondents to consider the quality of life of people with intellectual disability (Bigby, Bould & Beadle-Brown, 2017).

In this study, I sought to understand and include the experiences of people with intellectual disability living in group homes. My research design, however, was not inclusive although I have drawn upon principles from inclusive research, such as using emancipatory methods with critical consciousness raising strategies (Freire, 1972/1996). Although I would have liked to have used an inclusive research design, initiated by people with intellectual disabilities and controlled by them (Williams, 1999), I had specific research questions to answer in relation to group homes. As a PhD candidate, I also had timelines and funding limitations which have been identified as barriers to inclusive research (Harris & Roberts, 2003) although I believe these could have been well managed within a PhD.

Instead, my research design could be described as collaborative. Johnson (2009) identifies collaborative research as involving people with intellectual disability in the process of doing the research (p. 252). Working collaboratively, I used a range of methods to support participants to have maximum control of the production of data and its interpretation. Later in this chapter, I outline my methods in detail, which were selected and developed within this collaborative frame.

Inclusive and collaborative research is founded on the understanding that oppressed groups, of which people with intellectual disability can be included, face barriers to participation and can be empowered to overcome these (Freire, 1972/1996). Johnson (2009) suggests that research is one way that people with intellectual disability can be supported to have a voice thus increasing their participation in civil society. Walmsley and Johnson (2003) argue that inclusive research does not merely position people with intellectual disability as sources of information or data, rather, people initiate and conduct research about topics which are meaningful to them. Inclusive research acknowledges and understands power within the research process and how it is exercised (Johnson, 2009). In my study, I chose to use methods such as PhotoVoice which positions participants as experts rather than as subjects of research. I used visual methods to ensure that participants were the one’s behind the camera, not the researcher, thus producing knowledge and data rather than being objectified through images. The use of images in research with people with disability involves ethical tensions and I discuss these later in this chapter.

Inclusive and collaborative research must support people with intellectual disability to exert control over the research process and outcome (Johnson, 2009). Therefore, my research methods were designed to be accessible. In my study, I used a combination of methods to enhance accessibility. In doing so, my methods were able to be tailored and adapted to suit individuals no matter their impairment or level of disability or their preferences, thus maximising collaboration. Walmsley and Johnson (2003) identify that participants may have different levels of involvement within different stages of the research process and my use of accessible research methods reflected this premise.

Importantly, collaborative research needs to be planned for and researchers must be prepared for collaboration from the outset. If I had only relied upon verbal conversations in my methodological approach, then a participant who did not use verbal language but wanted to participate would be vulnerable to exclusion from the study. However, this would not be the fault of the participant. Rather, the fault would lie entirely with the unprepared researcher who had ill-considered her methods and methodological approach.

That is not to say that all people with intellectual disability can be included in all types of research. Nonetheless, too often people with intellectual disability are positioned as too hard, too difficult or too disabled or too impaired to participate in research. Group home research, in particular, uses the medical model of disability, with its focus on impairments, to position the challenges of collaborative and inclusive research as the fault of the individual. This is particularly relevant for people with more severe and profound intellectual disability. Subsequently, researchers rely upon proxy and third-party respondents to speak for or on behalf of members of this group. Thus, people with more severe or profound intellectual disability are vulnerable to being excluded from directly participating in research because of inaccessible methods and problematic attitudes and assumptions. In group home research, there is overwhelmingly a distinct lack of inclusive and collaborative research methods.

Inclusive and collaborative research begins from the starting point of planning and preparation from the researcher. In their study of refugees with disability, Harris and Roberts (2003) challenged barriers to participation in qualitative research. The authors drew upon the social model of disability to inform their conceptual framework. The social model of disability, with its emphasis on the ways in which society disables individuals (Oliver, 1990), considered linguistic, health and impairment barriers. They employed strategies such as producing accessible information for participant recruitment, ensuring physical accessibility at interview locations and factoring in the costs associated with transport. Interview duration was tailored to meet the health needs of participants and interviewers were supported by the researcher and interpreters, including sign language, were engaged as required. The requirement for extended time for both the interviewers and the interviewees was factored into the planning and funding stage of the research design. The researchers anticipated that in research, as in society, people with disability would face barriers to participation and funding and support was arranged to support inclusion and collaboration.

Which bush track will I walk along? And who will I walk with? Identifying people who live in group homes to participate in a study about home is not a straightforward endeavour. People with intellectual disability who live in group homes are not an easily accessible group (Clement & Bigby, 2009). Sampling, in qualitative research, refers to the ways in which participants are selected for study and I used purposive sampling, which Blaikie (1993) argues, is the sampling approach most appropriate when specific groups of people in specific contexts are sought. Consistent with its purpose, the study specifically sought people with intellectual disability living in one group home for the sample. To support an in-depth ethnographic exploration of the group home, a small sample size was purposively sought. Home, within the group home environment, is largely unexplored from the perspectives of people who live in group homes thus a small sample size is appropriate. Additionally, Flick (2006) argues that sampling is not only focused on the participants selected for study but also the sites where participants can be found.

Identifying intellectual disability. All residents living within group homes managed by disability service organisations are subject to eligibility requirements which they must meet in order to receive accommodation and support services. One of these eligibility requirements is assessed intellectual disability. Vacancy management processes secure admission to a group home and individuals must have an assessed intellectual disability to be considered through this process. Eligibility requirements also form part of funding and service agreements between providers of accommodation and support and the state. Therefore, in this study, potential participants had been previously assessed by the disability service organisation, the Organisation[15], which owned and operated Lake House, as having an intellectual disability. By definition, intellectual disability is characterised by intellectual functioning, generally represented as an IQ score, with associated deficits in adaptive behaviour, with the disability occurring in the development period, before the person turns eighteen (American Psychiatric Association, 2013). However, within this classification, people who live in group homes have varying levels of intellectual disability and abilities.

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[15] The disability service organisation which owned and operated Lake House is henceforth referred to as the Organisation.

Identifying a group home. Group homes for people with intellectual disability can be difficult sites within which to research. Group homes are part of complex, bureaucratic organisational systems, with multiple layers of gatekeeping. I discuss the complexities of gaining access to the research site in more detail in the sections below. Although group homes can range in size from 3-5 bedrooms through to 10–15 bedrooms, for the sampling frame I identified a group home as a place where more than one person with intellectual disability resided, supported by rostered staff employed by a disability provider.

The geographical location of the group home was considered insofar as proximity to the researcher's own home was desirable for a study where deep immersion in the field was required and travelling long distances would have been unsustainable over a longer period of fieldwork. Unlike more traditional ethnographies, where the researcher may travel to a faraway land and live amongst the community for an extended period of time, more contemporary ethnography does not always follow this model. In my study, I would be dipping into and out of the field and thus geographical location was a consideration when identifying a group home for the study.

In some services, there are group homes for children and young people with intellectual disability. These group homes may be part of child and family services and are less likely to be part of disability service organisations. However, some group homes such as short-term accommodation or respite facilities do support children and young people. The purpose of my research was to understand the experiences of adults with intellectual disability living in group homes. Therefore, children and young people under the age of 18 were excluded from the study.

Gaining access to participants: The bush track is long and winding. Conducting ethnographic research within a group home environment, over an extended period of time, is a challenging endeavour and requires the full adoption of the elements of 'fluidity and flexibility' posited by O'Reilly (2012). People with intellectual disability who live in group homes live behind multiple layers of bureaucracy and gatekeepers and are cloistered within disability service organisations. The bureaucracy which surrounds group homes means they do not typically exist nor operate in isolation and are usually clustered together under the management of a disability service provider. In the case of Lake House, this was the Organisation. Therefore, group home residents, potential research participants, cannot be approached directly. Instead, access to participants must be negotiated through the disability service provider.

Disability service organisations are complex structures (McEwen, Bigby & Douglas, 2014), with multiple layers of bureaucracy, programmatic silos (Soldatic, van Toorn, Dowse & Muir, 2014) and multiple gatekeepers (Clement & Bigby, 2013) and this was the case for the Organisation involved in my study. Disability service organisations also have their own interests to serve, and service providers may or may not be supportive of the proposed research depending on their own attitudes towards the research and their own perception of potential benefits. An organisational perspective, which necessarily considers risk to brand, risk to reputation also considers beneficence in relation to its own interests. This perspective and motivation are not necessarily the same as considering the desire of people with intellectual disability who live in group homes to participate in research which directly affects them.

With these specifics in mind, I considered a range of disability service providers to approach. It was the support of my Principal Supervisor at the time that facilitated my contact with the Organisation. Her own networks and contacts within the Organisation, and her strong rapport with senior managers, brokered our first contact. Our introductory meeting was a convivial encounter at a coffee shop where my supervisor and I met with a senior manager from the Organisation. Drawing upon my years of experience working within group homes and my in-depth knowledge of their bureaucratic systems, I undertook specific preparatory work for this meeting.

I was aware that our request to undertake an ethnographic study within a group home for people with intellectual disability was a new experience for the Organisation, the senior manager, myself and my research supervisors. At our introductory meeting, I wanted to be prepared to answer practical questions about the research, such as what would the Organisation be required to do? Who would I like to be involved? How long might data collection last for? The senior manager was supportive of more research in group homes, an area she had been working in for several decades. The senior manager was keen to support group home research and was particularly enthusiastic about a research methodology that was participatory and collaborative with people who live in group homes.

The strong rapport between my supervisor and the senior manager fostered a sense of collaboration and enthusiasm for the study, of which I was appreciative. Gaining the confidence of the senior manager was a critical first step and permitted my entrée into the field. However, this steadfast support from the senior manager proved to be critical in the latter stages of the study and at times when obstacles on the bush track appeared immovable.

Selecting a site for the research: Which bush track will I choose? With the senior manager's support, we set out to choose a suitable site for my study. Flick (2006) identifies site selection as an important part of the sampling framework. It was agreed that children and young people under the age of 18 would be excluded from the study and any group home arrangements which supported children and young people would be excluded. I did not have any pre-existing relationships with the Organisation or anyone supported or employed by the Organisation thus there were no conflicts of interest to be considered.

The senior manager used her practice wisdom to consider group homes where the staffing contingent may be receptive to a researcher coming and observing over a long period of time. In some group homes, there was industrial action occurring and in others there had been recent changes in either staff or residents and the senior manager felt these sites were already in a state of flux; adding a researcher to the mix was undesirable. The senior manager was a font of knowledge. Although removed from the day to day management of the group homes within her region, her knowledge of the sites, the staff teams and the residents was detailed and exhaustive. There were several group homes which the senior manager thought might be suitable however one of these was geographically distant which would have made fieldwork difficult to sustain over time. I did not have particular requests as to the composition of the group homes or the complexity levels of the residents and I was largely guided by the senior manager. After fruitful discussions, the senior manager, my supervisor and I agreed upon one group home to approach for possible participation in my study. This was a group home for eight people with mild to moderate intellectual disability located in an outer metropolitan area. This group home was called Lake House.

Being introduced to Lake House. Once the senior manager and I had selected a site, with my supervisor's assistance, a plan was devised to discuss the study with the staffing group at Lake House. To this end, the senior manager established an initial meeting. My supervisor and I met at Lake House, where the meeting had been arranged at the Cottage[16] at the rear of the property. With the senior managing chairing, we met with the Lake House staff team, although a full contingent was not possible as some members were on annual leave. My supervisor and I outlined the proposed study and answered the few questions that were asked. At this stage, the purpose of the meeting was to introduce the study and to gauge whether the staff members might be willing to support having myself in their midst for an extended period of time. The staff members were not asked to provide informed consent and were not considered to be participants of the study. However, given the amount of power that direct support workers have within group homes and the associated power relations with group home residents, it was important for me to gain their support. In many ways, I felt the staff team was participating in the study because of the influence of the senior manager. The staff team did not raise any concerns about the research, but they also did not demonstrate any enthusiasm for the study.

Writing to family members, next of kin and Guardians. The next stage in the process, having secured the support of the Lake House staff team, was for the senior manager to write to the family members, next of kin and Guardians of the housemates. I was asked to draft a letter outlining the proposed study, which the senior manager then contextualised and distributed with an invitation to attend a house meeting scheduled for some six weeks later. In the letter, my contact details were provided and those of my supervisor and the senior manager. I included the participant information sheet for Guardians (Appendix B) and consent form for Guardians (Appendix C). Alternative arrangements were offered for those who may not be able to attend the house meeting but who might have questions or who may wish to discuss the proposed study further.

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[16] The Cottage is the staff quarters located at the rear of Lake House.

The house meeting. Six weeks later, I attended the house meeting at Lake House. Chaired by the service co-ordinator, the house meeting was a regularly scheduled meeting of the housemates with the supervisors. Agenda items usually included items the housemates wished to raise, such as any upcoming appointments or holidays or important events. The house meeting was also an opportunity to discuss everyday concerns with the service co-ordinator. This house meeting, however, had been set aside especially for the purposes of the study. Scheduled for 5pm, when the housemates had all arrived home from work or day placement, the house meeting was held in the downstairs lounge room of the group home. There were no family members, next of kin or Guardians present.

Prior to the meeting, I had distributed a participant information form for group home residents (Appendix D) and consent form for group home residents (Appendix E) to the service co-ordinator who, in turn, had asked the supervisors to go through the information with the housemates. The support workers had done so, advising of their discussions with the housemates. As a result, two housemates had indicated that they did not wish to participate in the study. At the house meeting, I provided an overview of the proposed study and the service co-ordinator and I led a discussion with the housemates. At times, the co-ordinator or the support workers asked questions or encouraged the housemates to ask me questions. I have summarised the process of gaining access to potential participants at Lake House in Figure 2.

After discussion and questions, I left the participant information sheets and consent forms with the participants and an additional form called the ‘I would like to talk to you form.’

After the house meeting: the “I would like to talk to you” form. Having worked in group homes for many years, I was aware that some residents have limited access to telephones or may be dependent on staff to use the telephone. There is often very little privacy afforded residents when they use the telephone, although this varies from group home to group home. Who people call, and how long they talk for, is often determined or monitored by staff, so the potential participants at Lake House could potentially face a number of barriers should they wish to talk to me directly to discuss the research privately. Given these circumstances, I developed an ‘I would like to talk to you’ form, in plain English (Appendix F) which accompanied the participant information sheets and consent forms. The ‘I would like to talk to you’ form was intended to enable potential participants to notify me that they would like me to contact them. The arrangements were, if I received the form, I’d then contact the individual, arranging a suitable time and place to meet or we could talk further on the telephone, depending on the preferences of the individual. Alternatively, individuals could complete the form and ask a family member or friend to contact me on their behalf. Attached to the form was a reply-paid envelope with my address at the university.

In practice, however, there were several limitations with this form and with my approach. At the house meeting, as I handed out the ‘I would like to talk to you form’, I realised there were too many forms. The supervisors had discussed the plain English participant information with the participants prior to the meeting yet there was too much information and too many forms at the house meeting. It was overwhelming. The housemates politely took the forms as I handed them out but, in reality, the forms were inaccessible to them without the support of the supervisors, which defeated their purpose. Although I had supplied stamped, self-addressed envelopes, some of the housemates would have required support to mail the form. In hindsight, it would have been preferable to arrange to meet with the housemates, individually, away from Lake House. In the end, the forms were not used, they added unnecessary complexity to an already complex process. However, they were a learning opportunity and a lesson to remind me that no matter how well intentioned nor experienced I was at working in group homes, or at working with people with intellectual disability, there was always more to learn and always room for improvement.

The road was long and winding to gain access to potential participants for the study. In Figure 2, I have visually represented the steps involved, illustrating the way in which they are connected to one another.

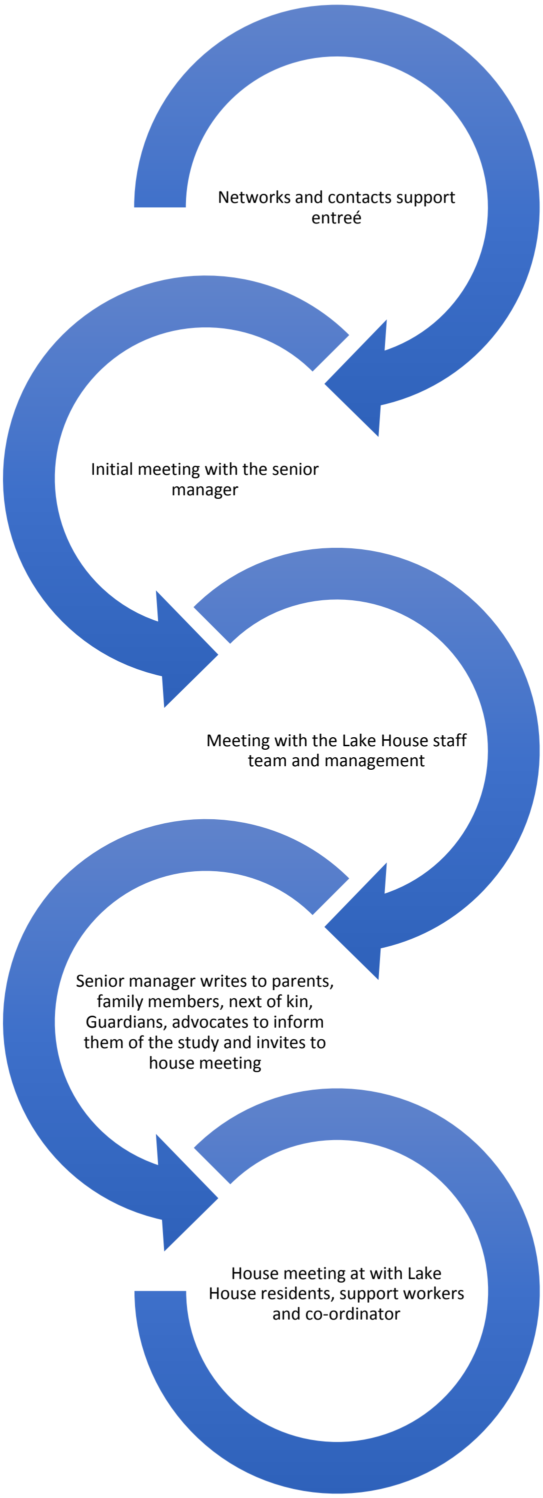

Figure 2. The process of gaining access to potential participants at Lake House involved multiple steps

INFORMED VOLUNTARY CONSENT

As discussed in the earlier sections of this chapter, contemporary research with people with intellectual disability is influenced by the sad and difficult historical legacy of the abuse of this cohort in research. With a history of inhumane and exploitative abuses under the guise of research, such as the Willowbrook study and abuses exposed from the Second World War, researchers must thoroughly and diligently work to ensure genuine, informed voluntary consent (Iacono, 2006).

The National Statement acknowledges that people with intellectual disability are not a homogenous group and capacity to consent to research, and the ability to participate in research, will vary from person to person (National Health and Medical Research Council (NHMRC), 2015, p. 58). An individual's capacity to provide consent cannot be measured by psychological assessments, adaptive behaviour scales and IQ scores alone. Iacono (2006) cautions against these types of tests when assessing capacity to provide consent because an IQ score, in and of itself, cannot determine how an individual best receives information or how they make decisions, or the contexts which enhance decision making. Such tests and assessments rely heavily on verbal language skills and may not be an accurate measure of an individual's capacity to provide consent. Rather, a more appropriate measure is suggested by Iacono (2006) where researchers identify areas where the individual already provides consent in other aspects of their life, for example, managing their own bank account and signing their own bank forms or similar legal documents. While these types of decisions do not automatically equate with an individual being able to provide consent to participate in a research study, it provides a guide for researchers.

Intellectual disability is a permanent condition that is characterised by significant limitations in cognitive functioning and adaptive behaviours (American Psychiatric Association, 2013). However, people with intellectual disability are not a homogenous group and the presence of intellectual disability does not mean an individual cannot provide consent to participate in research. For each housemate, each potential participant, I asked the supervisors to provide examples of the types of decision each person could make in their life. Although this varied from person to person, there was a sense that the housemates made many decisions in their own lives. I also worked with the supervisors to ascertain the communication preferences and needs of each housemate prior to first contact.

Participant information sheets were developed in a range of formats, to meet the needs of participants (Iacono & Murray, 2003). One version was in plain English, also known as easy read (Appendix B). The easy read version avoided jargon and acronyms as much as possible and was used to supplement oral information that I provided to participants. The provision of plain language statements to potential research participants is standard research practice, especially for participants who have an intellectual disability. However, Iacono (2006) argues that researchers need to move beyond simply providing plain language statements and to use a wide variety of mediums. Ellem (2010) in her study of life stories of ex-prisoners with intellectual disability in Queensland, designed easy English participant information and consent forms and used photographs to supplement the text.

Iacono and Murray (2003) argue that informed consent is multifaceted and complex and urge consideration on an individual project basis (p. 41). One of the challenges in gaining informed consent in ethnographic research is the unknown length of time of fieldwork. Initially, I used vague terms such as I would be at Lake House for a long time or until I had collected enough data, however, such vagaries were not useful for the housemates. Decisions are sometimes made at the outset of a process and then the actual experience, or practical realities, of the decision can be different to what was expected. Similarly, due to the prolonged nature of ethnographic research, a participant may agree to participate in the research only to find that the actual process of participant observation or conversations or other methods were not what they expected and perhaps even made them feel uncomfortable. In this way, the experience may be different to what they imagined ethnographic research would be like when they first gave consent. From the outset, I assured housemates that they could change their mind at any time, even if they signed the consent form initially. I provided participants with the 'Withdrawal of Consent Form' (Appendix G) but also spoke with them about what the form meant and that nothing would happen if they withdrew their consent. Gaining informed consent in ethnographic research, then, is a process that does not begin and end with the signing of consent forms (Knox, Mok & Parmenter, 2000).

Throughout fieldwork, I would pause at strategic intervals, such as after my first month in the field or at the 3-month milestone, or when there had been particular changes in circumstances in the household. This pause enabled me to check-in with the housemates, individually, as part of a continual process of gaining informed voluntary consent. In this way, consent was not static, and participants were free to withdraw their consent at any time without consequence.

Household consent form. An extra stage of consent was important in my study, given the research site was a home for eight residents. Not all the residents living at Lake House agreed to participate in the study. However, as the study was to be conducted in their home, it was important to ensure that all residents felt comfortable with my presence in their home. The specific parameters for non-consenting residents was that I would not collect any data about them and they were free to ask me to leave their home at any stage throughout the study. All residents were informed of the study, and what the presence of the researcher might mean for them in their home. All of the residents of Lake House signed the household consent form and a blank version can be found in Appendix H.

Organisational requirements of the researcher. The Organisation was satisfied with the ethical approach of the study and the approval of the university's human research ethics committee (HREC). The Organisation did not require any additional ethical approval for the study. However, in order to undertake research within a group home, the Organisation required me to have a criminal history screening and to obtain a Disability Services Positive Notice card[17] (colloquially called a yellow card). I obtained both prior to attending Lake House for the first house meeting.

Minimising risks of harm or discomfort to participants. Due to the deeply personal nature of the topic, talking about home and experiences of home can be unsettling, particularly if there have been negative or difficult experiences. In my study, there was a risk that participants may feel discomfort or distress in talking about

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[17] At the time of the study, under state government legislation, persons engaged by non-government service providers were required to undergo criminal history screening every three years. This requirement applied to non-government service providers who received state funding to provide disability services. This requirement was inclusive of employees, volunteers and students.

home or having myself in their home over an extended period of time. To minimise this, I was aware at all times that my presence may adversely affect the housemates and I was always willing to leave Lake House if there were difficult circumstances or should the housemates appear upset. Throughout fieldwork, I reinforced with the housemates that they had the authority to ask me to leave their home or to stop observing at any time and there would no consequences in doing so. I emphasised that I would always respect their wishes. Nonetheless, I envisaged it may be discomfiting to have someone in their home undertaking research over a long period of time. I spoke with the supervisors and the service co-ordinator and asked them to be aware of any possible impact on the housemates from my presence. I also organised for QUT counselling to be available for participants should they feel upset or distressed at any time. I worked with QUT counselling to provide them with general information about intellectual disability to support their work should the need arise.

Choosing pseudonyms together. As part of the ethical requirements of this study, the housemates' real names were not used. Rather, the housemates and I worked together to choose pseudonyms. Interestingly, the housemates were somewhat perplexed as to why their real names could not be used. They were not concerned with being identified or having their stories told. Nevertheless, each housemate and I spent time together choosing a pseudonym that was 'just right' for each individual. This proved to be an enjoyable process and turned into an opportunity to build rapport, to develop insight into the housemates' personalities, and mine, and to find out what was important to each person. Fleisher (1998) argues that ethnographers must obtain the trust of group members in order to understand "the complexities of and motivations for real-life behavior." (p. 52).

The housemates each chose a pseudonym that was meaningful to them. Bella, for example, chose her pseudonym based a movie character from a film she loved. Rose chose her pseudonym based on her mother's favourite flower and Maggie chose her pseudonym to honour a beloved family member. Andrew was nonplussed about the whole exercise and Josh chose his pseudonym because "I've always wanted to be a Josh. It suits me, I reckon." For Chloe, however, who uses few verbal words, it took us some time to decide on a pseudonym. Together, we browsed magazines, or her family albums filled with photographs. We looked at junk mail which advertised books and DVDs, exploring these for character names or finding album covers of the LPs that Chloe had stored at the back of her wardrobe. Looking for inspiration, we delved into a wide range of material and this process gave us time to get to know each other and supported my understanding of Chloe's communication style and preferences. We also had a lot of fun together.

The selection of pseudonyms provided an opportunity for me to get to know the housemates and I to get to know each other better, developing our relationships. Importantly, I did not want to choose or impose pseudonyms for the housemates and we took our time with the process.

Maintaining and sustaining access to the field. One of the challenges of all ethnographic research is maintaining and sustaining access to the field over a prolonged period of time. It can be difficult to describe to participants what extended time in field might mean and it can be difficult to envisage what this might feel like in advance. I regularly checked in with the housemates to ascertain how comfortable they were with me staying in the field. Over the course of 18-months of fieldwork, the housemates indicated they were supportive of my continued presence in their home.

FIRST STEPS ON THE BUSH WALK: ENTERING THE FIELD

At this stage of the study, the preparations for my trek along the metaphoric bush track had commenced and I had the necessary ethical approval, organisational support and 'buy-in'. Further, I had an identified research site and the informed voluntary consent of the participants. In the next section, I describe entering the field and I outline the methods used in the study. Methods are the tools and techniques for data collection which I took into the field (Blaxter, Hughes and Tight, 1996). In order to make the research process as clear as possible it is important to articulate the methods used and how they relate to the methodological approach of the study (Crotty, 1998, p. 6). In my study, I used three methods; participant observation, ethnographic conversations and visual methods. However, each method was used to augment the other. For example, conversations were a critical part of participant observation and visual methods elicited descriptive conversations and so forth. In the following section of this chapter, each method is described separately in order to provide clarity about the technique and how it was applied in this study. However, in the field, I used the methods flexibly, dynamically, interchangeably, and sometimes, all at the same time.

PARTICIPANT OBSERVATION

The collection of data first hand through prolonged immersion in the field of study and through the researchers' observation of and participation in the culture under study are inherent characteristics of the ethnographic methodology. Participant observation is a method employed to understand social and cultural phenomena. Participant observation has been employed in group homes for people with intellectual disability in other ethnographic studies although their number is few. Clement and Bigby (2008; 2010) undertook participant observation in group homes in Victoria, Australia and McGhee (2014) used participant observation to explore support worker knowledge in group homes also in the Australian context. Croft (1999) used participant observation, interviews and document analyses over a period of twenty-three months to understand what life was like for a group of men living at Esplanade, a community-based group home in the UK. Levinson (2005) used participant observation as part of his ethnomethodology. De Waele and Van Hove (2005) used participant observation in a large Flemish residential care service for people with intellectual disability with high support needs. Characterised by close engagement with the culture under study, each of these studies used participant observation over extended periods of time.

In my own study, over a period of eighteen months, I spent 932 hours in the field at Lake House. Undertaking fieldwork, I participated in everyday life at Lake House, but I did not stay overnight within the home. By participating in the field, I became part of Lake House, immersed in Lake House. I was there in the group home, participating with the housemates in the full and varied activities of daily life. My observations were overt, and the housemates were able to ask me to stop observing or participating and were able to ask me to leave their home at any time. Respecting the privacy of the housemates, I did not observe any aspects of personal hygiene such as toileting, showering, dressing or bathing. By immersing myself in everyday life at Lake House, I developed understandings of the physical and material culture, naturally occurring routines, conversations and social interactions to support my understandings of the culture of Lake House (Fossey, Harvey, McDermott, & Davidson, 2002, p. 727). Participant observation is a method of data collection which supports the ethnographer to develop rich, deep understandings of behaviours, experiences, patterns, and interactions in the culture under investigation. I used participant observation as part of a suite of methods, including ethnographic conversations, PhotoVoice, visual elicitation and a range of visual methods as tools of inquiry, which I detail later in this chapter.

Denscombe (2014) suggests that participant observation is useful when seeking to understand experiences from the point of view of participants, such as my research question which asked, “What is it like to live in a group home?” Using an inductive approach in the study, I was open to exploration (Flick, 2006). At Lake House, I used participant observation to develop emic perspectives. By positioning myself in the naturalistic setting and by participating in the everyday activities of the housemates, I developed understandings of insider experiences (Blaikie, 1993). These experiences supported my understanding of meanings, connections, relationships, and patterns of home at Lake House. When Bella was washing the dishes, I was right there beside her drying the dishes and putting them away in the cupboard. For Andrew’s birthday, the housemates, supervisors and I went out for dinner to celebrate. On Saturday night, I watched DVDs and ate popcorn, sitting on the couch side-by-side with the housemates. When Rose cleaned out her wardrobe, I sat on the floor beside her as we sorted her clothes into piles. When Josh went to the park next door, an activity not permitted by the supervisors, I went with him and we sat on a park bench, chatting. Flick (2006) argues that participant observation is useful when researchers are interested in meanings and interactions and seek to understand these within particular environments. The group home environment is hectic, oftentimes chaotic, filled with multiple interactions and activities, an environment that is not easily controlled for research purposes. Flick (2006) notes the benefits of participant observation in such environments.

Fieldwork in the home: Positioning myself in the field.

"We need an extra chair!" – Andrew

Fieldwork within a home environment necessitates special consideration of the intimate, deeply personal nature of home. Mayall (2000) identified dilemmas for researchers when working in the context of the family home. Although focused on conversations with children in the family home, Mayall (2000) found that, "…as a guest in the family home, the researcher's social position does not have clearly established parameters; it has to be negotiated" (p. 116). This, too, was true of my own role at Lake House. The group home was clearly divided into two positions; supervisors and housemates. The supervisors occupied the Cottage and had access to resources and knowledge and were in a position of authority within the Organisation. The housemates occupied Lake House and were positioned as clients or service users of the Organisation. Where, then, was a place in Lake House for me to occupy? Andrew illustrated this dilemma perfectly when we first tried to sit together at the heavy, wooden dining table in the downstairs kitchen. The table had space for four housemates and there was no space for a visitor. Using his initiative, Andrew said, "We need an extra chair!" and he cobbled together a crate and blanket, positioning it at the end of the dining table, where he sat, offering me his chair at the dining table.

In considering how I would position myself at Lake House, my accumulated years of experience working in group homes proved beneficial. From my experience, I knew that if I aligned myself as more like a staff member, a supervisor, or an official visitor then the housemates, too, would position me as an authority figure. I was conscious of the power relations that occur within group homes. As a pseudo-supervisor, I would occupy a different role to the housemates. I worried that the housemates would not feel comfortable to tell me their true thoughts and feelings about the group home if they perceived me as a pseudo-supervisor. I worried that I would not genuinely become part of Lake House if I became a supervisor figure.

In the field, my positioning was continuously tested, and I often had to think on my feet. For example, on one occasion early in fieldwork the supervisor invited me to join him in the Cottage to read the client files and to discuss with him details about the housemates. I declined the offer. I considered how my actions may be perceived by the housemates. At Lake House, all official visitors congregated in the Cottage, co-ordinators, auditors, senior managers, community visitors and the like. In the field, I consciously avoided the Cottage as much as possible, to avoid positioning myself at Lake House as a supervisor, manager or official visitor. Instead, I worked consistently with the housemates to carve out my own space and position at Lake House.

Fieldwork required me to consider the possible implications for the housemates should my work expose housemates breaking the Lake House rules or finding ways around the rules. Examples of such, which are detailed in the findings chapters which follow, have the safeguard of the distance of time. For example, I did not make known the sexual relationship between Josh and Bella until I wrote about it several years after fieldwork. By this time, the relationship had long been exposed and there were no risks to Josh or Bella. During fieldwork, I did not encounter any legal harms associated with rule-breaking.

"Lisa's uni book." In order to participate authentically in everyday life at Lake House, I needed to have a role. Otherwise, I was always supernumerary, out of place, like an outsider sitting in the corner with my clipboard, making observations, hoping not to be noticed. Croft (1999) in her ethnography in a group home, described the ways in which she worked with the participants to create a specific role for herself; that of researcher. Intentionally, Croft (1999) did not try to minimise her presence in the field, "I participated in interactions, thereby creating a role for myself within this community and a role for myself within the residents' narrative performances" (p. 333).

My role at Lake House was different; I was neither a housemate nor a supervisor. Significantly, my role at Lake House could not be neutral. I could not be positioned as a passive observer. Instead, I needed to find ways to genuinely become part of life at Lake House. Importantly, my role needed to support building rapport with the housemates, and to support a burgeoning relationship between us over time. I couldn't position myself as a fellow housemate. After all, I would leave Lake House each day and return to my own home. I had access to resources, such as my own money and my own vehicle, which the housemates identified as characteristics of supervisors. Therefore, positioning myself as a peer, or fellow housemate, would not have been genuine. In her study with male, second-generation immigrants, Bucerius (2013) details the differences between herself, a female from a different socioeconomic and ethnic background, and her participants (p. 691). More different than alike, Bucerius (2013) found that she was not positioned as an outsider, rather she found their differences led to deeper and more nuanced understandings (p. 717).

I was also not a supervisor. Conscious of the power hierarchy at Lake House, I did not want the housemates to perceive that I held authority over them or that I was working for the Organisation. In the end, it was not my problem to solve alone. Fairly quickly after I commenced fieldwork, the housemates found a role for me. At first, they, too, grappled with where to put me, physically and metaphorically, where did I fit at Lake House? The housemates positioned me as a student, a role they were familiar with, having hosted TAFE or university students on work experience placement previously. The housemates accepted that I was in their home to find out what home was like at Lake House and to write my "uni book." As a student, the housemates accepted that I was not a peer or a friend, but I was also not a supervisor. I was therefore a student at Lake House and the housemates' saw themselves as contributors to "Lisa's uni book." Madden (2010) argues that "in the field one is never out of character" (p. 71).

Being ethnographic. Participant observation relies on the ethnographer's senses and feelings in the field. The ethnographer uses all her senses. When the housemates were washing dishes or cleaning up after dinner, I worked alongside them. I was there when the supervisor appeared at the back door and issued instruction, I felt the tension and I heard the silence in the room as the housemates listened intently. Madden (2010) describes this process as being ethnographic*:*

> Participant observation is a whole-of-body experience that has us observing with our eyes as we participate, but we also 'observe' with all our senses. Touch, smell, taste, sound and sight come together to form the framework for memories, jottings and consolidated notes that form the evidentiary basis of ethno-graphic writing. Good ethnographers will use their whole body as an organic recording device.
>
> Madden, 2010, p. 23

I like Madden's (2010) description of being ethnographic, rather than doing ethnography or completing or undertaking ethnography. As the primary instrument in the research, ethnographers use their whole bodies to collect data. At times, I was fully immersed in activities or conversations or events at Lake House. At other times, too, I would try to slip away for a few moments to reflect and think about what was occurring in the field at that particular moment. Being ethnographic, at Lake House, was never all the one thing. Sometimes, I would move to the fringe of the kitchen and look at the scene unfolding before me. At other times, I was right there peeling onions or handing Andrew the knife to cut the tomatoes. De Waele and Van Hove (2005) argue that participant observation is "used in order to get close to the lived experience of the actors on the institutional stage…" (p.626). Participant observation provided me with the flexibility to be able to do so.

Field notes. A hallmark of ethnographic research, field notes are an integral part of data collection, used to record and document what the researcher is finding in the field. The researcher records various aspects of the culture, the participants, various activities and events, the sights, smells and sounds, and the thoughts and feelings of the researcher herself. Field notes are a not a faithful representation of real events (Madden, 2010, p. 98). Rather, they are written with interpretation from the ethnographer. When the ethnographer chooses to record one quote but not another or when she writes a short description of one event but a longer one for another moment in time, she is choosing what to record from her own ethnographic gaze (Madden, 2010, p. 99). Field notes are evocatively described by Madden (2010) as;

> "…almost magical scribbling: raw, primary, unadulterated; a window onto real human lives and events." (p. 97)

At times, my field notes were rich with description and I used both a paper journal and electronic notes. At other times, my field notes were structured and systematic. Voluminous, descriptive and rich in detail, my field notes also supported my reflexivity, as I paused to reflect and consider how my own experiences and behaviours may influence the observations and experiences in the field (Mulhall, 2003).

Ethnographies of group homes are scarce yet the few that exist offered useful insight into how field notes can be recorded and utilised within the group home environment. Firstly, the practical challenges of recording field notes in situ was significant. At Lake House, privacy was scant. Moments to oneself were seldom and a moment alone was rarer still. Opportunities to covertly write field notes while I was in the field were far and few between. McGhee (2014) in her ethnography of knowledge of support workers within group homes, found the presence of her notebook in the field did not detract from her interactions with participants nor the quality of her observations (p. 117). In contrast, Levinson (2005) in his ethnomethodology at Driggs House, a larger group home for people with intellectual disability, never openly carried a notepad (p. 60), reasoning that a notepad would detract from a rapport with residents (and staff members). Instead, Levinson (2005) used "the hour-long subway ride home to begin writing. Once I caught the rhythm of the place, I learned how and in what circumstances I could jot things down" (p. 60).

At Lake House, I always brought a notebook and pen with me, carried in my handbag, but I rarely carried these on my person. Instead, I'd intentionally put my handbag away and begin participating in activities with the housemates. As I developed, as Levinson (2005) so eloquently says, a rhythm of the place, I also developed a rhythm for my field notes. Typically, I arrived at Lake House earlier than arranged, and parked down near the lake in a car park a little way away. Here, I reviewed my field notes, reflected, and then drove up the hill to Lake House to start fieldwork. Once or twice, if there were moments during the day that were quiet, I took out my notebook and scribbled a few paragraphs, but this was not always practical, and I felt uncomfortable. To me, it felt like subterfuge. In any case, I wanted to be present with the housemates, immersed in the field, and not distracted or separate, taking notes. I stopped this covert scribbling quickly.

Instead, after field work, I left Lake House and drove to my spot by the water, taking out my laptop to write. If the weather was pleasant, I wrote at a picnic table overlooking the lake, with Lake House up on the hill behind me. If the weather was inclement, I wrote huddled over my laptop in my car, cramped, but typing fast to capture all that I could. Just as I had adjusted to the rhythms of the place, the housemates too adjusted to my rhythms and patterns. When I arrived at Lake House, carrying my handbag, I was always looking for a place to put it. I declined the offers of the supervisors to keep my belongings in the Cottage, despite their admonishments to me and their advice that it was not safe to leave my personal belonging with the housemates. Instead, I started putting my handbag on a kitchen bench, or carting it upstairs and downstairs, or leaving it in one lounge room or the other. My haphazard approach was disconcerting for Bella, who found my handbag “in the way.” Instead, Bella began a new routine where she greeted me and then offered to take my handbag to her room, putting it on the bottom shelf of her book case. Bella demonstrated great care in doing so, showing me how she was locking her bedroom door and assuring me my handbag would be safe. Maggie, observing Bella’s gesture, also offered to secure my handbag in her bedroom if I was spending time upstairs. Our joint problem solving was enjoyable and I appreciated the care the housemates took of my belongings, while also noting how there was no room at Lake House for an outsider, where even a newcomer’s handbag was out of place. These are the practical challenges of fieldwork within a group home.

In any event, one day, being lackadaisical with zipping up my handbag, Bella saw my notebook and asked me if I wanted to carry this. “No, no” I assured her, “I’ll write in it later.” Bella nodded and secured my handbag in her usual way. However, later, when we were sitting outside at the round table talking, she gestured for me to get my notebook. “Write this down,” she told me, “It’s important.” With my permission, Bella returned with my handbag and I retrieved my notebook and she chatted with me and watched to see if I was writing her words down. The other housemates, observing us, also wanted to participate. It then became customary that at regular periods throughout the week, I would bring out my notebook when we were all sitting together, usually outside but perhaps inside at the kitchen table, and I took notes of some of our conversations.

It was in this way that the detailed portraits, which are found at the end of this chapter, were largely developed. The importance of my notebook, to the housemates, was heeded. At one point, when I brought a laptop to Lake House for uploading our photographs, I tried using the laptop to type our conversations, taking notes on the clunky, grey keyboard. However, the laptop was somehow more obtrusive than my notebook, or more formal. With the lid up, the laptop seemed to physically present a barrier between myself and the housemates. Typing furiously, it seemed I was performing an official recording function, almost like minute taking at a meeting, rather than the more collaborative way we had used my notebook. Whether this was my angst alone is difficult to tell, as if I asked the housemates if I could use the laptop they would always oblige and acquiesce, suggesting that I knew best, and they would support whatever would help me the most. I disliked the laptop and felt it was getting in the way of the flow of our conversations. I ceased this practice and we used the laptop for our photographic work, but I no longer tried to use it for note taking. Mulhall (2003) notes that these dilemmas of when, where and how to record field notes are negotiated by the relationships the researcher has with those in the field (p. 31). The housemates and I collaborated and developed approaches that suited us.

In addition to my field notes, I also kept a field diary, which was reflexive and cathartic in nature. I used my field diary at the end of each visit to Lake House, however, I was also continuously writing in my field diary as thoughts or ideas or feelings arose. The reflexive nature of my field diary allowed me to consider not just the events of the day but to take a deeper look and to look for the why and the how of interactions and activities. My field diary also recorded and helped me sort through my emotions. Writing was a way of getting out my feelings onto the pages. My field diary was electronic, which supported me to write more than a handwritten diary.

As part of my responsibilities, I also ensured that field notes, research records, ephemeral items and my field diary were stored and kept secure, in accordance with university policy. My raw notes and reflections were kept in locked filing cabinets at the university and my electronic files were password protected. At times, I used my field notes in supervision meetings where we would discuss emerging themes, or I received constructive feedback and suggestions on interpretations (Winter & Munn-Giddings, 2001). My field notes and diary were used to support my reflections and for analysis and the development of themes.

ETHNOGRAPHIC CONVERSATIONS

In many types of qualitative research, conversations are a natural part of rapport building and relationship development with participants. This is particularly true in ethnographic research; conversations are key to engagement with participants in the field. Conversations typically require the exchange of verbal language. Ethnographic conversations can be structured and unstructured, arising spontaneously or more intentionally and thoughtfully. Driessen and Jansen (2013) discuss in detail the importance, and hard work, of small talk which they describe as critical to understanding the culture under study. Sluka (2007) argues that the success of fieldwork depends upon the ethnographer's ability to sustain and maintain relationships in the field, a key part of which is conversation and small talk (Driessen & Jansen, 2013).

Madden (2010) identifies the importance of conversations in ethnographic research, emphasising "(t)he usual character of ethnographic conversations lies in the tension between the 'naturalness' of good conversation and the 'instrumentality' embedded in the ethnographic endeavour" (p. 57). However, conversations with the housemates at Lake House were not always a straightforward endeavour. Chloe, for example, did not use verbal language as her primary method of communication. Ethnographic conversations in this context needed to be conceptualised beyond verbal language alone.

Conversations with participants who used very little verbal language. Qualitative research has a fondness for verbal approaches. For some people with intellectual disability who may have more complex communication needs verbal approaches, such as an interview, may not maximise their abilities and strengths (Finlay & Antaki, 2012) and researchers may lack appropriate interviewing skills Sigstad & Garrels, 2017). Researchers often require participants to fit in with the desired research approach, rather than the research approach being flexible and fitting in with the individual. Ethnographic conversations were ideally suited to contextualisation based on individual needs and preferences.

Conversations at Lake House, then, did not rely on verbal language alone. Chloe, for example, used COMPIC[18] and we could converse using this medium, supplemented by her gestures and use of objects. Often, Chloe and I would role play or would work through scenarios using photographs, her facial expressions and attentiveness were great strengths that supported our communication. I am experienced working with people who have complex communication and Chloe was creative and tenacious, willing to persevere with me as I learnt her individual preferences and techniques for communication. Together, we could communicate successfully. At times, Bella, too, used only one or two words to make her point, often

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[18] COMPIC are computer generated pictures, often simple line drawings that are used to represent a word or concept (scopeaust.org.au).

supplemented with gestures or using objects to support me to understand. Less frequently, Bella used idiosyncratic signs that I came to know and understand over time. Rose, too, often spoke using long stories, recalling excerpts from her past, intermingled with her thoughts of the present that made it difficult to have a straightforward dialogue. Working together, the housemates and I developed our own ways of communicating and having conversations.

At Lake House, I initially envisaged using a digital recorder for conversations in the field. However, once I commenced fieldwork I chose not to record. Firstly, I felt having conversations recorded would get in the way of our natural interactions and conversations in the field. I wanted to participate in everyday life at Lake House rather than record everyday conversations. Secondly, I did not want to include some housemates who used verbal language in conversations that were able to be recorded, while excluding other housemates whose non-verbal conversations could not be recorded. Both conversations were valuable. In hindsight, I could have considered using video to record our non-verbal conversations. One of the limitations of my decision not to record our conversations, was the lack of a transcript which would have ensured the words of the housemates were recorded verbatim. A transcript would also have been useful for data collection and analysis. By electing not to record conversations, I relied on my memory, which is imperfect, and may not have captured direct quotes exactly, or at the precise moment in time.

Further, without a recording, I was interpreting the housemates' conversations rather than supporting their own voices to be heard, at least directly. However, my approach was more collaborative, and I was able to work flexibly, building on the strengths of each individual. My approach built strong rapport and engagement with the housemates. Our conversations built a strong foundation and supported our ongoing relationships. Finding different ways of communicating with each other formed a bond between us, as we problem-solved together. Together, we learned to speak and to listen to one another in a continual fashion. As Madden (2010) says;

> "One never really stops being an ethnographer regardless of how comfortable and 'natural' one feels in a conversation space. The recorder that resides in the body of the ethnographer is always 'on'." (p. 59).

VISUAL METHODS

In this section, I begin by setting the scene for using visual methods with people with intellectual disability in qualitative research. Visual methods are increasingly being utilised in qualitative research with people with intellectual disability and have the potential to enhance the inclusion of participants who may otherwise be excluded (McVilly & Dalton, 2006; Ramcharan et al., 2004). Yet, the use technology with this cohort necessarily entails both benefits and challenges (McNaughton & Light, 2013). The use of visual methods must also be considered within a context where people with disability have been, and continue to be, subjectified and objectified in images. Thus, in this section, I describe how the housemates and I worked collaboratively, drawing explicitly upon principles from inclusive and collaborative research approaches (Walmsley & Johnson, 2003; Walmsley & The Central England People First History Project Team; 2014; Williams, Simons & Swindon People First Research Team, 2005; Walmsley, Strnadová & Johnson, 2018).

The interpretive frame for this study, embedded in my research design, supported the housemates and I to work collaboratively, interpreting and thinking critically about images together (Freire, 1974). I provide more detail about this later in this chapter. I used visual methods to build understandings of home, to elicit conversations about home and to think critically about meanings of home. By using visual methods in this way, the housemates and I adopted a dialogical approach which worked well with participant observation and ethnographic conversations. Yet, at Lake House, dialogue was not always straightforward as I worked with some individuals who used little or no verbal language. Importantly, I emphasise that visual methods were not used to replace verbal language or as a substitution, rather, visual methods supported and enhanced our dialogue.

In this study, ethical tensions arose with the use of visual methods in the group home context, an environment which is highly supervised and regulated and within which the housemates experience some vulnerabilities. In this section, I illustrate and describe the ethical tensions arising but provide a more detailed discussion in Chapter 7.

Visual methods and research with people with intellectual disability. Often used as part of a suite of methods, the use of visual methods in ethnographic research continues to emerge (Banks, 2001). With the advent of various technologies, such as the camera in the nineteenth century, ethnographers have had an increasing array of technologies with which to explore and understand people and cultures (Banks, 2001). Visual methods lend themselves well to collaborative research (Chaplin, 1994; O'Brien, Dhuffar & Griffiths, 2014) and participatory research (Pain & Francis, 2003) by offering a diverse range of materials and technologies which can be tailored to individual participants or cohorts. Visual methods are increasingly being used in participatory research with people with intellectual disability (Boxall & Ralph, 2009; Povee, Bishop & Roberts, 2014; Booth & Booth, 2003; Jurkowski, 2008). At Lake House, each housemate had different strengths and preferences and visual methods provided me with a multitude of tools to be able to be genuinely person-centred in my approach.

However, people with intellectual disability are particularly vulnerable to being objectified through the use of images. Boxall & Ralph (2009) argue that photographs, in particular the clinical photograph of the medical institution, have been used to classify people with disability, using images to highlight visual clinical differences in order to segregate this cohort from society (p. 47). The use of photographs has also been a technique used to expose the lives of people with intellectual disability to public scrutiny, particularly exposés of institutional life which were hidden from public view (Thomson, 2001). Iacono (2006) writes that all researchers working with people with intellectual disability do so "…in the shadow of the Willowbrook study and other similarly infamous experiments conducted with individuals who were vulnerable because of their limited capacity and/or being in a powerless position… (p. 173). So, too, are researchers using visual methods with people with intellectual disability working in the shadow of previous exposés and portrayals of this cohort through images.

As discussed in Chapter 2, Blatt and Kaplan (1966) used photographs in their seminal work *Christmas in Purgatory* to expose the extreme neglect and suffering of people with intellectual disability who had been hidden away from society behind institutional walls. The photographs portrayed the squalid conditions within which people with intellectual disability were held and the authors used photographs to show and document human suffering. Further, the authors chose to use black blocks in the images to hide the faces of the people photographed, thus portraying the subjects in the images as faceless objects of pity.

Such distressing images have portrayed people with intellectual disability in a one-dimensional way, portraying them in devalued roles (Wolfensberger, 2011). The use of images of people with intellectual disability in this way has contributed to what Wolfensberger (1998) termed common “wounds” (pp. 12-24), positioning people with intellectual disability in deviant roles such as that of non-human, sub-human, menace or object of dread, object of pity, sick or diseased, among others. Contemporary image-based researchers, then, must work in ways that do not perpetuate such devaluing.

Further, images have been used to subjectify and objectify people with disability. Casper and Talley (2005) argue that because the dominant view of people with disabilities in society is to see them as subjects to be controlled. Casper and Talley (2005) raised concerns that visual methods, such as taking photographs of people with disabilities, can perpetuate the objectification of people with disabilities through the production of images *about* them and not *with* them. Moreover, knowledge about people with disabilities, and people with intellectual disability specifically, has often been produced through the use of images by people without intellectual disability (Boxall, Carson & Docherty, 2004).

In my study, I worked in the shadow of the legacy of how people with intellectual disability have been treated through visual images and this consciousness informed my use of visual methods. Working within an empowerment frame, I used visual methods to position the housemates as the experts. In the following section, I describe in detail how I did this, ensuring that the housemates were the ones in control of the camera or were the ones constructing their own scrapbooks about home or using their own creativity through drawings.

However, it was not sufficient for me to have a passive or neutral role. Positioning the housemates as the experts behind the camera, for example, was only part of the process. As the researcher, I was part of the collaboration, not set aside, and I continually needed to consider how I provided just the right amount of support and assistance at times, knowing when to step in and to step out. I needed to use my knowledge of power relations within the group home to ensure that scrapbooking, for example, was participant led and that my questions or comments or insights elicited conversation but did not begin to take over and lead. Cocks and Cockram (1995) argued that participatory methodologies which genuinely involve people with intellectual disability can contribute to knowledge creation. In this way, the housemates and I worked collaboratively, producing knowledge together.

The use of visual methods and technology in qualitative research with people with intellectual disability. Modern times are characterised by technological advances which are emerging at a rapid rate. The potential use of technology for people with disability is significant, offering increased accessibility, social inclusion (Renblad, 2000; McClimens & Gordon, 2009) and social participation (Adkins, Summerville, Knox, Brown & Dillon, 2012).

Technological advances for people who require communication support have occurred on an unprecedented scale with the rise and rise of specialised software and applications (Dolic, Pibernik & Bota, 2012; McNaughton & Light, 2013). There is an emergent body of knowledge on the use of mobile technologies to support inclusive research with people intellectual disability (Cumming, Strnadová, Knox & Parmenter, 2014; Strnadová, Cumming, Knox, Parmenter & Welcome to Our Class Research Group, 2014).

Mobile technologies have increased societal awareness and acceptance of augmentative and alternative communication systems. Whereas more traditional and clinical augmentative and alternative communication devices may have been stigmatising, the use of technologies such as iPads, are socially valued, providing "...a rather elegant solution to the social integration problem. Kids with even the most advanced dedicated speech device are still carrying around something that tells the world 'I have a disability.' Kids using an iPad have a device that says, 'I'm cool.' And being cool, being like everyone else, means more to them than it does to any of us." (Rummel-Hudson, 2011, p. 22). However, other scholars have criticised notions of normalisation in the role of technology (Moser, 2006) and instead have emphasised relationships with technology that provide for "creative practice that embraces difference" (Adkins et al., 2012, p. 503).

Interpreting images: A picture doesn't tell a thousand words, a picture needs a thousand words. The early work of visual ethnographers was predominantly positivistic in nature (Daly, 1997). Concerned with bringing objectivity and scientific rigour to the methodology (Pink, 2007) visual methods were used as a way of proving that researchers were really there in the field. Visual methods were used as a way of documenting what researchers were seeing in the field (Malinowski, 1922/2014) and visual images held utility in the dissemination of their research to wider audiences (Martin & Martin, 2004). Using a positivist stance, scholars used images as a way of detaching oneself from subjectivities (Pink, 2007). With the researcher positioned behind the lens of the camera, photographs were considered a way of adding objectivity (Collier & Collier, 1996). Used within a positivist, realist frame, images were equated as fact, even epistemologically irrelevant (Azzouni, 2004) because their existence and their interpretation were thought to be unquestionable. A black cat, therefore, was a black cat and a red chair was a red chair and this was to be accepted as fact, as reality, interpreted based on our "naked senses alone" (Azzouni, 2004, p. 371).

In contrast, Berger (1972) argued that there was never just one way of looking at things and that, "…we are always looking at the relation between things and ourselves." (p. 9). Rose (2001) posited that visual ethnography supported understandings of culture "…by making it visible." (p. 11). Like any method, the way in which the researcher uses visual methods is informed by her epistemological stance. Banks (2001) argued that "'method' is inseparable from 'theory' and 'analysis'" (p. 150), thus the methods I used in this study were influenced by my theoretical and epistemological perspectives (Denzin & Lincoln, 1994). In my study, with its interpretive stance, I considered how I would produce, collect and interpret visual material (MacDougall, 1997, p. 276 such as photographs, drawings and scrapbooks.

Using images as an objective science was not the aim of my study. Indeed, it was the subjectivities, the subtleties, the nuances, the individual interpretations that I sought and valued. Shaffir (1999) argues that it is the rich descriptions, subjectivities and interpretations of culture and the people under study that bring richness and complexity of understanding to ethnographic research.

I sought to use visual methods to further develop emic perspectives of what life was like within a group home. Using a dialogic approach, I used visual methods to prompt and probe, to elicit conversation and to prompt thinking about home as a type of critical consciousness (Freire, 1972/1996). However, it was important that my approach was not researcher led. Rather, working collaboratively, the housemates and I used visual methods together to co-produce knowledge about home. In doing so, it was important for me to consider how the images and visual material would be interpreted and by whom. In ethnography, where the researcher is the primary instrument for data collection and analysis (Madden, 2010), her role in interpreting data is significant. However, using the principles of inclusive and collaborative research approaches (Walmsley & Johnson, 2003) interpretation is also not just the exclusive domain of the researcher alone. I was not the only one to interpret and analyse data.

The old adage, then, that a picture tells a thousand words is not entirely accurate when considering visual images within an interpretive paradigm. Chaplin (2005) in her exploration of the photograph in theory emphasised the multiplicity of ways in which a photograph can be interpreted, ways that may be quite different to the intentions of the photographer. Chaplin (2005) provided an example of a photograph she took of a family standing outside their front door. In the image, the family is comprised of a father and three sons. The participants provided a caption for the image of “motherless boys” (p. 3) from which the viewer makes their own assumptions and interpretations. Such interpretations are based on the viewer’s own cultural background, expectations and experiences, and their own value judgements. Left to stand alone, the image may be interpreted by the viewer as a family who have lost their mother or a family growing up without their mother. As Chaplin (2005) provides further context to the image we come to understand that the mother was overseas attending her father’s funeral (p. 32). Further, the participants had wanted to have a little fun with the photograph and captioned it motherless boys with perhaps mischievous humour.

Thus, exploring an abstract concept such as home was ideally suited to the use of visual methods which supported a dialogic approach where I used visual methods with participant observation and ethnographic conversations. I used visual methods to elicit conversation and to prompt thinking about home as a type of critical consciousness both for myself and the housemates.

Dominated by photography and video in its early days, visual ethnography now has a host of rapidly changing technologies available such as mobile phones, iPads and computers. Visual methods can also include non-mechanical options such as drawing, creating diagrams, painting, sculpting, quilting, mapping, graphing, craft and scrapbooking.

Often used dialogically (O'Brien, Dhuffar & Griffiths, 2014), visual methods have been used to support researchers to more deeply explore and understand the people and cultures under study (Malinowski, 1922/2014; Pink, 2007). Through elicitation of dialogue with participants, visual methods can support participants and researchers to think critically about phenomena (Mitchell, DeLange, Molestane, Stuart, & Buthelezi, 2005). Methodologically, this was particularly relevant to my study, where the housemates and I used visual methods together with participant observation and ethnographic conversations in order to explore and develop rich, deep understandings of home, moving beyond superficial constructions. The use of visual methods was ideally suited to this task and to the exploration of such an abstract concept as home.

There were a number of tensions arising in my study with the use of visual images with a vulnerable cohort. Moreover, there were tensions arising from undertaking visual ethnography within the private, intimate space of home. Specifically, the group home was a site of complex power relations, highly regulated and governed, which brought with it ethical and methodological concerns about the use of visual images in my study. A more in-depth discussion of ethical and methodological concerns is provided in Chapter Seven with particular consideration of the use of visual methods in future research.

In her seminal text, *Doing visual ethnography,* Pink (2007) emphasised that visual images should not replace words, rather visual images have the potential to elicit conversation, to represent ethnographic knowledge, and to support critical thinking about phenomena. In my own study, Pink's (2007) emphasis that visual images should not replace words was especially important with participants with intellectual disability for whom verbal language was not always their preferred communication system or was not an individual strength. My aim was not to seek to replace words with images, rather, I sought to support and enhance opportunities for dialogue by using visual images with each person in their preferred way.

Perhaps I shouldn't use photographs of the housemates. All researchers have a responsibility to challenge the objectification of people with disability, however, it is particularly relevant for research involving visual images. Although Casper and Talley (2005) identify the ways in which visual methods can position people with disability, it is also important to extend this thinking. O'Brien, Dhuffar & Griffiths (2014) emphasise that visual methods are used dialogically, and this was also true for my study where I proposed using visual methods in conjunction with participant observation and ethnographic conversations. One option to avoid the objectification of people with disability in images is to avoid taking photographs or at the very least to avoid including photographs in research publications. This option has been taken up by researchers using visual images with participants who may be vulnerable to identification or who may be subject to stigmatisation.

Smith (2015) in her study exploring the complexity of sex work used visual images to augment interviews, noting that the participants in her study took over 100 photographs between them. Smith (2015) provides a detailed account of her method, where the participants took photographs based on statements the researcher provided them at interview. Participants then took photographs using their own cameras or smart phones or a digital camera made available to them by the researcher (pp. 242-243). The participants brought the photographs with them to the interview where the researcher uploaded them onto her laptop, producing a CD of the photographs for the participants. The author writes that she did not publish any of the photographs due to concerns about the stigmatisation of women engaged in sex work and concerns about identification, and thus exposure of their sex work, which may have been kept secret from others (p. 243).

Smith (2015) argues that she used the photographs for "elicitation purposes only, and I would not use them as data in their own right." (p. 243). Yet, Smith (2015) does not address other relevant ethical considerations, such as how identifying details in participant description would be managed and there are lengthy descriptions included in publication of participants and their engagement in sex work. Using photographs to elicit data necessarily means that more information is yielded, thus, the researcher has to contend with more detail, any of which could potentially be identifying. The authors' decision to omit photographic images yet to include the detail elicited through images and interview exemplifies the tension held within research which uses visual methods. Visual images are assumed to be objectifying and identifying, yet description is not considered in the same way.

Using visual methods within an empowerment frame. In the next section I discuss the empowerment frame within which the photovoice method has been constructed. The theoretical foundations of photovoice influenced my choice of the method for my study. Using visual methods within an empowerment frame positions people with disability as the producers of visual images, supporting them to tell their own stories in their own way, rather than positioning participants as passive subjects. In my study, I used Freire's (1974) work on oppression, to guide the way in which I used visual methods to acknowledge and address power relations, which are complex and nuanced within the group home context. Using visual methods offered the opportunity to explicitly acknowledge existing power relations, as I had initially understood the and then, later, to come to develop much more sophisticated understanding of power relations at Lake House. O'Brien, Dhuffar and Griffiths (2014) argued that visual ethnography "…makes explicit a desire to shift the power dynamics of knowledge creation away from researcher-driven enquiry and towards a more egalitarian pursuit of knowledge through collaborative introspection and public display." (p. 4).

Nevertheless, there was an inherent insufficiency in my approach to using visual methods within an empowerment frame. Merely positioning participants behind the camera does not empower participants. I learnt more about this when I began fieldwork and as the housemates and I worked together producing visual images and having rich, complex conversations about home. In Chapter 7, I discuss further the problematic way in which I conceived empowerment in this study and the ways in which my problematic assumptions influenced my use of visual methods. In the next section, however, I discuss what I actually did and how the housemates and I went about it.

The dialogical use of visual methods with people who may have little or no verbal language. In my study, the housemates used a variety of ways to communicate and verbal language was not always able to be used. In visual ethnography, where visual images are used dialogically, I needed to consider how I would approach this dilemma. In have discussed the importance of building rapport and part of this was developing understandings of how the participants communicated. However, it was also necessary for the housemates to understand me and how I communicated so that we could develop a feeling of reciprocity; a key feature of communication partnerships. In Chapter 7, I discuss in more detail the ways in which the housemates and I used photographs to augment our communication and the importance of considering a dialogue as not only limited to verbal language. In Chapter 7, I work reflexively to consider the ways in which the housemates and I used visual images with verbal and alternative communication systems and the methodological challenges and opportunities we encountered along the way.

Photovoice[19]. A visual method founded on anti-oppressive principles, PhotoVoice is a method located within a theoretical framework of empowerment and critical consciousness (Freire, 1974; Freire, 1972/1996). A method of participatory action research, PhotoVoice acknowledges and values people's expertise within their own lives. Using photography and problem-posing techniques, participants use cameras to document aspects of their lives that are then consciously considered. As a visual and participatory method of qualitative research, PhotoVoice has been used in research with people with intellectual disabilities (see, for example, Booth and Booth, 2003; Jurkowski, 2008; Jurkowski & Paul-Ward, 2007; Povee, Bishop & Roberts, 2014). In my study, I used PhotoVoice as part of my methodological approach, in conjunction with participant observation, ethnographic conversations and other visual methods outlined in this section.

Typically, in PhotoVoice style, participants receive a disposable camera and are encouraged to take photographs based on an agreed theme. The housemates and I chose the theme 'what does home mean to you?' as our initial starting point. I

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[19] PhotoVoice is written in different ways in the literature. I have intentionally used the spelling, PhotoVoice, capitalising both Photo and Voice, to emphasise the equal importance of the two core elements of the method; the use of photographs and the voice of participants.

purchased disposable cameras for each of the housemates. Before beginning our photography, the housemates and I discussed the etiquette of taking photographs, also a common approach in PhotoVoice (Wang & Redwood-Jones, 2001; Jurkowski, 2008). In a small, intimate home environment, such as Lake House, we considered how we would go about taking photographs, developing our own rules for not infringing upon other people's space or belongings, or invading another's privacy. I facilitated initial discussions with the housemates about privacy and confidentiality, however, the housemates responded with a request to make up a sign with rules for taking photographs. At Lake House, the housemates are surrounded by rules and responsibilities, often communicated via signs, typed and printed by the supervisors in the Cottage and stuck on the walls, fridges and noticeboards of Lake House.

For my own purposes, a conversation about protocols for taking photographs would have sufficed, however, the housemates wanted a sign, drawing on the familiarity of signs at Lake House. However, we adopted a new approach to sign-making; the housemates would make this sign and not the supervisors. This small change was empowering. The housemates enjoyed taking responsibility for the content of the sign, crafting their own rules for taking photographs. The development of the sign provoked discussion and raised dilemmas which we solved together. This simple task provided opportunities to deeply consider aspects of the method and its application within a group home environment. To this end, we brainstormed a list of rules for taking photographs and together we wrote them on A4 paper. Our rules were:

Lake House: Our Rules for Taking Photographs

Respect others!

Respect privacy!

Ask for help if you don't know how to use the camera!

Be truthful!

Ask permission!

Don't take photographs of anyone crying!

After we put the sign together, Rose suggested that we could all sign our name on the sign, "like making a commitment", she said. The housemates and I agreed and we all signed the document. I have omitted including a photograph of our sign here because of the identifiable signatures. The inclusion of the exclamation points at the end of each rule is significant. Often, in the other signs around Lake House, rules are emphasised through exclamation marks. In accordance with this Lake House convention, the housemates included exclamation marks in our own sign of rules for taking photographs.

Freire's (1974; 1972/1996) notions of empowerment and critical consciousness are foundational elements of the PhotoVoice method and were significant in this study. The process undertaken by the housemates in developing their own sign, traditionally the realm of the supervisors, was empowering. Small changes in power are significant at Lake House, where the housemates' lives are encompassed by the rules of others.

Coming to prominence through Wang, Burris and Yue Ping (1996) in their study of women's reproductive health in the Yunnan Provence of China, the PhotoVoice method was originally termed *photo novella.* Wang, Burris and Yue Ping (1996) provided participants with cameras to support them to document and explore aspects of life in their rural village and their everyday lives. Photo novella supported participants to tell their own stories and to articulate their needs through visual images, using photography as a tool of expression and a tool of empowerment. The *photo novella* or storytelling aspect of PhotoVoice was significant in the present study.

Once we established our etiquette for taking photographs and committed to these, we began taking photographs. Some housemates preferred to take photographs with me and I would act as a type of technical support. Sometimes the housemates deferred to me and would give me the camera to take a photograph, however, I always gently encouraged the housemates to take the photographs themselves. Chloe, for example, was initially unsure of what to do and was not confident of using the camera. Over time, her self-confidence grew as she realised she was not only capable of taking photographs independently, but her efforts led to high quality photographs. Seeing the product of her efforts, combined with my gentle encouragement and words of belief in her, Chloe's confidence expanded and increased. Andrew, on the other hand, was already adept at taking photographs but he preferred to wait until I was available because he enjoyed the process of our discussions. "Let's go, Lisa" he would say as we wandered around Lake House chatting as he took photographs and offered commentary and shared anecdotes. This was valuable data. It was also enjoyable, and

Andrew and I had a good time taking photographs together. I was there as a companion and provided no technical assistance for Andrew who was extremely competent. Andrew, however, provided technical support for other housemates, a role he enjoyed and a role that was appreciated by the other housemates.

As a participatory approach, PhotoVoice has great utility in supporting participants to tell their story, in their own way (Wang & Burris, 1996; Wang, Ling & Ling, 1996). The storytelling aspect of PhotoVoice was significant in my study. Rose and Maggie enjoyed taking photographs of each other and I would accompany them, listening to their stories and banter as they shared insights about home. Our process of taking photographs also deepened my understandings of their relationship. With a stream of seamless conversation, Maggie would give Rose instructions to stand straighter, move closer, move left or right, to turn her head or to brush her hair or change her shirt before a photograph in order to get the very best shot. Rose enjoyed this interaction with Maggie and they would often take photographs together whether I was present or not. Josh and Bella, too, enjoyed taking photographs of each other and enjoyed telling me the stories behind different photographs.

In this way, the photographs the housemates took were accompanied by stories and shared experiences. The act of taking photographs was itself a journey together, creating new memories and experiences that the housemates shared with the supervisors, their families or workmates. Thus, the photographs were socially constructed; they were not isolated, objective, detached images. The housemates used their own agency with the photographs, to create images of home, to share stories of home and then, to reflect on and consider what was important to them about home.

Critical consciousness (Freire, 1974) is a foundational element of the PhotoVoice method. The photographs the housemates took provoked conversations about home, but they also provided opportunities to look at Lake House differently. Taken for granted aspects of everyday life, such as the yellow sticker on each bedroom door which simply said ‘bedroom’, was viewed in a different light through the photographs. Sitting out the back, at the round table in the back yard, the housemates compared photographs and I prompted discussions about the yellow sticker. “Never noticed that before, love,” Andrew responded when I asked why all the bedroom doors had the exact same sticker. The photographs enabled us to see the familiar in a different way. Identifying the stickers prompted discussions about the housemates about why life at Lake House was structured in this way.

The critical consciousness aspect of the PhotoVoice method is powerful in research within group homes for people with intellectual disability, who are a cloistered group, surrounded by multiple levels of gatekeeping, accoutred in the rules and regulations of disability service providers. Opportunities for people who live in group homes to voice their opinions, ideas, to share their experiences of home, and to influence policy and program development for accommodation and support services, are limited. At Lake House, we used PhotoVoice as a way for the housemates to think about their lives and to begin talking about their lives.

Opportunities are developed for the voices of participants to be heard, through their images, to communicate with policy makers (Wang & Burris, 1994). However, in my study, I found that the housemates' voices were already formed prior to the commencement of my study. Rather, using PhotoVoice within an anti-oppressive framework, understanding and acknowledging the oppression of people with intellectual disability who live in group homes, where their voices are largely hidden behind disability service provision, supported critical thinking and reflection. This process, in turn, supported the housemates to make changes, as small as they may seem to outsiders. The process was empowering and built on housemates' strengths. Together, the housemates and I used PhotoVoice as part of the ethnographic methodology of the study, and together we co-produced knowledge about home, and in particular, home at Lake House.

However, although PhotoVoice is an empowering, participatory method, the way the researcher uses this method in the field can enhance or hinder these aspects of the method, as I illustrate in the following section about our use of disposable cameras.

Disposable cameras. The housemates were familiar with photography and were interested in taking photographs of their home. Initially, we used a disposable camera which is typical in PhotoVoice studies (Booth & Booth, 2003). The use of disposable cameras is perhaps also a reflection on the time in which the studies took place. Disposable cameras would also have been more cost effective than other methods.

However, in our work at Lake House, disposable cameras were not successful. The disposable camera does not allow mistakes to be rectified and the housemates and I were making many mistakes as we got used to using the cameras. As the housemates made mistakes, such as taking a photograph with their finger blocking the image, or having the photograph on the wrong angle or, as I was apt to do, taking a photograph of the floor or my foot, the housemates became discouraged. The disposable cameras were difficult for Andrew to use, with his vision impairment, as there was no viewfinder and it was difficult to see what one was taking a photograph of. Additionally, the disposable cameras did not make a "click" sound, which is the noise a camera makes when a photo is taken. The housemates found this confusing, as they were familiar with cameras that had this click feature and appeared to want to use the click sound to help them determine when the photo was taken. A further significant problem with the disposable cameras was the considerable delay involved in processing the prints from the camera. Sometimes several days would pass before the images were printed and then returned to the participants for our discussion. Then, when we reviewed the photographs, the moment in time was lost, or was no longer of interest to the housemates and this impeded conversational flow.

After waiting for days to receive the prints, it was also then discouraging to find some photographs were flawed, blurred, featured a thumb or a finger or were not of good quality. The housemates became discouraged and the process appeared to be reinforcing their belief that photography was not something they were capable of doing, another task they couldn't do.

Positioning the housemates as grateful recipients of a gift. Using funds from my student bursary, I purchased six disposable cameras for the housemates. I realised my error as I brought the cameras to Lake House and began to distribute them to the housemates, who were polite, thankful and very grateful to me for the cameras. Inadvertently, I had positioned the housemates as grateful recipients of a gift. Although I had interpreted the disposable cameras as having a functional purpose, a tool for the method of research, the housemates were pleased to receive such a gift. I had, foolishly, assumed the small cost of the disposable cameras meant the objects had little worth, however, for the housemates to have a camera of their own was highly significant. Inadvertently, I had established a power differential between myself as the ‘provider’ or ‘giver’ of gifts and the housemates positioned as grateful recipients of the gift. This was a dynamic that, as a researcher and as an individual with many years of experience working in group homes and working with people with intellectual disability, that I should have known to avoid. My thoughtlessness evidence of the fact that one’s work in reflexively challenging one’s own beliefs, privileges and ideas is never finished.

By purchasing and providing the disposable cameras, I had, albeit inadvertently, positioned the housemates as dependent. Further, I had also neglected an important part of the relationship I was trying to establish with the housemates; I was making unilateral decisions and imposing my decisions on our group. Eager to start the PhotoVoice process, my initial steps were ill-conceived, although informed by the literature and typical processes of PhotoVoice.

Using a digital camera. With the challenges we encountered using disposable cameras, the housemates and I discussed the option of using digital cameras. Rose, in fact, had her own digital camera which she elected to use. I borrowed a Canon digital camera from the university, which was a basic point and shoot model. The digital camera provided the capacity to erase mistakes immediately and the housemates quickly learnt how to delete photographs using the ‘trash’ button on the camera. Growing in confidence, the housemates were encouraged to take photographs and grew less fearful of making a mistake. If the lighting, for example, was not good and the image turned out too dark, it could be immediately erased, and another photo taken straight away. Similarly, if housemates posed for a photograph (such as standing together under a tree) and the shadows blocked out faces, then this could be immediately erased, and the housemates could move to another area immediately for a better-quality photograph. In this way, the housemates became the ‘directors of scenes’, especially as they became more and more confident with the device and my support role grew less and less.

However, there were still some challenges that we encountered with the digital camera. The viewfinder was very small and often dark, so it was difficult to capture photographic scenes accurately. For Andrew, with his vision impairment, the digital camera was inadequate. I worked with the university to try to find a more accessible model for him, but other models had the same problem. The viewfinder provided an immediate snapshot of the image but in a very small window. Only one person at a time could look at the viewfinder window to see the photograph. The housemates were often interested in looking at the photographs immediately after the shot was taken, asking, for example, “show me how it turned out”, “what do I look like?”, “oh no, Rose, you have your eyes shut in this one, let’s take a better one.” The camera was often passed from person to person, so everyone could see the photographs. When we returned to the table for a conversation about the photographs it was again difficult to have a conversation about specific images because they were not immediately available. Again, there was a delay in having to take the camera to a store to have the photographs physically printed, for the housemates to peruse and discuss and for the housemates to include in their photograph albums or scrapbooks. A better solution was required.

Using laptops and iPads to create slideshows and digital collages. As the housemates and I moved away from using disposable cameras we explored using a digital camera with a laptop. The housemates took photographs on the digital camera, which I borrowed from the university, and together we uploaded the photographs to the laptop. We could then see the photographs on the laptop screen and manage the images, creating a slideshow or collage. Initially, we used PowerPoint to create slideshows with the digital images. Josh and Andrew were particularly interested in this approach and I provided initial support with the technology. However, the housemates were quickly able to manage PowerPoint with minimal support from me and created their own slideshows, adding music or special effects.

Once complete, Josh and Andrew invited us to gather around the kitchen table as they played the slide show for us. Sometimes, the supervisors would join us too. The visual slideshows prompted conversations and discussion about home, with the housemates and me contributing different perspectives or offering different insights in response to the slideshows. The process of creating the slideshows was interactive and elicited conversations as we debated the merits of which photographs to include, which music to select. Creating a slideshow was also an opportunity to tell a story of home and the housemates and I worked together to develop a narrative about home for the slide show. In developing the slideshows, we asked “What is important about home? What does home mean? What do we want to tell the audience about home? How can we illustrate this story of home using a slideshow?" The slide shows were available for the housemates to keep. For example, once complete I downloaded the slide show onto a USB for Andrew and he took the USB home to share with his mother. Josh, too, took a USB home with the slideshows he had created to share with his mother and his cousins.

However, there were limitations with using the laptop. In particular, the trackpad was finicky and difficult to use. Requiring two fingers pressed down on the trackpad and then simultaneously dragging the trackpad to scroll through a page, for example, was difficult. Instead, we used a mouse attached to the laptop which made these tasks easier. In any event, for some housemates, such as Chloe, Rose and Maggie, they found using the laptop difficult, either with the trackpad or the mouse. The alpha-numeric keyboard on the laptop was also problematic, requiring an understanding of letters and typing. For example, if we uploaded photographs to the computer, there was a requirement to label the image, and this required use of words or numbers such as, "Lake House 12 August 2010". Some of the housemates struggled to use the keyboard and although they were keen to do so it was a labour-intensive task that often detracted from the main purpose of the activity; discussing the photographs.

I experimented with different laptops. Those available through the university were Windows, which were not as intuitive or easy to use as Apple laptops. We tried using my own laptop, a MacBook, which was easier to use but there were concerns raised by the university and the Organisation that I was using my own personal laptop which would not be covered by insurance if it was broken during fieldwork. Nevertheless, the housemates were exceedingly careful with my laptop and told each other to be careful of "Lisa's computer". However, this process raised ethical issues for me, as the housemates never had access to technology of their own. This was disempowering and once again positioned me as the powerholder as I had access to a range of technological resources.

Eventually, we trialled using an iPad, which I borrowed from the university. The iPad eliminated the need to use a keyboard and the interface was more accessible using a touch screen and icons. The housemates found the iPad easier to use. Once photos were uploaded to iPhoto these were synchronised with the iPad, which was easily viewed by everyone. Weighing 900gms, the iPad was portable and easy to manoeuvre. The iPad was able to be viewed in Portrait or Landscape and the view could be easily changed by lightly tapping the iPad. The icons on the iPad were large and easy to see, easy to touch and required less steps for the user, compared to the laptop, making the device more accessible for the housemates. Chloe enjoyed using the iPad but was initially reluctant to do so in front of others and waited until we had some time together alone, without the other housemates around. Bella, Maggie and Rose enjoyed using the iPad, but Bella preferred scrapbooking and Rose preferred drawing. At the time of fieldwork, the iPad did not have an inbuilt camera, as later models do, so we were still using a digital camera with the iPad which was, at times, cumbersome, albeit less so than the laptop. The iOS interface was easy to navigate and the iPad's reliance on icons rather than words or texts was preferable to the alpha-numeric keyboard of the laptop. Often, the icons were intuitive, with the housemates instantly recognising the music icon, for example, with its musical note. Using the icons, supported the housemates to easily create a soundtrack to their photographs and we found apps that were easier to use than PowerPoint.

One such app was Diptic, which the housemates and I discovered through experimentation and trial and error with a variety of different apps. Diptic, an app for creating and sharing photo collages, was accessible and easy to use. In Diptic, there are pre-set layouts which were chosen by touching a template. Then, photographs were easily manoeuvred and could be placed in frames within the template chosen. One of the limitations with using Diptic, however, was its reliance on internet access. The housemates were disadvantaged in this process, not having access to the internet at Lake House, except through the Cottage. Lack of internet access also limited the housemates' ability to share photographs through social media such as Facebook or Twitter or on photo sharing spaces such as Flickr or via email. Adding to another power imbalance, Diptic was only available to the housemates when I was present, with the iPad and with mobile internet data. This meant that the housemates could only work on their photo collages when I was present. On some occasions, the housemates and I accessed Wi-Fi when we went to cafes or McDonalds, but these outings were also facilitated by myself with access to my vehicle. However, the housemates and I found the iPad easier to use and affordable, with the Diptic app costing $5.99 at the time. For future research, having an iPad available for the housemates to use at any time, in the same way that we used disposable cameras, would be beneficial.

Using technology has become part of everyday life and the housemates were aware of iPads, laptops and digital cameras even if they did not have direct access to them. Using the iPad facilitated conversations between the housemates and their family members, parents and friends. Oftentimes, family members had shared photos at family gatherings and now the housemates also had photos to share. In other ways, too, our use of technology provided storytelling opportunities. Andrew's nephew, for example, had recently purchased an iPad and he and Andrew had lots to talk about with Andrew's use of the iPad for his own project.

The housemates enjoyed being part of these modern processes, they each knew nephews or cousins or friends who were using such technology. Through the study, the housemates had access to technology that may not have been otherwise available. Using an iPad was a valued activity, which the housemates could share. For example, when Josh told his cousin he was using an iPad, his cousin said, "Bro, you can't use an iPad" and Josh said, "Hey mate, yes, I can. I can do it on my own, too."

Scrapbooking. With historical roots and traditions, scrapbooking has been described as somewhat of a ubiquitous hobby (Christensen, 2011). Scrapbooking is the practice of taking photographs and collating them into a personal album, typically using embellishments, narrative and various decorative styles to adorn each page (Goodsell & Seiter, 2011). A traditional form of cultural expression (Christensen, 2011), early scrapbooks contained poems and coloured flowers and personal mementos (Potter, 1948). With the advent of photography, scrapbooking burgeoned and commercialised into an industry worth billions (White, 2005). Scrapbooking communities have emerged with people undertaking the craft sometimes referring to themselves as 'scrappers' (Christensen, 2011).

Scrapbook pages are often decorated and embellished and there are many decorative items available to purchase. Scrapbook authors can choose to place one image on the page, perhaps adding a heading or some text, or scrapbook authors can choose to create a collage. Stickers can represent emotions or feelings. In many ways, the creative opportunities are endless.

Scrapbooking has been used in qualitative research in a number of ways. Williams and Lent (2008) used scrapbooking as an intervention for grieving children.

In their study of pupil voice, Cremin, Mason & Busher (2011) used scrapbooks to support students to express their views on identity and schooling (p. 589). Using photographs which students took throughout the school term, the students created scrapbooks. As a point of contrast, a small sample of teachers were also asked to produce a scrapbook, which was then used during interview as a type of visual elicitation (p. 589). The authors found the use of scrapbooks particularly advantageous for students with low literacy skills but also to support students to discuss difficult, ambiguous or hard to describe concepts:

> We hoped that pupils who struggle with expressing themselves verbally might find their photographs useful as a prompt during the interview. This was particularly pertinent as we were exploring issues of identity and schooling that might be difficult to put into words. (p. 589)

The authors found scrapbooking a useful adjunct in their research and emphasised the utility of the method for students, emphasising the capacity for photographs in the scrapbooks to help students express themselves. Other scholars have also emphasised such utility with scrapbooking.

Maller and Strengers (2018) used a memory scrapbook to augment interviews in their study which examined social practices of international university students, some of whom had a first language other than English. Maller and Strengers (2018) used their memory scrapbook with participants to prompt discussion and to probe further, thus deepening the verbal conversation. For participants who do not use verbal language, or for participants who may not have strong verbal language skills, visual elicitation can be useful as a way of encouraging dialogue. The way in which Maller and Strengers (2018) used the memory scrapbook to accompany the interview was indicative of a communication partnership, albeit a very short one as their interviews were limited to 30 minutes per participant. This communication partnership, however, is at the heart of visual methods used within the research paradigm. The communication partnership requires the researcher to work with the participant and to use the visual images in a responsive and reflexive way. In my exploration of home, for example, the housemates and I used photographs which they had taken of Lake House to prompt and promote discussion about home. At times, the photographs prompted the sharing of an anecdote or a recollection of a memory of home.

In my study, the housemates and I used scrapbooking collaboratively. Each housemate developed an individual scrapbook of home, using photographs they had taken of Lake House. The process of scrapbooking was dialogical, and we used scrapbooking time to have rich conversations, to share anecdotes or humour which built our rapport. The process of scrapbooking elicited conversation and critical thinking about home. Not all the housemates chose to create scrapbooks. Maggie, for example, preferred other crafts and said she had enough on her plate without a scrapbook. Those housemates who undertook the scrapbooking, however, enjoyed the process immensely. Bella, in particular, relished the time to create and to develop her own book about home. In Figure 3, Bella is creating her scrapbook, using photographs and glue and stickers. Her intense concentration is evident. She called this "being in the zone."

Figure 3. Bella creating her scrapbook of home.

Scrapbooking provided opportunities for the housemates to create a tangible account of home. However, scrapbooking was also a process rather than just an activity of producing the actual scrapbook itself. The process of scrapbooking involved the housemates and I taking several outings to shopping centres and various department stores, art and craft shops and bargain shops to explore the different types of scrapbooks available and the vast array of decorative embellishments. It would have been quicker and easier if I had purchased the scrapbooks myself and then returned with them, en masse, to Lake House and distributed them to the housemates. However, efficiency was not the goal. Rather, the trip in the car to Kmart with Bella was an opportunity to talk more, to converse together without the hustle and bustle of the busy household interrupting us. Or, after choosing her scrapbook, Chloe and I sat at a café enjoying a coffee and a coke, perhaps sharing a donut, and she'd show me the decorative embellishments she had chosen.

Some housemates purchased large A3 style scrapbooks, other housemates, such as Josh, preferred a smaller notebook style scrapbook. Each scrapbook was chosen by the individual housemate and decorated any way they wished. Bella used glue on the back of her photographs and developed a type of storyboard, beginning with an introduction to Lake House. Through her photographs, Bella created a journey through the house, showcasing her favourite parts of the house, including her orderly pantry in the kitchen. Bella also had photographs of Josh, who worked with her to recreate his afternoon routine of lying out on the couch "chillaxing", as he called it, where he would wait for Bella to return home from work. Bella filled her scrapbook with photographs of her room, including her desk with her collection of nail polishes.

Following the rules, we had established for taking photographs, Bella asked the supervisors permission to take their photos and she created various photo opportunities. In one photo, Bella and the supervisor pretended they were looking through cookbooks together to choose a recipe in order to recreate Bella's cherished routine of 'Tuesday night cooking'. Bella spent hours on her scrapbook. She would often bring her work to the outside table or to the kitchen table, sometimes working alone and sometimes working with the other housemates. Sometimes Bella and I would work on a particular page together and this elicited conversations about home and what was important to Bella.

Andrew was keen to use lots of text in his scrapbook. He liked to write notes on pieces of paper he scavenged from the Cottage, with permission, and he wrote stories, often asking me to check his spelling. Then, Andrew folded the stories into tiny parcels which he stuck inside the pages, perhaps next to a photograph or in a compilation at the back of his scrapbook. The method facilitated conversations and supported a deeper exploration of what home meant for each individual, and the photographs and the scrapbook elicited rich, detailed data.

The scrapbooks were valuable for the housemates as they began to build a picture of home at Lake House. Oftentimes the housemates' history of home could not be remembered clearly or had been lost as staff members who had once known the housemates left and moved on. Individual histories of home may have been lost in corporate archives. The scrapbooks were an opportunity for the housemates to make and keep memories of home, capturing their own thoughts and feelings of home, in a way that they could keep. The scrapbooks proved to be useful storytelling devices as the housemates showed their scrapbooks to family members, friends and workmates.

DRAWING

The use of drawing as a visual method in qualitative research has become increasingly participatory (Literat, 2013). As method, drawing offers opportunities for participants to express themselves creatively, to reflect upon their work and to discuss their work with others. Drawing holds the potential of "…painting a more nuanced depiction of lived realities, while simultaneously empowering the research participants and placing the agency literally in their own hands." (Literat, 2013, p. 12). The act of drawing positions the artist as expert in the topic; it is their artwork and they are free to create. Drawings can facilitate emotional expression and the physical act of drawing can facilitate a different type of thinking and perception (Gauntlett, 2007). Drawings are inherently subjective thus participants are free to express themselves and such subjectivities are valued. Further, drawing provides opportunities for participants to think about what they want to create, providing time for reflection and contemplation (Gauntlett, 2007).

In my study, I again used a dialogical approach to drawing whereby the housemates and I discussed and talked about their drawings about home. Often, the drawings facilitated story-telling. Rose, in particular, loved to draw and created many artworks about her childhood home with her family, which shaped her dreams of home for the future. Through her drawings, Rose recalled her childhood or conjured memories of her time living in a flat on her own. There was also a convivial aspect to the drawing process. Maggie, who didn't like to draw, recalling her "failures, as she called them, at art class at school, chose not to participate. "I'm just not very good at drawing," she told me. However, Maggie enjoyed sitting beside Rose as she constructed a drawing. In these moments, the pair would chat and natter away about what Rose was drawing. Kindly, Rose and Maggie always made sure that I was included, too. In this way, our collaboration was reflective of Freire's (1974) pedagogical style, which discourages a hierarchy between the researcher and participants (Literat, 2013).

Drawing was also fun. Rose, for example, relished the opportunity to draw and was prolific. Each drawing held possibilities for engaging others in conversation as she shared her stories and anecdotes of home. Her drawings were interesting and full of details which provoked a curiosity in others.

For me, the narratives and stories which accompanied the drawings were important for interpretation. Looking at a drawing, I interpreted the work through the lens of my own life course, my own perspectives and understandings. On the other hand, the housemates had very different life courses to my own and may have intended something completely different. Drawing, as a highly interpretative research method (Literat, 2013, p. 93), provides complexities for validity (Silverman, 2001). However, by using the drawings with ethnographic conversations or comparing and contrasting with photographs or using drawings to elicit the sharing of knowledge about home. Again, this collaborative strategy supports the artist to not only have a voice and to express their voice, but also positions the researcher as a listener (Literat, 2013) and a learner.

Working reflexively is important when using drawing as method, just as reflexivity is important in ethnographic research (Roberts & Sanders, 2005; Lichterman, 2017) whether it uses visual methods or not. Multiple interpretations of visual material are possible. In my study, the housemates and I used drawing as a process through which interpretations were built over time rather than a one-off interpretation of the final, finished product.

Drawing, as a participatory visual method, has received much less attention than photography and video (McIntyre, 2003) and, at the time of writing, I was not aware of drawing being used as method in group home research. While not all the housemates chose to draw, the opportunity to have this choice was important in and of itself.

WALKING ALONG THE BUSH TRACK: DATA ANALYSIS

In ethnographic research, data begins to be generated as soon as the researcher enters the field. In this way, data is generated from the outset and LeCompte and Schensul (2013) note that data analysis begins concurrently with data collection (p. 11). In this section, I describe my process of data analysis.

In ethnography, from the moment the researcher begins making notes, data analysis occurs. I found that writing down my notes helped me to organise my thinking. As the ethnographer writes her notes, she is already organising and analysing the data, structuring, categorising and identifying themes in her notes. Madden (2010) emphasises that, "(t)he meaning-making process has already begun at the point the notes were written" (p. 140).

One of the challenges I encountered in data analysis was the sheer volume of ethnographic material I collected. I had a voluminous amount of field notes and my own reflections and writings in my field diary. In addition, I had a range of other data sources, such as photographs, scrapbooks, drawings, the process of PhotoVoice, conversations and my own experiences and observations from the field. These data sources were used to complement my field notes (Madden, 2010, p. 108) rather than used separately or distinct from my field notes. The considerable volume of ethnographic material collected in my study was overwhelming and required rigorous organisation while, at the same time, challenging myself to remain flexible, creative and curious.

Ethnographic analysis requires the researcher to sort through the raw data collected, organising the data, reviewing and reflecting upon the data and creating smaller piles of summarised data (Patton, 1990). The ethnographer is constantly and continuously discovering patterns and themes in the data, linking to other patterns and themes (Patton, 1990). Consistent with the interpretivist paradigm of the study, I used the data to build and refine themes, and used constant, comparative analysis.

Reflexivity was an important part of my analysis and in thinking more deeply about my own interpretations of the data. Did my experience working in group homes over many years help or hinder my interpretations? While it was impossible to separate my own values, beliefs, ideas, experiences, and biases from data analysis, it was possible to work reflexively. The recursive nature of my data analysis was embedded within my processes of constant comparison and reflection and review, developing richer, deeper, understandings of Lake House (LeCompte & Schensul, 2013). Where I wrote in my field notes, "the kitchen was stark and unhomely" I recorded this as my own impression, an etic perspective. Bella, however, had a different perspective when she said, "the kitchen is my favourite room in the house." Both these etic and emic perspectives were useful, both interpretations of the same space were important.

Throughout fieldwork, I was constantly checking and re-checking my data. Often, I would test my initial interpretations with the housemates but sometimes I would use my impressions to guide my observations or conversations in the field. In this way, I focused more specifically on some areas in my observations, or I used probing questions to more fully explore another area. This process of checking and re-checking, or narrowing and focusing, occurred throughout fieldwork, as LeCompte and Schensul (2013) say, "… (ethnographic researchers) …develop and test initial interpretations of the data as they go along, continuing the process even up to the point at which the final page of the last report is written" (pp. 13 - 14). Described as the hallmark of ethnographic research (LeCompte & Schensul, 2013, p. 32), recursivity requires the researcher to continually reflect and re-order what is happening in the field based on feedback from the field.

Coding and thematic analysis. Using an inductive approach, I sifted, sorted, organised, reflected and reviewed the data to develop codes and themes (LeCompte & Schensul, 2013). As my fieldwork extended, my immersion within the field was deeper and brought new understandings through the data collected and my recursive analysis. I collected and coded data, and conceptualised categories and themes (Miles and Huberman, 1994). I used NVivo (NVivo for Mac version 10.2.2) to support my organisation of text and the development of themes. Consistent with the inductive research paradigm, I used the technical aspects of NVivo to support continual reflection and review.

King (2010) reports from her ethnographic study, that she chose not to use a computer-assisted, qualitative data analysis software favouring the process of sorting themes by hand, which she found useful, as "…(it) gets me 'closer' to the stories" (p.71). At times, in the beginning, I augmented NVivo with my own manual indexing of data, using a coloured highlighter on photocopies of my fieldnotes, using one colour per code. I found this was particularly useful for drawing out specific quotes or for constructing particular themes. At times, I felt NVivo took me away from the stories of the field, however, my manual approach of coding and thematic analysis also contributed to fragmentation and with such a large amount of ethnographic data I was quickly disorganised and overwhelmed. I returned to NVivo to support my analysis. Indeed, in other ways, I found that the process of using NVivo enhanced my immersion in the data by requiring me to look at the data in multiple ways.

My deep immersion in the field offered detailed ethnographic descriptions in my field notes, borne out of my closeness to the field, however, using NVivo provided a sense of distance from the field, which was valuable for reflection. This process of stepping in and stepping out of the data was part of my recursivity. Using NVivo made it possible for me to take a step back from the field to find patterns and themes that I couldn't see while I was so deeply immersed in the field. Other scholars have avoided computer assisted software because of this distancing effect (O'Reilly, 2012; McGhee, 2014), however, I found this distancing useful at times. Working inductively, themes, categories and concepts emerged from the data (Elo & Kyngäs, 2008, p. 107), however, NVivo did not analyse, interpret and construct meaning in and of itself, "…for the theory is not automatically churned out by the program when it has sorted the ethnographic notes. If only this were so!" (Giampietro, 2008, pp. 41-49).

LeCompte and Schensul (2013) argue that ethnographers are in a "…sometimes tedious and often exhilarating two-step process of analysis of raw data and interpretation of analysed data." (p. 11). My data was not a collection of objective facts that would speak for itself, rather, I was constantly analysing and interpreting the data. Madden (2010) is adamant that ethnographic data is not left to its own devices in ethnographic research, rather the ethnographer is constantly interpreting:

> To do otherwise, to say that the facts in the notes will do the talking, is to abdicate responsibility for analysis and interpretation, and what qualitative social scientist in their right mind would want to give over the power of analysis and interpretation to 'data'? (p. 115).

Even as I exited the field, my analysis and interpretation continued. The final stage of analysis is done at some distance in time and space from the field and blends with final interpretation of the data; it gives researchers time to gain perspective on their experiences and the lessons they have learned (LeCompte & Schensul, 2013).

Summary. This section has described ethical considerations and implications for the study and the ways in which I gained access to the field and recruited participants. In this section, I have outlined the ways in which I approached informed voluntary consent and I emphasised the lengthy and complex process of gaining access to participants who live in group homes. I have emphasised the challenges in group home research of positioning oneself in the field and I outlined my process for considering the power relations in such positioning. In this section, I have described the methods I used in the study and I have discussed the ways in which the housemates and I adapted these methods to make them our own. This collaborative problem-solving served to enhance and strengthen my relationships in the field. I finished this section by discussing my recursive approach to data analysis. I extend the discussion of methods in Chapter 8 where I provide a clear and substantiated articulation of what this study can add to emerging literature on collaborative research and the use of creative, participatory methods with people with intellectual disability.

In the next section, using a range of ethnographic material, I provide a brief introduction to Lake House, which was the setting for my research. This introduction is followed by a series of detailed portraits of each of the housemates, the participants in my research. The housemates and I worked together throughout fieldwork to develop these detailed portraits and to provide a sense of their life courses. The portraits became a source of enjoyment for both the housemates and I and were works in progress throughout fieldwork, which we continually added to over time. The portraits are presented here as an introduction to the housemates, however, some of the portraits were not finished until my very last day of fieldwork.

LAKE HOUSE: A BRIEF INTRODUCTION

Figure 4. Lake House.

Lake House, Figure 4, is an older style home, architecturally similar to other houses in the neighbourhood. The exact age of the property is unknown by the housemates. Collectively, the housemates estimate that Lake House must be quite old as some have known of its existence prior to coming to live there, drawing on their decade's long involvement with the Organisation[20] that owns and runs Lake House. Neat in presentation, the small front garden is tidy and well maintained although there is an absence of personal elements such as potted plants, garden ornaments or decorative features present in some of the neighbouring homes. The lawns and gardens are maintained by the Organisation; however, Josh often receives a few dollars if he

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[20] The term Organisation is used to refer to the entity which owns and operates Lake House. The Organisation provides specialised accommodation and support for people with intellectual disability and has many other group homes within its holdings.

chooses to mow the lawns. Hedges along the front fence line provide privacy and some garden space, however, the front yard is not utilised.

Two storeys' in height, Lake House is physically separated into two distinct abodes with four housemates residing upstairs and four housemates residing downstairs. An external staircase at the front of the property is rarely used, with housemates, the supervisors and familial visitors entering the home through the rear of the property. Two of the upstairs bedrooms have balconies facing the street; lattice has been erected to provide privacy. Rose, who has one of the balcony bedrooms, keeps a few potted plants on the balcony in lieu of a table and chairs, which are not permitted. The physical structure of Lake House has been considerably modified over time to include three bathrooms, two kitchens and two shared lounge rooms. Each housemate has an individual bedroom and the property has been modernised to include air conditioning in each bedroom and air conditioning in the two lounge room areas. For reasons of occupational health and safety, all bathrooms, the kitchens, dining areas and laundry have non-slip flooring.

The main outdoor area of the property is the backyard which is furnished with an outdoor table and chairs, a barbeque, and a large shade sail. More recently, a small deck was constructed although at the time of writing it was unable to be utilised because of health and safety concerns about the absence of railing. Also located in the backyard is a basketball ring, collectively purchased by the housemates and frequently used by housemates and the supervisors, and a medium sized vegetable patch. At the back of the property there are three carports, a small grassed area with a hills hoist, and the staff quarters. Adjacent to Lake House is a public park with considerable parkland, popularly frequented by families and visitors on weekends and regularly utilised by the housemates.

ORGANISATIONAL CONTEXT

Lake House is owned and operated by 'the Organisation' a large provider of disability specific accommodation and support. The organisational structure is complex[21] and has many hierarchical streams. The supervisors report to a Service Co-

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[21] I have intentionally omitted any detail about the organisational structure and the staffing contingent at Lake House. Due to the complex and unusual nature of these arrangements, specific details risk

Ordinator, who manages several group homes, including Lake House, and who, in turn, reports to an Area Manager who reports to an Executive Manager. The organisation has a Chief Executive Officer who is accountable to the Board of Management. The role of the supervisors at Lake House is to support the housemates with the tasks of daily living, to protect and ensure their safety, skill development, community access, budgeting and support to access healthcare services in the community. The supervisors maintain client files, a household diary, and complete many different types of paperwork as required by the organisation. The supervisors, and indeed each role within the organisation, must adhere to organisational policies and procedures, legislation and State and National disability service standards. Lake House is examined in more detail throughout the thesis.

In the following section, I introduce the housemates to the reader through their individual detailed portraits. Some portraits are lengthy while others are very brief, indicating the amount of information each housemate wished to include.

INTRODUCING THE HOUSEMATES: DETAILED PORTRAITS

Specific to each individual, the detailed portraits vary in length and style. Working with each housemate individually, we compiled the portraits together over my eighteen months of fieldwork. Oftentimes, we worked on the portraits alone, however, the housemates also sought information from one another, or drew on shared experiences to complete their portrait. Some housemates did not know their age or year of birth and while this information would have been easily verifiable from the supervisors, the portraits are not a compilation of facts found within client files. Rather, the portraits are individual stories, experiences, anecdotes and perceptions, providing a picture of each person, unique, and as detailed, or not, as each person wished. The portraits were also a journey together, the housemates and I would dip and out of the portraits, adding or deleting information, and crafting the stories together.

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identifying individual staff members and even the Organisation itself. To avoid this, and to maintain confidentiality, I make only vague references to the staffing arrangements.

Josh: The sociable young man. "I'm a sociable young man," Josh tells me directly, as he likes to describe himself. Josh is slim, broad shouldered, with short brown hair and a huge smile. Josh has a cheerful disposition and is a friendly, outgoing person. Of his age, Josh is not entirely sure, hazarding a guess, however, that he is younger than thirty. An important part of Josh's childhood, cars are his passion and he happily recalls spending every moment he could around them, holding tools for the older men in his family as they worked on engines and tuned the motors, repairing lawn mowers and motorbikes. Josh recalls the sounds of the engines as the men revved them and the enjoyment he felt when an idle engine sparked to life. The men would high-five and pat each other on the back, always including Josh in the celebrations and congratulating him as the "best little helper". Josh felt proud to be a part of the success and to be included and acknowledged by the men in his family whom he respected greatly. Later, when Josh was older, the men used to ask him for his expertise, "What do you reckons wrong with this one?" "OK, I taught you everything you know matey, now it's your turn, give this one a go" and Josh was given the privileged job of making the repairs autonomously, transitioning from helper to the "main man". Finally, Josh felt he had earned the esteemed respect of the older men, becoming a valued part of the group. Josh recalls these times as the best of his life.

Identity and self-perception

Josh identifies himself by "his syndrome"[22], his disability. Josh talks openly about his syndrome and is well educated about the syndrome's specific features and characteristics. As part of Josh's syndrome, he identifies that intellectual disability is an inherent characteristic, however, he is quick to correct any potential judgments about this diagnosis by stating, "I'm not a retard though." Josh prefers that the correct name of his syndrome is used. The rarity of his syndrome has led to feelings of isolation for Josh, feeling that no one else can truly understand what it is like for him. Josh tells of one occasion where his mother invited him to a musical concert, an event which he admits he was initially uninterested in, preferring to stay home. However, wanting to make his mother happy, as it was clear she wanted to attend the concert, he

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[22] Due to the rarity of the syndrome, I have not specified the name as it could identify Josh. This was a source of tension between Josh and I; he wanted to talk openly about the syndrome and wanted me to raise awareness of the syndrome through its inclusion in the thesis. Josh also felt the syndrome was an important part of his own identity and that it should be included.

acquiesced. Josh took little notice of any information about the concert and arrived, "watching the clock", wondering when they would be going home. Josh and his Mother took their seats in the concert hall and Josh paid little heed as the first performers gradually moved on stage, in single file. The performers, a choir group, moved into position and faced the audience, silently waiting for the cue to commence. The lighting changed, and the faces of the performers were illuminated, and it was in this moment that Josh realised that one of the choir singers had the facial features associated with his syndrome and he was stunned to realise that he was looking at a person who shared his syndrome.

> What are the chances! I'd never met anyone else with (the) syndrome. And there she was, this beautiful girl in the choir, looking out at me.[23]

Josh was amazed to see another person who shared the syndrome and after the concert performance Josh met with the young lady, a meeting that had been prearranged by his mother who had heard of the singer from friends. Josh asked her, "a thousand questions" and left the meeting inspired, impressed with her success and her attitude that she was going to be a singer "no matter what"; her syndrome was not going to stand in her way. Josh was grateful to his mother for organising the opportunity and he recalls not feeling so alone in the world from this point onwards. In the following passage, Josh discusses the impact his syndrome has had on his life, and his mother's life, who for many years was Josh's primary carer.

> I knew growing up that I was a little different. Sometimes, in photos, I'd get this (syndrome) look and I'd say, Mum, get rid of that photo, I have my (syndrome) look. I think it was hard on Mum. She raised me on her own and she did a real good job. It's not Mum's fault I was born with my (syndrome), it's just one of those things, nobody's fault. The doctors told us not many people in the world have my (syndrome). I think Mum feels guilty sometimes cos the (syndrome) made it hard for me to learn and I never really could read or write. Mum did the best job in raising me and caring for me.

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[23] These excerpts are from conversations in the field.

For most of his life, Josh lived with his mother and it was, “just the two of us against the world.” Although, as Josh moved into adolescence, he described himself as, “a real handful”, often challenging his mother, and he acknowledged that he gave his mother an increasingly hard time. Josh says his syndrome was partly responsible, but he also felt frustrated and angry as a teenager for “no reason”. His memories of this time in his life were that he felt unhappy, felt different to other people, felt like he had no friends and he felt increasingly isolated as he saw his cousins growing up, moving out of home, having relationships and children and getting jobs. Josh felt like he would never do these things, because of his syndrome, and he felt like he was somehow missing out. Josh says it was his anger that prompted his move into “care”, as he was no longer able to live with his mother.

Life in care

Leaving his home with his mother was a transition for which Josh felt unprepared; he remembered feeling lost and uncertain about the future. Josh cannot clearly remember when he first moved out of home, and he described a sense of confusion, unsure where he lived or with whom. This fugue-like state that Josh described was indicative of his anguish and grief at the reality that he would, most likely, never again live with his mother. Intellectually, Josh knew that he could not go back and live with his mother but his grief at being separated from her was intense.

> I liked all the people I was living with, but they weren’t Mum. If I got upset or got sick I only wanted to call Mum. (Some of) the supervisors were real nice, but it wasn’t the same. Only Mum knows what I need when I’m sick and only Mum knows how to calm me down if I get upset. Mum knows me best. Sometimes, people told me to grow up, that grown men don’t need their mothers but that’s bullshit. I still felt like I needed Mum, but I tried not to talk about it too much. I didn’t want anyone to think I was a sissy. If it got too bad I would just ring Mum on the quiet and she would tell me to come home.

Josh says that the first few years living in care were fuzzy, but he remembered one group home, in particular, Silverstone Place[24].

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[24] Silverstone Place is a pseudonym chosen by Josh.

Silverstone Place

Silverstone Place (Silverstone) is a large group home funded by the state government and managed by a large disability organisation that has a long history of service provision to people with intellectual disability. This is the same Organisation which owns and operates Lake House. Josh says that he lived at Silverstone for a long, long, time. Josh lived at Silverstone with nine other men, who Josh referred to as “other clients”, reflecting the service language used within group homes. Josh said the supervisors worked in pairs and there was always someone on duty. Josh had mixed feelings about his time at Silverstone and while he thought some of the supervisors were, “really nice” and he was good friends with one or two of the clients, but he said a lot of other clients gave him a hard time, threatened him and some of the supervisors would yell, hit, or punch the clients. Anxiety was a constant feature of his life at Silverstone and Josh recalls always being on edge. “I can’t really talk about it”, was Josh’s first reaction when he thought about Silverstone. “Nothing against you Lisa, it’s just I don’t wanna get into trouble.” Josh felt, years later, that there was still the risk of repercussions for him if he spoke out against Silverstone or described the events that occurred there. “Sometimes, we’ll be out in the car, maybe going shopping or something and we’ll drive past Silverstone. It still gives me shivers down me spine.” Josh lived at Silverstone with Andrew, one of the housemates Josh now lives with at Lake House. Josh said that he and Andrew got on well enough at Silverstone, but they weren’t close. When Andrew moved out (to Lake House), Josh recalls thinking Andrew was a, “lucky bastard” because he got his chance to go.

Walking was a lifeline for Josh and he would often take long walks when he felt upset or needed to get away from Silverstone. Almost every day Josh would walk, preferring to walk alone to maintain his fast pace. If Josh had sufficient funds he might dash to the local shops and purchase a soft drink but if money was tight he was content to hightail it to the foreshore, the local park or simply through the neighbourhood streets. Josh’s fast pace was often reflective of his mood; the more upset, frustrated or angry he was, the faster he would walk, head down and taking little notice of the scenery, intent on walking, often without a particular purpose, sometimes to challenge himself to see just how fast he could walk. Hours later he would return to Silverstone, physically exhausted, but still not ready to come home.

Eventually, an offer to move from Silverstone to Lake House was presented to Josh and he declares he literally jumped at the chance. “I just jumped up and down, like I really jumped, I was that excited!” he said. Prior to his move to Lake House, Josh and his mother visited several times and their first impressions were positive. “We drove up and I saw the house, it looked so cool. Mum said it looked great.”

Moving to Lake House

Josh knew some of the housemates at Lake House and he knew Andrew from Silverstone. Despite this, Josh remembered how anxious he felt about moving to Lake House, “I was so nervous. I wanted them to like me. Mum liked Lake House and I really, really wanted to go live there.” At the time, there was only one bedroom available at Lake House, downstairs, and Josh did not have a choice of bedroom.

When Josh and his mother visited Lake House, he wondered how he would be able to fit in all of his belongings:

> When Mum and I first checked out Lake House, I didn’t think I’d have enough room for all my stuff. You know, my car collection, posters, photos, clothes and things Mum bought me back from her holidays. The [supervisor] told me, “You won’t need all that here, Josh. Leave it all behind. This is your new life. We have everything you need.

However, Josh was happy with the room and was happy to live downstairs. One of the first things Josh did, upon moving into Lake House, was to decorate his bedroom and put up posters of his favourite racing cars and racing car drivers. Josh also displayed some family photos, including some photos of his mother and some of his cousins. These posters and photographs provided comfort for Josh, images to remind him that while he was now living in a new, and sometimes strange, place he still had the comforts of home. The other housemates at Lake House quickly welcomed Josh and he soon settled in, taking a little time to learn the household routines. Some things were similar to Silverstone, “I got on the chores roster pretty much straight up. We had a chores roster at Silverstone, so I knew about ‘em” and other things took a little bit of getting used to, “Some nights I’d wake and think ‘Where the hell am I?’ I’d look around me room and think holy shit what’s this? Then I’d wake up properly and remember I was here (at Lake House) and think ‘Thank Christ’.” Josh was relieved to discover there did not appear to be any initiation games for the “new boy”, unlike his previous experiences at Silverstone, although one of his new housemates had a very loud, high-pitched voice which would often give him a headache, “That took a bit of getting used to!”

Living at Lake House

Since those early days, Josh feels like he is truly settled at Lake House now. He has some good mates and gets along with everyone, including the supervisors. Yet, given the choice, Josh would like to return to live with his mother. Josh misses her terribly and keenly feels her absence. Understanding that it is not realistic, Josh accepted that he cannot live with his mother and comforted himself with visiting her regularly and going home for all the important days such as holidays (Christmas, Easter, and long weekends) and for family birthdays, including his own. One housemate (unnamed), however, continues to agitate Josh, “(Name) is just so loud! It really pisses me off, I can’t stand it.” Josh recounts ongoing arguments with this housemate and he often seeks support from the supervisors. Normally, Josh is a relaxed and easy-going guy, however, the conflict with this housemate irritates him and he says he can become quite agitated. Josh would prefer not to live with this housemate although he has no choice about who lives at Lake House. Oftentimes, the conflict between Josh and this housemate is so frustrating for him that he will call his mother and ask to come home for a visit. If this is not possible, Josh goes for a long walk, replicating the successful strategy he used at Silverstone when it all became too much for him. Josh says he feels better after a walk and some days he just needs to “get away”.

Andrew: “The IT Guy”. Describing himself as, “really into IT (information technology)”, Andrew has a passion for electronics. Within Lake House, where Andrew said he has lived for ages, he is considered the, “IT guy.” Whenever the TV cords would come loose, the DVDs needed to be reset, or the Wii set up, everyone, including the supervisors, called Andrew to solve the problem. Andrew said that he has always enjoyed IT and helping other people. Andrew explained that it is important to be patient because not everyone understands technology.

Self-concept of intellectual disability and encountering negative attitudes

Andrew has an intellectual disability and significant vision impairment and he refers to himself as, “epileptic.” Andrew said that he prefers to be called, “the IT guy” and not “the disabled guy who can’t see.” Andrew was teased as child, called a “retard” and other derogatory names, and he said even to this day he has negative encounters with people who give him a hard time because of his disability. Travelling on public transport can be difficult for Andrew as, at times, he encounters negative attitudes. Andrew described an interaction with a local bus driver:

> The sun was in my eyes and I couldn’t see the number of the bus. I looked but couldn’t really see it. I got on the bus and asked the bus driver if he could tell me what number this bus was. He got narky and said, “It’s on the front, are you blind?” I got real angry then and told him, “Well, mate, I pretty much am blind!”

Andrew said he has experienced verbal abuse when travelling on public transport with teenagers sometimes hassling him and calling him a “retard”. Andrew said that he tells them to “piss off”, but if the teenagers persist he will get up and move seats or he will walk away, just as he said his mother has taught him. Sometimes the bus driver or other travellers intervene and tell the teenagers to cut it out. Andrew says that his housemates will also “stick up for me” and will tell the teenagers to, “stop being awful”, “grow up” or “get lost.”

Living at Lake House

Andrew said he has lived at Lake House for, “ages and ages.” Andrew described his bedroom at Lake House as a bit of a mess, but he said he likes it that way. In his bedroom, a single bed is placed under the window. Andrew said he is proud of his bedroom. Andrew displays framed photographs on his bedroom walls, photographs of his mother, his nephews, and his extended family. He has a collection of technological devices in one corner of his bedroom; an old computer that no longer works, a large array of cords, several remote controls. This collection was indicative of Andrew's strong interest in technology. Andrew is adept at working with technology, suggesting that I watch channel 11, which, at the time, was a new HD channel. Andrew's DVD collection is extensive; he enjoys watching movies and shows in his bedroom.

Experiences of home

Andrew has lived with his family, in particular his mother, and in several group homes, including Silverstone Place which he shared with Josh several years ago. Andrew moved from Silverstone to Lake House because Silverstone was a "very bad place" and he was very unhappy there. Andrew was reluctant to talk of his experiences at Silverstone because he feared he would "get into trouble". Andrew has asked that I do not include any details here.

Andrew said he was "the baby" of the family, and he has older sisters who live nearby. Andrew's mother lives a few hours away and Andrew enjoys catching bus and train to visit her, spending several weekends each year at her place. While visiting his Mother, Andrew said that he is always very polite and respectful because he is a "good son". Andrew said his mother is very proud of him, and he tried hard to do his best to make her proud. Andrew has other family interstate and he talked about his nephews and nieces and their partners and the recent births and marriages. Andrew explained that while he doesn't get to see his interstate relatives very often his mother keeps him informed of the family news.

Bella: "Domestic Goddess." Bella said she had lived at Lake House for "ages" and recalled many former housemates who had come and gone over the years. Bella proudly called herself a "domestic goddess", a title enthusiastically embraced by the other housemates who praised Bella's cooking and housekeeping talents. The housemates said Bella always managed to make everyone feel at home. Bella's passion was cooking, and she pored over cookbooks searching for recipes. Each Tuesday night, Bella was rostered to cook, and she received 1:1 support from her keyworker. Each week, Bella scoured her recipe books, marking recipes and consciously pairing one main and one dessert for her Tuesday evening meal. Bella relished spending time with her keyworker, going grocery shopping, collecting supplies and making a special effort for her Tuesday night “date night”, as she called it. Bella had lived downstairs at Lake House for “a long, long time” and said she required a downstairs bedroom because of her “fits” (epilepsy). Bella was comforted by the security of living downstairs, citing practical reasons, such as an ambulance being able to reach her should it be required after a seizure. Bella spent hours in her bedroom, which she had decorated meticulously in pink, her favourite colour. Bella’s desk was particularly important to her, a space where she would peruse her cookbooks, searching for different recipes.

Bella said she was “strict” about household cleanliness; it was important to keep things neat and tidy around the house and she was adamant that everyone followed the household chores roster. With the chores complete, Bella liked to, “kick back” and relax in the lounge room, watching a DVD or listening to music with Josh. Bella referred to herself as “girly” and loved painting her nails, wearing perfume and body lotions. Bella loved painting her nails different colours. One of Bella’s favourite household activities was to rearrange the pantry. Bella would pull out all the pantry items onto the dining room table, check for expiry dates, clean the shelves and then rearrange all the food items and baking equipment. Bella’s collection of pink cupcake moulds, cupcake papers, rolling pins and spatulas, and other baking ware was significant. Bella said she had saved up, over time, and purchased her equipment during special outings with her keyworker[25]. Bella worked four days per week at a nearby sheltered workshop[26], as she called it. Bella said she had worked there for “a million years.” Bella described her work as packing and unpacking boxes and cutting material. Bella described it as a good place to work and she continued to enjoy her work after many years. Recently, Bella reduced her time at work to four days per week as she found it too exhausting to work five days per week. Bella said she was getting

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[25] A keyworker is a direct support worker from the group home who is appointed to be the primary worker for the client. A keyworker has responsibility for developing and implementing individual client plans, supporting the client to achieve goals and usually has the most knowledge of the client. The keyworker will typically support the client at medical appointments and will be the point of contact for family members and professionals. Each housemate at Lake House has a keyworker.

[26] Now called Australian Disability Enterprises (ADE’s), the housemates referred to their workplaces as ‘the sheltered workshop’, using the terminology of some two decades ago. I have honoured the language and vocabulary of the housemates and have also used the term sheltered workshop in context.

older but was unsure of her age. Bella was hopeful that once she got her energy back that she would be able to increase her days at work.

Intellectual disability and communication

Bella said her intellectual disability made it hard for her to “add up”, “remember”, and “learn things”. Bella said she required support with “many things”. Bella’s communication is difficult to understand for people who are unfamiliar with her and she preferred to use short words and sentences. Bella used gestures to aide explanations and often asked Josh or Rose to speak on her behalf. Bella had Down Syndrome and she had received disability support services all her life. Bella recently lost all her hair and wore a bandana when going out.

Living at Lake House

Bella said she loved living at Lake House. The one thing she wanted to change was the limited funds available for craft. Each Saturday, Bella went bowling where she had been part of a bowling team for people with disability for many years. Bella enjoyed catching up with friends, having a coffee and bowling. Recently, Bella and her team won a trophy, which she proudly displayed in her bedroom on her bookcase. Typically, Bella was vague about her family and told me that Lake House was her real family. Although Bella had many family photographs and shared family stories and memories, it appeared to me that Bella was reluctant to discuss her family. Bella said her mother lived a long way away from Lake House.

An avid crafter, Bella enjoyed drawing, scrapbooking, painting, pottery and paper craft. Knitting, however, was “ok” sometimes but crocheting was, “too hard” and time consuming. Bella stated her desire for a dedicated craft room at Lake House, to store her art supplies, ribbons and papers. Bella stated that, ideally, there would be a craft room upstairs and a separate craft room downstairs.

Rose and her dream home. Rose had just celebrated a “significant birthday” but asked me to keep her age a secret because “a lady never tells her age”. Rose was the youngest of twelve siblings, some of whom she saw regularly and some of whom lived interstate. Rose fondly recalled living with her parents and growing up with all her brothers and sisters and family pets. Rose had lived at Lake House, as she said, "for a really long time", and Rose loved living at Lake House. Over the years, Rose had lived on her own at times, and felt bereft, lonely and isolated. Rose said those were her "dark days" where she often felt scared and alone. Rose preferred to live with other people and enjoyed living at Lake House with her friends. At Lake House, Rose lived upstairs and had a close relationship with Maggie who also lived upstairs. Rose and Maggie had lived together for "ages" and were good friends. Rose and Maggie had known each other long before coming to live at Lake House. Rose said she liked all the people she lived with, and she liked the supervisors a lot. Rose said it was nice to know she could talk to the supervisors if she was upset, or needed help with something, and she could always rely on the supervisors.

Identity and intellectual disability

Initially, Rose was reluctant to include any information about her disability. Maggie encouraged her and said there was nothing wrong with having a disability. Rose described her intellectual disability as "small." Rose recalled being called derogatory names, particularly as a child, but she said even last week she encountered taunts from local teenagers who called her names. Rose said she ignored them and came home and told the supervisors. Growing up, Rose didn't go to school, rather, she stayed home to help her mother. Rose said her Mum told her, "We can't all be good at school, but we all have something we can be good at." Rose said she was her mother's "little helper" and she helped her run the busy household. Rose was proud of her role within her family and pleased that her mother could always rely on her. Rose was independent using public transport, accessing the local shopping centre on a regular basis. Rose and Andrew would go to the local shops on Saturday morning, when the other housemates were bowling or at other activities. Rose considered Andrew a good friend. Rose was artistic and enjoyed drawing and colouring-in books and has a large collection.

Early days at Lake House

Rose enjoyed living at Lake House almost from the very beginning. She was worried and concerned about her dog, who went to live with her sister, but she enjoyed having company and her friendship with Maggie was of high importance. Initially, Rose was given a bedroom where another resident had recently died, and Rose remembered waking up in a sweat at night and having nightmares until she was relocated to another bedroom upstairs. Rose remembered her first key worker at Lake House and how he helped her find things to do during the day and "helped me with things like going to the doctor, getting my eyes checked and looking after me."

Rose's dream home

While Rose enjoyed living at Lake House, she was adamant that it wouldn't be forever. Rose dreamt of getting married, having a family and having her own home in a nearby suburb. Recalling the long, lonely years after the death of her parents, Rose dreamt of a home, which she and her husband would move into after their dream wedding. Rose had asked Maggie to be her bridesmaid. The pair spent hours planning Rose's wedding, deciding what to wear, selecting hairstyles and choosing the types of flowers for the Church. After such discussions, Rose was often motivated to start a "health kick" and regularly dieted in preparation for her wedding, in order to have the dress she desired. Rose adored children and said she would like to have babies to complete her dream of a house in the suburbs with a husband, children and a pet dog. Rose imagined her husband going off to work in the morning while she saw the children off to school.

Rose dreamt of her stay at home role, taking care of her family, cooking meals and keeping the home clean and tidy. Rose imagined spending her days looking after her family; including ironing her husband's business shirts, which she says was a task she detested, but was willing to do for the sake of her family. Maggie and Rose imagined several scenarios together, about Rose's dream home, and a favourite scene was one where Maggie came to visit. Rose talked about bringing out "the linen" and "good china"; Rose had carefully kept an heirloom tablecloth which her Grandmother had embroidered. Rose imagined she would use the special tablecloth when Maggie visited. Rose imagined she would use the pretty plates with old fashioned roses, and Rose would serve homemade cake or biscuits. Maggie and Rose would spend hours together, in Rose's dream home, chatting together over a cuppa. Maggie, too, imagined bringing a hostess gift for Rose, sharing tea and cake together in Rose's dream home. Rose imagined keeping a spotless home, just as her mother did and her grandmother before her. Rose imagined following in their footsteps. Rose, too, imagined a large family with several pets. Rose said she would be moving to her dream home in “a year or two”.

Maggie: “The Crafter”. Maggie was in her late 40s and had lived at Lake House for “a long time”, having lived with her family prior to moving to Lake House. Maggie lived upstairs and had a close friendship with Rose. Maggie’s family would pick her up each weekend and take her to visit Maggie’s Nanna. Then they would have coffee or an early lunch. Maggie’s passion was craft; she had a vast collection of tapestries, cross stitch and craft supplies in her bedroom. Maggie spent weekends, Christmas, Easter, birthdays and other special occasions with her family. Maggie said her intellectual disability was “one part of me” and said she needed help with writing. Maggie said that we all need help with things, from time to time, and she liked helping others as well.

Chloe. Living upstairs at Lake House, Chloe shares the top floor with Maggie and Rose. Unsure of her age, Chloe was the youngest in her family and had a close relationship with her sister and her mother. Chloe had lived at Lake House for, “a very long time.” Reserved and quiet, Chloe was less likely to interact if others were present, frequently deferring to others and being overtaken by more talkative, dominant people. Preferring to take her time to get to know new people, Chloe would often refuse to communicate until she felt comfortable. Difficult to understand at first, Chloe’s style was often hidden away so many people assumed she couldn’t communicate. It took time to understand Chloe’s gestures and hand signs. With no verbal language, Chloe had become adept at getting her message across using a range of sounds and prompts and gestures but relied upon having a rapport with the person before using these.

A source of pride, Chloe’s bedroom was filled with photographs of her family, which she enjoyed showing, hinting at the stories behind the smiling faces in the images. Chloe’s personal possessions and keepsakes were lovingly displayed and cared for. In her bedroom, there was a television which she enjoyed watching, preferring to view her shows in her room rather than in the shared lounge room. Chloe enjoyed buying and drinking coca cola and storing the empty or partially empty bottles in her bedroom. Chloe’s collection was substantial, and she was proud of each bottle.

Chloe had a close relationship with her mother and sister and she liked to “go home” to them at every opportunity. Chloe’s visits home, however, had been less frequent recently due to her mother’s ill health. Chloe described her anguish about this and was hopeful that her mother would get better soon.

REFLECTION AND SUMMARY

Following from Chapter 3, which outline the research design and conceptual framework for the study, this chapter has discussed the way in which the study was implemented and conducted. Using the metaphor of a bush track, I have emphasised the ways in which the research plan was considered and constructed. I discussed ethical implications associated with the study and specific considerations required for research within the group home, which is a personal, intimate setting with power relations that must also be considered. In this chapter, I discussed the multiple levels of gatekeeping that are inherent in group home research and the ways in which I negotiated this to gain access to the field. I discussed the ways in which I approached informed voluntary consent with the housemates and participant recruitment. In this chapter, I described in detail that methods used but emphasised the dynamic and relational elements of my approach. The housemates and I worked together to make the methods our own. In this chapter, I also discussed data analysis and the ways in which analysis in ethnographic research begins from the very first moment that data is collected. The second part of the chapter briefly introduced Lake House and then the housemates were introduced through a series of individual portraits which we developed together throughout fieldwork.

The next chapters. The ethnographer searches for patterns in understanding people and culture (Angrosino, 2007) and I did this through full immersion in the field. The nature of ethnographic field work means that in the field I used methods interchangeably thus producing different types of ethnographic material. The following two chapters present the ethnographic findings which take the form of excerpts from the field, my own observations and narration, PhotoVoice, ethnographic conversations, my reflections with excerpts from my field journal and ethnographic writing with rich descriptions, photographs and drawings. My aim in writing ethnographically was not to document every aspect of Lake House nor to offer a definitive account of everyday life. I have used Clifford’s (1986) notion of allegory to provide an interpretation of aspects of life at Lake House, using the full range of ethnographic material gathered in the field. I have used allegory in my ethnographic writing to represent patterns and cultural practices (Clifford, 1986) at Lake House.

Chapter 5: Welcome to Lake House

This chapter presents the ethnographic findings from eighteen months of fieldwork at Lake House. In this chapter, I use a range of ethnographic material to explore everyday life at Lake House. Working collaboratively with the housemates, I explore the physical and material culture of the group home. I then use a temporal point of view to explore the daily routines and activities of the housemates. In this chapter, I show that Lake House is not a homogenous site, rather, it is full of many different experiences and interpretations of home.

WELCOME TO LAKE HOUSE

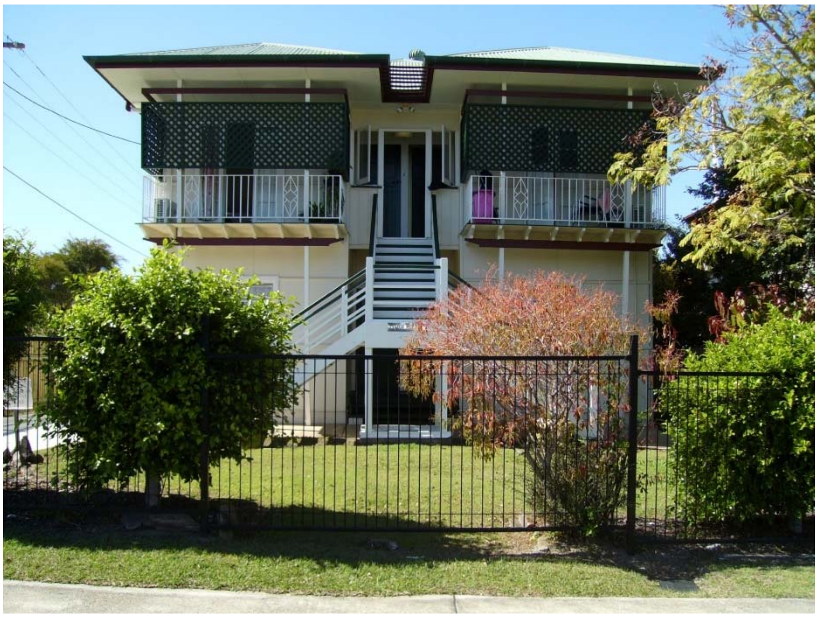

Figure 5. Welcome to Lake House.

Preoccupied with my surroundings, I began to suspect I was lost, despite following the confusing instructions of the GPS, which, at one stage, sent me around in circles. On the passenger seat were various handwritten notes that I'd made to help me locate this group home where I hoped to commence my fieldwork. Driving through the suburban streets, I noticed the double-storey, post war houses in the neighbourhood, icons of this waterside area. Abruptly, I pulled over to the curb to further inspect a home with a cream coloured façade that had caught my eye, Figure 5. With the engine idling, I noticed the neat, orderly presentation of the property, the fibrous sheeting was well maintained, the top exterior chamfer board, offset with a dark burgundy trim, meticulously painted. Two balconies upstairs were adorned with dark green lattice, nailed to the square shaped posts. Looking closely at the front yard, I examined the wooden staircase hidden behind shrubs placed at intervals along the fence line. With a white balustrade, the double-sided staircase was commanding, the dark green steps seemed like delicate waterfalls, flowing off either side of the narrow wooden landing. Crisp and uncluttered, the exterior seemed somewhat sanitised, like the outside of institutional buildings. The unsuppressed use of the dark green paint reminded me of group homes I had seen before, where a bulk purchase of paint had been stretched to maximise value for money. I noticed the dark green paint on the handrails of the staircase and, again, meticulously applied beneath each window at the front of the property in one long, precise stroke. Turning the engine off, I stepped out of my car, standing on the footpath as the hot sun beat down on the back of my neck. Shading my eyes from the glare, I looked intently at this grand, stately building. “Ah yes”, I thought, “This was Lake House.” I had arrived. Welcome to Lake House.

THE BRONZE PLAQUE

Established by a small group of parents, Lake House was a dream envisaged, a hoped-for future for their adult children to ensure they were provided for long after the parents were gone. With few alternatives to institutional living, and ever diminishing government funding and disinterest, parents throughout Australia have a long history as strong advocates, lobbying, fundraising and creating opportunities for their adult children. As parents grew older, like all parents, they worried for the futures of their children, who in all likelihood, would never be able to be completely independent and would require some level of support throughout their lives. As parents contemplated a future for their adult children, a future when they themselves were no longer able to provide the care, they purchased land or designed group homes or established disability service organisations with or without government support. However, over the course of my fieldwork, I asked many people within the Organisation when Lake House was first established. No one knew. Although the exact era was unknown, I estimated that Lake House may have been established in the 1950s or 1960s, at a time in Australian history when there were few services available for people with intellectual disability and their families, other than institutional care.

The bronze plaque at the front of Lake House, so formal looking to me, was testament to the work of these parents who broke new ground, who stepped in when governments were stepping out, stepping sideways or making no progress at all. On many occasions I tried to find out more about the parents who established Lake House, I would have liked to have known their names and their stories. Nevertheless, I imagined their story might be similar to other parents who advocated, fundraised and worked with their local communities to raise awareness of disability and to build acceptance and understanding in an era when intellectual disability was not well understood by the community.

Parents of children with intellectual disability were often the instigators of social and community inclusion, although they may not have thought of their actions in such terms. The dominant medical discourse, the authoritative advice of the time, urged parents to place their children in institutions with parents even paying for the service (Walmsley, 2005). There were few alternatives. In her oral history, Amanda Millear spoke of her own "good fortune" (Henderson & Bigby, 2018, p. 3) in never being placed in an institution, recalling the struggle of her parents who resisted the advice of the medical experts. Instead, Millear went to a special education boarding school and went home on school holidays and some weekends (Henderson & Bigby, 2018, p. 3).

Temby (2005) shares a rich, deeply personal account of her family's struggles and efforts in relation to her son, Rowan, and his moves in and out of institutions. When Rowan was born, Temby and her husband were told to relinquish him to the care of the institution and to never visit him again, Temby (2005) writes, "…(a)t first we obeyed their instructions but then I started visiting him with his brothers and sisters. Institutionalization was what happened to most people with intellectual disabilities." (p. 137). Temby (2005) paints a picture of the struggle to find different options for Rowan, from institutional living to returning to family to choosing to live in a Steiner community. Temby (2005) recounts the struggle she and her family endured:

> *Two years of advocacy and endless repetitions in many varied ways to numerous recipients within the government bureaucracy finally achieved a move for Rowan with his two friends into a suburban home. From his bedroom window he looks down a front lawn to the street, and clothes dry on a line in the backyard. The*

> *three staff who alternate in overnight stays are all of the same mind about personal dignity and importance. (p, 144).*

As I stood at the front of the property, looking at the bronze plaque with its coating of dust dimming the shine it might once have possessed, I thought about the history, the hard work, the passion and dedication behind the plaque. I wondered when the plaque had been fixed to the wooden beam, and by whom, and I imagined a small group of people standing around the front yard of this property, the sum of their hard work, a house in the community surrounded by neighbours' houses and just around the corner from the waterfront. I imagined this small group of people watching as the plaque was secured, with their hopes and dreams for the future laid at the feet of this stately, double-storey, weatherboard house which, over time, they hoped would become a home for their adult children.

In a somewhat jolting way, my reverie and romanticised imaginings of the history of this house, Lake House, was quickly brought down to earth as I examined the building further. In contrast to my sentimentality, there also seemed to be something familiar about Lake House, something immediately distinguishable about the neat, uniform façade. To my trained and experienced eye, there was a familiar 'group home look' about this space. The trim, well maintained lawns were green despite the hot sun and dusty conditions of the season, the concrete paths swept clean.

The first time I saw Lake House, I had noticed that attempts had been made to personalise the front yard, such as the two large pot plants placed at the bottom of the double-sided wooden staircase. Precisely placed atop a concrete square, each pot was the exact same distance from the concrete landing pad at the end of each staircase. Adding formality to the property, the heedful placing of the pots was an aesthetic juxtaposition; in an effort to personalise the space a distinct air of stiffness and precision had been created. Everything seemed definitively organised. Contributing to my sense that this home was imperial, and imposing, was the presence of the bronze plate, secured to the old wooden staircase, visible from the street. In a beautiful, classic font etched into the brass, the plaque announced, "Lake House."

REPORT TO THE OFFICE

On my first day of fieldwork, as I walked down the concrete driveway at the side of the property, scorching hot from the heat of the day, I paused to examine a sign in the front yard, Figure 6 that had surprised me. Smallish in size yet prominently displayed at the front of the property, the sign was nailed to an old wooden stake with its weather-worn instructions, written in faded black stencilling, 'All visitors report to the office at rear of house. Please'

Clearly visible from the street, the sign was tattered, two rusty nails securing the officious weather worn writing, the 'please' tacked on at the end of the sentence almost as an afterthought of politeness. The very construction of the sign epitomised efficient industry, with its gathering of small rocks placed at the base of the smooth, unvarnished wooden stake, pooling in neat formation to prevent the sign from falling over in the windy weather typical of the waterside location.

Figure 6. The sign at the front of Lake House.

Placed at the entrance to the property, the sign acted as a threshold, an invisible boom gate. Customarily, the threshold, the physical entrance to a home is crossed when entering or leaving the home. Controlling the space between inside and outside, the threshold reinforces the boundary that establishes home as a private place rather than a public space (Garvey, 2005; Dowling & Mee, 2007). The ability to control the boundaries of one's abode has been identified as an important element of home (Somerville, 1992) with the threshold being both a physical barrier and an important psychological element of home (O'Brien, 1994). Standing, looking at the sign, I wondered who controlled the threshold at Lake House and I wondered who the people were who passed by this sign each day to enter Lake House. What might life be like lived behind this sign? What was the inner world, the private space of home like at Lake House? Touching the edge of this clumsy, bureaucratic sign, I walked past it, crossing the threshold and, obeying the faded black, weather worn stencilled instructions, I reported to the office at the rear of the house.

In the next section, I use a temporal point of view with a range of ethnographic material to explore the rhythms and routines of everyday life at Lake House. The devolution of institutions led to an era of unprecedented reform that has slowly unfolded across some three decades at the time of writing this thesis. As discussed in my literature review, deinstitutionalisation emphasised the opportunities for people with intellectual disability to experience the "patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society" (Nirje, 1969, p. 181). Shifting away from segregated models of housing and support, group homes were established as ordinary homes, in ordinary streets. Within these smaller residences, people with intellectual disability have the opportunity to move through the normal rhythms of everyday life such as going to work, living in the community, developing independent living skills, having relationships and being included within their communities. But what is the lived experience of people with intellectual disability who live in group homes? In the next section, I have used an ethnographic voice to illustrate everyday life at Lake House. Significantly, everyday life was vibrant and different and heterogeneous with a multitude of individual moments of meaning. In the next section, I blend and weave outsider and insider perspectives. I begin by considering the ways in which ideologies of deinstitutionalisation are contrasted with everyday life at Lake House.

BUSY MORNINGS

Weekday mornings at Lake House are hectic, as the housemates and the supervisors begin their day. A time of bustle and activity, the patterns of these mornings are predictable and consistent, unfolding in much the same way each day. Walking down the driveway, arriving early one morning, I heard crockery being stacked and the loud, clanging noise that cutlery makes as it falls into a deep wooden draw. Other sounds seemed rushed; a cupboard slamming, chairs scraping across the lino[27]. I rapped on the back door, waiting to be invited inside, peeking through the rear window with its faded lace curtain. Catching glimpses of the housemates rushing around inside, squeezing past each other in the small, compact kitchen, I could see them moving in familiar patterns, moving almost on auto pilot as is the habit of people who know each other well.

"Come on in, Lisa!" Andrew invited, hearing my knock on the door. Entering the kitchen, I thought, "It looks smaller this morning", as the housemates filled the space with their activities; getting plates out for breakfast, buttering toast, retrieving items from the refrigerator, packing lunches. Standing awkwardly in the hallway, not quite in the kitchen, not quite outside it, but on the edge, I was trying not to get in the way. This seemed like a metaphor for my fieldwork where I was not quite an insider, not quite an outsider but perhaps somewhere on the edge of it all. Bucerius (2013) refers to this as becoming a "trusted outsider" (p. 692). Bella stooped, retrieving a plate from the cupboard, selecting the first off-white plate from a neatly stacked pile. Meanwhile, Andrew ran a comb through his troublesome hair, slipping the comb into the back pocket of his neatly ironed work pants. The collar of his fluorescent yellow work shirt was damp, dark patches against the brightness, remnants from an earlier shower, which Andrew preferred in the morning. Catching my eye, Bella smiled, making sure I was watching her carefully wrap her sandwich, the same ham and cheese sandwich she made every day, with the crusts kept on and cut into two neat rectangles just as her mother used to do.

Suddenly, loudly, the supervisor appeared, vociferously issuing instructions well before he had even opened the back door and stepped inside. This prompted Bella and Andrew to abandon their tasks and immediately take a chair at the table.

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[27] Lino is Australian slang for linoleum, a type of floor covering that is easy to wash.

Proceeding to hand out the morning medications, the supervisor was oblivious to my presence, absorbed in his tasks, a familiar part of the morning routine. Checking the paper record he held in his hand while juggling the large plastic dosette boxes, the supervisor put the papers down on the table. Asking Bella her name, and then Andrew, the supervisor dispensed the round and oval multi-coloured pills. Prepared, Andrew had brought his orange juice to the table, ready to swallow his tablets, the large purple pill he took required several sips to get down. With the morning medication dispensed, Bella and Andrew jumped up from the table and continued their routine, returning to their tasks, while the supervisor went upstairs to continue the medication regime.

Standing awkwardly on the edge of the kitchen, I wondered what I should do? Bella was rinsing some dishes at the sink and I asked if I could give her a hand. "Sure" she said, smiling, reaching over to grab the worn, red and white checked tea towel with a hole in one corner. "Catch" she laughed as she threw it at me. Bella rinsed, and I dried, forming a rhythm, familiarity building between us, creating our own synchronicity. As I opened the cupboard to put the glasses and dishes away, Bella tapped my arm, "Wait." she instructed. "I'll help you." Bella took the clear water glass which I had just dried and placed it precisely at the front of the neat row of glasses inside the cupboard. Next, using a serious of gestures, Bella showed me how to stack the plates, the small bread and butter plates in a neat stack and the larger, dinner plates forming their own tower next to the bowls which sat perfectly nested inside one another. Our task complete, Bella said, "Good job!" reaching over to give me a high five as we laughed. In the morning, I sensed a confidence about Bella, observing an assuredness in her movements, as she seamlessly moved from one task to the next, a flow to her routine that held no hesitation. Where I may have found the monotony of the routine tiresome, Bella's long-established routine was satisfying, providing a sense of comfort to her, as she completed her tasks with pride and competence.

Unzipping his backpack, Andrew set about packing his lunch, finding a spot for his sandwich, before zipping the pack securely. Pausing, he seemed to reconsider, opening the backpack again. Moving towards the hallway table, where the house phone sat atop the thick, yellow phone directory, Andrew grabbed a handful of tissues from the tissue box and said, "Just in case." He pushed the tissues into his backpack. Looking up to check the wall clock, Bella turned to Andrew and said, "Let's go." With a farewell to me, they walked out the back door, heading to the front of the property where for so many years now the white bus came to take them to the sheltered workshop.

Upstairs, Maggie and Rose shared a similar routine as they prepared for their day, their mornings filled with convivial conversations. Always well dressed and neatly presented, Maggie encouraged Rose to assume the same standard, fussing over a tucked in collar or straightening a skirt. Rose, amenable to these adjustments, stood still, smiling, as Maggie fussed over her. Oftentimes, Rose consulted Maggie about her attire, "Does a yellow shirt look better with this white skirt or should I choose a pink shirt instead?" This companionable banter goes back and forth all morning, until it is time for Maggie to leave and catch her bus to work. Attending a local 'Living and Learning' (L&L)[28] program, specifically for people with intellectual disability, Rose had a more leisurely pace to her morning and more variety in her weekly timetable than some of the other housemates.

Predictable and steadfast, the morning routine was a regular pattern of tasks and activities, always rushed, with the supervisor on duty running between upstairs and downstairs. Anticipating each step before it occurred, the housemates developed a rhythm of the day with few deviations. Upstairs, Rose and Maggie got themselves ready for work in much the same way as Bella and Andrew did downstairs. Chloe and Josh, however, approached their days differently; two disruptions to the well-practiced dance.

Chloe's Morning Routine. An early starter, Chloe begins her day at 5.30am, rising, making her bed and walking out the door to commence her two-hour commute to work. During my fieldwork, I was not able to directly observe Chloe's morning routine for two reasons. Firstly, Chloe's start time was earlier than the commencement of the supervisors' shift. When I raised the possibility of observing Chloe's morning routine I was met with a categorical 'not possible'. My official role at Lake House was recorded as a volunteer and there were fears of negligence and liability should I

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[28] L&L is a living and learning program which Rose undertakes each week with a local disability service provider. The L&L program supports a small number of people with intellectual disability to access activities in the community, to develop independent living skills and offers a range of art and craft programs.

fall or injure myself at this early hour. The Co-ordinator told me it would be a breach of duty of care to permit me to start so early.

Secondly, Chloe did not want me present for her morning routine. Preferring to be alone in the mornings, Chloe liked to go through this quiet moment of the day in peace, at her own pace. Instead, Chloe was happy to tell me about her morning routine to give me a sense of how she started her day. Using very few words to communicate, Chloe could not tell me directly about her morning routine, so we worked together over several weeks to build a picture together, exploring her rituals and routines.

Time consuming and challenging at times, frustrating for each of us as we sometimes couldn't understand exactly what the other was saying, we nevertheless developed ways to talk and listen with each other. Despite the challenges, or perhaps because of these, we enjoyed working together, persisting, wanting to understand one another, with a rapport building between us that strengthened over time. For me, working with Chloe on her morning routine provided an opportunity to get to know her better. The time we informally allocated to work together at Lake House was interpreted by the other housemates as 'work time' and we were largely uninterrupted, a significant benefit as Chloe was often elusive when others were present. For Chloe, having the opportunity to communicate about the minutiae of her day was a rare occurrence and one she seemed to enjoy.

Figure 7. Chloe's bedroom at Lake House.

Often, the best way we had to communicate with each other was through demonstration and modelling. Chloe enacted a 'pretend morning', demonstrating how she made her bed, modelling the way she smoothed the wrinkled quilt. I would provide a running commentary and we often laughed together when I said, "Oh, I get it now, Chloe! Yes, I can see exactly what you mean." Using photographs also helped our communication. For example, Figure 7, was a useful prompt for our conversation where Chloe pointed to the doona cover or the blanket at the end of the bed and I was able to see exactly what Chloe had been trying to tell me. Afterwards, I went away to write the excerpts returning on my next visit to read them aloud to Chloe. She would nod or shake her head if my writing was not correct until we constructed an accurate version. Over time, we developed Chloe's morning routine which we called 'Up Early.' The following excerpt is our collaboration, with Chloe's ideas flowing into my written words.

> **Up early**
>
> I start my day before anyone else. When I get up the house is quiet, and everyone is still asleep. My alarm, which sits beside my bed, is set for 5.30am but I don't really need the alarm, I get up on time every day. I'm never late. I get dressed and make my bed. My doona cover must be perfect, smooth, no wrinkles and my soft black blanket must be folded neatly, in thirds, to lie at the foot of the bed. Every day I tap the blanket twice as I leave the room. The blanket and doona cover are gifts from my sister and I love them. They are special to me.
>
> I take my backpack to the kitchen and have a glass of water. I always rinse and dry the glass and put it away in its proper place. I never leave a mess. I am quiet, so I don't wake anyone up. Sometimes I take a sandwich to work, which I make the night before, wrapped tightly in cling wrap, and placed in the fridge. Sometimes I forget and leave the sandwich sitting in the fridge. I will eat it when I get home.
>
> I have a new travel card and I am worried about leaving it behind. I did that once and got a fine. A huge fine. I don't want to get a fine again. I double check my wallet to make sure I have my travel card. Sometimes I forget to 'swipe on' or to 'swipe off' and I got another fine for this. Another big one.

> My travel card worries me. I walk to the bus stop. I wait for the bus. I get the bus to the train station and catch two trains to work. It takes a while to get to work but I don't mind. I love my job. I like to get up early.
>
> ~ Chloe (with Lisa's writing)

"I like to ease into the morning, I like to slide into the day.": Josh's Morning Routine. A self-described, laid-back guy Josh prefers a later start in the morning. Waiting until the other housemates depart for work, Josh would wander into the kitchen to make himself a cup of coffee or, sometimes, he'd drink a can of Pepsi. Described by the supervisors' as "contraband", soft drink was highly sought after by the housemates, a treated enjoyed by all but prohibited by the supervisors due to health concerns and weight regulation. Maximising the peace and quiet of the morning, Josh liked to enjoy a can of Pepsi without interference from the supervisors or his housemates. Watching me, Josh said, "I know you won't dob, Lisa."

Rarely eating at this time of the day Josh told me, "I don't do breakfast." "You don't get hungry in the morning?" I inquired. "Nah. I never have done. I've never been a morning person. I might get something at smoko[29]." Relaxed, his demeanour calm, Josh took a leisurely approach to the morning. Taking advantage of the predictable rhythm of the day Josh had had carved out space in the day to enjoy the peaceful ambience of Lake House which was so fleeting and rare. Relishing the moment, Josh stretched his hands back behind his head, turning his face to the sun, as he contemplated the day ahead. "Ah yes, mate", he told me, "This is the life."

GOING TO WORK

An important part of the daily routine for the housemates was going to work. With the exception of Josh, all the housemates have a daily timetable of work or day programme activities. Andrew and Bella attended the sheltered workshop and wore a uniform, a high vis[30] shirt, track pants or jeans, and closed in shoes. Spending their

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[29] Australian slang for morning tea. Josh will sometimes eat toast or a sandwich for morning tea which is around 10.30am.

[30] A high vis shirt is Australian slang for a highly visible shirt. Andrew and Bella's shirts have fluorescent yellow across the shoulders. High vis shirts are used in some workplaces as part of health

work days collecting and sorting clothing donations from charity bins in the local neighbourhood, Andrew and Bella have attended the disability enterprise, which they call the sheltered workshop, for many years. Recently, Bella celebrated over 30 years of service. Enjoying her work immensely Bella said, "I got my jobs to do. I do a good job. I got friends at work. I got my uniform!"

Going to work was a ritual of preparation, an important part of the day but preparations were ongoing throughout the week. Each morning, Bella inspected her work shirts, her uniform, ensuring they were clean and properly ironed. Each Saturday morning, Bella laundered and ironed her five identical work shirts, taking care with each item. Looking polished and professional was important to Bella, who took pride in her uniform. Bella explained:

> I wear my uniform. It says here, (pointing the logo on her shirt) that I'm part of the company. I want to look my best cos I'm part of the company.

Bella's pride was evident, as she talked about the company and her sense of belonging. Bella was highly motivated to go to work each day and rarely missed a day in her 30 years of service. Andrew, too, looked forward to going to work each day, where he was ever hopeful of going out on the truck;

> Today I'm going out on the truck. It's the best. Some days it gets boring at the workshop, just hanging around, nothing to do. I like to be busy, don't like getting bored. Mum says I get ants in my pants! (chuckles) Going out on the truck is great. I sit in the front, next to the driver and sometimes help with directions. I know where we're going. Sometimes we wind the window down, me and the supervisor, and we just sit and chat while we're waiting for them to unlock the (charity) bin. [Supervisor] introduced me to AFL footy, I never knew much about it before, cos it comes from down south. But [supervisor's name] told me all about it. [Supervisor] barracks for Hawthorn so I do too and now I listen to the Saturday arvo games on the radio and we talk about the match on Monday.

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and safety regulations. The high vis shirts are part of the required uniform at Andrew and Bella's workshop.

Also working in a sheltered workshop for many years, Maggie enjoyed her work, which she described as sorting through materials from the charity bin donations. On other days she worked in the Op Shop[31] selling clothes and homewares. The Op Shop was an employment arm of the same Organisation which owned and operated Lake House. Maggie loved her retail role, especially speaking to customers who would often seek her expertise. Maggie answered customer questions, showed them new stock and collected money paid for goods. Being front of house was Maggie's favourite part of her job and she enjoyed her work immensely. Maggie had worked for the company for over 20 years and she had many long-time friends whom she met through work. Apart from having a little more variety I her day, Maggie said there was nothing else she would rather do.

With a weekly timetable of activities, Rose attended L&L four days per week. At the beginning of each term, Rose chose the activities for her timetable, making her choices based on cost. Preferring creative pursuits, such as painting and drawing, Rose's favourite activity was photography, as she explained;

> Wednesday's, I do photography. I got asked if I wanted to do something different on Wednesday's, to try something new, but there's no way. I love photography and I love [photography teacher]. Wednesday's are my 'never miss' days – come rain, hail or sunshine!

Looking forward to L&L each day, Rose enjoyed seeing her friends, some of whom she had known for many years. The only downside to L&L, Rose reflected, was the absence of a pay check. Instead, Rose paid a fee each term for the activities, some of which, such as photography were expensive and incurred additional fees and charges because of materials and production costs. At times, Rose could only afford to attend three days per week and she discussed her options each term with the supervisors. Together, they worked out how much Rose could afford to spend.

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[31] An Op Shop is Australian slang for Opportunity Shop, a charity shop which sells donated clothing and homewares. Often located in shopping centre car parks, charity bins are scattered around the neighbourhood as repositories for donations. The charity bins are emptied by the company and taken to the sheltered workshop where the employees sort the items. Good quality items are sent to the Op Shop, where Maggie works, and are sold to the public.

COMING HOME FROM WORK

My fieldwork at Lake House began to take a familiar ebb and flow of time, with periods of hectic activity in the mornings interspersed with quieter periods through the day when the housemates were out at work. Josh shaped his own days around the familiar ebb and flow, avoiding the morning rush and then basking in the quiet solitude. Josh enjoyed pondering, not hurrying, taking his time to plan his day. These moments of solitude were precious to Josh, the absence of noise and instructions soothed him. “I can hear myself think” he told me, shaking his head while grinning. Early in the afternoon Josh prepared for the other housemates to begin returning home from work. The following ethnographic piece illustrates how Josh liked to spend the afternoon and shows the ebb and flow of the daily routine at Lake House. Josh and I wrote the first part of this piece together, which he called “Chillaxing”, his term for the perfect combination of chilling out and relaxing.

“Chillaxing”

Checking over his shoulder, Josh looks at the silver and white clock in the kitchen and makes his way towards the yellowing, worn couch in the downstairs living room. Straightening the blue towel that sits atop the couch, Josh eases himself down with a sigh, taking his time to stretch and crack his knuckles. It is just past 2.30pm, and I join Josh in the lounge room, sitting in one of the single chairs, although Josh offers me a bean bag if I would like to chill out. The backdoor opens and Rose arrives home, having finished her L&L program for the day, she dumps her backpack and stretches. “Good day?” Josh asks. Rose nods, smiling and shares an anecdote with Josh and I, causing us to laugh, Josh chuckling in his characteristic way. Checking the clock, Rose says “I’m starving. Should I make something to eat or wait for Maggie?” Josh shrugs and Rose says she’ll wait. “I’m gonna take this upstairs” she tells us and bends down to retrieve her pink and black backpack, groaning as she slings it over one shoulder. “I’m getting old, Josh, this thing gets heavier every day.” Josh chuckles and says there is nothing wrong with getting old, it’s better than the alternative.

I rise and follow Rose, the backdoor slamming behind us as we trod upstairs. Once inside, Rose unpacks her backpack, unloading a bright pink lunchbox onto the wooden dining table. Fishing inside the backpack, Rose brings out a half-eaten apple, looks at me and puts her one finger over her lips, a sign that I shouldn’t say anything and keep quiet about the apple. Rose throws the brown core into the bin, adding a crumpled piece of cling wrap from her sandwich, before rinsing the lunchbox and leaving it on the sink to drain. Taking her backpack into her room, Rose unpacks her pencil case and some library books. Throwing the books onto her neatly made bed, with the bright floral doona cover, we sit down together, and she tells me about the books and her outing to the local library with her group today. Later, Rose opens her wardrobe and checks the inside of the door, where her weekly timetable is neatly displayed, printed and laminated and stuck to the door with globs of blue tac. Checking her schedule for tomorrow, Rose tells me it's bowling, and she shares a humorous anecdote about her bowling team and we both burst into laughter. Then, Rose sorts through her large collection of colouring books, showing me the animals, fairy princesses and one, she says, is "for boys" with its pictures of trucks and earth moving equipment.

Wrinkling her nose, Rose shakes her head and places the book with the red fire engine on the front cover at the bottom of the pile of colouring books, retrieving her pencil case, stuffed full of coloured pencils and a pencil sharpener or two. Her arms full, Rose takes her books and supplies to the outdoor table on the balcony where we sit together awaiting Maggie's return home.

A favourite part of Rose's day was coming home from L&L. When Rose used to live on her own, this time of day was when she felt the loneliest. At Lake House, though, she said she always had someone to talk to, someone to share her day with. While she waited for the others to return home, Maggie in particular, Rose typically sat the table on the upstairs balcony, surrounding herself with her drawing book, a cup of tea, digital camera and her lanyard with keys to her bedroom, as shown in Figure 8. An avid photographer, Rose began using camera again as part of our PhotoVoice work. Just as Josh enjoyed his daily ritual, Rose, too, enjoyed the predictability and constancy of her routine which offered her a sense of safety and security that she had once been so elusive.

Figure 8. Rose relaxes after day placement.

Downstairs, at 3.30pm, Andrew and Bella returned home from the sheltered workshop. As Bella came in the backdoor she yelled out, “Hi, honey, I’m home!” before she could even see Josh on the couch. Bella trusted that he would be there, and he was, as he called out, “Hey beautiful!” from the couch. Sprawled, his toes hanging over the edge of the sofa’s arm, Josh was in his favourite position for “chillaxing”. “How was your day?” he yelled out to Bella. Pausing just inside the back door, Bella unzipped her backpack, taking out her lunch box, setting it aside on the sink. With a huge smile, Bella walked over to Josh and leant down to give him a kiss, “Good” she said, returning to the kitchen to collect her backpack. Hauling it over her shoulder, Bella walked down the hallway to her bedroom to change out of her work clothes.

Also walking down the hallway was Andrew, who threw his backpack on his bed. Standing up, Andrew counted out the change in his pocket, loose coins which he squirreled away in his work pants. Stacking the coins neatly, in small towers on his bedside table, Andrew turned his attention to the washing basket in the corner of his bedroom. The pile has grown larger overnight, seemingly mysteriously, and he will add more to the pile this evening after his show. The washing grows ever larger until Saturday which is officially washing day.

‘Chillaxing’ has shown the predictable, everyday rhythm of the day at Lake House and the different ways in which the housemates used the space, going about their afternoon activities. This time of the day was sometimes referred to by the supervisors as ‘free time’, a pause in between the busy activities of the day. After Andrew and Bella returned home from their workshop, approximately 3.30pm, Maggie arrived home, and then, much later, Chloe returned home. After ‘chillaxing’, the busy-ness recommenced with a flurry of activity for mealtime preparations. The rhythms of the day at Lake House were predictable and monotonous, with little variation, day after day, week after week, month after month.

To me, there was something artificial in the rhythm of the day. As adults, the housemates returned home at 3.30pm in the afternoon, a pattern of the day more akin to the time school children return home rather than working adults. The work Andrew, Bella, Maggie and Chloe engaged in was also somewhat artificial. Although they went to work each day, arriving promptly, they were not paid award wages. Instead, each week they received a small reimbursement despite their many hours of labour. For Rose, her timetable of L&L activities appeared to offer her a choice of activities, but these activities were undertaken with other people with intellectual disability. Thus, they were somewhat segregated from the community. While giving the illusion of social inclusion, most of the activities which Rose undertook were in the company of other people with intellectual disability. The segregated, programmatic nature of the activities suggested an illusion of social inclusion. Is this what Nirje (1969) envisaged in his principle of normalisation?

The ethnographic piece, ‘chillaxing’ has provided insight into the astucious rhythm of the day for the housemates of Lake House. The piece has also illustrated how some of these rhythms are different than those for people without intellectual disability. Further, the piece has illustrated that within this artificial reproduction of the normal rhythms of everyday life, the housemates worked together to construct meanings of home. Their banter was genuine. There was a sense of comfort, security and relaxation. Lake House become a place of meaning, not because of the reproduced normalcy of the routines but because of the sense of belonging, the social and emotional elements of home, the laughter and shared experiences. These meanings were produced by the housemates. Here, in ‘chillaxing’, it was not the services provided by the group home that constructed home. Instead, it was the genuine connections and relationships between the housemates that forged home.

DINNERTIME

Preparations for the evening meal commence from 5pm onwards, with allocated tasks prescribed by the chores roster. Typed on A4 paper, the chores roster was kept inside a tattered, worn plastic sleeve, stuck to the front of the refrigerator in each household. Allocating tasks such as setting the table, cooking and washing up to each housemate on a rotational basis, the chores roster formed the locus of control for the dinnertime routine. The following ethnographic piece, 'Spaghetti bolognaise' illustrates the way in which the evening unfolds at Lake House.

Spaghetti bolognaise

According to the chores roster, Andrew's designated day for cooking the evening meal is Wednesday. We are standing in the kitchen, in that awkward space of time before dinner preparations commence, where the housemates and I are 'hanging around'. Characterised by waiting, this time of the day also has a relaxed feel about it, unstructured, and the housemates are chatting, convivial and relaxed and anticipating a nice meal. As the clock ticks closer to dinnertime, however, there is a distinct change in the air. It is not yet time to start dinner but there is not enough time to start another activity. The housemates appear on edge and the relaxed, casualness of the free time we enjoyed just moments ago is replaced with a sense of anxiety and anticipation and there is tension in the air.

Josh appears antsy as he opens the fridge, ponders its contents, closes the door and then moves to the pantry which also fails to produce anything to satisfy him. Shrugging, he returns to the fridge and begins his search anew. Bella is sitting at the dining table, waiting, chatting to Josh intermittently, asking what he is doing and what is he looking for? Andrew is leaning against the sink, ready for action yet not prepared to commence the requisite tasks of cooking dinner until the supervisor arrives. I, too, am leaning against the sink and find myself fidgeting, I feel like I should be doing something. This time of waiting appears to have made the housemates agitated; Josh is pacing, Bella is chattering, Andrew is shifting from one foot to the other. I also feel agitated, find myself feeling tense, on alert, waiting for the cue to permit me to spring into some sort of action (although I am not sure what form this would take).

Bursting through the back door, the supervisor arrives in a flurry of movement that startles us all. Bella springs up from the dining table, Andrew immediately straightens his posture, correcting his slouch, and Josh exclaims, “Finally! I’m starving!” The supervisor hustles past me, clearly, I am in the way, and I manoeuvre myself to stand by the fridge, somewhat out of the way but perhaps an even worse choice. The supervisor fires directions at Andrew, instructing him to get out the large pot with the lid and to fill it with water and salt, adding “but not too much or it will be too salty”. “Yes, I’ll be careful” he replies and while he retrieves the cooking pot, I squeeze past Bella, who is setting the table, and obtain the salt from the pantry. Handing it to Andrew, he gives a quick, “thanks” but the supervisor catches me and says, “Oh, no, we don’t use that salt. We use the one on the table. Don’t we Andrew?” Andrew nods but doesn’t meet my eyes and hands the salt back to me. He then retrieves the small, plastic salt and pepper shakers that are kept in the basket in the middle of the dining table. I return the salt to the pantry and feel like I’ve been reprimanded. Moving back to my ‘spot’ on the outer of the kitchen, I am, once again, out of the way. I would like to help further but fear being a nuisance. I wondered why it mattered which salt was used. Nonetheless, I feel as if I’ve made a mistake using the wrong salt and am reluctant to help further in case I make another inadvertent error.

Andrew fills the pot with water, turning the tap to lower the pressure as the water begins to rise. I observe Andrew’s competence in this task, he anticipates what comes next very well. The supervisor shouts another instruction. The supervisor is loud. Very loud. The jarring voice shocks my ears as the supervisor, forcefully, shoots out a string of rapid-fire instructions. Moving quickly, responsively, with a sense of urgency, Andrew opens the packet of spaghetti, putting the torn plastic top in the bin. The supervisor shouts at him “did you put that in the recycling bin Andrew?” “No, no” he answers, “I put it in the right bin.” The supervisor nods and Andrew waits in front of the stove, watching the pot of boiling water.

Meanwhile, Bella is setting the table in her usual careful and methodical way. Setting the table is her designated task as per the chores roster. I admire the way she lines up each fork to be exactly three-quarters of the height of the black placemat. She repeats this for each place setting and I ask her if there is anything I can do to help.

She pauses and then asks me to retrieve four water glasses. She pauses, thinking, and then says, “No, we will need five tonight, Lisa, cos you’ll be here with us.”

Opening the cupboard door, I notice how orderly the contents are. The dinner plates are neatly stacked one on top of the other, the bread and butter plates are similarly arranged, bowls are nestled inside one another and the water glasses are lined up in neat rows that begin at the edge of the shelf and follow, orderly, all the way to the dark recesses at the back of the cupboard. Taking out two glasses, I place them on top of the bench and then, stooping, retrieve three more. I take them to the table and place one glass at the top of each placemat. Bella thanks me and then moves each glass so that it is over the right-hand corner of the placemat. There are only four placements, a fifth one does not exist, so Bella sets a place for me, leaving a space in the middle of the cutlery the same size as the other placemats. She readjusts the glass I placed. Once our work is complete, Bella stands back to admire the table setting and I say, “looks good!” She nods and smiles and reaches over to dust away a speck on the tables’ edge. Her set task now complete, she looks over at Andrew, who has tipped up the packet of spaghetti and is stirring the pot as the stiff pasta strands fall into the boiling water.

Unexpectedly, the supervisor shouts out “Andrew! Did you wash your hands before starting cooking?” Andrew jumps, his body taut and he realises his mistake. “No, no, sorry, sorry, I forgot.” He leaves his station at the stove and goes to the sink immediately, pressing down twice on the dispenser of hand soap. Rubbing the mixture between his palms it foams, and he moves the foam around his hands, so they are saturated. “Andrew, you know you have to wash your hands before starting dinner, mate.” Andrew nods, now putting his hands under the tap with its running stream of water. “Yeah, I know, sorry.” I watch as his shoulders sag, a physical response to the supervisor’s criticism. The supervisor turns to me and says, “You’ve gotta watch them all the time,” a wry smile and small shake of the head, “yep, you’ve gotta watch them like a hawk.” I do not respond but I know that Andrew can hear this conversation and I wonder how it makes him feel.

By this time, Josh is lounging back in the dining room chair, ostensibly in the way of all the activity which is occurring around him. His arms are stretched behind his head as he casually surveys the mealtime preparations. Every now and then he chips into the conversation, adding some anecdotes from his day or an observation. In the bustle of the kitchen, his comments are largely ignored, both by the housemates and the supervisor. I clearly hear his comments and, naturally, want to respond but remain quiet so I can observe the interactions without interrupting or diverting their natural course. Josh seems unfazed by the unresponsiveness of his companions, and my own lack of response, and he prattles on regardless, as Bella and Andrew work around him to the sounds of the supervisors' unrelenting instructions.

As the water boils with the spaghetti, Andrew turns his attention to the large, deep fry pan he has positioned on the front burner of the stove. Reaching to the left of the counter, he retrieves the olive oil and pours two measures into the pan. The supervisor, who has been cutting onions on the chopping board next to the stove, passes the board to Andrew who scrapes the onion pieces into the pan. Using a wooden spoon, he gently moves the onion backwards and forwards as it browns. It appears to me, as I watch his movements, that he has done this task many times before. It seems routine, he anticipates the next step in the task and moves the onion to one side of the pan as the supervisor opens the tray of mincemeat, tipping it into the pan. "Now" the supervisor instructs "make sure you get all the lumps out of that." Andrew nods and begins breaking down the mince, using the back of the wooden spoon until there is an even texture. Checking, the supervisor praises Andrew, "good" and then reaches over and pours two jars of passata to the meat mixture. There is an aroma of cooking meat in the air that has now settled in the kitchen. I find it nauseating, difficult to breathe, a response arising from my own aversion to meat, but Josh has a different reaction. "Mmm, that smells good mate!"

"Add some salt and pepper to that, Andrew," the supervisor instructs. He does so, retrieving the small, plastic salt and pepper shakers from the basket in the middle of the dining table. A few shakes of each and he returns them to their correct spot. Andrew moves to the sink, seeking the cutlery draw, and retrieves a teaspoon. Returning to the stove he dips the spoon into the tomato mixture and tastes, considers, then places the spoon in the sink. Reaching back to the basket on the table, he retrieves the salt shaker and adds a couple more shakes to the pan. The supervisor has rinsed the chopping board used for the onions and stood it upright in the sink to drain. The large, cook's knife used for the chopping has also been rinsed and as the supervisor lays it on the draining board instructions are issued, "This knife is very sharp. I don't want anyone touching this ok?" Andrew nods, Bella replies yes, and Josh says, "I bet it's not as sharp as the knife at my Mum's place. She's got a real beauty, it's huge." Josh pauses to demonstrate a rather exaggerated size, "And I use it all the time. She trusts me." The supervisor ignores Josh's anecdote and hovers over Andrew's shoulder as he stirs the tomato mixture. "That needs some herbs now I reckon." Andrew leans over to the pantry door and selects some dried herbs which are neatly lined up on the third shelf. Scattering the herbs into the pan, he replaces the herb containers, taking some extra time to ensure they are returned to their line in the row of herbs in the pantry.

As the tomato pan simmers, it begins spitting drops of tomato onto the white stove top. Noticing this, Andrew adjusts the burner temperature. This is a good demonstration of his skill in cooking this meal, I note, he has observed and adjusted as required. Reaching over to take the lid off the large pot of pasta, he nods and asks the supervisor "Do you think this is ready now? It looks ready to me?" The supervisor checks and says, "Yes, it's ready. Turn the burner off and drain it in the sink. But be careful!" Andrew turns the burner off, but the supervisor intervenes, "Actually. You'd better let me do that," and takes over the task, bringing the large pot of water to the sink. "Andrew, grab me the strainer, will you?" The supervisor has blocked his path, standing between Andrew, who has remained at the stove, and the cupboard where the strainer is kept. Andrew walks back around the dining table and accesses the cupboard, "Hurry up Andrew, this is heavy!" the supervisor says. Andrew retrieves the strainer and places it in the sink as the supervisor pours the hot water and pasta, returning the pot to the stove once it is empty. Andrew reaches into the sink and lifts the strainer up, shaking it, to ensure the pasta is drained. The supervisor returns to the sink and Andrew puts the strainer back down. The supervisor picks up the strainer and shakes it, replicating Andrew's exact movements just moments before.

At this stage, Bella has gathered the bowls for the pasta and hands them to me and, in turn, I hand them to Andrew. He holds the bowls steady as the supervisor serves the pasta. The supervisor then takes each bowl, one by one, to the stove and scoops on top the bolognaise mixture, handing the full bowls to Andrew who places them on the table. Meanwhile, Bella asks Josh to move as he is blocking the fridge door, he scoots his chair in further and Bella slips behind him to retrieve the packet of parmesan cheese from the fridge. Placing the packet on the table, Bella takes her seat and Andrew joins her at the table. Josh has begun eating, "I'm so starving," he says.

The supervisor lets out a large sigh, as we both lean against the sink, watching the housemates eat their dinner. “Well, that’s that job done. I’d better get upstairs and see what’s happening up there.”

The housemates say muffled goodbyes, in between bites of pasta, and I am left wondering if I should sit down and join them or follow the supervisor upstairs. But where would I sit? All the seats are occupied. Noticing me just standing there, Andrew silently gets up and goes to his room, bringing out a solid box and placing it at the end of the table. He gathers up his pasta bowl and places it at the end of the table and motions for me to take a seat, in his place. Bella grabs more cutlery for me and passes them along. The housemates are silent, eating their pasta with gusto, and I join them at the table.

Illustrating the rigidity of routines at Lake House, ‘Spaghetti bolognaise’, shows how the housemates carefully negotiated the space. With an overt power hierarchy, Andrew’s trepidation was evident as he performed each part of the task carefully, cautiously, to avoid getting into trouble from the supervisor. Every aspect of the mealtime preparation was carefully controlled, and the power and authority of the supervisor was oppressive. I felt this acutely when the supervisor and I were standing watching the housemates eat their dinner. The physical contrast between the two of us standing, watching, monitoring, while the housemates sat at the table, was emblematic of the power hierarchy. And, I wondered, what were we supervising? The housemates were perfectly fine.

The rapid-fire instructions issued by the supervisor reminded me of my time working in institutions, where there was always a rush to get things done so we, the staff, could sit down and relax. The bossy, controlling nature of the supervisor reminded me of my colleagues in the wards of Kew Cottages. I recalled often hearing from my colleagues that we needed to get everything done quickly so we could ‘have an easy shift’. Bella, however, had a different interpretation. With her familiar routine, she went about her tasks competently, with confidence, she knew what to do and when to do it. For Bella, with her struggle to manage new tasks, the familiarity of a well-rehearsed routine, repetitive and monotonous, brought comfort. Josh, on the other hand, was nonplussed by the harried supervisor, casually chatting away regardless. This excerpt has shown the different interpretations of the same moment in time.

'Spaghetti bolognaise' also highlighted the lack of space at Lake House for visitors. There was no physical space for visitors. This was symbolic. Andrew was creative in retrieving the box, moving places, and creating a space for me at the table. My presence as the fifth member of the group was an unusual occurrence. The supervisors did not stay for the meal or for conversation and there were never any visitors to Lake House at dinner time. No one else ever joined the housemates at the table.

I now return the next part of the household's evening routine. After dinner, there are more chores to be done and the chores roster has specifically prescribed the routine. Tuesday nights, when Bella cooked, Josh and Andrew did the dishes. Upstairs, there was a similar routine. The housemates also needed to make their lunches for work, or day placement, the next day.

> **Preparing lunch for work the next day**
>
> In the kitchen, Bella was taking out items from the pantry and issuing instructions for Josh to retrieve items from the fridge. I asked Bella what she would like me to do, and she suggested I gather the cutlery and crockery. Josh checked with Bella if she wanted one tomato or two? Bella confirmed one would be sufficient. The supervisor came in through the back door and asked what was happening. Bella advised she was making salad for lunch and the supervisor praised her efforts, coming over to see what ingredients she was using. The supervisor suggested a salad dressing and Josh asked if another type of dressing could be purchased at the weekly shop, one his mother used at home. The supervisor said she and Bella would keep an eye out for it on their next trip to the supermarket. I finished my tasks and asked Bella what I should do next, Bella suggested selecting crockery, and the supervisor showed me where the plates and bowls were kept.

BEDTIME

By 8.30pm, most of the housemates were in bed, or relaxing in their rooms watching TV or a DVD. By this time of the night, Lake House was quiet, in stark contrast to the noisy chaos that resounded when all the housemates were home, busy with their routines and activities. Sometimes Josh was still up at this hour, stretched out in his usual style across the couch. This was a perfect time for us to have a chat, uninterrupted. At other times, Josh went to his room earlier in the evening to listen to music, or to flick through his car magazine, or perhaps to watch a movie. Each night, the house was left spotless, all the dishes put away, no rubbish left lying around, and all leftover food stored securely. A final check by the supervisor ensured everything was in its place. Then, retiring for the evening, the supervisor left Lake House, ensconcing himself in the Cottage, perhaps completing shift records, communication diaries or reconciling financial records, amongst a range of administrative tasks.

Leaving for the day, I closed the cold metal screen door behind me, walking down the driveway to my car, which I routinely parked at the front of Lake House. As was his custom, Andrew would escort me to my car, carrying my bags and making sure I put my seatbelt on. This ritual became a source of comfort to me. Sometimes we would chat, another opportunity to talk uninterrupted, but other times we walked in a companionable silence.

Sometimes, when Andrew was away, I would take this walk alone, reflecting on my fieldwork from the day. In these moments, I would stop on the nature strip and turn to face Lake House. I saw the soft, amber light emanating from Rose's bedroom upstairs, the light scattering from behind the dark green wooden lattice. Oftentimes, there was also a light on in Josh's bedroom, or, in his darkened room I could see the flickering glow from his television. Sometimes, the housemates left the hallway light on which would cast a glow over this stately home, quiet and peaceful at this late hour. As I paused and reflected on the day, I unlocked my car, the headlights causing a small disruption in the blanket of darkness that had fallen over the quiet street. Turning my key in the ignition and buckling my seat belt as Andrew always told me to do, I left Lake House, driving to the end of the street, turning left, returning home.

WEEKENDS

In contrast to the rigid, predictable, monotonous weekday routines, weekends at Lake House offered some variety. The housemates kept a division between upstairs and downstairs, going about their business almost in parallel fashion. Much like the supervisors, I would move between upstairs and downstairs, spending time with each household. However, once the supervisor finished their shift, loaded their belongings into their vehicle and drove away, there was a distinct change in routine. In the downstairs kitchen, I heard Rose talking to Andrew and watched as he followed her upstairs. Intrigued, I followed them and found Andrew crouched behind the TV cabinet in the lounge room, trying out different cords. Rose stood in front of the television with a remote in hand. “Anything now?” Andrew asked. “No. Nothing yet.” Rose replied. Andrew moved more cords, his whole body almost entirely behind the cabinet with just his sandal-clad feet visible from where I stood. “Ok. What about now?” Andrew questioned. “Yes! That’s it! You did it!” Rose exclaimed as the dark TV screen came to life and we heard the unmistakable sound of the Wii menu, its silly music making us all laugh. Reversing out from behind the cabinet, Andrew grinned. “Thanks heaps.” Rose beamed, “I’ve been waiting all week for you to come up here and fix this.” “Yeah” Andrew frowned, “I had to wait until [supervisor] left so I could get up here to help you.”

My time on the weekends fascinated me. Hitherto all week the housemates had given the impression of compliance, acquiescence and a relinquishment of personal preferences and desires in order to conform to the demands of the group home. On the weekends, however, when the housemates were often home together for hours at a time with no supervisor on duty, there was a different routine, a different pace. I was interested in the intentional calculation Rose and Andrew had made to evade detection, as they broke the household rule and crossed the threshold between upstairs and downstairs.

Friday nights. Approached with great enthusiasm, Friday nights at Lake House were a great social opportunity. The housemates would go to the local RSL[32] for a

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[32] RSL stands for Returned Serviceman’s League and is a type of club. Membership is required for a small fee each year. Upon admittance, members can gamble and there are usually a few options for a meal and a drink. On weekends, the RSL provided live music for its patrons.

meal, some drinks and dancing. The housemates have been doing this for a long time and enjoy their routine. It is also an opportunity for the housemates to go out unaccompanied by the supervisors, who remain behind Lake House. The ritual of getting ready to go out, is an important shared experience for the housemates, captured in the following excerpt.

A night out at the RSL

"Thank f*** it's Friday" Josh says, with a grin, knowing the reaction his words will provoke from Bella. On cue, Bella admonishes, "Josh! Language!" "Oh c'mon" he tells her, moving closer, "You've worked your ass off this week, you deserve a night out baby". Smiling, Bella nods, and Josh takes her into a warm embrace. Maggie often says, affectionately, of Josh, "He could charm the pants off a snake oil salesman, that one!" By now, Bella has forgotten Josh's indiscretion with his swearing and they join the other housemates and me to chat about our plans for the evening. At 6pm, two taxis will arrive at Lake House, a standing booking, to take the housemates and me to the RSL. In his typical laid-back fashion, Josh chills out on the lounge room couch, but also keeps a close eye on the clock in the kitchen. Bella joins him in the lounge room and Andrew emerges from his bedroom, freshly showered, wearing what he calls his 'going out clothes'. Josh issues a low wolf whistle. "Cut it out!" Andrew says and grabs a bean bag to sit with us in the lounge room.

Maggie appears at the back door, dressed up and wearing make-up, a contrast to her normally bare face. Tonight, she has put a new clip in her hair which she shows us. Chloe, almost unrecognisable out of her favourite windcheater, is wearing a dress and sandals, with a light cardigan draped over her arm. Her shiny hair is loose around her shoulders. Maggie says, "Take a seat, Chloe, I'll braid your hair." Maggie sits on the couch and Chloe sits on the floor at her feet while Maggie separates Chloe's hair into strands of three, deftly moving her fingers, weaving the braid. Securing the ends with a pink tie, Maggie pats Chloe on the shoulder "All done" she says. Josh wolf whistles again and we all laugh. Ever hopeful, Maggie suggests that a pink bow would be a lovely addition, but Chloe shakes her head, the glossy braid will suffice for tonight. Chloe checks her handbag, a small, faded black leather bag with a long strap she wears across her body diagonally. With each item she finds in the bag, Chloe nods her head, as if checking off a mental checklist. Satisfied, she fastens the clasp, adjusting the strap and moves towards the staircase, turning back to look at Maggie to see if she is ready. Maggie nods and together they walk out the back door and head to the Cottage to tell the supervisors they are ready for the evening.

Josh, Bella and I are waiting in the lounge room. Josh looks handsome with his freshly washed hair still damp, the collar of his blue shirt a little darker from the moisture. His shirt is tucked into his pants, secured by a black leather belt, and his dark leather shoes are shiny. Relaxed, he has his hands behind his head and his feet on the couch. The supervisor appears at the back door and says, “Ok, is everyone ready? Got everything? Make sure you have everything.” The supervisor runs through a list, counting each item on their fingers. “Keys, money, purses…” Josh interjects here “wallets!” he says. The supervisor, familiar with this interjection and perhaps a little weary of it, says “Yes, Josh, or wallets” and continues counting items. Nothing is forgotten. “Ok” the supervisor says, “It’s nearly time for the taxi. I want everyone to be on their best behaviour tonight. Josh, not too much to drink please and Andrew, be careful of the strobe light on the dance floor. Ok, let me look at you.” The supervisor checks the housemates one by one and makes suggestions, “adjust this or that,” he says. For a moment, I wonder if the supervisor is going to also check me over, but he moves past me without a glance. Josh wolf whistles again and everyone begins to laugh again until the supervisor turns to look at him sternly. “That’s enough of that, Josh. I want you to be sensible tonight, please.” The laughter stops, and everyone is standing in the lounge room, fidgeting. Andrew stands up, getting up from the bean bag first on one knee and then putting his elbow on this thigh, he pushes himself up. “Hey mate, you know what you need?” Josh tells him “Some good aftershave! You know the ladies love it, mate. You can borrow some of mine if you like. I’ll lend ya the lucky one.” The supervisor frowns, “Josh, that’s enough of that. If you can’t be sensible you might find yourself not going out tonight. You can stay home with me and do some paperwork instead if you like.”

The housemates are quiet, and the supervisor instructs them to wait out the front for the taxi. One by one we file down the long driveway at the side of Lake House, in silence, until we get out the front. The supervisor has returned to the Cottage and the housemates resume their banter. Soon, we are all laughing at Josh's jokes again and looking forward to our night out at the RSL.

Being together. Friday nights were a much-anticipated weekly ritual where the housemates spent time together without supervision. Being together was an important part of their week. In other ways, too, the housemates demonstrated companionability. The seamless way in which Bella and Andrew shared the kitchen in the morning, as they got ready for work, was harmonious and synchronous. Companionability was evident through the housemates' familiarity with other, and each other's routines and preferences. Identified in the literature as an important element of home, companionability is part of belonging, contributing to a sense of home. Tuan (1975) for example, identified belonging as an important element of home, which Sixsmith (1986) expanded upon in her definition "comfort, relaxation, familiarity contribute to a sense of belonging to home: (p. 287). In her framework of home, Sixsmith (1986) identified quality of relationships, friends and entertainment, happiness, and belonging as elements of home. In the literature on group homes, specifically, the focus is often on creating a home-like environment. Yet, the housemates created this for themselves within an environment that was often the antithesis of home, with its regimentation and control, its rigidness and depersonalisation. However, there were few friendships or social opportunities outside of the household. The insular nature of companionship at Lake House was reflected in the enclosed lives of the housemates.

THE COTTAGE

Located in the backyard of Lake House, the Cottage was a detached, fully self-contained building for the staff quarters, Figure 9. The Cottage had a staff bedroom, bathroom, kitchen, lounge room and office. The supervisors carried the keys to the Cottage and the housemates were not permitted to enter without permission. Clearly the domain of the supervisors, the Cottage was a clear delineation of space. The sign at the front of Lake House directed visitors to report to the office at the rear of the property, colloquially referred to as the Cottage.

The Cottage was also a repository of valued resources. Here, in the staff quarters was where the money was kept. Medications, printer paper, computer and internet access, envelopes, sharp scissors valuable for scrapbooking, and chemicals to clean the bathroom, were all sequestered in the Cottage. The supervisors kept their car keys in the Cottage, vehicles which provided highly sought-after access to the community, grocery shopping, excursions for new clothes or a clock for Bella’s bedside. The Cottage was also where the housemates went if they had a problem to solve, or when they needed advice, it was the place where they sought out the knowledge and assistance of the supervisors. From solving the problem of Rose’s torn pillow cover, to organising Christmas holidays to Noosa, the housemates turned to the supervisors in the Cottage in times of need. As Rose said, “it’s where I go when I need to have a chat, if I’m upset or angry, I just go to the Cottage and talk it out.”

The supervisors kept master keys at the Cottage. The supervisors had keys for all the locked cupboards at Lake House and for all the rooms in the property, including client bedrooms. In the Cottage, the chores roster, weekly menu plan and all the signs and instructions were printed, laminated and then taken to Lake House where they were taped to various surfaces. New policies and procedures emerged from the Cottage, distributed to Lake House from the Organisations’ head office, accompanied by explanatory instructions provided to the supervisors by the Co-ordinator. Unwritten rules and regulations were formulated in the Cottage, such as the division between upstairs and downstairs, a solution to the problem of the recently introduced ‘maximum five bed number’ policy for all group homes within the Organisation. These policies, rules and regulations directly impacted housemate behaviour, and the supervisors, were required to implement the policies.

Each evening, the supervisor on duty would retire for the evening to the Cottage, their shift beginning again at 6am the following morning. The housemates were able to predict the supervisors’ routines by watching the Cottage. On Friday nights, for example, Bella would peer out the kitchen window to see when the supervisor turned the light off in the bedroom. Once this occurred, she would tell Josh. “The coast is clear!” she’d say, in her role as designated look-out. Then Josh would slip out the front door, or sometimes, his bedroom window, with a wave of thanks towards Bella, he would head off to the local pub.

Figure 9. ‘The Cottage’. The staff quarters represented the locus of authority and control at Lake House.

BED NUMBERS AND TIDY BEDS

The problem of “bed numbers.” A grand, stately building, Lake House, Figure 10, had endured extensive renovations and remodelling over the years. The interior of the post war era architecture had been reshaped into a facility suitable as a group home for eight residents with a purpose built, separate living quarters for the staff. Owned and operated by the Organisation, Lake House was larger than the average community-based group home. As a large provider of a range of disability services, the Organisation received government funding for the provision of accommodation and support to people with intellectual disabilities which it delivered through hundreds of community-based group homes throughout Australia. Contemporary group homes, often purpose-built in Australia following the ongoing devolution of large-scale residential centres, often had a maximum cap of five residents. Lake House was problematic in this regard, as one of the senior managers within the Organisation told me, “Yes, with Lake House, you see, we have the problem of bed numbers.”

The language of ‘bed numbers’, despite its clinical connotations, remains widely used within the disability sector. It is a problematic term for several reasons; first and foremost, because of the reductive positioning of people with intellectual disability as numbers within a system. Yet, Lake House, and many other group homes like it, were built in a different era and despite the extensive renovations the property had undergone, the Organisation continued to grapple with the problem that Lake House was larger than it should be. From the street, Lake House did not appear to be as large as it was. The scale of the property was illuminated best when viewing the property from the public park next door such as in Figure 10.

Figure 10. Lake House is a large, stately property, supporting eight residents.

UPSTAIRS AND DOWNSTAIRS: A HOME DIVIDED

During my first week at Lake House, I came to understand how the Organisation responded to this problem of "bed numbers" that is, having more residents than stated in the Organisational policy. The property was divided into three distinct living quarters; upstairs, downstairs, Figure 11, and the staff quarters. Rose, Maggie and Chloe lived upstairs, and Josh, Andrew and Bella lived downstairs. Each living quarter had its own kitchen and dining area, adjacent to the lounge room, and then bedrooms followed down the hallway, two on each side. The bathrooms were beside the kitchen. The physical delineation of space at Lake House was an obvious solution to the practical problem of a large number of residents within the group home. However, the ways in which the housemates negotiated the space, the ways in which the supervisors vigilantly reinforced the demarcation of the household were less obvious and took me some time to understand fully. The following ethnographic piece, 'Upstairs and Downstairs' illustrates the way in which the demarcation of the household was experienced by the housemates.

"Upstairs and Downstairs"

During my first week of fieldwork, I had been chatting with Josh and Andrew downstairs at the outdoor table, which had become the hub of our activities and conversations. Rose and Maggie usually came downstairs to join us although Chloe rarely did, preferring to stay upstairs in her bedroom. Hearing a loud car engine in the distance, Josh announced "[Supervisor's name] is back! Wonder what he and Bella got me at the shops?" The supervisor cautiously drove down the concrete driveway and idled the engine, opening the boot of the vehicle before stepping out. Jumping up, Josh and Andrew began unloading the grocery bags, placing them on the landing of the external staircase. The supervisor said, "Now, hold on, wait a minute, some of those are for upstairs and some for downstairs. Let me look and see." Dividing up the grocery bags, the supervisor asked Rose and Maggie to carry their allocation upstairs, adding, "I'll be up in a minute to help label the cold stuff." Meanwhile Bella, who was out of the car and had now joined Josh and Andrew at the landing, directed them to take the remaining bags inside, "They're ours" she said, "For downstairs." At times, the supervisors were active in ensuring there was no mixing of the two households. On one occasion, I was keen to visit with Rose, Maggie and Chloe upstairs, having spent the morning downstairs. Andrew offered to come with me and we began climbing the stairs when we heard a loud voice, exclaiming, "Andrew! Where do you think you're going? Get back down to your area!" Andrew paused and turned around, steadying himself using the dark green handrail, his heavy, thick summer sandals catching on the steps as he maneuvered himself. I paused, unsure what to do. Should I continue upstairs? Would I be reprimanded? Should I turn around and return downstairs? Where was my area, exactly? As I hesitated, considering my options and a little afraid of getting into trouble from the bellowing supervisor below, Andrew said, “It’s ok, love, you go on up.”

Figure 11. The external staircase at the rear of Lake House separates the two households.

The supervisors’ use of the space was in stark contrast to the rigid way in which the housemates’ movements were controlled and restricted. At dinnertime, I observed the supervisors regularly going up and down the stairs with one quipping, “Who needs a gym membership, when you’ve got these stairs to keep you fit?” During these times, the housemates did not visit each other, dinner was held separately and reparations after dinner, usually watching TV in the lounge room or retiring to bedrooms to relax, were entirely separate.

Tidy beds. At Lake House, there were many rules and regulations. Sometimes, these rules and regulations took the form of official signs, which were printed and laminated and posted to the walls around Lake House. However, there were also more subtle, unspoken, rules and regulations that were never written down but, nonetheless, were well known to the housemates. Over time, this unwritten culture became familiar to me, too. The supervisors expected the housemates to comply with the informal rules and regulations and they directly influenced the ways in which the housemates experienced everyday life. The housemates, who were fully cognisant of the rules and expectations, incorporated them into their everyday activities through a type of internalisation. In this way, there was a type of sub-culture at Lake House, a space unseen and unknown by outsiders. The following section illustrates the different ways in which the housemates negotiated the strictures of Lake House.

"Make sure your bedroom is clean and tidy"

Each of the housemates at Lake House had their own, individual bedroom, which they were permitted, by the supervisors and the Organisation, to decorate and to fill with personal belongings. Bedrooms were the only space within Lake House that could be personalised, and the housemates were required to keep their bedrooms neat and tidy at all times. The housemates were subjected to regular inspections from the supervisors.

In the early stages of fieldwork, the supervisors were anxious and worried about how Lake House might appear to a university researcher. Despite my reassurances, and my calm, quiet nature, I was not able to allay their anxieties. In the following exchange, Rose and the supervisor are preparing for our first day of taking photographs.

> "Rose don't forget please, if you are having photographs taken tomorrow then you will need to make sure your bedroom is clean and tidy. I want you to go through it today and pick up any clothes on the floor and put them in the laundry. While you're at it, your room could do with a good dusting please. I'll come and check on you before I go." The supervisor issued his instructions to Rose, as she and I were standing in the kitchen. Tomorrow, we had decided, would be our first day taking photographs. The supervisor appeared eager to ensure that Rose's bedroom was neat and tidy. Rose called this making sure it her room was in "ship shop shape".

When I arrived the next day, about 9am, Rose was sitting on the back stoop, waiting for me. "Lisa, I got up at 5am to make my bed for you!" She told me. During the inspection the previous day, the supervisor had made several suggestions that needed work, he said, before Rose could take photographs of her bedroom. Rose had cleaned her bedroom for quite a while before becoming discouraged and enticed away by Josh who had suggested a DVD night in the downstairs living room. Instead, Rose got up early and cleaned her room and made her bed, getting ready for our photographs.

Tidy beds were indicative of the level of influence the supervisors had over the everyday lives of the housemates, who were expected to have tidy beds at all time. Bedrooms were frequently inspected by the supervisors to ensure compliance. Some housemates, Josh and Andrew in particular, only intermittently made their bed. Andrew, who loathed this task, made his bed if prompted by a supervisor but would test the boundaries, often, by leaving it unmade. Josh, however, was less compliant. Josh's refusal to make his bed was a source of significant frustration for the supervisors who tried a variety of different ways to get Josh to make his bed. To this end, the supervisors had recently informed the housemates that bedrooms would be inspected each Monday morning by the Service Co-ordinator, the frontline manager who oversaw Lake House and two other group homes in the nearby area. Each Monday morning the Service Co-ordinator visited Lake House during the day, when the housemates were at work. The Service Co-ordinator role is one of administration, aimed at employee and administrative management and the Service Co-ordinator role was not to inspect individual bedrooms nor to assess cleanliness. Indeed, I never observed the Service Co-Ordinator actually doing so.

However, out of frustration at Josh's non-compliance, the supervisors worked together to construct a story that the Service Co-ordinator would now be inspecting the housemates' bedrooms each Monday morning. The supervisors led the housemates to believe that if the Service Co-ordinator caught them with an unmade bed, or a messy bedroom then they would be "in big trouble." This tactic created an air of fear and anxiety for the housemates. This notion of "getting into trouble" or too many "strikes" effectively ensured that each morning the housemates made their beds and kept their bedrooms clean and tidy. However, Josh remained nonplussed. He had a good relationship with the Service Co-ordinator, who he described as a "really nice lady." Thus, Josh continued to leave his bed unmade, his bedroom messy, confident in his belief that he could "sweet talk" his way around the Service Co-ordinator if need be.

In any event, Josh was, usually, the only housemate home during the day and he was dubious about these so-called inspections, not quite believing the supervisors' story.

A tidy bed for Bella, however, held different meanings and making her bed was an important part of her daily routine. Whereas other housemates were coerced and deceived into making their beds each day, as described above, Bella automatically performed this chore each morning, even doing so enthusiastically. Bella said that she liked to have a tidy bed and a neat and tidy room. Bella took great pride in her housekeeping and regularly attended to tasks such as changing the sheets, dusting the bureaus and draws and vacuuming the bedroom floor. Bella's efforts were appreciated by the supervisors, who often complimented her on her housekeeping abilities. For Bella, the notion of inspections and audits, either real inspections undertaken directly by the supervisors or the fictional, yet believable, audits undertaken by the Service Co-Ordinator, were an opportunity for her to demonstrate her competence. Taking pride in her work, and her sense of achievement and competence as a good housekeeper, Bella relished opportunities to display her skills.

The importance of bedrooms at Lake House

In contrast to the uniform, homogenous, shared spaces of Lake House, individual bedrooms were locales of self-expression, creativity, individuality, treasured memories and keepsakes. Bedrooms were used for sleeping, taking a nap during the day, entertaining other housemates or as a relaxing escape from the general milieu of the household. Bedrooms displayed souvenirs, keepsakes, mementos, photographs of family and friends and were a haven for choice of décor, within some the limitations. However, even here, in this most personal and intimate of space, the influence of the Organisation pervaded. The colour of paint for the bedrooms was allocated on the basis of gendered stereotypes; blue feature walls for "boys" and pink feature walls for "girls" as seen in Figure 12. This was the language used by the supervisors' and the housemates. It was rumoured, according to the housemates, that the Organisation had received a 'special deal' on bulk purchasing of the paint. Thus, pink and blue feature walls could be found across many of the group homes owned and operated by the Organisation. It was not permissible to change the colour of the feature walls, which greatly angered Josh but was passively accepted without question by the other housemates. Bella was happy with pink, as it was one of her favourite colours whereas Andrew was nonplussed about his blue feature wall.

Figure 12. Bella's bedroom.

At Lake House, female housemates had pink feature walls in their bedrooms, Figure 12, while male housemates had blue feature walls. Bedrooms were repositories of memorabilia, framed photographs, keepsakes, games, puzzles, books, DVD collections. Josh, a self-confessed 'rev-head', proudly displayed car racing posters and on his bureau, which his mother purchased for him. He also displayed his aftershave collection and various gifts from family and friends. Josh had a collection of family photographs, some framed and sitting on his bureau, others loose and kept in draws, which he would bring out periodically and change the framed display. Hanging from the curtain rail was a Chinese tassel, a gift from his mother from one of her travels.

In Bella's bedroom she had a desk, where she enjoyed spending time alone drawing, writing and listening to music. Bella liked to spend time at her desk filing and painting her nails, and she had an extensive nail polish collection. Ritualistically, she moisturised her hands each evening, sitting at her desk with the lamp on and quiet music playing. Bella would often change her nail polish, choosing colours based on her mood.

As well as sanctuaries from the outside world, or the chaotic, busy, noisy, everyday life of Lake House, bedrooms were troves of treasured memories. Chloe, who spent a significant amount of time in her bedroom, had thoughtfully decorated her bedroom. On her bedside table there were some framed photographs of her family. Each evening, before going to sleep, Chloe took time to acknowledge each photograph. Chloe found the ritual of coming to her room, closing the door and turning on the television calming. Next to her television, Chloe had arranged a collection of small gifts from her family which included soaps, figurines, photographs and keepsakes. On her bureau, Chloe kept a collection of partly consumed coca cola bottles, neatly lined up in a row. Referred to by the supervisors as 'rubbish' or 'junk', these bottles were important to Chloe:

> Coke is expensive and they (fellow housemates) drink it. Here it's mine. Nobody else. I come home once, and it was chucked out, put in the bin, so I got it out and put it back. It's mine. Nobody touch it, I lock my door and its mine.

Within Lake House, certain items were in high demand, Coke being one of the most sought-after items. Chloe needed to keep it secure in her bedroom or it would have been consumed by the other housemates, or so the story went when told by the supervisors. However, during my fieldwork, it was not the other housemates who disturbed Chloe's treasured collection of Coke. Instead, Chloe communicated to me an incident where the supervisors cleaned, or audited, her bedroom while she was at work and what was deemed rubbish, the half-consumed bottles, had been thrown out. Chloe's disappointment at such actions led to a renewed hoarding of the coke bottles, which created more tension between Chloe and the supervisors.

Locked bedrooms and bedroom keys. The process of enforced conformity and compliance was evident at Lake House with the requirement for all housemates to keep their bedrooms locked, as seen in Figure 13. Standardised and impersonalised, each bedroom door featured a yellow stick with 'bedroom' which juxtaposed the notion of bedrooms as individual sites of self-expression. At times, the housemates resisted the imposition of this generic sticker. On one occasion, one of the housemates had attempted to remove the sticker from their own bedroom door. However, their efforts were discovered by the supervisor and they were reprimanded. The sticker remained. Another housemate had suggested that the individual's name be placed above the sticker, such as “Andrew’s Bedroom”, however, the supervisors would not permit this adaptation, for reasons unknown.

Figure 13. Each bedroom at Lake House features the same yellow sticker.

Housemates were consistently vigilant, ensuring that their bedrooms were kept locked at all times, as shown in Figure 13, in accordance with the rules of the group home. The bedroom keys were generally kept on a lanyard, which was hung around the neck, ensuring the keys stayed on the person. Keys were not to be shared or loaned. On several occasions I encountered housemates at the local shopping centre. I noticed that even when out in public, or away from Lake House, the housemates kept their bedroom keys on the lanyard around their necks and they told me they did this, so the keys did not get lost. The safety and security of these keys was critical to the housemates, as was the desire to avoid ‘getting into trouble’ from the supervisors for losing their keys.

Andrew’s Neat and Tidy Bed

At Lake House, the supervisors emphasised the importance of tidy beds. Although a reluctant bed-maker, Andrew did make his bed nicely if we were taking photographs. On the surface, then, Figure 14, appeared to be an image of Andrew's neatly made bed, his bright coloured doona smoothed out nicely. When Andrew showed the supervisors this photograph, he was praised for his neat and tidy bed. Like all of us, they interpreted the photograph according to their own frame of reference and what they wanted to see. Through PhotoVoice, however, Andrew was able to explain this photograph in more detail. For Andrew, the importance of this photograph was not the neatly made bed, rather, it was the television and the jumble of messy cords in the corner of the image. With few savings, and a meagre income from his pension, most of which was consumed by the board and lodging costs of Lake House, Andrew had saved his money for years to be able to afford to have a television in his bedroom.

At the time, a new range of digital TV channels had just been added and for the first time, Andrew was able to watch what he wanted to watch, when he wanted. There was no more sharing of the TV in the common lounge room. Instead, Andrew could go to his room, get some "peace and quiet", uncommon in the busy Lake House household, and he could lie in bed, switching channels with his TV remote. Andrew's television heralded new opportunities for autonomy and self-determination, the ability to be his own person and to make his own choices in a household he shared with seven other people. This was significant for Andrew. Through PhotoVoice, I was able to understand the ways in which Andrew interpreted the space and the image proved to be an excellent storytelling device, eliciting great conversations.

The old adage that a picture says a thousand words is not true. A picture needs a thousand words. Andrew's story telling illustrated what was important to him about home, yet all the supervisors saw was a neatly made bed. This image illustrated that Andrew had a strong voice, strong ideas and opinions about home. Moreover, this image also illustrated that there was no one to listen.

Figure 14. Andrew’s bedroom.

REFLECTION AND SUMMARY

This chapter has provided an introduction to Lake House through a tour of the home from multiple perspectives. The material and physical culture of the group home was explored. Many of the features of the group home could be considered homely, or home-like, however these features were often conduits of institutional discourse. Lake House, a group home founded on Nirje’s (1969) principle of normalisation, looked like an ordinary home in an ordinary street yet this illusion was quickly disrupted. The sign at the front of Lake House acted as a threshold, a boom gate, a gatekeeping apparatus. Control of the threshold was by the supervisors. In this chapter, I have shown how Lake House is a contradictory space with artificial reproductions of ordinary rhythms of the day. The pervasiveness of the supervisors controls every aspect of Lake House from cooking spaghetti bolognaise to making a neat and tidy bed.

Complex ideological problems, such as the number of bed numbers that a group home should have, were negotiated through a division of the household. The lack of physical space at Lake House for visitors was symbolic. However, the housemates did not only passively follow the rhythm and routines of Lake House. Rather, this chapter has illustrated ways in which the housemates use the rhythms and routines to construct their own meanings of home. Chillaxing on the couch illustrated the relational elements of home at Lake House, constructed by the housemates, these moments in time carved out in between the predictable, monotonous rhythms and routines. Indeed, for some housemates, the predictable, consistent routines of Lake House brought comfort and stability and a sense of confidence. There were rebellious moments, such as Josh's steadfast refusal to make his bed, which brought forth institutional responses of power and discipline. However, these acts of resistance were also ways of producing home.

Chapter 6: Mops and Buckets

INTRODUCTION

This chapter is the second findings chapter of the thesis. In this chapter, I explore the institutional frame of Lake House, manifest in the signs and symbols, rules and regulations. However, there is more to Lake House than the institutional frame. In this chapter, I show the ways in which the housemates negotiate and experience these unhomely and un-home-like elements. I conclude this chapter by exiting the field, the last stage on the metaphoric bush track I used in Chapter 4 to describe the research process.

SIGNS AND SYMBOLS

Signs and symbols were prolific at Lake House. In the kitchen, Figure 15, there was a continual flow of signs stuck to the refrigerators, often updated with new additions simply pasted on top of the existing signs. These signs were reminders, constructed and typed up the supervisors in the Cottage, then printed and laminated. Once uniform in presentation, the signs were secured to the fridge with tape or the odd magnet. Rose, a prolific drawer, had tried previously to post some of her drawings on the refrigerator door but her artworks were always removed. They were taken down by the supervisors and Rose was told to cease cluttering up the refrigerator with her drawings.

Instead, lists, rosters and timetables are prominent. These signs and symbols highlighted, in a strong visual way, that Lake House was also a workplace for the supervisors, as well as a home for the housemates. In Figure 15, on the wall above the water fountain, are floor plans and evacuation procedures and instructions for emergency procedures. Signs proliferate on other walls and in the laundry, too. In Figure 16, these signs stipulate workplace health and safety requirements such as the storage of hazardous chemicals. Cupboards in the laundry are locked so that poisonous substances are not accessible. On Saturday morning, a favoured day for laundry, the housemates must go to the Cottage and ask the supervisors to unlock the laundry cupboards, so they can access laundry detergent and the like. Washing day, then, became a series of steps which the housemates negotiated with the supervisors.

However, the housemates work in and around the signs. Often the rules and instructions were internalised or known by heart. Sometimes, though, the signs were ignored. In thinking about the signs, I often thought about my own home and its complete absence of signs. In my home, I constructed my own rules and regulations and if I forgot to check the use by date on the milk then I was forced to pour it down the sink, a natural consequence. However, having worked in group homes as both a support worker and a manager, I understood the requirements to have a safe workplace and to also safeguard the people we support.

Looking at Figure 16, I could see the sign for workplace health and safety and in one way it represents an institutional element, a visible representation of the tension inherent within spaces which are both workplace and residence. Taking another look at the image, I can see the utility of the sign and, looking again, I can see that the sign looks quite harmless. In a way, it is not too bad. However, my interpretations of Figure 16 illustrate how we see within an image what we want to see, and our interpretations are informed by our own experiences and expectations. On a checklist of what makes a good group home (Bigby & Bould, 2017), a sign may not meet the standard. These types of tools also influence the way in which we interpret the space around us.

However, Figure 16 represented something quite different for Andrew and Josh. One Saturday morning, as Andrew was completing his laundry, he took his wet clothes out of the washing machine and left them on the bench, as seen in Figure 16. Having been up early, Josh, too, had completed a load of washing and had placed them in the basket on the floor. Andrew wanted to join me to take photos together and Josh wanted to join us as well, chatting as we moved around Lake House, wondering what would make a good photograph. Preoccupied, we had all forgotten the wet washing sitting in the baskets. When the supervisor arrived, admonishments were made, and Andrew put the camera down and took his washing basket out to the line. I felt a sense of frustration. We had been in the middle of our activity, but the supervisor had determined that the washing was more important. This focus on domesticity at the expense of creativity was an irritation to me. Did it matter if the wet washing waited a little longer? In contrast, Andrew prioritised the instructions of the supervisor and promptly complied. Josh, however, was less keen and he bribed Andrew with two dollars, asking him to put out his washing, too, “just while you’re at it, mate.” Andrew shook his head and told Josh to keep his money, he would do it for free, adding, “What’s one more load between friends?”

Figure 15. The kitchen is filled with signs and symbols.

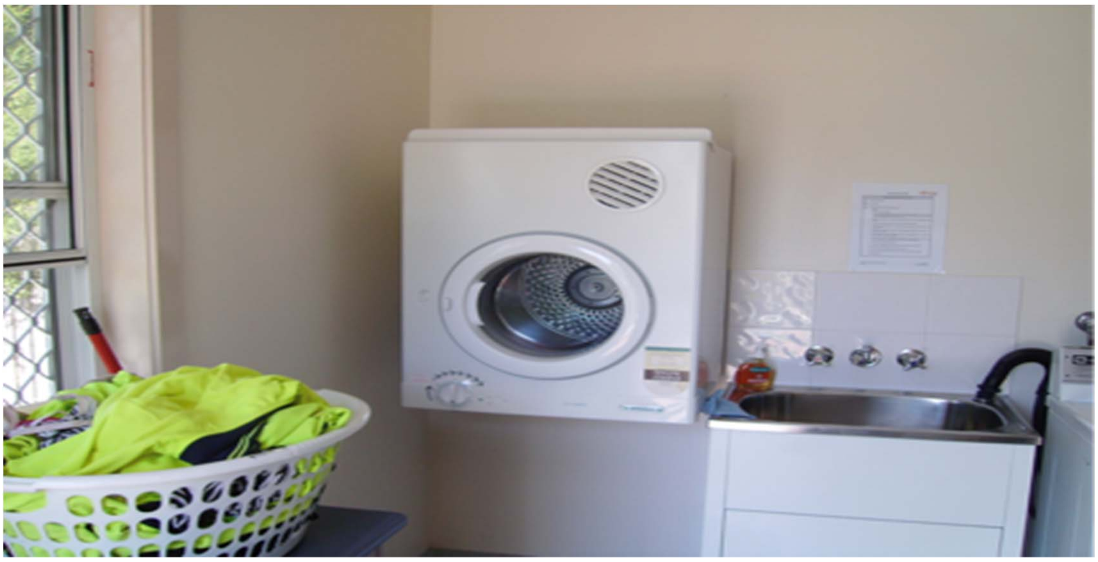

Figure 16. The laundry also has many signs, typed and laminated and stuck to the walls.

Signs and symbols, at Lake House, were representations of a culture that was highly regulated and structured by the supervisors. Signs brought clarity to the task for those who could read them, but I wondered what purpose the signs really had for the housemates who couldn't read. Signs and symbols at Lake House were everywhere. I was particularly struck by the somewhat ironic use of the shared space, covered in laminated signs endlessly emanating from the Cottage. In these shared spaces, the housemates were not permitted to have personal belongings. Various discourses described why, ranging from personal security and safety and an accompanying narrative that items could be stolen or broken, to a rationale of fairness. This discourse, initiated by the supervisors but internalised by some of the housemates, emphasised that it would not be fair if one housemate put more personal belongings in the shared spaces than another. From my own perspective, I thought it was unfair that the shared spaces were so stark and sterile, so un-home-like that the supervisors had appropriated the space for themselves and the proliferation of signs on the walls seemed unbounded.

CUPS AND SAUCERS

Lake House was bound by block treatment in unexpected ways. At times, the Organisation treated the housemates as a homogenous entity. In my own writing, too, I have reflected upon my use of the phrase 'housemates', which tends to imply the housemates are lumped together. These types of practices, such as referring to group homes by their street name or talking about group home residents, are conventions found across the disability sector. These types of habits tend to deny or ignore the individuality of people who live in group homes and it is this unconscious use of such concepts and terminology that can lead to a type of othering of people with intellectual disability. My attention was drawn to the implications of working in this way through the following scenario.

> Bella was particularly keen to show me the new crockery that had been purchased. Leading me into the kitchen, Bella informed me that [administrator's name[33]] had visited Lake House and dropped off the new crockery; plates, bowls, cups and saucers. There were two sets of identical crockery; one for upstairs and one for downstairs. The old crockery had been boxed up and removed. Bella loved the new crockery, she said, and was protective, entreating everyone to "be careful" and "don't break" the new pieces.

I found the bulk purchasing of the crockery perplexing, considering the exact same prints and patterns would now be found throughout a large number of group homes within the Organisation. Why had individuality been denied? Admittedly, the bulk purchase of the crockery was more cost effective, however, the joy and pleasure of choosing one's own crockery had been removed.

> Maggie was disappointed not to have been able to choose the new crockery. Still, she was philosophical, suggesting that she might ask her Dad if she could choose some new crockery for them to use at home. Rose thought the new crockery was ugly. Instead, Rose preferred greens and yellows, rather than the pinks and purples that featured on the new settings.

The provision of the cups and saucers appeared to satisfy house rules and meet functional requirements without consideration of the implications. It appeared to me that the Organisation had focused on the crockery as utilitarian items, with an emphasis on efficiency and functionality, insisting on uniform design and construction. At Lake House, the bread and butter plates, the cups and saucers, the bowls and dinner plates came to be stored in the exact same spot in the kitchen cabinet for upstairs and downstairs, with convenience touted by the supervisors as the rationale for this uniformity. I was unclear whose convenience was referenced.

It also appeared to me to be paradoxical; the Organisation had intentionally separated Lake House into two distinct living areas, upstairs and downstairs, because of concerns about bed numbers, yet the bulk purchasing of cups and saucers reinforced

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[33] Holding an administrative position at Head Office, this staff member who was responsible for the requisition and purchase of crockery across a large number of group homes within the Organisation.

the homogenisation of Lake House. I wondered, but refrained from inquiring, whether the supervisors or the administrators from Head Office, would like someone to bulk purchase their crockery to use at home, without any input into design or consideration of personal preferences. Indeed, two of the supervisors brought their own cups from home because they preferred drinking from these, with a finer china, or a preferred handle or pattern, rather than the cups supplied from the Organisation. Yet, the housemates were denied such preferences.

However, there was one housemate who resisted the imposition of the new crockery. Chloe, in her own quiet way, began to bring cups, saucers and plates from her bedroom, and commenced using these.

> Sitting at the dinner table, I was surprised to see Chloe bring out her own crockery from her bedroom and set these at the table. Rose and Maggie observed Chloe but made no comment. Dinner was served. Rose and Maggie used the new crockery, and I had brought my dinner in a microwave container from home. Chloe ate dinner from her own plates. We finished our meals with a cup of tea, and I watched as Chloe washed her dishes, dried them and then returned them to her bedroom.

Chloe's quiet act of resistance was a powerful assertion of her will and preference. Chloe did not use words to articulate her refusal to use the new crockery, but her actions spoke volumes. On one occasion, as we were in the kitchen together, the supervisor entered and asked Chloe what she was doing. Visibly annoyed, Chloe scowled and put her arm out with her palm raised, like a gesture of 'stop'. The supervisor said, "Oh, I see" and turning to me, he said, "That gesture means, 'talk to the hand'. You know, from Seinfeld?" I was not familiar with the reference but in any event this gesture proved effective and the supervisor moved on and left Chloe alone. Steadfast in her resolve, Chloe's actions left no room for doubt about her will and preference and her refusal to comply. In the following scenario, Chloe exercises her own will and preference and encourages me to do the same:

> We were standing in the kitchen, waiting for the kettle to boil. Rose grabbed the milk from the fridge and Maggie opened the canister of tea bags. Rose retrieved four cups from the cupboard and placed them on the kitchen bench,

> while Maggie placed a tea bag in each. Chloe took a tea bag out and placed it on the bench before returning the cup to the cupboard. She then repeated this with a second cup, while Rose, Maggie and I silently watched. From the cupboard, Chloe retrieved two cups, one was with Daffy Duck and one was a souvenir from a theme park in Queensland that she had visited. She held the cups out towards me, lifting them up and down, indicating that I should choose one. I pointed to the blue and white cup with the dolphin, from the theme park, and Chloe put this on the bench, returning the tea bag. She then repeated this with her Daffy Duck cup. When the kettle was boiled, Maggie poured the hot water into the four cups and Rose added a dash of milk to three, remembering my preference for no milk. Silently, we took our cups of tea to the outdoor table and began chatting about the weather.

EVERYDAY LIFE

Everyday life at Lake House is complex and full of contradictions. In this next section, I use ethnographic material to illustrate the ways in which the housemates negotiate everyday life at Lake House. In so doing, the housemates show how they construct meanings of home within the group home environment.

Televisions. An integral part of the housemates' lives was television. Each of the housemates owned a television which they kept in their own bedroom. In the shared lounge rooms (upstairs and downstairs), there was a television that could be watched, and viewing was scheduled according to a household roster. Under the guise of fairness, the supervisors had constructed a roster which stated who can choose what to watch on the television per each night of the week. The purpose of this roster was to avoid conflicts and squabbles about what to watch on TV. The supervisors used the language of "equity" and "fairness" to justify the television roster, ensuring that the shared resource, the television, was accessible to all housemates. It appeared to me to be somewhat of an institutional response to a common dilemma experienced in households everywhere each night of the week.

However, now that the housemates each had a television in their own bedrooms, they could watch television uninterrupted and with their own choice of program. This opened up a host of new opportunities. Bella was particularly appreciative of her television set. She said it reminded her of being loved and cared for by her mother, who bought the television set for her. Televisions were important to all the housemates, providing them with a level of freedom and choice that they did not have elsewhere in Lake House. In their bedrooms, housemates could choose how loud to have the volume (within reason, complaints from the supervisors or fellow housemates notwithstanding), what channel to watch, which DVD to view. Here, in their own private sanctuaries, the housemates had the ability to relax and unwind without chatter or noise from the supervisors or other housemates. Rose's television, Figure 17, sat atop her bookcase in her bedroom, strategically placed so she could lie on her bed and watched television. Frequently, Rose invited Maggie into her room and the pair squashed up together on the single bed and watched shows together. One day per week, Rose went to the local library with her L&L program and she would borrow a range of DVDs to watch throughout the week.

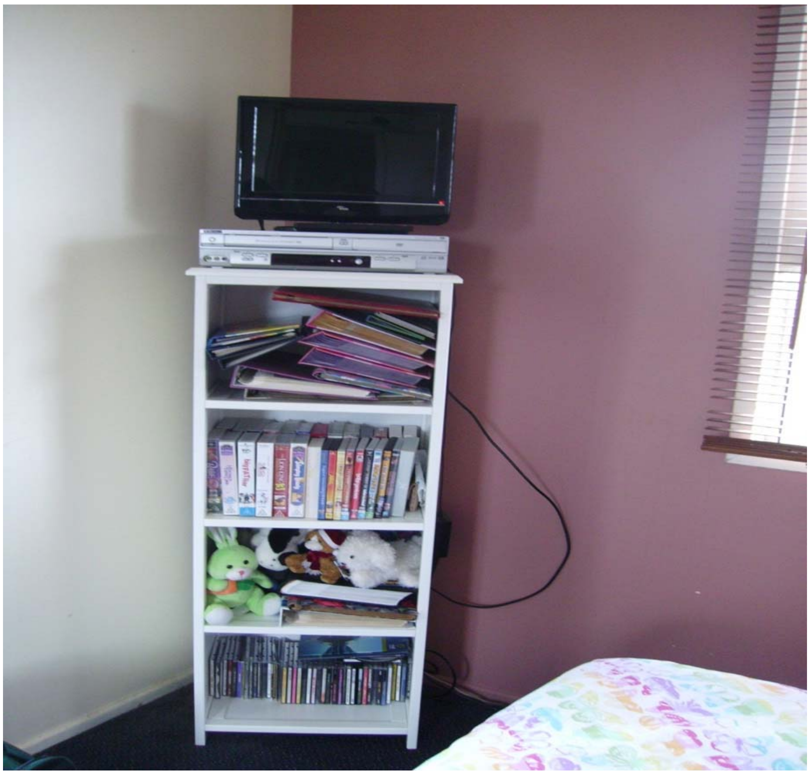

Figure 17. Rose's television.

For Andrew, having a television in his bedroom was very important. As the resident "IT Guy", Andrew's television meant a new foray into technology as he worked out the features. To be able to do so in the privacy of his own bedroom was, as he said, "pretty damn good." In Figure 18, Andrew's television can be seen, and he very much enjoyed watching weekend sports in his room. In many ways, the individual televisions had created a barrier to interactions amongst the housemates as they sequestered themselves away. However, for Andrew, his television was part of his growing collection of electronics and his bedroom was where he undertook hobbies, worked on his projects and relaxed.

At Lake House, bedrooms became sites of personalisation, reflecting individual personalities. Bedrooms were spaces where the housemates were free from the rigidity of household rules and rosters. Bedrooms become small, personalised microcosms of home within the more institutional environment of the group home.

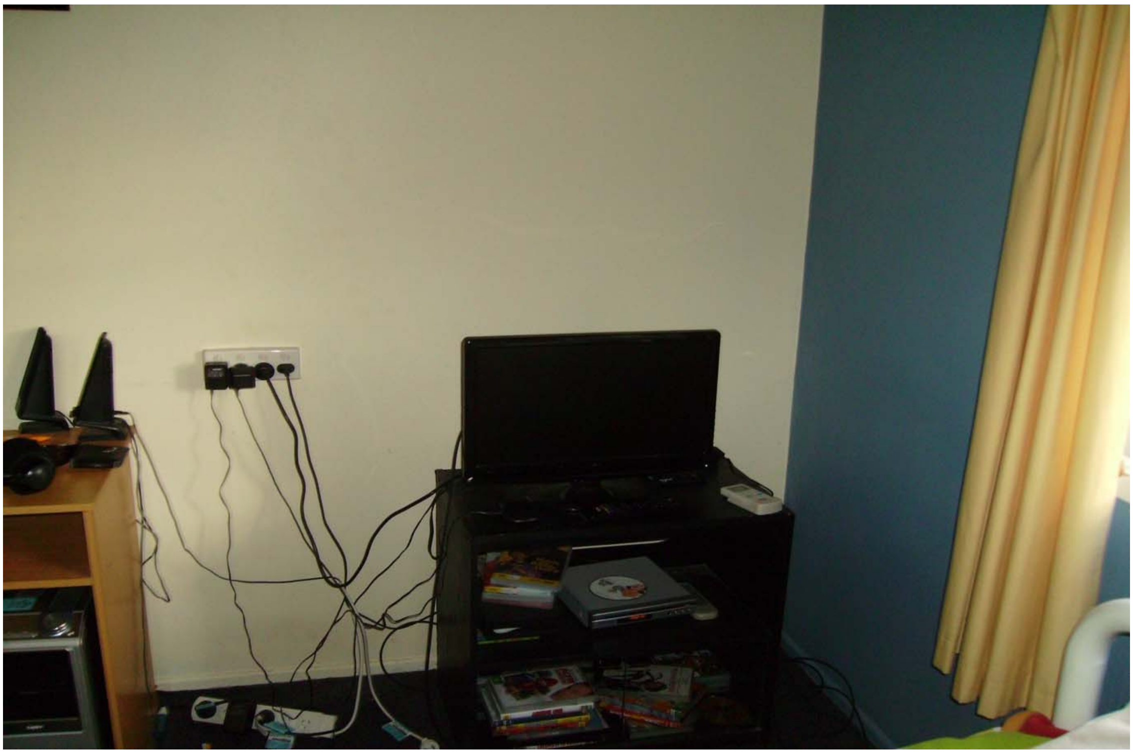

Figure 18. Andrew's television and electronics are part of his identity as the "IT Guy" at Lake House

MOPS AND BUCKETS

Daily life at Lake House was highly regimented, with chores rosters, cooking rosters, and checklists of tasks to be completed. This regimentation was strictly enforced by the supervisors, who constantly provided surveillance and supervision to ensure the housemates complied with the rosters and associated expectations. In an effort to create a homely, home-like space, every aspect of Lake House was neat and orderly and well controlled, as illustrated in Figure 19. The result was a space which was tightly controlled and cleaned and kept neat and tidy. The outside spaces of Lake House, for example, are perfect and immaculate, as shown in Figure 19. Yet, this home-making was not the result of a proud home owner or a tenant who enjoyed a neat and tidy home. This home-making was the result of employed labour by other parts of the Organisation. A gardening work crew tended to the yards of all the group homes in the area and their work tasks were to ensure that the properties are well maintained. Josh, for example, who was quite partial to mowing was not permitted to mow his front lawn. This was the domain of the work crew. Instead, Josh co-opted a lawn mower from his neighbours and completed his rounds, cutting lawns and gardening in other people's yards for some cash in hand.

In other ways, too, Lake House was orderly and structured. During fieldwork, I was often at Lake House when the supervisors were on shift, but I was also at Lake House during the periods of the day when there were no supervisors. This gave me a golden opportunities to see the housemates in two very different contexts. According to the household roster, the supervisors finished their morning shift and then there was a gap of several hours before the supervisor returned in the afternoon for their sleepover shift. This window of opportunity was particularly interesting on the weekends, when most of the housemates were home together and not attending their day programmes. In my fieldnotes, I began to record these moments of time when the supervisors were absent as 'moments of freedom', where housemates were more relaxed and the 'best behaviour' displayed by some individuals was eased, albeit never entirely discarded.

Over time, the housemates became less wary of me and were more willing to trust me. As I aligned myself with the housemates, and not with the supervisors, I began to observe many shenanigans, which was critical for my research. To have the opportunity to participate with the housemates during these rare moments provided me with richer, deeper data and insights into the real life of the housemates at Lake House.

Figure 19. Every aspect of Lake House is neat and orderly and well controlled.

One of our favourite places to sit and talk was at the outdoor table, under the shade sails, at the rear of Lake House. The space was conducive to larger gatherings and was frequently used to celebrate birthdays or special occasions, but it was also amenable to everyday gatherings such as having a cup of tea, eating lunch, or just relaxing after work. On the back wall of Lake House, close to the outdoor area, was a designated section for mops and buckets, Figure 20, where the items were hung in a neat, deliberate formation. Usually, there were four mops and four buckets lined up in precise order, even the nails upon which the mops were hung were precisely spaced out with an equal gap between each. However, one day an aberration occurred that led to a gap in the meticulous order, shown in Figure 20, where there was one mop and one bucket missing. The incident of the missing mop and bucket is explained in the following scenario:

Every Saturday morning, as per the chores roster, Bella is tasked with cleaning the downstairs bathroom, which includes mopping the bathroom floor. While she was completing this task, Andrew, Josh, Rose and I were sitting together at the outdoor table, chatting and enjoying a cup of tea. Suddenly, we heard Bella make a noise inside, and she rushed out the backdoor, waving around a broken mop. “Look!” she said. “Shit!” Andrew replied. Josh got up to examine the broken mop, quickly declaring, “Yep. It’s knackered.” Bella was very anxious, and Andrew compounded this by saying, “You’re going to get into big trouble when [supervisor’s name] comes on [shift].” “What can we do?” Bella asked. Rose suggested putting the mop in the bin, but Josh negated this, “The handle’s too long, it won’t fit” and Andrew said, “[Supervisor’s name] will see it in the bin for sure.” “What about putting it ‘round the side of the house?” Andrew suggested. However, this too, was inadequate as the broken mop would eventually be detected by the supervisors. “I don’t want to get into trouble!” Bella exclaimed. “I know!” Josh said. “Let’s chuck it over the neighbours’ fence!” There was some discussion about this, Rose was nervous, but the others supported the idea. Andrew asked me what I thought of the proposal and I countered with, “What do you think you should do?” Andrew nodded and said, “Ok. Let’s do it. But we can’t dob. No one can tell [supervisors] about this. Not one word to anyone. Ok?” Everyone agreed. After some to-ing and fro-ing about who would actually throw the mop over the neighbours’ fence, Josh grabbed the handle and threw it and Andrew grabbed the mop head and threw it. When it landed with a thud on the other side of the fence, there was a moment of silence as we contemplated what had just occurred, before bursting out laughing together. “But look…” Bella reminded us, and there was the bucket that had been allocated to this particular mop. “What about the bucket?” she asked. “Let’s chuck that too!” Josh replied. This time, Bella and Rose grabbed either side of the bucket and threw it over the fence. The crime had been covered up. At least, for now.

~ excerpt from fieldnotes

Figure 20. Mops and buckets

GETTING INTO TROUBLE

This notion of 'getting into trouble' was a recurring theme at Lake House and the housemates were always conscious of not getting into trouble or, more accurately, not getting caught and getting into trouble. Josh, the flagrant breaker of all the rules at Lake House, proved exceptionally adept at not getting caught and he was often assisted by the more rule-abiding housemates to ensure his success. The following excerpt illustrates how Josh and Bella worked together to keep his escapades hidden from the supervisors, who were sleeping at the back of Lake House in the Cottage.

> Bella asked Josh if he was going out tonight (Saturday night) and he said, "Yeah. I reckon I could go a beer or two tonight." "Ok", Bella nodded, and went to the front door and unlocked it. "Use the front door when you get back but make sure you're quiet! [Supervisors'] can still hear you if you're noisy."

Josh regularly walked to the local pub on a Saturday night where he would "sink a few beers", chatting with the locals, before walking home again. He would pre-arrange with Bella to have the front door unlocked so he could leave and enter unseen by the supervisor on duty. Josh's escapades were never discovered and Bella's 'aiding and abetting' was never revealed.

"Don't dob." An important informal rule at Lake House was the prohibition on eating snacks in the lounge room. The supervisors carefully monitored to ensure the housemates did not eat snacks in the lounge room, both upstairs and downstairs. The housemates also monitored one another to reinforce the rule, at least during the week. There was one exception to the rule; Saturday nights. Through carefully planning, the housemates prepared for their evening, as illustrated in the following excerpt:

> [Supervisor] was preparing to finish their shift for the night and retire to the Cottage. Andrew was in his bedroom, watching television. Bella was in her bedroom, writing at her desk while Josh and I were talking at the kitchen table. Chloe, Maggie and Rose were upstairs. [Supervisor] made their final rounds for the evening and then retired to the Cottage. Within ten minutes, the housemates had all gathered in the lounge room downstairs. Josh had moved the couch and brought out the beanbags. Andrew had brought out some biscuits from his bedroom and Bella had procured a large bag of chips which had been hidden in the back of the pantry. Suddenly, quietly, Maggie, Chloe and Rose appeared at the back door and Josh ushered them inside, encouraging them to "get comfy" in the lounge room before offering everyone a drink of Pepsi, which he had been saving for a special occasion. Josh settled next to Bella on the couch while Andrew was charged with setting up the DVD player. Rose turned the lights off in the lounge room as Bella sipped her drink and reached over to grab a chip from the bag that was being shared around. I could hear the crunching of biscuits and chips but otherwise there was silence, an air of anticipation seemed to fill the space as the DVD started.

Prior to the supervisor retiring to the Cottage for the evening, the housemates had intentionally created the impression that they were planning to go to bed, yet, once the supervisor was safely ensconced in the Cottage, the DVD night began. The following morning, we were sitting at the kitchen table, talking about the DVD we had watched the night before:

> Bella recalled a moment from the DVD which she had particularly enjoyed, Josh readily agreed and shared his favourite moments. Andrew suggested a rerun of the DVD might be in order. [Supervisor] appeared suddenly, coming in through the back door, and I noticed the housemates go quiet. [Supervisor]

> remarked on how quiet everyone was this morning and I noticed Josh and Bella sneaking a peek at each other. Andrew said "Yep, just thinking about all the stuff we gotta do today."

On other occasions the housemates worked together to create the illusion that they were complying with the rules of Lake House and demonstrated the expected behaviours when the supervisors were present.

> We were sitting down at the outdoor table, when Bella called out from the kitchen "It's time!" I checked my watch and it was 12.15pm. "C'mon, [supervisor] be here soon," Bella told Josh who confirmed that the supervisor would be arriving for their shift at 12.30pm. The housemates got up from the table and started a game of basketball. Josh, however, remained seated. "Gotta exercise," Bella reminded him. "Yeah, I know, I'll wait till I hear [supervisor's] car and then I'll get up." True to his word, Josh heard the supervisor's car some streets away and stood up, "They're coming! I can hear them" he said. As the supervisor drove down the driveway, to park their car in the carport at the rear of Lake House, the housemates had created the illusion they had been playing basketball all morning. Once the supervisor congratulated them and went inside the Cottage, the housemates sat back down at the table again, with Bella exclaiming, "I'm exhausted!"

The housemates were very aware of the supervisors' rosters and would maximize opportunities when the supervisors were absent or not on shift at Lake House.

> Josh, Bella and Andrew were sitting outside at the outdoor table and waved goodbye to [supervisors] as they finished their shift and left Lake House. Bella waited until the sound of [supervisors] car was no longer audible and yelled out to Rose, who was on the balcony upstairs, "Righto, coast is clear!" Rose came downstairs with her purse, ready to walk to the shops.

The housemates always ensured they were home on time and throughout my fieldwork, they were never caught by the supervisors.

Control of the body. Another way the Organisation insisted on conformity and compliance was in relation to food. The housemates' diets were rigidly monitored, and the supervisors influenced every aspect this process from purchasing and acquiring the food, to its preparation, menu planning and consumption. As a general rule at Lake House, the consumption of 'junk food', soft drinks, cakes and biscuits was not permitted except on special occasions such as a birthday celebration. Some of the housemates were on diets, such as Bella who had a weekly diet plan, which included set goals. Each Monday, Bella had a weigh-in, which she explains:

> On a diet. Look, Lisa, I've lost weight. (Bella twirls to show me). [Supervisor] has my plan. I got to weigh in on Monday's, on the scales there (Bella points to the Cottage). [Supervisor] writes it down (in Bella's file). That's the keyworker job. ~ Bella.

One day, Bella and I were getting ready for lunch. I had brought my own container of salad from home, which Bella had put in the fridge for me upon my arrival. It was a beautiful, warm, pleasant day and Bella suggested that we eat outside.

> "I've got salad too, Lisa." Bella told me. She had prepared a plate with ham, lettuce, cucumber, tomato and small cubes of cheese. As we took our salads outside, to eat at the outdoor table, [supervisor] passed by and stopped to inspect our lunches. "Good, Bella!" [supervisor] said. "You'll be at goal weight in no time if you keep this up!" "Your salad looks good, too, Lisa, very healthy." At this point, Rose joined us at the table with her salad sandwich. "Look [supervisor]!" she pointed to her meal, "I'm healthy too!" "Yes, Rose, a good choice from you too. Keep up the good work, ladies, you'll be fit and healthy soon."
>
> As the other housemates came to join us at the table, bringing their healthy lunches with them, Josh was the exception to the rule. He brought a can of Pepsi and refused offers of a salad or a sandwich. "Nah," he said. "I'm not into rabbit food!" The supervisor finished duty and drove away from Lake House, leaving the housemates and I to finish our lunches. Bella got up and took her salad plate inside, which was half eaten.

> I heard the microwave ping and Josh said, “Oh, I know that sound, I bet Bella’s got something good!” and he left the table to check out what Bella was doing in the kitchen. Together, they returned to the table, both holding steaming bowls full of hot frankfurts, covered in tomato sauce and cheese. “Didn’t you like your salad, Bella?” I asked. “Nah. But [supervisor] says I got to be healthy.” At this time, Rose had also thrown away her salad sandwich and went upstairs to retrieve a box of biscuits. “Where did you get them from?” Josh inquired. “I got them at the shops when I was at day program”, Rose explained, turning to me, “But we gotta wait til [supervisor] leaves to eat them, or else we’ll get into trouble.”

BREAKING THE RULES

As my fieldwork progressed, the housemates and I developed a deepening trust and respect and I was gradually included in what I have called the sub-culture of Lake House. Not visible from the outside, the sub-culture has been constructed amongst the housemates. Even the supervisors were not aware of what was happening, often right beneath their noses. One of the most effective ways to illustrate the sub-culture is through the process of breaking rules, which I explore in the next section.

When the supervisors were on duty, there was a general compliance with the Lake House rule of having two separate households. However, over time I began to notice that there was one exception to this rule. Josh. On weekends, Josh freely traversed between upstairs and downstairs, walking up and down the stairs many times throughout the day. Unlike the other housemates though, Josh also freely traversed upstairs and downstairs during the week, in full view of the supervisors. Josh surprised me one day as I saw him boldly walking up the staircase, as the supervisor was in the back yard talking to the other housemates. He was upstairs for a few minutes and I found myself feeling nervous for him, wondering if, perhaps, the supervisor had not noticed him. I watched Josh walk back down the stairs, at his usual fast pace, and I turned to watch the supervisor. There was no reaction. This time, it was not possible for Josh to be unseen, as he launched into an impromptu star jump on the staircase landing. Josh continued down the stairs and returned to the kitchen to make himself a snack. I wondered why Josh was free to break the unwritten rule whereas I had observed other housemates being reprimanded for a similar offence. Later, when the supervisor was in the Cottage, I asked Josh about this and he flashed his trademark grin, explaining, "Lisa, rules are made to be broken."

Small acts of defiance. The housemates worked together, using their collective knowledge of the rhythm and routines of Lake House, to undertake small acts of defiance. At times, I was faced with some interesting dilemmas. What was my role when I encountered these small acts of defiance? Where did my obligations lie? What should I do? These dilemmas served to be highly valuable and provided opportunities for me to really think through what was happening, highlighting the complex web of power relations at Lake House. Although I call these dilemmas, to assist in working through the different aspects, the housemates experienced such dilemmas everyday day. While I found these examples instructive, informative, and interesting and complex, I acknowledge that my perspective was one of curiosity and not one of necessity or survival.

In the next section, I use a few different ethnographic pieces to illustrate the ways in which the housemates create an illusion of compliance, on the surface, but I show how they work together beneath the surface to evade the institutional gaze.

> **Social inclusion in the group home.** One of the hoped-for ideals of the group home, was the ability to foster the inclusion of people with intellectual disability in their communities, neighbourhoods and society at large. As community-based models, the group home was intended to provide opportunities for residents to make connections with their neighbours, their local shop-keepers, to go to the local dog park and to participate in all the varied activities of community life.

Neighbourhood encounters

Fieldwork at Lake House required me to carefully consider my role and to make choices about how to position myself in the field each day and every day. At the outset, I was determined to position myself as more like a housemate, and less like a supervisor, so that I could earn the trust of the housemates. However, I underestimated how difficult this would be. On several occasions, during the early days of fieldwork, I was invited by the supervisors to park my car in the carport at the rear of Lake House. Standard practice for other visitors from the Organisation, such as the senior manager, co-ordinator and administrative personnel, the expansive concreted undercover spaces were big enough to accommodate three vehicles at one time. I observed, however, that other visitors to Lake House, such as family members, parked their vehicles at the front of the property. Thus, a delineation became apparent between those who crossed the threshold and used what was effectively the staff car park, and those who did not.

Intentionally, I resisted the invitations by the supervisors and co-ordinator and, instead, parked my car on the street, close to the curb, either directly out the front of Lake House or a little further up outside the neighbour's house, Figure 21.   Initially, my decision was to avoid aligning myself as a supervisor, but unexpectedly, my refusal to park my vehicle at the staff car park irritated the supervisors. Frequently, I was subjected to lectures by the supervisors; telling me my car would not be safe parked on the street that I would not be safe accessing my vehicle at night. Despite the irritation of the supervisors, I continued to park my car out the front of Lake House.

Figure 21. My car, parked out the front of Lake House, led to neighbourhood encounters.

Unexpectedly, there were two advantages to my practice. The first was the proximity of my vehicle to the neighbours' property which often led to impromptu conversations and engagements with them as they became familiar with me. A friendly hello, or a quick chat if I happened across the neighbour gardening in her front yard, led to longer chats as we got to know each other. Bin night, in particular, was a terrific opportunity for the neighbours and I to cross paths and talk, happening across one another as the neighbour wheeled their bin to the curb where my car was parked. These opportunities for convivial conversations were enjoyable and pleasant but also informative. One neighbour, whose beautiful garden I had often admired, had lived in the neighbourhood with her husband for some 40 years. Her knowledge of the growth of the neighbourhood was vast, having bought their own property on a war pension in the 1950s. Over the years, this neighbour and her husband had watched as Lake House welcomed residents and said goodbye to others.

I had asked the supervisors if they knew the neighbours and they said they did not. I had erroneously assumed that the housemates didn't know the neighbours either. With the supervisors present, the housemates rarely ventured past the front yard, however, I soon learned, when the supervisors were absent the housemates did not adhere to such boundaries. Josh, with his love of long walks, knew many of the neighbours, often some streets away, where he was invited in to have a beer or a cup of tea. I discovered this one afternoon when I accompanied him for a walk and he shared anecdotes of the neighbourhood. I learned that Gary[34] had upgraded his car to a grey Toyota due to his expanding family, reluctantly trading in his beloved Ford Escort which he had restored with Josh's help. I met Sharon and her new boyfriend, who often had a drink with Josh at the local pub, however, they were suspicious of me and told Josh they would catch up with him another time. Mrs Barnard, recently widowed, waved to us as we walked by and Josh promised to come back for "tea and bickies" another time. Josh pointed out several of the neighbours who paid him for lawn mowing services. Jane was a particular favourite because, in addition to payment in cash, she always provided Josh with a can of Pepsi when his job was complete.

Rose, too, also knew many of the neighbours, and she shared with me their stories as we sat on her balcony behind the lattice, cross legged and uncomfortable because of the absence of chairs. In fact, as Rose explained, her penchant for yelling out to the neighbours to say hello from her balcony had precipitated the erection of the dark green lattice that now hid her balcony from the street. Undeterred, Rose demonstrated how one could, at just the right angle, lean out over the balcony railing and still wave to the neighbours, albeit with the risk of falling over the edge ever present. Andrew, too, knew some of the neighbours but he had a special relationship with Mrs Manders, who lived across the road and whom he had known for many years.

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[34] All neighbours' names are pseudonyms that the housemates and I selected.

In fact, as Andrew explained, during his recent epileptic seizure at the local shops, when an ambulance had been called, Mrs Manders had happened to be "down the street" at the time and was able to tell the paramedics Andrew's address. When Andrew returned home from hospital he visited Mrs Manders with a card, thanking her for her assistance that day.

The illusion the housemates created when the supervisors were present was intentionally duplicitous, to avoid getting into trouble. In order to meet the rules and regulations, chiefly, of not talking to strangers and only venturing beyond Lake House with permission, the housemates created the illusion of compliance. Yet, in the hours when the supervisors were absent, I observed the convivial conversations and interactions between the neighbours and the housemates.

Disobeying instructions. At Lake House, each action had its own set of reactions and consequences. At times, these were predictable and foreseen and at other times they were unexpectedly opaque. In the following scenario, Chloe and I were positioned in a way where we disobeyed the instructions of the supervisor. In many ways, instructions were provided by the supervisors indirectly, sometimes accompanied by moralising dialogue, sometimes with subtle disapproval. There was also a sustained, immovable tension between Chloe and the supervisors, an accumulation of interactions over time. While I present the following scenario as a description of one instance, it came replete with a history of intense feelings and past experiences and these are the palpable tensions upon which the scenario sits.

The old, stained, faded windcheater

During my first few weeks of fieldwork, I noticed that Chloe was often absent from group activities within Lake House. Although always polite, I found Chloe somewhat reticent and elusive. For example, if another housemate interrupted our conversation, she backed away often returning to her bedroom. The constant hustle and bustle of Lake House made it difficult for Chloe and me to have any privacy or a chance to sit and talk. Still, I made a special effort to seek her out, to create opportunities for us to spend time together but, at first, I was met with unexpected resistance. The supervisors had observed my attempts to spend time with Chloe and cautioned me, "She shouldn't be rewarded for bad behaviour" one told me and another, to my surprise, offered, "You'll get nothing out of that one." Over time, the supervisors became increasingly irritated with me for spending time with Chloe. I began to pay particular attention to the interactions between the supervisors and Chloe, which I observed were mostly curt, officious and lacking any warmth. At times, I also observed a contest of wills between Chloe and the supervisors.

This was illustrated one day when Chloe and I were in her bedroom taking photographs. The supervisor barged in without invitation nor explanation and told Chloe she was to change her windcheater immediately. Chloe shook her head. "You cannot have your photograph taken wearing that!" the supervisor said, "That windcheater is filthy, it's got stains all over it." Still, Chloe refused. The supervisor turned to me and said, "She can't have photographs taken wearing that!" When I failed to reply, the supervisor demanded, "Well. What are you going to do?" I paused and considered.

In part, I understood the supervisors concern. In photographs, subjects are generally presented at their best, with neatly combed hair, big smiles for the camera and dressed nicely. I understood the concern of an old, faded, stained and grotty windcheater appearing in a photograph. It was also true that I would not present myself in this way for a photograph. Further, my training in disability studies focused heavily on social role valorisation (Wolfensberger, 1972; 2000) which was ingrained in me. One part of this philosophical ideology was ensuring that people with intellectual disability are presented as valued members of the community; clothing, style and neat presentation was a part of this. This was always balanced with understanding a person's will and preference. For example, if a person we supported was going for a job interview but planned to wear a white shirt that was stained, as support workers our role would be to encourage the individual to choose a clean shirt. While it was important to consider the individual's choice, in this example to wear a white shirt, it was equally important that the individual present themselves in a socially valued manner, which require them to wear a clean shirt. I understood the principle and I understood the supervisors concern about Chloe wearing a dirty windcheater.

However, I did not understand why the windcheater was important to Chloe. The supervisor assumed she was being obstinate, difficult, but offered no further explanation. In the exchange with the supervisor, Chloe, now agitated and behaving stubbornly, was also not offering an explanation. When the supervisor asked me abruptly, "Well. What are you going to do?" I replied, "Chloe and I are going to take the photographs." Throwing their hands up in the air, the supervisor shook their head and left the bedroom.

Asad (1986) argues that the ethnographer's role is one of learner, where the researcher is reflexive about her position in the field and how her behaviour fits in with participants and how it does not. Crapanzano (1980) advises ethnographers to examine their effect on the fieldwork setting as a source of cultural understanding. Rabinow (1996) has criticised the work of early anthropologists who failed to be reflexive about their own impact on the cultural site of examination. In the interaction above, I was not a neutral observer. Nor was my decision to continue with the photographs with Chloe necessarily the correct one.

Did I disagree with Chloe's decision to wear her old, stained windcheater in a photograph? Yes, I did. Did I side with Chloe against the supervisor? Perhaps. Did my decision have a positive impact on my relationship with Chloe? Certainly. Did my decision adversely affect my relationship with the supervisor? Absolutely. However, for whatever reason, this old, stained, faded windcheater was important to Chloe and these were her photographs; this was her experience of Lake House. Chloe's encounter with the supervisor illustrated that she was prepared to put her foot down, to be 'non-compliant', and to openly refuse to obey the instructions of the supervisor. At Lake House, such resistance was not easy to enact. In her own way, Chloe was resisting the rules and taking a stand; the windcheater was important to her. In her own way, Chloe was also constructing home.

“The Ugly Book”

In the upstairs lounge room, the disability service standards booklet was displayed on a coffee table as per the requirements of the Organisation, Figure 22. Unable to read or understand its contents, nonetheless, the housemates were aware this booklet was important and that it must be displayed at all times. One day, Rose and Maggie and I were upstairs together when Maggie took the photo shown in Figure 22, with the spiral bound book sitting in its mandated space. After taking her shot, Maggie turned to Rose and I and said, “That has got to be the most god-awful, ugly book I have ever seen!” Through fits of giggles, Rose added, “In fact, this book is so ugly, it would win the Guinness Book of Records!” Doubling over in laughter, tears in her eyes, Maggie said, “It would win a trophy for being so ugly! A trophy for being the most ugly book in the entire world.”

Figure 22. The disability service standards booklet is displayed on a coffee table in the upstairs lounge room.

This ugly book was a source of constant irritation for Rose and Maggie who had tried many attempts to get rid of it. Sometimes, the pair would hide the book away, hoping that the supervisors wouldn’t notice and taking delight in the shared secret. On this day, I was laughing along with Maggie and Rose, enjoying their antics. I watched as Maggie gave the go ahead and Rose took the booklet, their giggling escalating to fits of laughter which saw them both doubled over and gasping for breath. Recovering somewhat, Rose stood before the television cabinet, carefully lining up her aim, as Maggie slid the small, lower door open. With a grunt and a “hurrah!” Rose chucked the booklet and we watched it fly through the air before landing inside the cabinet with a thud. Maggie and Rose erupted with cheers and Maggie slammed the door of the cabinet shut as they threw their arms in the air. “Victory!” Maggie shouted.

This small act of defiance was short-lived, as, later that day the supervisor noticed the book was absent and asked Maggie and Rose to return it to the table. Obviously familiar with their antics, the supervisor supposed that they had hidden it, once again, but now was time to return it to where it belonged. Nonetheless, Maggie and Rose persisted. They were innovative and creative and tireless in their efforts to make this ugly book more attractive. In Figure 22 Maggie and Rose had placed a decorative, floral table runner across the low set coffee table because, as Maggie explained, “We just have to do something with it! Lisa, tell me, truthfully, have you ever seen anything as ugly as this book before?”

Solidarity. These small moments of resistance were important moments shared between the housemates. In the anecdote of the broken mop, the housemates correctly assessed the environment and knew that the mop and bucket had to be discarded. True to form, as the supervisor left the Cottage and wandered up towards Lake House, he noticed the aberration straightaway, a gap in the specified sequence. Here, the housemates’ moral code of “don’t dob” was enacted and, despite significant pressure from the supervisor, the housemates were steadfast. Without a guilty party to punish, the supervisor issued a file note to all of the housemates. Including myself. This punishment was significant, particularly for Andrew and Josh who knew from previous experiences that a file note, or an accumulation of file notes, could lead to eviction. Nonetheless, the moral code was adhered to and remained unbroken, the housemates undivided. This, in turn, created a sense of belonging amongst the housemates, a sense of solidarity and fellowship that could withstand the pressures exerted upon them by the supervisors. Maggie and Rose, too, demonstrated a solidarity in relation to the ugly book. It appeared the supervisors were well aware of what they are up to, but they went along with the ruse to a certain degree. These small acts of resistance were significant in an environment where they housemates had little control and these acts served to strengthen the bonds between them. Bonds which, at times, not even the supervisors could break.

EXITING THE FIELD: TAKING OFF MY BUSH WALKING SHOES

Prolonged immersion in the field is one of the hallmarks of ethnographic research. As an embodied methodology, ethnography demands the researcher use all of her senses in the research process and by the end of fieldwork I had become accustomed to doing so. The rhythms and routines of Lake House were by now very familiar to me and in many ways, I had become a part of the space. I knew from experience that when one or more of the housemates were absent from Lake House, perhaps visiting family or away with appointments, then the rest of us keenly felt their absence. As I approached the end of my fieldwork, I knew that my absence at Lake House would be noticeable and I felt anxious for the housemates.

Undertaking research within a group home creates a type of intense familiarity between researcher and participant who have spent so much time together within the comparatively small space of the group home. I was cognisant of the fact that people with intellectual disability who live in group homes experience many people coming into and out of their lives due to high staff turnover in disability support work. Further, I knew that the housemates had diminished social networks and I worried that my absence may be felt more acutely. I heeded the advice of Hammersley and Atkinson (1995) who urge the researcher to be sensitive when leaving the field, understanding that participants may feel adrift, having become accustomed to the researchers' presence over so many months. Throughout fieldwork, the housemates and I had many discussions about the end of my fieldwork and I took great care to prepare them for my eventual departure. To this end, as my final day approached, the housemates appeared to me to be well prepared for my embarkation. I had planned to provide an afternoon tea, to mark the occasion, and to provide an opportunity for us to say our goodbyes. Unexpectedly, the housemates became annoyed with me, even angry with me, as I wrote in the following excerpt from my field diary:

> Sitting at the outdoor table together, the housemates and I discussed, at great length, having an afternoon tea to mark my last day at Lake House. My

> intention was to bring a cake, some drinks, and to have the opportunity to thank the housemates for their participation in the study. However, when I suggested this Josh and Bella were really pissed off! They reminded me that Bella was the "Party Queen" and would do a much better job of organising a celebration than me. Further, Josh raised the age-old Lake House debate of Pepsi vs Coke; he felt he should accompany me shopping to ensure that Pepsi was purchased. Andrew and Rose suggested that they would also like to go shopping. Maggie was nonplussed. Later, Chloe talked to me about cake and shared her opinions about the type of icing that should be included. Astutely, the housemates also mentioned that if we held the afternoon tea when [supervisor A] was on duty then it was unlikely we would be permitted to have cake and soft-drink. However, if we held the afternoon tea when [supervisor B] was on shift we would have more chance of success. I felt properly reprimanded. Together, we set a date, consulting our schedules and the Lake House staffing roster. We wrote a shopping list for the celebration. Andrew and Bella took turns to write, while Josh gave suggestions about food and drinks to serve. Rose chipped in with her opinions and when I left for the day I was given strict instructions that we would be going shopping together on my final day and I was not to purchase a single thing without them!

After all my proclamations of the importance of collaborative work in ethnography, I stumbled at the end of my fieldwork and slipped back into the bad habits of support workers who 'do for' people rather than 'do with'. The housemates forgave me. Together, we planned a lovely afternoon tea, which had a celebratory feel about it as we ate cake and drank soft drink at the outdoor table under a blue sky that would have been at home in any postcard.

Nonetheless, I had given scant regard to preparing myself for my departure from Lake House. I had envisaged that when data collection ceased after saturation, I would leave the field, imagining, perhaps, exiting as a final step, as a physical act of "getting out" of the field (Buchanan, Boddy and McCalman (1988, p. 65). After eighteen months of fieldwork, I had taken care to prepare the housemates for my departure (Berg, 2007) but I had failed to prepare myself. In some way, I had even expected that I might be keen for this phase of my study to be over, one step close to completing my PhD.

However, I found myself reluctant to leave the field. In Chapter 4, I used the metaphor of a bush walk along a track to consider the different phases of my study. Exiting the field, then, was the final leg of this metaphoric bush walk but unexpectedly I found I did not want to finish the expedition. I did not want to remove my bush walking shoes and as I circled around the end of the track, I found myself upset and more than a little sad. In meetings with my PhD supervisors, I would discuss the need to gather some more data or the need to wait a little while longer to exit. I found myself slowing down, intentionally prolonging the journey, even as my energy was flagging, I was not quite willing for the bush walk to end.

In preparing to exist the field, I had limited my conceptualisation of this stage in the research process (Daft, 1983). After spending so long at Lake House, I had been concerned that the housemates may feel bereft without me, however, it was I who felt bereft without them and I had not prepared myself at all. I had not acknowledged nor fully understood the emotional stress I would feel upon leaving Lake House. Czarniawska (1998) identifies psychological stress in ethnographic research as a significant aspect to consider when exiting the field but I was caught unawares. Further, exiting the field was not a singular last step, rather, it was an inherent part of the research process (Michailova et al., 2014, 140).

The iterative nature of fieldwork, however, was reinforced whereby exiting the field provided opportunities for me to consider my findings, to consider Lake House, with the benefit of some time and space away from the field. After exiting, I utilised my time and space away from Lake House away from fieldwork for reflection. In this way, I continued the metaphor of the bush track, conceptualising leaving the field as taking off my bush walking shoes and putting them away but realising that memories of the walk remained with me. The bush track had been traversed, yet the sounds, sights, experiences along the way were remembered. This space away from the field allowed me to reflect, review and consider the field, which Michailova et al. (2014) call an “epistemological necessity” (p. 141).

However, even once I had left the field entirely, I found that memories would surface at inopportune times. I was crossing the road once and nearly caused an accident as I paused to check the make and model of a car that I knew Josh would particularly love. I exclaimed loudly in a quiet library when I happened across a recipe for a dessert Bella had been describing from her childhood. Coffey (1999) argues that ethnographers never completely leave the field, as it remains with them in their bodies, hearts and minds.

There is a paucity of knowledge about exiting the field in group home research and little is known about its impact on both research participants and the ethnographer. There were few previous studies to guide me or to prepare me for leaving Lake House. Michailova et al. (2014) argue that, "(w)hen exiting becomes visible, it can be reviewed and discussed by others, and others can learn from it" (p. 141). Thus, exiting Lake House was much more than preparing a celebratory or 'thank-you' afternoon tea. Upon reflection, I feel that I exited the field rather poorly. Although I had considered the impact of my departure on the housemates I had failed to consider the ways in which exiting the field is an important part of the research process. I had also failed to consider the impact of leaving Lake House on my own self. Even now, years later, I can vividly recall my time at Lake House, the housemates and our shared experiences and adventures. Lake House, too, has become part of my own story.

REFLECTION AND SUMMARY

This now concludes the two findings chapters from the thesis. In Chapter 5, I explored the physical and material culture of Lake House. Everyday elements, which might have been considered as homely or home-like elements, contributed both to a sense of home for the housemates but were also conduits for the routinisation of everyday life. Further, I explored the ways in which Lake House was a contradictory space, a home but also a workplace for the supervisors. Power relations were complex and nuanced and manifested in different ways. Yet, in spite of these un-home-like characteristics of Lake House, my findings have illustrated the ways in which the housemates constructed meanings of home within the group home environment.

In Chapter 6, I delved beneath the surface of Lake House to explore a type of sub-culture, one which is not visible to outsiders. Unspoken rules and moral codes, such as 'don't dob' were foundations of the sub-culture, which the housemates had devised for themselves. In this chapter, I illustrated the sub-culture through small acts of defiance, through breaking the rules. In so doing, the housemates have constructed home for themselves through bonds between them.

Exiting the field was not what I had imagined. I had considered the step to be the last stage on the metaphoric bush track, but I had not considered my own vulnerabilities. While challenging in ways I had not expected, exiting the field also provided space and distance from which I could consider my ethnographic material in new ways. This dynamic dance of immersion and withdrawal enhanced my analysis and strengthened my ethnography. Yet, the dance remains incomplete without consideration of the ways in which the dancer herself is affected and the music and songs she takes with her from the field.

Chapter 7: Discussion

Home is where the heart is. Trouble is, some days, I just don't know where my heart wants to be.

– Josh.

INTRODUCTION

This chapter encapsulates the findings from my study. I begin by using a literary style to illustrate the ebb and flow of an ordinary day at Lake House through temporal and spatial dimensions, drawing upon all of my ethnographic material. I use an allegory *Birds in the Banana Tree* to examine and consider how space is produced within the group home. Using Lefebvre's (1991) theory of social space, I extend understandings of group home life beyond the one-dimensional preoccupation in the literature with staff practices. In this chapter, I discuss homemaking and the home-making practices of the housemates. At Lake House, home-making occurs in and amongst complex power relations and technologies of governmentality which are not immediately apparent to others. Thus, an ethnographic methodology provided a way of seeing beneath the surface.

In this chapter, I draw upon Foucault's (1982) notions of governmentality to examine technologies of discipline and technologies of the self. The housemates actively resist and subvert the known rules of Lake House, using their own agency to resist the gaze of the group home. In doing so, the housemates use subjugated knowledge productively. Thus, a synopticon (Mathieson, 1997) is produced whereby the watched are also the watchers.

In this chapter, I challenge the ideological foundations of group homes as utopian reproductions, contrasting such ideals with the everyday experiences of the housemates at Lake House. In my study, the housemates were not passive recipients of staff practices. Rather, the housemates formed a type of subculture, one rarely seen or detected by outsiders, which was only understood through *Lebenswelt*[35]. I examine

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[35] From the German, *Lebenswelt* refers to "life world" (Childers & Hentzi, 1995, p. 362). Ethnography seeks to understand *Lebenswelt* through everyday life over time (Bucerius, 2013, p. 693).

the group home as neither a utopia nor a dystopia but as a type of 'other space', a heterotopia (Foucault, 1986). I conclude by discussing Lake House as a space which was socially produced, inverting the utopian ideal of home, a space that juxtaposed other spaces. Then, in Chapter 8, I discuss the implications from my findings and recommendations for future research.

UNDERSTANDING DAILY LIFE THROUGH ALLEGORY

At Lake House, the banana trees that line the boundary of the property are not ideal places for the small birds that live in and around the group home. The large, shiny leaves of the banana tree offer little shelter or protection from predators. The small birds have no interest in the unripe bananas that hang in tight green bunches from the branches. Sitting outside on the upstairs balcony, the housemates and I often observed these delicate, busy little birds flitting through the banana trees on their way to the dense shrubs or taller trees in the backyard with more appropriate, heavy set foliage. The banana tree, then, was a type of other space, neither a place for the birds to rest or shelter nor a place to find food, yet a space that the birds utilised and negotiated nonetheless.

The birds in the banana tree

At sunrise, the birds begin chirping in harmonious rhythm as Chloe, the first in the household to rise, wakes long before her alarm sounds. Euphonious, these little feathered creatures live part time in the banana tree next door and part time in the dense shrubs and trees of Lake House that line the neighbours' fence. Hesitatingly, the birds' flitter, randomly, from tree to tree, crossing the property boundaries in their nescient way. Chloe's weekday routine is far more systematic, each morning commences with her making her single bed, neatly drawing up the purple and black floral cover and smoothing the plush, soft blanket across the foot of the bed, both gifts from her sister. Chloe moves through her morning routine, as she has done for many years now, getting dressed, tying her hair back in a thick elastic band, taking her backpack from the closet. She moves through each step sequentially, meticulously, finishing her routine by straightening items on the low wooden dresser she has brought with her to Lake House from her childhood bedroom in her mother's house.

Chloe leaves her bedroom with the pink feature wall and pulls the door behind her, the door with the yellow sticker and the black writing that says “Bedroom”, the same sticker found on all four doors in this section of Lake House. Turning, Chloe locks her bedroom door with a key that hangs from the yellow lanyard she always carries around her neck. Padding to the kitchen in her socks, Chloe sits at the dining table and puts on her sneakers, securing the velcro tags. Uninterrupted at this early hour, Chloe is a solitary figure as she begins her day, listening to the sounds of the birds. Lake House remains silent. Now, it’s time to make a cup of tea.

In the kitchen, over Chloe’s left shoulder, are a series of officious signs taped to the fridge and walls. Printed in large, bold letters the signs host numerous instructions and directions and reminders to the housemates. “Put the correct items in the recycling bin!”, “Check the use by date on the milk!” “Remember to take out the rubbish!” The exclamation marks, positioned at the end of each directive, makes the signs seem urgent, yet, together they blend into one, the details lost amongst the plethora. The housemates cannot read the signs, cannot read the words. Indeed, Chloe pays no heed to the signs as she retrieves the milk from the fridge, omitting to check the use by date, letting the fridge door close behind her as she moves to the bench near the back door to turn on the kettle. Pouring a third of milk into her favourite mug, Chloe adds a tea bag and one level teaspoon of sugar and looks out at the birds while she waits for the kettle to boil. On the ceiling, high above the fridge, are bright orange pipes that connect the fire system, their vibrant hue in stark contrast to the muted, cream coloured walls. Green exit signs, like the ones found in shopping centres, hang from ceilings and walls. The kitchen walls display evacuation maps and floor plans with print so small they are hard to read, the words cryptic to the housemates in any case. These signs, I am told, are for the ‘men in suits’, as Josh calls them, the auditors who come unannounced at different times throughout the year to inspect Lake House and ensure compliance with standards and legislation.

Chloe makes her cup of tea and sits at the table, her thin frame and narrow shoulders barely taking up any space, swamped by the large green windcheater she favours, of which the supervisors heartily disapprove. The salt and pepper shakers are neatly aligned in the basket in the middle of the table. The kitchen is an orderly space, everything has a place. Chloe doesn’t disturb the careful order, quietly washing her mug, using the tea towel to wipe every edge before placing the mug back inside the cupboard in its designated spot. Inside the cupboard, too, everything is in order. The crockery neatly stacked, the glasses lined up in neat rows. Slipping out the back door, past more paper signs with bullet points, long lines of black text running down white pages, Chloe slings her large backpack over one shoulder and walks to the bus stop. If the supervisors could see her, they would admonish her, worried about her posture, Chloe is always told not to put her backpack on one shoulder alone. However, there are no supervisors to see her at this hour, her favourite time of day, only the birds in the banana tree, as her footsteps fall evenly as she walks down the long, concrete driveway to catch her bus.

Upstairs, the morning silence is broken with cupboard doors opening and closing, the scraping of the solid wooden dining chairs across the lino, a shout of 'who used the last of the milk?' Maggie and Rose, unexpectedly, erupt into fits of giggling, with loud, gasping breaths, a shared joke between them. Although the kitchen is small, with little room to move, Maggie and Rose share the space companionably. In between laughter, Maggie hands Rose the mugs and teaspoons while Rose fills the kettle, unravels the teabags from their ties and places a spoonful of sugar in one mug but not the other. Maggie moves to the fridge and gets the milk, and waits, pausing while Rose pours the hot water, Maggie follows through with the cold milk; a well-practiced synchronicity between them.

Downstairs, the housemates emerge from their bedrooms, these too feature the yellow labels with 'bedroom' written in black text and, identical to upstairs, the bedrooms for females have a pink feature wall while the bedrooms for males each have a blue feature wall. Bella and Andrew begin their morning routines, skirting around one another in the tight yet functional kitchen, the space identical to the one upstairs, homogenous and rigidly ordered. The rules of Lake House do not permit personal items in the common areas and there is no personalisation found here in the kitchen, testament to compliance with the rules, its starkness a homage to functionality and order. Andrew goes to the pantry and grabs a box of cereal, Bella slides past him to get to the fridge.

The housemates are confident here, in their morning routine they are assured, and there is a familiarity, a predictability, in their movements, a comfort in the monotony. Suddenly, and jarringly, the back door opens in a flourish, the screen door slamming loudly as the supervisor barrels through, barking instructions back and forth, rapid fire, which causes Andrew, Bella and I to jump. ‘Meds! Meds! It’s time for Meds!’ the supervisor shouts, disrupting the synchronous movement, signally the next part of the morning routine; the medication regime. Andrew and Bella immediately sit down at the table as the supervisor checks dates of birth and asks for names before dispensing the tablets into waiting hands. Prepared, Andrew has a large glass of water on the table and Bella, too, has anticipated this regime and has the cup of tea she prepared earlier. The supervisor issues praise and then leaves the kitchen, moving upstairs, to repeat the bellowing and barking. Hearing the commotion downstairs, Rose and Maggie are already sitting at the dining table, ready for their medications, too.

After the other housemates leave Lake House for the day, for their work or day programme activities, Josh arises, his slumber unaffected by the hustle and bustle of the morning routine, warm and safe beneath his doona with the red racing car. Often, Josh begins his morning with a Pepsi and one of his carefully rolled cigarettes, contraband at Lake House, but he ignores this rule as he sits at the round, wooden table in the backyard. By now, the supervisor has left for the day, their morning shift complete, to return later in the afternoon. The day stretches ahead for Josh as he puts his hands behind his head and shuts his eyes, his face turned toward the sun. Today, Josh is mowing a neighbours’ lawn for some cash in hand which, he says, will pay for his beers at the pub this Saturday night. First, though, he must procure a lawn mower. Josh ponders this dilemma as he finishes his Pepsi, crushing the can in his hand before flinging it into the recycling bin, the loud noise startling the small birds who fly out of the nearby bush and into the sky.

At 3pm, Lake House comes alive again as the housemates begin to return home. The supervisors’ car is once again parked in the carport, which can accommodate up to four staff vehicles. The supervisor is in the Cottage, the staff quarters and office, complete with computer, internet, phone, printer and locked filing cabinets. Each Monday morning, the co-ordinator works from Lake House, occupying the Cottage as she reviews the paperwork and the household budget, to ensure accounts are in order, receipts are correctly placed and to monitor the correct completion of the communication book and shift reports. In the deep drawers of the locked, heavy metal, filing cabinets are old file notes and incident reports, records of any misdemeanours by the housemates.

Recently, there has been an absence of incident reports, the housemates have been compliant and well behaved. Still, the co-ordinator is required to monitor and to report back each week to the Organisation. Bella and Andrew return home together, the bus from their sheltered workshop dropping them at the front of Lake House. Both are wearing high vis shirts and carry backpacks. Bella retrieves her empty lunchbox and puts it in the sink as she sings out to Josh "Hi honey, I'm home!" Josh, who is lying on the couch, stretched out fully, his toes on the arm rest, yells out "Welcome home, honey! How was your day?" Every day their routine is the same, Josh calls it 'chillaxing' as he waits for Bella to get home. She brings him a Pepsi and they sit on the couch and chat. Meanwhile, Andrew has emptied his backpack and changed clothes, putting his work clothes in a pile for Saturday, which is washing day according to the chores roster posted in the kitchen.

Rose, too, has returned home and she enters downstairs, knocking first as is her custom, and joins Josh and Bella in the lounge room. When Maggie returns home, Rose joins her upstairs as they call out for Andrew to come and help them set up the Wii. The supervisor enters the backdoor, the leisurely pace is disrupted as the chores roster is consulted, tasks appropriated, and dinner preparations begin. The first to leave Lake House this morning, Chloe is the last to return in the late afternoon, walking upstairs with her heavy backpack she goes straight to her bedroom and closes the door. The supervisor spies her and yells out "You shouldn't carry your backpack like that, Chloe, it's very bad for your back!"

Tonight, the menu plan announces, is sausage night, for both upstairs and downstairs. This is a favourite meal, on weekly rotation. It's Josh's turn to cook tonight and he halfheartedly turns the sausages in the silver electric frypan, more interested in his conversation with Bella than the sausages which are barely sizzling on the low heat. On the stove beside him, a pot of water boils, already filled with chunks of potato which Bella has prepared earlier with the assistance of the supervisor. A small bowl of frozen peas sits on the bench, covered in plastic wrap, waiting to go into the microwave. Andrew has set the table and has taken tomato sauce from the fridge, placing the red bottle on the table, before reconsidering and, returning to the fridge, he takes out a hexagonal glass jar of chutney as well.

The supervisor flits between upstairs and downstairs, issuing various instructions, adding a sense of chaos to the already well organised routine. Debate is raging upstairs between Maggie and Rose about whether to add the frozen corn cobbs to the pot of boiling water on the stove, which also has chunks of potato, or if the cobbs might be better in the microwave. Maggie consults the supervisor, who says the microwave would be preferable. Rose takes out a container of margarine and talks about how her mother used to always put 'butter and salt' on her corn when she was growing up. At home the corn was always homegrown. Rose fondly recalls the large family gatherings they had celebrating the harvest of the corn, which used to grow in their backyard in rows she had planted earlier in the season with her father.

Dinner is ready, and the supervisor returns to the Cottage to complete some paperwork and to file the daily reports. Everyone has been well behaved this evening. Except, perhaps, for Chloe, whose deliberate isolation has frustrated the supervisors. Upstairs, Rose and Maggie are eating dinner together at the table, Chloe has refused to come out of her bedroom for dinner. Rose has left a plate for her, setting it on a dining chair which she has brought to Chloe's bedroom door. Maggie added cutlery, and upon further discussion they debated adding a glass of water, Maggie eventually deciding it might spill so they omitted it. Downstairs, everyone is eating, too. After the meal, the supervisor returns and consults the chores roster, issuing further tasks and monitoring the cleanup. Crossing off a checklist, attached to the inside of the pantry door, the supervisor discusses with Bella the next grocery shop. Tonight, is bin night and the supervisor works with Andrew to check the contents, ensuring the recycling is correctly separated. Together, they discuss the remaining chores for the evening.

Upstairs, the supervisor notices that Chloe has not come out of her room to have dinner. The supervisor enters Chloe's bedroom and a muffled conversation can be heard. Chloe emerges, followed by the supervisor, and sits at the dinner table while the supervisor reheats the food in the microwave. Chloe eats a little, the supervisor watches, and then is called away as Rose asks for advice about what to wear tomorrow. Finishing her meal, Chloe washes her dishes and puts the plate and cutlery away and makes herself a cup of tea. After all the chores are complete, the supervisor returns to the Cottage to finish off the remaining paperwork.

Upstairs, Chloe has retreated again to her bedroom and Rose and Maggie finish a bowling tournament on the Wii, with the volume turned down low as per the long list of written instructions on the wall titled 'Rights and Responsibilities of Everyone

Who Lives at Lake House!”. Again, the exclamation mark emphasises the importance of this list of rules which, although the housemates cannot read the list, the sign reminds them of the time the neighbour complained about the noise and they all got in trouble, with the Wii removed for a week as a penalty. Downstairs, Josh and Bella are watching TV together, curled around each other on the couch. This would not be permitted if the supervisor was present as Bella’s mother has strictly prohibited a relationship between the two. The supervisors, albeit reluctantly, now monitor the pair for hand holding or ‘public displays of affection, which Josh, laughingly, calls “PDAs”. Andrew has gone to his bedroom to tinker with his electronics, his new TV on low volume in the background as he works.

By now it is about 7.30pm and both kitchens are pristine, the bins emptied, all the chores completed and soon it will be bedtime. The housemates retire early for the evening, some having showers before bed, their clothes laid out and organised for the next day. The busy-ness and chaos of the afternoon and early evening have been replaced by a calm, relaxing atmosphere that also feels empty. If any troubles arise during the night, the housemates may call the supervisor at the Cottage, where they sleep but are not officially on duty again until 6am the following morning. Today’s routine will be repeated tomorrow, and again the next day, following suit until the weekend when new routines emerge.

As always, Josh is the last to go to bed, watching TV in the dark as the set casts a greenish glow over his face. He switches from channel to channel then turns the set off and wanders down the long hallway towards his bedroom. All is quiet again at Lake House and the birds in the banana tree have long ago settled for the night.

The allegory, *Birds in the Banana Tree*, was used to encapsulate the findings from this study. In particular, the allegory illustrates the ways in which space was produced at Lake House. The rhythm and tempo of an ordinary day shows a complex intersection of service provision intertwined with the home-making practices of the housemates. In many ways, the group home was ill-suited to the needs of the people it served. Institutional features, panoptic surveillance, a dominant focus on personal care tasks and the physical and material attributes of the abode provided a cultural context which was difficult to associate with home.

In the next section, I discuss the social, spatial practices performed by the housemates through their daily activities. The home-making practices of the housemates were rarely seen by outsiders and were not well understood by the supervisors and personnel within the Organisation. Yet, it was from these practices that meanings of home were made.

HOME-MAKING

Home-making has not been considered in the disability specific literature on group homes to date, which has been dominated by a focus on staff practices and organisational culture (Bould et al., 2018; Bigby & Bould, 2017; Bigby, Bould & Beadle-Brown, 2017c). Lefebvre's (1991) theory of social space provides a lens through which home-making at Lake House can be considered. Lefebvre (1991) argued that space does not exist, rather, it is produced, thus encouraging an examination of everyday life (Elden, 2004).

This section discusses the active home-making practices of the housemates at Lake House. Far from passive recipients of care, living within an institutional environment, the housemates used various home-making techniques to construct genuine meanings of home.

"Listen to your heart." The bright green cover of Josh's scrapbook, Figure 23, was a colourful debut, a creative prelude to the pages that lay within. Meticulously, Josh had prepared his scrapbook of home, which he used as storytelling device, a way of sharing his journey with others, to circumambulate his experiences of home. Above all else, Josh emphasised the importance of listening to your heart and following your dreams. His quote, which I used to introduce this chapter, emphasised the conflict Josh felt about where his heart belonged. Torn between home at Lake House and home with his mother, it was not the house, the physical abode, which created home. Rather, home was a place accompanied by a sense of belonging, a connection with loved ones and space one yearned to return to. Paradoxically, home was also experienced through feelings of yearning and connection. The longer Josh spent away from his Mum, for example, the more he realised that was where his heart wanted to be.

Home, then, was a space imbued with emotion (Gorman-Murray, 2007). Yet, this was not always the romantic notion one assumes. For Chloe, for example, feelings of isolation and grief were intensified at Lake House. Visits home to her mother and sister served to reinforce how this space was gradually slipping away. At Lake House, Chloe's spatial practices of secluding herself in her bedroom for long periods of time were ways of resisting the disappearing nature of her 'real home'. While Lake House was not a sanctuary (Somerville, 1992), Chloe created her own sanctuary within her bedroom, carving out a space where she belonged, surrounding herself with memorabilia that connected her to her family.

These social practices illustrated that space at Lake House was not neutral but was always being-produced (Giorgi, Padiglione & Pontecorvo, 2007).

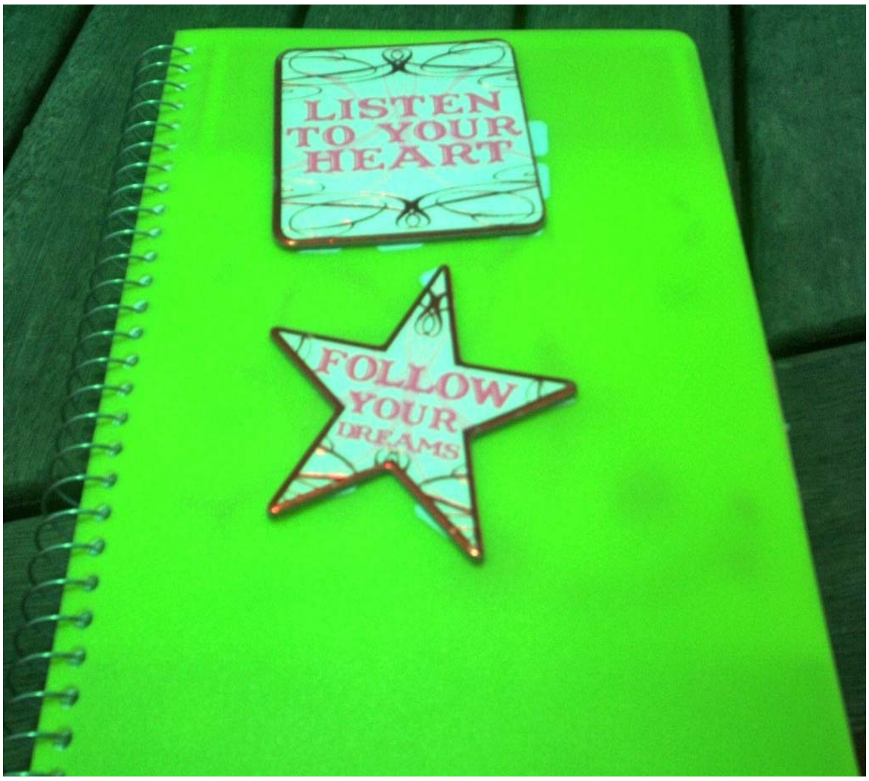

Figure 23. Josh's scrapbook of home.

The production of home. Everyday life at Lake House was highly structured and organised, fluid and dynamic. On the one hand, this routinsation of everyday life was a form of block treatment of the housemates, who were subject to regimes, rules and regulations (Goffman, 1961/1991). On the other hand, the housemates experienced and interpreted these aspects of everyday life heterogeneously. On the surface, Lake House was observed to be a totalising and oppressive environment characterised by rigidity and inflexibility. However, through *Lebenswelt* a deeper understanding of everyday life at Lake House was formed. Concomitantly, the rigid, inflexible environment of Lake House empowered Bella. Working in the kitchen, preparing the evening meal on her designated night, Bella exuded a sense of confidence. She moved around the kitchen expertly, fluidly, retrieving a knife and chopping board, mixing bowls and saucepans. Opening the refrigerator, Bella stooped to take out vegetables from the crisper, referring to her large, 'Easy Read' Kraft cooking book, with its large illustrations of the vegetables needed in the recipe. Bella looked forward to her night of cooking, as per the chores roster, the predictability and consistency providing a sense of satisfaction and enjoyment, a space to demonstrate her competency. Bella used to the group home regime to produce space for herself, constructing meanings of home. These were her home-making practices.

Chloe, on the other hand, resented the imposition of the rules and regulations and resented having to spend more and more time at Lake House when she wanted to be home with her mother and sister. Chloe's home-making practices at Lake House, then, were focused on her bedroom, where she produced her own space, carving out a niche for herself, surrounded by cherished photographs and objects and memories of her family. Withdrawing more and more into her bedroom, Chloe resisted the instructions and demands of the supervisors, telling them to 'talk to the hand'; an effective strategy as she was often left alone, left to her own devices. Chloe's resistance was part of her home-making.

Maggie and Rose produced home together, using the rhythms and routines of the day to connect with one another, drawing upon their decade's long friendship. The pair would often help one another with designated chores, giving each other a hand even when it wasn't ones own designated night. Josh and Andrew, too, produced home in different ways. While Andrew preferred to abide by the Lake House rules, Josh enjoyed pushing the boundaries, each home-making in their own way.

In an environment where shared areas were not permitted to be personalised, the housemates used home-making practices to decorate their bedrooms. Bella's bedroom, which made use of the standard pink feature wall found in all the female bedrooms, was filled with personal photographs, memories of holidays, special gifts from family and friends. Bella's home-making practices transformed her bedroom into a warm, comfortable space where she spent time each evening at her desk, with the lamp dimmed low, writing, making cards or painting her nails. Bella's bedroom décor was carefully selected, her pink curtains matching her doona cover by design. Bella spoke fondly of the process of home-making; the time spent saving her money and the outings with the supervisor to home furnishing stores. Josh decorated his bedroom with car posters and Andrew filled his room with bits and pieces of technology, storing his collection in various places around the room in an order known only to him.

Home-making practices have been identified as ways of producing boundaries of space, distinguishing home-life within the walls of the abode from the public life outside the walls. Gullestad (1984), in an ethnography of working-class Norweigan women, found home-making practices produced and maintained these boundaries between inside and outside. Tuan (1975) posited that home was a place "to which one withdraws and from which one ventures from" (p. 189). Through their home-making practices, the housemates produced spaces in their bedrooms as sanctuaries from the outside world. Chloe's use of this space, as a place in which to retreat from the outside world, demonstrated her use of the space as a way of making sense of the world (Dovey, 1985).

Concepts of homeliness and home-like-ness are problematic when considering the group home environment, despite the disability sectors historical, penchant for such evaluative approaches (Wolfensberger, 1972). As outlined in the literature review, in Chapter 2, concepts of homeliness and homelikeness have been used to evaluate group homes, to assess how 'homely' these environments are (Clement & Bigby, 2008, p. 18).

On the surface, Lake House appeared to me to be un-homely. From an outsider's perspective, I observed the duplicated spaces of upstairs and downstairs as un-homely, as uniform, deprived of individuality and personalisation. I interpreted the uniformity of these spaces as impersonal, clinical, and institutional. *Lebenswelt* however provided a deeper understanding of the ways in which the housemates use the un-homely space. The way in which Josh waited on the couch for Bella to come from work, chillaxing as he would say, personalised the space. Instead of trinkets or personal items decorating the space, it was the way Josh used the space that created home. A material environment that was stark and impersonal did not prevent home from being constructed. The print of the parrot above the couch, an identical version found upstairs above an identical couch, was of no importance to Josh. However, for me, as an outsider, the homogenisation of space at Lake House was striking.

Blunt and Dowling (2014) argue that home is neither the dwelling nor the feeling, but the relation between the two. Home is an affective space, shaped by emotions and feelings of belonging, as well as a material dwelling. Josh demonstrated the emotional feelings attached to his use of the space, this was what was important to him, rather than the physicality of the unhomely space.

Home-making practices. Formed through shared experiences, the housemates had developed a camaraderie, where they relied upon one another with an esprit de corps that belied the petty scraps and arguments and admonishments of "who used the last of the milk?" The housemates' coterie was evident, even strengthened, through united acts of resistance, evading the apparatuses of surveillance, with a collective and strategic resistance against a panoptic system. In the ethnographic piece, below, I explore the coterie in order to convey how the coterie supported meanings of home at Lake House to be produced.

The Housemates' Coterie

> It was a warm, sunny, day with a picture-perfect blue sky and fluffy white clouds which Maggie said reminded her of balls of wool. Sitting outside, at the worn outdoor table with the heavy, uncomfortable wooden chairs, Josh regaled us with stories of a recent escapade, which had us in fits of laughter. For a moment, Bella disappeared inside and through the window I could see her checking the large, silver and white clock in the kitchen. Reappearing, Bella's mood was visibly changed, her body tense and taut, she said, "Yep, it's time" and the laughter stopped. We sat in silence, waiting. "Here it

> comes" Andrew said as we heard the loud, gravelly sound of a car engine growing louder as it came closer. "[Supervisor name] is here." With a well-rehearsed synchronicity, the housemates rose in unison. Andrew retrieved a basketball. The housemates began playing, throwing the ball back and forth half-heartedly, watching the driveway, as the supervisor approached, the sound of the car engine now thunderous and hurting my ears. The supervisor paused in the driveway, idling, and wound down the window, "Good to see everyone exercising!" Then, frowning, the supervisor said, "But, you should all have sunscreen on. Bella? Where's your hat?" Winding the window up, the supervisor drove to the staff carport as the housemates and I looked at each other, vacillating. Disquieted, there was an air of apprehension amongst us, as the housemates wondered what they should do; continue playing the game or go inside and apply the sunscreen? Josh shrugged, and Andrew looked down at his shoes. Bella moved from foot to foot. Finally, breaking the tension, Maggie said, "Let's go. Sunscreen." The housemates dispersed. Just moments ago, there had been laughter and rueful shaking of heads at Josh's antics. Now, though, the atmosphere had been repossessed, transposed with the pulsating rock music emanating from the supervisor's car radio joining with the sepulchral sound of the car engine, which droned on and on.

A coterie formed through shared experiences. The housemates negotiated life at Lake House by working together, their coterie affirmed through their steadfast fellowship. The pervasiveness of surveillance at Lake House subjected the housemates to daily scrutiny from the supervisors, whose praise and punishments shaped housemate behaviour. In many ways, this panoptic environment formed a sodality amongst the housemates. A file note for Josh was experienced as a file note for all. A reprimand for Rose, who had left the chicken out on the bench overnight, was a reprimand for all. The housemates were finely attuned to the rhythms of group home life. Bella, in the excerpt above, predicted the time the supervisor arrived on shift, triggering a change in the housemates' behaviour. Working together, the housemates intentionally crafted an illusion that they had been exercising, staying healthy, playing basketball, rather than sitting around which was frowned upon by the supervisors. Formed through years of experience of group home life, the housemates were cognisant that the illusion would only work if they were all in concert.

At Lake House, the housemates had an unwritten rule which codified their conduct, “don’t dob.” Developed together, this moral code served the housemates well over time. Illustrated throughout my findings, “don’t dob” was evident in everyday life from the cover-up and solidarity surrounding the incident of the broken mop, to the hiding of the forbidden chip packets in the lounge room on DVD night, to the teamwork demonstrated to support Josh to escape Lake House, undetected, to go to the pub. “Don’t dob” was an ethos stronger than any set of rules or regulations typewritten and laminated and stuck to the walls.

It was here, within the coterie, that meanings of home were produced. Despite the institutional elements of Lake House and the strictures of everyday life, the housemates produced home together because of the ways they worked together against the panoptic system. More powerful than staff or Organisational attempts at homeliness or to make Lake House look homely, and more powerful than policy limitations on the numbers of beds in the service, the housemates constructed meanings of home for themselves. Working together to avoid getting into trouble, to avoid a file note, created a shared purpose amongst the housemates. The literature has emphasised that home is where one has control (Andrews, Kearns, Kontos & Wilson, 2006) and in an environment with high levels of external control it was through the coterie that the housemates found and exercised control. In addition, some of the housemates found control outside of Lake House with family.

Shared critical experiences are a fundamental element of home and, generally, these shared experiences are termed in positive, somewhat romantic ways, such as the celebration of birthdays or anniversaries or the welcoming of a baby to the family. Such experiences are formative of deep associations with home (Sixsmith, 1986, p. 287). My findings illustrated the ways in which critical experiences at Lake House deepened the friendships amongst the housemates. Home was created through shared experiences, a sense of protection over one another, and a sense of working together, even at times working against the supervisors. Home was created through shared experiences, the good and the bad, through warm-hearted camaraderie, convivial banter, shared laughs and jokes, and also tears and shared techniques for survival.

Home was produced through the ways in which the housemates helped each other out, such as Andrew, the self-proclaimed “IT Guy”, setting up the Wii for Maggie and Rose, and their good-natured teasing of him. The housemates understood the rhythms of Lake House and their acts of resistance, of breaking the rules, of refusing to dob on one another, served to strengthen their bonds and formed the coterie. In doing so, the housemates used their own surveillance techniques and accumulated knowledge as tools to inform acts of resistance, to avoid getting into trouble and to evade the apparatuses of surveillance. Working together, the housemates developed their own moral code and these shared experiences formed and shaped a coterie amongst them, which they relied upon to navigate everyday life at Lake House. It was through the housemates' coterie that meanings of home were constructed.

ETHNOGRAPHY, HOME AND LAKE HOUSE

In this section, I consider the contribution of ethnography to knowledge about group homes, which is often produced through service-centric perspectives. Ethnographic writing has much to offer group home research and can work together with dominant, positivistic approaches to develop more fulsome understandings of home within the complex, contradictory space of the group home.

Knowledge about group homes is developed, predominantly, from disability-specific perspectives, where the model is understood as a formal disability service. In contrast, the fundamental elements of home, such as sanctuary, belonging, or self-expression, are rarely considered. Conceptualised as sites of service provision, group homes have been explored, examined, evaluated through staff practices, staff culture, staff knowledge and funding and service models. In my review of the literature, in Chapter 2, I identified a paucity of knowledge about the group home from the perspectives of the people who live in these models of accommodation and support. My findings make a contribution to knowledge about everyday life within the group home, thus somewhat bridging the gap. My findings offer a different point of view from which to consider the group home. While the dominant hegemony is one of service provision, my findings illustrate the ways in which support is experienced by the housemates and how home extends beyond support alone.

Home within a non-home. My primary research question asked, "How do people with intellectual disability who live in a group home understand and experience home?" The answer to this question was very different for each housemate. Bella, for example, considered Lake House her "real home", however, Chloe did not. For Chloe, home was with her mother and sister. Ethnography supported my reflexive interpretation of their experiences and perceptions. Moreover, my findings showed that Bella and Chloe constructed home based on where they felt they belonged.

How then can a service system alone construct home for Bella and Chloe? The disability specific literature is preoccupied with whether group home residences look homely based on the presence or absence of institutional features (Robertson et al., 2008; Bigby & Bould, 2017). Yet, the notion of 'homely' is a deeply personal construct. A minimalist, organised environment might suit one person but feel stark and bare to another. Are all group homes to look alike based on some type of external criteria or checklist developed from criteria which academics or service providers think is 'homely'? Indeed, I would argue these types of attempts to homogenise home do not create a 'homely' environment for people who live in group homes, rather, they appropriate institutionalisation with its characteristic block treatment (Goffman, 1961).

Studies which consider whether group homes are homely or home-like tend to ignore human agency. My study makes a contribution to knowledge in this way by illustrating, ethnographically, how Bella used the structured, institutional routinisation of everyday life at Lake House productively. Bella used the chores roster and the cooking roster as opportunities to create and make home for herself and these technologies bolstered her confidence and enhanced her home-making. In contrast, Chloe resisted such routinisation and found ways to refuse and disrupt the demands made of her by such technologies and the supervisors who insisted she follow the prescribed household routines. And in so doing, Chloe, too, made home for herself.

At times, Lake House was experienced by the housemates as both oppressive and totalising and, concomitantly, as a place of belonging and sanctuary. On the surface, the impersonal, shared spaces of Lake House with their proliferation of directive, authoritative, signs, were not home-like. However, my findings illustrated the ways in which the housemates used their individual bedrooms as spaces of creativity and self-determination, using the space to express themselves, constructing their identities. Andrew surrounded himself with his electronics, reinforcing his identity as the "IT Guy" while, at the same time, living with a blue feature wall which was imposed based on sexist, gendered stereotypes. Bella, meanwhile, loved the pink feature wall and this enhanced her home-making. Her outing with the supervisor to purchase items with which to decorate her bedroom was a source of joy and illustrated the social and relational elements of home. In a space that was constructed by the Organisation as homogenous, enacted through bulk purchases of paint, Andrew and Bella used the space in different ways, but both made the space their own.

Was Lake House a home or a non-home? Ethnography provides ways of holding onto contradictory conceptualisations and by using rich, thick ethnographic description I was able to resist temptations to simplify or reduce the space.

Listening better. The housemates of Lake House had much to say about home but had few opportunities to be heard. In the ethnographic piece, ‘Up Early’, Chloe and I worked together to craft her morning routine. As someone who did not communicate using verbal language, Chloe was often spoken to, spoken about, spoken for but she rarely had the opportunity to chat about the minutiae. For those of us who use verbal language, this opportunity is largely taken for granted as we chatter throughout the day to whomever will listen to us. A quick conversation while preparing dinner, for example, may reveal a difficult day or a conversation overheard on the bus on the way home which we share with our partner or child or friend. Chloe was someone who understood everything that was said, her receptive language was good, but she had few opportunities to express herself. I have argued that the onus is not on Chloe to talk more, rather, the onus is on those around her to listen better. The ubiquitous term, active listening, has become such a cliché that its real meaning has been lost. In essence, we need to listen better, and my study makes a methodological contribution in this area.

Writing ethnographically enabled me to bring the symbolic and affective elements of home (Collier, Phillips, & Iedema, 2015, p. 695) to life and to explore them in ways that have rarely been explored before. For both Chloe and I, writing this small excerpt about her morning routine was time consuming and required a great deal of good will and perseverance on both our parts. As such an early riser, Chloe’s morning routine was unknown to others. The supervisors, who typically started their shift at 7am, did not observe Chloe in these early hours. Using a range of visual methods, Chloe and I recreated her morning routine and in so doing, I learned how she brought elements of home, her real home with her mum and sister, into her everyday life at Lake House. Chloe's genuine home, her real home, was not about notions of homeliness or home-likeness constructed by outsiders.

Writing ethnographically helped me to explore and comprehend Chloe's diasporic feelings, which she could not articulate through verbal language. Together, we co-produced knowledge about home.

By taking photographs, for example, we found we had very different interpretations of the same image. What appeared to me, at first, to be a neatly made bed was actually the result of a treasured routine for Chloe. Our work exemplified Ryle's (1949/2000) point about interpretation and the ways in which the ethnographer comes to know the difference between a twitch and a wink. Therefore, a picture never told a thousand words, rather, each picture required a thousand words, using thick, rich detailed description. In my study, 'writing culture' (Clifford and Marcus, 1986) was a way of producing knowledge about home at Lake House. My study has shown how ethnography can support the voices of people with intellectual disability to be heard in this space. Ethnography also provides opportunities for others to listen.

In the next section, I discuss other ways in which the housemates' voices were oppressed or unheard through mechanisms of surveillance and disciplinary technologies. I explore and discuss the complex grid of power relations at Lake House that were an integral part of group home life. These power relations influence and shape the very essence of home. An examination of power relations at Lake House also reveals the ways in which the housemates' used their voices in order to be heard, perhaps through small acts of resistance and subversion. At Lake House, the housemates often spoke through their actions, which is a powerful language in and of itself. However, this sub-culture was largely unseen and unheard by outsiders.

POWER RELATIONS AND LAKE HOUSE

Power within group homes is often considered in a binary way; that of service provider and service user. In group homes, paid support workers are often considered the authorities or holders of power, the providers of support, while group home residents are positioned as subjects of power (Nunkoosing & Haydon-Laurelut, 2011). At Lake House, power was much more nuanced, extending beyond such a dichotomy to various types of power relations. Surveillance at Lake House manifested in many forms; the housemates were watched over by the supervisors, but their behaviour was also regulated and controlled through various technologies. Household rules, chores rosters, the routinisation of everyday life were ways in which housemates' behaviour was regulated. However, the housemates also used their knowledge of such technologies productively.

In this section, I have used Foucault's concept of panopticism (Foucault, 1977) to consider the ways in which surveillance functioned at Lake House. Surveillance at Lake House was not a one-way mirror. While the supervisors used various technologies to surveil the housemates, in turn, the housemates used their knowledge of this surveillance to evade the gaze. In doing so, the metaphoric panopticon became a type of synopticon (Mathieson, 1997). Moreover, as the housemates worked together to evade the gaze, in so doing, they constructed meanings of home for themselves.

Governmentality and Lake House. The modern group home has been designed as both an alternative to the past and as a problematic for the future. Stuck in this interstitial space, the group home is perpetually conflicted, striving to provide quality service provision for people with intellectual disability within a model that has stagnated. Understandings of power relations within group homes often fail to consider the agency and resistance of the people who live in group homes (Bould, Beadle-Brown, Bigby & Iacono, 2018; Bigby & Bould, 2017a). Practices of freedom (Simons & Masschelein, 2005), are as much a part of Foucault's (1985) governmentality as techniques used by society, the state or by institutions to govern, mould and shape populations. Simons and Masschelein (2005) underscore Foucault's emphasis thus, "For Foucault argues that freedom, like power and government, must be brought into practice…(f)urthermore, Foucault maintains that power and freedom are not mutually exclusive entities; rather, power and freedom are intrinsically linked with each other (Foucault, 1982)." (p. 209).

Understanding group homes through this lens brings forth understandings that totalisation and individualisation can occur concomitantly and, indeed, they do not exclude one another (Simons & Masschelein, 2005). The assumption that deinstitutionalisation has concluded and, thus, the emancipation of people with intellectual disability is at the heart of what troubles Altermark (2017) who articulates his concern thus:

> It shall be made clear right away that the purpose here is not to deny that the living conditions of people with intellectual disabilities have improved because of deinstitutionalisation (see Bigby 2005; Clement and Bigby 2010, 25-27; Tøssebro 2005). Neither is it to argue that deinstitutionalisation was not important. My problem is more specific: it concerns how the perceived break between the oppression of the past and the emancipatory ambitions of present policies operates as an unacknowledged presumption for how the contemporary government of intellectual disability is interpreted. (Altermark, 2017, p. 1317).

Examining and understanding power relations within group homes, then, demands exploration of technologies of governmentality but also an examination of technologies of the self. Drinkwater (2005) emphasises that modern assumptions of liberalism also influence governmentality in the group home context:

> I want to suggest, in the spirit of Foucault, that supported-living arrangements exemplify not an emancipation, nor even a humanitarian reform, as much as a new dispersal of power relations, one that is entirely in keeping with the modern drive to greater efficiency. (Drinkwater, 2005, p. 229).

Governmentality, then, considers tensions between the individual realm and the social realm (Simons & Masschelein, 2005). In the following section, I consider different types of power relations at Lake House and different techniques for constructing desired behaviours. At Lake House, power relations extended beyond the hierarchical and the institutional remnants, however, they were not absent; rather, they became interlinked, constitutive of Drinkwater's (2005) notion of new dispersals of power relations. For example, while Lake House, a group home, was developed based on notions of community inclusion, it strongly operated as a site of exclusion from the community, through disciplinary techniques. The housemates disrupted this by constructing their own community connections and pathways and doing so when the supervisors weren’t looking. The panopticon is reversed as the housemates watch the watchers and use their knowledge productively.

Power hierarchy. A distinct, top-down power hierarchy was well established at Lake House. Oppressive and rigid, this sovereign power (Foucault, 1977) was illustrated in the ways in which the two groups conceived of themselves; as supervisor and as housemate. Foucault (1988) showed that in order to constitute ourselves we must do so through the exclusion of others (p. 146). Discourses of power at Lake House were found in the ways in which the housemates referred to their paid support workers as “the supervisors”, positioning themselves as the supervisees.

In many ways, Lake House worked to shape and reinforce these identities. Reflecting upon the experience of Josh and his mother, when they first visited Lake House, there were ways in which he was positioned as a housemate from the very beginning. When Josh was told to leave all his car collections and other memorabilia behind because “we have everything you need”, this was a way of establishing his new identity as that of housemate, encouraging him to leave his old self behind.

Goffman (1961/1991) described the ways in which the asylum worked to strip back an individual’s identity upon admission to the asylum, thus establishing a new identity for the person; as patient. In many ways, Lake House, too, operated in this way. Belonging to the housemate group meant that one had to rely on the supervisors for access to resources and valued activities. With limited literacy skills, members of this group relied upon the supervisors to read and interpret written materials. Members of this group were expected to comply with the instructions and directions of the supervisors, who held the authority to punish or reward the housemates or to withdraw or enable access to resources or activities. Holding positional authority, the supervisors had the ability to direct the everyday lives of the housemates, setting the rules and routines, structuring everyday life at Lake House. Significantly, such positioning of supervisor and housemate was also on the basis of presence or absence of intellectual disability which determined whether one was a service provider or a service user.

Each group member had specific roles and responsibilities. The supervisors constantly surveilled and monitored the housemates, checking for compliance, noting and reporting aberrations. The housemates performed their roles and had even internalised these roles. Nonetheless, the binary distinction of roles at Lake House as supervisor and housemate was far more complex. At times, the housemates themselves operated as pseudo-supervisors. Bella, for example, adept at grocery shopping, held the role of instructing Josh and Andrew at the supermarket, holding the money and asserting her role as the one who interacted with the checkout operator. Due to her competence in this task, Bella expected to have the front seat of the vehicle when going grocery shopping. The front seat, prized amongst the housemates, was a symbol of power and also the supervisors' reward for Bella's competency and skill, her assistance, in grocery shopping. Recognising Bella's valued role in this task, the supervisor ensured Bella had the front seat, and, accordingly, on these outings, Josh and Andrew automatically sat in the back of the vehicle.

However, astutely, Josh and Andrew would not accept Bella sitting in the front seat of the vehicle on outings that were not grocery related. Rather, they disputed her authority and competed with her for the prized front seat, often admonishing her and reminding her of the need to be "fair" and "share". On these occasions, Josh and Andrew adopted an informal rostering system, where Josh sat in the front seat one way and Andrew claimed the front seat on the way home. Interestingly, the driver, who was a supervisor, did not intervene or influence these arrangements which the housemates negotiated amongst themselves.

Hence, power at Lake House was more fluid than a binary delineation of housemate and supervisor. The housemates demonstrated an astute understanding of power relations at Lake House. Andrew's conscious decision to behave as less than competent when cooking the spaghetti bolognaise with the supervisor is an example where he used his knowledge of power relations purposefully. Andrew fulfilled his expected role of the supervisee, the client, deferring to the supervisors' directions, complying with instructions and deliberately holding back from a full demonstration of competence. Yet, on the weekend, when the supervisors were not present, I observed Andrew cooking his spaghetti independently, without any assistance or supervision. Andrew often spoke of his mother's advice, which he heeded, "keep your head down and bum up", which meant doing what was expected in order to avoid getting into trouble. Although it was unclear what sort of trouble Andrew may have been in had he demonstrated his good cooking skills, it was clear he had his own reasons for holding back.

In other ways, the supervisors were not always the power-holders, their power was fluid and subjective. The supervisors were themselves the subject of power from the Organisation, required to follow operational policies and procedures. In turn, the supervisors were monitored by the Co-Ordinator, who was monitored by the Area Manager and so forth. Disability support workers are themselves an oppressed and powerless group, at times, with a history of exploitation, poor working conditions, and issues of understaffing and low pay. The supervisors were also subject to power from family members, whose instructions they were expected to obey. At times, the housemates used their knowledge of the limits of the supervisors' authority to their advantage. Chloe, for example, was not always compliant with the supervisors' requests and instructions. Over time, she had developed a highly effective strategy of telling the supervisors and other housemates to "talk to the hand" when she did not wish to engage or follow instructions. Although Chloe was subsequently labelled by the supervisors as non-compliant or difficult or challenging, her strategy was surprisingly effective. Further, Chloe's 'talk to the hand' disarmed and infuriated the supervisors, thus effectively disrupting power relations. Quite unexpectedly the person who had been subjected to power became the holder of power, using this knowledge productively.

Agency and resistance at Lake House. Power at Lake House was complex and nuanced. The housemates demonstrated their knowledge of the grid of power relations and showed how they used this knowledge productively. This study has illustrated the ways in which the housemates created an illusion of compliance with the rules and regulations of Lake House in order to subvert them. The housemates employed different strategies to achieve this. Resisting the imposed routines, the housemates would wait until the supervisor left or went to sleep before going for a walk or watching DVDs. An inherent part of resistance was collusion. The housemates created their own moral code, 'don't dob', to cover for one another. Problem solving together to avoid getting into trouble was another key strategy of resistance, illustrated by the collective ideas to hide the broken mop and bucket and the solidarity enacted when the housemates were threatened with punishment in the form of file notes.

Other acts of resistance included hiding the ugly book, stashing soft drink and food, disobeying instructions, breaking the rules, covert sexual relations and Chloe's overt 'speak to the hand'. These are what might be called subtle strategies (Scheyvens 1998; Bell, 2012) yet they formed a type of subculture at Lake House, one rarely seen or detected by outsiders. Petesch, Smulovitz and Walton (2005) described agency as being able to envisage different paths (p. 42) and this was illustrated by the housemates through their strategies of resistance. Further, if one strategy proved ineffective, or was detected by the supervisors, then other strategies were enacted. Thus, resistance was fluid and dynamic and creative and never static. This fluidity in itself was a type of agency within constraint (Bell, 2012).

The Cottage. A fulcrum of authority, the Cottage was reminiscent of the nurses' stations that sat in the middle of the wards of the institutions where I had worked in the 1990s. Acting as the locus of control, the Cottage was the physical embodiment of the power hierarchy, the binary distinction of roles at Lake House. In many ways, the Cottage was the hub of surveillance in the panoptic system of Lake House. From their vantage point, the supervisors were able to see the housemates, but the housemates could not see into the Cottage. Thus, the housemates never knew if the supervisors were watching them or not. Often, the supervisors yelled out instructions from within the Cottage, "Josh! Leave that lizard alone!", "Andrew! Get your washing off the line!" or "Rose! I need to see you! Come here, please!"

However, the housemates also watched the Cottage and with this knowledge they were able to predict the supervisors' movements. Bella's role on Friday nights as lookout for Josh meant she watched for the supervisors' bedroom light to be extinguished before giving Josh the "all clear" signal for him to begin his night-time adventure to the pub. At other times, Maggie and Rose would sit at the table on the upstairs balcony, watching for the supervisor to emerge from the Cottage. This movement was a sign for the two women to "get moving", where Maggie would announce "breaks over!" and she and Rose would get up and move inside to begin dinner preparations.

The Cottage was the physical hub of authority at Lake House and a repository of power. The Cottage was where visitors and other authority figures congregated. Each Monday, the Co-ordinator worked from the Cottage, reviewing incident reports, completing administrative tasks and ensuring the supervisors had complied with the expectations of the Organisation. Meetings, which Andrew called "official business", were all held at the Cottage. An athenaeum of aberrations, recorded in file notes, incident reports, client files and communication books, the Cottage held years' worth of past transgressions stored in metal filing cabinets for perpetuity. Thus, the Cottage was a way of recording and storing surveillance. Even when the housemates were not physically being observed or surveilled, their movements were being detailed and recorded through shift reports, notes in the communication books, in client progress notes and monthly reports for the Area Manager. Rewards and punishments emanated from the Cottage. It was a space where file notes were written, and the supervisors worked together to develop and meter out appropriate punishments, such as when Rose was prohibited from attending a social outing because of defiant behaviour exhibited during the week.

Although the Cottage was the exclusive domain of the supervisors, its very existence was only possible because of the existence of the housemates. Client files were only possible because there were clients. Staff communication books only existed because of the existence of the housemates. Indeed, there would be no supervisors and no Organisation without the housemates. In this way, the housemates, while often physically excluded from the space of the Cottage, were inherently part of the space.

Lake House and the metaphoric panopticon. Throughout historical epochs of care, people with intellectual disability have been subjected to various types of power aimed at regulating and producing docile bodies (Tremain, 2005). Both Goffman (1961/1991) and Foucault[36] (1963/2012; 1977; 1980) wrote of the gaze in total institutions with Foucault first using the concept in *The Birth of the Clinic* (1963/2012) and later defining it thus;

> There is no need for arms, physical violence, material constraints. Just a gaze. An inspecting gaze, a gaze which each individual under its weight will end by interiorising to the point that he is his own overseer, each individual thus exercising this surveillance over, and against, himself. A superb formula:

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[36] O'Farrell (2012) argues that Foucault's (1963) use of 'le regard' has been translated as 'the gaze' but in fact this is an imperfect translation.

> power exercised continuously and for what turns out to be a minimal cost. (Foucault, 1980, p. 155).

Foucault's notion of panopticism (1977, p.195) was a useful theoretical concept within which to consider power at Lake House and the ways in which disciplinary power, surveillance and knowledge, operated within the group home environment. Semple (1992) refers to Foucault's use of Bentham's Panopticon as "…an emblem of modern power." (p. 108). As discussed in my review of the literature in Chapter 2, Foucault used Bentham's design of a penitentiary system of surveillance where inmates were never sure if they were being watched by guards posted at the watchtower at the centre of the circular, imposing structure of the Panopticon. Bentham's design of the Panopticon used space to position guards as unseen, through use of mirrored glass, and prison inmates were cast into space where they could always be seen. In this way, inmates were led to believe that they were under constant surveillance and thus docile and compliant bodies were produced. The mechanism of the panopticon was used by Foucault to illustrate how disciplinary power operated differently from sovereign power (Havis, 2014).

Surveillance was an apparatus of power at Lake House. The Cottage was the physical embodiment of surveillance, the hub from which the supervisors surveilled the housemates, almost a type of panopticon in and of itself. At Lake House, the housemates' behaviour was constantly monitored, and the supervisors enforced the routinisation of everyday life. Using combinations of praise and reprimands, the supervisors constantly monitored housemate behaviour searching for aberrations. Pervasive surveillance, a feature of everyday life at Lake House, meant the housemates were constantly watched by the supervisors and desired behaviours reinforced through regimes of regulation, punishment and reward metered out by the supervisors. When the supervisors were present, the housemates generally chose to comply with their instructions and directions. However, even when the supervisors were absent, the housemates had internalised the rules and regulations and thus monitored and regulated their own behaviour. When Andrew performed his role in making spaghetti bolognaise, he was presenting a version of himself based on his knowledge of the gaze of the group home. Andrew used his knowledge of the gaze to self-regulate his behaviour.

The supervisors relied upon surveillance as a disciplinary mechanism, regulating the housemates' behaviours who, in turn, regulated their own behaviour. Even when the supervisors were not present, the housemates often behaved as though they were. At times, my role at Lake House was a difficult one. The supervisors sometimes expected me to surveil the housemates and behave like a pseudo-supervisor. Yet, I tried to resist such positioning. I explore this in more detail in the following excerpt:

Spoilt milk

As the housemates and I worked together creating scrapbooks of home, using images, drawings and anecdotes we had collected, we often sat at the heavy wooden table in the back yard. Part of the convivial nature of our work was sharing cups of tea while we worked. In both the downstairs and upstairs kitchens, there was an identical sign stuck fast to each refrigerator reminding the housemates to check the use-by-date on the milk before consumption. In many ways, the sign was entirely ineffectual. Firstly, the housemates could not read the sign. Secondly, the sign had been on the refrigerators for so long that it had been forgotten by everyone long ago. However, the sign provided something tangible that the supervisors could point out to auditors, or to the Co-ordinator, or to Community Visitors that demonstrated to others that the supervisors were, in fact, being diligent in their duties. In effect, the supervisors had made a sign to show others that they had taken steps to protect the housemates from falling ill from drinking curdled milk.

I contrasted this sign, whose edges were yellowing and beginning to peel away from the fridge the glue loosening with age, with the incident where the housemates and I all received a lengthy lecture from the supervisor for not putting the groceries away on the landing (see section 'Getting Into Trouble' p. 187). The supervisor had assumed that I would take a role of pseudo-supervisor in their absence, whereby it was my job to remind the housemates to put the groceries away. This example reinforces the binary that housemates are always at the bottom of the power gradient, when even visitors such as me are assumed to be quasi-supervisors.

While we were scrapbooking, I had indeed noticed that the groceries were sitting on the landing in the hot sun, but I had not said anything. As Bella wandered into the kitchen to make our cups of teas, she had asked Josh and Andrew to put the groceries away and they said they would do so shortly. Bella prompted and reminded them, but they chose to continue scrapbooking. Bella, too, could have put the groceries away herself but she chose to wait for Josh and Andrew to do so. In any event, later that day, Bella went to make herself a cup of tea and discovered that the milk that had been purchased earlier that day had spoiled and needed to be discarded. She shook her head as she poured the 2 litres of milk down the drain, holding her nose for effect as she called Josh and Andrew to come and see what had happened. “Shit!” Josh said while Andrew shook his head. Turning toward the mug she had placed on the bench, next to the kettle, Bella said, “No cup of tea!” Andrew suggested she might try tea without milk, but Bella shook her head, disappointed. The next day, Bella, Josh and Rose went to the local milk bar and purchased some new milk, after requesting some money from the supervisor who again provided a lecture about the importance of putting groceries away.

However, it appeared to me that it was the disappointment that Bella experienced at not being able to have her cup of tea, something she very much enjoyed, that ensured she never again left the groceries out in the hot sun. Neither the deteriorating sign stuck to the fridge nor the lectures and admonishment issued by the supervisor were as effective in changing Bella’s behaviour as the disappointment she felt from not having her beloved cup of tea.

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Power relations at Lake House were complex and nuanced. Panopticism, at Lake House, was not a one-way mirror. The housemates, too, constantly watched and surveilled the group home environment. The housemates surveilled the supervisors, using their knowledge of their movements to create spaces for resistance or to escape the gaze. Through their surveillance, the housemates’ intimate knowledge of the patterns of everyday life at Lake House and the patterns of the supervisors proved to be advantageous. This was exemplified when Bella pretended to eat a healthy salad for her lunch while the supervisor was present, gaining praise for her healthy choices. Then, when the supervisor finished his shift, Bella promptly put the salad in the bin and made herself a plate of cheerios with tomato sauce instead.

Goffman (1961/1991) wrote of the ways in which inmates in the asylum found ways to escape the gaze, often through resistance. Knowledge of the metaphoric Panopticon at Lake House empowered the housemates to maximise opportunities to escape the gaze. The housemates' knowledge of the patterns, rhythms and routines of the supervisors enabled them to create opportunities to break the Lake House rules, without detection. Josh snuck out the front door, or his bedroom window, on Saturday night, once the supervisors retired for the evening, using his knowledge of the gaze productively in order to escape undetected. Bella, too, was his accomplice and provided the signal for when the supervisor had retired for the evening. Eating chips in the lounge room on DVD night, for example, was a carefully constructed exercise. Andrew and Bella only brought out the potato chips, treats which were not generally permitted at Lake House, once the supervisors had retired to the Cottage for the evening. Further, the treats had been smuggled into Lake House in the first instance when the supervisors were not on duty, thus, the contraband was not detected. Andrew and Bella went to great lengths to conceal the potato chips in their bedrooms, choosing hiding places carefully, with the knowledge that the supervisors could go through their bedrooms at any time, but most likely when Andrew and Bella were away at work.

At times, surveillance was welcomed by the housemates. The supervisors regularly inspected the housemates' bedrooms to ensure they were clean and tidy. On the surface, this approach appeared to me to be oppressive. Rose, however, enjoyed having a tidy bedroom but identified that she often lacked motivation for the "big jobs" of cleaning and tidying. Working together in her bedroom, Rose and the supervisor dusted the bookshelf in synchronicity; Rose removed books as the supervisor ran the feather duster across the surface, and then Rose returned the books. Then, the supervisor dusted their spines and, moving lightly across the top of each book, skirted over to intentionally dust Rose exclaiming, "Ooops!" as they both burst out laughing. Symbiotically, they completed the requisite task, transforming the interaction into an opportunity for banter, humour, and shared anecdotes and conversation. The surveillance, then, was productive, an assurance for Rose that the job would be done properly and to a satisfactory standard. Further, the presence of the supervisor motivated Rose to "do a good job" and Rose enjoyed the companionship. The supervisor appeared to enjoy the interaction too. Finishing the task, Rose and the supervisor collected the bags they had filled with clothes to donate to charity and took them to the supervisors' car.

Indirect surveillance. Foucault's (1977) concept of disciplinary power describes specific power relations which operate on individuals. There were many forms of surveillance at Lake House and indirect surveillance was a technology upon which the supervisors and the Organisation relied. The men in suits, for example, the unseen auditors at Lake House were used as a way of influencing housemate behaviour. Lake House folk lore held that the auditors required the housemates to maintain a clean bedroom at all times. And because one never knew when an auditor may visit, the supervisors encouraged the housemates to be prepared because, so the legend went, "you never know" what might happen if the men in suits happened across an untidy bedroom. The myth of the men in suits ensured that the housemates lived in a state of trepidation and, thus, were more amenable to requests to keep their bedrooms neat and tidy. However, there were also small acts of resistance. Josh maintained a laissez-faire attitude, unresponsive to the threat of the men in suits happening across his messy bedroom with clothes strewn across the floor and an unmade bed. His attitude was a source of frustration for the supervisors who continuously nagged him to clean his bedroom to no avail. In turn, their obvious exasperation was a source of amusement and satisfaction for Josh.

Chloe, too, had developed a repertoire of insubordination, her stubbornness was highly effective. At times, Chloe didn't feel like cleaning or tidying her bedroom and during these times the supervisors were unable to persuade Chloe otherwise. Instead, the supervisors utilised the time during the day while Chloe was at work to enter her bedroom "give it a good going over", cleaning until it was pristine and, in the process, discarding her treasured collection of half-empty coke bottles.

Power is everywhere. In considering power at Lake House, then, it is useful to consider Foucault's notion that "power is everywhere" (Foucault, 1980). Rather than considering power as something which is exercised by some upon others, power is considered to be a relation. Some scholars have found limitations with Foucault's theorisation of power, critiquing his overemphasis on technologies of power (Hughes, 2005). Other scholars have turned to the work of Guattari and Deleuze to emphasise ways in which power can be used to resist and to reverse Foucault's "coercive structures into process of emancipation" (Holmes, 2007, p. 2).

At Lake House, power was more akin to a grid of power relations than a hierarchical structure of power with the power-holders at the top of the hierarchy and the power-less at the bottom. The metaphoric panopticon of Lake House could be understood as part of a totalitarian environment whereby totalising surveillance was oppressive. However, the housemates demonstrated how they used their knowledge of the gaze productively, their knowledge of the existence of the panopticon advantageously. Thus, power, and the metaphoric panopticon, was not reduced to only being oppressive (O'Farrell, 2012, p. xi). The housemates, too, constantly watched and surveilled the supervisors. The panopticon, then, was not a one-way mirror, or a one-sided apparatus. Instead, the panopticon was a place from which the housemates were seen and observed by the supervisors, but it was also a place which the housemates were cognisant of, a place where the housemates also observed the supervisors, watching the panopticon and using its patterns and temporal motions to their advantage. As the metaphoric panopticon, with its all-encompassing gaze, was watching the housemates, they, too, were also looking back, constantly watching and monitoring the panopticon.

Reflection and summary. This section has highlighted the complex, nuanced grid of power relations at Lake House. Power, often conceptualised in terms of power-holders and the powerless, was not so distinctly defined at Lake House. Within a constrained environment, the housemates nevertheless demonstrated agency and resistance. Bell's (2012) notion of agency within constraint provided utility within which to consider how the housemates worked within this frame. The housemate's knowledge of the rhythms and regimes of Lake House enabled them to evade the gaze, using power productively. Although carefully carved, this space of resistance was not immediately visible to me and was only made known through extended periods of time in the field combined with a strong foundation of trust amongst the housemates. Thus, 'thin agency' (Klocker, 2007) was inverted as power was used productively and the housemates constructed meanings of home for themselves.

HETEROTOPIA AND THE GROUP HOME

Emerging from an institutional history, the group home model of support has a legacy which is never far from the surface. Disability service providers and the disability sector more broadly has consciously applied its efforts to creating homes for people with intellectual disability which are the antithesis of institutional living. Ironically, then, in so doing, the sector has created spaces which are neither mini-institutions nor do they fully achieve the ideals of home, community engagement and social inclusion. Group home research has tried to provide ways for service providers to create more homely and home-like environments for the people they serve (Robertson et al., 2008). Yet, these efforts have served to create artificial reproductions of home. This section of the discussion chapter considers the ways in which the disability sectors endless quest for the ideal reproduction of home contributes to more and more inauthentic representations of home. The group home model of accommodation and support has inverted many of the fundamental elements of home, thus creating small worlds which reflect and contrast home (Foucault, 1986). In this way, group homes can be considered a heterotopia, a type of other space.

Utopia considered. A utopia is characterised as a type of idealised space, a perfect society (Davis, 1981). Although a clear definition of utopia is elusive (Claeys, 2013), notions of idealised spaces can be found. In urban development, for example, once so-called undesirable suburbs have been gentrified and marketed as "idyllic landscapes to ensure a variety of lifestyle fantasies" (Macleod & Ward, 2002, p. 154). Former residents, however, may reject the new transformations thus illustrating the problematic of considering utopia as one type of thought or space. Home has often been conceptualised as a romanticised ideal (Rubenstein, 2001), typified as a sanctuary, a refuge from the outside world, a place of tranquillity (Coontz, 1992), even a sacred space (Dolgin, 1999). Reflecting upon my fieldwork at Lake House, it was hard to weigh up the chaotic, busy everyday life with such ideals of tranquillity. In my own experience of Lake House, from my very first day fieldwork, I found the bustling environment noisy, often chaotic, with very little space where one could sit and think or gather one's thoughts. I often found it quite impossible to get even a moment's peace to think. At times, when my fieldwork was finished for the day, I relished the quiet, peaceful time that Andrew and I would share as he walked me to my car. There was a sense of constant activity and chatter at Lake House, always so much to get done, urgently, so many tasks to complete; tranquil was not a word I would have used to describe Lake House.

For Rose, however, the 'busy-ness' of Lake House was an aspect she loved, cherished and deeply enjoyed. After the death of her mother, Rose had spent time in "independent living", which was service language for having a flat in the community where she lived alone with drop-in, outreach support a few times a week. Rose recalled coming home from work, her heart sinking as she turned the key in the door to find an empty flat, cold, dark, with no one to welcome her home. Sitting on the couch in the dark, alone, Rose would cry for hours, the loneliness she felt overwhelming her. Holidays were the worst, when no one would come and there was no work to escape to. Holidays, events which Rose had so looked forward to when her mother was alive, were now lonely, isolation occasions. On weekends and in the evenings, Rose would sit by her front window, hoping for someone, anyone, to walk by. During these times, home may have been tranquil, my own ideal, but it felt empty to Rose, "it was like a prison" she told me "I'd unlock the key and enter my very own prison cell, closing the door to the outside world behind me." There was no sanctuary at home, only loneliness and isolation. In contrast, Rose enjoyed the constant movement of Lake House where "there is always someone to talk to, someone to tell your troubles to or a shoulder to cry on."

Within the group home, I found these romanticised, utopian ideals of home were juxtaposed through everyday life. For example, home, often referred to as a place of belonging, which Sixsmith (1986) described as, "comfort, relaxation, familiarity contribute to a sense of belonging to home" (p. 287), was contrasted by the housemates' lived experiences. For Bella, Lake House was a place where she felt she belonged, the group home provided a space for her to really come into her own. In the kitchen, moving around the space with an assuredness that spoke of confidence and competence, Bella was not struggling to be recognised. Her self-appointed nickname as the "Domestic Goddess" of Lake House was apt and spoke of her identity, her position at Lake House, her niche, her own "corner of the world" (Bachelard, 1964, p. 4). In contrast, when we were out at the local shopping centre and Bella was the subject of stares from strangers or young children who would point at her and ask their mother's what was wrong with her, Bella retreated into her shell. At Lake House, Bella was almost unrecognisable from the insecure, awkward, fragile woman I sometimes glimpsed in unfamiliar situations with strangers. At Lake House, I saw in Bella the comfort, relaxation and familiarity that Sixsmith (1986) spoke of as constitutive of a sense of belonging.

Nonetheless, in contrast, there was Chloe who categorically rejected Lake House, steadfastly refusing to identify the group home as a place where she belonged, yearning to return to her family home. For Chloe, her sense of comfort, relaxation and familiarity were all found with her mother and sister. Lake House was a place to be when she couldn't be at home, her real home, as her mother's health deteriorated and necessitated Chloe's placement in the group home. Thus, belonging, one part of a sociability associated with utopia (Claeys, 2013) and an element identified in the literature as a fundamental element of home (Sixsmith, 1986) was sui generis at Lake House, influenced by the biographical histories and experiences of each housemate. Belonging was a feeling, but it was also tied to place. For Bella, Lake House was a distinct place of belonging especially when contrasted with places where she felt she did not belong. For Chloe, though, the place she felt where she belonged was not the place where she currently found herself. In many ways, Chloe's memories of her family home were the source of her sense of belonging. She kept these memories alive and interwove them with her everyday life through her morning ritual, for example, thus, a sense of belonging had temporal as well as spatial elements.

Utopianism, or an idealised space, is found in the literature on group homes where scholars have tried to develop evidence-based guides to good group homes (Bigby & Bould, 2017). The utility of such guides for service providers is significant. Yet, surprisingly, the guide to good group homes by Bigby and Bould (2017) was developed without the inclusion of people with intellectual disability. Moreover, the authors describe the target audience for the guide as families or carers trying to assess a group home for someone they support and professionals seeking direction about what makes a good group home (Bigby & Bould, 2017). By not including people with intellectual disability in either the consultation or development of the guide nor by considering this group to be a target audience, the guide becomes problematic.

Attempts to produce good group homes must consider the ways in which home is a space which is being-produced (Lefebvre, 1991) and must necessarily consider the agency of people with intellectual disability. With good staff support, group home residents, including people with severe and profound intellectual disability, can be actively supported to express choice and preferences within their home. People with intellectual disability are not merely the recipients of good group home service provision, they are actively part of the *being-produced* space. As service providers try to provide good group homes, reproducing utopia, they must reimagine home and service provision as their exclusive domain. Utopia is not just an aesthetically pleasing cityscape. Inherent within utopian societies are notions of ideal sociability (Claeys, 2013, p. 145) which, in a group home context, requires consideration of the ways in which spaces of home are created intersubjectively (Price, 2000). This demands the inclusion of multiple social actors in the co-production of home.

Reproducing utopia. Disability services are adept are trying to reproduce the conditions of everyday life for the people they serve, with normalisation's (Nirje, 1969) principles well embedded. The production of group homes through the reproduction of heteronormative standards of home has been the hallmark of the group home model. At Lake House, this 'ordinariness' at the heart of the group home model (Towell, 1988) was a façade. The neat and tidy front garden, for example, was too neat, too well maintained with no personalisation of the space. The housemates were not involved in maintaining the space nor in its planning and decoration. In fact, the front garden was never used by the housemates. Whereas neighbouring houses had garden ornaments or decorative features, personally chosen and placed by the occupants, the front yard at Lake House was curated by others. That the housemates could contribute or may have wishes and desires about the garden, did not occur to the supervisors who saw this space as the domain of the gardening work crew. Such silos of labour were privileged over home-making activities. Thus, disruptions to ordinariness (Towell, 1988) were much more than just physical location and appearance.

The reproduction of home for people who live in group homes also fails to recognise the agency of people with intellectual disability who live in group homes. Instead, residents are positioned as passive recipients of the service model. In large part, disability service systems have assumed responsibility for striving to reproduce a type of homogenised utopia with the group home model of accommodation and support. Lefebvre's (1991) theory of social space recognises the intersubjectiveness of the production of space. Why, then, is the production of home within the group home considered the purview of service providers alone?

Enduring conceptualisations of group homes as sites of service provision, where utopian ideals of home are reproduced, fail to consider the ways in which home is constructed and made by its occupants. At Lake House, the housemates had come to live together because of bureaucratic vacancy management systems designed to fairly ration scarce resources in the face of high unmet need. In stark contrast, the literature on home for people without intellectual disability emphasises the importance of reciprocal, freely chosen relationships and a sense of belonging (Somerville, 1992; Mallett, 2004; Blunt & Dowling, 2014). This contrast is also found when considering Article 19 of the UNCRPD (UN, 2006) which specifically states that persons with disabilities have the right to choose where and with whom they live and that they are not obliged to live in a particular living arrangement (p. 13). Yet, group homes remain unable to offer such choice and control although the potential to offer this under new paradigms of support, such as the NDIS, remains to be seen.

However, for Rose and Maggie the vacancy management committee had achieved service user compatibility, service-centric language for what Rose and Maggie simply called ‘getting along’. More than this, though, Rose and Maggie shared an enduring bond, a close friendship and considered themselves sisters. Over time, through living together at Lake House, they became chosen family. In contrast, for Chloe, her mother’s deteriorating health necessitated her placement at Lake House and the vacancy she occupied arose from the death of a former housemate. Lake House was not her home. Vacancy management was not responsible for the reproduction of home, rather, in both exemplars, it was the ways in which the housemates experienced and produced the space that created home or non-home.

The intensely personal, individual nature of home is also not recognised in the reproduction of home for people with intellectual disability through the group home model. Standardisation of group homes, under the guise of quality service provision, can work to deny individual self-expression.

At Lake House, the sign at the front of the property immediately distinguished this home from other homes in the neighbourhood thus disrupting the ordinariness of the abode. Bigby and Bould (2017) suggest, in their guide to good group homes, that “there are no signs at the gate or front door with the logo of the organisation or other things that might suggest this home is different from any other in the street." (p. 7). Removing the sign at the front of Lake House would be a good start, an easy task to complete, but it would also be insufficient and superficial. The sign at the front of Lake House was emblematic of a deeper problem of complex power relations and the infantilisation of the housemates as requiring protection and care.

The removal of the sign again assumes that home can only be produced through staff or service provider actions. Bachelard (1964) conceptualised home as a way of being in the world. If that world is continually shaped and constructed by others on our behalf, then we are rendered powerless. By paying scant attention to the social and affective elements of home, and Lefebvre's (1991) theory of social space, utopia will continue to be interpreted, constructed and reproduced by others, bound to remain in the domain of service provision.

Dystopia and the group home. Dystopia, described as typically an "inverted, mirrored or negative version of utopia, the imaginary bad place as opposed to the imaginary good place" (Claeys, 2013, p. 155) is a way of considering Lake House and its characteristics of the total institution. Despite the best efforts of the disability service system to reproduce utopian ideals of home for group home residents, these efforts remain reproductions, replicas of an idealised space. Home has been described as a sacred place (Dolgin, 1999), romanticised as a "…haven in a heartless world" (Kumar, 1995, p. 159). With its encompassing character, rigidity, block treatment and congregation of people on the basis of intellectual disability, Lake House embodied the dystopian total institution (Goffman, 1961/1991). In attempting to reproduce home, the group home instead reproduced power imbalances rooted in a paternalistic preoccupation with the protection and care of people with intellectual disability. Thus, the housemates re-experienced stigma and devaluation (Wolfensberger, 2002) at Lake House by positioning them as impaired, defective, deviant and in need of correction, surveillance and control.

The sign at the front of Lake House was the first visible indication that movement was tightly controlled and subject to the authority of the supervisors. From the moment one crossed the threshold, one become subject to this authority. Some technologies were carceral in nature. For example, the housemates were not permitted to leave the premises without the prior knowledge, and permission, of the supervisors.

Even access to the adjoining park next door was prohibited. Constant surveillance, a hallmark of the total institution (Goffman, 1961/1991), pervaded everyday life at Lake House. The control and regulation by the Organisation, a single authority, was evident through the policies and practices which prescribed expected behaviours. Exemplars of this included the various signs and symbols that adorned the walls of Lake House; storage of hazardous chemicals, written, laminated instructions above the washing machine that directed the performance of this domestic task, the fire evacuation plans, the multitude of signs posted on the refrigerator issuing instructions to the housemates to check for use by dates or reminders to defrost the meat for the evening meal.

On one hand, the signs and symbols regulated the housemates' behaviour. On the other hand, a benevolent intent was detected. For example, the laminated instructions for the washing machine were intended to support the housemates with their domestic duties, increasing independent living skills. The instructions were prescriptive in order to assist the housemates. However, the instructions also served to regulate and control housemate behaviours, creating docile, compliant bodies (Foucault, 1977). Moreover, the signs were not helpful in practice because none of the housemates could read them. Some housemates, based on their own personal experiences, interpreted the presence of the signs as warnings, as cautions and something to be followed or else one would get into trouble.

Through the material and physical culture and social regimes, Lake House positioned the housemates as subjects to be fixed, or treated, or cured through interventions of the supervisors, the experts. This biomedical view (Foucault, 1961) of intellectual disability dominated everyday life at Lake House. Tremain (2005) argues that governmental practices "into which the subject is inducted and divided from others produce the illusion that they have a prediscursive, or natural, antecedent (impairment)." (p. 11).

Within this context, Lake House was a space produced on assumptions that different techniques and mechanisms were required to govern their conduct (Foucault, 1977). This type of governmentality is a feature of what Altermark (2017) calls the "post-institutional landscape" (p. 1316). The shared areas within the home, for example, were constructed to be impersonal, homogenous, and subject to constant surveillance to ensure continual control and compliance. Small, seemingly insignificant items were called to order. The basket of condiments in the middle of the wooden dining table, upstairs and downstairs, was constantly monitored to ensure the salt, pepper, sauce bottles and paper napkins were kept orderly. Supervisors reminded housemates to return items to the baskets and, in turn, the housemates reminded one another to keep things orderly, thus internalising the rules and regulations of Lake House. The group home model purports to increase and enhance the independent living skills of its residents, through staff support and instruction, yet, the very model is based on one group (the supervisors) governing another group (the housemates). The governing roles were so well entrenched at Lake House that, at times, some housemates adopted the role of the governors.

Bella, for example, adopted the role of pseudo-supervisor during mealtimes, ensuring the other housemates returned items to their correct position within the household. If Andrew, for example, did not return the unused paper napkins, or if Josh hastily shoved a used napkin into the basket, breaking the prescribed order, Bella would reprimand the offender. Typically, Andrew followed Bella's directions in order to avoid an escalation and the eventual involvement of the supervisor. Josh, however, often did such things to provoke Bella and he used his charm to cajole her, to soothe her and to, ultimately, get away with breaking the rules.

Other technologies, such as the bulk purchase of paint for the feature walls in the housemates' bedrooms indicated a type of conformity. In his study of British Army life, Hockey (1986) also found technologies which reinforced conformity such as the required buzz cut hair at induction or the regulation uniform and army kit. At Lake House, bedroom colours were allocated according to gender. Females had a pink feature wall and males a blue feature wall. Other types of conformist practices included the bulk purchasing of identical sets of crockery, stored in identical ways upstairs and downstairs. Rational arguments supported such decisions. The bulk purchase of crockery was cost effective. However, the effects of such decisions were not considered. These actions served to strip away individual identity and self-expression, fundamental elements of home identified in the literature (Sixsmith, 1986; Bachelard, 1964; Blunt & Dowling, 2014) as important to the construction of home.

Other examples of institutional culture at Lake House included proliferation of signs and instructions, the list of rights and responsibilities posted on the lounge room wall and the chores roster. The chores roster was interpreted differently by each housemate. For Chloe, the chores roster was hostile, intrusive, demanding of her time and often a source of conflict between herself and the supervisors and her fellow housemates. Using the chores roster to reference Chloe's non-compliance, the supervisor said, "Chloe, the chores roster says it is your turn to wash the dishes. Don't go to your bedroom! You've got your chores to do. Look, it says so right here." Or Maggie chided her, "Chloe, you have to pull your weight. We are all on the chores roster. It's not fair to us if you don't do your share." Oftentimes, Chloe ignored the chores roster, leaving Maggie and Rose to complete her chores, which, at times, they resented. On several occasions, I observed the supervisors becoming frustrated with Chloe as she refused to follow the chores roster, their frustrations peaking when Chloe enacted her 'talk to the hand' stance (see Chapter 6).

In contrast, Bella loved the chores roster. It was her assurance that each Tuesday night was dedicated to her chosen meal; the recipe chosen, and ingredients sourced in advance. Significantly, the chores roster also ensured the allocation of the supervisors' time, ensuring one-to-one time which was rare in a household with seven others. Thus, Bella referenced the chores roster in positive terms. It was a tool that supported her and supported the activities she wished to undertake. Bella also enjoyed the sense of predictability and consistency the chores roster offered, interpreting it thus, rather than as a rigid schedule imposed within a total institution.

Despite the fact that Lake House itself had not devolved from an institution, instead it was parent led and community based from its inception, and despite the fact that the supervisors had never worked within institutions, the group home retained and sustained dystopian, institutional elements. How, then, did this come to be? As a community-based, home-like model, the group home was not intended to be a mini-institution. Founded on an ideological base of normalisation and social role valorisation, group homes have nonetheless largely failed to realise these ideals. Foley (2016) has argued that normalisation and social role valorisation are not a "static theory" (p. 178) and that their foundational assumptions, that people with intellectual disability are a devalued marginalised group, creates a "…self-fulfilling prophecy" (p. 178).

I have argued in this thesis, however, that there is more to the story. Through *Lebenswelt,* everyday life at Lake House contrasted starkly with the utopian ideals with which the group home model of accommodation and support was designed (Nirje, 1969; Wolfensberger, 2000). Concomitantly, the environment was also interpreted and negotiated individually by the housemates. Within this institutional frame the housemates were not passive. Using their own strategies and technologies, the housemates produced space for themselves. Lefebvre's (1991) theory of social space supports a more nuanced understanding of home and how home is produced. Lake House was both an institutionalised space and a place of resistance, where the housemates had agency and created a space of diversity. Efforts by the supervisors and the Organisation to create a conformist, homogenous space were countered by efforts by the housemates, who resisted and subverted the space, overtly and covertly. *Lebenswelt* provided a way to see and understand these practices. Lake House, then, was neither a reproduced utopia of home nor a dystopian total institution.

Lake House as an 'other space'. As neither a utopia nor dystopia, Lake House can be considered as a type of 'other space', a heterotopia. Lake House can be understood as a socially produced space that inverted the utopian ideal of home, a space that juxtaposed other spaces. Foucault's (1970; 1986; 1988) concept of heterotopia considers spaces that reflect, contrast and invert other spaces, creating small worlds within worlds, like matryoshka dolls. Foucault (1998) used the mirror as a metaphor to consider heterotopia, the image one sees in the mirror is not the real image rather it inverts and reflects space. Shoshana (2014) described heterotopia as, "…a space in which different and contradictory elements can exist simultaneously. In this sense, heterotopia represents heterogeneity and simultaneity." (p. 531).

Foucault (1986) first described his notion of heterotopia, outlining a variety of types of 'counter-spaces' such as prisons, asylums, cemeteries; these 'other spaces'. Baer and Ravneberg (2008) used Foucault's heterotopia to consider the inconsistent and juxtaposed spaces outside and inside prisons, largely rejecting Goffman's (1961) total institution with its binary distinctions between inside and outside the institution. In their study, the authors used heterotopia to more fully consider ways in which prisons, a separated social space, also exist within society, indistinct social spaces. The authors argued, "…such contradictions are already embedded within the idea of incompatible juxtapositions so important to the idea of heterotopia." (p. 209). Baer and Ravneberg (2008) proposed that heterotopia more fully theorised carceral space than Goffman's (1961) total institution, with "a dynamic and often contradictory state of betweenness." (p. 205). Schliehe (2016) used heterotopia to consider young women's carceral spaces in Scotland but questioned the utility of doing so, contesting Baer and Ravneberg's (2008) emphasis. Schliehe (2016) argued that Goffman's ideas, in particular ideas about the semi-permeability of total institutions (p. 31), retained relevance as a theoretical model in carceral geography.

Although Lake House was not a carceral space per se, it maintained characteristics of a carceral space and a total institution with high levels of surveillance and restrictions on movement. The group home inverted many of the fundamental elements of home identified in the literature for people without intellectual disability.

Lake House can be understood as a type of 'other space', also imbued with a dynamic and contradictory betweenness (Baer & Ravneberg, 2008, p. 205). Where home was identified as a place for self-expression, Lake House restricted and constrained the housemates through the routinisation of everyday life. The housemates, however, inverted the space again through resistance and agency, productively using the space of Lake House. The interstitial space of home at Lake House, this betweenness (Baer & Ravneberg, 2008), highlights the complexity of disability service provision, which typically focuses on one dimension of space; reproducing utopian ideals of home for people with intellectual disability. The ways in which service provision also reproduces characteristics of the total institution within the group home model are largely ignored, the process of deinstitutionalisation assumed complete. The totalising characteristics of Lake House, then, are assumed to be implementation failures which can be rectified through staff training, practice leadership or increased organisational resources. Altermark (2017) contests this perception arguing it fails to understand how power operates within disability services;

> By this view, remnants of the past are made anomalies. At the same time, this perspective can never detect if and how power operates within present disability services as something other than a residue of practices that our governments and international organisations have sworn themselves free from. (p. 1319)

Heterotopia, then, offers a lens through which to consider this 'other space' of home within the group home. Lake House inverted the idealised, utopian view of home espoused by Bachelard (1964) through to Sixsmith (1986). The imagined "dark past" (Altermark, 2017, p. 1316) of dystopian institutions is not countered through reproducing utopian ideals of home. Johnson (2006) posits that, "(h)eterotopia not only contrasts but also disrupts utopia" (p. 84). As Altermark (2017) argues, "…more subtle and productive practices of governing people with intellectual disability" (p. 1320 have emerged.

Meanings of home at Lake House were multilayered, complex, with positive elements of home such as autonomy, self-expression, belonging and security coexisting, sometimes paradoxically, with more institutional features such as regulation, compliance, control, monitoring, surveillance and insecurity of tenure. Thus, Lake House was a space which lay between the utopian notions of home and the oppressive influences of the dystopian total institution (Goffman, 1961/1991). It was in this interstitial space, too, that the housemates produced meanings of home.

Heterotopia is a concept which has been interpreted and reinterpreted by scholars from many disciplines. However, Foucault's articulation of heterotopia remains ill-defined with Soja (1996) describing the concept as "frustratingly incomplete, inconsistent, incoherent." (p. 162). Despite this, heterotopia provides a lens through which to see the group home as a counter-site where the policies of deinstitutionalisation have not erased the exclusion of people with intellectual disability from society. Rather, Meininger (2013) posits that heterotopia are symptomatic of society which continues to exclude marginalised and oppressed individuals. Significantly, Meininger (2013) asserts that "…the exclusionary processes that are the sources of the Foucauldian heterotopia are not eliminated when institutions are dismantled" (p. 31). More than aberrant implementation failures, which can be fixed through a reproduction of utopian ideals of home, there has been a transformation of technologies of government (Altermark, 2017). This transformation can be seen and better understood through deep, rich explorations of everyday life for people with intellectual disability who live in group homes such as in the present study.

In understanding the group home as a heterotopia, a more nuanced analysis of how power operates is possible, one which recognises new governmentalities and the agency and active home-making of people who live in group homes.

Reflection and summary. This section has considered the group home as a heterotopia, drawing upon Foucault's (1970) use of the concept. As a space outside everyday social space, Lake House inverted many of the fundamental elements of home. Striving to reproduce utopian ideals of home fails to recognise how new technologies of government and exclusionary practices influence the production of home for people with intellectual disability. Although Lake House embodied totalising characteristics, a more nuanced understanding of the housemates' agency and resistance shows how home was a socially produced space. In this section, I have used Foucault's concept of heterotopia to cast a light upon power relations which are often disguised under assumptions of the completion of deinstitutionalisation. Such assumptions perpetuate the myth of deinstitutionalisation as a modality for transforming the oppressed to the empowered. Rather, my study shows how home is a space that is produced, and co-produced, not constructed and imposed by others.

Instead, I have argued that understanding the group home as a heterotopia supports analyses of why exclusionary practices are sustained and maintained. In this section, I have also illustrated active participants in heterotopic spaces, resisting, subverting rules and actively home-making; creating home within a non-home.

HOME AS AN IMAGINARY

The conflation of house and home has been identified in the literature as problematic (Blunt & Dowling, 2014). Home, for the housemates, was not necessarily a physical dwelling nor geographically located at Lake House. Chloe's home was with her mother and sister and her yearning for her home was intense. Chloe's memories of home sustained her at Lake House where she felt displaced. On the other hand, Josh considered Lake House as one of his two homes, his other home. His real home, he said, was with his mother. Andrew, too, called Lake House his other home, connecting his feelings of belonging and sanctuary and happiness with his home with his mother. Andrew also had other places he called home; when he went home to visit his father and step-mother, or to spend the weekend with his sister. For Maggie's, home was made up of the memories of hot summers at Christmas at the family home in the country with all her relatives and her grandmother. Bella was the only housemate who spoke of Lake House as her real home.

For Rose, home was an imaginary. Lake House was a temporary home. Filled with memories from her childhood and her family, now long passed, Rose's dream home was no less real for its imaginary. Interweaving her past and present, Rose envisaged a future of her own design, an ever-changing fantasy that was unstoppable. In her imaginary, Rose could be whomever she chose; a mother, a wife, a best friend, a hostess, a home-maker and an interior designer.

Home, then, is part bricks and mortar, part social and emotional and perhaps part poetic, just as Bachelard (1964) envisaged. Despite the rigours of Lake House, which the housemates endured each in their own way, home as an imaginary remained. Andrew surrounded himself with cords and controls, electronic bits and pieces, a production of space which was both material and imaginative. As the 'IT Guy', Andrew could often be found in his bedroom, happily tinkering away, perhaps hopefully waiting to be called upon to fix a problem or to help out in some way.

Intangible feelings are not found in the handbooks and operation manuals of group homes yet they are no less important than the occupational health and safety requirements or hazard controls or communication books. At Lake House, home was produced through an intermingling of each.

REFLECTION AND SUMMARY

This chapter has encapsulated my findings, illustrating everyday life at Lake House in ways that are not obvious to outsiders to the group home. Drawing upon Lefebvre (1991), I have discussed the ways in which home, at Lake House, is socially produced and have emphasised that it is not just the staff who produce home for the group home residents. Ethnography provided a way of seeing the subculture the housemates actively developed, a subculture rich with meanings of home.

This chapter examined power relations at Lake House, showing the ways in which the housemates, who were subjected to techniques of discipline and governmentality, used their subjugated knowledge to produce meanings of home. Group homes are settings which are un-home-like in many ways, inverting the utopian ideal of home which services strive to provide. In this chapter, I have examined Lake House as a type of heterotopia.

In the next chapter, the concluding chapter for this thesis, I discuss the implications from my findings. My findings have shown that the home-making practices of group home residents need to be more fully understood, understanding home as a space which is co-produced. Yet, within group homes where is the heart? As Josh shows from the front cover of his scrapbook, home is a place where you can follow your dreams, home is where the heart is.

Chapter 8: Conclusions

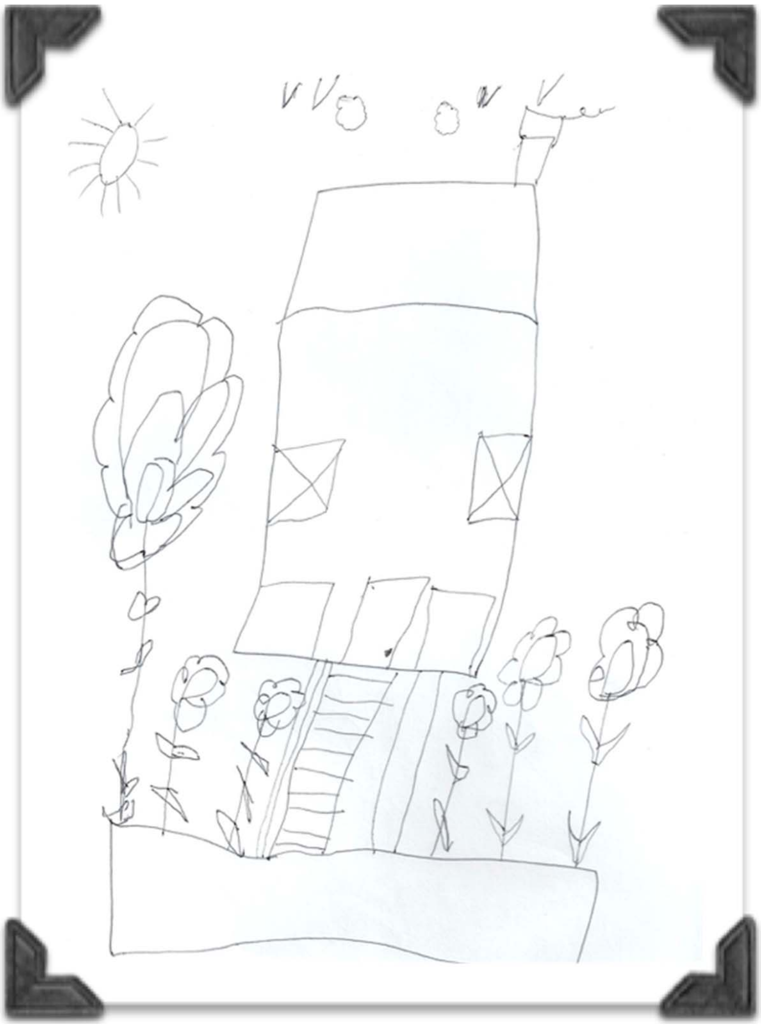

Figure 24. Rose's drawing of Lake House, titled 'My Home'.

INTRODUCTION

As I conclude this thesis, I return to the beginning and consider how this interesting and challenging journey unfolded. I begin by revisiting the research questions which framed my ethnographic journey. This study aimed to understand what home was like for people with intellectual disability living in a group home. Each housemate had their own understandings and interpretations of home and what made home meaningful to them. In Figure 24 Rose drew Lake House surrounded by a beautiful rose garden which evoked memories of the hours she spent with her mother gardening as a child. Although there were no roses at Lake House, Rose included the flowers in her drawing as remnants from her past and as inspiration for her future dream home.

In this chapter, I articulate the argument for my thesis; that the group home is complex, contradictory space that is less than ideal at times yet nonetheless the group home is a space which is always being produced. The housemates of Lake House had much to say about home, yet their voices were often overlooked, unheard or subsumed by more dominant service-centric voices. There is, therefore, a paradox of service provision whereby the more services try to control and construct home for people with intellectual disability the less home-like group homes become.

In this chapter, I consider the ways in which service-centric approaches to the provision of housing and support have not been good at hearing the voices of people who live in group homes. This thesis has used a range of approaches to support the voices of the housemates of Lake House to be articulated and to be heard. In this chapter, I outline the methodological contributions from my study. Contemporary approaches to the provision of housing and support for people with intellectual disability are influenced by historical epochs of care and legacy arrangements which are not easily dissolved in the short to medium term. The group home model of accommodation and support remains a contradiction in a contemporary environment of individual choice and control. In the contemporary Australian context of the NDIS, with its hallmark of consumer-based purchasing control, I wonder how home can be purchased?

My thesis has considered the superficial ways in which home is predominantly considered by the disability sector and disability scholarship. This superficiality has led to false assumptions about what makes a good group home. My thesis has encouraged a deeper exploration, and understanding, of group homes that moves beyond checklists of homely or homelike-features.

In this chapter, I discuss the limitations of my research and consider recommendations for future research. People with intellectual disability who live in group homes remain a cloistered group, hidden away by multiple levels of gate-keeping. However, the experiences of this group are significant, both in terms of disability-specific knowledge about group homes but also towards knowledge about home more broadly.

As the final chapter in my thesis, I use this space to conclude my personal journey, considering my own vulnerabilities as a researcher. To close, I offer a personal epilogue and use an ethnographic voice to illustrate the resilience of the housemates and the challenges I encountered as a researcher in saying goodbye.

REVISITING THE RESEARCH QUESTIONS

My own motivations and curiosity about group home life were formed long before I began this research journey. My experiences working in the disability field worked hand in glove with my academic endeavours to provoke a deep curiosity within me about home and how home was experienced within the group home model of accommodation and support. Through a chance encounter, I was called to work one day and asked to take a shift in a group home where Jerry lived. Jerry challenged me to try to understand what life was like for him, even if just for a little while. Heeding Jerry's advice, his challenge has influenced my life over the years and motivated me to undertake this study. Jerry's challenge, too, influenced my methodological choices and conceptual framework.

I began this research journey by asking the primary research question:

- How do people with intellectual disability who live in a group home understand and experience home?

In order to answer the primary question, I also explored the following research questions:

1. How do people with intellectual disability who live in group homes construct meanings of home?
2. What are the attributes that they identify as essential to home?
3. What influences enhance and detract from achieving these ideals?

In answering these questions, however, my thesis does not provide a definitive account of what life is like within group homes and I do not seek to speak on behalf of nor represent people with intellectual disability who live in group homes. My study was positioned within a particular time and place and context and therefore provides an interpretation of life at Lake House that results from my own ethnographic journey. Many other interpretations are possible.

ARTICULATION OF ARGUMENT

My thesis has emphasised that people with intellectual disability have much to say about home and about what it is like to live in a group home, the dominant contemporary housing model to have emerged from deinstitutionalisation. However, disability services, policymakers and researchers have, traditionally, not been very good at listening. Group home research and policy has become dominated by service-centric approaches, which has served to create an imbalance where home has been considered as a service to be delivered for people with intellectual disability. My thesis has made a methodological contribution to knowledge by using creative, participatory methods within a collaborative frame to support the voices of the housemates to be heard. Together, we considered and articulated ideas about this abstract, complex, confusing, contradictory notion of home.

Through an exploration of everyday life at Lake House, my thesis developed understandings of home as a space that was produced through a complex intersection of service delivery and the home-making practices of the housemates. My thesis illustrated a group home governed by rigid, inflexible rules and regulations aimed at producing docile and compliant residents and, in many ways, docile and compliant supervisors. My thesis also illustrated the ways in which the housemates were active, creative and tenacious in their home-making. Far from passive recipients of care, the housemates of Lake House resisted, subverted the rules and constructed meanings of home for themselves, within an environment that was often un-homely or un-home-like.

My thesis has shown a paradox of service provision whereby the more disability services try to create home for people, the less home-like group homes become. In doing so, artificial reproductions of home have been produced. Thus, I argue that a new paradigm of support is required which understands that home is a being-produced space, a complex co-production between service provider and service user. Within this new paradigm of support, however, people with intellectual disability must lead and they must be provided with the right support in order to do so.

Through the experiences of the housemates, through *Lebenswelt,* my thesis makes a contribution to knowledge about group homes and what it is like to live in a group home. At Lake House, home was not a romanticised, utopian ideal. Home was also not only a totalising, oppressive dystopia. Rather, the group home was a space in between, a type of heterotopia. Thus, my thesis also contributes to knowledge about home more broadly. My thesis poses challenges for future research, for policy makers, service providers and scholars to hear the voices of people with intellectual disability who live in group homes. Yet, the question remains, who will listen?

BROAD SIGNIFICANCE OF THE RESEARCH

In Australia, group homes have typically been based on the great Australian dream, the suburban home, a detached house in the suburbs with a backyard and room for a growing family (Blunt & Dowling, 2014). Yet these heteronormative ideals of home are contrasted with the experiences of the housemates of Lake House who were not permitted to have intimate relationships, were unlikely to ever have the opportunity to have a family and who in all probability will be engaged with the disability service system for the rest of their lives. Is this the great Australian dream?

The inflexible, rigid rules and routines of Lake House sat in contradiction with the new paradigm of disability support in Australia and the NDIS. Characteristics of the group home more generally, such as block treatment, vacancy management regimes and the congregation of people on the basis of diagnosed disability, are challenged by the new paradigm of support yet, at the same time, they have remained the same. This stagnation stands in stark contrast to the heart and soul of the NDIS; choice and control. Integral to the NDIS is effective planning, as the mechanism through which participants identify their dreams and aspirations and individual funding is allocated on the basis of goals identified within a participants' plan. Planning is predicated upon person-centred approaches despite a limited evidence base about the efficacy of the approach (Collings, Dew & Dowse, 2017, p. 273). My study has illustrated how mantras of person-centred planning can have little influence on the everyday experience of home within a group home.

In many ways, the group home model is the antithesis of person-centredness. The prolific rules and regulations and the routinisation of everyday life directed the ways in which everyday life occurred at Lake House. Home, then, was more service-centred than person-centred. The central tenet of person-centred approaches is that supports are structured according to the needs and aspirations of the person (O'Brien, 2002) and that the person is at the heart of all decision-making. The features of everyday life at Lake House were at odds with the contemporary mantra of person-centredness.

Part of this incongruence, I suggest, was the way home was considered by the Organisation and the way home continues to be considered by the disability support system. If planning for home remains focused on the type of housing and support which can be procured through consumer purchasing schemes, such as the NDIS, then home will continue to be reduced to physical and material elements alone. My study has challenged this conceptualisation, reconsidering home not as a space produced by service providers alone but as a space which is co-produced. People with intellectual disability must be positioned as the primary producers of home, not service providers.

Moreover, home is not a concept that can be procured, rather, home is produced. Person-centred approaches must be reconsidered within this context. Rather than placing the person at the heart of services, the person should be positioned as directing services, with the appropriate supports required. Much like a conductor in an orchestra. For many people with intellectual disability, home is a concept which will be co-produced with others.

Increased marketisation, an inherent part of the NDIS and, more broadly, an inherent part of neoliberal paradigms, provides opportunities for an expansion of housing and support beyond the group home model. Consumers are now positioned to demand more flexible and individualised options. How the market responds remains to be seen. The experience of home for people with intellectual disability is inextricably influenced by these contemporary factors.

My study illustrated the ways in which the housemates constructed meanings of home for themselves, emphasising the social and affective elements of home. Much more than bricks and mortar, or models of staffing support, home was deeply personal and influenced by the biographical histories of each housemate. Smith (2013) described the elusive nature of home:

> Assigning meaning to home is akin to describing snowflakes drifting in a winter storm; there is such profusion and variety in their shapes, sizes and design that the possibilities are endless. (Smith, 2013, p.41).

Incongruent with contemporary paradigms of support, the group home has become a disability-specific problematic what can only be solved through better service provision. My findings contest this assumption and encourage a different conceptualisation of home. At least in the short to medium term, the group home model is here to stay. Over time, the model may dissipate and be replaced with a wider range of housing and support that is more responsive to consumer demands. However, a new paradigm in disability support is also required which should consider the ways in which home is a space that is continually produced through the home-making practices of the occupants. Disability support should recognise that it is these home-making practices through which individuals imbue the space of home with meaning.

Within group home research, person-centred active support has been demonstrated to improve the engagement of people with intellectual disability in meaningful activities and social relationships (Bigby & Beadle-Brown, 2016). However, this approach still conceptualises the group home as a site of service provision and focuses on staff practices alone. I argue that this has created a one-dimensional understanding of home. Instead, if the group home model was conceptualised as a genuine home first and foremost then active home-making would be considered as an integral part of being at home. There would be no question, then, that group home residents would be involved in making dinner, in vacuuming the floor, in watering the pot plants because these are all tasks associated with home; these are home-making practices. Home is no longer a site of service provision; home is a concept which is co-produced.

Methodological contributions to knowledge. Creative, participatory methods have the potential to increase the inclusion of people with intellectual disability in research. Engaging with creativity holds possibilities for better exploring the social and affective elements of home, which are rarely considered in group home research yet are of paramount consideration in meanings of home. Situated within a collaborative frame, creative, participatory ethnographic methods recognise the agency of people with intellectual disability and are participant led rather than researcher led. Yet, the researchers' position is not neutral. Researcher skill must include the ability to provide just the right amount of assistance (Beadle-Brown et al., 2012).

The voices and experiences of people with intellectual disability who live in group homes are rarely heard. The over-reliance upon research methods which have excluded people with intellectual disability from group home research is being challenged. In the contemporary context of the NDIS in Australia, and the continuing movement towards more individualised options internationally, the group home model of accommodation and support is being re-considered. Perpetuating the use of exclusionary research methods, such as proxy interviews or third-party observation within a positivist frame, will mean that people with intellectual disability who live in group homes will continue to be spoken for by others. Ultimately, then, only the voices of services and academics will be heard in this social debate.

In my study, I have shown how the supervisors of Lake House, and the Organisation, did not fully understand what life was like for the housemates. Thus, there are inherent dangers in service systems speaking for people with intellectual disability through research and by researchers deriving findings only from those who are the most verbose and articulate. Service systems will make assumptions and assertions about group home life which are from their own perspectives and which serve their own objectives, even in the most altruistic of services. Exclusive research methods, while convenient for researchers, can no longer be allowed to dominate as the only source of knowledge about group homes. This hegemony must be resisted and actively countered so that the voices of people with intellectual disability are heard. My study has shown how ethnography and visual methods can support such resistance.

Ethnography is ideally suited to acknowledging different, multiple realities (Fetterman, 1998; Skeggs, 2001) and my study has illustrated the heterogeneity of group home life. Rose (2014) argues that visual ethnography supports the understanding of culture by making it visible. My study has shown how there are multiple layers of visibility within Lake House that were not readily apparent to outsiders. Visibility within the group home, however, can be risky. Researchers working within group homes must always consider the power relations and consequences to participants of this visibility within this particular context. However, the consequences of visibility are not always negative. Throughout my study, I have cautioned against the oversimplification of ethical tensions arising from the use of visual images with a vulnerable cohort. I have urged researchers to resist the simplistic equation that visual images make people with intellectual disability vulnerable. By using visual methods thoughtfully, the housemates and I have shown group home life as complex and nuanced. This was a productive use of visibility.

It is imperative that traditional knowledge about group homes, produced by professional experts alone, is challenged. When the group home literature is dominated by service centric perspectives, people who live in group homes are positioned as passive recipients of a service. The housemates and I used visual images to resist this passive positioning. Instead, the housemates and I used visual images as a type of social action thus supporting an intersubjectivity (Wight-Felske, 1994) where knowledge about home was produced collaboratively. Thus the subjectification of people with intellectual disability can be challenged by using visual methods within a frame of empowerment and critical consciousness.

However, in considering an empowerment frame, I have argued that simply putting the camera in the hands of the participants is not sufficient and does not address issues of disempowerment. Both metaphorically and practically speaking, one must ask where does the camera come from? If the camera is bestowed upon participants how is this empowering? Visual methods in and of themselves are not empowerment tools nor inherently participatory or inclusive, despite such conflation in the literature.

In my study, the housemates used visual methods for self-expression, constructing scrapbooks or using drawings to creatively explore meanings of home. Using problem-posing techniques, the housemates and I used visual methods to think critically about home at Lake House. The production of images about home, especially group home life which is frequently hidden from view, was important. By using various technologies, the housemates were able to express their ideas about home within an environment where they needed to be cautious about expressing ideas. These ‘dangerous ideas’ were often critical of the group home service model, which could have had negative consequences for the housemates. By using visual methods together, the housemates and I created a type of collective action which, once started, was difficult for the staff or the Organisation to stop. Thus, we used power productively rather than only considering power as an oppressive force. Visibility became a safeguard.

In my study, I have emphasised that people with intellectual disability who live in group homes are indeed a vulnerable cohort, but I have urged resistance to types of protectionism. Stifling the voices of people who live in group homes because of concerns about their vulnerability or a superficial understanding of ethics neither protects nor empowers them. Removing images from publication or avoiding the use of images in research with people with intellectual disability is a simplistic resolution to complex ethical tensions which should be acknowledged and addressed and thought about collaboratively.

On the other hand, my study was not an exemplar of emancipation nor empowerment. Often in research that uses photovoice there is an assumption that the method provides a voice for the voiceless. Yet, my study has shown that the housemates had much to say about home, they were not voiceless. Rather, there were few people to listen to them. By using visual methods, the housemates and I created opportunities to engage others in dialogue about home, another form of social action.

Unless people with intellectual disability are genuinely engaged and supported in contemporary debates then home will continue to be conceptualised only as a type of service model. In 2000, Annison argued that the label of home had been liberally mis-applied to a range of service types yet this must not be allowed to continue to be the case.

LIMITATIONS

My study was concerned with one particular group home, Lake House, set in a particular time and context with a particular group of people living and working together. My study took place in a suburban Australian context where disability service provision was on the cusp of unprecedented change with the implementation of the NDIS. As such, my study would not be able to be replicated, which has long been a criticism of ethnographic research (LeCompte & Goetz, 1982). Nevertheless, replicability was not the aim of my ethnographic research, which emphasised subjectivity. However, the detailed descriptions of the ways in which I used particular methods, the ‘how-to’ of my study, may lend itself to further research, or research approaches. In this way, I sought to inform future research through explication of my own methods rather than to provide an exact description for replicability.

Moreover, my study had limitations in terms of generalisability. The housemates’ perspectives and experiences were influenced by their unique biographical experiences and my study does not seek to represent all people with intellectual disability nor all group homes. Using emic and etic perspectives and ethnographic material, I developed an interpretation of home at Lake House that was not intended to be definitive. There may well be other interpretations and perspectives of Lake House thus my findings cannot be generalised.

My study was not a redemptive measure, it did not seek to speak for the housemates or on their behalf. My interpretations of their perspectives and experiences may not be the way others would view the circumstance or situation. In working ethnographically, I endeavoured to be reflexive, however, I inevitably saw Lake House through the lens of my own experiences, values, biases and perspectives. In particular, my experiences working in group homes and my own scholarship in group homes inevitability influenced the ways in which I saw Lake House and therefore also influenced my interpretations.

A further limitation of my study was the lack of clarity and practical application which my findings provide. In my work, I have often heard disability service providers say, “Just tell me what I need to do, and I will ensure we do it.” Ethnography lacks this type of clarity and practical application. Instead, in my study I emphasised the complexity of home and rejected a checklist of elements which can be completed by service providers to produce home for the people they serve. In doing so, I muddied the waters of service provision which has created challenges in practical application. However, my study complemented and challenged other studies of group homes, in particular the dominant hegemony of group homes as sites of service provision. In a sector which is unfamiliar with ethnographic researcher, it is up to the ethnographer to convey and communicate her findings in meaningful ways and I have argued that the personal experiences and stories of the housemates have much to offer service providers and policy makers.

A further limitation of my study was that I did not include participants with severe and profound intellectual disability or people with multiple and complex needs.

Increasingly, group homes will become models of support for these cohorts. Ethnography has much to offer in this regard and is ideally suited to work in this space. Therefore, future research may warrant being extended to consider and understand the experiences of people with higher, more complex, support needs who live in group homes.

RECOMMENDATIONS FOR FUTURE RESEARCH

Knowledge about group homes can be co-produced using a range of methodologies and methods, including but not limited to, the methods I have used in my study which included participant observation, ethnographic conversations, and visual methods. The emergence of new technologies holds possibilities for greater accessibility and greater inclusiveness in qualitative research in particular. Ethnographies of group homes are scarce, with only a handful of studies using this methodological approach. Ethnography challenges and complements the more dominant, positivistic approaches in this research space.

Creative writing techniques are not often used in group home research however I have argued that ethnographic writing has much to offer future research. Literary devices enable the researcher to move beyond documenting a space, to provide a range of interpretations and to illustrate different concepts and their interplay. The use of literary devices in ethnographic research is well established (Langness & Frank, 1978; Clifford & Marcus, 1986) and such techniques hold great utility for future group home research. Further, the use of storytelling devices, such as images, creative writing, drawings, scrapbooks and technologies such as iPads, have significant potential in group home research. There is an emerging body of literature involving the use of visual methods and technology with people with intellectual disabilities (Strnadová et al., 2014) and my study adds to this knowledge. My use of collaborative ethnographic methods has shown how people with intellectual disability can be engaged in group home research, however, my study also showed how much the housemates enjoyed being involved. With the paucity of ethnographic research in group homes, there are few ‘how to’ guides for future researchers.

As service systems evolve, the experiences and expertise of people with intellectual disability must be paramount. Inclusive and collaborative research approaches have much to offer future research into group homes in this regard. In particular, emancipatory research where people with intellectual disability "…lead and control the research" (Strnadová & Walmsley, 2017, p. 133) holds significant potential and importance. Inclusive and collaborative research approaches have the potential to challenge the continued exclusion of people with intellectual disability from group home research. As Strnadová and Walmsley (2017) point out:

> Inclusive research is essentially value-driven. It sets out to change society with people with intellectual disabilities as active partners and contributors. (p. 133).

Since Walmsley (2001) first coined the term 'inclusive research' there has been an emergent body of research using emancipatory and participatory approaches with people with intellectual disability (Strnadová & Walmsley, 2017). However, even within an inclusive research frame, there is still the potential for researchers to speak on behalf of people who live in group homes. The inclusion of researchers with disability does not, in and of itself, ameliorate the potential for outsider perspectives, judgements and interpretations of home to be made. Researchers with intellectual disability should not be positioned to speak on behalf of people who live in group homes, even if they themselves have similar life experiences. All researchers working within this space must work reflexively. And appropriate support must be provided in order to do so.

In my study, I used collaborative ethnographic approaches which may offer some utility for future research endeavours. PhotoVoice, an empowerment technique that has effectively been used with marginalised and disenfranchised groups (Wang & Burris, 1994; Jurkowski, 2008; Gant et al., 2009), has the potential to further explore what life is like within group homes and how home is experienced, and constructed, with people with intellectual disability behind the camera. PhotoVoice has been used in research to promote the inclusion of oppressed voices but the method also has the potential to engage others and to support others to listen. This component, largely ignored in group home research, is vitally important as new types of support emerge within contemporary disability support paradigms. Methods are required to engage and hold the interest of policy makers, thinkers, urban designers, property developers, and specialist disability service providers, to support these groups to listen and understand. The voices of people who live in group home must be heard and strategic engagement with key bodies will enable the voices of people with intellectual disability to be amplified amongst the noise of politicisation and service provision.

Future research must also consider the specific skills required of researchers working in this space. Researchers must understand the impact of intellectual disability on expressive and receptive communication, information processing and comprehension skills while at the same time recognising individual strengths and skills and emphasising person-centred approaches. Researchers must also understand the impact of life course experiences, so that asking questions such as 'what does home mean to you?' is understood within the frame of the individuals' life experiences. While generalisations are cautioned against, many people with intellectual disability have experienced poverty, homelessness, institutionalisation, exclusion, infantilisation, paternalism, and may have experienced support under the guise of protection and care. The impact of such life experiences must be acknowledged and understood in group home research in particular. This has implications for researchers because such important processes require extended time, a challenge in the contemporary, competitive research environment where funding is scarce and limited.

Increasingly, group homes will support people with more complex support needs. Further research must consider the ways in which people with more severe and profound intellectual disability can be genuinely included. It is no longer sufficient to claim that this group are unable to be engaged and therefore only others are able to speak on their behalf. Such attitudes reflect a lack of skill by researchers. Successful engagement of people with severe and profound intellectual disability occurs every day by family members and skilled support staff. Researchers should learn from these experts.

In particular, people with complex communication are frequently excluded from group home research because they cannot verbally participate in interviews or because they may need extra time or because they do not fit the mould for particular methodologies. Researchers must become excellent communication partners and must be guided by the expertise of the individual and their supporters. This will, necessarily, demand that researchers possess or develop skills in effectively working with people who use augmentative and alternative communication systems.

With good support, inclusive methodologies and accessible methods, people with severe and profound intellectual disability can be engaged in group home research. Although there will be limits to the levels and types of participation, which will be individually guided and defined, I have argued against exclusion and tokenism. Further, I have argued that it is not the complex communication nor the complex behaviour support needs nor the level of intellectual disability that requires changing in order for people to participate in group home research. Instead, the onus lies squarely on researchers to develop their skills and experience in working in this space. This will also require reconsideration of standardised methodological approaches and tools and debates about research rigour and validity. My study has offered a range of methods which could be further extended and adapted in future research. It is critically important that researchers keep trying and keep disseminating their work so that knowledge in this area continues to grow.

Group homes can be difficult places for researchers to access, as others have shown before me (Clement & Bigby, 2013). The stringent and multiple levels of gatekeeping, difficult to navigate silos and bureaucracies and, increasingly, the neoliberal context of the contemporary disability sector makes access to group homes for research difficult. In many ways, such systems serve to isolate people who live in group homes further. Thus, it is even more important for future researchers to persist and to be tenacious as they continue to access people with intellectual disability who live in group homes.

In my study, I have also emphasised that group home research should not be considered the domain of disability scholarship alone. In many ways, in so doing, group homes continue to be considered very differently for people with intellectual disability. An expanded research focus on home would support exploration of other types of home arrangements; in-home support, outreach, independent living models, boarding houses, shared supported family arrangements or living arrangements where there are a mix of people with and without intellectual disability living together. In the contemporary context of consumer-directed disability support, in times of greater consumer choice and control more innovative models of accommodation and support will assuredly continue to emerge. Future research should consider these new, emerging arrangements. As well as new and emergent models of accommodation and support, people with intellectual disability who continue to live in large residential centres and long-stay hospitals should not be forgotten in future research about home. Their closures are far from complete.

Moreover, the wider literature on home, housing studies and human geography would significantly benefit from the learning more about the experiences of people with intellectual disability who live in group homes.

PERSONAL EPILOGUE

As an embodied research methodology, ethnography requires the researcher to use all of her senses. However, as I conclude my ethnographic journey, such words seem staid and beige and barely begin to capture all that I experienced and felt and saw and heard and pondered throughout my time at Lake House. At times, I was frustrated by the environment within which the housemates lived. I often felt guilty, wondering if I should have done something differently or if I could have done more. My ethnographic experience was never straightforward; it was tumultuous, heart-breaking at times, exhausting, frustrating and such an indescribable joy. Yet, my ethnographic journey was not mine alone and I do not wish to conclude with only my voice. In this final ethnographic piece, which I present below, I have tried to capture the familiar, comforting routine that Andrew and I had almost every day throughout fieldwork; the epitome of our time together. In the scenario below, we enacted our same routine but Andrew's matter-of-fact resilience is contrasted with my own fragility as I left Lake House for the final time.

A final farewell

As was our custom, Andrew walked me to my car on my final day of fieldwork. I had known this day was coming, I had been preparing for my last day at Lake House almost since the beginning of fieldwork. Yet, now that it was here I felt spectacularly unprepared. I was pensive, thinking up opportunities for when we might meet again, reluctant for this day to be our last. I turned and said to Andrew, "I'll miss this walk of ours. I'll miss you, we must keep in touch." I observed his composure and contrasted it with my own turbulent feelings as he said, "Over the years, love, I've gotten used to people coming and going, people always leaving. Some people stay a short while and some people stay a long while. It's just the way it is, you see." He shrugged his shoulders, clad in the familiar, threadbare blue polo shirt I had come to know so well. “But, at the end of the day, we’ve all got to say goodbye. It happens to the best of us.” I wanted to argue, to reassure him, to tell him that this wouldn’t be the case this time. Instead, I was at a loss for words as I silently watched him take my bags to the car one last time.

I lingered at my car door, hesitating, as I pressed the button on my car keys to unlock the vehicle. As I opened the car door, sliding into the driver’s seat, Andrew watched me buckle my seat belt, just as he always did. As the belt clicked into place he nodded, then left my side and put my bags in the boot, slamming it shut. The closing of the boot made the car panels shudder, the reverberating noise heightened by the cavernous size of the boot lingered in my ears. In his customary way, Andrew gave the boot two robust taps with his knuckles and yelled out, “Rightio!” I started the car engine and slowly inched the car forward, making a quick shoulder check for other cars as I pulled out into the street, driving away from Lake House. I pressed the button to wind the window down. As I reached the t-intersection at the end of the street where I always exited, my indicator ticking over, I looked in my rear-view mirror and saw Andrew, his arm raised waving goodbye. Just as he had always done, he stood there, standing steadfast, waving to me, and giving me his trademark ‘big country wave’. I reached out my window and waved back until I rounded the corner, his lone figure disappearing from view. For a moment, as I drove away I imagined I heard Andrew’s voice, in the deep timbre I had become accustomed to, telling me, “It’s ok, love, it’s all going to be ok.”

~ Farewell, Lake House, farewell.

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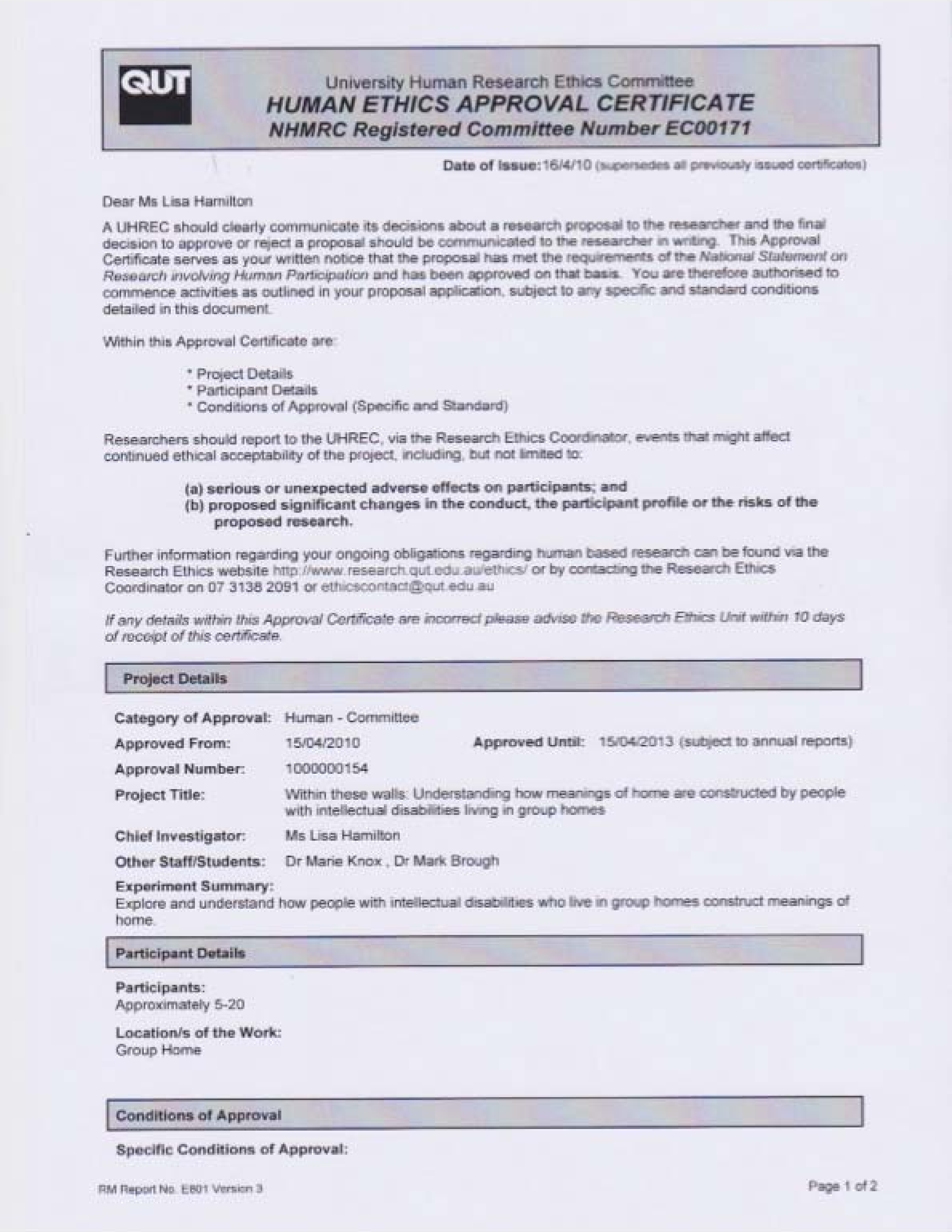
Appendices

Appendix A: Human Research Ethics Approval Certificate



University Human Research Ethics Committee

HUMAN ETHICS APPROVAL CERTIFICATE

NHMRC Registered Committee Number EC00171

Date of Issue: 16/4/10 (supersedes all previously issued certificates)

Dear Ms Lisa Hamilton

A UHREC should clearly communicate its decisions about a research proposal to the researcher and the final decision to approve or reject a proposal should be communicated to the researcher in writing. This Approval Certificate serves as your written notice that the proposal has met the requirements of the *National Statement on Research involving Human Participation* and has been approved on that basis. You are therefore authorised to commence activities as outlined in your proposal application, subject to any specific and standard conditions detailed in this document.

Within this Approval Certificate are:

* Project Details
* Participant Details
* Conditions of Approval (Specific and Standard)

Researchers should report to the UHREC, via the Research Ethics Coordinator, events that might affect continued ethical acceptability of the project, including, but not limited to:

(a) serious or unexpected adverse effects on participants; and
(b) proposed significant changes in the conduct, the participant profile or the risks of the proposed research.

Further information regarding your ongoing obligations regarding human based research can be found via the Research Ethics website http://www.research.qut.edu.au/ethics/ or by contacting the Research Ethics Coordinator on 07 3138 2091 or ethicscontact@qut.edu.au

If any details within this Approval Certificate are incorrect please advise the Research Ethics Unit within 10 days of receipt of this certificate.

Project Details

Category of Approval: Human - Committee
Approved From: 15/04/2010 **Approved Until:** 15/04/2013 (subject to annual reports)
Approval Number: 1000000154
Project Title: Within these walls: Understanding how meanings of home are constructed by people with intellectual disabilities living in group homes
Chief Investigator: Ms Lisa Hamilton
Other Staff/Students: Dr Marie Knox , Dr Mark Brough

Experiment Summary:
Explore and understand how people with intellectual disabilities who live in group homes construct meanings of home.

Participant Details

Participants:
Approximately 5-20

Location/s of the Work:
Group Home

Conditions of Approval

Specific Conditions of Approval:

RM Report No. E801 Version 3 Page 1 of 2

Appendix B Participant Information Form for Guardians

PARTICIPANT INFORMATION for QUT RESEARCH PROJECT

Within These Walls: Understanding how meanings of home are constructed by people with intellectual disabilities living in group homes.

Research Team Contacts	
Lisa Hamilton, PhD Student <Phone number> Lisa.hamilton@student.qut.edu.au	Dr Marie Knox, Principal Supervisor <Phone Number> m.knox@qut.edu.au

Description

This project is being undertaken as part of PhD studies for Lisa Hamilton, who is undertaking her studies at QUT.

The purpose of this project is to explore and understand how people with intellectual disabilities who live in group homes construct meanings of home.

The research team consists of Lisa Hamilton and her Principal Supervisor, Dr Marie Knox. The research team requests your assistance because currently very little is known about the lived experience of people with intellectual disabilities who live in group homes, despite the fact that group homes are the dominant form of accommodation and support for people with intellectual disabilities.

Participation

The participation of the person for whom you are legal guardian is voluntary and can be changed at any time. Even once the consent forms have been signed and the study commenced, participants and/or their Guardian can still withdraw from the study. There are no consequences for withdrawing from the study

The decision to participate, or not to participate, will not impact on your relationship with [Organisation’s name] or impact on the services received by the person from whom you are legal guardian.

Participation in the research study will involve a participant observation, conversations and visual activities.

Participant observation involves the researcher visiting the group home and spending time at the group home. Usually many hours are spent at the group home, and this could occur over many months. The role of the researcher is to understand and learn about the group home by spending time in the group home and interacting with the people who live there.

Conversations with participants may include covering topics such as:

- What do you like most about living here?
- What would you like to change?
- What sorts of things do you do at home?
- Do you have visitors at home? Who comes to visit you?
- Do you go out much? How do you get to activities?
- Who do you live with? Do you like sharing your house?
- How long have you lived here? Where did you live before?
- Do the staff help you at home? What sort of things do staff help you with?

Some conversations may be recorded on tape, and the participant will be given a copy. Most conversations, however, will occur in the course of visits to the group home and will not be taped.   The decision about which conversations to tape will be made with the participant. For example, a conversation about the establishment of a household vegetable garden and how this has strengthened friendships within the group home might be recorded. This would provide insight into aspects of the group home that participant's value and see as important.

Visual activities include providing participants with a camera and/or a video camera, so they can take photos or video of their home and identify aspects of the group home that are important to them. All visual images produced are the property of the participant and it is up to the individual to decide if they would like to give permission for the visual images to be used in the research study.   It is intended that a scrapbook of home is an activity that would be available to participants and to use their photos to create a scrapbook. The scrapbook is intended as way of recording individual personal histories about home, that participants can keep.

Expected benefits

It is expected that this project will benefit participants by giving them the opportunity to have their say about home and what is important to them. This opportunity has not been available before. Group homes are the dominant form of accommodation and support services for people with intellectual disabilities, yet little research is available about whether the people who live in group homes consider them to be genuine homes. This research study will add to the knowledge in this area.

Risks

There are no risks beyond normal day-to-day living associated with participation in this project. However, talking about home could cause some participants some distress at times. If this occurs, QUT provides for limited free counselling for research participants of QUT projects, who may experience discomfort or distress as a result of their participation in the research. Should you wish to access this service please contact the Clinic Receptionist of the QUT Psychology Clinic on 3138 0999. Please indicate to the receptionist that your family member or the person for whom you are legal guardian is a research participant.

Confidentiality

All comments and responses are anonymous and will be treated confidentially. The names of individual persons are not required in any of the responses. Neither staff nor [Organisation's name] will know who is participating in the study and they will not receive any data or information about participants. Only the researcher (Lisa) will know who is participating.

All notes taken during observations will be de-identified and the real names of participants will not be used. Tapes will be stored securely at QUT where the researcher has a desk and locked filing cabinet. Only the researcher will have access to the filing cabinet. Staff and [Organisation's name] will not have access to the tapes nor know what is on the tapes. If a conversation is recorded and then the participant changes his/her mind, then that tape (and any copies) will be destroyed and will not be used in the research study. Participants will receive a copy of the tape where conversations are recorded at the completion of the project, if they wish.

All visual images are the property of the individual who took the photos or video. Where participants give permission for the photos or video to be used in the research study, the visual images will be stored securely at QUT in the locked filing cabinet of the researcher. If a participant takes photos or video footage and then changes their mind, the photos and video will be destroyed and will not be used in the research study. Where participants wish to keep their photos or video the images will not be destroyed and will remain the property of the individual who took the photos or video, however, any copies of the photos or video will be destroyed. Options will be discussed with the individual about how to securely store these images, for example, a sealed envelope in a safe place in their bedroom, or in the staff filing cabinet, or with Lisa at QUT.

Scrapbooks are the property of the individual who made the scrapbook and will be theirs to keep. If a participant feels that they no longer want to participate in the research study, they are still able to keep their scrapbook if they wish to.

Consent to Participate

We would like to ask you to sign a written consent form (enclosed) to confirm your agreement for the person for whom you are legal guardian, to participate. Where individuals have a legal guardian provide consent for them, the individual will still be asked if s/he wishes to participate and asked to co-sign the form. Alternatively, the individual can provide verbal consent which will be tape recorded.

Questions / further information about the project

Please contact the researcher team members named above to have any questions answered or if you require further information about the project.

Concerns / complaints regarding the conduct of the project

QUT is committed to researcher integrity and the ethical conduct of research projects. However, if you do have any concerns or complaints about the ethical conduct of the project you may contact the QUT Research Ethics Officer on +61 7 3138 5123 or ethicscontact@qut.edu.au. The Research Ethics Officer is not connected with the research project and can facilitate a resolution to your concern in an impartial manner.

Appendix C: Consent Form for Guardians

CONSENT FORM for QUT RESEARCH PROJECT

Research Team Contacts	
Lisa Hamilton, PhD Student <Phone number> Lisa.hamilton@student.qut.edu.au	Dr Marie Knox, Principal Supervisor <Phone number> m.knox@qut.edu.au

Within These Walls: Understanding how meanings of home are constructed by people with intellectual disabilities living in group homes.

Statement of Guardian Consent

By signing below, you are indicating that you:

- have read and understood the information document regarding this project
- have had any questions answered to your satisfaction
- understand that if you have any additional questions you can contact the research team
- understand that you are free to withdraw your consent at any time, without comment or penalty
- understand that you can contact the Research Ethics Officer on +61 7 3138 5123 or ethicscontact@qut.edu.au if you have concerns about the ethical conduct of the project
- understand that the project will include audio and/or video recording with consent
- agree for ____to participate in the project

Name ……………………………………………………………………

Signature ……………………………………………………………………

Date ………………… / ………………… / …………………

Statement of Consent

Your guardian said it is ok for you to participate in Lisa's research study. But you have to say it is ok as well. If you sign below you are saying that you would like to participate in Lisa's research study.

Name ……………………………………………………………………

Signature ……………………………………………………………………

Date ………………… / ………………… / …………………

Appendix D: Participant Information Residents

PARTICIPANT INFORMATION for QUT RESEARCH STUDY

Within These Walls: Understanding how meanings of home are constructed by people with intellectual disabilities living in group homes.

Research Team Contacts

Lisa Hamilton, PhD Student <Phone number> Lisa.hamilton@student.qut.edu.au	Dr Marie Knox, Principal Supervisor <Phone number> m.knox@qut.edu.au

Description

This research study is being undertaken as part of Lisa's university work for her PhD. Lisa goes to university at QUT in Kelvin Grove.

The purpose of her research study is to find out what home means to you. Lisa would like to talk to you about your home and find out the things you like about your home and the things you'd like to change.

Lisa requests your assistance because it is important to us that you can have your say about your home and that you can tell us what you think about your home.

Participation

Your participation in this research study is voluntary. If you do agree to participate, you can stop taking part in the research study at any time and nothing will happen to you. It is ok to say no and to stop taking part.

[The Organisation's Name] does not know you are participating in the research study and no one else will know either, except for Lisa and her supervisor, Marie.

Lisa would like to come to your home and spend time with you there; while she visits your home she would like to talk with you and will ask you questions. You don't have to answer any of her questions if you don't want to. Some of the questions that Lisa might ask you are:

1. What do you like most about living here?
2. What would you like to change?
3. What sorts of things do you do at home?
4. Do you have visitors at home? Who comes to visit you?
5. Do you go out much? How do you get to activities?
6. Who do you live with? Do you like sharing your house?
7. How long have you lived here? Where did you live before?
8. Do the staff help you at home? What sort of things do staff help you with?
9. Anything else about home you'd like to talk about

Lisa would like to find out about the things you do at home so she will spend some time at your home and doing activities with you. Lisa has a camera and a video camera and, if you want to, you can use these to take photos or video of your home or to show Lisa what things are important to you. We can use the photos and make a scrapbook, if you want to, and you can keep this scrapbook. It will be a scrapbook about your home. Lisa might ask you if she can use some of the photos in her work. You don't have to agree to share your photos, they are your photos and you can decide what you want to do with them.

Expected benefits

This research study will help people who live in group homes by finding out what are the good things and what are things that need to change. This research study gives you the chance to have your say and to talk about what your home is like. This helps us to know more about group homes. Right now not much is known about group homes even though lots of people live in group homes. We need to know more about group homes so we can make them better.

Risks

Lisa will be talking to you about home and visiting you. She will always ask if this is ok with you but sometimes you might feel upset talking about your home or it might make you sad to think about your home. If this happens you can talk to a counsellor who works at QUT, but does not know Lisa. This counsellor is free. You can make an appointment for counselling by calling the QUT Psychology Clinic on 3138 0999 and tell the receptionist that you are part of a study for QUT. You can also ask a family member, friend or your guardian to make an appointment for you.

Confidentiality

If you decide to participate in Lisa's research study, Lisa won't tell anyone. If you have a guardian, then they will need to say it is OK for you to participate and you can talk to them about what you want to do. Lisa won't tell [The Organisation's Name] that you are participating in the study. Everything you tell Lisa will be confidential and private. If you tell Lisa something about your home she won't tell the staff or [The Organisation's Name].

Lisa might tape record some of the conversations but she will always ask your permission first and tell you what she would like to record. You can say no at anytime and tell Lisa not to tape or to stop taping. If you tell her it is OK, Lisa might use some of these taped conversations in her work but you can decide whether you want her to do this or not. Lisa will give you a copy of the tape recordings for you to keep at the end of the study. Lisa's copy of the tapes will be stored safely at uni, where Lisa has a desk and a locked filing cabinet. Only Lisa and her supervisor, Marie, will be able to listen to the tapes. No one else will have access. Staff and [The Organisation's Name] will not know what is on the tapes. If you record something with Lisa and then later decide you don't want to, then Lisa will destroy the tape so it can't be used. You can do this at any time and it's ok.

Lisa has a camera that you can use to take photos or video of your home. If you want to take photos or video then these are yours and you can keep them. You can decide what you want to do with your photos or video. Lisa might ask if she can use some of the photos or video footage in her work, which might be published. It is up to you to decide whether you want to do this or not, you don't have to, and nothing will happen if you say no. You can also talk this over with a friend or family member or your guardian, if you have one. If you take photos or video and give Lisa a copy and then change your mind, that's ok. Lisa will destroy her copy of the photo or the video footage, and your copy too if you don't want it, and no one will see the photos. If you give permission for Lisa to use the photos or video in her work, it will be stored at uni in her locked filing cabinet. Only Lisa will have a key to this filing cabinet. Staff and [The Organisation's Name] will not be shown your photos or video unless you want them to. If other people in your house are also taking part in Lisa's research study, then they won't be able to take any photos or video of you without your permission.

Lisa can work with you to make a scrapbook out of the photos you take, if you want to. This scrapbook is yours to keep. Lisa might ask if she can use a copy of your scrapbook in her work and it is up to you to decide if you want her to do this or not. If you start the scrapbook but then decide you don't want it anymore, Lisa can destroy it and it won't be used at all. Lisa won't show your scrapbook to anyone, it is up to you who you share your scrapbook with.

Consent to Participate

We would like to ask you to sign a written consent form (enclosed) to say that you agree to participate in Lisa's research study. If you have a guardian, they will sign the form with you. If you want to give verbal consent, then you can do this by recording your consent on tape. Lisa can help you access a tape and tape recorder.

Questions / further information about the research study

Please contact the Lisa or her supervisor, Marie, if you want more information about Lisa’s research study.

Lisa’s number is <insert number>

Marie’s number is <insert number>

Concerns / complaints regarding the conduct of the research study

If you have concerns about Lisa’s research study or if you want to make a complaint then you can contact the QUT Research Ethics Officer on 3138 5123. This person doesn’t know Lisa and doesn’t have anything to do with the research study. You can also ask a friend, family member or your guardian to contact this person to make a complaint on your behalf.

Appendix E: Consent Form Residents

CONSENT FORM for QUT RESEARCH STUDY

Research Team Contacts	
Lisa Hamilton, PhD Student <Phone Number> Lisa.hamilton@student.qut.edu.au	Dr Marie Knox, Principal Supervisor <Phone Number> m.knox@qut.edu.au

Within These Walls: Understanding how meanings of home are constructed by people with intellectual disabilities living in group homes.

Statement of consent

By signing below, you are indicating that you:

- have read and understood the information document regarding this research study
- have had any questions answered to your satisfaction
- understand that if you have any additional questions you can contact the research team
- understand that you are free to withdraw at any time, without comment or penalty
- understand that you can contact the Research Ethics Officer on +61 7 3138 5123 or ethicscontact@qut.edu.au if you have concerns about the ethical conduct of the research study
- agree to participate in the research study
- understand that the research study will include audio and/or video recording with my consent

Name:	
Signature:	
Date:	

Appendix F: ‘I Would Like to Talk to You’ Form

“I Would Like To Talk To You”

Hi Lisa,

My name is ___________________________________

Please contact me because I would like to talk to you.

Appendix G: Withdrawal of Consent Form

WITHDRAWAL OF CONSENT FORM FOR QUT RESEARCH PROJECT

Within These Walls: Understanding how meanings of home are constructed by people with intellectual disabilities living in group homes.

Research Team Contacts	
Lisa Hamilton PhD Student, QUT 3204 6606 Lisa.hamilton@student.qut.edu.au	Dr Marie Knox Principal Supervisor, QUT 3138 4614 m.knox@qut.edu.au

I wish to WITHDRAW my consent to participate in this research study.

Nothing will happen to me because I withdraw my consent. Things will still be OK between QUT and me, and between [insert Agency name] and me.

Name ....

Signature ....

Date .... / .... / ....

Appendix H: Household Consent Form

HOUSEHOLD CONSENT FORM for QUT RESEARCH PROJECT

Plain English

Within These Walls: Understanding how meanings of home are constructed by people with intellectual disabilities living in group homes.

Research Team Contacts	
Lisa Hamilton	Dr Marie Knox
PhD Student, QUT	Principal Supervisor, QUT
<Phone number>	<Phone number>
Lisa.hamilton@student.qut.edu.au	m.knox@qut.edu.au

Statement of Consent

We have spoken with Lisa about this research study and have read the information sheet about the study, or have had someone read the sheet to us.

Being involved in the study means that Lisa will visit our home. We have discussed this together and agree that it is OK for Lisa to visit our home.

Before visiting Lisa will always make an appointment and let us know she is coming, she won't just turn up unannounced.

Lisa will only visit our home with our permission. We can change our minds about participating at any time.

By signing this form, we agree to let Lisa come to our home.

If we sign this form today, we can still change our minds later. Nothing will happen if we change our minds; it is OK to change our minds.

Name ……………………………………

Signature ……………………………………

Date ………… / ………… / …………

[Repeat for each member of the household]

Name ……………………………………

Signature ……………………………………

Date ………… / ………… / …………

Name ……………………………………

Signature ……………………………………

Date ………… / ………… / …………

Name ……………………………………

Signature ……………………………………

Date ………… / ………… / …………

Name ……………………………………

Signature ……………………………………

Date / /

Name

Signature

Date / /