

***Finding the Collective Voice —  
the role of family and community in  
improving housing options for adults with  
disability***

**by Susan Margaret Bailey**

Thesis submitted in fulfilment of the requirements for  
the degree of

**Doctor of Philosophy**

under the supervision of  
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June 2021

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I, Susan Bailey, declare that this thesis is submitted in fulfillment of the requirements for the award of Doctor of Philosophy, in the Faculty of Design Architecture and Building at the University of Technology Sydney.

This thesis is wholly my own work unless otherwise referenced or acknowledged. In addition, I certify that all information sources and literature used are indicated in the thesis.

This document has not been submitted for qualifications at any other academic institution.

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## PREFACE

This doctorate study responds to the lack of housing for people with disability to address their needs or desires to have their own home. Governments in Australia have neither planned for nor invested in sufficient, good-quality housing for adults with a disability who are over 18 years of age and who live with family or friends but need or want to choose their own home. Some of these women and men (referred to as ‘adults’ in this thesis<sup>1</sup>) are excluded from mainstream social housing systems and specialist disability housing such as group homes (National People with Disabilities and Carers Council 2009) because they are not considered homeless or needy enough. Yet many of them, and their families who encounter the costs associated with disability, are financially disadvantaged. This study presents 11 case studies where new homes were established for more than 44 adults. Few case study participants had the resources to purchase, build or rent the housing component to establish the adult’s own home in the communities that support them day to day. Individual funding for the paid support component to enable adults to live independently from their family caregiver was made available in New South Wales and the Australian Capital Territory in anticipation of the emerging National Disability Insurance Scheme (NDIS), which commenced in 2013.<sup>2</sup> This thesis presents the creation of the adult’s own home as a significant achievement of families — and of not-for-profit non-government organisations (NGOs). These new homes were conceived before NDIS funding was available where families and adults did not have sufficient financial means to fund paid support, housing or both. This study is relevant for adults who are not eligible for the NDIS, or who are eligible for NDIS funding for paid support but not eligible for NDIS funding for accommodation in Australia. The success of the recently established specialist disability accommodation (SDA housing) system in Australia, funded under the NDIS, is outside the scope of this study, although some of the housing in the case studies is now classified or ‘enrolled’

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<sup>1</sup> Daughters and sons with a disability are referred to as ‘adults’ or ‘adults with disability’ because they are over 18 years of age. This thesis also uses the terms ‘daughter’, ‘son’, ‘child’, ‘children’, ‘person’ and ‘people with a disability’ if appropriate in the particular context. In relation to NGOs, these adults may be called a ‘client’, ‘person with a disability’ or ‘people with disability’. ‘Person with a disability’ and ‘people with disability’ includes children and other people with a disability who are not adults in a case study.

<sup>2</sup> Bostock et al. (2004, p. 48 citing Lord & Hutchison 2003) described the worldwide movement towards individual funding for support paid direct to the person rather than a service provider, including the grants paid to individuals for their purchase of support services in Western Australia from 1993.



as SDA housing. The SDA housing system, as well as policy that underpins it, will need regular, independent evaluation over the coming years.

This study of activities and strategies to secure government funding for housing and paid support has five aims. First, it investigates the role of families and NGOs as advocates and change agents. Both families and NGOs acknowledged, listened and responded to the voices of adults whose housing needs had been neglected by governments. These families engaged in advocacy to meet the housing needs of these adults, as well as the housing goals and objectives of their daughter or son. Second, this study explores the activities and strategies undertaken by families and NGOs as allies of the adults (Panitch 2008). Both families and NGOs garnered broader support for the objective of establishing the adults' own home and institutional support to commit funding to achieve this objective. Third, it listens to the voice of families and NGOs who were found to create new homes in new ways, where traditional disability services and housing systems had not done so. In this thesis, these separate housing systems and the housing assets within them—both mainstream and specialist disability housing—are collectively referred to as 'social housing'.<sup>3</sup> Fourth, this study acknowledges the lifelong service-providing and caregiving role of parents, other family members, carers and friends. It demonstrates the shifting roles of traditional institutions, whereby families became designers and/or providers of government-funded housing services and chose the key workers to deliver paid support. Parents worked within, around and across traditional service and system boundaries to secure resources and implement their designs, create more housing options and ensure better services when governments and service providers did not do so. Their volunteering, organisation, housing advocacy and home-making activities are different facets of unpaid caregiving. Fifth, this study

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<sup>3</sup> Family and Community Services (FACS), a former agency of the NSW Government, defined social housing to include public, community and Aboriginal housing in NSW, all of which are described as 'secure and affordable rental housing for people on low incomes with housing needs'. FACS and other government agencies do not include specialist disability housing, such as group homes or other NDIS-funded (SDA) housing in the description of social housing (<https://www.facs.nsw.gov.au/housing/help/ways/social-housing>, last viewed 2 October 2019). However, this thesis includes group homes and other SDA in the term 'social housing' in order to mitigate segregating housing systems in conversation, mindset and usage. The availability of capital funding for SDA does not of itself segregate that type of housing from other housing (e.g. AccessAccom's Penrith Sheffield Quarter combines SDA usage apartments with apartments for other tenants).

shares what these parents and NGOs have learned from the action they took,<sup>4</sup> what worked and did not work, and the importance of the communities they supported or constructed.

Across each case study, self-determination, control and choice were highly valued. Parents frequently made decisions for or with their children. This included decisions made with and on behalf of a daughter or son with a severe or profound limitation relating to a disability. A severe or profound limitation is described by the Australian Bureau of Statistics (ABS) Survey of Disability, Ageing and Carers (SDAC) as a limitation with the greatest need for help, assistance or support with activities (ABS 2018). Due to the type of disability and support needs of each adult, it was the system-level activities of parents and NGOs that attain the housing and paid support. They enabled the transition away from living with families, and they created choice, which the adults were not able to do themselves. The researcher was cognisant that the interests and priorities of adult daughters or sons and their parents can differ (Curryer, Stancliffe & Dew 2015). However, it was not the purpose of this study to identify those differences, or to study the adults' participation in system-level choice (although data were collected on individual wishes and preferences communicated by the adults to their parents). In this sense, the study is not family research. Importantly, the new homes these parents and not-for-profit NGOs established brought more people and community into the lives of each family and adult.

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<sup>4</sup> They developed new, stronger tactics when their polite requests for assistance and better services failed (Panitch 2008, p. 7).

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The thesis is written in Australian English. The spelling and terminology in Chapters 4–7 will be changed to their US equivalent when submitted to US journals.

## LIST OF ABBREVIATIONS AND ACRONYMS

ABS	Australian Bureau of Statistics
ACT	Australian Capital Territory
ADHC	Ageing, Disability & Home Care, a Department of Family and Community Services (NSW)
CDLS	Cornelia de Lange syndrome
CHP	Community housing provider
CRA	Commonwealth Rent Assistance
DADHC	Department of Ageing, Disability & Home Care (NSW)
DSP	Disability Support Pension
EMES	European Research Network (named after the emergence of social enterprises in Europe research program)
FACS	NSW Department of Family and Community Services
HILDA	Household, Income and Labour Dynamics in Australia
HOME	Home Owners Mutual Enterprise
HREC	Human Research Ethics Committee
ISL	Individual supported living arrangements
ILO	Individual living options
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
NFP	Not-for-profit
NGO	Non-government organisation
NSW	New South Wales
PaRA	Parent-assisted residential accommodation
PwD	People with disability
RASAID	Ryde Area Supported Accommodation for Intellectually Disabled Inc.
SAIF	Supported Accommodation Innovation Fund
SDA	Specialist Disability Accommodation
SDAC	The Survey of Disability, Ageing and Carers
SIL	Supported Independent Living
SILC	Supporting Independent Living Co-operative
SRV	Social Role Valorisation

SSDAAG	Sutherland Shire Disability Accommodation Action Group
TEPSIE	Theoretical, Empirical and Policy Foundations for Building Social Innovation in Europe
UK	United Kingdom
US	United States of America

## GLOSSARY

ACT Housing	The agency of the ACT Government that manages public housing in the ACT.
Ageing, Disability & Home Care (NSW)	Formerly a division of the NSW Department of Family and Community Services that funded or provided disability services and support accommodation including group homes.
Benambra Intentional Community	The public housing development in which the intentional community is located in Canberra.
Carer and caregiver	A person who provides care, support and other assistance to a person with a disability. Caregiver is a term used to refer to unpaid parent caregivers.
Community housing	Community housing is a type of social housing rented by a community housing provider to people who need housing. Some of the properties rented out by community housing providers are owned by or subject to the interests of a government agency or government-owned statutory corporation of a state or territory government.
Community housing provider	A community housing provider is a company or co-operative registered as a community housing provider under the <i>Community Housing Providers (Adoption of National Law) Act 2012</i> (NSW) and the National Regulatory System for Community Housing. It is a non-government organisation that provides a type of social housing on behalf of a state or territory government.
Commonwealth Rent Assistance	A non-taxable income supplement paid by the Australian Government to eligible people to help them pay rent, excluding rent for public housing.
Disability ACT	Disability ACT was the ACT Government agency that funded disability services in the ACT before the NDIS commenced.
Disability Royal Commission	Australia's Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability.
Disability Support Pension	An Australian Government payment to help cover rental costs for eligible people.

Family and Community Services (FACS)	FACS was a department of the NSW government until its functions and responsibilities were transferred in 2019 to a newly formed cluster agency called the Department of Community and Justice.
Group home	A dwelling where a number of people with disability live together in a domestic setting with or without paid support whether or not payment for board and lodging is required.
HILDA survey	The Household, Income and Labour Dynamics in Australia (HILDA) survey is a household-based panel study conducted annually since 2001. It collects information about economic and subjective wellbeing, labour market dynamics and family dynamics. It is funded through the Department of Social Services. The Melbourne Institute at the University of Melbourne designs and manages the study.
Housing NSW	A division of the NSW Department of Family and Community Services.
Housing Pathways NSW	Housing assistance system in NSW for the management and administration of applications for government-funded mainstream housing.
National Disability Insurance Agency (NDIA)	The statutory agency that implements the NDIS and administers the allocation of NDIS funding.
National Disability Insurance Scheme (NDIS)	The Australian Scheme that provides individual funding for paid support and SDA housing in Australia.
NSW Housing Register	A single list of people approved as eligible to wait for social housing and remain on that list. The NSW Housing Register is an element of the Housing Pathways NSW system for the management and administration of housing assistance.
Pathway or housing pathway	A person's experience of housing over time. The term can also refer to a policy pathway to ensure people can access housing, and the system that provides policies, processes and other tools to assist people into housing or, conversely, restrict access.

Participant	Person eligible for NDIS. Not all participants will be eligible for SDA housing or SIL support in an SDA house.
Productivity Commission	The Australian Government's advisory body on microeconomic policy and regulation relating to social and environmental issues.
Public housing	Rental housing owned and managed by FACS or another government agency.
Quality and Safeguards Commission	An independent agency that regulates, audits and enforces quality and safety of NDIS supports and services.
Specialist disability accommodation (SDA)	NDIS housing payments for specialist disability accommodation and the SDA housing itself.
SDA Design Standard	The SDA Design Standard (edn 1.1 issue date 25 October 2019) applies to specialist disability accommodation (SDA) where an application for enrolment is made from 1 July 2021 ( <a href="https://www.ndis.gov.au/providers/housing-and-living-supports-and-services/specialist-disability-accommodation/sda-design-standard">https://www.ndis.gov.au/providers/housing-and-living-supports-and-services/specialist-disability-accommodation/sda-design-standard</a> ).
SDA housing	Specialist disability accommodation funded by SDA under a rental model.
Social housing	Government-funded subsidised housing for people on a low income — particularly people who receive Australia's Disability Support Pension, Newstart or Job Seeker. This thesis uses the term to include group homes and other SDA as well as public housing and community housing.
Supported Independent Living (SIL)	Individual funding for independent living supports under the NDIS.
Survey of Disability, Ageing and Carers (SDAC)	A survey undertaken and published by the Australian Bureau of Statistics semi-regularly. SDAC surveys were conducted in 2012, 2015 and 2018.

## **ABSTRACT**

This study explored the activities, strategies and transactions of parents and not-for-profit non-governmental organisations (NGOs) that acquired resources and created the power to establish new homes for adults with a disability. The study used theories of institutional entrepreneurship, power, social entrepreneurship and social innovation to explain the interaction between families, the state (as provider of individual funding for paid support or housing) and NGOs to create more housing for adults with a disability. These families and NGOs took action when traditional specialist and mainstream housing systems were constrained and difficult to access. Innovative models of housing, support and community were created or supported by these families and NGOs working with other people, organisations and institutions. These initiatives, which combined resources and inputs from different sectors and systems to meet housing needs in new ways, are presented in this thesis.

Qualitative data collection involved semi-structured interviews and document analysis in 11 case studies where new homes were established for more than 44 adults. In six family case studies and five NGO case studies, parents and NGOs were economic actors and bricoleurs who became innovators who refused to accept limited financial resources as a reason why these adults could not have their own home. Cross-case analysis using Engeström's (2001) cultural-historical activity theory revealed the importance of: family advocacy, empowerment through collective action with other families, allies and resources drawn from the parent or NGO's community or network; institutional entrepreneurship through organisation forming, new models of housing with paid support and governance models; institutional support from like-minded politicians, bureaucrats and NGOs; and bricolage, where families and NGOs combined bits and pieces of resources and other inputs to establish housing and deliver paid support in new ways. Families and NGOs in the case studies were empowered to attain new homes through their persistence, individual funding received from government, and capital funding where needed.

The study demonstrated that the institutions of family, the state (through government and politicians) and the not-for-profit sector (through NGOs) can achieve new models of housing and support when they collaborate, combine



resources and act together without regard for sector boundaries. In short, these actors achieve more together than they could achieve alone. To encapsulate their efforts, this study presented the development of their organised action, purposeful networks, collaboration and shifting power relationships, giving effect to the voice of parent advocacy, collective action and family groups.

## **1 INTRODUCTION**

The study for this thesis is case study research of organised families who created new living arrangements so their adult daughters and sons with a disability were able to move out of the family home and live in their own place. Like-minded NGOs that helped to create new homes for the adults were also studied. This thesis confirmed that the essential elements for housing with paid support were the same in each case study: control over the location of the home; choice of carers or key workers who provide paid support; and the community of social relationships in the life of each adult, including choice of housemates. The study confirmed there was no guidebook or manual for achieving success to secure these elements. Rather, parents in these families and NGOs transformed the lives of the adults and created homes for them by learning activities as they undertook them (Church & Rogers 2006; Engeström 2001).

### **1.1 ACTION TO CREATE PATHWAYS TO NEW HOUSING**

Parents and NGOs created new housing strategies for adult daughters and sons because entrenched systems and traditional strategies were inadequate and unresponsive to their input. NGOs and government agencies were aware that the demand for housing with paid support was not met by existing housing or disability service systems that depended on government funding (Association for Children with a Disability New South Wales [NSW] 2014; NSW Legislative Assembly 2008; Productivity Commission 2011; Sach and Associates, Miller & Burke 1991). Resourcing barriers (such as the cost for the purchase of land or housing, and impediments to financing their purchase), system barriers (such as a lack of government-funded housing and inadequate housing allocation processes) and policy barriers (policies for the allocation of housing that excluded the adults, and failure of government to invest in sufficient housing or commit to policy change in social housing) impeded pathways to government-funded housing for these adults. Attitudes, beliefs and assumptions were other barriers. In 2014, for example, recommendations for the allocation of resources for government-funded specialist homelessness services<sup>5</sup> were silent on

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<sup>5</sup> Specialist homelessness services are emergency accommodation with staff on site for people who are homeless or at risk of homelessness.

housing for people with disabilities (Deloitte Access Economics 2013, cited in KPMG 2015). Even today, governments and housing providers view housing for people with high support needs as ‘separate’.

At the time research participants took action, group homes were the dominant type of housing (or ‘supported accommodation’) because government policy would not separate housing from the support that adults required (Sach and Associates, Miller & Burke 1991, p. 1).<sup>6</sup> As a consequence, traditional group homes were a segregated model. People were allocated or matched to a group home by government agency staff only when vacancies arose and, even then, based on the capacity of a group home to support the person with her or his particular disability. The location of the group homes was not a primary consideration when the need for housing was urgent. Group living for people with a disability, who were away from their own communities and with housemates they had not previously met, was unsuitable for many adults and unsatisfactory for the parents in this study. Many parents interviewed had witnessed negative outcomes in group home living for other families and adults. They were not prepared to accept the traditional group home model, controlled by an independent service provider, for their daughter or son to live in. The group home model, as it was designed and operated at the time, was considered a type of institutional living (Sach and Associates, Miller & Burke 1991, p. 7). Yet the need or desire to live in a house that adults or their parents were proud to have as the adults’ home, where they could live with particular friends or people known to them, was not accommodated. In any case, specialist group homes and mainstream public housing or community housing were not available for the adults in the case studies when they, or their parents as their representatives, asked for their own home. This experience was confirmed in Australian Housing and Urban Research Institute (AHURI) research, which identified barriers in addition to the lack of housing. In fact, adults living with their parents or in group homes were ‘a low priority in housing allocations’ (Wiesel et al. 2015, pp. 2, 54–5) for mainstream social housing because they were not considered homeless.

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<sup>6</sup> Residential centres for larger groups are still in use. The number of ‘residents’ who have recently entered large residential centres is not publicly available.

There were no administrative systems, policies or processes to ensure that housing allocation for adults operated equitably and efficiently. Instead, administrative systems for receiving, acknowledging, processing and tracking housing applications were poorly developed or were not used effectively at the time these families and adults sought government-funded housing. As an example, adults with high support needs in the case studies were excluded from the public housing waiting list. More recently, the Disability Housing Futures Working Group (2016) expressed the dominant view that housing for people with a disability remains tied to their need for support. This Working Group is a national working group that explores solutions for the shortage of affordable housing for people with disability in Australia. The Working Group stated that mainstream social housing is 'a viable option for only a small minority of people with disability<sup>7</sup> (less than 12%), despite evident need' (Disability Housing Futures Working Group 2016, p. 15). Although this view limits the potential of mainstream social housing, it is an informed perspective because the Chair of Disability Housing Futures is a former Chief Executive of Housing NSW in the Department of Family and Community Services (FACS), which is one of the government agencies relevant to this study.

Barriers to accessing social housing include segmented social housing registers and non-priority waiting lists (Wiesel et al. 2015, p. 54). In relation to specialist disability housing, at the time the research participants sought housing for their daughter or son, a NSW government agency within FACS<sup>8</sup> would record the names of eligible adults who wanted or needed their own place on a list that was formally called the Register of Requests for Supported Accommodation. But the register was not a waiting list, and priority of access was only provided to people who were homeless or at risk of homelessness (Association for Children with a Disability NSW 2014, p. 58). Lack of access to housing, lack of paid support and lack of assistance for caregivers led to the blocked beds problem in NSW. This occurred when beds in respite accommodation were unavailable for use ('blocked') when families did not return to collect children or adults from their

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<sup>7</sup> Intentional Community Case #2, the Co-Resident Support Model and the Enabled Housing Model in this thesis challenge this assumption.

<sup>8</sup> Ageing Disability and Home Care (ADHC) was separate to Housing NSW, but both were departments of FACS.

short stay in respite accommodation. These children or adults continued to use the beds until the government made new homes available. The blocked beds problem was not a policy, but it was known to the NSW Government and the agency that managed the Register of Requests for Supported Accommodation (NSW Legislative Assembly 2008).<sup>9</sup>

A narrow conception of what constitutes appropriate housing for adults needing high levels of support required housing and support services to be tied together. From the perspective of the government (NSW Government 2006), this meant the family home was the only option for the adults when group homes were not available. In any case, the state has been dependent on parent caregivers for decades (Llewellyn et al. 2003), and unpaid caregiving has been a lifelong career for many parents. In a National Housing Strategy discussion paper, Sach and Associates, Miller and Burke (1991) acknowledged that parents of people with disabilities:

*also inadvertently, are part of the housing system. They tend to be the largest providers of housing, particularly for people with mild and moderate disabilities, but also many with severe disabilities.*

(p. 29)

Reports prepared for governments and their agencies or government inquiries have presented the family home as the best option for adult daughters and sons, but have provided no evidence to support this proposition (Eyler 2005; NSW Government 2006; NSW Legislative Council Standing Committee on Social Issues 2010; NSW Ombudsman 2004; Richmond 1983a). Some parents seek to exercise the right to care or not to care for their child in the family home (Sach and Associates, Miller & Burke 1991, p. 15) and, historically, many elderly parents have preferred or been able to keep their children with them. In either scenario, at some stage, parents may prefer or need their children to live in housing with paid support that does not require day-to-day family involvement. The ageing population of unpaid caregivers (Deloitte Access Economics 2015) and the lack of caregivers for people aged over 65 with a severe or profound

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<sup>9</sup> More recent but superseded policies in NSW include the Allocation of Places in Supported Accommodation Policy (2009). This was replaced by the Accommodation Support Policy (2015), which was published by the ADHC within FACS. ADHC was closed down after the National Disability Insurance Scheme commenced in Australia.

disability (Deloitte Access Economics 2020) will constrain the supply of unpaid care in the family home in the future. This will remove the family home as an option for many adults.

It is therefore important that housing systems — both disability and mainstream — have policies, processes and practices that operate to allocate housing equitably and efficiently. These should include support to apply for housing, acknowledgement of housing applications, an efficient assessment process and regular, timely updates regarding the progress of an application. The importance of administrative systems to support housing applications is implicitly acknowledged by the government. Housing Pathways NSW is the name of the administrative system for managing applications for mainstream social housing established by FACS. In its current form, Housing Pathways NSW is described as a system that provides coordinated information about housing assistance, a single application process, common eligibility criteria, a standard assessment process and a waiting list (FACS 2018).

However, there was no formal pathway or government-funded assistance for adults with support needs to access new housing at the time these families or adults requested it. The proposition that there was no pathway to apply for housing, along with ineffective administrative systems for housing allocation, is consistent with the academic literature. In the literature, the term ‘pathway’ is used to describe a person’s experience of housing over time (Clapham 2002; Flanagan et al. 2019). Researchers for AHURI found that the housing pathway for people with a disability who also need paid support has been crisis-driven. They found that people with disabilities who have support needs and live with an unpaid caregiver typically secure access to government-funded housing when their caregiver is ill or dies (Wiesel et al. 2012).

In NSW, parents who were research participants had been informed there was a different pathway to secure social housing for their children when they were older, and a different accommodation needs register than the public housing waiting list. These research participants eventually learned there was no housing waiting list for their children. This type of exclusion is socially constructed through a combination of economic, social and political processes. Somerville (1998) explained that housing processes reinforce social exclusion through continual

housing shortages, failure to build accessible housing and social segregation of available housing, which denies access to certain groups (Somerville 1998, pp. 772–3). The literature and experience confirmed there were housing process problems at a minimum, in addition to inadequate services to support children living with families in NSW (Association for Children with a Disability NSW 2014; Eyer 2005; NSW Legislative Council Standing Committee on Social Issues 2010; NSW Ombudsman 2004; Productivity Commission 2011). In response, the families in this study created their own pathway to secure sufficient government funding for the housing and paid support their adult children needed.

NGOs also acted to advance the interests of adults who needed their own home. The five NGO research participants expressed awareness of, and responded to, the housing needs or wants of adults or family members who supported the adults as caregivers. The traditional approach was to find a vacancy in a group home, relocate the person with disability to live there and be cared for by staff of an NGO not previously known to the person, and never move again. Traditional NGOs serve the community generally and broader interests in accordance with their social mission (Defourny 2014, p. 34). They may not have immediate knowledge or expertise to address a particular person's needs when they are not well known to them. But the conundrum is that these traditional service providers, as well as the government agencies that funded their services, had the capacity to contribute land and buy or build housing. Their role is still important because housing, land and government funding are the missing pieces needed to build more new homes. The five NGO research participants offered an alternative solution to the traditional approach. The NGOs knew the adults first, discussed options with them, their family members or other caregivers, and then looked for a solution to address their housing needs. Although this person-centred process might take some time, four of the NGO research participants created pathways into housing that did not exist previously and, in the case of Challenge Southern Highlands in Case #10, built new housing.

Last, this study demonstrates how families and NGOs, working in collaboration and cooperation, crossed sectoral boundaries to bring together the necessary actors and their contributions to create pathways into housing as well as new homes. But governments cannot expect people with disability who need their

own home in the future to separately replicate the same level of effort demonstrated by the families and NGOs in this study. Governments cannot require people with disability to have family members or other advocates organise in groups, take collective action, advocate and still wait years to attain housing for an adult with no certainty of the outcome. Not all people with disability, or their parents, can attain housing on their own; many need advocates to assist them (Parent Protey, Case #6). Advocacy to attain housing is a significant burden for people with disability, as well as their families and other advocates, who could otherwise be working to improve the service system and achieve other essential outcomes rather than working to achieve access to housing, which is a basic human right.

The balance of this chapter introduces the families and NGOs in this study as innovators and change agents, presents the narrow definition of success adopted in this thesis, describes the use of activity theory to study barriers and enablers to achieve new models of home, outlines the different models of disability and presents the definitions used in this thesis, including key concepts. The thesis structure concludes this chapter.

## **1.2 SUCCESSFUL CREATION OF NEW HOUSING MODELS**

Families and NGOs addressed housing needs by designing, delivering and governing new models of housing with paid support. The activities, strategies and transactions of these families and NGOs to create new housing models were studied as institutional entrepreneurship, social entrepreneurship and social innovation. The role of families and NGOs shifted from volunteer and advocate or service provider to problem solver. They became co-producers of new housing models, alone or with other families and connections. Parents and NGOs used connections with actors across all levels of government. They organised to engage directly with political actors and develop power to achieve housing success.

Necessity led to invention in a context where housing needs are chronically unmet. A narrow definition of success was adopted, namely, 'the attainment of an object according to one's desire' (Oxford English Dictionary Online 2000). Success was therefore the attainment of the desired housing objectives,



including any compromise the parent or NGO was willing to make to achieve those objectives. It was not an aim of this study to develop a new definition of success or construct a definition with a list of desirable outcomes, indicators or other measures. In fact, the housing objectives of the research participants were modest. Housing objectives became more ambitious when parents chose an overriding philosophy and values that partners, who delivered housing or paid support, were required to believe in and follow. In this latter category of case study, partners were required to advance the adults' interests in their homes by acting in accordance with the philosophies and values of the parents.

In all case studies, housing objectives changed over time. This could occur when families worked in a group and new objectives were agreed as a collective. Chapters 4–7 describe a range of different housing objectives that were achieved by parents acting alone or in groups, with allies and NGOs working for and on behalf of adults, their families and other caregivers. Housing objectives could also change when adults expressed their preferences after they moved into their new home, or when parents achieved their initial goals but later wished to achieve something else or something more. The focus of this study was the activity to achieve the housing objectives at the time the research data were collected, rather than housing objectives or achievements since that time.

This narrow definition of success is not an understatement. For every example of success in each case study, there are one or more examples of inaction, delays, setbacks or lack of success as a consequence of the activities of other actors the parents were counting on. These setbacks included, in different case studies, a daughter being moved back to the end of the public housing 10-year waiting list because Housing NSW could not offer appropriate accommodation, the loss of land secured from the Department of Health, and NSW agency staff objecting to the use of Commonwealth Government funding to build a cluster of houses designed by parents. Other experiences of families working hard to achieve housing for adults included personal loss such as divorce, the inability of parents to work, the agency's refusal of requests for immediate assistance when there was an illness in the family, and unresponsive agency staff when an adult needed to move into emergency accommodation quickly. Some of the

barriers to achieve the housing objectives of parents or NGOs for adults are identified in the next section.

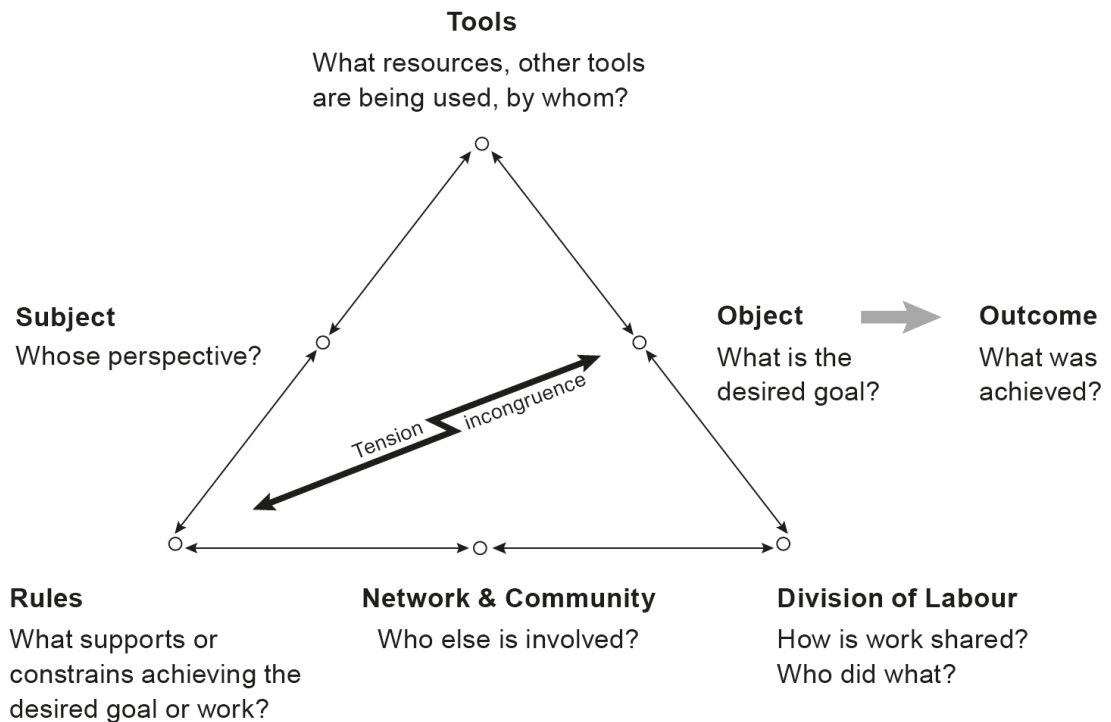
## **1.3 BARRIERS AND ENABLERS**

### ***1.3.1 Cluster of inputs and factors***

Cultural–historical activity theory (activity theory), developed by Engeström (2001), was used to examine the cluster of inputs and factors that enabled parents and NGOs to achieve their housing objectives for adults because success was multifactorial. Activity theory provided a structured framework for studying the interaction of six elements within an activity system or unit of activity, multiple connecting activity systems and activity systems interacting with other systems, like housing system rules. The six elements are as follows:

- 1) the ‘object’, which was the desired goal or objective of the activity from the perspective of an actor or group of actors
- 2) the ‘subject’, which was the individual, group or organisation that desired the object their activity sought to achieve
- 3) the ‘community’, which was the network and community of individuals and organisations that contributed to achieving the desired object
- 4) the ‘tools’, which included the financial and non-financial resources, methods or approaches, ideas and strategies that the subject or others contributed and used to achieve the desired object
- 5) the ‘division of labour’ or ‘who did what’, which was the way in which work was divided between the subject and their network or community of actors to achieve the desired object
- 6) the ‘rules’, like policy and legislation that supported or constrained activities to achieve the desired object. Rules also included norms, attitudes, practices, routines and professional conduct that supported or constrained what the subject was trying to achieve.

Figure 1 is based on Leadbetter’s (2008, p. 202) representation of an activity system as an analytical tool with key questions to be answered.

**Figure 1: Activity system as analytical tool**

In this research, the subject was an individual parent acting alone, but with allies in two case studies, a group of families acting together as a collective in four case studies, and an NGO working with adults, families or friends in five case studies. Community denotes the individuals or organisations that shared the desired housing objective with the subject. In some situations, individuals and organisations in the subject's network of relationships were willing to perform a role at the subject's request, while the purpose or outcome of their contribution may have been of limited interest to them. This study extends the element of 'community' to 'network and community' so that helpful actors, who may not share the subject's objective, are still acknowledged. The division of labour is determined by available tools or existing rules. For example, governments provided funding for paid support when persuaded, but not skills and expertise, which they had outsourced. Conversely, adults and their caregivers contributed skills and expertise in disability and understanding the needs and support requirements of the adults but, frequently, they did not contribute financial resources. This may be a consequence of a caregiver's lack of paid employment or the cost of disability over their child's lifetime. Families therefore pursued government funding and more government assistance.

The boundaries of the case are the elements of human activity systems identified in Vygotsky (1978) and Leont'ev's (1978) activity theory and expanded and developed by Engeström to include social and contextual factors (Engeström 1999, 2001; Villeneuve 2011). Social and contextual factors are important when actors are navigating political, policy, housing and service systems over long periods. Changes to social and contextual factors over time can influence the subject's prospects of success. The history of an activity system, or connected activity systems, is one of five principles that Engeström (2001, pp. 136–7) used to explain cultural–historical activity theory. The five principles are outlined below:

- 1) an artifact-mediated, object-oriented activity system is the primary unit of analysis
- 2) an activity system is a community of multiple points of view, traditions and interests
- 3) the problems and potentials of activity systems are understood against their own history
- 4) tension and incongruence between the desired objective, community and network, tools and rules are the impetus for change
- 5) when aggravated, contradictions can lead to 'collaborative envisioning and a deliberate change effort' (Engeström 2001, p. 137).

These principles framed the analysis of family and NGO activities in this study. Activity theory also provided a structured framework for identifying the barriers and challenges to the achievement of housing objectives, the actors involved in creating or retaining those barriers, and the enabling factors or inputs that enabled the subject to overcome barriers when they arose. Some of the barriers and enablers identified in the literature are described below.

### **1.3.2 Barriers**

Section 1.1 described resourcing barriers, system barriers, policy barriers and attitudinal barriers to the creation of new housing for adults. In reality, there are few housing options and no choices when families and NGOs cannot afford to buy, build or rent housing. Both families and NGOs have turned to the government for assistance when they could not solve the housing problem on

their own. The same barriers and additional impediments were identified in Franz et al.'s (2014) research of person-centred approaches to private housing for people with disability. Those additional impediments were relational barriers in the lack of coordination between government departments and the lack of an aligned approach between individuals and support organisations. Franz et al. (2014) identified environmental barriers such as housing design and location, lack of appropriate information and rigid tenancy options. They also identified personal barriers associated with the capabilities or capacity of individuals or families, which were described as financial, intellectual or emotional impediments (Franz et al. 2014, pp. 2, 86–7). But it is arguable whether housing systems should respond to the unmet housing need, and success in housing should be possible, irrespective of the capabilities, capacity or personal traits and characteristics of the person with disability, family member or other caregivers. Otherwise, it may follow that only parent advocates with environmental factors and timing on their side, or key allies who are able *and* willing to commit the necessary resources, will achieve the adult's own home.

### **1.3.3 Enablers**

Enablers are the cluster of factors and inputs necessary or required to achieve the desired housing and paid support for the adults, including choice of location, choice of housemate and choice of key workers. Families and NGOs used their capacity to act as agents of change and seek ways to create new homes outside the housing and service systems, which excluded and ignored the adults (National People with Disabilities and Carers Council 2009). These families and NGOs then demonstrated their agency to solve the problem of where the adults would live. Families and NGOs mobilised the power of their ideas, expanded public support for their vision and challenged the barriers that stood in their way through collective action, vertical advocacy at all levels of government, and public campaigns as needed (Mathie & Gaventa 2015, p. 3). Factors and inputs for each case study are described in Chapters 4–7.

### **1.3.4 Emergence of new models**

In this study, the traditional group home with a single provider of both housing and paid support was not the preferred model. The lived experience of disability

for residents in some of these homes is currently the subject of hearings held by Australia's Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (Disability Royal Commission), which was established on 4 April 2019 by the Commonwealth Government. Testimony both critical and in favour of group homes has been given by experts and victims of abuse. Given that there are approximately 17,000 people currently living in group homes in Australia (Commissioner Sackville 2019),<sup>10</sup> testimony in the Disability Royal Commission acknowledged that it will be difficult to replace the traditional group home model quickly:

*While it may be arguable other options [to group homes] are preferable, there is much less research on other models, and the reality is it will be many years before other options replace group homes. (Bigby 2019, p. 399)*

A significant body of research on models of home as an alternative to the traditional group home has been undertaken by families, NGOs and researchers. Frequently, this research is not published for academic or commercial purposes. Some self-funded research was undertaken by parents who were research participants, and many research participants shared research findings with politicians and bureaucrats.

Some governments and agencies published their own studies. Decades ago, the National Housing Strategy discussion paper prepared by Sach and Associates, Miller and Burke (1991) identified new models using different types of housing and new ways of organising people to provide support as an alternative to the traditional group home:

*Australian society is moving towards a highly disaggregated housing and support service system ... [Future] housing options*

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<sup>10</sup> No single organisation is collecting and sharing up-to-date, accurate data regarding where people are living. The ABS Census data are unreliable due to self-reporting issues. The ABS Survey of Disability, Ageing and Carers (SDAC) notes validity risks in its reported data. National Disability Insurance Agency (NDIA) data regarding what living arrangements are needed or wanted by adults who are eligible for the NDIS may be compromised by the focus on reporting satisfaction with their existing arrangements. In addition, reliable aggregate data regarding where adults are living were previously published by the Australian Institute of Health and Welfare (AIHW) (there is a significant body of historical analysis, literature and research sitting behind AIHW reports). But the work of the AIHW is affected by the transition to the NDIS and new NDIS categories for government-funded services. NDIS-funded services are different from the service categories previously reported. The status of data on services and needs at the state and territory level for other people with disability who are not eligible for the NDIS is also unclear.

*will range from full or part equity in home ownership, to cooperatives, to shared housing, to improved access to private rental housing, to fully supported 24 hour accommodation, to respite and crisis accommodation, to improved boarding housings and to a range of local housing solutions which have been developed in local communities. Life for people with disabilities will take on the same complexity as that of the wider community. (Sach and Associates, Miller & Burke 1991, p. 8)*

There is also a growing body of research on different models. The Individual Supported Living Project, led by Professor Errol Cocks and others across Australia, contributed to our understanding of the nature and outcomes of these arrangements (Cocks et al. 2014). Dr Phillipa Carnemolla (2020) provided additional insights into outcomes for people with intellectual disability who are living and supported in apartments built by an NGO in an urbanised, high-density location.

In an National Disability Insurance Scheme (NDIS) context, housing type and design are currently driven by the capital funding framework for 'specialist disability accommodation' (SDA or SDA housing in this thesis). Importantly, 'legacy stock' and 'existing stock',<sup>11</sup> which were previously funded by a state or territory government, including traditional group homes, have transitioned to the NDIS to be financed through SDA funding. This means that *both* traditional group homes and innovative housing models for people needing person-to-person support 24 hours a day, seven days a week, or overnight, are funded by the NDIS as SDA when they meet the National Disability Insurance Agency's (NDIA's) requirements for enrolment. What is important with the new models in most of the case studies is the ability to choose housing and paid support, whether the housing is public housing, NDIS-funded SDA, other social housing or privately rented housing. Equally important is the influence of new ideas and approaches to new homes by families and NGO service providers with a different mindset, working with the objective that all of these adults will live good lives with the best

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<sup>11</sup> Legacy stock is residential accommodation for six or more people, which includes the remaining large residential centres still in operation. Existing stock is accommodation that obtained an occupancy certificate prior to April 2016, and has been accommodation for five or fewer permanent residents who have a significant functional impairment and/or very high support needs since 1 July 2016 (KPMG 2018, p. 1).

paid support in their community close to friends and family. This study contributes important practical knowledge about how families and NGOs set about creating, delivering and governing new models themselves.

#### **1.4 DISABILITY MODELS AND DEFINITIONS**

It is necessary to address the meaning of disability, but there is no single definition, interpretation or meaning. Altman (2001, pp. 97–8) described different perspectives, models and classifications that explain different definitions adopted for different purposes. In Australia, a policy definition of disability is drafted to determine an adult's entitlement to the disability support pension (DSP), which is an income payment from the Australian Government to eligible people. Government policy for social housing requires no more than a fixed percentage of an adult's DSP to be charged by a social housing provider for their rent. An economic/vocational model defines disability by 'one's ability to be employable' (McGowan 2003, p. 22), and a socio-political perspective explains disability as 'whatever public officials say it is' (Hahn 1985, p. 102; Pal 1992, cited in McGowan 2003).

The medical model of disability and the social model of disability are the two dominant models that define disability in medical, policy and research literature. The medical model assumes a person is disabled by their impairment as an individual attribute, while the social model explains that disability is socially constructed and attitudes, practices, rules and physical environments in society disable people (Barnes & Mercer 1996; Barnes, Mercer & Shakespeare 1999). The framework established by the World Health Organization's (2001) International Classification of Functioning, Disability and Health (ICF) combines a medical model (impairment) and a social model to recognise that functioning and disability occur in a context of environmental and personal factors not limited to the person's health.

The social model of disability explains socially constructed barriers. Such barriers are manifest in the way society treats people with disability (e.g. grouping them together in an institution) and fails to include them (e.g. excluding them from government-funded housing systems that others can access). These barriers, or the experience of them, are identified in this study. Thomas (2004)



said that disability encompasses ‘the social disadvantages and exclusions that people with impairment faced in all areas of life; employment, housing, education, civil rights, transportation and negotiation of the built environment, and so forth’ (p. 18). To address these issues, efforts to redefine the social position of people with disability have adopted a rights-based approach (Barnartt, Schriener & Scotch 2001, p. 431) and an emancipatory approach (Barnes & Mercer 1997). The human rights framework is a rights-based approach, while advocacy for the inclusion of people with disability, and equality of opportunity to access housing, is an emancipatory approach.

The human rights perspective includes, but is not limited to, the rights of people with disability under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD; United Nations 2006), which was ratified by Australia in 2008. The UNCRPD defined disability as ‘the interaction of long-term physical, mental, intellectual or sensory impairments, and attitudinal or environmental barriers’ that hinder equal participation in society. Australia’s Disability Royal Commission is responsible for applying the human rights framework in its proceedings, and it has the power to investigate the experience of people with disability in housing and other areas of life. Research participants in this study give expression to a rights-based perspective.

## **1.5 OTHER DEFINITIONS**

There are recurring concepts and themes in this thesis that are introduced in this chapter and the literature review in Chapter 2. Some of the recurring concepts that are not addressed in Chapter 2 are explained here. The term ‘model’ is a recurring concept used in different ways. It is applied to the concepts of housing, paid support and services when combined in a residential setting (Kugel 1969, p. 11). ‘Model’ is also the term used to tie together the elements that parents and NGOs combine to create the adult’s own home, including the organisation of people who live or work in the household with them, or who govern the arrangement to ensure it is working well. The term ‘model’ includes the functioning household entity that can be observed if one were invited to visit these adults. The term and its component elements can also be part of ‘a continuum of services’ that adapt and respond quickly to an adult’s changing

needs over time (Kugel 1969, p. 10). Although this study focuses on the activities, strategies, transactions and other inputs that various actors contributed to achieve the new models in each case study, the models also offer a menu of component elements, characteristics, philosophies and values that guide them, any of which other families or NGOs may seek to replicate. The models reflect feasible innovations in the means to achieve the adult's own home, as well as the ends achieved. These models comprise elements that are 'perceived as a right' (Kugel 1969, p. 11).

The term 'housing' is used to refer to the house or the bricks and mortar component of a home. Housing refers to houses collectively and the activity of providing a house. The term 'home' is a valued and idealised concept that Annison (2000) distinguished from housing, house and residential settings for people with disability unless the attributes of home are present. Annison's (2000) literature review identified the main attributes of a 'genuine' home as a multifaceted concept with important social and psychological meaning but 'no single contributing attribute' (pp. 251–2, 254). O'Brien's (1994) analysis of home as a holistic concept for people with developmental disability identified three essential dimensions:

*people with severe disabilities have their own homes when they experience a sense of place; when they, or their agent, control their home and the support necessary to live there; and when they experience security of place by holding the valued role of home owner or tenant. (p. 3)*

The purpose of O'Brien's (1994) analysis was to evaluate service-centred residential settings for people with an intellectual disability. Like O'Brien, Annison distinguished a service-centred home from a 'genuine' home. He described the importance of a person's control and choice over their home, and the support they need to live there, as 'choice in selection of place; choice in selection of co-residents; some control over the number of co-residents; and control over funds and support staff' (Annison 2000, p. 253).

The term 'group home' requires an explanation. Group homes have been a residential setting popular with governments since at least the 1970s. A group

home is defined and understood in various ways. It is possible for a group home to become a genuine home where people choose or like who they live with, who sometimes become friends, and who choose to continue living together. Conversely, there is a view that group home settings can be institution-like. Clement and Bigby (2010) defined a group home as 'accommodation for between four and six people, where *extensive* or *pervasive* staff support is provided to the residents both in the home and when leaving it to use community-based settings' (p. 15). Bigby et al. (2014) defined group homes as 'small, 24-hour staffed ordinary houses' (p. 348). Group homes are a staffing model, and there is no evidence that there are better quality-of-life outcomes for residents in a group home with six people compared with a smaller number of two or a larger number of, say, eight people living together in a well-designed home environment. Stancliffe et al.'s (2007) study confirmed earlier findings (Stancliffe & Whaite 1997) that some people experienced loneliness in group home settings with 24-hour staffing. For the purpose of this thesis, the following characteristics are understood to be common to most group homes, but there may be exceptions. First, they involve only small groups of people living together. Second, the number of people living in a group home is prescribed by government policy, which is a feature adopted by the NDIS SDA rules. The number of people living together is selected for staffing and funding purposes, and is usually between four and six people. The number also reflects the capacity of ordinary houses to be occupied by staff at the same time as the people living there (although the number of staff and residents may not be a comfortable fit given the types of disability of adults living together and the physical configuration of the housing asset used as a group home). The maximum number in new SDA housing is currently up to five long-term residents although no research has established that there are better outcomes for this number of people living together. That is, there is no evidence that people with disability have more negative outcomes or unacceptable quality-of-life living in a group of seven or eight people outside institution-like residential settings. Third, group homes that have not been recently built are often ordinary-looking houses in ordinary streets. Some of these houses were built in the 1960s, 1970s or 1980s and were designed to suit the lifestyle of people without disabilities in those decades. For example, depending on the street or suburb, such houses may be better suited

to people who can jump into their car to visit a local shopping centre or other services. Fourth, on-site paid support, including 24-hour staffing, is historically the primary purpose for the traditional group home and is its distinguishing feature. The extent to which staff engage with the people living in a group home, and the culture of provider-run group homes, has been the subject of research (Bigby & Beadle-Brown 2016).

‘Family’ means the adult’s representative, which is frequently a family member who is a relative. In each case study, the relative who was a representative and caregiver was also the parental research participant. Family can include other people living in the same household or nearby, such as neighbours, friends and relatives. In relation to the adults themselves, this study does not assume or view adults as dependent but rather family members as interdependent. For example, adult daughters and sons depend on families or NGOs to provide housing when the state will not do so. Families depend on these adults to settle in and be happy in their new home. Adults depend on NGO service providers and staff in their home to provide paid support in a manner that is respectful and ensures the adults are comfortable, happy and safe. But adults are not passive recipients of care and support (Lister 2010; Rummery 2007). They express wishes and preferences (verbally and non-verbally) to communicate whether they are happy in their new home and prepared to remain living there.

The term ‘support’ has a separate definition for NDIS purposes, but an independent living perspective is preferred for this thesis. Therefore, the terms ‘support’, ‘disability supports’ and ‘paid support’ are used to denote the involvement of an independent third party, employed paid carer, paid support staff or other key workers who provide paid person-to-person assistance. ‘Formal support’ is another term used for paid support. Similarly, unpaid support is sometimes called ‘informal support’ or ‘informal assistance’,<sup>12</sup> but payment of a wage or salary in exchange for employment on a full-time, part-time or casual basis is the key distinction between the two categories. When paid support is not available, the adult depends on unpaid caregiving. Unpaid care, and unpaid caregivers who are frequently parents, includes three scenarios irrespective of

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<sup>12</sup> In 2018, the Australian Bureau of Statistics (ABS) SDAC defined a carer as a person who provides informal assistance to a person with disability (Whitelaw 2018).

the scope or nature of the care given: caregiving performed willingly but without a choice; caregiving performed unwillingly and without a choice; and caregiving performed willingly by choice. Parents who cannot or will not perform a day-to-day caregiving role, or who need a break from it, can still 'care for' or 'care about' their child who is receiving paid care. They may still provide different types of caregiving according to their ability, including weekend or backup support. Historically, parents as caregivers have not had any choice in this matter. Whether the adults or unpaid caregivers in each case study could exercise free will, or whether they had access to government funding for paid support in the family home, should not be relevant to the right of people with disabilities to live in their own home. Such matters are outside the scope of this study.

'Community' has hundreds of different meanings in the literature. Participants used the term to refer to the *geographic location* where people live; a *community of identity* with the people who are its members, like disability and possessing or expressing similar needs and common interests; and *issue-based communities*, which focus on particular issues, such as the pursuit of housing, social inclusion and equal rights (Craig 2007). Community membership is a related concept that includes identity, action and belonging (Lister 2010, pp. 197–8). Marshall's (1950) post-war theory of citizenship explained that a community bestows status and rights on those who are full members (Lister 2010, p. 197), but 'lived citizenship', and the experience of it, is shaped by social, cultural and material factors at a local level (Smith et al. 2005). Disability is one of these factors (Lister 2010, p. 196).

## **1.6 THESIS STRUCTURE**

This research is presented in the thesis by compilation format. It includes a combination of four chapters and four papers that will be submitted for review and then publication. Chapter 2 provides a narrative literature review of the historical social and policy context of the study. Chapter 3 presents the research design, methodology and analysis process. Chapters 4–7 comprise four papers prepared for publication. They contain standalone literature reviews that reflect the reframing and unfolding study.

Chapter 4 is the first paper prepared for publication. It applies the theory of institutional entrepreneurship to three case studies where parents created family governed, person-centred homes for adults. The chapter presents these innovative initiatives as different types of social innovation: first-time innovation, governance innovation and scalable innovation. It brings together the fields of institutional entrepreneurship and social innovation.

Chapter 5 is the second paper prepared for publication. It uses three case studies to explore the barriers that confronted families when their daughters or sons wanted or needed their own home. One-, two- and three-dimensional views of power (Lukes 2005) explain barriers created to exclude discussions of housing needs with the government as funder, and power-within, power-to and power-with to mitigate and overcome these barriers to achieve housing. The chapter presents parents who found the power-to challenge the lack of engagement by the government in meeting housing needs, and the exercise of power-with other families and supportive politicians to challenge the status quo.

Chapter 6 is the third paper prepared for publication. It studies the collaboration and resource-sharing by families and not-for-profit NGOs to establish new co-resident models through collaboration and working together in two case studies. Both case studies demonstrate the importance of families and NGOs working across sectoral boundaries to address the housing need (Shergold 2016). Engeström's (2001) cultural–historical activity theory is used to analyse the contribution of inputs from the family or household sector, the not-for-profit sector, and the government or public sector to achieve housing, paid support and housemates as companionship.

Chapter 7 is the fourth paper prepared for publication. It studies the person-centred design of the built environment. This case study demonstrates how the participation of parents in the design and build processes was key to families attaining the cluster model of homes they wanted for their children and meeting the needs and wishes of their daughters and sons. The concepts and phenomena of social entrepreneurship, bricolage and social innovation are common to Chapters 4–7.

Chapter 8 outlines the contributions and policy recommendations of the thesis, identifies the limitations of the research, demonstrates achievement of the study aims, highlights areas for future research and presents the final conclusions. For reference, abbreviations, acronyms and a glossary of terms are presented on pages xviii–xxii.

## **2 LITERATURE REVIEW**

This chapter presents a narrative literature review. It focuses on the social and historical context for volunteering, organisation, advocacy and home-making by families, other caregivers and community organisations that sought to establish housing with paid support for adults. Families, and the community organisations they established, aimed to include adults in community life as conceived at that time, and to create supported accommodation. Action taken by parents to attain new homes reflected the tension between attitudes and beliefs regarding the family's role in caregiving, and whether the state should meet the housing needs of adults. To the extent that the state provided supported accommodation, responsibility for appropriate and sufficient housing with support services was relocated to not-for-profit non-government organisations (NGOs) through outsourcing. The capacity of NGO service providers and outsourced service arrangements is capped by the funding allocated by the government.

In addition to the literature review presented in this chapter, Chapters 4–7 include supplemental literature reviews focusing on the specific topics presented in those chapters. Together, these literature reviews complete a systematic review of disability, housing, entrepreneurship, innovation and power literature. The breadth of the literature review demonstrates the complexity of the topic being investigated.

The systematic literature review commenced by examining the failure to introduce a national disability scheme proposed by the Australian Government in the 1970s. A review of disability, carer and housing data published by the Australian Bureau of Statistics (ABS), the Australian Institute of Health and Welfare (AIHW) and AHURI identified gaps and limitations in the available accommodation supply data and understanding of the housing needs of people with disabilities, including adults living with ageing caregivers. Research into the housing needs of ageing adults living with ageing caregivers was infrequent and out of date for an area where housing needs are increasing (Llewellyn et al. 2003; Qu, Edwards & Gray 2012). As a consequence, the housing needs of ageing adults living with ageing parents was inadequately documented and not quantified (Carney & Keyzer 2007).



The effect of the transition to NDIS funding on disability service and supported accommodation data published by the AIHW before the NDIS commenced, and the lack of baseline data for evaluation of the NDIS and comparison between historical supply data and future NDIS data was reviewed. Development of the design of the SDA framework (introduced in Chapter 1), and the lack of understanding of the housing needs of people with disabilities who were not eligible for the NDIS, were also part of the literature search. The aim of the research was to understand the experience of families who sought and achieved new homes for their adult children where housing supply was inadequate. What were their desired housing objectives? What housing outcomes were achieved, and how?

Disability literature occupies separate but overlapping fields of study (education, health, nursing, occupational therapy, rehabilitation counselling, psychology, social work and disability). The literature search focused on housing and care models, funding models, choice and control of housing by people with disabilities, and quality of life. From a systems perspective, the literature review included public policy, public expenditure management, government budgeting and family studies. Review of the activity theory, institutional theory, organisational theory and power literature provided the theoretical foundation for the research. In addition to the academic literature, a significant body of grey literature comprising reports by or for governments and their agencies provided the policy and political context.

The researcher also enrolled in the study of social enterprise with the University of Newcastle to navigate that area of the literature quickly. The social enterprise, social innovation, bricolage and social entrepreneurship literature provided the conceptual frameworks and language for communicating the activities undertaken by the parents and NGOs who pursued resources and opportunities to meet the housing needs of more adults.

The narrative literature review that follows discusses the themes identified. This chapter concludes with a discussion of the demand for housing choice and the government's loss of expertise in the design and delivery of new models, as well as its distancing from government responsibility for meeting housing needs through its outsourcing practices.

## **2.1 SELF-DETERMINATION, AUTONOMY, CHOICE AND CONTROL, AND EMPOWERMENT**

Adults with a cognitive disability have been identified as having self-determination when they take control of their lives, exercise agency and make quality-of-life choices and decisions in accordance with their own will and preferences. Choices and decisions must be ‘free from undue external influence or interference’ (Wehmeyer 2003, p. 177, cited in Curryer, Stancliffe & Dew 2015). For adults with different types of cognitive disability, agency to choose where and with whom they will live (United Nations 2006) may be exercised through family members, friends or trusted others if needed (Kendrick 1996). The vision of parents and NGOs — namely, to enable adults to learn to live independently from their families, learn new skills in household life, learn to make their own decisions that will keep them safe, and exercise control and choice in their relationships with others — may be an aspiration.

Choice of where and with whom to live requires two or more options (Stancliffe 2001, p. 91). Choice from available options must be free from influence or interference if adults are to exercise choice freely (Lewis, Millington & Marini 2015). However, the continuing involvement of family members, friends, guardians or trusted others is necessary for decision-making or choice-making where assistance is needed (Kendrick 1996, cited in Curryer, Stancliffe & Dew 2015, p. 395). Adults with a severe or profound limitation need more assistance to make or communicate their decisions. Adults who need less assistance, but who have no previous experience of matters they chose or that their representatives chose for them, must be supported to change their mind about living in their new home if that is their wish. Settling in to their new home may not occur with the first move, and some adults will choose to return to the family home if this is an option.

## **2.2 ORGANISATION AND ADVOCACY**

Generations of parents have empowered their children with disabilities to participate in all manner of community life. Parent advocates have organised themselves and formed groups to improve the service system and opportunities for their children. As their children became adults, parent advocacy for

government assistance with housing and paid support aimed to ensure these adults were as self-sufficient as possible.

Dave Earl is the brother of a woman with Prader–Willi syndrome. Earl's thesis on the history of parent-run organisations for children with intellectual disabilities in NSW between 1950 and 1968 consolidates an important body of knowledge of family activities. Over that period, the NSW Government (2007) 'made little provision for [the care or support of] intellectually disabled children' (p. 22), preferring their location in the family home with parents as caregivers. When it directly addressed the subject, the NSW Government stated that assistance to people with disability is a shared role (NSW Premier McKell's speech in 1946, cited in Earl 2007, p. 55). Earl reported that the system of state care for people with intellectual disabilities in NSW in the late 1950s was firmly 'ad hoc'. There was some accommodation only for 'difficult children' who would live in hospital institutions when they were older (Earl 2007, p. 28).

These earlier generations of parents contradicted and rejected the expectation that families would be lifelong caregivers. Family groups formed community organisations to raise funding and establish privately run residential care or 'supported accommodation'. These examples of collective self-help and mutual support — through volunteering, advocacy and forming organisations — were partly a response to the narrowing role of the government and the failure of the state and market actors to meet the needs of people with disabilities after World War II (Burns, Williams & Windebank 2004).

Family governed organisations became significant service providers. The Spastic Centre of NSW (now the Cerebral Palsy Alliance) was assisting dozens of children with cerebral palsy by 1952. Approximately 2,000 people and around 1,200 families were using the services of the Subnormal Children's Welfare Association by 1962. By the 1960s, people with intellectual and other disabilities in NSW were receiving assistance from 'a complex web of interrelated voluntary and charitable organisations' (Earl 2007, p. 73) supported by an ad hoc system of subsidies and grants from different government departments (Earl 2007, p. 61). The NSW Government's apathy persisted. In 1960 and 1962, two committees appointed by the NSW Government recommended that the government expand its support for people with intellectual disability, but the NSW

Government chose not to enact those recommendations. Instead, the burden of lifelong caregiving was left to families, knowing it was a government responsibility or, at a minimum, a shared responsibility.

In the 1960s, the principles of normalisation<sup>13</sup> defined criteria against which the quality of accommodation and service programs could be assessed to ensure that people with intellectual disability lived their lives as other people did (Nirje 1969, p. 181; Wolfensberger 1998, p. ix). In 1968, the Australian Council for the Mentally Retarded, an umbrella organisation of parent groups, issued a strategic invitation for international experts to visit and report on the schools, sheltered workshops and supported accommodation across Australia. Informed by normalisation principles, as well as the Scandinavian legal and service structures they had seen driving social change for people with intellectual disability overseas, the experts reported that the arrangements in Australia were benevolent segregation and needed to change (Earl 2007, p. 125). Their report began decades of discourse in Australia regarding new ideas about ways of living, advocacy for adults to live differently, the principles of normalisation and, later, social role valorisation, which supplanted normalisation over time.

Volunteering, organisation, advocacy, establishing new homes and home-making were all part of the continuum of caregiving in its multiple forms. Naples (1998) described 'activist mothering' or political activism as a central component of mothering. Panitch (2008, pp. xii, 3) described the activist mothers of disabled children as feisty and determined advocates. Family members and caregivers as a broader group have contradicted and rejected inaction by governments in Australia for decades by taking action, building networks and forming organisations to achieve more housing with paid support, as well as policy change to enable it.

## **2.3 VOLUNTEERING AND CAREGIVING**

### ***2.3.1 Volunteering***

The activities of the parents described in Section 2.2 comprised unpaid work, voluntary work and volunteering. Advocacy, forming organisations, volunteerism

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<sup>13</sup> Normalisation was reconceived as social role valorisation in the 1980s (Wolfensberger 1998).

and mutual support to secure resources and achieve choice of housing were all part of the continuum of unpaid caregiving by parents in its multiple forms. Although the literature focuses on different types of volunteer work and recommends the measurement of it (Davis Smith 2000), caregiving for immediate family and friends in a household or domestic setting is usually excluded from these studies and their recommendations. Conversely, studies of the care economy traverse paid care, unpaid care in a household and government investment in the care sector (Himmelweit 2013; Murray & Adams 2012).

Ideas about volunteering are part of the political and cultural heritage drawn from Britain, although voluntary principles in Australia have assumed their own character (Oppenheimer 2000). In 2000, then Prime Minister John Howard identified the use of volunteers as an element in the social coalition between 'different levels of government, business, the charitable non-profit sector, and individuals, rather than continually relying on governments to solve social problems' (Oppenheimer & Warburton 2000, p. 1). The relatively hands-off approach of Australian governments contrasts with the development of different approaches in the US and the UK. In the US, national and state legislative frameworks regulate the provision of human services in terms that reflect civil rights and the disability rights movement. The UK Prime Minister's Office was also more proactive than Australian governments because it adopted the role of an enabling state and implemented policies to 'help people to help themselves' in the early 2000s (Blair 1999, p. 13, cited in Lister 2010). Lyons and Passey (2006, p. 92) contrasted Australian governments' lack of recognition of the contribution of not-for-profits to Australia's economy and society with UK government policies, which explicitly encouraged the initiatives of not-for-profit NGOs in the UK's third sector between 1997 and 2004.

In its review of the need for a national disability insurance scheme, the Productivity Commission (2011) used the concept 'informal' in its distinction between formal support or formal care, which the government will fund, and informal support or informal care in a domestic setting or household, which, it stated, is the responsibility of parents or the community, and the government will not fund. These terms describe a constructed boundary between a workforce

that governments will fund and support in other ways (e.g. recognition through licensing or registration, investment in relevant standards, funded training programs) and a domestic workforce that governments will not measure, value or support in the same way. However, there is clear support for measuring and valuing unpaid caregiving given the contribution of that type of unpaid work to economic activity and the wellbeing of individuals, families and society (Deloitte Access Economics 2018). Reports that have sought to measure unpaid caregiving are summarised below.

### **2.3.2 Caregiving**

An unpaid caregiver or carer is a person who provides unpaid care and support to a person who has a disability, mental illness, chronic condition, terminal illness, alcohol or drug issue, or a person who is frail aged. They do not receive a salary or wage for the care they provide. Caregivers can be a family member, friend, neighbour or other kin or non-kin connection with whom the person cared for has a social relationship (Deloitte Access Economics 2020, p. 7). Unpaid caregivers are an integral part of the system for disability care and support (Carers Australia 2021).

Attempts to measure the scale and types of caregiving across Australia, as well as the economic value of unpaid caregivers as a financial asset in the Australian economy, have been commissioned by organisations independent from the government. Appendix A provides a broad description of the findings of an important series of reports by Deloitte Access Economics commissioned by Carers Australia. The 2020 report estimated the replacement value of the cost of care for people with disability and different types of support needs (Deloitte Access Economics 2020). The value of the cost of unpaid care for people with a profound disability was estimated to be \$51.6 billion, \$23.1 billion for people with a severe disability and \$2.6 billion for people with a moderate or mild disability.

Governments in Australia are aware of the decline in unpaid caregiving (Hill, Thomson & Cass 2011) and its implications for policy, including 'adapting the formal care sector to meet the needs of older Australians' (Deloitte Access Economics 2015, p. iv). The Household, Income and Labour Dynamics in Australia (HILDA) survey, which is an annual household panel survey, and the

less frequent ABS Survey of Disability, Ageing and Carers (SDAC), which is a sample survey of households, both collect unpaid caregiving data. Deloitte Access Economics (2018) uses HILDA data to estimate the average hours per week spent on unpaid care for the ill, disabled and elderly. However, HILDA data only measure unpaid care by people aged 15 or older. The Terms of Reference for the Productivity Commission inquiry into the need for a national disability insurance scheme cited the government's concern with the continuing decline in the availability of unpaid care. The Terms of Reference also noted the pressure that the decline in unpaid care would place on disability systems that were inadequate (Productivity Commission 2011, p. v). The Productivity Commission was asked to consider the contribution of, and impact on, informal or unpaid care as a design issue for the NDIS (Productivity Commission 2011, p. vi). But the final Inquiry Report stated that the NDIS would not replace or displace family and community support (Productivity Commission 2011, p. 13), noting it would be beyond the financial means of any government to replace informal or unpaid support provided by families or others. Although the parent or family as primary caregiver and housing provider is the cheapest option from the perspective of the government, the level of assistance these caregivers need from the government to sustain caregiving arrangements in the family home is not measured, and the lack of it may contribute to the decline in caregiving. Australian governments are certainly aware that family caregivers need more assistance than they receive (Productivity Commission 2011), and a lack of sufficient assistance from the government may leave families who want to keep their adult child at home with little choice other than to seek a new home for them. Table 1 lists the family activities that then need to be performed to replace unpaid caregiving with paid support for adults to live independently of their unpaid caregivers.

**Table 1: Replacing unpaid caregiving with paid support**

<b>Need/object</b>	Lifelong support and caregiving.
<b>Subject</b>	Families and adults.
<b>Tools</b>	Support/caregiving by unpaid carers — frequently a family member.
	Advocacy and activism to transition caregiving to paid key workers.
	Government commitment to fund paid support/caregiving.
<b>Network and community</b>	Family members, other families, neighbours, friends, local communities, disability service organisations, politicians, bureaucrats and governments.
<b>Division of labour</b>	Support and caregiving by unpaid carers — frequently a family member. Families pursue resources. Families advocate for government assistance. Governments provide funding for paid care when persuaded.
<b>Rules</b>	Limited, if any, government recognition and assistance.
	Failure to measure and plan to replace unpaid caregiving.
	Attitudes and priorities for government funding as enablers and barriers. Government must be willing and able to provide assistance, or required by government policy to do so.
	NDIS includes the replacement of unpaid caregiving when it is reasonable and necessary for people who are disabled enough.
<b>Contradictions</b>	Volunteer caregiving has been commandeered for government purposes. Further, unpaid caregiving may be preferred by adults or family members for different reasons.

## 2.4 INSTITUTIONAL SUPPORT FOR PEOPLE WITH DISABILITY

In addition to replacing unpaid care with paid support, and providing more assistance for some unpaid caregivers, Australian governments have been asked to demonstrate their support for the right of people with disabilities to choose where and with whom they live (United Nations 2006, article 19). The failure to reform models of supported accommodation was evident when the NSW Government was slow to respond to ‘changing patterns in residential services’ that were occurring overseas for decades before action was taken in NSW. Sweden enacted a statutory commitment to meet housing needs in 1954 (Bank-Mikkelsen 1969, pp. 261–3). An expert agency was established to ensure



the law was followed, with representatives of service users included in the composition of the agency's membership (Grunewald 1969, p. 261). In 1959, Denmark passed progressive legislation granting people with intellectual disability 'civil rights in nearly all respects', including the right to leave their parent's home to be trained, taught and pursue employment (Bank-Mikkelsen 1969, pp. 230–4).

It was another 20 years after these developments before the NSW Government engaged Commissioner David Richmond to complete an 'Inquiry into Health Services for the Psychiatrically Ill and Developmentally Disabled' in NSW. The so-called 'Richmond Report', delivered in 1983, recommended that people with 'developmental disability'<sup>14</sup> in NSW should no longer live in institutions with people who had mental health disability or psychiatric illness (Richmond 1983a). Richmond recommended that people with developmental disability be rehoused into 'normal houses' in the community (Recommendation Part 1, rec. 3(ii); Part 2, p. 41) (Richmond 1983b). He appropriated the concept of 'normal' to describe housing with paid support, presumably referring to the group home model still used today.

The Richmond Report recommended that government-funded services be based on principles of normalisation. For this purpose, the Richmond Report gave primacy to living in the family home where possible. To sustain those living arrangements, the provision of respite and shared care for families would be important. The Richmond Report also recommended that responsibility for the cost of support to live in the community be transferred from the Health Department to the Community Services Department of the NSW Government. The Mental Health Commission website published the former Commissioner's statement that bed closures in NSW institutions had actually begun in the 1960s to remove the pressure on the health budget and reduce costs (NSW Mental Health Commission 2014). Other views posit that the commencement of deinstitutionalisation in Australia in the 1960s was part of the international disability rights movement (Wiesel 2019, pp. 74–5). Thus, it is possible to view

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<sup>14</sup> In the Richmond Report, the term 'developmental disability' was used to include 'intellectual handicap, severe epilepsy, cerebral palsy, brain damage acquired in childhood, and ... other neurological disorders needing similar provision' (Richmond 1983a, p. 10).

the commencement of the closure of institutions at that time from this alternative perspective. Nonetheless, the continuing use of large residential centres in Australia — at least in NSW — suggested contradictory objectives within the government.

Notwithstanding the recent contributions of the state, territory and federal governments to the capital funding of SDA housing under the NDIS, there is no measurable commitment to increase the supply of different types of housing for people with disabilities. Davy et al. (2019) reported the omission of government housing objectives in their review of Australia's 2010–2020 National Disability Strategy (Department of Social Services 2019). Governments have maintained the group home model for people with high support needs by re-funding them as SDA housing with NDIS capital funding, while state and territory government-funded public and community housing remain the dominant models for adults with low support needs (Productivity Commission 2011a, p. 25). These systems are segregated models with separate administrative systems overseen by different bureaucrats and managers. In parallel with the commencement of the NDIS, the NSW Government transferred the specialist group homes it owned or funded to the not-for-profit sector, although many were ageing assets. As a result of leasing or reselling them, their new owners may be able to earn SDA funding from the NDIS if people eligible for the NDIS choose to live in them. More government investment in all types of housing, as well as engagement with the innovative initiatives achieved in the case studies, will assist governments to learn and think about other ways to increase housing options for adults to choose from.

## **2.5 HUMAN RIGHTS FRAMEWORK**

Australia's ratification of the UNCRPD in 2008 requires active steps to take appropriate legislative, administrative and other measures to promote the human rights of people with disabilities in Australia (Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability 2019). The requirements of Article 3 of the UNCRPD include:

*respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of*

*persons; non-discrimination; and full and effective participation and inclusion in society.*

These principles reflect the desire for autonomy and control over one's own life through freedom from dominant and authoritarian institutions and systemic disadvantage (National People with Disabilities and Carer Council 2009, p. iv). In relation to living arrangements, specific principles in Article 19 of the UNCRPD require parties to (among other things):

*recognize the equal right of all persons with disability to live in the community, with choices equal to others ... ensuring that: a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement.*

Article 19 brings together 'the hybrid themes of the concept of place of residence, of standard of living and the UNCRPD's requirements around choice, decision-making personal control and right to self-determination' (Eastman & Kayess 2019, p. 391). Although Article 19 relates to choice of living arrangements, it does not confer a right to live independently.

Australia's Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (Disability Royal Commission) began proceedings in 2019 to examine and address the occurrence or risk of violence, abuse, neglect and exploitation of people with disability. The Disability Royal Commission has begun its investigation of different settings and experiences of people with disabilities, including living arrangements. The public hearings of the Disability Royal Commission in December 2019 heard evidence that the rights in the UNCRPD need to be brought into Australian domestic law for those rights to be fully operative. In addition, the experience in accommodation for many adults can fall short of the standards of freedom from discrimination, degradation or abuse. Violence, abuse, neglect and exploitation of people with disability is a particular risk for people locked away from the broader community because they have different ways of communicating and are supported by people who are not alive to these risks or who may be perpetrators. Because these risks can exist in any

setting, Professor Robinson (2019) from Flinders University asked the Disability Royal Commission to explore the experience of people with disability inside the family home, including children who experience family violence. Proceedings of the Disability Royal Commission are planned to conclude in 2022.

Activity theory was used to analyse and understand the interdependent elements required to recognise and exercise a person's right to live as independently as possible. This included elements that implement a human rights framework. Table 2 lists the existing and missing elements required to more effectively support a human rights framework.

**Table 2: Activity system framework to support control and choice**

<b>Need/object</b>	Implementation of the right of people to independent living.
<b>Subject</b>	Adults and parents.
<b>Tools</b>	International human rights framework.
	Freestanding legislation to give effect to right to independent living (hard law). Missing.
	Maximise housing opportunities. Missing.
	Coordinate implementation of UNCRPD across government. Missing.
	Ensure government agencies comply with UNCRPD. Missing.
	Provide advocacy services. Commitment of government to fund advocacy. Missing and/or insufficient funding for housing advocacy.
	Peer and family support.
	Autonomy from the disability service system through organised family governance/choice and control of provider and key workers.
	Autonomy from disability specialist housing system pursuing existing community resources to achieve different types of housing/private rental, public housing or community housing.
	Joint decisions regarding services, providers and key workers — if necessary, with trusted others.
<b>Network and community</b>	Peers, advocates, families and service organisations.
<b>Division of labour</b>	Adults to have choice and control over services and housing.

	Government to ensure compliance with UNCRPD. <sup>15</sup>
	Government-funded framework to oversee pathway to housing so adults can live the lives that others live.
	Ensure that adults are able to live in a community with housing options equal to others, and that those options support inclusion.
	Government to develop housing pathway policy for people with disability.
	Government to monitor disabled people's access to information, advice and advocacy services.
<b>Rules</b>	Adoption of human rights framework (although limited implementation of the human rights framework to this point).
	Policy and rules only offer a limited type and quantity of funded services, which limits choice.
<b>Contradictions</b>	Government must pass legislation to require agencies, NGOs and housing systems to comply with the UNCRPD.

## 2.6 HISTORICAL CONTRADICTIONS

Prior to commencement of the NDIS, disability services and housing services for people with disabilities were accessed through state or territory government agencies. Barriers, tensions and contradictions within and across these services and housing systems are described in this section.

### 2.6.1 Structural barriers within government agencies

In NSW, both mainstream and specialist disability housing systems and disability services were accessed through FACS. FACS was a department of the NSW Government until 2019, when its functions transferred to a newly formed agency. FACS operated two separate divisions at the time. Housing NSW was responsible for social housing except specialist disability housing. Ageing, Disability and Home Care (ADHC) was responsible for group homes and disability services until the NDIS commenced. Housing NSW and ADHC had a separate management structure, different bureaucrats and agency staff overseeing their operations, and different Ministers of the NSW Government (Minister of Housing and Minister of Disability, respectively). ADHC transferred most group homes to NGOs before it closed down in 2018.

<sup>15</sup> This assumes that governments are funding the construction of housing for adults with a disability on both a planned and responsive basis.

There were tensions or contradictions across and within disability service and housing systems funded or delivered by ADHC before the transfer of those homes. First, group homes were the only option for people who needed housing with paid support, assuming there was a vacancy. Second, the fact that the government had to provide or fund the services meant that it also had no choice in the matter, although it had control over the type and quality of services for people with disability that it would fund. Historical underfunding of disability services, outsourcing the provision of services to the not-for-profit sector, and contracting processes provided some context for the tensions and contradictions between the objectives and priorities of successive governments as funder, not-for-profit organisations as service provider, and adults and families as service user.

### ***2.6.2 Historical underfunding***

Underfunding disability services and housing was a systemic issue. In 1986, the *Commonwealth Disability Services Act* enacted a new framework for funding and providing support services for people with disability in Australia. State and territory governments enacted parallel legislation, committing to the same set of principles and objectives through an agreement with the Commonwealth Government. However, funding from the Commonwealth Government to state and territory governments was insufficient to implement and achieve the intended outcomes under the legislation (Parmenter 1999, p. 327). This led to 'a three-tier system where some people with a disability received contemporary models of service, others received traditional segregated services, and some received no support at all' (Parmenter 1999, p. 327). The shortfall of funding was particularly evident in accommodation with paid support. This situation of underfunding the housing component continues today.

### ***2.6.3 Outsourcing and privatisation***

The commitment to protect 'the rights and the citizenship of people with disabilities' (Parmenter 1999, p. 330) was weakened when state and territory governments transferred responsibility for services to the not-for-profit sector. At a disability service system conference in 2015, in preparation for the full rollout of the NDIS, the then Chief Executive of ADHC, Jim Longley, explained that the

NDIS had been designed around the provision of services by NGOs to increase choice. In his opinion, the NDIS was not a sustainable system in the long term if state and territory governments continued to provide disability services. He stated that some governments in other states and territories were avoiding the issue and continuing to provide services. In his opinion, those states or territories would not remain in the NDIS for the long term; otherwise, state and territory governments in Australia would end up funding a federal responsibility. Longley was silent on the role of the NSW Government in the provision of housing and services for people with disability who are not eligible for the NDIS. How this larger, second group was to receive housing and other services was not clear. To the extent it was able to do so, the NSW Government ceased providing disability-specific services to people eligible for the NDIS when it commenced. In 2017, ADHC began transferring the 'business' of providing group home services and other supported accommodation across NSW to NGOs. Under the NDIS, paid support is funded separately and, in theory, different providers can be chosen to deliver paid support in group homes regardless of whether they are government-run or government-owned. The NSW Government may have perceived the risk that group homes, or the workforce of paid staff working within these homes, would become a stranded asset in government hands.

#### ***2.6.4 Contracting and tendering processes***

A key feature of outsourcing government services to the not-for-profit sector is the competitive contracting and tendering processes adopted by the government (Gilchrist & Butcher 2016). The procurement framework and contracting practices can lead to a number of challenges that both the government and NGOs must navigate. First, government-contracting practices and funding criteria under those contracts impose conditions (Barraket 2008, p. 3) that achieve the objectives and priorities of the government rather than the mission of the NGOs. Second, it is possible to lose sight of the objectives and priorities of people with disability, which is the purpose of the services. Yet the person with a disability is not a client or consumer with real choice in this scenario.

Third, government funding criteria have propelled NGOs to become increasingly managerial and professional in the delivery of human services. The professionalisation of the not-for-profit sector, as well as the distancing of NGOs

from unmet needs in civil society in Australia today, creates a situation whereby adults and their families are no longer a 'client' for life. Fourth, there has been a shift in the membership of not-for-profit organisations and the participation of volunteers in NGO activities. The growth of the not-for-profit sector as a government-funded market has reduced or removed the exercise and power of collective action and community organising through these organisations (Mathie & Gaventa 2015, p. 9). It may be that bottom-up, grassroots initiatives outside these organisations will overtake NGOs in understanding and meeting social need.

### ***2.6.5 Who controls funding and contracting now?***

In 2011, the Productivity Commission confirmed that disability care and support in Australia was 'underfunded, unfair, fragmented, and inefficient', giving 'people with a disability little choice and no certainty of access to appropriate supports' (Productivity Commission 2011a, p. 2). Shortages in government funding, assistance and support contributed to an unsustainable, high-cost, crisis-driven disability service system (Productivity Commission 2011a, p. 5). The Productivity Commission acknowledged that the disability service system in Australia was not 'a genuine "system" in which different elements work together to achieve desired outcomes' (Productivity Commission 2011a, p. 5). The Productivity Commission also noted that adults were still required to live with their parents 'instead of moving into independent supported accommodation' (Productivity Commission 2011a, p. 5). Further, the traditional 'block' funding model (determined by 'client numbers' and services stipulated by the government) stifled 'innovation and flexibility' (Productivity Commission 2011a, p. 6). In its Final Report, the Productivity Commission recommended that disability care and support should be a core function of government. It recommended a national disability insurance scheme be designed and funded to better meet the needs of people with disability, as well as their families and caregivers (Productivity Commission 2011). Australia's NDIS commenced on 1 July 2013. State, territory and Australian Government funding has been consolidated under the NDIS. The cost of the NDIS is supplemented and sustained by increasing the Medicare levy, which is paid by Australian taxpayers to also fund free and lower-cost health services. It remains the role of the government to ensure that the NDIS works,



set the standards for what the NDIS delivers, and measure whether it is meeting its aims and objectives, as well as the expectations of the Australian citizens who fund it. It was proposed that the person with a disability and their representative would control the contracting of NDIS-funded support, although the extent to which service providers control individual funding to meet their costs requires a separate study. Agencies of the Commonwealth Government must evaluate the NDIS, quality of support and profit-making across the service sector.

## **2.7 HOUSING NEED AND SUPPLY**

The SDA Pricing and Payments Framework to guide the approach to SDA funded under the NDIS was agreed by the federal, state and territory governments in 2015 (KPMG 2018, p. 4). The SDA Pricing and Payments Framework was intended to support only a small number of people eligible for SDA funding into their own home (\$700 million annually was anticipated to be spent on housing stock for approximately 28,000 NDIS participants estimated by the Productivity Commission in 2011) (KPMG 2018, p. 4). The NDIS SDA Rules 2020 is the mechanism that gives effect to this intention. Under the SDA Rules, which commenced in 2017 (KPMG 2018, p. 5), SDA (or SDA housing) is limited to people with a significant functional impairment or very high support needs who also meet 'SDA needs requirements' (SDA Rules 2020, Part 2). SDA needs requirements under the SDA Rules introduce a range of factors the NDIA will take into consideration — for example, whether SDA housing represents better value for money than other supports for the person.

People with a significant functional impairment or very high support needs are a subset of the group of people eligible for the NDIS and a subset of a larger number of people with disabilities who need housing but are not eligible for the NDIS. It is feasible to update estimates of people who are eligible for NDIS-funded support *and* need housing because the NDIA is able to access, collect and report those data. The NDIA should also locate, quantify and report the number of people who are NDIS-eligible, who live in group homes or larger residential centres, and who need or want to move. All levels of government working together have the means to locate, quantify and report the housing needs of people with disabilities by location, age of caregiver and age of adult

using existing community resources (e.g. child and family health centres and carer service organisations, health and ambulance systems, guardianship tribunals, the location of recipients of the Commonwealth Government carer allowance, and the location of recipients of assistance from local governments for meals and transportation).

However, at this time, there are still ‘insufficient data, research and policy clarity about housing for people with disability’ in Australia (Disability Housing Futures Working Group 2016, p. 5). Analysis of housing needs data, where available, was undertaken for Disability Housing Futures by Dr Ilan Wiesel. The Disability Housing Futures Working Group (2016, 2017a, 2017b) estimated that there is not enough housing for 35,000–55,000 people who are eligible for the NDIS.

Wiesel updated his estimate of housing needs in his testimony to Australia’s Disability Royal Commission. Wiesel (2019, p. 81) estimated that 100,000 adults who are eligible for NDIS support funding to live independently will need access to affordable housing in the near future. Wiesel made recommendations to achieve better housing outcomes to be delivered by all levels of government:

*So what I would like to see from the Royal Commission is ... for governments to come up with plans to address unmet need, and to provide a supply of housing that is affordable for people with disability that gives them choice about where they live, that is suitable for people in terms of the design, the management of their homes, that is well located, that is not segregated. If some people choose to live in group homes ... that should be an option that is provided but other people should have many other housing options — housing and support options. (Wiesel 2019, p. 81)*

Advocate-led social enterprises in Australia, such as the Summer Foundation, work to address the gap in SDA housing supply data that is planned or in the pipeline from the perspective of SDA housing providers (Summer Foundation & Housing Hub 2021; Summer Foundation & Social Ventures Australia 2020). Organisations like the Supporting Independent Living Co-operative (SILC) analyse NDIS-published supply data from a housing need or demand perspective.

## **2.8 CONCLUSION**

The literature review identified gaps and limitations in the available accommodation supply data and understanding of the housing needs and wishes of families for adults still living in the family home. The extent to which government agencies possess unreported data or understand where adults with disabilities need or wish to live is not known. In the absence of adequate data or forward planning by the government — specifically, for adults with a disability living with parents — the grassroots, bottom-up activities of families and NGOs to create new homes for adults in their local community provide some of the missing information. The aim of the research was to understand the activities, strategies and transactions that these families or NGOs undertook or entered by interviewing them. This study uses action research to also capture the housing achievements of families and NGOs as part of the continuum of caregiving and home-making at a point in time over the lives of the adults in the case studies.

### **3 RESEARCH DESIGN**

This chapter presents the philosophical approach to the case study design used in this research. This philosophical approach had implications for the research process, the data sources and the researcher's role as research instrument, all of which are described in this chapter. The main research question, the criteria for the selection of case studies and the sample of case studies are also outlined. Descriptions of the data collection and analysis methods, including the use of activity theory, issues of validity and reliability, and the approach to the ethical conduct of the research, conclude this chapter.

#### **3.1 PHILOSOPHICAL APPROACH**

##### ***3.1.1 Epistemology***

The philosophical approach for this study was based on Lincoln and Guba's (1985) conception of naturalistic inquiry, which is the study and interpretation of human behaviour in a natural setting. Subjectivism was the epistemology adopted for this study; it determined the selection of an interpretivist theoretical perspective. This subjective, interpretivist perspective informed the methodology, the research process, and the logic and criteria for the research. Essential features of Lincoln and Guba's (1985) subjective, interpretivist perspective include the interpretation of the lived experience of human behaviour from the perspective of a person directly affected.

##### ***3.1.2 Implications for this study***

Parents who took action to establish new homes with paid support for their daughters and sons were directly affected by barriers to accessing government funding for housing or support. Hence, the areas of interest in this research reflect the parents' perspective — particularly the challenges or barriers that parents overcame to get their daughters and sons into their own home and how they did so. In the NGO case studies, the experience of NGOs with like-minded CEOs and managers who supported more adults in their own home was interpreted from each NGO's perspective.

### **3.1.3 Ontology**

The subjective interpretivist stance of this study required a constructivist approach to identify the nature of reality. In a study of a social setting, reality means different things to different people. Thus, this study adopted a constructivist ontology to reflect multiple constructed realities (Lincoln & Guba 1985, p. 37).

### **3.1.4 Implications for this study**

Because ontological issues and epistemological issues emerged together, were compatible and were 'difficult to keep apart conceptually' (Crotty 1998, pp. 16–7 online), the researcher adopted Crotty's (1998) preference for using the term 'ontology' only when it was necessary to talk about reality as 'being'.

### **3.1.5 Subjectivity and objectivity in qualitative research**

A qualitative study cannot be completely objective and neutral (Holloway 1997), and there is more than one subjective dimension to consider in this study. In addition to the subjective perspectives of the research participants, the researcher brought her own beliefs, biases and values to the interpretive research. These interacted with the research participants in the selection of the sample, the data collection and the selection of data for publication (Lincoln & Guba 1985).

But qualitative researchers also 'counterpoise subjectivity and objectivity' (Ratner 2002). In this study, activity theory, which contributes categories of elements with objective meaning, was selected for the data analysis. Leont'ev (1978) distinguished activity from other types of interaction with elements of the world in two respects. First, research participants undertaking activities have needs and objectives. They interact with artefacts, signs and other instruments or tools that have objective meaning to meet those needs and achieve those objectives. Second, the activities are organised around objects like instruments or tools that have objective meaning (Kaptelinin n.d.). These objective elements offer a counterpoise or balance to the subjective perspectives.

### **3.1.6 Implications for this study**

In this study, data collection within the activity theory framework identified the use of objective items for data analysis. Such objective items included tools with

tangible characteristics like government funding, social contacts who were allies, and purposeful social networks that offered institutional support or community resources. Philosophies and values that were central to the activities, strategies and transactions of the families and NGOs in this research were derived from externally constructed bodies of knowledge. In particular, the human rights framework and social role valorisation were externally defined as global social movements. Data analysis in this study identified that activities, strategies and transactions were structured and organised around other people and organisations, service systems, characteristics of the core elements of each model of home and the changing roles of parents and NGO service providers, all of which had objective meaning. The researcher as primary data collection instrument is discussed next.

### **3.2 RESEARCHER AS DATA COLLECTION INSTRUMENT**

Lincoln and Guba (1985) explained the importance of using the researcher as a data collection instrument when a subjective, interpretivist approach is adopted. They observed that the researcher's interaction with the research participants enables the researcher to understand and evaluate the meaning of that interaction throughout the research (Lincoln & Guba 1985, p. 39). The researcher can sense and respond to personal and environmental cues in the interview, and both the researcher and research participants interact with the situation of the interview to make its dimensions explicit. Lincoln and Guba (1985, pp. 193–4) also listed other important advantages or strengths. The human researcher is adaptable and able to collect 'information about multiple factors — and at multiple levels — simultaneously' (Lincoln & Guba 1985, p. 193). The researcher can grasp pieces of information in a single, holistic view. The researcher can learn about social and organisational settings simultaneously. The researcher can test hypotheses with research participants in the interview, in which hypotheses and understanding are created. The researcher can summarise data on the spot, 'feeding them back' for clarification, correction and amplification. In addition, the researcher can explore atypical or idiosyncratic responses to test their validity and 'achieve a higher level of understanding than might otherwise be possible' (Lincoln & Guba 1985, p. 194). This subjective, interpretivist approach raises

issues of bias and reflexivity, which are discussed in Section 3.2.2. Other implications are discussed first.

### **3.2.1 Implications for this study**

In this study, a single researcher interviewed all research participants. The advantages of this approach included the opportunity to bring together all constructed realities and multiple interview data as a holistic study (Stordy 2012). Insights were gleaned from patterns emerging from the data during the interview process, and the interviews provided an opportunity to explore the presence of the conceptual elements and phenomena of social entrepreneurship, bricolage, social innovation and power as the research unfolded. Each interview also provided an opportunity for cross-case comparison of data on the spot.

The researcher was conscious of the risk of misinterpretation of data when comparing collected data from one case study with others. However, each research participant possessed strongly held views regarding what they were trying to achieve and what they eventually achieved. Their views held firm during each interview. It was therefore difficult to misinterpret or overlook matters that were important to the research participants. Nonetheless, the issues of bias and reflexivity, which arise in qualitative research using the interview method, were present.

### **3.2.2 Bias and reflexivity**

Researchers must be reflexive when the interview method is used because the beliefs, biases and values of the researcher and research participants are always present. This enables 'evaluation users to judge for themselves the nature and extent of evaluator bias in the inquiry process and results' (Lincoln & Guba 1985, cited in Greene 1993, p. 35). Merriam and Tisdell (2016, p. 16) recommended that researchers identify, monitor and openly acknowledge their biases because it is not possible to eliminate them. This means that researchers must account for how their views have affected the research process and research findings.

Reflexivity also requires an understanding and acknowledgement of the researcher's and research participants' respective power and how they exercise it. For example, the researcher may highlight some aspects of the interview but repress others. Reflexivity in qualitative research has been described as 'self-

disclosure at different points in the research process' (Probst & Berenson 2014, p. 814). Stordy (2012) recommended that reflexivity be exercised during all stages of the research process. Table 3 presents Stordy's (2012, pp. 94–5) representation of the four levels of reflexivity suggested by Alvesson and Skoldberg (2009).

**Table 3: Levels of reflexivity**

Aspect/level	Focus
Interaction with empirical material	Accounts in interviews, observations of situations and other empirical materials
Interpretation	Underlying meanings
Critical interpretation	Ideology, power, social reproduction
Reflection on text production and language use	Own text, claims to authority, selectivity of the voices represented in the text

### **3.2.3 Implications for this study**

In this study, reflective practice commenced when selecting the research topic and research participants. The researcher reflected upon whether the success of the families who achieved housing created a bias in favour of selecting a sample of parents who were highly energetic, skilled, determined to succeed and able to do so. The researcher also reflected on whether people with a particular socioeconomic background or particular skills were more likely to succeed in their efforts to create housing. In addition, the research questions required the study of families and NGOs who had achieved housing to explore factors relating to success in attaining their housing goals and objectives. Hence, the research question contained a bias towards 'success' within it. The narrow definition of success described in Chapter 1, and the recognition of delays, inaction and setbacks or failures in this study, are intended to address this issue.

The research topic was inherently political because it examined the housing needs of a group of adults that had not been met by existing housing systems or services provided or funded by the government. Although the researcher initially assumed that adults and their families were excluded, neglected or oppressed, the research participants did not share that perspective and did not use that language. The researcher adjusted her assumptions and was required to listen closely to what the research participants were saying, how they were saying it



and their meaning. In each interview, the interviewer gave the lead role to the voice of each research participant, their perception of what was possible, what they could not accept and what they would achieve. They did not conceive of barriers they could not tackle or overcome, although they may not have known that at the time the activities were undertaken.

The interview process allowed the researcher to adjust her assumptions and perspective when collecting and analysing the data both on the spot and after the interviews. She was conscious that some events in some case studies were traumatic for some research participants for a period of time; the participants decided what information they would share about this. The researcher was also required to consider the research participants' perspective on the effect of the decisions they made to carry out their activities. One example was the belief that the families would have more power to achieve housing by acting in a large group. The researcher continued to scan environmental developments to explore whether other factors might also apply.

There are three final points of reflection. First, the lens or perspective of parent advocates was prioritised, which was the aim. Parent advocates have not told the story of their experience with housing. The parents who were research participants are experts in disability and in the experience of exclusion from government-funded housing systems in NSW and the Australian Capital Territory (ACT). Second, there were other voices to be heard on these issues. For this reason, the research question was adjusted to include and listen to the NGOs' perspective. It was unsurprising that the study of NGO activities to create more housing for more adults provided evidence of cooperation and collaboration between NGOs, adults, and families and friends. The adult children were not interviewed because the system-level activities, strategies and transactions of the parents and NGOs were the focus of this study. In addition, nine adults in the case studies had very high support needs, four adults were non-verbal and the researcher was not known to any of the adults, although she had met three of them. Third, the study of the parents' activities and experiences sought to address the conceptual and practical challenges of evaluating access to housing when the Productivity Commission's (2011) report into disability service and support provision did not design a pathway into housing for the future. The study

used baseline data to evaluate whether the housing experience for people with disability and their families had improved since the implementation of the NDIS for adults who are and are not eligible for the NDIS.

### **3.2.4 Reflection on the effect of 'self'**

The researcher is a mother, lawyer and feminist. She had children later in life and did not contemplate sacrificing work to raise her children. The researcher had one week of work experience at the Parramatta Psychiatric Centre in 1976. She remembers some of the incidents that occurred that week; otherwise, she had no experience with disability until she became a volunteer director on the board of a disability service provider in 2014. Approximately half of that organisation's 'clients' were living in a group home, and the remainder lived with ageing parents or other family members. The researcher did not explore gender issues in caregiving. She was conscious that some fathers are the primary caregiver; in other families, fathers increased their caregiving role when they retired from paid work, were semi-retired, or when the physical demands of caregiving increased with the age of both the children and the parents.

The researcher has personal experience with the public sector and bureaucracy as an employee and daughter of a career public servant. The researcher is aware that public servants, bureaucrats and administrators require rules to determine what they will or will not do, and they are constrained by those rules. If the children in the case studies were not disabled, they may be considered homeless or at risk of homelessness. This study reflects the researcher's resolve to contribute to the knowledge of families who have not yet achieved housing for their children.

## **3.3 RESEARCH QUESTIONS**

The main research question for this study is: *How do families or NGOs create new homes for adults with a disability?* This question is addressed more fully by additional sub-questions in Chapters 4–7 of this thesis. There are four sub-questions in Chapter 4:

- RQ1: What were the philosophies and values that guided the elements of home that parents were seeking to create for their children?

- RQ2: What action and transactions did parents undertake to create these homes?
- RQ3: How did other people, organisations or institutions empower parents to select and recombine inputs from different systems with family resources to create these homes?
- RQ4: How far did the action of parents and/or government agencies and/or NGOs initiate institutional change?

There are four sub-questions in Chapter 5:

- RQ1: Did people, organisations or institutions in positions of power create barriers that limited access to government-funded housing for adults?
- RQ2: What were those barriers and how were they created?
- RQ3: What strategies did parents develop to mitigate those barriers and secure housing?
- RQ4: What tools did parents use, who did they work with as allies to achieve housing, how was the work shared, and what rules or policies were in the way or helped achieve their purposes?

There are four sub-questions in Chapter 6:

- RQ1: What models did families, friends or NGOs choose in order to create more housing and different types of housing with paid support for adults?
- RQ2: What were the elements and characteristics of each model?
- RQ3: What were the contributions or inputs to each model?
- RQ4: What interaction or collaboration occurred between NGOs, families and friends to implement these models, including new ways of working and learning together, sharing power and expanding resources?

There are three sub-questions in Chapter 7:

- RQ1: What type of home did parents choose for their daughters and sons with an intellectual disability?
- RQ2: What home did they achieve?

- RQ3: How did they accomplish that home?

Each sub-question is discussed in the relevant chapter, and a synthesis discussion is presented in Chapter 8.

### **3.4 CASE STUDY AND INTERVIEW METHOD**

This research used an exploratory comparison case study approach to focus on two units of analysis. The primary unit of analysis was the 'activity' taken to create the adults' own home with paid support for one or more adults. The secondary unit of analysis was the 'actor' who undertook the activity. The case was the activity to attain the housing objective. The boundary of the case was denoted by the six elements of each activity:

- 1) What is the desired goal? The object.
- 2) Who desired the goal? The subject.
- 3) Who worked with the subject to achieve the desired goal? Their network and community of actors.
- 4) What resources, strategies and other tools, methods or approaches were used to achieve the desired goal? The tools.
- 5) Who did what? The division of labour.
- 6) What rules, professional conduct, routines, norms or attitudes supported or constrained what people did to achieve the desired goal? The rules.  
(Leadbetter 2008; Martin 2008; Villeneuve 2011)

In the family case studies, the actor was the parent(s) acting alone or in a group. In the NGO case studies, the actor was the NGO acting alone or with an adult and/or their family.

Interview and secondary data were collected to explore the activities undertaken by families and NGOs to create new homes for adults in 11 case studies. Parents took action about future housing in five out of six family case studies between 2002 and 2018. At the time of writing, all families continued to be involved in changing and improving their child's living arrangements. An iterative approach using abductive reasoning ('weaving back and forth between data and theory': Bryman 2016, p. 23) was carried out by identifying patterns and themes within and across the case studies. The case study approach and interview method

recognised the importance of choosing research participants who were knowledgeable experts about the activities they undertook, the service system and the policy context.

### **3.5 ETHICS**

Ethics approval for the research was given by the University of Technology Sydney's (UTS) Human Research Ethics Committee (HREC) in 2017. The Committee agreed that the application for approval met the requirements of the National Statement on Ethical Conduct in Human Research 2007 (National Health and Medical Research Council 2007). The approval number is UTS HREC REF No. ETH17-1412, and the approval letter is attached as Appendix B. The approval number was included on all participant information sheets and consent forms, and the research was undertaken in accordance with all UTS policies and guidelines. The information sheets and consent forms were approved by the HREC and have been used without changing them. Consent to interview research participants who also acted through an incorporated or registered legal entity (three family case studies and five NGO case studies) was received from the Managing Director, Chair of the Board or Chair of the Managing Committee of the organisation prior to those interviews.

Research participants received information about the study in writing and verbally at the beginning of their first interview. An information sheet and a consent form were provided prior to data collection. All research participants gave their written consent to disclose their data, except for two parents in one family, as well as a former bureaucrat and a manager of one service provider. A third parent requested that her name, her child's name and their location not be disclosed. The researcher complied with these requests.

Some of the research participants in some of the case studies have publicly shared their names and information in different fora regarding the homes they have created for their children. Three family case studies have created a website to share information regarding the homes their children live in. For two of the case studies, it is difficult to de-identify the names of the parents and their sons because this information is publicly available. The NGOs in the four NGO case studies also have information available on their websites. Many research

participants have credible reputations and are well known to other families, caregivers, politicians and service providers for their contributions to the field of disability.

Conversely, there were private spheres that were inaccessible when interviewing the parents. This can be the case with family research (Daly 1992). Occasionally the 'tape recorder' was turned off on request, and some information was 'off the record'. While these rich data are not disclosed in the thesis, they assisted the researcher in gaining a more complete understanding of their situation. This is ultimately reflected in the solidification of some of the findings. Conflict or disagreement within family groups is outside the scope of this research. The contributions of other parents, grandparents, extended family and friends were also outside the scope of the study, but these important relationships were referred to in some interviews.

### **3.6 SAMPLING**

#### ***3.6.1 Selection criteria***

The primary criterion for inclusion in the sample of case studies was success in attainment of housing with paid support for an adult. There are six family case studies that present different housing models with different models of support established for more than 44 adults. There are five NGO case studies that present examples of close collaboration between NGOs, adults, families and friends to also achieve new homes for adults. There is one unsuccessful NGO case study, which was the fifth NGO case study (Home Owners Mutual Enterprise [HOME] Case #11). The case studies were purposively selected from among parents who had spoken publicly about the homes they had created, except one family case study, which was introduced to the researcher by a community organisation. Two NGOs were introduced to the researcher by research participants. The other three NGOs were identified because they were publicly known for their efforts and achievements for people with disability.

SILC Co-operative Case #7 was a spin-off case study from Parent-assisted Residential Accommodation (PaRA) Co-operative Case #3. SILC was established to help other families replicate the PaRA model. Mr Steve Anthony, a research participant, established both the PaRA household and the SILC entity

and model. Hartley Lifecare Case #8 was a spin-off case study from the Intentional Community Case #2 to focus on Hartley's role as the host agency in the co-resident support model designed by the parents in Case #2. Two parent research participants introduced the researcher to Hartley.

### **3.6.2 Disability type**

The sample was disability agnostic. The exclusion of case studies by applying a medical model of disability was inconsistent with the philosophy of inclusion of all people irrespective of their type of disability. That is, the selection criteria did not require a particular disability type or eligibility for paid support. The researcher resolved that it was inappropriate to approach families to participate and then exclude them because the adults were too disabled, not disabled enough or did not have a particular type of disability. It was unclear whether the adults would be eligible for funded support under the NDIS, which was progressively rolling out when this study commenced. In addition, the approach to NDIS capital funding for SDA housing was still under negotiation between Australian governments when the interviews began.

The adults with disability were not interviewed because this thesis specifically explored the activities undertaken by parents and NGOs to create pathways to new housing for adult children. The activities, strategies and transactions to achieve housing objectives were undertaken at the system level by parents or NGOs, and not the adults. The fact that four of the adults were non-verbal, and seven (including the four) had very high support needs may explain why the families were driven to set up housing and remain actively involved in the adults' new living arrangements. In each case study, the parents were experts in their child's disability, their child's needs (including support), the disability service system, disability and housing policy, and the cost of disability and government funding. The parents determined the housing needs of their adult children.

Table 4 lists the types of disability of the adults in the case studies. One adult is not included in the table because the interview with her parents was conducted on the condition of confidentiality.

**Table 4: Types of disability**

Adult 1	Daughter has CDKL5 syndrome (X-linked serine/threonine kinase cyclin-dependent kinase-like 5) with a severe intellectual disability and very high support needs. Key workers are present in her home.
Adult 2	Son has Phelan–McDermid syndrome with a severe intellectual disability, very high support needs and cannot live alone. Son lives with a co-resident.
Adult 3	Son has Down syndrome and lower support needs but cannot live alone. Son lives with a co-resident.
Adult 4	Son has autism, high support needs and cannot live alone. Son lives with two housemates. Key workers are present in his home.
Adult 5	Son has autism, aphasia, high support needs and cannot live alone. Son lives with two housemates. Key workers are present in his home.
Adult 6	Son has a moderate intellectual disability, needs a key worker on site and for meals but can live alone in his individual villa.
Adult 7	Daughter has neurological/learning impairments from infant stroke and low support needs. Drop-in support is sufficient.
Adult 8	Daughter has neurological/learning impairments from infant stroke and higher support needs. A key worker is on site, including meals.
Adult 9	Daughter has autism, high support needs and is generally non-verbal. Key workers are on hand.
Adult 10	Son has Cornelia de Lange syndrome with a severe intellectual disability, autistic-like behaviours and anxiety. He is mostly non-verbal and cannot live alone. Key workers are on hand.
Adult 11	Son has a severe intellectual disability but no diagnosed syndrome. He has some verbal skills. A key worker is on hand at all times, although he does not require one-to-one support 24/7.
Adult 12	Son has a moderate intellectual disability and Cerebral Palsy. He is very wary of people he does not know. He cannot live alone. Key workers are on hand.
Adult 13	Daughter has an intellectual disability, autism and hemiplegia. She can live alone with drop-in support or a friendly neighbour. Daughter lives with two housemates.

### **3.6.3 Characteristics of research participants**

Family characteristics and personality characteristics of parents, NGO CEOs and managers were not criteria used in the sample selection, data analysis or findings to identify a relationship between activity and housing success for four reasons.



First, personality characteristics have a constructed meaning. They are difficult to identify, measure and verify through research methods. Psychological studies have used personality tests, but this is not psychological research. Further, the relationship between attitudes, knowledge, behaviours and activities as a measurement of empowerment has lacked specificity in earlier research (Koren, DeChillo & Friesen 1992).

Second, a construct of personality characteristics is an exercise of academic power. This artificial analysis could potentially create a barrier to discoveries that would be helpful for other adults, families and NGOs who are trying to create housing for adults with disability. It implies or posits that those particular characteristics are a necessary requirement to achieve housing.

Third, it is a separate construct to identify success in housing through the lens of the 'hero' family member, individual entrepreneur or so-called 'change agent'. A cluster of factors (Eisenstadt 1980, cited in Battilana, Leca & Boxenbaum 2009) pertain to the attainment of housing objectives; that is, success is multifactorial. In addition, circumstances and factors at the community and government level that are hidden, difficult to measure, unknown or not disclosed also vary between case studies. Support garnered by families at the community level and within the government are complementary (Mathie & Gaventa 2015, p. 5). It is unlikely that one will exist without the other. Ultimately, these actors and their activities achieved change by working with others and building community support and institutional support with the commitment of government funding.

Fourth, it is not possible to study the personality characteristics of parents who achieve success in the service system and those who do not if the immediate situation at home and the parents' management of day-to-day activities is excluded. This individual and family information can be sensitive, confidential and subjective. Consent issues may involve multiple family members, which requires their trust. And it was evident from the (unsuccessful) attempts to recruit unsuccessful case studies for this research that necessary and sufficient trust for a study of families is difficult to establish if a relationship between the researcher and potential research participant does not exist before the research.

The sample did not include families or NGOs representing Aboriginal or Torres Strait Islander peoples of Australia or culturally and linguistically diverse minority groups in the Australian population because of the limited nature, scope and timeframe of the PhD research. Some families in these groups may contend with multiple layers of disadvantage, and additional ethics approval would be required. The parents and NGOs interviewed were not required to contend with barriers constructed around language and culture.

### 3.6.4 Sample

The six family case studies and five NGO case studies in the sample are listed in Table 5 and then summarised.

**Table 5: Case study sample**

Case study	No. of families interviewed	Total no. of interviews	No. of PwD** in home	Providers involved
Own Home — Case #1 (NSW)	2 (4 parents)	6	1–2	No (at time of interview)
Intentional Community — Case #2 (ACT)	2 (2 parents)	4 (+ Hartley Case #8)	3	Yes — Hartley (Case #9) and ACT Housing
PaRA Co-operative 1 — Case #3 (NSW)	2 (2 parents)	4	3	Yes — replaced by family governed co-operative as registered provider
Sutherland Shire Independent Living — Case #4 (NSW)	3 (3 parents)	6	18+	Yes — service provider and CHP*
Ryde Cluster — Case #5 (NSW)	3 (3 parents)	2 (3 parents in each interview)	15	Yes — service provider and CHP*
Eastern Suburbs Community Living — Case #6 (NSW)	1 (1 parent — widow/husband died during interviews)		1	Yes — service and housing provider
SILC Co-operative 2 — Case #7 (NSW)	—	2 (founder and Operations Manager)	—	SILC is the registered SIL provider

Case study	No. of families interviewed	Total no. of interviews	No. of PwD** in home	Providers involved
Hartley — Case #8 (ACT)	—	1 (CEO)	—**	Hartley is the registered SIL provider
JewishCare NSW — Case #9 (NSW)	—	1 (Disability Services Manager)	—	JewishCare is the registered SIL and SDA provider
Challenge Southern Highlands (SH) — Case #10 (NSW)	—	1 (General Manager)	—	Challenge SH is the registered SIL and SDA provider
HOME — Case #11 (NSW)	—	1 (Board Chair)	—	HOME is a group of entrepreneurs who have not yet achieved their model of home

\* Community housing provider

\*\* PwD = People with disability

### **3.6.5 Family case studies by type**

There were six family case studies. Three family case studies demonstrated different models for between one and three adults with higher support needs. Two family case studies used different models for two large, separate groups of adults with mixed support needs. One family case study was a parent who created a home for a single family member with low support needs. Table 6 presents the elements and characteristics of each family case study listed above.

The family owned apartment, public housing and private rental properties in Cases #1, #2 and #3 are not NDIS-funded SDA housing. However, based on their disability and support needs, the adults in the three case studies would be eligible for SDA funding if they moved to housing that is owned or operated by an SDA registered provider. Over the course of this study, the NDIA, which administers the NDIS, introduced a rule that requires a registered NDIS service provider to be engaged as a necessary precondition to the payment of supported independent living (SIL) funding for personal support to live independently. In contrast, the NDIS individual funding for paid support received by the daughter in Own Home Case #1 was self-managed at the time her parent was interviewed. This changed when housemates were invited to live with the daughter. A service

provider was then engaged to manage the support services in the daughter's home.

**Table 6: Family case studies by type**

<p><b>Own Home #1:</b> The home in this case is a family owned apartment built in a chosen location. The living arrangement is family governed. The parent selected and employed the key workers herself. NDIS individual funding for paid support to live independently was self-managed. An NDIS-registered service provider was not used to employ staff initially. When the daughter began sharing with housemates, a service provider was engaged to manage the paid support.</p>
<p><b>Intentional Community #2:</b> The three separate homes of the three adult sons in this case are embedded in an intentional community created for them. Intentional community residents are chosen neighbours. Hartley is the host agency of the co-resident model of support and the employer of the three co-residents. The ACT Government built public housing for the three sons and intentional community residents (public housing is not an essential characteristic if this model is replicated.) The sons are empowered as head tenants under their individual lease agreements.</p>
<p><b>PaRA Co-operative 1 #3:</b> The home for the three sons in this case is a family governed shared household in a chosen location. The three families have established the PaRA Co-operative as the household operator. PaRA oversees the running of the household in accordance with co-operative and democratic principles. The house is privately rented. The PaRA Co-operative is the tenant. Members of the PaRA Co-operative are staff who have been employed for more than 12 months, as well as the parents. SILC is a family governed registered co-operative that has taken over the role of registered NDIS service provider for paid support. SILC now employs the key workers for PaRA.</p>
<p><b>Sutherland Shire Independent Living #4:</b> The homes for 18 adults in this case are two villa complexes that are home to six residents each, a single five-bedroom group home (on three different blocks) and an individual who moved into existing community housing, all in the Sutherland Shire. The villas are an independent living model with on-site staff and an opt-in communal area, including a dining room. Adults have their own kitchen and lounge area in their individual villa. The adults in each villa complex receive different levels of SIL funding for paid support. Although different NDIS SIL providers can be engaged by individuals living in each villa, generally this does not occur. Key workers are on site. The housing is owned (or managed on behalf of a government agency) by a community housing provider. (Community housing is not an essential characteristic if this model is replicated, nor is the villa building design a distinguishing or chosen characteristic.)</p>
<p><b>Ryde Cluster #5:</b> The homes for the 15 adults in this case are located in a cluster design on a single block of land in the Ryde area: a five-bedroom house; six single-bed units; and two two-bedroom villas. The buildings are classified as SDA housing. All adults living in the cluster receive individual NDIS SDA funding, which is paid to</p>

the community housing provider that owns or manages the houses in the cluster. (Community housing is not required or necessary for this model.) The adults receive different levels of SIL funding, and there are key workers on site, including overnight.

**Eastern Suburbs Community Living #6:** The home for the daughter in this case is part of the Waverley Community Living Program, which is designed to transition adults with disabilities to independent community living. The houses are owned by Waverley Council or rented from Bridge Housing, which is a community housing provider that has partnered with Waverley Council. The daughter is a tenant with two housemates who are also participating in the Program. She is employed and is not eligible for NDIS SDA funding or NDIS SIL funding because she has a mild or moderate intellectual disability.

The twelfth case study was a confidential family case study. Two parents from the same family were interviewed on one occasion together. Their data cannot be disclosed; however, the interview with the two parents cannot be unheard. The information in their interview was therefore used to validate the research findings. The arrangements established for their daughter changed after their interview, and a second interview to capture those changes will be undertaken post-thesis. After receiving the ethics documents, three 'unsuccessful' case studies declined to participate in this research. Three research participants from two family case studies that remained in the sample also withdrew for personal reasons. A protocol of two follow-up approaches was chosen: first, as a courtesy, and second, as a safeguard precaution to ensure the invitation to participate had not been overlooked.

### ***3.6.6 NGO case studies by service provider***

Five NGO case studies are described in Table 7. Challenge Southern Highlands Case #10 is the only NGO case study that had built new SDA housing. It was also the only case study to secure land from a local council. Land or social housing remains a necessary condition and requirement for the attainment of homes. None of the other NGO case studies had provided housing, including HOME Case #11, which has been unsuccessful to date. Table 7 describes the elements and characteristics of each NGO case study listed above.

**Table 7: NGO case studies by service provider**

<b>Description of Cases #7, #8, #9, #10 and #11</b>
<p><b>SILC Co-operative 2 #7:</b> In this case, SILC is a not-for-profit registered co-operative and registered charity. It was formed to support families to set up family governed homes for their family members in NSW. The person with disability must be eligible for NDIS SIL individual funding. SILC is then engaged as their low-cost SIL service provider if chosen. The family governed homes are established with SILC's assistance, but families must locate a rental property in their chosen location, find other families to manage their household together (their children become housemates) and choose key workers. SILC was conceived as a co-operative of co-operative members. Each household establishes a household operator as a separate legal entity that becomes a member of the SILC co-operative. Household operators and their families are required to observe and support co-operative principles including democracy, equality and mutual support (e.g. demonstrated through sharing resources, information and decision-making).</p>
<p><b>Hartley Case #8:</b> Hartley is a not-for-profit NGO and registered charity that works with families to provide paid support for people with disabilities in the ACT. It is registered to provide NDIS SIL services, and it supports clients in more than 30 homes. Hartley's philosophy is to provide 'person centred support that actively involves family and friends under a family governance model'. Its staff are trained in active support (<a href="https://www.hartley.org.au/about-us/philosophy">https://www.hartley.org.au/about-us/philosophy</a>, last viewed 9 February 2021). Hartley is the host agency of the Co-resident Support Model for the three men living in the Benambra Intentional Community in Case #2.</p>
<p><b>JewishCare NSW Case #9:</b> JewishCare is a not-for-profit NGO and registered charity that provides aged care, mental health, family and child, and disability services. JewishCare (like Challenge Southern Highlands below) is registered to provide SDA and SIL services. The three-year Enabled Housing pilot project presented in Chapter 6 has concluded. JewishCare has new projects underway.</p>
<p><b>Challenge Southern Highlands Case #10:</b> Challenge Southern Highlands is a community-based not-for-profit NGO and registered charity. It operates the Welby Garden Centre as an Australian Disability Enterprise in the Southern Highlands of NSW. Challenge Southern Highlands secured land from the local council with the assistance of parent storytelling, and a grant from the NSW Government to build Challenge House. Challenge Southern Highlands is now a registered SDA provider and is also registered to provide SIL support for the adults living in Challenge House.</p>
<p><b>HOME Case #11:</b> HOME was formed more than 10 years ago by a mother and her friends, who were inspired by the Deohaeko Support Network in Canada. HOME's vision is to establish a community for people with moderate intellectual disabilities to share with others in housing to be built in Sydney. These adults are not eligible for NDIS SDA funding, but it was intended that the partnership with families would include family co-funding. HOME's advocacy to the NSW state and local governments received a positive response. The NSW Government provided funding for a feasibility</p>

study, which HOME completed. However, HOME has been unsuccessful because land in the Sydney area is expensive and difficult to locate. A partner who is willing to co-fund and build the development is required. HOME has been lobbying a local council for land and approached a property developer to include the model in its development without success.

The researcher was fortunate to visit Challenge House, built by Challenge Southern Highlands (Case #10), on the day of the interview. A local builder and an architect worked with Challenge Southern Highlands for a year on the design. This is reflected in the high-quality design features of Challenge House, including fit-out and the building materials chosen to reduce ongoing property maintenance costs. The builder won an award for Challenge House as the best construction under \$2 million. A duplicate plaque is up on a wall at Challenge House.

HOME Case #11 has not achieved housing at this time. The researcher was fortunate to attend a meeting of all board members of HOME. The Chair of HOME, and the mother who founded HOME with a friend, have separately established independent living arrangements for their daughter and son. This is consistent with other unsuccessful case studies the researcher attempted to recruit. Namely, parents who have been unsuccessful in their attempt to create housing as a collective effort for a group have separately established independent living arrangements for their own children.

### **3.7 Location**

The research participants in the case studies were located in Australia. Family led, community-based initiatives to create new homes with paid support characterise 11 case studies. Nine case studies were located in NSW, and two case studies were located in the ACT. Intentional Community Case #2 is a family case study located in the ACT, while Hartley Case #8 is an NGO case study located in the ACT and is related to Case #2.

### **3.8 Interview procedure**

In total, 15 parents participated in the research for six family case studies involving 14 adult children who had moved into their own home. A total of 42 adults in these case studies attained their own home. Each family case study

nominated which family members would be interviewed. Three politicians were approached to participate in the research of family case studies. One former politician agreed to participate and was interviewed. One former politician did not respond. One sitting politician responded through his staff. That Minister was not available due to his work commitments, but ethics documents were sent to him. A former bureaucrat who assisted one family group in one case study was interviewed on condition of confidentiality. A second bureaucrat was approached for an interview and responded by email, but did not agree to be interviewed. A manager of a service provider in Eastern Suburbs Community Living Case #6 was interviewed on the condition of confidentiality because he was new to his role.

An additional parent advocate was interviewed because of her relationship with, and knowledge and understanding of the activities of, parents in Case Studies #1, #4 and #5. There are multiple potential case studies within her interview data. This research participant was not included in the sample as a family case study but will be a spin-off case study if she consents. Her interview data offer a thick description of the development of power and the attainment of success through hope, which will be developed as a standalone publication at a later time.

The single actor perspective as 'subject' was consciously chosen to avoid the need to reconcile conflicting interpretations and perspectives. This reflects the researcher's bias towards ensuring the voices of the families are heard. In addition, many individuals in the organisations the parents dealt with have moved on in their careers, are no longer with the organisations they were with at the time, or the relevant government agency in NSW no longer exists and cannot consent to the interview of agency staff. The researcher aims to interview politicians, bureaucrats and community housing providers after the publication of this thesis if they want to be interviewed. NGO service providers who possess knowledge of at least one case study in the sample may be willing to contribute their perspectives after publication.



### 3.9 DATA COLLECTION

The methods used for data collection were semi-structured interviews of one or two family members in a single family case study, two family members in two of the three family case studies (new homes for three adults) and three family members in the two large family group case studies (new homes for 15 or more adults). All parent research participants in the family case studies were interviewed twice, with two exceptions. In Own Home Case #1, one parent was interviewed once and the other parent in the same family was interviewed at least three times. The reason for additional interviews in Own Home Case #1 was that the family had purchased properties to support the growth of short-term accommodation on the Central Coast in NSW. Formerly known as respite services, short-term accommodation is funded under the NDIS to some extent.

Research participants in the NGO case studies were interviewed once. Each interview lasted more than one hour at a location chosen by each participant. There were two research participants in SILC Co-operative Case #7 because one research participant was also a research participant in PaRA Co-operative Case #3. There was one research participant in NGO Case #8, and the interview was conducted at Hartley's head office. However, the parents who engaged Hartley as the host agency for their co-resident model of support were interviewed separately for Case #2. The parents have participated in multiple interviews, which can be accessed via YouTube and Hartley's website, for different purposes. There was one research participant in JewishCare Case #9, with the interview conducted at JewishCare's head office. JewishCare was identified from the interview of a parent research participant in Eastern Suburbs Community Living Case #6 because JewishCare provides employment for her daughter. The researcher received a copy of the independent review of the Enabled Housing Model in which JewishCare was a joint venture partner. There was one research participant in Challenge Southern Highlands Case #10. The researcher met a key worker and a resident when visiting Challenge House. The interview also commenced at the Welby Garden Centre. The researcher was given a tour of the head office where many people worked, and she was introduced to different employees performing a broad range of tasks.

Semi-structured interviews with probing questions were used to gain a deeper understanding of the memories, experiences, perceptions and meanings related to the activities and interactions with other actors from the perspective of the parents in the family case studies and the NGO research participants in the NGO case studies. These memories, experiences, perceptions and meanings explain the models that emerged from new ideas, the strategies chosen to secure support and resources to give effect to those models, and the relationship between the strategies and the models achieved. The interview questions in Appendix C and Appendix D were developed during the research design stage and review of the literature. Prior to commencing the interviews, the interview questions in Appendix C for the family case studies were approved by the UTS's HREC. The interview questions in Appendix D for the NGO case studies were based on the interview questions in Appendix C and were provided to the UTS Ethics Secretariat.

Historical documents included personal letters and emails, diary records, public documents, media releases, and newsletters prepared by research participants, their organisations and advocates who were organising campaigns and other collective action by parents over the same period. Contextual data were collected using the interview method and grey literature published by government departments as well as agencies and bodies reporting to the government, and website material including public submissions to parliamentary inquiries, published reports, and radio reporting of family organised rallies and protests. The historical documents confirmed events, timelines and external factors that influenced the activities of parents as described in their interviews.

All interviews were recorded and transcribed, except for what was intended to be the first interview of one parent (which was documented from notes taken by the researcher). Interviews and available historical documents were managed using NVivo qualitative data analysis software. While thematic analysis is often used in case study research to analyse data, this study used activity theory as the analytical framework that structured the data analysis.

### 3.10 DATA ANALYSIS

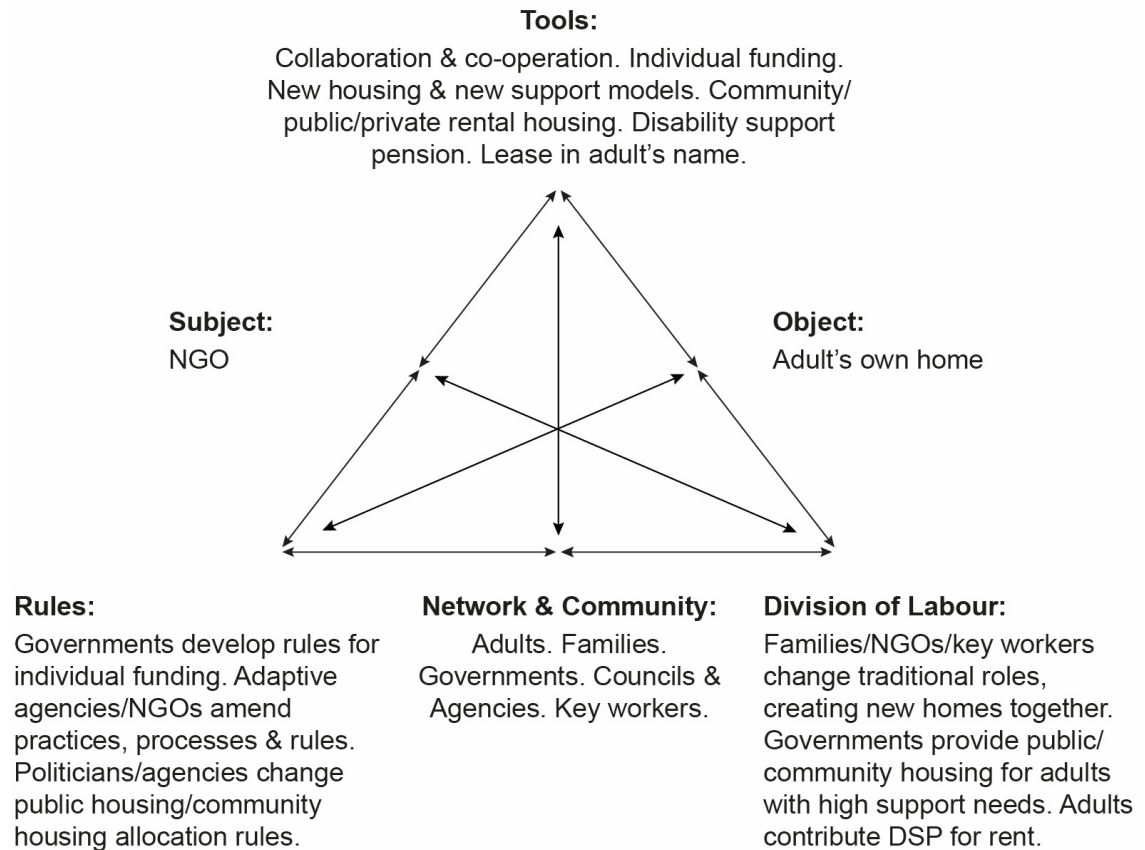
Cultural–historical activity theory (activity theory), which was developed by Engeström (2001), was used to study the cluster of inputs and factors that enabled parents and NGOs to achieve their housing objectives. Activity theory provided a structured framework for a cross-case comparison of activities, strategies and transactions and a comparison of interconnected activity systems that enabled success over time.

Data were collected and analysed using the six elements of activity theory described in Chapter 1: (i) the desired goal, as object; (ii) who desired the goal, as subject; (iii) who worked with the subject to achieve the desired goal, as network and community; (iv) the resources, strategies and other tools, methods or approaches used to achieve the desired goal, as tools; (v) how work was shared or who did what, as division of labour; and (vi) the rules, including policy and law or norms, attitudes, practices, routines and professional conduct, that supported or constrained what people did to achieve the desired goal, as rules (Leadbetter 2008; Martin 2008; Villeneuve 2011).

Activity theory provided the framework to study contradictions within and between activity systems. Contradictions existed where the values, priorities and objectives of actors attempting to work together were inconsistent or incompatible, tools were inadequate or rules were barriers to be overcome. In each case study, contradictions within and between activity systems were analysed and depicted by lightning bolt symbols or lightning lines (Martin 2008). Resolutions of contradictions in a case study were depicted by removing the lightning bolt symbol. Figure 2 identifies the resolution of contradictions and the removal of barriers to achieve the desired housing object. For example, tools were adequate when individual funding for paid support for life was secured from the government. The government's priority for continuing control or ownership of the housing assets was addressed when some of the new houses were classified and managed as public housing or community housing. Rules supported the attainment of housing objectives when they were amended. Policy changes included individual funding before the NDIS commenced. Forward-thinking NGOs registered as disability service providers for the first time or changed their rules to implement new models of support. When new homes were created, key

workers became important members of the network and community supporting the adults.

**Figure 2: Activity theory identifies resolved contradictions**



Because the activities, decisions and transactions of families and NGOs occurred over many years, it was necessary to create a chronology for each case study and a timeline of key events of when progress and setbacks occurred; the relationship between activities or interaction and collaboration between actors; and the relationship between events of a particular type, the contribution of resources and making progress. The chronology for each case study was another important technique for cross-case comparison. The chronology was used for comparing and understanding the activities of two or more parents in the same case study over time. It assisted with the distinction between individual effort and collective effort. The chronology was used to compare the interview data and activities of parents with publicly available information. The chronology, publicly available information and historical documents provided a context for the interaction between research participants and other actors, key events, setbacks

and turning points, including policy reform, the emerging NDIS and experimentation with individual funding for disability support.

### 3.11 VALIDITY AND RELIABILITY

Both qualitative and quantitative research are concerned with producing valid and reliable knowledge (Merriam & Tisdell 2016, p. 235). However, Lincoln and Guba (1985) reinterpreted the four criteria for judging and evaluating quantitative research (internal validity, external validity, reliability and objectivity) (Merriam & Tisdell 2016, p. 235) because, different from quantitative research, qualitative research is based on assumptions about reality. Lincoln and Guba (1985) developed four alternative criteria for judging the trustworthiness (Leininger 1994; Rubin & Rubin 1995) and soundness (Leininger 1994; Lincoln & Guba 1985) of the process and findings of qualitative research. Lincoln and Guba's (1985) four criteria to evaluate qualitative inquiry were used in this research:

- 1) credibility
- 2) transferability
- 3) dependability
- 4) confirmability.

Table 8 outlines Christensen's (2012, p. 117) representation of Trochim's (2006) comparison of the four conventional criteria for quantitative research and the four alternative criteria for qualitative research.

**Table 8: Criteria comparison for judging quantitative and qualitative research**

Quantitative research 'validity'	Qualitative research 'soundness'
Internal validity	Credibility
External validity	Transferability
Reliability	Dependability
Objectivity	Confirmability

Morse et al. (2002) argued that validity and reliability remain appropriate criteria for attaining rigour in qualitative research. However, Lincoln and Guba's (1985) alternative criteria are consistent with the subjective, interpretive approach. The four criteria of credibility, transferability, dependability and confirmability have been addressed in the following manner.

**Credibility:** Credibility replaces the criterion of internal validity adopted in quantitative research. It is concerned with ensuring that the research findings and interpretations from this study are credible from the perspective of the research participants. Lincoln and Guba (1985, p. 296) contended that credibility is established first by carrying out the study in a way that enhances the probability it will be found credible to the research participants, and second, by establishing that the findings are believable and approved by the research participants. Credibility was enhanced in this study by ensuring the sample was appropriate and recruiting knowledgeable and experienced families and NGOs as research participants (Morse et al. 2002). In addition to the method of selection described in this chapter, the knowledge, experience and learning of the research participants was a significant contribution to 'efficient and effective saturation' of the data 'with optimal quality data and minimum dross' (Morse et al. 2002, p. 18).

Credibility of the interview data was established through the length of time spent with each research participant, and by conducting more than one interview with the parent participants. The transcription of the interview data ensured that the research participants were comfortable and satisfied with the data collected. The two interviews with parents provided additional benefits. The parents had time to consider the context and scope of the study, and they had sufficient time to select the information they wished to share and how they wished to express their story. The researcher had time to learn about the parents' ideas and objectives, their perspectives on the cultural parameters of caregiving, and their experience of disability, the service system and the accessibility of government-funded housing without the restriction of a single interview. The individual and collective aspirations of the families for the adults' own home were similar but different, as were their experiences with barriers to housing and the shifting roles and power relationships between the families, the not-for-profit NGOs they worked with, government agencies and bureaucrats, and politicians as agents of the state. Trust between the research participants and the researcher as an outsider was built through respect for confidentiality. Concerns expressed by the research participants when they disclosed particular information to the researcher were acknowledged and addressed. Interview transcripts were corrected to ensure accuracy and to omit sensitive or irrelevant information when requested.

Triangulation techniques were adopted to improve credibility. Triangulation of the data was achieved by using different types of data sources in the study (Lincoln & Guba 1985). Multiple research participants in each case study also provided cross-validation of information from different sources. Publication of the research, or preparing the research for publication, provided another opportunity to check the data, analytic categories, interpretations and conclusions. Using the same research questions for each interview, it was possible to corroborate 'evidence from different sources to shed light on a theme or perspective' (Cresswell 2007, p. 208). Historical documents and grey literature retained by parents or accessible online were reviewed to verify the interview data, such as recalled events at a particular point in time. In particular, the chronology for case studies was compared with historical documents and grey literature to validate context and policy settings in NSW and nationally. Second interviews provided an opportunity to play back information for a reaction or response from the parent participants.

Publication of this study and preparing Chapters 4–7 for publication ensure that the methods and findings are explained, the veracity of the use of the research data is transparent, the contribution of parents and NGOs is acknowledged, and their achievements are accessible to the research participants themselves and other families and NGOs. Trust must be maintained when using the information and reporting the findings publicly. Although two research participants nominated code names to de-identify their information where indicated, they signed consent forms to disclose their information and agreed to the identification of their names in the relevant paper prepared for publication. One research participant requested that personal names and the location of her daughter's home not be identified, and the researcher complied with this request. The names of some of the daughters or sons are available on accessible websites, so these are publicly known.

Efforts were made to include the NGO perspective. It was difficult to identify NGOs that initiated solutions to the housing problem over and above their business-as-usual services, or who advocated the need for NGOs to do more to assist adults into independent living arrangements. However, the NGOs in the

sample had a proactive mindset and were committed to helping adults achieve their own home.

**Transferability:** Transferability of the research, methods and findings to the broader world and other contexts replaces external validity as the criterion traditionally adopted in quantitative research. Transferability requires a thorough description of the context, methods and assumptions 'central to the research so that other researchers may make informed judgments as to whether the research transfers to the context in which they are working' (Christensen 2012, p. 117). In relation to methods, the sample selection process and criteria for inclusion were described previously. In particular, the sample was not selected on the basis of the type of disability, need for support, eligibility for or receipt of government-funded support, or parent or family characteristics. Selection of the sample by reason of success in the achievement of housing meant it was difficult to recruit research participants. It is expected this will be a challenge to overcome in future research on the topic.

The interview questions for the family case studies in Appendix C were approved by the UTS HREC. It was not necessary to alter the research questions during the study, although the semi-structured interview questions allowed new ideas to be introduced in the interview. Research questions for the four NGO case studies in Appendix D were developed to align with the family case study research questions, with additional questions relating to market, sector and organisation purpose, mission and strategy.

Each research participant answered the questions from their own perspective in different ways. Although findings at the individual and family levels are not directly transferable, access to the questions and answers of each research participant, and Chapters 4–7 for publication, aim to provide a more complete understanding of the individual, family, community, political and policy context that varied over time, as well as the experience, learning and achievements of the research participants, so that other researchers can make their own judgement regarding use.

Last, the research results can apply to other settings, notwithstanding that the research results will be different. The findings provide baseline data to evaluate



whether the replication and sustainability of similar living arrangements are currently possible with and without the NDIS, whether governments are more actively engaged in meeting housing needs, and whether barriers to secure housing for adults persist.

**Dependability:** Dependability replaces the criterion of reliability that is traditionally adopted in quantitative research. Dependability is the criterion adopted to account for changes to the context within which the research occurred. Within the constructivist paradigm, 'change is expected' (Mertens 2005, p. 351). It also recognises that the exploratory case study research design is 'emergent' and 'not laid out in advance' (Lincoln & Guba 1985, p. 317). However, changes to context must be identified and documented. Four decisions were made to limit the effect of context change early on.

First, the decision to limit this research to case studies located primarily in NSW was important to avoid the complexity of system, rule and political differences across different states and territories. Second, although the recruitment of research participants was problematic, those who agreed to participate in the research had all achieved housing for adults at the time they were approached, except HOME in HOME Case #11, which had not yet secured the land it needed for housing. Third, the exclusion of the NDIS as the context of the study was a conscious decision. The relevant activities, events and achievements preceded the NDIS. Although the NDIS had commenced before the study began, its rules and practices were continuing to develop during the research. In addition, the adults were transitioning to the NDIS during the research. It was not possible to directly compare NDIS funding for housing or support across each case study due to different levels of NDIS funding for different support needs, for which each adult is assessed differently. Hence, the quantum of their funding and the relationship between the quantum of funding for support and the homes established by the parents were outside the scope of this study. Fourth, the area of interest was historical activities, which required looking back on change in the context of each case study after the event. Historical changes in context over time were captured in the interview data. These changes, for example, to the policy context and the support or lack of it from politicians or bureaucrats, are documented in the chapters prepared for publication. More recent changes

demonstrating a shift in roles and power between the family and the state are documented in Chapters 4–7. Relevant sections of each chapter for publication were provided to the appropriate research participants for checking.

In terms of the research method, the interview questions for the family case studies were approved by the UTS HREC and were not changed. A rich description of activities, strategies and transactions was obtained from the responses of 15 parent participants, without departing from the research topic. Although a research protocol was not prepared due to the complexity of cross-case comparison, it is appropriate to prepare a research protocol if the research continues post-thesis. This is important if a stepwise replication procedure with more than one researcher is adopted.

**Confirmability:** Confirmability replaces the concept of objectivity that is traditionally adopted in quantitative research. Confirmability is the criterion concerned with the degree to which the results could be confirmed or affirmed by others. Confirmability requires an audit trail to track the data to its source, confirmation that data have been checked, that data analysis procedures have been checked for consistency and opportunities for bias and distortion of interpretation have been removed (Mertens 2005, pp. 15, 257, 350).

Tangible evidence created during the research is available for audit. In relation to data collection, all interviews were recorded and transcribed. Research memos, field notes, mind maps, chronologies and activity theory diagrams were created during the literature review and interviews. Activity theory diagrams were generated during the data collection and analysis to ensure that elements of the key activity systems had been captured. This led to decisions about components or elements common to more than one case study, and key differences or lightning bolts to depict tension, contradiction, conflict and other relationships, some of which were unusual. The comprehensive structure of the activity theory model eliminated distractions and managed the risk of researcher fatigue. In addition, the activity theory model was responsive to the individual human subject perspective, the collective perspective, the historical perspective, and the role of the government and politicians when they finally committed their support.

Theory rather than data analysis informed the completed analysis. The activity theory model provided an auditable structure for the interaction between the data and analysis, confirmed that the data collection and analysis followed the same process, and ensured that the researcher acted in good faith (Bryman 2016). Multiple data sources and research participants for a single case study are key. In the chapters prepared for publication, direct quotations are used to support the inferences drawn from the data (Mertens 2005).

## **4 INSTITUTIONAL ENTREPRENEURSHIP**

This chapter is the first paper prepared for publication. The purpose of this chapter is to explore elements of family action to create person-centred homes for adults, as well as the pathways to achieve those homes. It contributes a study of family entrepreneurship and innovation to the field of institutional theory (theory contribution). The chapter examines the design, delivery and governance of new models of housing and support for adults as institutional entrepreneurship and social innovation. It examines the family activities, tools and transactions that parents used to secure and organise resources to solve housing needs (practice contribution). The chapter contributes the use of activity theory for data analysis in the field of family studies (practice contribution).

Three case studies of parent action are presented to demonstrate how families formally organised to establish autonomy from the service system and exerted control through family governance in order to choose the elements and characteristics of the adults' new homes. Engeström's (2001) cultural–historical activity theory is used to examine the differences between the three case studies from the parents' perspective. These actors designed and delivered new, independent living arrangements themselves. In doing so, they adopted new roles and relationships with the government, the service system, each other and their children. A cross-case comparison identified five features of the innovations implemented: (1) the innovations were social innovations to address unmet housing needs; (2) the social innovations were grassroots, bottom-up family led initiatives; (3) the social innovations were first-time innovations; (4) governance innovations included family governance; and (5) scalable innovations that were used for more than one adult could be replicated by other adults and families if they so chose. The three case studies were identified as Own Home Case #1, Intentional Community Case #2 and PaRA Co-operative Case #3. They are described in Chapter 3 and in this chapter.

## 4.1 INTRODUCTION

In Australia, group homes<sup>16</sup> located in community neighbourhoods have been the standard model funded by government for adults who need paid support to live in their own home. However, group homes were not an option at the time the parents in the three case studies sought housing for their daughter or son, as there were no vacancies in any of those homes in Canberra and Sydney. Nor were there options for families to oversee the operation of those homes or share control over the staffing arrangements. Ultimately, these parents preferred a different model of home — one that allowed them to (1) choose a location for their daughter or son's home close to friends, family and their work or day program, (2) personally interview and select the key workers who would provide paid support, and (3) govern or oversee all relevant arrangements related to services and the household. In addition to the social organisation of these homes, the activities of these parents confirmed that the built model and type of housing that families wanted for an adult family member to live in had changed over time and required a more flexible range of options (NSW Government 2006, p. 6, citing Bostock et al. 2001 and Morris et al. 2005). For example, people with disabilities may prefer to rent housing with a group of friends for social, safety or financial reasons, or where they are permitted to live with partners, children or siblings. Parents want the same options for their daughter or son, particularly if renting a house or apartment offers the only opportunity for them to have their own place. Governments have acknowledged the need for a range of housing and social options:

*The concept of a group home as 'normal' has become increasingly problematic in the context of social and cultural change. There is now a far greater range of housing and an increasing number of people without disabilities choosing to live in medium and high-density housing, villages and intentional communities. (NSW Government 2006, p. 6, citing Bostock et al. 2001)*

This chapter explores the elements and characteristics of three different family governed models, as well as the activities, decisions and transactions that

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<sup>16</sup> Also referred to as specialist disability accommodation, or SDA, under the NDIS.

parents undertook to achieve them. The activities and transactions that parents entered into demonstrate the different ways they designed and set up new homes, oversaw the delivery of paid support, and organised to remain involved once the homes were established. The chapter starts with a literature review to examine the use of governance generally, and family governance in particular, in the field of disability service systems. It also describes mechanisms of governance as an institutional framework and proposes institutional entrepreneurship as a theory of action whereby the parents are the institutional entrepreneurs initiating institutional change.

Next, this chapter presents the research methodology, describes the sample of research participants and explains how case study analysis was undertaken using cultural–historical activity theory (Engeström 2001). The three case studies are then presented, followed by a discussion of the research findings. This chapter concludes that the changing roles of parents, their design and delivery of new models of home, and their changing relationship with key workers, service providers and other families are scalable, family led innovations that more families can achieve with institutional support from government. This chapter thus demonstrates the use of family governance as an organising framework to create and govern the adults' own homes as an example of institutional entrepreneurship, which is discussed in the literature review below.

## **4.2 LITERATURE REVIEW**

This section provides a brief review of the literature that explains the concepts of governance and family governance, the use of family governance in the field of disability services, family governance as a mechanism of governance, and institutional entrepreneurship as a theory of action whereby actors leverage resources to advance the interests that are important to them. This section also identifies types of social innovation from the literature and an activity theory of change based on the activities of these parents.

### **4.2.1 Governance**

The definition of family governance in this chapter is based on governance as a foundational concept and family governance as an institutional mechanism of governance. The Institute of Internal Auditor's (IIA, 2017) definition of

governance captures elements common to other definitions (Anderson et al. 2017). For the purpose of this study, the IIA's definition is adapted by replacing the need for an incorporated organisation with a governing board so that 'governance' is defined as a combination of processes and structures that inform, direct, manage and monitor activities towards the achievement of objectives. This adapted definition of governance can be used in relation to any actors overseeing the achievement of organised objectives. The definition is applied in this research to describe governance that informs and guides the activities, decisions and transactions of the adults themselves, as well as their family members and other carers and friends who organise informally or formally and, if formally, whether or not they incorporate. The definition is applicable whether adults, other family members or other carers act alone or collectively, just as it is possible to have a single-member corporation. Where adults, other family members or carers act collectively, there can be a group that forms a governing body to choose and make decisions to implement the processes and structures. The objectives can be the objectives of the individual or of the collective.

#### **4.2.2 Family governance**

People with disability, family members or other carers may not be satisfied with service providers, user control over those services or the type or quality of the services offered. Kendrick (2011) described various models in which adults or families design and oversee or administer their own service arrangements as family governance. For the purposes of this study, 'family governance' is defined as a mechanism that combines processes, structures, social relationships and roles to organise and align actions, decisions and transactions to ensure that services and service providers align with families' philosophies and values, or families design and/or deliver services in accordance with their philosophies and values instead. This definition of family governance draws upon the meaning of governance as a foundational concept and family governance as an institutional mechanism of governance, as described in Section 4.2.3. Of course, models of family governance are based on the assumption that disability policy and systems will permit control and choice by the adult or their representative (including family members where appropriate). Arguably, control and choice require the self-management of funding by adults or trusted representatives. But

in any case, families require government agencies and service providers to share power, authority and control with adults and, where appropriate, their representatives.

It is a priority of disability policy in various Western countries to offer choice and control of funded services through individual funding mechanisms (Collings, Dew & Dowse 2016). However, individual funding models are described by different names and can have different meanings. For example, individual funding under Australia's NDIS can be self-managed, plan-managed or NDIS-managed. Self-managed is the term used under the NDIS when the adult or their representative controls and manages their NDIS funding with independence from a service provider (NDIA 2020). Kendrick (2011) noted that terms used in other countries include 'self-directed', 'self-determined' and 'consumer/family governed' (p. 63). But the introduction of individual funding assumes that services are available to choose in a market. It also assumes that people with a disability are confident to make that choice, are permitted to do so (Bigby & Ozanne 2001) and will have the opportunity to do so (Curryer, Stancliffe & Dew 2015).

During the course of this study, the NDIA, which administers the NDIS, developed a rule to stipulate that NDIS funding for SIL can only be paid to an NDIS-registered service provider that is incorporated, and it cannot be paid directly to the adult or their representative for self-management. This rule may have been formulated as a safeguard against fraud in the belief that NDIS funding paid to an incorporated legal entity is less likely to be misused and is easier to trace. This rule is now a mechanism for regulating and auditing the compliance of registered service providers with the NDIS Quality and Safeguarding Framework, which also commenced during the course of this study (Department of Social Services 2018).

Kendrick (2011) described a variety of organisational options or models that give the person with disability or their family representative more power, authority and control over the services received. These options or models can combine elements of different systems. One of these models is third-party hosting by an incorporated service provider (a host agency) of arrangements chosen by people with disability or families, other carers or friends. Another example is incorporation by family members, other carers or friends to administer a single



adult's service arrangement. A model that originated in Canada is microboards, which can be chosen by some families who opt to incorporate (Kendrick 2011, pp. 65–6). Microboards are 'a small group of people, typically committed family and friends of a person ... [who] form an incorporated association for the benefit of that person' to help them 'achieve their goals for a good life. They put the person's goals, dreams, needs and desires at the centre of their decisions and actions (i.e. a person-centred approach)' (Microboards Australia n.d.). But incorporation is not necessary in every case. The parents who participated in this research adapted the meaning and model of family governance for their situation. In each illustrated case, the parents used the term 'family governance' to denote autonomy from the service system, at least in part, and empowerment of the adult, or the adult through their representative. Empowerment in this scenario pertains to oversight and administration of services and support, or retaining 'complete decision making authority' where oversight and administration is delegated (Kendrick 2011, p. 64).

#### ***4.2.3 Institutions of governance***

Williamson explained institutions of governance as a mechanism or mode of governance that operates at the level of individual transactions. Markets and hierarchies are examples of institutions of governance (Williamson 1996, pp. 4–5, 7). Other examples of institutions of governance include the family, bureaucracy and the state. Williamson (1996) distinguished these first-category institutions of governance from a second category of institution that operates at the level of the institutional environment. This second category of institution in the institutional environment includes informal constraints and formal rules: the operation of norms, values, beliefs, laws and rights. Institutions in this second category operate to constrain first-category institutions of governance (Williamson 1996, pp. 4–5). This is consistent with the view of institutional theorists that institutions comprising norms, values, beliefs, laws and rights shape and influence organisations and their interests (DiMaggio & Powell 1991, p. 28). The three case studies in this chapter demonstrate the family as a first-category institution of governance — namely, oversight and control at the level of individual transactions through family governance. Government policy and laws are second-category institutions that constrain family governance.

Williamson (1996, p. 11) explained that mechanisms of governance in the first category (e.g. family governance) are institutional frameworks against which the integrity of a transaction or set of transactions between different people or organisations can be decided. This is critical when parties to the same transaction possess, or behave in accordance with, different institutional norms, values, beliefs and rules that are contradictory or in conflict. Making the same point, although using different concepts, Friedland and Alford (1991) explained that institutions, individuals and organisations interact, but their so-called 'organising principles', 'central logic' or 'rules' can contradict and conflict (DiMaggio & Powell 1991, pp. 29–30). This is resolved by applying or preferring a particular logic at the individual transaction level (e.g. the profit-making objective of the capitalist marketplace v. family advancement of family interests at the lowest cost). Friedland and Alford (1991, pp. 232–63) described differences between institutions in terms that reflect views and perceived norms — arguably idealised aspirations — at the time they were writing, although literature and research have continued to explore this area (Thornton, Ocasio & Lounsbury 2012):

*The institutional logic of capitalism is accumulation and the commodification of human activity. That of the state is rationalization and the regulation of human activity by legal and bureaucratic hierarchies ... That of the family is community and the motivation of human activity by unconditional loyalty to its members. (Friedland & Alford 1991, p. 248)*

The above differences in the characteristics of institutional logic occupy the context that families navigate to accomplish their housing objectives. In the case studies, family governance was the chosen mechanism of governance and was applied as an alternative to the institutional logic of the marketplace that is frequently selected (Williamson 1996, p. 5). The role of family governance in the three case studies was to reconcile or avoid conflicting interests of family, government and market, but to give priority to creating person-centred homes to advance the interests of adults and/or parents (DiMaggio 1988).

#### **4.2.4 Institutional entrepreneurship**

Government funding criteria reflect institutional norms, values, beliefs and rules that create or represent organising principles or a central logic. These organising principles or central logic create an institutional inertia or pressure that forces funded organisations 'to adopt similar practices or structures to gain legitimacy and support' (Battilana, Leca & Boxenbaum 2009; Seo & Creed 2002, citing DiMaggio & Powell 1983). Disability service or housing sector NGOs seek legitimacy or support from peers and government, and government as funder requires NGOs to offer the same services with limited variations for the service user to choose from. Funding criteria can constrain change unless institutional entrepreneurs (including NGOs) challenge the status quo and push back.

DiMaggio's (1988) notion of institutional entrepreneur explained how actors contribute to changing institutions despite institutional inertia or pressure. The concept of institutional entrepreneur is underpinned by two different concepts and two different streams of literature — institutions and entrepreneurship (Garud, Hardy & Maguire 2007). Three institutions are relevant in this context: the family (represented by family members); the state (represented by governments, politicians, their agencies and bureaucrats); and the quasi-market (in which NGO service providers operate with government funding). Institutional change is initiated when, for example, the role or power relationship between the three institutions changes. Entrepreneurship as the second concept is the pursuit of resources or other opportunities beyond those currently controlled by the entrepreneur (Stevenson 2000). In this study, families pursued opportunities to create new homes with the assistance of government funding that had previously been paid directly to service providers. Payment of individual funding to adults or their representatives initiates institutional change subject to government rules or limits regarding how individual funding is allocated or used.

DiMaggio (1988) defined 'institutional entrepreneur' as organised actors who leverage available resources to advance interests they value highly. Battilana, Leca and Boxenbaum (2009) developed DiMaggio's definition by proposing 'a model of the *process* of institutional entrepreneurship' that requires evidence of two elements (pp. 67–8). First, actors must initiate change that diverges from existing institutional practices and structures in a particular field of activity.

Second, actors must actively participate in implementing divergent change by securing and using resources to that end. In the three case studies, the pursuit and garnering of resources from government and other sectors (including individual funding), leveraged by parents to advance the interests of adults to live independently and the interests of families who needed or wanted adults to leave home, is institutional entrepreneurship.

The disability service system prescribed by public policy and funded by government is the institutional context for this research. Traditional service providers are predominantly not-for-profit NGOs with a monopoly in that field of activity, historically by region, at least in NSW. Families are proponents of divergent change when their philosophies and values for a model of home with paid care and support diverge from the institutional logics or beliefs of government, its agencies and NGOs, which deliver disability and housing services in 'markets' constructed by governments. Divergent change includes family governed activities by which resources are pursued and used, and housing is created by families to overcome the limitations of housing supply by government. Divergent change includes the pursuit and use of resources from non-traditional sectors for housing for people with disability. Divergent change includes family led initiatives to achieve housing by acting alone or in groups, and by mobilising NGOs, politicians and bureaucrats to actively support the family's vision of a family governed home for their children. Families who met housing needs in innovative ways with government funding, or other resources they secured, is institutional entrepreneurship and social innovation.

#### **4.2.5 Social innovation**

The Theoretical, Empirical and Policy Foundations for Building Social Innovation in Europe (TEPSIE, 2014) identified innovation for a social purpose using social means as 'social innovation'. In the three case studies, the grassroots, bottom-up activities of families and other actors (social means) working together to meet housing needs (social purpose) created different types of social innovation, including first-time innovations, governance innovations and scalable innovations. First-time innovations include innovations that are taken from elsewhere and are new in a particular context or new to the person or group using them (TEPSIE 2014), as well as new ideas, practices and approaches that

are not copied from elsewhere. First-time innovations in the three case studies included families choosing traditional approaches (e.g. organising people like key workers) and tools (e.g. registered co-operatives), but using those activities, transactions and structures for new purposes or in new ways (e.g. to govern these homes or register family governed entities as employer and/or service provider). Governance innovations included different models of family governance and family governed living arrangements that changed the role of families in the creation and support of the adults' home with government funding. Each new type of family governed approach was a governance innovation, and literature on governance innovations is limited (Krlev, Anheier & Mildemberger 2018, p. 19). Scalable innovations are innovations that can be replicated, copied or used by, or for the benefit of, more people, usually because institutional support exists — for example, families working together (family as institution), governments assisting adults or families through funding or policy change (government as institution) and established, reputable NGOs assisting through active involvement as chosen by the adults or families (NGOs that are institutional organisations in their field of activity; disability service providers and traditional housing providers are institution-like). The family governed homes or other innovations can be 'small in scale and locally based', or seek growth (TEPSIE 2014, p. 12). In this research, innovations driven by parents were scalable with a combination of family, NGO and government support. Using elements from different sectors (household, public, not-for-profit or private) or different service systems (housing or disability), and employing key workers directly, the long-term institutional response to these models will be reflected in government policy as it changes. In the usual way, government may seek to standardise these models in accordance with the norms, values, beliefs, laws and interpretation of rights by government.

#### ***4.2.6 Activity theory of change***

Eisenstadt (1980, p. 848) observed that institutional entrepreneurs are one variable among 'different constellations of the variables considered relevant to the process of social change'. In their process of institutional entrepreneurship, Battilana, Leca and Boxenbaum (2009, p. 67) explained that enabling factors and key activities are in that constellation. They identified field characteristics

and the social position of the institutional entrepreneur as enabling factors. They also identified two key activities of institutional entrepreneurs to achieve social change, namely, developing a vision for change and mobilising allies to support the vision. Developing a vision and generating support for it includes developing and sharing ideas for change, explaining the reason and making a case for it (Battilana, Leca & Boxenbaum 2009, p. 78). Mobilising allies includes advocacy, persuading helpful allies to support the vision, and engaging with people who have the resources or authority to help achieve the vision, or who can introduce the institutional entrepreneur to someone who has the resources or authority to achieve the change. Battilana, Leca and Boxenbaum (2009, p. 70) noted that few criteria need to be met to act as institutional entrepreneur. Actors do not need a grand plan to alter institutions, they do not need to be aware they are contributing to change, and they do not need to be successful and achieve change. The activity theory model was used to analyse the factors or inputs in the constellation of variables, including the key activities of parents, which are described in Sections 4.3 and 4.4.

## **4.3 RESEARCH METHODOLOGY**

### ***4.3.1 Units of analysis***

An exploratory comparison case study design was selected to focus on two units of analysis. The primary unit of analysis was the 'activity' to secure or create housing with a high level of paid support for adult family members. The secondary unit of analysis was the 'actor' who undertook the activity to achieve the housing objective. In the three case studies, the actor was an individual parent or more than one parent working together in an organised group. The case was the 'activity' to attain the housing objective. The boundary of the case was denoted by the six elements of each activity system identified by Engeström's (2001) model: (i) the desired goal, as object; (ii) who desired the goal, as subject (namely, a single parent in Case #1), parents acting together as Getting a Life in Case #2 and parents acting together in Case #3; (iii) who worked with the subject to achieve the desired goal, as a network and community of actors; (iv) the resources, strategies and other tools, methods and approaches used to achieve the desired goal, as tools; (v) the way work was shared or

divided, as division of labour; and (vi) the rules, professional conduct, routines, norms and attitudes that supported or constrained what people did to achieve the desired goal (Leadbetter 2008; Martin 2008; Villeneuve 2011).

#### **4.3.2 Research questions**

The research questions this chapter aims to answer are:

- RQ1: What were the philosophies and values that guided the elements of home that parents were seeking to create for their children?
- RQ2: What action and transactions did parents undertake to create these homes?
- RQ3: How did other people, organisations and institutions empower parents to select and recombine inputs from different systems with family resources to create these homes?
- RQ4: How far did the action of parents and/or government agencies and/or NGOs initiate institutional change?

#### **4.3.3 Sample of research participants**

The three purposeful case studies were identified by approaching four parents who spoke publicly about creating new models of home. In 2015, the parent in Case #1 organised and spoke at a parent-led symposium for parents who were interested in creating a home for their adult daughter or son. In 2016, two parents who were research participants in Case #2, and one parent who was a research participant in Case #3, spoke at the NDIS Housing Innovation Showcase at the invitation of the NDIA, which administers the NDIS. A second parent was a research participant in Case #3. One parent in Case #2 and one parent in Case #3 were not interviewed. In total, the research participants included five parents of five adults with disabilities. The adults were aged between 24 and 32 years at the time of the research. They had high to very high support needs, except for one young man, who was unable to live alone but who 'can read and write a little, and is able to catch a bus independently once shown'. This group of adults lived with different types of disability, including intellectual disability, CDKL5 syndrome, Phelan–McDermid syndrome, Down syndrome, autism and aphasia.

The primary criterion for inclusion in this research was that the parents had attained a new home for their adult daughter or son by taking action themselves. Each parent had established a family governed home with individual funding for paid support from their state or territory government before the NDIS commenced. Ethics approval for the research was given by the UTS (HREC REF No. ETH17-1412) in 2017. The research participants in Cases #1, #2 and #3 gave their written consent to be identified.

#### **4.3.4 Procedure**

The methods of data collection were semi-structured interviews of one parent in Case #1, two parents in Cases #2 and #3, and a review of historical documents where available. All participants who were parents were interviewed twice (or, in Case #1, more than twice because the family in Case #1 had purchased buildings to lease to a trusted manager of respite or short-term accommodation on NSW's Central Coast. The second parent in Case #1 was also interviewed in relation to setting up short-term accommodation for other families.) A single interview of any parent participant was not sufficient time to collect data because the activities of the parents to create models of home and care involved years of hard work. The CEO of the NGO service provider in Case #2 was interviewed on one occasion. Semi-structured interviews with probing questions were used to gain a deeper understanding of the meaning, perspectives and experiences related to their activities. All interviews were recorded, transcribed and then managed, along with available historical documents, using NVivo qualitative data analysis software.

#### **4.3.5 Backwards mapping**

Interview data collected the immediate goals and long-term goals of parents for their daughter or son's own home, how their ideas for their child and their inclusion in community life were formed or emerged, when their thoughts turned to accommodation, how ideas for the models themselves developed, and why they chose particular elements and characteristics. Similarities and differences between the activities, decisions and transactions of the parents, including parents in the same case study, were analysed. Backwards mapping or working backwards from the goals achieved is a process used in the theory of change

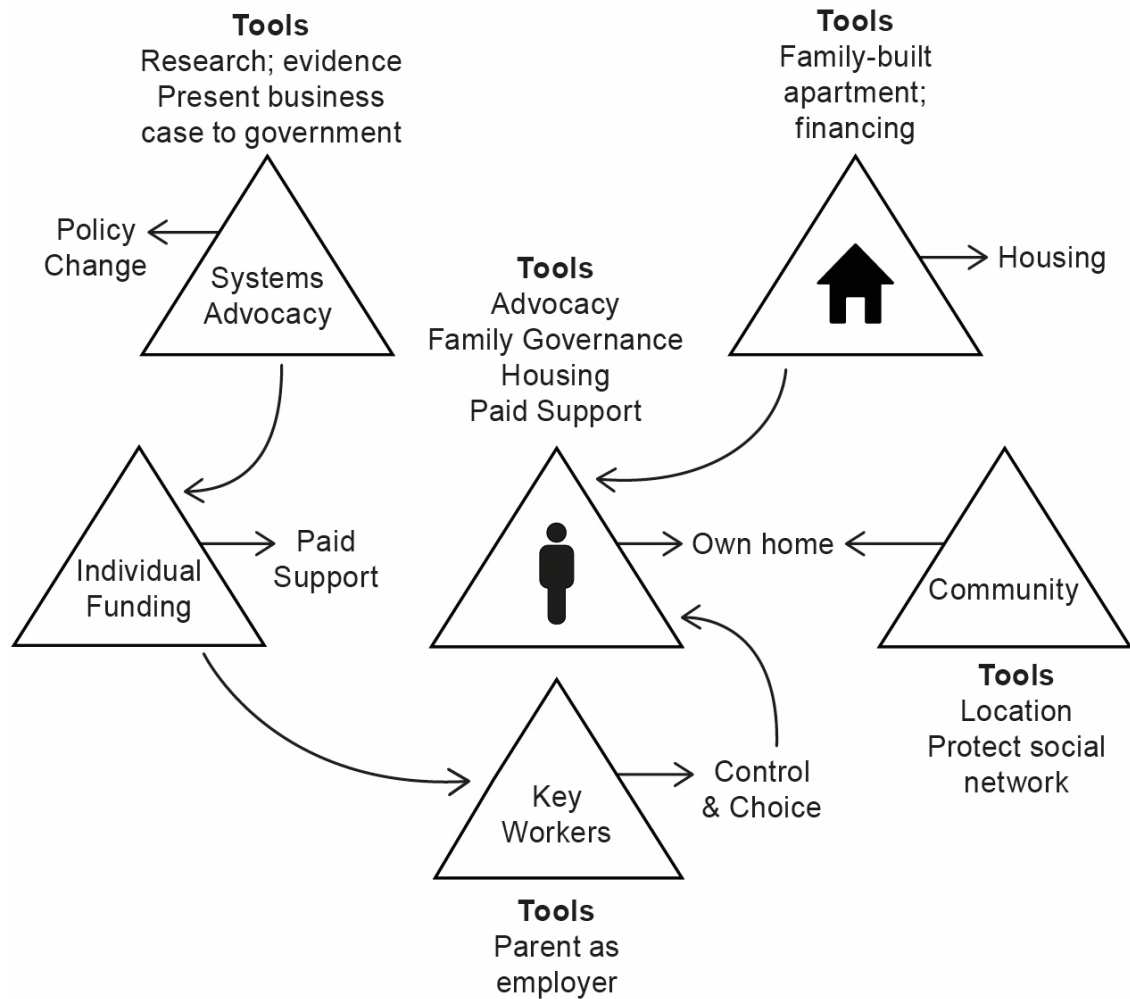


literature to connect the outcomes achieved with the desired goals, and the objectives with the inputs (Weiss 1995). Data analysis included working backwards from the different characteristics of each element in each model, the relevant activities, decisions and transactions the parents undertook, and other factors or inputs that were part of the context. In this chapter, the role of these families and the models they achieved as institutional entrepreneurship are the area of focus.

#### ***4.3.6 Activity theory for data analysis***

While thematic analysis is often used to analyse data in case study research, this study uses activity theory to structure the data analysis. Engeström's (2001) cultural–historical activity theory provided the framework to identify a series of connected, interdependent activity systems necessary to achieve the housing goals and objectives. Each series of connected, interdependent activity systems were individual 'mini-steps' taken to achieve earlier and mid-term goals and objectives. Achievement of these mini-steps was among the cluster of factors and inputs that contributed to achieving long-term goals and objectives (Weiss 1995).

The connected, interdependent activity systems illustrated that multiple factors must be successfully addressed and inputs secured to increase the prospect of creating each adult's own home. The connected activity systems begin with making tools for later use. Joint, collective activity with others is also necessary to secure resources and other opportunities (Leont'ev 1981, p. 208). How work is shared, or who did what (referred to as the division of labour), is mediated by tools and mediated socially. This process of mediation distinguishes 'short-lived, goal-directed actions from durable, object-oriented activity systems', which can be collective and interdependent (Elster 2015, p. 187; Engeström 2000, p. 960). Figure 3 illustrates the connected, interdependent activity systems or mini-steps of the parent in Case #1 to create her daughter's own home. This presentation of the emerging map of activity systems unifies action research, activity theory and theory of change and is an innovative contribution of this thesis.

**Figure 3: Connected, interdependent activity systems****4.3.7 Chronology and timeline**

A chronology was created for cross-case comparison and comparison between activities of two or more parents within the same case study. The chronology of events was also used to compare the interview data and activities of parents with publicly available evidence of policy change at the same time, some of which spanned decades. Demographic data such as the age of the adult children were also tracked in the chronology. Each chronology and historical document identified the type of interaction between the research participants and other actors. Because parents engaged in years of work to achieve and sustain the housing they established, a timeline was prepared to highlight key events, pivotal moments and turning points for some of the research participants. The timelines distinguished individual from collective activity.

#### **4.3.8 Concepts from theory**

Data analysis applied the conceptual building blocks and elements identified in the literature regarding institutional entrepreneurship, governance and family governance, entrepreneurship, and social innovation. The purpose was to understand whether the activities, decisions and transactions of the actors, as well as the tools they used, met the criteria articulated in those theories. The criteria include the pursuit and use of resources to achieve housing as entrepreneurship, the design and execution of family governed models and structures as divergent change from traditional organising principles or logic of traditional service providers, the social means for social ends driven by family led objectives as social innovation, and the changing roles of families as institutional entrepreneurship. This is explained further in the description of the case studies and in Section 4.5.

#### **4.4 CASE STUDIES**

Own Home Case #1 was a study of the activities, decisions and transactions of Ms Katrina Clark, who created a home for her daughter in a family owned apartment on the Central Coast in NSW. The NSW Government provided individual funding for paid support before the NDIS commenced. After transition to the NDIS, the daughter's individual funding for paid support was self-managed. Ms Clark selected and directly employed carers who lived in the local community, and she actively included her daughter in different facets of community life. Ms Clark invited housemates to live with her daughter. At the time she was interviewed, Ms Clark stayed in her daughter's home every second week to provide overnight care herself.

Intentional Community Case #2 was a study of the activities, decisions and transactions of a group of three parents who created the Benambra Intentional Community in a suburb of Canberra. Three parents formed Getting a Life, the first family governing group in the ACT. As Getting a Life, the parents established autonomy from the service system for their sons and for themselves as their representative. Getting a Life chose not to incorporate, but the parents acknowledged that family governed groups are different to each other (Richards & West 2014).

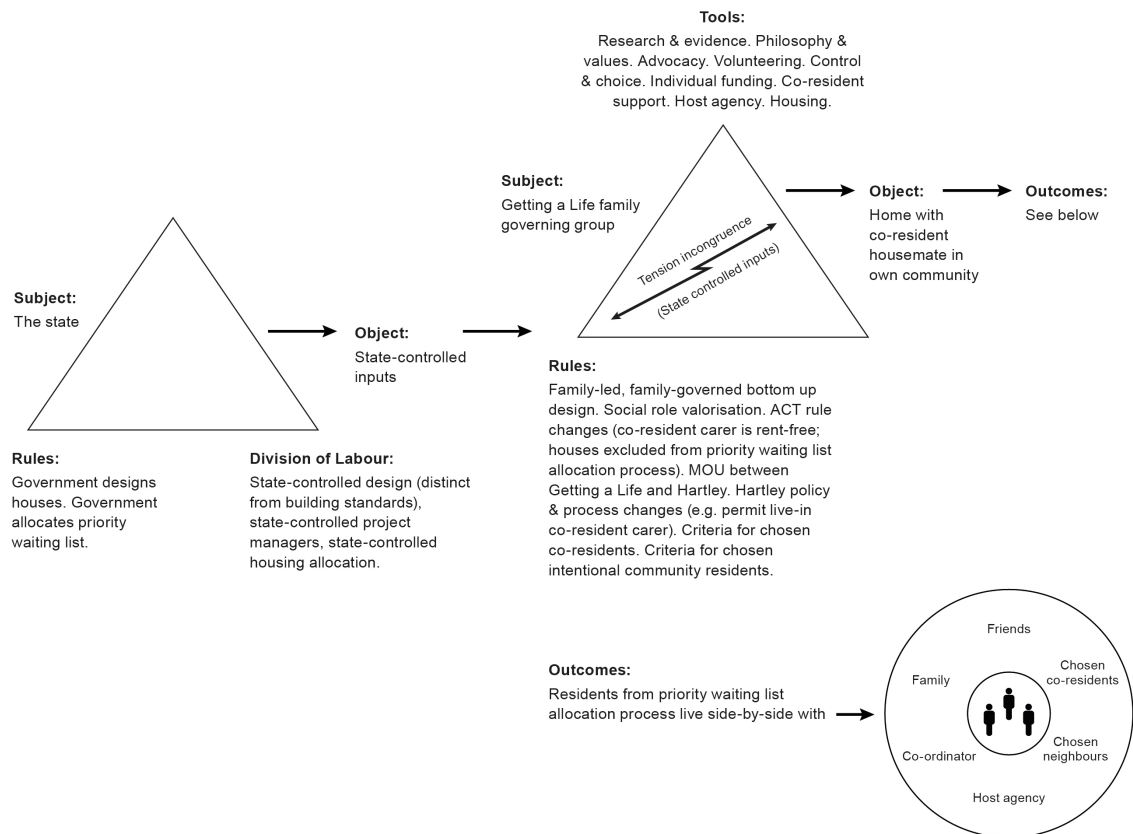
Over many years of advocacy, one of these parents, Ms Sally Richards, had asked the ACT Government to establish an intentional community whereby people could apply to live with her son. When the parents of Getting a Life joined forces to work together to establish an intentional community, there were more years of advocacy as a collective. Eventually, ACT Housing acquired the land for the community in a suburb of Canberra chosen by the parents. The three sons now live in three separate houses in their community, with three co-resident carers. The parents of Getting a Life appointed Hartley Lifecare ('Hartley') as the host agency for the co-resident model under a memorandum of understanding acceptable to Hartley and the parents. Hartley is a not-for-profit NGO and a registered charity that is NDIS-registered. Hartley employs the co-residents.

As Getting a Life, the parents developed the criteria for the selection of intentional community residents. People who wanted to live in the community with their three sons applied to be interviewed and chosen. Twenty-one people in 10 houses are intentional community residents (Richards & West 2014, p. 19). The ACT Government allocated the other 15 houses to people on the ACT Housing waiting list. These 'non-intentional community residents' (Richards & West 2014, p. 19) live side by side with the intentional community residents.

Figure 4 for Case #2 depicts two activity systems that describe inputs to achieve the homes of three sons living in the Benambra Intentional Community. Getting a Life's activity system on the right-hand side in Figure 4 describes the tools for the parents to secure the three elements desired to support these living arrangements (the intentional community, a co-resident model of support and the host agency). The tools were an outcome of a series of interconnected activity systems similar to those depicted in Figure 3 for Case #1. These tools were the culmination of many years of work. In addition, all elements of the homes that the sons live in, including the Benambra Intentional Community, were initially possible because the ACT Government and ACT Housing responded with significant assistance. Government assistance included individual funding for a co-resident carer and three houses, including accommodation, for the co-resident. Hartley was a like-minded NGO that worked with the parents to implement their co-resident carer model, which it continues to support as host agency.

The activity system on the left-hand side describes the contribution of housing by the ACT Government as a state input. Unlike the activity system in Figure 3, public housing was the tool (and type of housing) chosen by the ACT Government, which permitted residents from the public housing waiting list to live side by side with the three men and their intentional community residents. The parents had no control or choice over the elements of the activity system on the left-hand side. Figure 4 depicts the outcome of this hybrid design as a result of government input. In every case study, the living arrangements are an evolving model. In Case #2, when the parent participants were interviewed, they were still regularly meeting with ACT Housing to discuss their model.

**Figure 4: Benambra Intentional Community inputs**



Disability ACT provided the funding for paid support for the sons before the NDIS commenced. Although a shortfall in the funding for co-residents was addressed over time, the father of one of the young men moved in with his son to cover the initial shortfall. The son's younger brother then moved in as unpaid co-resident. All co-residents are now funded under the NDIS. Ms Richards and Ms Karen Connaughton were the two parents interviewed for this case study. Mr Eric Thauvette, the CEO of Hartley, was also interviewed. Ms Richards and Ms

Connaughton continue to support the intentional community and meet with ACT Housing every six weeks. These parents matched themselves as compatible with Hartley because they share the same philosophies and values.

PaRA Co-operative Case #3 was a study of the activities, decisions and transactions of a group of three families who established PaRA to manage the household supporting their three sons who live together in a house in Chatswood, a suburb of Sydney. The housing element of the model was quick to execute because the sons live in a privately rented house. For paid support, Mr Steve Anthony had negotiated to employ some of the staff from the government-funded accommodation his son had previously lived in, and the staff were willing to work in Chatswood. When PaRA started, a third-party not-for-profit NGO service provider employed the staff and a separate house manager. Eventually, the three families decided to perform the role of service provider and employ the key workers themselves in order to reduce the running costs and direct all funding to benefit their sons. They then registered PaRA as a co-operative and service provider. More recently, they engaged the family governed SILC as the NDIS-registered service provider, and SILC employs the staff. Mr Anthony and Mr Mark Goodmanson were the two parents interviewed for this case study. Their sons were among the first group of students to attend the Giant Steps School for children and young adults with autism in Sydney. Giant Steps aims to build a community around the families whose children attend the school. These parents matched themselves as compatible to oversee their children's home together. The next section answers the research questions in this chapter.

#### **4.5 FINDINGS**

The tools of government policy, and the housing and service systems based on that policy, were not responsive to the needs of the adults or the housing choice of parents at the time. Parents therefore took action themselves to establish family led, family governed homes that they had designed by combining different inputs from different systems. Ultimately, these grassroots, bottom-up initiatives were sustained with government support. This section describes the philosophies and values that guided these parents, their selection of elements of

the home, and the action and transactions they undertook to create the pathways to deliver these homes.

#### ***4.5.1 Control and choice and family governance***

The parents adhered to their personal philosophies and values. In each case study, these included control and choice and family governance. In Case #2, the parents also thought about and planned good lives for their sons as adherents to the principles of social role valorisation, which is a global social movement in disability. In Case #3, the parents designed their model for their sons' home and organised key workers around the values and principles of the international co-operative movement. Within these frameworks, the parents developed their vision of home, built allies and mobilised support for their vision.

#### ***4.5.2 Action and transactions of parents to create new homes***

The action and transactions undertaken by parents included control and choice over the employment of key workers, the engagement of a host agency in Case #2 and setting themselves up as a registered service provider in Case #3. The mechanisms for these activities and transactions ranged from direct employment, co-residents employed by a host agency and a registered co-operative as the structure for collaboration between families, their chosen NGO service provider and key workers who worked together to support adults living in their own home. Key workers and parents were both members of the registered co-operative.

#### ***4.5.3 Combination of inputs from different systems***

People, organisations and institutions who enabled the parents to create these homes included government, which committed to providing individual funding for paid support and the DSP to contribute to the payment of rent and other expenses. The ACT Government provided additional support when it built public housing for the three sons and their intentional community in Case #2. The NSW Government provided additional support when it initially paid the private rent for the PaRA model before the three housemates moved in. NGO support enabled the co-resident model of support in Case #2 and the initial set up of the sons' house in Case #3. The co-residents who support the young men in their intentional community in Case #2, and the key workers who support the adults

in Cases #1 and #3, empower the adults to live independently of their families. All of the adults have continued to live in these arrangements.

#### ***4.5.4 Institutional entrepreneurship through change***

These family governed models demonstrate the changing roles of parents as institutional entrepreneurship. The parents designed and implemented each model in partnership with government funding and the support of key workers with whom the parents have a direct working relationship. Through family governance, parents established their child's autonomy and their own independence from the traditional service system and traditional service providers. In each case study, the traditional service-centred group home controlled by a traditional service provider was not chosen.

In Case #2, Hartley is a like-minded NGO that performs the role of host agency and custodian of the co-resident model of support. Hartley is using the co-resident model as a new type of support for more people with disability when it is appropriate for them and they choose it.

In Case #3, the registration of PaRA as a co-operative and a disability service provider was a first-time innovation. The PaRA model in Case #3, and the parents' activities and transactions that established it, have a direct relationship with the formation of SILC. SILC's purpose is to help more families establish family governed homes for their children based on the PaRA model. SILC was established with Australian Government seed funding based on the organisation's commitment to become a self-funded service provider by earning fee-for-service revenue once established. SILC provides assistance to help families navigate through the SIL and SDA funding pathways to paid support and housing for their children under the NDIS, although applications for SIL and SDA funding can involve delays. SILC is not a housing provider but assists families to choose the characteristics of the family governed household they want for their children, as well as the role and nature of their involvement as family governance of the household.



These findings address the research questions in this chapter. The next section selects research data presenting the actions and transactions these families engaged in to achieve their vision of home as it emerged over many years by exercising control and choice through family governance.

## **4.6 DISCUSSION**

### ***4.6.1 Timeframe***

In each case study, the process to attain homes took years, and after governments committed to help the families establish the new homes, progress took more years. Decisions and action that should only take days took months. Analysis of the research data showed the reasons for the timing of the interaction between parents and powerful politicians or bureaucrats. These politicians and bureaucrats, who had committed to provide the assistance requested by the parents, appeared to be more hands-on in their collaboration with parents after a significant event. Case #2 illustrates the length of time that elapsed before achieving the housing goals and objectives for the intentional community. In her housing advocacy, Ms Richards regularly met with service providers, bureaucrats, politicians, community organisations and professional organisations like architects. Appendix E provides a copy of Ms Richards' original record of meetings she initiated and attended between 2002 and 2011, when she stopped keeping a record of her meetings.

Ms Richards formed Getting a Life with Ms Connaughton and another parent. They had already been working together for their sons when they agreed to turn their attention towards achieving an intentional community as a group. In 2007, they lodged their proposal and business case with the ACT Government to request homes in an intentional community for the three young men. In 2008, Ms Richards instructed architects to prepare a concept plan for the design of houses for residents who would live in the community. However, progress in executing this vision was slow. Things began to move more quickly, and bureaucrats were more hands-on, after Ms Richards' husband suicided in 2009. Ms Richards had initiated all meetings with politicians, bureaucrats and agency staff before her husband's death. When her husband suicided, Ms Richards was invited to meet with the most senior bureaucrat who would help her attain the intentional

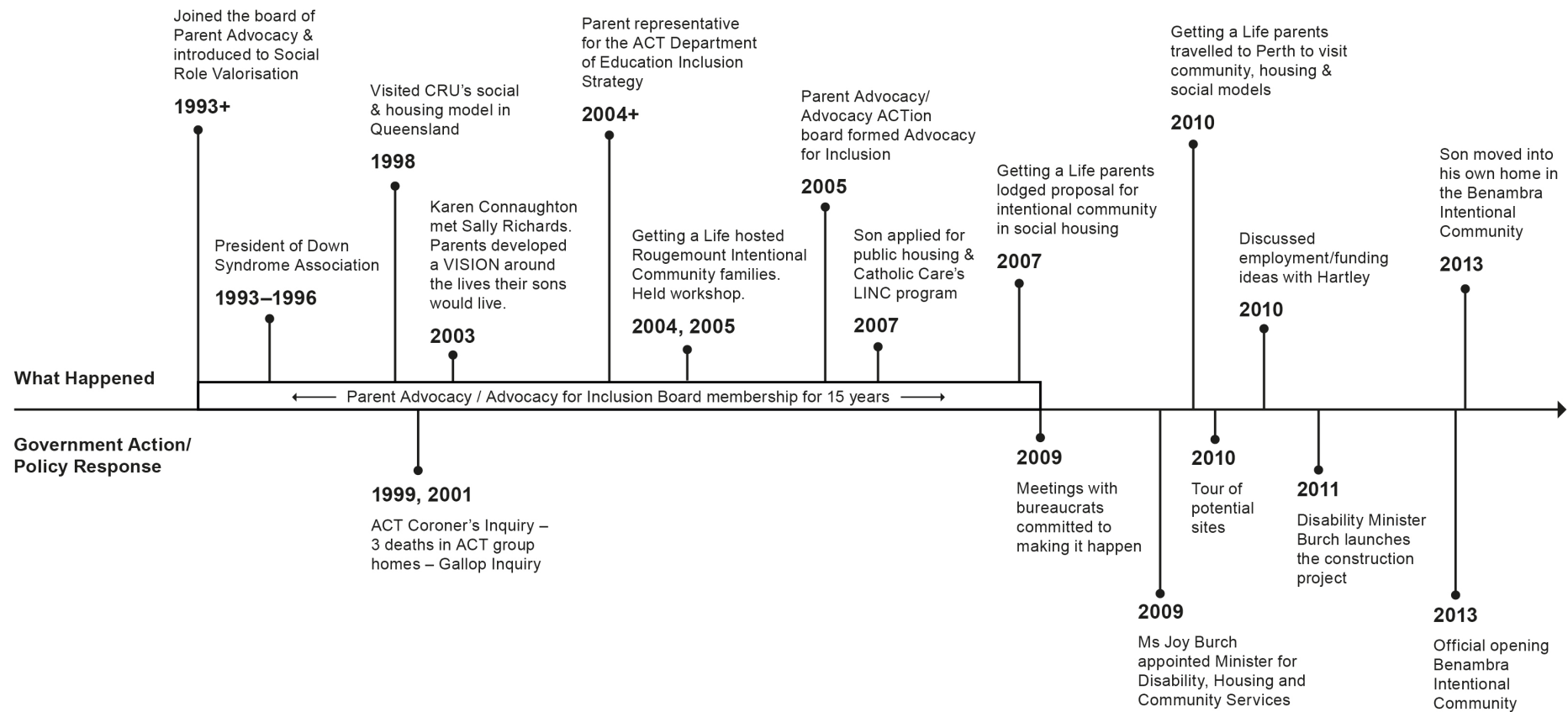
community more quickly. ACT Housing and the families visited potential sites for the intentional community in 2010, and the construction project was launched by the new disability minister in 2011, although the agency declined to use the concept plan, preferring to build houses in a row. In Richard and West's (2014) book, the parents reported more than 140 meetings between Getting a Life, bureaucrats and politicians between 2004 and 2013, when the three young men finally moved into their new homes.

#### ***4.6.2 Individual and collective action***

A chronology and timeline of key events identified the period over which the parents pursued individual objectives, and the period over which they pursued shared objectives together. This occurred for different reasons in each case study. For example, the parents did not have the financial resources to build or purchase their child's own home. They believed or were told that they were more likely to succeed in their pursuit of government-funded housing if they worked as a group. Further, the parents were prepared to make certain compromises by pursuing collective objectives. In Case #2, the timeline of Ms Connaughton's activities identified her years of individual work and the point in time when collective action began through the Getting a Life family governing group (in Figure 5).

**Figure 5: Karen Connaughton’s individual timeline (Case #2)**

**Timeline Case #2.2 – Education & housing advocacy – Karen Connaughton and Daniel**



When families acted together, collective preferences, collective decisions and collective choice were pursued. Acting together gave family groups the stamina to persist in their efforts to achieve elements of their model of home with particular characteristics. The selection of where the adults would live and who they would live with are some of these characteristics. In Case #2, for example, the parents had always stated that the intentional community must be located on the south side of the city centre:

*Parent Connaughton, Case #2: There's a lot of people who say 'Hi' to Daniel and look out for Daniel around the community because they know him. So, we'd always been really clear that we wanted it on the south side. And if Dan lived over on the north side, it would have just been really traumatic for him because he doesn't know the buses; nothing would be familiar.*

None of the land offered initially was on the south side. But the parents held out for the right location, even though it meant a further delay of more than 12 months (Richards & West 2014, p. 28):

*Parent Connaughton, Case #2: That was one of the really big advantages of having a group, because you do get exhausted. As my husband says: 'When one's getting exhausted the other one's just revving up'. It was around that time that we said: 'Well, we're going back to the minister one more time, to say these are the reasons we can't accept [the north side]'.*

Tyler (2011) explained that the extent to which groups are motivated to act for their members will depend on the nature and strength of their social connection, and whether the connection is based on shared 'attitudes, emotional connections, shared identities, common values, trust in the character and motivation of others, and a joint commitment to using fair procedures to exercise authority and make decisions' (pp. 1–2). During each interview, the parents in Cases #2 and #3 separately volunteered the values they shared with other parents in their group, including fairness in collective decision-making and the importance of their compatibility to continue to support the homes together after

they were set up. Philosophies and values were explicitly adopted and shared by the parents.

#### **4.6.3 Philosophies and values**

The philosophies and values of the research participants influenced the design of the model for each adult's home, the operation of each adult's household and the inclusion of key workers and neighbours in the lives of their child.

##### **4.6.3.1 Social role valorisation: Case #2**

In terms of *how* the adults would live, the parents in Intentional Community Case #2 were adherents to the philosophy of social role valorisation (SRV). The philosophy and practice of SRV are underpinned by critical concepts, namely, the 'personal social integration and valued social and societal participation' of the individual. Wolfensberger (1998, p. 123) articulated SRV to ensure people are valued and that they participate in valued activities that take place in valued settings. Ms Richards made the decision that she wanted an intentional community for her son when she learned about the Rougemount Intentional Community in Canada:

*Parent Richards, Case #2: I heard about the Rougemount Intentional Community, where people with disabilities are there first and other people are invited. And I thought, 'well that's what I want to do', because Jackson's level of disability is so profound he's always at the bottom of any list. He never gets choice or control, key words of the NDIS, over anything in his life.*

The Case #2 parents defined an intentional community in their book *A Place to Call Home* (Richards & West 2014, p. 11):

*An intentional community is a neighbourly, welcoming place to live where residents respect, help and are friendly to each other and are committed to creating a community of support. Residents have elected to move into Benambra knowing that three young men with a disability are living there. All residents welcome diversity and acknowledge the gifts and talents of each person.*

#### **4.6.3.2 Family governed home: Case #3**

In PaRA Co-operative Case #3, it was also important that the young men live in their own community. Mr Anthony described the problems when his son was living in a government-funded house located 60 kilometres from the family home:

*Parent Anthony, Case #3: He was living too far away from home, too far away from his day program, in an area where he had no familiarity, and no friends or family, all of which was very stressful for him. And equally as important, they only used agency staff and so he had no consistency in staff.*

CEOs of two NGO service providers who were allies of Mr Anthony and his son organised a meeting with the most senior bureaucrat in the relevant government agency. At a meeting attended by all of these people, Mr Anthony said:

*This is costing you a lot of money. Can we suggest a different approach where we're involved in his life, he lives closer to home, he's got consistent staff, so family governance, through [the existing provider]?*

Mr Anthony (2009) provided the agency with a costed proposal for a family governed home as a third alternative or 'middle ground' between the extremes of 'virtually all family' arrangements in the family home or 'virtually all state' living arrangements in group homes. Mr Anthony acknowledged that 'all family' arrangements or 'all state' living arrangements may be the most desirable for many families. However, he articulated a family governed model for his son and asked the agency to allow him to establish it (Anthony 2009, p. 67). As a result of his advocacy and financial cost modelling, comparing the cost of the then existing accommodation with Mr Anthony's alternative proposal, the bureaucrat agreed to the parents establishing the family governed home as a pilot. The basis of the pilot was that a small group of three adults selected by the parents would live together, and the service provider, operating the accommodation their son was leaving, would provide the support services in their son's new home. The philosophy, values and principles for a family governed arrangement were accepted by the government and the service provider as the basis for the pilot.

In 2010, Mr and Mrs Anthony set up their son's home in private rental accommodation located six kilometres from the family home. Some of the staff from the government-funded house, who their son liked, agreed to move with their son to Chatswood. Mr and Mrs Anthony then invited two young men who had been to school with their son to live in the house with him. After the first 18 months, the pilot was evaluated as a success by the government agency, with good outcomes for all stakeholders. In arrangements with family groups, there is sometimes a change of residents who live together as part of the matching process. In 2012, Mr Goodmanson's son joined the PaRA household to make it his own home.

#### ***4.6.3.3 Community life: Case #1***

In Case #1, Ms Clark did not anticipate the connection with the local community that a young group of committed key workers living locally would offer her daughter. These carers or key workers include her daughter in social activities with their own families, like family netball games on the weekend, and events in the community, like the Book Week Hat Parade at the local school. Ms Clark's daughter is mixing with young people who are interested in her and ask questions. This is something Ms Clark may not have been able to continue to offer her daughter now that Ms Clark's other children are older.

#### ***4.6.4 Co-operative values and principles***

In Case #3, the decision to adopt co-operative values and principles developed over time. The starting point was a decision of the three families that it would cost less if they were the service provider for the PaRA family governed home because they would be unpaid volunteers. In addition, they would have more control dealing with staff directly, as well as better services for their sons. The families approached the relevant government agency for approval to remove the existing service provider and provide the services themselves. At the time, the NSW Government was providing input into the Business Council of Co-operatives and Mutuals white paper, which proposed 'public service mutuals and co-operatives as a way of giving community and stakeholders ownership' in the delivery of government services (anon; Business Council of Co-operatives and Mutuals 2014). A senior bureaucrat suggested that this would be a good model

for the families to adopt. The three families decided that the seven values of a co-operative (self-help, equality, equity, solidarity, reciprocity, autonomy and democracy) reflected their values and were a good fit. Ultimately, the agency approved the adoption of a co-operative structure by the parents acting as PaRA, and the PaRA co-operative registered with the agency to provide disability services in the home of the three sons.

In 2015, the agency approved the registration of the PaRA co-operative as a service provider, and the PaRA co-operative registered as an NDIS service provider when the NDIS commenced. In 2019, the PaRA co-operative deregistered as an NDIS provider after SILC was engaged as an NDIS SIL provider for the three men. Mr Goodmanson described how the parents work well together:

*Parent Goodmanson, Case #3: We're all on the same page as far as the boys are concerned. So that side of it's been fantastic and I think that's one of the main reasons it has worked. You can have lots of disagreements about hours, like someone's had more hours than me. But we don't really have those. We have lots of discussions about it and try to make it work. There hasn't been a harsh word ever.*

#### **4.6.5 Action and transactions: family governance and innovations**

The PaRA Co-operative is a family governance innovation and a first-time innovation. The registered co-operative is a family governed structure that supports and oversees the operation of the household for the three men who live together. The PaRA model was established in partnership with the NSW Government. It also brings the partnership of family and key workers together, because staff who have been employed for 12 months become members of the PaRA co-operative with the parents:

*PaRA is the first family and staff governed co-operative operating in disability services in Australia. (SILC 2019)*

The Getting a Life family governing group is a family governance innovation and a first-time innovation because it was the first family governing group in the ACT. Getting a Life established the autonomy of the men, and the parents representing



them, from the service system and service providers operating within it. From time to time, the parents secure specific-purpose grant funding as Getting a Life. The Benambra Intentional Community is a separate innovation and is currently supported by two of the original three parents, but it is not family governed. The co-resident model of support and the host agency relationship are first-time innovations under a memorandum of understanding on terms acceptable to Hartley and the parents of Getting a Life. The CEO of Hartley provided his perspective of the innovations designed and implemented by the parents:

*NGO Thauvette, Case #2: The more innovative side of the model is the intentional community they've created around the live-in caregiver type model. That was new to us. There was a lot of work from the families to maintain it, and there still is a lot of work, although we support that also.*

#### **4.6.6 Others who empowered parents to combine inputs from different systems**

In Cases #1 and #3, the grant of individual funding for paid support by the NSW Government, and the combination of family and government resources, enabled both models. In Case #1, family resources included housing, which was a family asset. In Case #3, families contributed their model, volunteer labour and performed the role of service provider. In Case #2, the ACT Government's assistance included individual funding for paid support as well as public housing, which enables the intentional community. In turn, Hartley as host agency enables the co-resident support model. In Cases #1, #2 and #3, the families also maintained oversight of the quality of care, support and services through family governance. Because there was no third-party service provider, when the research participants in Cases #1 and #3 were interviewed, all administrative and compliance activities, including matters like payroll obligations and house maintenance, were the responsibility of the families. In this way, Cases #1 and #3 were most alike because they had not appointed an independent NGO service provider at that time, at least until SILC was appointed as SIL provider in Case #3.

In Case #2, the type of institutional support provided by the ACT Government and Hartley for the adults, their intentional community and each co-resident was significant. First, the ACT Government provided individual funding for support through Disability ACT, which later transitioned to the NDIS. Second, construction of new public housing by the ACT Government through ACT Housing was a significant contribution. It is not the practice of state or territory governments to make public housing accessible for people with disability with high support needs; thus, this was an innovation by the ACT Government. Third, ACT Housing changed the rules for public housing to permit a co-resident carer to live rent-free in public housing. Fourth, the ACT Government determined that the nominated number of houses for intentional community residents was excluded from the priority waiting list allocation process. (Not all of the housing at the same location was reserved for intentional community neighbours as desired.)

Hartley as service provider changed its policies and processes to become host agency and employ the co-residents. Hartley's board approved its delivery of the new model with carers or paid support as live-in co-residents. In addition, Hartley addressed any gaps in the model as needed:

*NGO Thauvette, Case #2: Depending on the needs of the individual, if there's a real hole, if there's something that's not being provided that's needed, we'll help them out.*

Table 9 describes the philosophies, values and partnerships as tools in each case. Philosophies and values guided the choice of housing objectives and desired outcomes. Family governance was the means or mechanism for attaining the homes that parents wanted for their children. Partnerships and collaboration were the means to accomplish housing objectives together.

**Table 9: Philosophies, values and partnerships**

	<b>Own Home Case #1</b>	<b>Intentional Community Case #2</b>	<b>Co-operative Case #3</b>
<b>Philosophies and values</b>	Choice and control to live independently with good-quality carers (key workers) selected by parent.	SRV, choice and control, family governance with a co-resident care model. Co-residents (key workers) selected by adults, parents and Hartley.	Choice and control, family governance and family governed with consistent staff (key workers) selected by parents. Seven co-operative principles.
<b>Partnerships that accept the philosophies and values</b>	Partnership between family, key workers and government.	Partnership between families/co-residents and other key workers, host agency, intentional community residents and government.	Partnership between families, key workers and government.

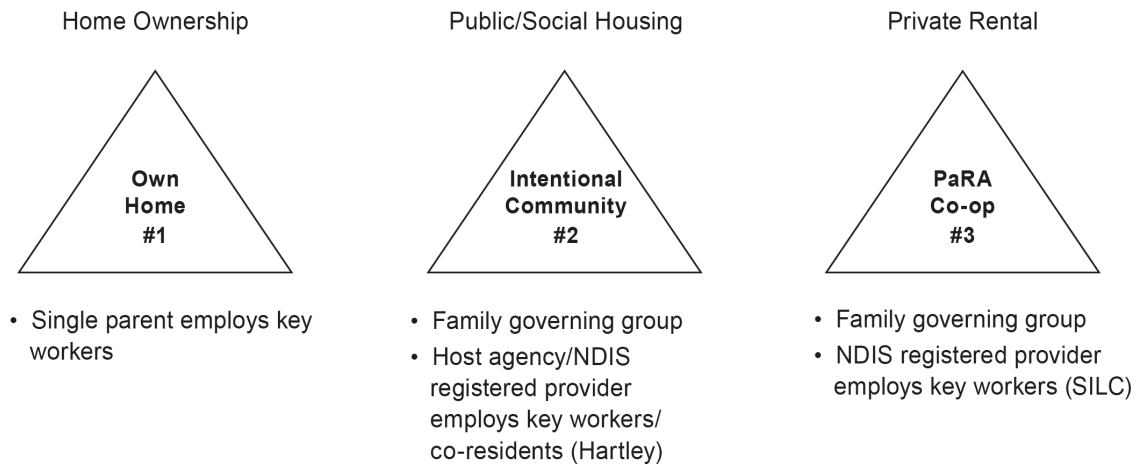
#### **4.6.7 Inputs from different systems**

Parents drew upon and combined different types of housing (family owned housing, public housing, private rental properties) and services (housing v. disability) sourced from different sectors (household, public, not-for-profit) to create different elements of different models of family governed homes from different systems.

##### **4.6.7.1 Types of housing**

The source of housing was different in each case study, and security of tenure was determined by the source of the housing. The security of tenure for the daughter's own home in the family owned apartment in Case #1 was potentially the strongest. In Case #2, the parents were confident that their sons have security of tenure in the houses owned by the ACT Government, although ACT Housing has a right to terminate the lease in limited situations. The security of tenure may be weakest with the privately owned house rented by the PaRA co-operative in Case #3. But the families are addressing this risk through their efforts to secure social housing for their sons. Figure 6 uses the activity theory model to compare the different housing inputs.

**Figure 6: Cross-case comparison of source of housing (#1, #2, #3)**  
**3 Case Studies**



#### **4.6.7.2 Good key workers**

The attitude, commitment and skills of key workers are critical for consistency in the quality of care and paid support the adults receive. In Own Home Case #1, Ms Clark found that a large number of people are willing to be employed to provide care and support in the local area where her daughter lives:

*Interviewer: The literature talks about ... tangible and intangible elements. There's accommodation, or bricks and mortar, care and community. Is anything missing?*

*Parent Clark, Case #1: Proximity to carers needs to be in here and availability of carers ... [On the Central Coast] we have better access to carers who are more willing to do caring work. It's also their mindset, their level of interest and their willingness to commit. It's intangible.*

The model for employment and the structure for oversight of the key workers vary because family governance differs between the models. In Own Home Case #1, the parent directly employed her daughter's key workers and appointed one of them as manager. In Intentional Community Case #2, the co-resident support model was designed by the parents with input from Hartley for its implementation and input from government through its funding. Mr Thauvette, Chief Executive Officer of Hartley, explained that co-residents are more than just staff:

*This model of support has increased the employees' dedication and commitment to the men they support, their families and extends to the intentional community. The support services we provide work best when families of the individuals are involved. The support workers get feedback on their work directly from the families, which is very powerful. (Richards & West 2014, p. 32)*

Although the parents select the co-residents with Hartley, the employment contract is between Hartley and the co-residents:

*NGO Thauvette, Case #2: We review [the employment contract] every year with the families and the co-resident. The families might say, 'You know what? We really need to highlight this part or do this differently', and we'll work through it. The type of people that end up getting hired in those positions are incredibly open and love to be part of something different. They're actually contributing to how it looks too. So we've met with the co-residents every year since we started, and we get their input into how it's working for them.*

In Co-operative Case #3, the household and key workers are an important community for the three men. Although it took his son three years to settle in to his own home, Mr Goodmanson's son is really happy, and his life has expanded:

*Parent Goodmanson, Case #3: In the kitchen, he wants everything put away in its spot. The new staff, or staff that were new to him, stretch his boundaries. They've got him hanging the washing out, starting cooking, doing the washing up. It's been great for him and a life changer for me.*

#### **4.6.8 Scalable innovation**

The family led innovations in the three case studies are scalable with the institutional support of families, NGO service providers, government and its agencies. The family governed home in Case #1 is a local, smaller model. It is quicker to set up, assuming that families have the necessary resources. It is also an individual living arrangement whereby the family does not rely on anyone else initially, but it can be used by a small group of two to three parents, other carers

or friends of adults who share a vision for this kind of home. In addition, Case #1 is an example of NDIS-funded support in a family governed home, which was self-managed when the parent was interviewed. Ms Clark had the skills to manage both the funds *and* paid support herself. Further, she employed carers directly, kept good payroll and accounting records, as well as compliance systems and records (as required of a small business), and she provided sufficient and appropriate evidence of her daughter's care to the NDIA when asked. This included information regarding the backup arrangements in place when staff called in sick, and how she ensured that staff were always at her daughter's home when she caught transport back from her daytime activities. The extent to which any of these factors or cluster of variables are relevant to the approval of self-managed NDIS funding for family governed homes is unclear. In addition, the extent to which the choice to self-manage is subject to the exercise of discretion by the NDIA over time is also not known.

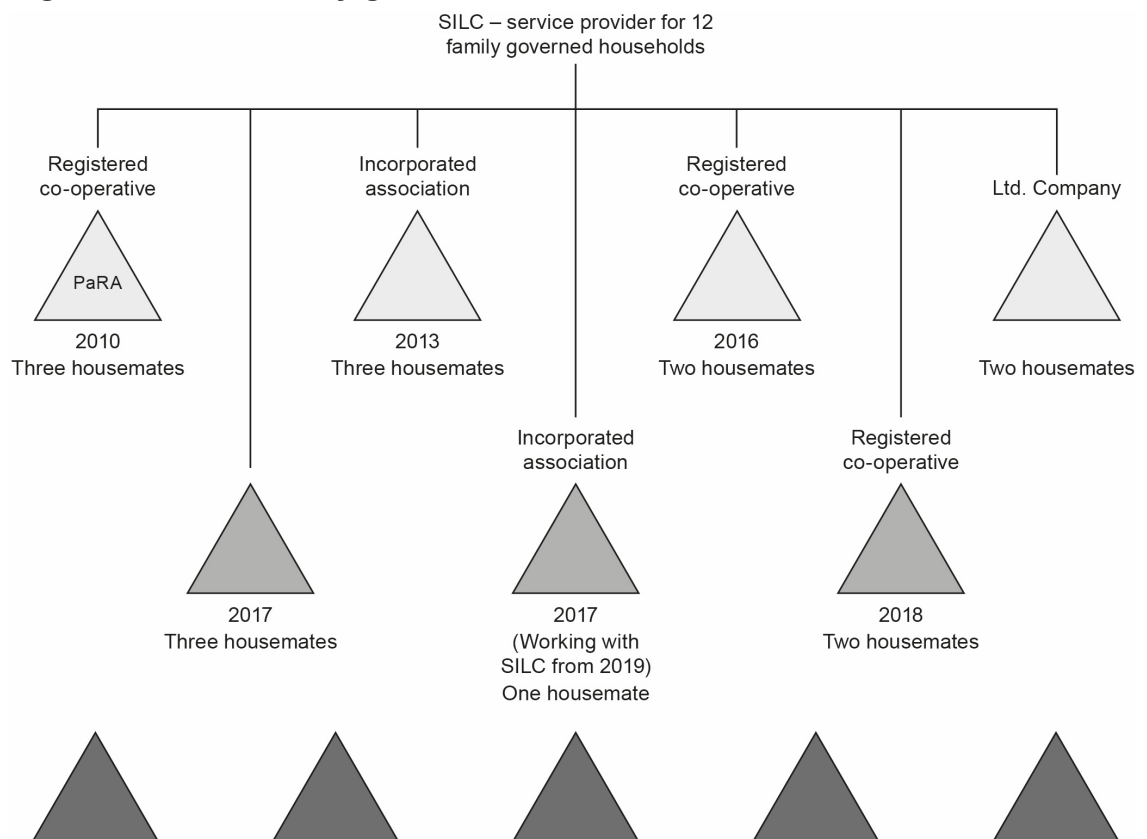
In Case #2, the intentional community requires land, so this model may be more difficult to replicate unless government is committed to assist more adults with land and housing. An intentional community can be replicated by anyone who has the resources to fund the housing requirements. Certainly, with sufficient government support, an intentional community can be replicated. Hartley uses the co-resident innovation with other people if it is suitable for them and they choose it. So, the co-resident innovation in Case #2 has been replicated with the institutional support of a reputable, established not-for-profit NGO.

In Case #3, Mr Anthony applied to a federal government agency for seed funding to set up SILC, a not-for-profit co-operative. The purpose of SILC was to assist more families to establish more family governed homes like the PaRA co-operative using individual SIL funding under the NDIS and privately rented properties. In 2016, SILC registered as a service provider with the NDIS; it is authorised to provide SIL services for people with approved NDIS SIL funding. At the time of writing, SILC has assisted families to establish 12 innovative family governed households with between one and three adults in each home. The adults in these 12 households did not need to join a waiting list because private rental accommodation and NDIS SIL funding enabled each individual living arrangement. In turn, the SILC model enables greater choice about where the

adults will live (and who they will live with) because the individual or their representative can organise SIL funding for the service provider and housing separately.

Under the SILC model, the families incorporate legal entities as the house operator for each household. House operators are corporate members of SILC, and family members are directors and members/shareholders of their house operator. Some of the house operators are proprietary limited companies, but families are encouraged to establish registered co-operatives in line with SILC’s ethos of ‘co-operation among co-operatives’. SILC currently has 12 corporate members, which means 12 household operators, including the PaRA co-operative, which was established before SILC. Figure 7 illustrates membership of SILC as a new pathway to the creation of family governed homes with SILC’s assistance.

**Figure 7: SILC’s family governed models are individual and scalable**



SILC enables the families to exercise control and choice over the design of each household, the relationship between families and staff, and the extent of the involvement of families as family governance. The 12 households are all a little different from each other. SILC offers a range of services from which its members can choose when their household is set up. SILC is also a learning hub where each member household and their key workers share what they are learning. Mr Anthony described his perspective as a parent:

*Innovation comes from need. Necessity is the mother of invention ... Our view is, let's work out how to do it, and we'll collect evidence along the way. But don't wait. You're not going to find the evidence, collect the evidence, unless we try something differently. Where there's a reason, then that's enough [of a reason] to do it.*

#### **4.7 CONCLUSION**

Driven to create positive housing outcomes with better care and better services, families initiated new pathways to achieve new homes. The resulting models and the processes for creating them were divergent to government-funded housing systems, which are traditionally controlled and operated by government agencies or service providers that the person with the disability has not chosen. These are housing systems from which adults living with families are frequently excluded. The family led homes in the case studies were initiated outside existing service and housing systems, but used housing resources from those systems (home ownership, public housing and private rental properties) with government assistance. Once governments contributed individual funding for paid support, the adults and their parents were empowered to secure paid support from a service provider chosen by them, or to directly employ key workers. In turn, the adults now have the power to change providers for housing or paid support, or both at any time. But it was the families who created the models and the pathway to them through family led design, housing advocacy for government assistance and building allies for their vision of a family governed home at every level. In these processes, the role of the families changed from service user to service provider in varying degrees.



The adult and their family's control over the choice and role of key workers also changed the way paid support was delivered. These families helped the key workers understand the needs of their daughter or son, worked closely with them to address issues on the spot, and worked in partnership with a high level of respect and trust for each other. It is the nature of disability support to have a regular turnover of staff, and the households are complex operations where things do not always run smoothly. But families support key workers to resolve issues when they arise.

The initiatives by parents in this chapter avoided the need for their daughter or son to join a waiting list for group home accommodation. These families overcame the exclusion of their daughter or son from waiting lists for the allocation of government housing, and overcame the exclusion of adults with high support needs from public housing and private rental properties. In turn, these innovative models with new attributes that govern the household's operation (family governance, control and choice, and person-centredness) are now present in those housing systems and property rental markets.

Politicians and bureaucrats representing the NSW and ACT governments trusted these grassroots innovators and supported the families to test their own ideas. Since the NDIS commenced in 2013, more adults are seeking their own home and are eligible for individual funding to live independently. We are at a tipping point where governments need to partner with more families, and more families need to deliver services themselves to meet their housing needs. NGO service providers must also be prepared to co-produce and co-govern homes with adults and, if they are involved, the families, friends or guardians of the adults. The effect of these initiatives at a local level and at a system level should be reflected in changing attitudes towards family led initiatives across government and the service and housing systems themselves. It is timely to measure whether the attitudes of other actors are shifting to support family led endeavours, and to ask traditional service providers to suggest ways they can partner with adults and families in family led initiatives.

A particular characteristic of the three family governed models presented here is that they have continued to adapt and evolve as the needs of the adult, the family or other circumstances change and new opportunities are identified or created.

For example, lifetime tenure in housing is now needed to ensure sustainable living arrangements for the three adults in Case #3. The advantage of these family governed person-centred homes is that they are able to achieve or respond to change with the support of the parents. The models will need to survive the death of the parents. The elements of location in the adult's community, good key workers and social connection to community life will remain constant throughout each adaptation to safeguard these adults. Mechanisms and transactions for the operation of each household, and the type of governance to support each adult in their own home and their key workers when parents no longer govern these living arrangements in the future, is another area for future research.

## **5 POWER**

This chapter is the second paper prepared for publication. Three case studies present action taken by parents to create housing with paid support for adult children. Parents aimed to see these adults settled in their own home in their own community. The case studies analysed the barriers confronting families who challenged the policies, attitudes and practices of successive governments, politicians, government agencies and bureaucrats who failed to provide more housing or choice of housing when paid support was also needed. One-, two- and three-dimensional views of power (Lukes 2005) are drawn upon to explain barriers created by people with power-over the political agenda to exclude discussion of the need or desire for adults to live in their own home. It demonstrates that parents possessed the power-to challenge the lack of engagement by government to meet housing needs, and they exercised power-with other families, their community, voting citizens and politicians who were allies to challenge the housing status quo. The three case studies are identified as Own Home Case #1, Sutherland Shire Independent Living Case #4 and Ryde Cluster Case #5 in Chapter 3. In this chapter, they are identified as Cases #1, #2 and #3 for ease of reading.

### **5.1 INTRODUCTION**

Some adults with disabilities in Australia live in government-funded housing, while others live with their family. Neither situation necessarily reflects the preferred choice of the adult or the family that cares for them. They are powerless in the face of government inability or unwillingness to provide more housing or a choice of housing with the support needed to live independently and well in either context. Politicians obfuscate their duty of care behind a tenuous economic argument. They claim that providing sufficient housing for all adults with disabilities is not feasible (NSW Government 2006, p. 3). But it is equally true to say that the government chooses to prioritise other interests.

Governments have been pressured into providing housing for adults when confronted by advocates who know how to push back. But it should not come to this. Three case studies provide examples of parent advocates who confronted housing systems that were inaccessible, unresponsive and crisis-driven at the

time (National People with Disabilities and Carers Council 2009; NSW Legislative Council Standing Committee on Social Issues 2010). They refused to accept a status quo that increasingly burdened families while caregivers aged until the family broke, and their adult daughter or son was allocated to government-funded housing anywhere there was a vacancy in NSW.

This research follows families engaged in systemic advocacy, public advocacy and housing advocacy, and uncovers the innovative strategies they created for building and exercising power. They engaged with housing and disability service systems to secure government-funded housing, but encountered resistance from bureaucrats who controlled access to resources in those systems. They experienced government and political processes that were reactive. Yet they found the power-to (Gaventa 2006) challenge the lack of engagement by government and the absence of rules to properly prioritise which areas of need for housing would and would not be met by governments. Violating the bureaucracy's norms for the behaviour of parents, they used their limited resources in innovative ways (bricolage) to advocate and exercise power-with (Allen 1999; Gaventa 2006) other families and politicians who were allies and who shared the families' perspective to challenge the status quo. Support from a small group of key politicians who were engaged with the need for housing was a turning point.

This exploratory case study research seeks to answer the following questions: Did people, organisations or institutions in positions of power create barriers that limited access to government-funded housing for adults? What were those barriers and how were they created? What strategies did parents develop to mitigate those barriers and secure housing? What tools did parents use, who did they work with as allies to achieve housing, how was the work shared, and what rules or policies were in the way or helped achieve their purposes? This chapter starts with a brief overview of literature on policy and practices for access to 'supported accommodation', the need for more housing, the three dimensions of power, and bricolage as a problem-solving pattern of behaviour of parents in their efforts to secure housing with limited resources. This chapter then describes the materials and research method, the research procedures, the use of Engeström's (2001) cultural-historical activity theory for data analysis, and the

use of interview data to prepare chronologies and timelines of key events, pivotal moments and turning points for cross-case comparison. The case studies are then described, followed by an explanation of the findings by applying the concepts from theory: power-over, power-to, power-within, power-with (Gaventa 2006; Tchida 2018) and bricolage (Lévi-Strauss 1972). The chapter discusses these concepts by analysing how parents developed four sources of power (organisational, community, relational, personal determination) and then presents the conclusions.

## **5.2 LITERATURE REVIEW**

The literature describes policy and practices that have created barriers to housing with paid support for young people and adults in NSW, the scale of housing needs for people with disabilities, families who improved housing options as advocates, and governments that improved housing options as funder and law maker. The power and bricolage literature explains the means by which families are empowered to meet housing needs when the interaction between opponents to more housing and challengers to the status quo is protracted and shared publicly.

### ***5.2.1 Barriers to housing with paid support***

Policies favouring unpaid care in the family household are under pressure. These policies are challenged by parents who provide unpaid caregiving indefinitely. Parents have complained to successive governments and reported that the services required for young people and the adults living with them were inadequate and underfunded or non-existent (NSW Legislative Council Standing Committee on Social Issues 2010; NSW Ombudsman 2004; Productivity Commission 2011). Services that are funded have been described as a type of lottery, with access dependent on where people with disabilities live, their type of disability and the services available in their area (Carter 2014; Productivity Commission 2011).

#### ***5.2.1.1 Barriers to housing for young people***

Children, young people and adults have confronted multiple barriers when they needed or wanted to leave the family home. The exclusion of their children from

respite services and supported accommodation at the time led to complaints to the NSW Ombudsman, government inquiries, public hearings and submissions that were published or confidential (NSW Legislative Council Standing Committee on Social Issues 2010; Productivity Commission 2011). Parents in the three case studies made submissions to these inquiries.

In NSW, the relevant public agency (disbanded after the NDIS began) was criticised for its inhumane requirement that parents satisfy authorities that their child was ‘homeless or at risk’ before they would be eligible for supported accommodation (Association for Children with a Disability NSW 2010, p. 9; NSW Legislative Council Standing Committee on Social Issues 2010, pp. 49–50). To meet this requirement, parents were required to publicly ‘relinquish’ care and guardianship rights:

*Parents have to die, be seriously ill or abandon their loved ones to even get into the system. This crisis driven scheme causes widespread mental and physical illness within the families and often leads to family breakdowns, which ends up costing the State and [the relevant public agency] even more money than if they actually funded the accommodation in the first place. (NSW Legislative Council Standing Committee on Social Issues 2010, p. 49)*

#### **5.2.1.2 Barriers to housing for adults**

Barriers to housing for people with disabilities continue into adulthood. Every Australian Counts is a community campaign that lobbies politicians for the NDIS in Australia. In 2015, Every Australian Counts conducted a housing campaign and prepared a Housing Action Plan based on submissions from 650 respondents. The Housing Action Plan (Every Australian Counts 2015) reported the existence of ‘massive waiting lists’ for accessible and affordable housing across Australia. Waiting lists for public housing, and social housing more broadly, vary as eligibility and needs change over time. The AIHW (2020) regularly publishes housing demand data based on the state and territory information it receives. But waiting lists for public housing and other types of social housing in each state and territory may not accurately report real housing

needs. The media usually refers to the waiting time as more than 10 years (O'Mallon & Osborne 2020), although it is shorter for different types of priority applicants, particularly if they are prepared to live in housing located anywhere.

There is no reconciliation of the data that record people on waiting lists for social housing with people in overcrowded homes, people in temporary housing, couch surfers, people who sleep rough and people with disability who live with a primary caregiver over, say, 65 years of age. In addition, the number of people on waiting lists for government-funded housing includes people without disability, and the percentage of people with disability on waiting lists is not reported, but it should be known by the NSW Government because special needs applicants are now able to identify special needs in their application. Respondents to Every Australian Count's housing campaign did not identify whether they were on a housing waiting list, although a number disclosed that they were homeless, and more than 51% expressed their desire to live in a home of their own that does not involve sharing with other people with disabilities (Every Australian Counts 2015, p. 5).

#### **5.2.1.3 Scale of housing need**

The number of adults who need government-funded housing but are unable to secure it is an estimate. Ongoing efforts to measure the need for housing and unpaid care are based on the annual HILDA survey and the less frequent SDAC conducted by the ABS. In their research for AHURI, Wiesel et al. (2015, p. 10) reported that four million people with disability (with around 800,000 primary carers) will not be eligible to receive NDIS-funded support but will receive information and referrals to mainstream services. Mainstream services include public and community housing. For many, this mainstream social housing will be the only option because the adults are more likely to be unemployed, on a DSP, experience homelessness or experience housing stress because they cannot afford the cost of a private rental (Wiesel et al. 2015, p. 1). Wiesel (et al. 2015, p. 34) identified a second category of more than 51,000 people with severe or profound disability between 25 and 64 years of age who live with their parents and who may seek to live independently with their NDIS funding. However, they found that these adults (living with families) are given a low priority status for the

allocation of social housing when vacancies arise. These attitudinal barriers are additional barriers confronting this group.

In 2016, the Disability Housing Futures Working Group identified between 35,000 and 55,000 people who qualify for NDIS support funding but will not have access to adequate housing in the private or social housing sector (Disability Housing Futures Working Group 2016). In its next report, the Disability Housing Futures Working Group (2017b) confirmed that a larger number of people will not be eligible for NDIS support funding, 'do not live in appropriate, secure affordable<sup>17</sup> housing' and will also need housing (p. 2). The Working Group stated that the need for government-funded housing on this scale requires 'innovation in the delivery of housing assistance' and more funding (Disability Housing Futures Working Group 2017b, p. 3).

#### ***5.2.1.4 Families improve housing outcomes***

People with disability have recognised that families can improve housing outcomes (Wiesel et al. 2015). They have done so by seeking out housing options, assisting their children to make formal applications for social housing or private rental properties, providing financial assistance if they are able or willing to do so, and seeking out other families and connecting through networks to create a pathway into housing for their children.

#### ***5.2.1.5 Governments improve housing outcomes***

Governments located overseas have also improved access to housing. In the US, the importance of federal legislation to ensure consistent progress towards best practice across each state distinguishes the effect of governments on positive housing outcomes from progress in countries that are a federation of self-governing provinces or states that lack national legislation, like Canada (Kovacs Burns & Gordon 2010) and Australia. Wolf (1990) analysed policy efforts in the US state of Connecticut to protect the rights of people with disabilities, including mental illness, to equal housing opportunity, emphasising 'personal

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<sup>17</sup> The term 'affordable housing' has different meanings. Under NSW Government policy, it means housing developed with some assistance from the state and/or federal governments that is available for rent to people on a means-tested income who meet other eligibility criteria (<https://www.facs.nsw.gov.au/providers/housing/affordable/about>). Rent for this type of affordable housing is calculated differently to rent for social housing. The Disability Housing Futures Working Group appears to give the term broader meaning (e.g. can people afford to pay the rent where they live?).



choice of where, how and with whom to live' (p. 100). The achievements with community housing in Connecticut were supported at the national level by legislation called the Fair Housing Amendments of 1988 (Wolf 1990, p. 108), and at the local level by 'zoning override' legislation. The zoning override legislation was intended to reduce the delays and high costs associated with building group homes by mandating that group homes for six or fewer persons 'be treated no differently than single-family residences for zoning purposes' (Wolf 1990, p. 102). To address the barrier of the cost of building group homes, as well as the preference for choice from a range of different types of housing, the Department of Mental Health in Connecticut shifted the emphasis from only building group homes to making use of other existing community resources, including government-funded rental assistance for privately owned rental housing. Choosing privately owned rental housing is a growing trend in Australia as a result of funding for support to live independently under Australia's NDIS. But the NDIS is only available to a smaller group of eligible people (estimated at around 410,000 people in 2011). And only a smaller subset of that group — estimated to be between 154,000 and 193,000 — will be eligible for NDIS SDA capital funding for housing assistance. Unmet housing needs for that smaller subset group was estimated to be between 83,000 and 122,000 in 2013 (Bonyhady 2013). These figures do not include people with disability who will not become NDIS participants and who need housing.

In the Australian context, the federal, state and territory governments developed the 2010–2020 National Disability Strategy (Department of Social Services 2019) to fulfil the human rights of people with disability under the UNCRPD (2006). The Australian Government adopted the UNCRPD in 2008, including article 19, which provides that people with disability have an equal right 'to choose their place of residence and where and with whom they live' (United Nations 2006). However, Davy et al.'s (2019, p. 21) review of implementation of the 2010–2020 National Disability Strategy identified:

*Affordable and accessible housing in the community, including supported housing options, were ... a missing aspect of the NDIS and the Strategy.*

The 2010–2020 National Disability Strategy ended in 2020, and progress against the principles enunciated in the strategy is unclear. Davy et al. (2019) suggested that the effectiveness of the next National Disability Strategy, which will be finalised in 2021, would be improved by stronger measurable goals and concrete targets (p. 5). It is anticipated that Australian governments will respond to the issues identified by Davy et al. (2019) in Australia's next National Disability Strategy.

### ***5.2.2 Challenging the status quo***

Lack of engagement with the problem of insufficient housing, as well as the continuing shortfall in appropriate accommodation, has created and continued existing system and financial barriers to adults choosing and getting their own home (Wiesel et al. 2015, p. 2). Parents in the case studies had no choice but to challenge the status quo if they wanted a different housing pathway for their children. They connected with other families and, in large groups, met with politicians in NSW to present their predicament. The researcher holds a selection of grey literature, including submissions and proposals for new models of accommodation, that was provided to the NSW Government, the relevant agency and the disability minister between 2005 and 2006, when the NSW Government reviewed models of accommodation for people with disabilities. However, at the end of that review, the NSW Government's preferred solution was a 'greater focus' on supporting people with disabilities in the family home, with services complementing the unpaid assistance provided by families and the community (NSW Government 2006, p. 12). When the NSW Government was unresponsive to the needs of people with disability, family members and other caregivers for more assistance and more funding, parent advocates took action. They turned to their local communities and Australian voters to build community awareness, influence public opinion and attract political support for more assistance by holding public meetings and rallies. The three-dimensional theory of power described in the next section provides a model for exploring the organisational, community, relational and personal power that the parents in the three case studies created through their advocacy, organisation, collective action and political allies, as well as their determination and persistence.

### **5.2.3 Three-dimensional power**

The relationship between families and power holders within the arms of government explains one-, two- and three- dimensional views of power-over in a political context, as well as attempts by families to address housing needs through power-to, power-within and, with the assistance of others, power-with.

#### **5.2.3.1 One-dimensional view**

The one-dimensional view of power enunciated by Dahl (1961) focused on the process of power, namely, 'overt dominance and control over decision-making and action' (Tchida 2018, p. 22). He conceived power 'as intentional and active', measured by 'studying its exercise through decision-making and ascertaining the frequency of who wins and loses' (Lukes 2005, p. 5) on key issues. This view of power requires observable conflict between interests, even when it is not possible for these interests to be articulated, observed or known (Lukes 2005, p. 19).

#### **5.2.3.2 Two-dimensional view**

Bachrach and Baratz's (1970) two-dimensional view of power introduced a second face of power, which is exercised when someone 'devotes his energies to creating or reinforcing social and political values and institutional practices that limit the scope of the political process to public consideration of only those issues which are comparatively innocuous to A' (Bachrach & Baratz 1970, p. 7, cited in Lukes 2005, p. 20). The second face of power 'is expressed not only through decisions made in the political arena, but also through decisions about which potential issues are *allowed* into the political arena, and which are kept out, which they refer to as "non-decisions" ... (Lukes 2005, p. 22)' (Pringle 2017, pp. 14–5). Bachrach and Baratz (1970) contended that non-decision-making can be 'empirically studied by observing issues that are present in public discourse (either through protests and demonstrations, or simply in fora that are not politically "recognised"), but are absent from the political agenda' (Pringle 2017, p. 15).

The second face of power is more nuanced. Examples of non-decision-making include:

*a means by which demands for change in the existing allocations of benefits and privileges in the community can be suffocated before they are even voiced; or kept covert; or killed before they gain access to the relevant decision-making arena; or, failing all these things, maimed or destroyed in the decision-implementing stage of the policy process.* (Bachrach & Baratz 1970, p. 44, cited in Lukes 2005, pp. 22–3)

The two-dimensional view of power also presumes observable conflict, whether overt or covert (Lukes 2005). Bachrach and Baratz (1970) developed a useful typology of forms of control by A to secure B's compliance. Their typology included coercion, influence, authority, force and manipulation, although authority and manipulation may not involve conflict.

### **5.2.3.3 Three-dimensional view**

Lukes (2005) added a third dimension to power, namely, ideology or hegemony, which has the power 'to prevent people, to whatever degree, from having grievances by shaping their perceptions, cognitions and preferences in such a way that they accept their role in the existing order of things' (p. 11, citing Anderson 1976–7; Femia 1981; Tilly 1991). The ideologies of family, family care and where the responsibility for caring lies between family and the state may be examples of this. The separate values, philosophies and aspirations of adults and parents (Lewis, Millington & Marini 2015, p. 49) do not necessarily conflict with the ideology of family and family care. Instead, adults and parents seek empowerment to change the location of responsibility for caregiving, and to ensure the sharing of it.

Lukes (2005, p. 16) argued that the 'real interests' of people subjected to domination are 'empirically recognizable', even when they go unnoticed by those who possess them. According to Shapiro (2006), critics of Lukes claimed that his third face of power defied evaluation because 'it depended on unobservable interests' (p. 146). Shapiro disagreed with these critics and contended that Gaventa's (1980) study of the Appalachian mining community demonstrated that it is possible to measure this third face. Gaventa detected 'changes in [a mining] community over time, comparing practices in relevantly similar and dissimilar

mining communities and observing the effects of interventions on the miner's perceptions of their circumstances' (Shapiro 2006, p. 146).

#### **5.2.4 Power-within, power-to and power-with**

Gaventa's framework explained how the three dimensions of power function within institution–community relationships (Tchida 2018). He later adopted 'three alternative forms of power common within the community development literature' (Tchida 2018, p. 23): power-with, which refers to solidarity (Allen 1999) and 'the synergy which can emerge through partnerships and collaboration with others or through processes of collective action and alliance building' (Gaventa 2006, p. 24); power-to, or agency as the 'capacity to act; to exercise agency and to realise the potential of rights, citizenship or voice' (Gaventa 2006, p. 24); and power-within, which refers to 'the sense of self-identity, confidence and awareness that is a precondition for action' (Gaventa 2006, p. 24).

#### **5.2.5 Synthesis of power literature**

Tchida (2018) developed a synthesis of the power literature and a 'resulting theoretical framework' (p. 41) to operationalise and assess institution–community partnerships in universities. Tchida compared Follett's (1924, 2003) notion of power-over (namely, hierarchical power) with disempowering tendencies (Follett 1924, p. 189), whereby 'the institution exclusively holds authority, control, and legitimacy' (Tchida 2018, p. 21), and power-with (namely, relational power), which is 'jointly developed' (Follett 2003, p. 101) with citizens, community members and institutions as collaborators (Tchida 2018, p. 21). Tchida explained that power-with and power-to are achieved where 'institutional control is relinquished'. Bhattacharyya (1995) explained that this occurs when communities are 'able to define what the problems are, how they are caused and what needs to be done with them' (p. 62, cited in Tchida 2018, p. 37). Tchida's synthesis included power-within or self-efficacy. Kretzmann and McKnight (1993, cited in Tchida 2018, p. 38) explained that power-within is the capacity and assets of a community and its members to meet their own needs or solve issues. Tchida (2018, p. 18) used her framework (see Table 10) to operationalise and assess whether institution–community partnerships through collaboration offered a more egalitarian sharing of power compared with, in her study, a

university's traditional dominating approach to community engagement. In that traditional dominating approach, the university would exclusively hold authority, control and legitimacy as elements of power-over (Tchida 2018, p. 1). Conversely, within the collaborative approach characterised as power-with, authority, control and legitimacy must be shared by the university and community in partnership. Tchida's framework distinguished the traditional dominating approach of universities exercising control, authority and legitimacy as 'expert' (doing things to and for communities) from the empowering approach whereby power is shared with community members as 'equally valued collaborators' (Stout 2018, cited in Tchida 2018, p. 16) and experts in their own right.

In a similar way, in the field of disability, government, bureaucrats and medical professionals have traditionally done things to and for people with disability and their carers as arbiters of what is best for both or either group. Unlike the collaboration between universities and community partners in which universities instigate power-sharing, government agencies and politicians in NSW did not initiate power-sharing with disabled people or their representatives to achieve an agenda for housing reform. Pushing back against these top-down attitudes and behaviours, people with disability and their representatives rejected the 'being done to or for' approach (Ms Richards, research participant) of government, bureaucrats and medical professionals as purported experts, where control or choice, authority and legitimacy were not shared with adults or their representatives as experts.

This chapter draws from Tchida's (2018) framework in Table 10 (with one alteration, which is marked \*) to explain the relationship between different types of power in the three case studies. The alteration to Tchida's framework replaces universities (when they exercise *power-over*) with government/bureaucrats/medical professionals who purport to have knowledge and expertise when adults and families or other caregivers are themselves experts.

**Table 10: Resulting theoretical framework**

<b>Dimensions of power</b>	<b>Mechanisms</b>	<b><i>Power-over</i> manifestations</b>	<b><i>Power-with</i> manifestations</b>
1	<ul style="list-style-type: none"> <li>• Political, financial and organisational resources</li> <li>• Positionality</li> </ul>	<i>Overt dominance</i> over decision-making and action <ul style="list-style-type: none"> <li>• Professional-centred</li> <li>• Extensive resources</li> <li>• Hierarchical mechanisms for planning and action</li> <li>• Relationships among power holders</li> </ul>	<i>Power-with</i> or solidarity <ul style="list-style-type: none"> <li>• Relationship-driven</li> <li>• Co-learning</li> </ul>
2	<ul style="list-style-type: none"> <li>• Values, beliefs, rituals</li> <li>• Institutional procedures</li> </ul>	<i>Latent dominance</i> over the decision-making sphere <ul style="list-style-type: none"> <li>• Outside-in</li> <li>• Institution-determined agenda and timescape</li> <li>• Values, beliefs, rituals and procedures to maintain exclusivity</li> </ul>	<i>Power-to</i> or agency <ul style="list-style-type: none"> <li>• Internally focused</li> <li>• Relinquishing institutional control</li> <li>• Institutional shifts</li> </ul>
3	<ul style="list-style-type: none"> <li>• Social construction and symbolic meanings</li> <li>• Cultural response to long-term power dynamics</li> </ul>	<i>Hidden dominance</i> over cultural and symbolic meanings <ul style="list-style-type: none"> <li>• Deficiency-oriented</li> <li>• Paternalist thinking</li> <li>• [*Government/bureaucrats/medical professionals] as the apex of all knowledge and expertise</li> <li>• Unquestionability of science and its methods</li> </ul>	<i>Power-within</i> or self-efficacy <ul style="list-style-type: none"> <li>• Asset-base</li> <li>• Reflection and humility</li> </ul>

Applying her framework to assess power-with, Tchida (2018, p. 20) defined power-with as relationship-driven solidarity and co-learning. In this chapter, solidarity and co-learning required collaboration and partnerships. Collaboration and partnerships were evident between adults and parents; parents as representatives of the adults with other parents; parents acting as a network, group or other collective; and caregivers and government through politicians who were allies where three power elements (control, authority, legitimacy) were shared. Examples of this collaboration and partnership include acknowledging and enacting the wishes, needs and choice of adults to drive the design of person-centred homes, building chosen homes in chosen locations, and delivering those homes together. However, there was conflict, tension and incongruence between the objectives of the parents (which a few politicians

shared) and the objectives of bureaucrats or agency staff. Hence, there was no power-with between these respective actors.

Tchida (2018) selected power dynamics between university and community partners as a frame of reference. In this chapter, power dynamics between adults, parents and government, politicians and bureaucrats (instructing and funding service providers) is the frame of reference. While universities initiated power-sharing and co-learning, bureaucrats, agency staff and traditional service providers did not initiate power-sharing or co-learning in the case studies.

Tchida (2018) identified concepts for identifying causal relationships. In this study, causal relationships require more than collaboration and working partnerships. Relationships between adults, parents, government, politicians and bureaucrats must empower adults and their representatives to choose and achieve the adults' own home when governments, politicians and bureaucrats otherwise control and limit available options or offer no choice at all.

#### ***5.2.6 Entrepreneurial bricolage***

The determination of parents to control and choose their child's own home in their own community was conveyed through a pattern of behaviour and activities identified in the literature as entrepreneurial bricolage. Acting as bricoleurs, parents were driven by necessity and undertook strategies such as combining, in new ways, the resources they had at hand (Baker & Nelson 2005; Lévi-Strauss 1972) or could access to solve the housing need problem. By refusing to accept their lack of financial resources, the lack of institutional support from government (Desa 2012; Mair & Marti 2009) and the lack of alignment between the objectives of parents and the objectives of agencies as barriers, parents used or repurposed their limited resources to solve the need for housing for their adult children. Parents volunteered and joined or formed organisations to create a platform for their ideas to reach a larger audience. They used their advocacy in the community and organised or attended rallies and public meetings. They also secured powerful community support to engage politicians and their governments. The parent advocates in the case studies mobilised growing public awareness of the housing need, as well as public recognition of people with disability and caregivers as experts, to ensure that politicians were listening and



local service providers were engaged in helping more people with disabilities, including their children.

Many community resources and community assets are available for use in this manner. Examples of such resources and assets were identified by Kretzmann and McKnight (1993). The gifts and capacities of people with disability are assets within the community (Kretzmann & McKnight 1993, pp. 69–71). The power of local associations and community organisations are resources that can be developed and used when those associations are willing to take on new roles and responsibilities (Kretzmann & McKnight 1993, pp. 133–39). When local governments are willing and able, they can accumulate and develop a range of resources specifically to share with needy citizens (Kretzmann & McKnight 1993, p. 172). Community housing providers in Australia are another underused community resource that can deliver person-centred housing with shared decision-making when there is active collaboration and power is shared with the adult with a disability and, if applicable, their representative. The Waverley Community Living Program in Australia is an example of the use to which community resources can be put to meet the need for housing. Waverley Local Council developed the Waverley Community Living Program for people with disabilities to learn to live independently. The program has partnered with a community housing provider to supplement the council's housing assets to deliver the program for independent living skills in council-owned or community housing. This is an example where housing assets in the community are used to support people with disability to remain in their community and live in their own home.

## **5.3 RESEARCH METHODOLOGY**

### ***5.3.1 Units of analysis***

An exploratory comparison case study design was selected to focus on two units of analysis. The primary unit of analysis was the 'activity' to secure or create housing with high levels of paid support for adult family members. The secondary unit of analysis was the 'parent' acting alone or in a group to achieve their housing objectives for their children and other adults. In Case #1, the actor was an individual parent. In Cases #2 and #3, the actor was parents working together

in an organised group of families. The case was the 'activity' to attain the housing objective. The boundary of the case was denoted by the six elements of each activity system identified by Engeström's (2001) model: (i) the desired goal, as object; (ii) who desired the goal, as subject; (iii) who worked with the subject to achieve the desired goal, as a network and community of actors; (iv) the resources, strategies and other tools, methods or approaches used to achieve the desired goal, as tools; (v) the way work was shared or divided, as division of labour; and (vi) the rules, professional conduct, routines, norms and attitudes that supported or constrained what people did to achieve the desired goal, as rules (Martin 2008; Villeneuve 2011).

### **5.3.2 Procedure**

Data were collected using semi-structured interviews with seven parents. One parent was interviewed in Case #1, three parents were interviewed in Case #2 and three parents were interviewed in Case #3. In the family groups, the researcher asked the families to identify the research participants to be interviewed. The primary criterion for inclusion in this research was that the parents had achieved housing by taking action themselves. Each interview lasted more than one hour and was conducted at a location chosen by the research participant. Probing questions were used to gain a deeper understanding of the meaning, perspectives and experiences that related to their activities. Historical documents were reviewed when these were available and offered by the participants. Historical documents included a large selection of grey literature collected by the research participant in Case #1 over many years.

A retired politician was also interviewed for Case #2. In addition, a parent advocate/activist who was not a member of any of the three case studies but was, unexpectedly, known to each research participant was interviewed. All interviews were recorded and transcribed and then managed, along with the available historical documents, using NVivo qualitative data analysis software. Ethics approval for the research was given by UTS (HREC REF No. ETH17-1412) in 2017. Written consent to interview the research participants in Cases #2 and #3 was obtained from a senior representative of the legal entity they had formed to act collectively. The research participants in Cases #1, #2 and #3 gave

written consent to be identified, although one parent requested that her name, her daughter's name and their location not be identified.

### ***5.3.3 Activity theory for data analysis***

Activity theory was used to analyse the activity systems of the parents from their perspective and to analyse the data for cross-case comparison. Activity theory accommodates the analysis of multi-system activity and collective effort across separate systems. In this study, family activity navigated political systems, service systems, family systems and community groups to secure more resources or combine resources at hand to meet housing needs in different ways. There were different types of collective effort, including groups of families acting together to achieve shared housing goals; interaction between parents acting alone or in a group and public actors; and interaction between local communities and parents when they held public meetings in protest over the lack of government-funded services and housing. Areas of interest were the strategies that parents developed and used alone or together to find and work with allies who would enable the attainment of their housing objectives. The phenomena of interest were the extent to which there was collaboration, working together and power-sharing with those allies (politicians and parents acting alone or in a group).

Conversely, this study examined the timing and extent to which actors' activities (blocking, limiting or delaying the achievement of housing objectives) created new barriers after the commitment of government funding. Another limitation was adults or parents who were given some government funding but who, from that point in time, were not invited or assisted to exercise choice as an expert (e.g. choice of location, choice of land, choice of housing design, choice of fittings and choice of service provider). The interaction between family members and public actors who created or maintained barriers that limited, delayed or altered what parents could achieve in housing was analysed as tension, incongruence and contradiction within the activity system to attain the parents' housing objectives. Concepts regarding theories of power and bricolage were applied to identify the tools used, the network and community of allies, and the division of labour as power-sharing.

### **5.3.4 Chronology and timeline**

A chronology was created for cross-case comparison and comparison between the activities of two or more parents within the same case study. A timeline was prepared to highlight key events, pivotal moments and turning points, including delays, inaction, setbacks, failures and achievements. Each timeline demonstrated the determination, effort and persistence of parents over a significant time period. A parent in Case #3 assisted by auditing her diaries over the relevant period to tally the number of meetings her family group had held with politicians, bureaucrats and service providers before the Case #3 parents attained housing. A visual representation of the number of meetings is located in Figure 11 in Section 5.6.1.

## **5.4 CASE STUDIES**

In Systemic Advocacy Case #1, Ms Clark left full-time work in around 2004 to focus on systemic advocacy. She joined and formed organisations that gave her advocacy a broader reach. Ms Clark volunteered with the Association for Children with a Disability NSW (ACD NSW) for 10 years, including a period as president. She produced five editions of *Through the Maze* with ACD NSW (2014), which was a detailed directory of information, advice and services for people with disabilities, families and carers, including supported accommodation to help people with disability, families, other caregivers and service providers. In 2006, Ms Clark established Taskforce Independence with other parent advocates to develop a formal vision and strategies to achieve new models of accommodation. She joined the Carers NSW Board, which was established in the interests of carers who look after their spouse:

*Parent Clark, Case #1: I felt that no one was thinking about families like myself. I was approached by the President of Carers NSW to sit on the Board. I did that to try and broaden their scope a bit.*

Ms Clark's initiatives to improve models of supported accommodation are described in this chapter as 'power-within', 'power-to' and 'power-with'.

In Sutherland Shire Independent Living Case #2, the parents formed the Sutherland Shire Disability Accommodation Action Group (SSDAAG) to achieve housing with paid support in their community for their adult children. They

believed they would have more power if families and caregivers worked together in a larger group. In 2007, they incorporated a separate legal entity to develop shared housing objectives and strategies to achieve housing as power-within, power-to and power-with.

Between 2004 and 2006, the parents in RASAIID Cluster Case #3 organised as the Ryde Area Supported Accommodation for Intellectually Disabled Inc. (RASAIID) to secure housing with paid support for their adult children in the Ryde area. The parents in the RASAIID community were in their 50s, 60s, 70s and 80s. Their initial plan was to ensure that their daughters and sons were settled in to their own home before the parents died or were unable to care for them. RASAIID parents developed the model of accommodation they wanted for the small community of adults who would live as a community within a community.

## **5.5 FINDINGS**

A number of historical system, policy and resourcing barriers limited the adults' access to government-funded housing. There was no pathway or system for people with a disability who lived with their parents to join a waiting list to apply for housing with paid support. There was no pathway or system that provided adults or their caregivers with assurance that they would have access to government-funded housing in the future. There was no system or process for housing applicants to apply for housing and then track their progress on a waiting list in a way that was transparent. There was no pathway or process for people with disability who needed paid support to access government-funded mainstream housing (i.e. public housing or community housing). In addition, social housing was frequently inaccessible through either its physical configuration or its location, and existing government-funded houses were insufficient to meet housing needs at that time.

It was necessary for institutional support to offer and deliver one or more available solutions to address the housing needs. Government support for funding both new housing and paid support was assistance that the parents actively requested but that was not forthcoming. The commitment of the government agency responsible for the allocation of existing housing assets to observe a fair and equitable allocation was an alternative solution that was not

offered. NGOs funded by government or other means could have offered their accommodation, but assistance from the not-for-profit sector was not available or received. Families had learned that services were underfunded and that their children and family members who were caregivers were on their own when their children were young.

As the children became adults and the parents persisted in their request for assistance, new barriers to address housing needs were created by politicians, bureaucrats and agency staff through inaction. In addition, the failure of the NSW Government to commit to policy change for models of supported accommodation after five years of consultation with people with disability and their caregivers constrained bureaucrats, agency staff and politicians going forward. There was no agenda for policy change henceforth. More than 23 adults in Cases #2 and #3, or their parents, were left with no option and no choice.

A cluster of factors had to align for the parents to achieve their housing objectives for their children. The support of disability ministers and agency staff to provide both housing and paid support was necessary. Government funding had to be allocated through the government budgeting process, and politicians had to determine a system for identifying and responding to the needs of adults across the state of NSW. Parents developed strategies to secure the support of key politicians to mitigate and overcome the barriers described using public advocacy, political strategies and connecting with other parents to request assistance together. When assistance and housing were still not offered, the parents mobilised their vision of home with others, expanded their caregiving role to develop their power as advocate with a larger platform for their voice to be heard, and built community support for more government assistance through public meetings. With the active support of local members who were politicians, and the visible support of people in their local community, a few key politicians in opposition (not yet in government) made a commitment to fund more housing with paid support and implement disability reform when their political parties were voted into power. These politicians became powerful (effective) allies when they were a member of a new government and met their commitment.

With growing public pressure and commitment to policy reform in disability across all levels of government, individual funding for paid support and the then

forthcoming NDIS would create the rules or policies that would assist adults who were eligible for the NDIS to live independently with paid support or care for life.

## **5.6 POLITICIANS, PARENTS AND THEIR COMMUNITY**

This section describes the political and policy context in which politicians, agency staff or bureaucrats created, maintained or were unable to remove the barriers that limited access to government-funded housing. There were constraints on political actors supporting the parents, and it took years for the housing objectives of the parents in the three case studies to evolve into a cause or objective that the NSW Government would share with them.

### **5.6.1 Role of politicians**

Parents in NSW were forced to request government-funded housing from multiple politicians in successive NSW governments because state and territory governments were responsible for housing for people with a disability at that time. In their interviews, the research participants separately spoke about their participation in rallies in 2004 to protest the NSW Government's proposal to cut funding to post-school options their children attended after leaving school:

*Parent Clark, Case #1: We were fighting the state government to retain post-school options funding because the government wanted to cut it back from five to three days per week. I couldn't believe we were living in a state where we had to fight TO RETAIN funding.*

As their children got older, the parents asked politicians where their children would live when the parents died or could no longer care for them. In NSW, housing for people with disabilities was the responsibility of the disability minister. In each case study, the parents enlisted the support of their local member of parliament ('local member') to introduce them:

*Parent Rollo, Case #3: Even though our local member wasn't able to actually provide what we needed, he put us in touch with the premiers and disability ministers. And so that was the beginning of our political strategy.*

But there was a high turnover in disability ministers, and parents learned from meeting them that their understanding and attitudes towards requests for housing assistance varied. Some politicians were interested and empathetic, some rejected requests for assistance and some said they wanted to help but did nothing. Some of the politicians informed the parents that they were constrained by controls over the allocation of government funding through the government budgeting process:

*Parent X: We had seven disability ministers over that time. Seven. And of course, every time the government changed, the minister changed.*

The disability ministers and premiers approached by the parents are listed in Table 11.

**Table 11: Powerful NSW politicians**

Period of tenure	Name and title
1999–2002	The Hon. Faye Lo Po MP Minister for Disability Services under Premier Bob Carr
2002–2005	The Hon. Carmel Tebbutt MP Minister for Disability Services under Premier Bob Carr
2005–2007	The Hon. Della Bosca MP Minister for Disability Services under Premier Bob Carr
2006–2011	The Hon. Andrew Constance Shadow Minister for Disability Services 2006–2008, and Shadow Minister for Ageing and Disability Services 2008–2011
2007–2008	The Hon. Kristina Keneally MP Minister for Disability Services under Premier Iemma
2008–2009	The Hon. Paul Lynch MP Minister for Disability Services under Premier Rees
2009–2010	The Hon. Paul Lynch MP Minister for Disability Services under Premier Keneally
2010–2011	The Hon. Peter Primrose MP Minister for Disability Services under Premier Keneally
2011–2013	The Hon. Andrew Constance MP



	Minister for Disability Services under Premier O'Farrell and then Premier Baird
2013–2017	The Hon. John Ajaka MP Minister for Disability Services under Premier O'Farrell and then Premier Baird
2017–2019	The Hon. Ray Williams MP Minister for Disability Services under Premier Berejiklian
2 April 2019 — current	The Hon. Gareth Ward MP Current Minister for Families, Communities and Disability Services under Premier Berejiklian

A vertical dimension to the momentum for political and policy change in the field of disability had built up. In 2008, establishing a national disability insurance scheme was supported at the federal level of government. In 2009, the Australian Government engaged the Productivity Commission to study the cost and feasibility of replacing the existing disability service system with a new NDIS. In July 2011, the Productivity Commission recommended that the state- and territory-based disability service systems be replaced by the NDIS, which would be funded by the federal, state and territory governments. The NDIS and its legislative framework commenced on 1 July 2013 to replace a system described by the Productivity Commission as unfair, fragmented and underfunded. In 2011, Disability Minister Constance was the first NSW Government politician to provide part of the funding needed to create housing for adults in two of the three case studies (Cases #2 and #3) as pilot projects. Minister Constance instructed his agency to assist with the execution of both property developments to build housing for two large groups of adults. The Minister instructed the agency staff to evaluate each pilot in order to replicate the models for the benefit of more people with disability across NSW. During the development project and construction, the families encountered further delays, inaction, setbacks, challenges and resistance from agency staff and the agency that would be closed when the NDIS commenced. This was a period of transition for agency staff who had exclusively held authority and control (Tchida 2018, p. 21) over the model of housing for people with disability and the allocation process up to this point. They were required to work with the parents to deliver the models the parents wanted, but the agency and agency staff still considered themselves the experts. The

parents encountered new attitudinal barriers during construction. For reasons not known to the research participants, the evaluation of each pilot was not undertaken before the agency closed down. The efforts of the parents to mitigate the barriers that confronted them throughout their development project are described below.

### **5.6.2 Role of parent advocates**

The parent-led initiatives to achieve housing for their children did not follow a linear process and took many years. Over that time, the parents connected with other families and advocates to create and build power, and to use this power to negotiate with others to attain a home for their children. Community awareness grew when the activities and advocacy of the parents and carers were public. In 2005, the research participants attended a grassroots campaign for ‘the hidden army of unpaid family caregivers’, which culminated in the ‘Walk a Mile in My Shoes Day of Action’ on 13 September 2005. The walk was in solidarity with ‘hundreds of 80 and 90 year old parents still caring with little or no assistance and no hope of ... assistance ever coming’. Carers laid pairs of old shoes on the steps of Parliament House in each capital city in the ACT, South Australia, Victoria, Queensland and NSW on that day (Association of Genetic Support of Australasia 2005, pp. 14–7). The research participant who had worked in the disability sector for more than 30 years described the situation for adults with disability when their parents die:

*Parent Foord, Case #2: I knew what was happening to people when parents died. It was horrendous. They could be sent anywhere, with people they didn't know, away from their own community. That was one of the reasons our organisation started. And I'd seen large institutions, which was heartbreaking. That I think too impressed on me the sort of care that would happen to our son when I wasn't around. The seed was actually sown then.*

Pressure from parents, other caregivers and friends of people with disabilities was increasing across the state. In response, between 2005 and 2006, the government agency held stakeholder forums to review the current models of supported accommodation. The researcher reviewed multiple submissions from

different parents that have been lent to her. Discussions were ongoing, but there was no change:

*Parent Foord, Case #2: [The agency] held about five years of stakeholder forums where they would do butcher's paper and we would attend. And we would see the same things written on this butcher's paper, five years in a row. In the end there were no more stakeholder forums because they couldn't, wouldn't, provide what we wanted. We weren't saying what they wanted us to say. We were saying what we wanted for our children. They stopped having these forums.*

Policy-makers and bureaucrats decided not to put the issue of more funding for supported accommodation or new models of accommodation on the policy agenda for debate within the executive or legislative arms of the government. This was an exercise of latent dominance under the second dimension of power-over. It was also a pivotal moment when parents turned to their local communities for their support to pressure the government to provide more assistance, better services, more funding and more housing for more adults. The next section describes the efforts of the parent advocates to mitigate barriers and create a pathway into housing for their children with the support of the community as power-within, power-to and power-with.

### **5.6.3 Role of community support**

Community support was important because the power of the citizen vote would influence politicians (Ms Carter, research participant). Research participants separately spoke about the social movement for change and the organisation of public meetings to raise public awareness and inform voting citizens that the service system for people with disabilities who were genuinely unable to help themselves was 'dysfunctional, chaotic, chronically underfunded ... and broken' (Carter 2014):

*Parent Rollo, Case #3: In those protests, meetings, forums, we were making connections with the wider community, making our needs known. And a lot of people had no idea what we were going through.*

In these settings, people with disability, parents and other caregivers had the opportunity to build their networks with each other. At the system level, adults who needed assistance to achieve more support, better services and housing had agency through their parents, and it was these parents who had power-to influence the public discussion, shift the policy debate and exercise power-with in solidarity with each other. In 2007, parents of children with disabilities, including Ms Clark (Case #1), Ms Shields (Case #3) and Ms Carter (research participant), established the Carers Alliance as a registered political party. These advocates aimed 'to bring issues affecting family carers into the political agenda' (*Sydney Morning Herald* 2007) and offered Senate candidates in the forthcoming federal government election.

In 2010, the 'Mad as Hell' national grassroots campaign and political lobby group was founded by two mothers: journalist Sue O'Reilly and communications consultant Fiona Porter. These parent advocates aimed to attract the voting power of people with disabilities, their families and other carers (Bourne 2010). Key events included the Mad as Hell political rally in August 2010, where people with disabilities, parents and other carers had direct access to federal and state government politicians and campaigners. In October 2010, NSW Premier Kristina Keneally and the Hon. Barry O'Farrell (who would win government and become the Premier of NSW the following year) both attended and spoke at the 'Show Your Strength' disability funding rally at the Sydney Opera House.

The opportunity for policy change in disability, more disability funding and new disability laws arrived when a new federal government was voted into power on a platform for national policy change in December 2007, and the citizens of NSW voted for a new NSW Government in 2011. With the change of political party in power at both levels, the new Disability Minister in NSW, Minister Constance, delivered on his pre-election commitment to the parents in Cases #2 and #3 and provided some of the government funding to build new homes and individual funding for care for life. Notwithstanding this progress, the parents continued to encounter barriers at the system level, while the NSW agency and its staff created new challenges for parents. Barriers created or maintained by government systems and bureaucracy are described in the next section.

## 5.7 DISCUSSION

### 5.7.1 Power-over: barriers to housing

This section describes housing system barriers as power-over, and the views, attitudes and behaviours of bureaucrats or agency staff as new challenges to overcome.

#### 5.7.1.1 Housing system rules: as barrier and power-over

An adult daughter of a family in Case #2 had filled in the paperwork to achieve her own place in public or community housing. She lodged her applications with Community Housing, NSW Housing and Women's Housing when she turned 19. Ten years later, NSW Housing rang to offer her a fourth-floor unit in a huge public housing complex. Her parent described this experience:

*Parent Research Participant X: We went to have a look but we didn't even go up to the fourth floor. Because if she lived there, she'd be accosted even before she got to the fourth floor. So that was a 'no'.*

*I rang NSW Housing back and said 'I am ringing on my daughter's behalf. Are you aware of where that unit is?' They said 'No, it's a two-bedroom unit that's become available'. I said, 'I have tried to make you aware of my daughter's needs. I'm not asking for a palace somewhere. But do you have people with special needs flagged?' And the person said, 'What do you mean by that?' I said, 'Isn't there an alert?' And the person said 'We don't use alerts. You just go on the list'. And then they just said 'Well, she'll have to go back to the end of the list'.*

Public housing policy at the time required three offers of housing in different locations before an applicant was put back to the end of the waiting list. Agency staff had no authority to change housing policy or processes but, in this case, the administrator used her discretion to dispense with two further offers. The agency's decision not to offer two more options as vacancies arose in order to achieve a better housing outcome for this young woman was an exercise of overt dominance under the first dimension of power. Housing policy and the priority

waiting list allocation process for public housing were manifestations of power-over.

#### **5.7.1.2 Bureaucracy: as barrier and power-over**

The parents in Cases #2 and #3 frequently made progress towards their housing goals when local members of parliament were actively engaged in working with them. But disability bureaucrats appeared to delay or block progress. For example, a local member introduced a group of families to the Department of Health, which was willing to provide a section of hospital land so housing could be built for adults to live there. But the transaction did not proceed due to the intervention of disability bureaucrats:

*Parent Research Participant Y: For years we were working towards this first goal, which was for us to build on land at the hospital. Our local member thought we could just carve off a little corner from the site. We had talked to [the relevant disability agency] and they'd nodded their heads. And we had the Health Department lined up. But then there was a reshuffle [in the agency]. So, we found the people we had been talking to [at the agency] had somehow disappeared and we had to start again.*

People from the Health Department attended a meeting with the agency and were prepared to hand over this piece of land to the parents. However, at the meeting, one man from the agency said: 'If you ladies can secure this block of land from Health for Disability, you'll be doing Disability a great service'. And then he said 'However, you see, [the agency's] services can only go, [the agency's] funding can only go, to the most needy in the state. And we can't guarantee that all of yours would be considered the most needy in the state'. The second man from the agency said, 'We can't guarantee that any of them would be'. Then, the people from the Health Department said, 'You mean that we would carve off this piece of land but it wouldn't necessarily go to this group of people?' And he said: 'Well, they're the rules'.

This was a pivotal moment and the failure of significant efforts to secure land. In response, these parents turned to their local community to garner community support for their housing objectives. In November 2009, they organised a public

meeting in the local area to resist their official treatment and invited the local media and all politicians. Garnering support from the community was a manifestation of power-with, pushing back against first-dimensional power-over as overt dominance (Tchida 2018, p. 23). The local member and Andrew Constance, who was then the Shadow Minister for Disability Services in opposition, were the only politicians who attended the public meeting. Building support from citizens in the community, and collaboration with the local member and shadow minister, was a manifestation of power-with, pushing back against the first dimension of power-over as overt dominance (Tchida 2018, p. 23).

### **5.7.2 Power-to: define the problem and the solution**

The community development literature recognises the capacity of communities to define the problem and decide on appropriate action to address it as a manifestation of power-to. Case #1 provides an example of that parent's power-to define the problem of housing for adults and the focus of action to solve it. In 2006, Ms Clark attended a Roundtable Conference with other parent advocates, where a speaker at the Conference explained the model for supported accommodation in Norway:

*Parent Clark, Case #1: Australian governments would often rely on the fact that they would say 20% of people in Australia have a disability, and this is the amount of funding we've got. They were impliedly saying: 'How on earth can we ever give the support that's required when there are so many people with a disability? It's always going to be breadcrumbs'. Yet at that Roundtable Conference, Professor Jan Tøssebro from a Norwegian University drilled down on the statistics. He identified a much smaller number of people with disability who needed funding to live independently. The paper I wrote in 2007 picked up on those statistics. It's a much smaller number and I saw it as a light which we could focus on. This is what it's going to cost. This is manageable.*

*So, I came up with some proposals about where the government was going to get the money from. I took the Baby Bonus money for example and re-directed it to people with severe disabilities. That's*

*my pivotal paper. I sent it to every Premier, every Prime Minister and every Disability Minister — state and federal.*

This presentation gave Ms Clark another way to define the problem of supported accommodation and propose a way forward. Ms Clark prepared a fully costed proposal for application of the model in an Australian context. She explained how the federal, state and territory governments could jointly fund supported accommodation for all adults with high support needs before they turned 30 years of age. She shared her proposal with politicians in government and opposition. She helped some politicians understand the need and solution for housing differently. The number of meetings between Ms Clark and politicians to discuss her paper, the number of follow-up meetings with their colleagues, and the seniority of the politicians she was introduced to, were indications that politicians at the national level were engaged with her ideas and willing to collaborate with parents and caregivers to meet housing needs. In parallel, governments had been listening to the voice of people with disabilities, carers, advocates and like-minded service organisations who were demanding more assistance and better services.

### **5.7.3 Power-to, power-within and power-with: bricolage**

Parents with limited resources in the case studies engaged in entrepreneurial bricolage, repurposing accessible resources to develop and sustain four sources of power: organisational power, community power, relational power and personal power. The first three sources of power were developed by joining or forming organisations for public advocacy (organisational power), using citizen power to build support for housing in the local community (community power) and creating political processes for housing advocacy to collaborate with politicians, build their support for a vision of home and secure government funding from them (relational power). Personal power, the fourth source of power, comprised the determination of parents, their persistence and their refusal to give up in their efforts to attain their housing objectives. The collaboration of families with each other, communities of people and politicians was a manifestation of power-with. Using public advocacy and community resources in new ways were manifestations of power-to. Using resources that were at hand and pushing back



against new barriers created by bureaucrats were manifestations of power-within or self-efficacy, as described below.

## **ORGANISATIONAL POWER**

### **5.7.3.1 Getting organised: power-to**

This is a generation of parent caregivers who have the means to incorporate and register as not-for-profit entities and separately register as charities if desired. Technology and the institutional frameworks that regulate the incorporation of companies in Australia enable this. Some of the parents formally organised without incorporation, but Case #2 parents decided their activities would be more effective (powerful) through an incorporated legal entity. Case #3 parents incorporated to register as a charity to raise the money they needed. In both case studies, each incorporated entity represented the collective of its members.

### **5.7.3.2 Incorporating and mobilising families: power-to**

A community of Case #2 parents in the Sutherland Shire knew it was important to be well organised to work effectively as a collective. A small group of these parents met with the Hon. Danna Vale, who was a local member of the then federal government. Ms Vale gave the parents critical advice: it is necessary for families to incorporate when dealing with government:

*Parent A, Case #2: Danna Vale said to us, 'If you're going to do this you need to do it properly. You need to get yourself organised. Get a committee. Get incorporated. Get your own letterhead. Go for it. Do it properly'.*

*Parent B, Case #2: She said, 'You can't just have a parent group. It won't go anywhere'.*

*Parent C, Case #2: Danna Vale said, 'You need to be incorporated'. And this gave us a lot of political power, which we didn't realise at the time. Every politician we met from 2007 until 2011 kept saying 'Oh, you're incorporated'. 'Oh, you're incorporated'. They realised we weren't going away.*

SSDAAG was incorporated in 2006. Its members developed shared objectives and strategies together. The philosophy and values of SSDAAG were person-centred, family led, control and choice. SDAAG developed and formally adopted three goals that aligned with these values:

*Case #2: First, to obtain supported accommodation for adults with a disability in the Sutherland Shire. Second, to obtain accommodation that is a tiered layer of care. Third, to create a 'Register of Need' for supported accommodation.*

The Register of Need for supported accommodation was SSDAAG's first priority. They were aware of parents in their 70s and 80s who believed that a Register of Future Need for accommodation existed within the relevant government agency, that the agency was aware of the need for accommodation for each adult, and that the agency would soon allocate housing to their adult daughter or son. But Case #2 parents were aware that the agency's Register of Future Need for supported accommodation no longer existed or was no longer in use. The need for an accommodation register gave the parents something tangible to request politicians to fix. The parents acting as SSDAAG were successful, and a register was established by the agency by 2009.

#### **5.7.3.3 Choosing to live in a community within a community: power-to**

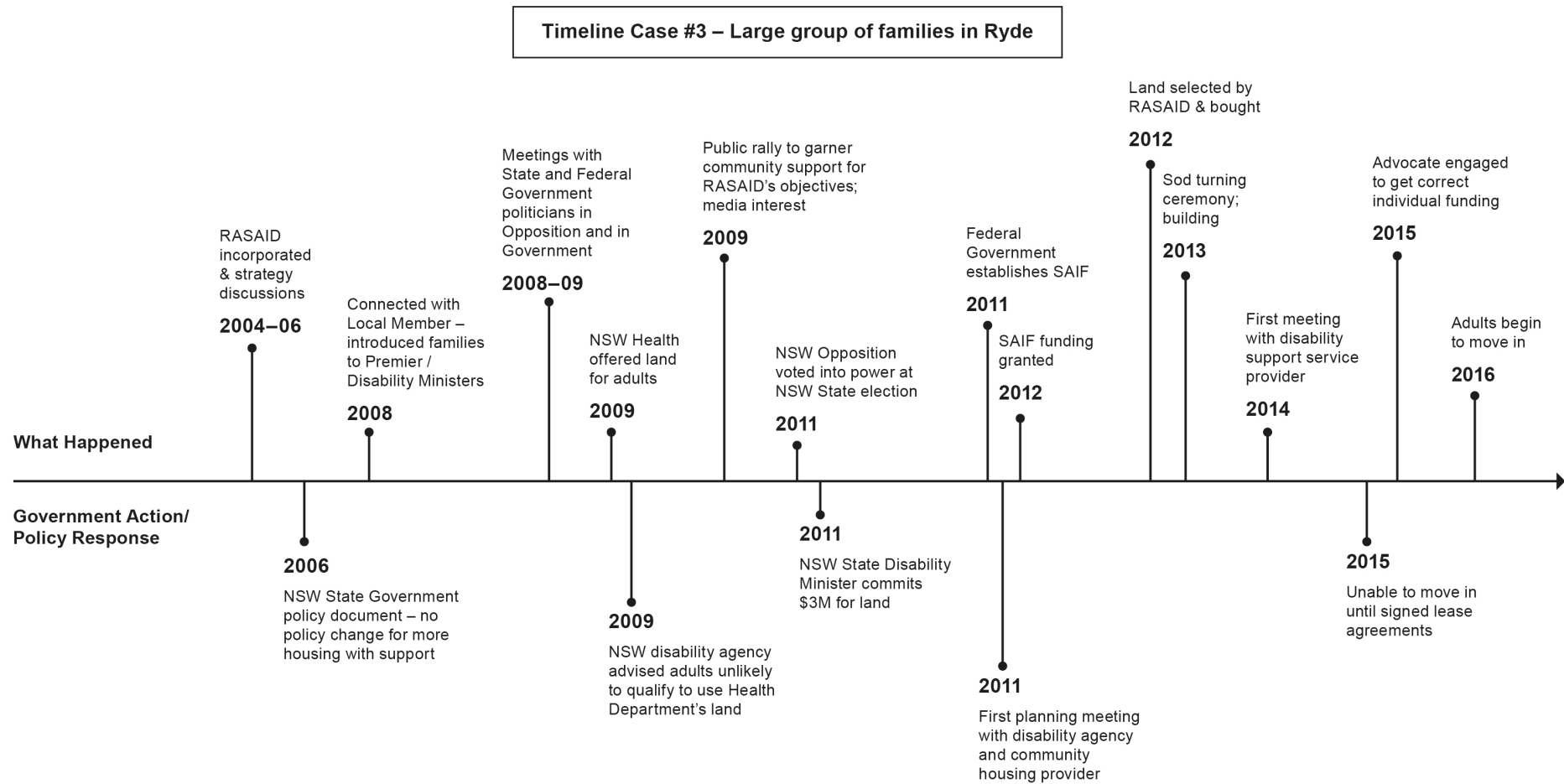
The Case #3 parents were socially connected before they formed RASAIID. From October 2004, they began meeting as RASAIID once a month. Ms Jenny Rollo was a founding member of RASAIID and had previously received an Order of Australia Medal for her services to disability. She learned the importance of the legal standing of an organisation for fundraising when she started the support group for people with her son's type of disability, their families and carers. Thus, RASAIID was incorporated to register as a charity to receive donations for the RASAIID community.

The philosophy, values and vision driving the action of RASAIID was individual choice, and that choice was for the adult daughters and sons to live in their own community within a community. The RASAIID community includes parents who established accommodation separately from the larger group, and one adult who lives in public housing. At the date of the interview of the research participants in

Case #3, there were 20 families in the RASAIID community, 'but there's only fifteen in the cluster. Fourteen families and fifteen people in the cluster'. (Parent Shields. Case #3).

Notwithstanding this success and financial assistance from the NSW Government, it took the Case #3 parents approximately 12 years between 2004 and 2016 to attain housing with support. Figure 8 illustrates this timeline.

Figure 8: Timeline Case #3



## **COMMUNITY POWER**

### **5.7.3.4 Meeting community need: power-within and power-to**

Power at the state level was difficult to achieve, and there were barriers for parents to overcome even when there was progress. Case #2 parents believed they would have more power with politicians and their government if they represented a larger group of people. Case #2 parents organised public meetings to establish the level of need for housing across the Sutherland Shire. At the public meetings, they invited other adults and carers to sign an application to be listed on a Register of Need. Ninety-three carers registered their attendance at the first public meeting in February 2007, and 95 registered their attendance at the second public meeting in March 2007.

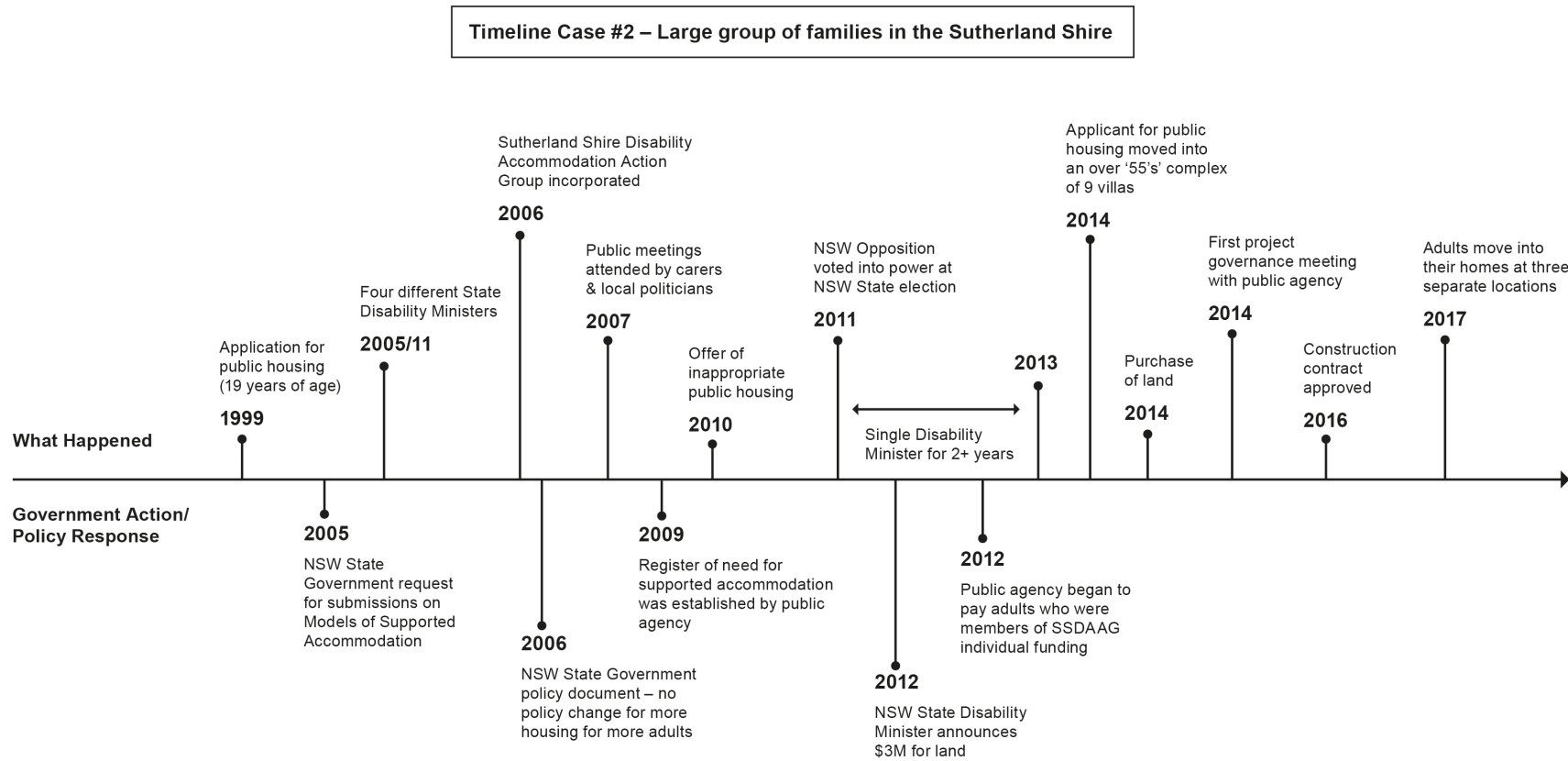
Case #2 parents also ran a postcard campaign. They distributed postcards by letterbox drop for people with disabilities and carers to fill in and return to SSDAAG if they were seeking a new home with support in the Sutherland Shire. SSDAAG delivered the postcards they received to the NSW Government:

*Parent Foord, Case #2: We did a postcard campaign, and each card stated our objectives. People would complete and return them. We've kept them all and this is just one bag. We used to carry these in on the train when we had a meeting with the Premier or the Minister, to tell them what we'd done ... Eventually we had 186 people on our Register who were saying they wanted supported accommodation.*

SSDAAG was successful. A Register of Need for accommodation was established by the disability agency by 2009 with the support of the NSW Government. SSDAAG created its own register so it had independent evidence of the need for housing in the Sutherland Shire. More than 140 people were recorded on the Register by December 2008. Using the community's need to push back against first-dimensional power-over where governments consider themselves the apex of all knowledge and expertise, solidarity between families and community members to establish the Register of Need was power-to (Tchida 2018, p. 23).

Notwithstanding this success, it took the Case #2 parents approximately 11 years between 2006 and 2017 to attain housing with support for their group of adults in the Sutherland Shire, as presented in the timeline in Figure 9. Ultimately, homes were constructed at three separate locations in the Sutherland Shire, and 18 adults under the SSDAAG umbrella moved into their own homes in 2017. The adult daughter who had applied for public housing in 1999 came under the SSDAAG umbrella and moved into her own villa in a complex of nine villas in 2014.

Figure 9: Timeline Case #2



## **RELATIONAL POWER**

### **5.7.3.5 Citizen empowerment: power-with**

Case #1 offers examples of activities to achieve system change through relational power. Ms Clark shared her paper on models of supported accommodation with politicians in opposition at the national level:

*Parent Clark, Case #1: I had a hard copy document. I learnt you had to have something to present. Politicians who read and met with me about my paper began to see the problem differently then.*

Ms Clark sent her paper on models of supported accommodation to Ms Maxine McKew, a Labor candidate in the forthcoming federal election who had recently resigned as an ABC (Australian Broadcasting Corporation) journalist. Ms McKew organised a meeting between Ms Clark and Senator Jan McLucas, who had been Shadow Minister for Ageing, Disability and Carers since 2004. Ms Clark's figures on the cost and how to fund disability housing had an effect on both Ms McKew and Ms McLucas, giving them another way of thinking about housing for people with disability and how the government could fund that housing. Ms McKew introduced Ms Clark to the Hon. Kevin Rudd before he became Prime Minister of Australia in 2007. Ms Clark was informed that Mr Rudd wanted to be an activist in disability and to reform federal, state and territory government relations in that area. Ms McLucas had been Federal Shadow Minister for Ageing, Disability and Carers since 2004, was a policy expert in the field and knew what was politically possible. Ms McKew<sup>18</sup> and Ms McLucas were politicians who paved the way for Ms Clark's paper and more politicians understanding her ideas in it.

After the Labor Party won the federal government election in 2007, Ms McKew introduced Ms Clark to the Hon. Bill Shorten, who was then Parliamentary Secretary for Disability and Children's Services. In April 2008, Prime Minister Rudd held the Australia 2020 Summit to shape a long-term strategy for Australia. Ms Clark applied to attend the Summit and present her concept for supported accommodation. She enclosed references from federal politicians from both

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<sup>18</sup> Ms McKew also publicly supported the RASAIID parents who lived in her electorate.



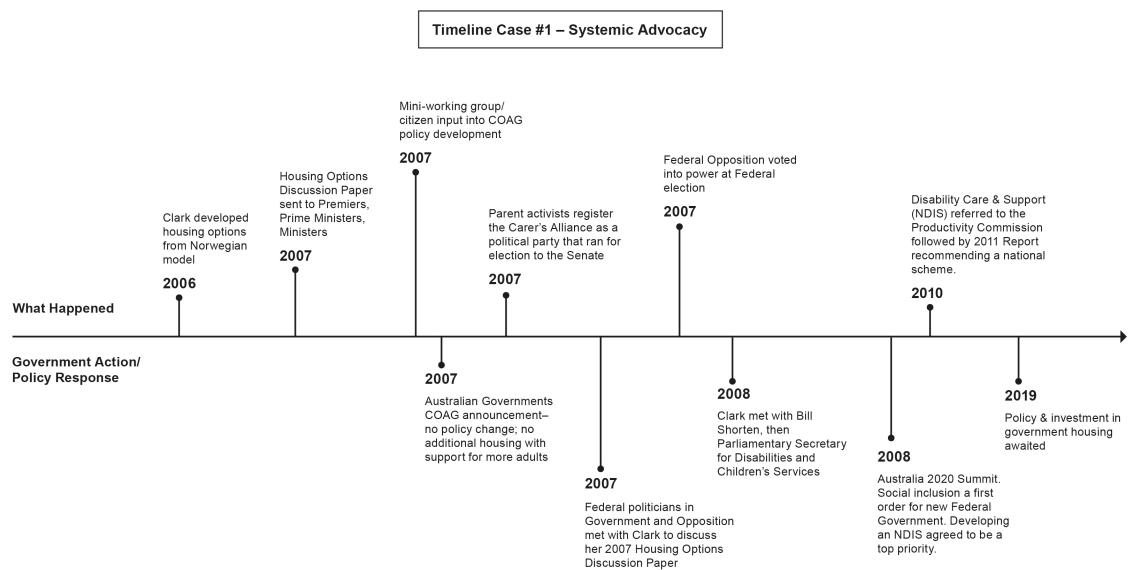
sides of politics with her application and was invited to attend. Ms Clark was one of a number of people approached by Mr Bruce Bonyhady AM, a disability reformer and economist, two days before the Summit. Mr Bonyhady asked Ms Clark to table his proposal for a national disability insurance scheme at the Summit. Ms Clark said, 'Send it through and I will do my best'.

At the Summit, Ms Clark was a member of the Strengthening Communities, Supporting Families and Social Inclusion Working Group chaired by both the Hon. Tanya Plibersek, Minister for Housing in the Commonwealth Government, and Reverend Tim Costello, a philanthropic leader. Ms Clark was one of two people who tabled the proposal for a national disability insurance scheme in that Working Group. In the Summit's wrap up meeting, Ms Plibersek selected the development of a national disability insurance scheme as the top priority for that Working Group. As a consequence, the NDIS was adopted as one of the top five initiatives the Rudd government would progress after the Summit. In 2009, Prime Minister Rudd announced that the Productivity Commission would examine the feasibility, cost and benefits of replacing the then state- and territory-based systems of disability services with a national scheme for long-term essential care and support for people with severe or profound disabilities. Ms McLucas became the Parliamentary Secretary for Disabilities and Carers in 2010 under Prime Minister Gillard, who succeeded Prime Minister Rudd. Mr Bill Shorten and Ms McLucas jointly announced the Disability and Care Report of the Productivity Commission when it was received in 2011. In relation to the Summit itself:

*Parent Clark, Case #1: There were so many good ideas because disability was just one of all the social problems in the world. Everyone was vying for their proposal to get on the table. Everyone was broken into groups. Everyone had to vote. Say there were 8 or 10 groups. So somehow, in amongst all that muddle, Tanya Plibersek just said, 'This has got to be there on the list'. It didn't appear on many people's final lists. Certainly, in my group it did. I wonder sometimes whether she remembers how important that was, what she did then. Because the proposal could easily have gotten lost.*

Murray, Caulier-Grice and Mulgan (2010) described the Australia 2020 Summit as ‘an innovative government-led exercise’ (p. 40) to involve the public in shaping what governments do. The Summit itself was a manifestation of power-with, a countervailing force to third-dimensional power-over, whereby governments consider themselves the apex of knowledge and expertise. Ms Clark’s determination and persistence as a systemic advocate was a manifestation of power-to and power-within. The timeline in Figure 10 presents the period of time over which Ms Clark’s systemic advocacy was undertaken.

**Figure 10: Timeline Case #1**



### 5.7.3.6 A few key allies: power-within and power-with

Over a period of more than 10 years, only one disability minister with authority to commit public funding actively engaged with the housing needs of adults, listened to parents and invited their new ideas for the design of creative new models of home with paid support for adults. That disability minister made a commitment to contribute government funding for the purchase of land, as well as individual funding for care (paid support) for life. His other activities were evidence that the interests of people with disabilities and their families were important to him. For example, the minister employed a parent advocate as his researcher, policy writer and adviser. In addition, five research participants separately acknowledged the importance of the minister’s contribution to opening the Nardy House accommodation for people with profound physical disabilities in his electorate in 2007 (<https://nardyhouse.org.au/history/>). Most

importantly, the minister always made himself available for face-to-face meetings with the parents in Cases #2 and #3. In their interaction, there was genuine collaboration, co-learning and idea sharing between this politician and parent advocates:

*Parent Danylenko, Case #2: The Minister knew exactly what was needed. He never faltered, that man; never faltered in supporting us.*

The relationship of collaboration and cooperation between families, a single disability minister and assistance from a handful of local members was a manifestation of power-with, pushing back against first-dimensional power-over in the form of overt dominance, second-dimensional power-over in the form of an institution-determined agenda, and third-dimensional power-over. The parents were the apex of knowledge and expertise when working with this particular minister (Tchida 2018).

## **PERSONAL POWER (DETERMINATION AND REFUSAL TO GIVE UP)**

### **5.7.4 Power-over: new barriers**

#### **5.7.4.1 Minister's commitment: resilience and power-within**

Determination, the refusal to give up and 'dogged perseverance' (Estelle Shields, research participant) were a critical source of power-within for families who persisted until they secured government funding, purchased land and constructed housing. It was a turning point when the disability minister committed A\$3 million for the purchase of land for the Case #3 cluster development in April 2011, almost seven years after RASAIID was formed. And it was a key event when the disability minister committed A\$3 million for the purchase of land for the Case #2 housing development in October 2012, six years after the parents formed SSDAAG:

*Parent Rollo, Case #3: The minister also gave us the promise of funding for care and that was huge; care for life.*

Political support for a national disability scheme was falling into place across Australia, with the Productivity Commission's final report publicly released in 2011. But there were more barriers for parents to overcome during

implementation. First, the cheque for the purchase of land was paid to two different community housing providers selected by the minister or his agency. Second, the amount was insufficient to both purchase land and build on it. Third, the minister had delegated the implementation of both housing developments to his agency and its bureaucrats. This meant that the agency had control over the use of the funding for construction of the new housing, and the community housing providers were accountable to the agency but not the parents.

### ***Land and building design***

Challenges included the failure of the agency and bureaucrats to share power to choose and control the selection of the block of land both by size and location in Case #2, and the building design, which shaped the social configuration of each home for the adults who would live there. In Case #2, a villa design for individual units was the only design that would fit on the shape of the small blocks of land the bureaucrats approved for purchase. The requirement for a communal room where the adults could have meals together was another battle. Each of these are examples of third-dimensional power-over.

Case #3 had other challenges. Initially, the agency would not permit RASAIID to select the land for purchase to build on. Then they would not permit RASAIID to buy the land until they had secured the additional funding for construction:

*Parent Shields, Case #3: We found several appropriate blocks of land. And every time we found a nice block of land [the disability agency] would just say, 'Well you can't tell us how you're going to build'. So, we weren't able to buy it.*

*Parent Rollo, Case #3: So that's when we started lobbying the federal government more strongly.*

The parents began talking to federal politicians. In 2011, the Australian Government established the Supported Accommodation Innovation Fund (SAIF) to commit A\$60 million over three years to fund the building of 'innovative, community-based accommodation places for people with disability' (Department of Social Services 2014). Politicians encouraged RASAIID to apply for SAIF funding to pay for the construction of the cluster because their model was innovative. But when RASAIID informed the NSW bureaucrats that they intended

to apply for SAIF funding, the bureaucrats said, 'No, that isn't for RASAIID'. RASAIID rejected the agency's opinion and lodged the SAIF application jointly with the community housing provider in November 2011.

The views and attitudes of the bureaucrats who attempted to create barriers to impede the progress made by parents were manifestations of power-over. Building support and obtaining assistance from politicians at the national level was a manifestation of power-with, pushing back against the first dimension of power-over as overt dominance (Tchida 2018, p.23). In April 2012, RASAIID and its housing provider were granted SAIF funding for construction as power-to.

### ***Model design***

The SSDAAG parents in Case #2 received funding to create an innovative independent living model as a pilot project. The NSW Disability Minister encouraged the SSDAAG parents to be creative, but the funding was paid to a community housing provider, and the bureaucrats who were responsible for the building work struggled to collaborate with the parents:

*Parent Danylenko, Case #2: We kept using the word 'creative' until one night, at a meeting with a bureaucrat, he said, 'What do you mean by creative?' And I said, 'Well, you know, maybe a villa complex with a parent, or a couple who would manage it, who'd be on site'. But it was so foreign to them. They wanted it the way it was always done and it has always worked. But in actual fact it hadn't worked. It wasn't working and they couldn't see it.*

The RASAIID parents in Case #3 received funding to create an innovative cluster design as a pilot project. The NSW disability minister wanted a pilot so that other people with a disability and their families could have the same model. But again, the funding was paid to a community housing provider chosen by the minister. The parents and the housing provider applied for and received a Commonwealth-sponsored grant from SAIF to build a cluster design. But agency staff kept saying to the parents that they did not approve of the cluster model because it would be built for 15 adults to live together and would rebuild institutions. Yet the cluster of houses had been designed to reflect what the adults wanted individually and

as a group who wanted to live together. The RASAIID parents defended their choice:

*Parent Rollo, Case #3: We're all very strong advocates for individual choice. And our individual choice was to have a community within the community.*

*Parent Shields, Case #3: Where each one would have their individual space but access to a wider community when they chose. And that's what we've got. So they can live in their own room. Or their own unit. And then they can just go out and find their friends when they want to.*

The solidarity between the adults and parents, co-learning how to design the home environment with each other, what they wanted as shared space, and sharing decisions were manifestations of power-with, a countervailing force to third-dimensional power-over, whereby governments considered themselves the apex of all knowledge and expertise (Tchida 2018, p. 23).

### ***Fit-out***

In Cases #2 and #3, parents were forceful advocates throughout the building process, including fit-out. In Case #2, parents had to continuously insist on items in the fit-out design to make the villas safe for the adults living there. These items included handheld showers, air conditioning, accessible power points, fly screens, non-slip shower floors, appropriate taps, a covered walkway, sensor lights, wardrobe doors that slide, window coverings that are easy to open, and blinds. Other challenges included the fact that project managers, architects and builders were designing and building for people with physical disabilities because they thought that was the type of disability that people had:

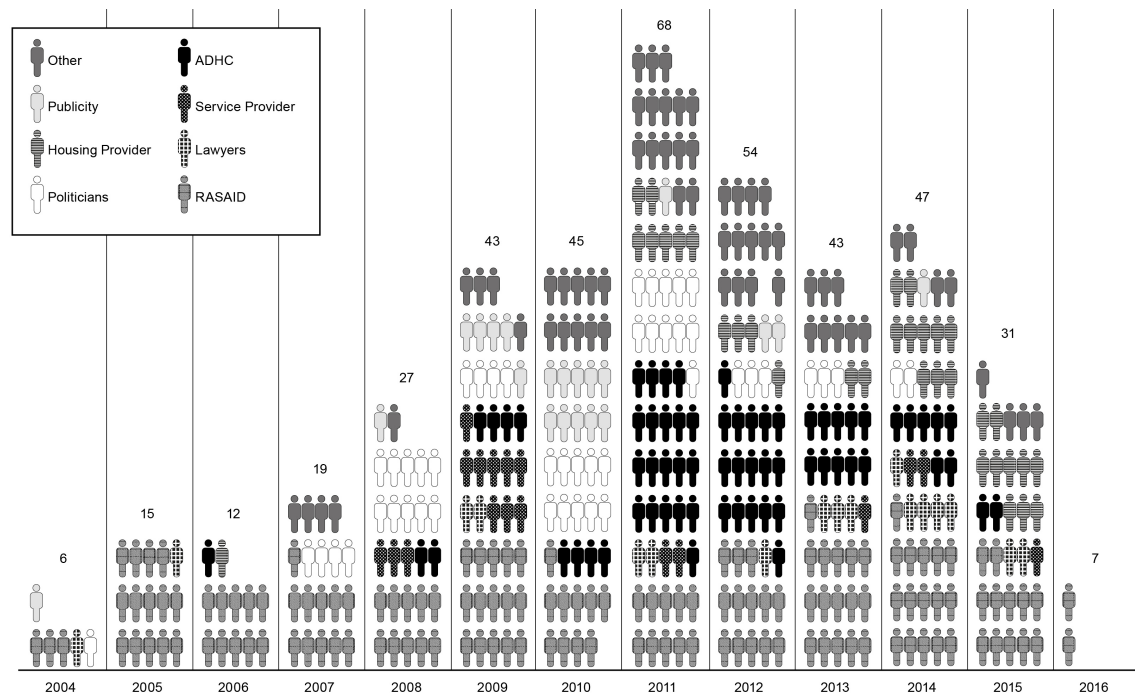
*Parent Research Participant: My daughter is non-verbal, and she wouldn't say what she wants but she would draw it. When the first architect asked us what we wanted, my daughter drew the bath. She loves to have a bath. I would often say that as a child she didn't have as many choices in life as her sister did. Every day she has a choice that she will have a bath or a shower. And a lot of people with autism love the sensation of water on their body. But the*

*project manager said we weren't going to have baths. So yes, we had to pick our battles and she now has a bath. But I still had to fight.*

**5.7.4.2 Determination and rejection of the status quo: power-within**

In Cases #2 and #3, it took many more years of further work and many meetings with all stakeholders before the housing was built. In Case #3, Figure 11 depicts more than 417 meetings for the RASAIID development between 2004 and 2016. This calculation is a parent's tally of most of the meetings in RASAIID's diaries. The tally does not include telephone meetings and the meetings at which RASAIID rejected 20 concept designs for their cluster.

**Figure 11: Spatial and temporal activity Case #3**



The purpose, number and timing of the meetings is informed by the Case #3 timeline earlier in this chapter. There were more meetings with politicians immediately before and after the election of the new federal government in 2007. There were meetings with politicians when RASAIID had publicity (local newspapers, radio, TV and a public rally) in 2009 and 2010. Most meetings occurred in 2011 and 2012, when RASAIID ‘received’ the first part of the funding they needed. In particular, the agency met regularly with RASAIID from 2011, and RASAIID met more frequently with the agency than the housing provider. Meetings with service providers were meetings with different service providers

until they chose the one they preferred. RASAIID engaged lawyers in 2011, but the adults did not move into the RASAIID cluster until May 2016. In 2017, the RASAIID adults received their NDIS funding for paid support when the NDIS commenced.

Table 12 summarises the strategies adopted in the three case studies, describing the bits and pieces families drew upon or created from their limited resources.

**Table 12: Strategies to develop power**

Case study	Action	Power manifestations
1, 2 & 3	Joining/forming/volunteering with disability organisations; developing advocacy skills, knowledge and contacts.	<i>Power-within</i> (self-knowledge) and <i>power-to</i> use limited non-financial resources as tools for action; develop more resources; mitigate barriers.
2 & 3	Connect and work with other families and local politicians for housing with support. Acting as bricoleurs, contacts were used to create power from the size of the need for housing and the size of the group of families.	<i>Power-with</i> or solidarity as tools for: relationship-driven collective action; interaction with community, business and politicians. <i>Empowerment</i> comes from other families, local politicians and co-learning.
2 & 3	Create organisations as separate entities and, if desired, incorporate. Acting as bricoleurs, organisations are used to raise funds. Incorporated organisations are used to represent a bloc of families.	<i>Power-to</i> create and use organisations as tools for action/interaction with community, business and government. Power pertains to the size of the entity's membership, unknown to government.
2 & 3	Establish governing body and apply family governance.	<i>Power-with</i> or solidarity between families as a basis for relationship-driven collective action with co-learning.
1, 2 & 3	Articulate and share vision, philosophies and values for advancing the adults' interests, including where and how they could live.	<i>Power-within</i> (self-knowledge) and <i>power-to</i> specify (to other actors) the problem, acceptable solutions and minimum requirements.



2 & 3	<p>Seek financial assistance from charities and local businesses or larger corporates. Persuade politicians to assist families by presenting data, establishing need and documenting a persuasive case.</p> <p>Media strategies and public meetings to rally support.</p>	<p><i>Power-to</i> define the problem, advocate preferred action to address it, and participate in political processes to give advocacy broader reach.</p> <p><i>Power-to</i> coordinate and manage important 'bits and pieces'.</p> <p><i>Power-with</i> cooperation with local politicians and media for mutual benefit. Empowerment comes from community and power-within.</p>
1, 2 & 3	<p>Connect, engage with and advocate to power-holders at each level of government.</p>	<p><i>Power-within</i> and <i>power-to</i> define the problem and action to address it.</p>
1, 2 & 3	<p>Collaborate and bargain with politicians who are allies willing to commit limited resources. Acting as bricoleurs, parents will make do with the resources offered by the state government. When the 'rules of the game' are clearer, they may need to seek resources from the Australian government.</p>	<p><i>Power-within</i> and <i>power-to</i> specify, collaborate, negotiate, bargain, compromise and persevere.</p> <p><i>Power-with</i> when governments commit resources including individual funding for 'care for life'.</p>
2 & 3	<p>Battle with bureaucrats in response to their purposeful delay during implementation (institutional support was weak or non-existent); and their refusal to relinquish or share control and decision-making authority.</p>	<p><i>Power-within</i> as bricoleurs who refuse to accept restrictions. Lack of opportunity or mechanism for adults and parents to share authority and expertise with public agencies or not-for-profit organisations is a manifestation of <i>power-over</i>.</p> <p>The failure of bureaucrats to relinquish institutional control is also <i>power-over</i>.</p>

## 5.8 CONCLUSION

It is conceivable that the few key politicians who were powerful allies — who committed funding and supported policy change — were opportunistic. Australian governments were aligning to introduce disability policy reform driven by public support for more government assistance to meet the needs of disabled

people. Assistance from the NSW disability minister, his premier and local members was enabled by the momentum for change that was building up across communities and at all levels of government. Temporal factors included Australia's ratification of UNCRPD (United Nations 2006), which acknowledges the basic human right of people with disabilities to choose where they live and who they live with. Individual funding and cash payment models giving some choice and control over social services were already used overseas, with better outcomes reported. In contrast, disability services provided by state and territory governments in Australia were underfunded, inadequate and broken. For the same reasons, there was no assistance from not-for-profit NGOs for the families in this chapter; at least not until the families secured housing and individual funding for care for life for their children.

Spatial factors included the change in political parties that had been in power at the national/Commonwealth and state/NSW level for more than 10 years. These new governments were not constrained by the way the previous incumbent governments had thought about old disability policy. Nor were they constrained by incumbent agency staff, although ADHC agency staff were still in place in NSW until the agency was closed down. Multiple government inquiries provided documentary evidence of the bureaucracy blocking change and leaving families and their children to fend for themselves. Underfunding that drove those practices at the state and territory levels was the responsibility of government.

New governments and new disability ministers had the opportunity to change government budgeting and resource allocation to achieve disability reform in line with voter expectations. It was a handful of politicians who came to power in the Australian Government who met with Ms Clark in Case #1 and learned from her ideas. And a handful of Australian Government politicians who paved the way for advocates, people with disability and other parents across the country to take action and achieve change. This included accepting the recommendation of Mr Bruce Bonyhady with Philanthropy Australia and Ms Helen Sykes with The James Macready-Bryan Foundation for a fully-funded universal national disability scheme in Australia. The mechanism for fully funding the NDIS could be a small addition to Australia's Medicare levy or private medical insurance rates. The former was adopted.

The bureaucracy or staff in the agency was a different matter. While many were friends and allies of the parents, it is unclear why some bureaucrats or agency staff in Case #3 were empowered to disregard the Australian Government's grant to build an innovative cluster. To disregard the approval process that preceded the involvement of those bureaucrats, and the failure to acknowledge the opportunity to collect an evidence base from each pilot, challenges 'community acceptance of government intentions and threatens citizen confidence in the processes agencies' follow (Institute of Public Administration 2012, p. v). For future housing projects, this thesis recommends adherence to a business case approach by governments and an alternative model that oversees agencies and the pathway to housing they offer.

## **6 SOCIAL ENTREPRENEURSHIP AND SOCIAL INNOVATION**

This chapter is the third paper prepared for publication. It presents two NGO case studies that demonstrate the collaborative effort and resource-sharing by families, friends and not-for-profit NGOs to enable new homes for adults with disabilities who choose to live with co-resident housemates. NGOs, families and friends worked closely together to produce two different types of co-resident models that were family designed, grassroots or bottom-up social innovations. Engeström's (2001) cultural–historical activity theory was used to analyse the process of creating and delivering these social innovations from the NGOs' perspective. Both case studies demonstrated the importance of families, friends and NGOs working across sectoral boundaries to pursue opportunities, combine resources and solve the housing need together (Shergold 2016).

### **6.1 INTRODUCTION**

Adults have a right to choose where and with whom they live in the community (United Nations 2006, article 19). But it is a right that is denied in practice by underfunded government systems. The paucity of appropriate public housing, other social housing and specialist disability housing like group homes<sup>19</sup> belie public support for adults having their own home in an Australian context. Parents find themselves locked into indefinite caregiver roles because adult children remain in the family home (Llewellyn et al. 2003). For many adults with support needs and families that care for them, the only way they will achieve their own home is to create that home for themselves.

Families and friends advocating for choice in housing for adults have designed solutions. They have developed new models for housing and support for adults, and collaborated with NGO service providers to implement these initiatives. In turn, the NGOs have learned new models to create more homes, learned new models of care, and learned to work with adults, families and friends to implement their ideas. These approaches have expanded housing and support options locally, empowered adults with choice, and supported families and friends in their chosen roles in each model.

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<sup>19</sup> Group homes funded under the NDIS today are referred to as specialist disability accommodation or SDA in Australia.

This chapter uses a case study approach to explain the activities of families, friends and NGOs (group of actors) to implement two different models of co-operative living with co-residents for two different purposes: first, a housemate model whereby the co-resident housemate facilitated adults living in their own home with subsidised rent ('rent supplementation') for both the adult and co-resident (Enabled Housing Model or Case #1); and second, a model of support with a co-resident housemate who provided live-in paid support under a family governed model with a host agency (Co-Resident Support Model or Case #2). Working together, the actors in each case study implemented new housing or support solutions that were not otherwise forthcoming through traditional government-funded housing systems or existing service models.

The research uses Engeström's (2001) cultural-historical activity theory to analyse the process of implementing these social innovations from the NGOs' perspective, describe the collaborative working relationships between the group of actors, and identify their respective inputs that contribute to further innovation while the phenomena of social entrepreneurship and social innovation evolve.

The following research questions are addressed in this chapter:

- RQ1: What models did families, friends or NGOs choose in order to create more housing and different types of housing with paid support for adults?
- RQ2: What were the elements and characteristics of each model?
- RQ3: What were the contributions or inputs to each model?
- RQ4: What interaction or collaboration occurred between NGOs, families and friends to implement these models, including new ways of working and learning together, sharing power and expanding resources?

A review of the literature explaining the conceptual framework for use of the terms 'entrepreneurship and social entrepreneurship', 'enterprise and social enterprise', and 'innovations and social innovations' emerging from the alliance between families, friends and NGOs is outlined below. The case studies are then described. Next, the research methodology and the use of activity theory as an analytic framework are explained, followed by a brief discussion regarding key

observations. Finally, the identified features of social innovation are presented in the findings section, followed by the conclusion.

## **6.2 LITERATURE REVIEW**

This chapter uses the literature of entrepreneurship and social entrepreneurship to study the 'family led' activities, decisions and transactions entered into by NGOs, in collaboration and partnership with families and friends of the adults, to establish innovative living arrangements for adults who need housing. Joseph A. Schumpeter (1934) was a seminal writer in the field of entrepreneurship (Swedberg 2000). His early writing was the starting point for modern-day literature presenting entrepreneurship as active social economic behaviour that is creative or innovative. Schumpeter's theory argued that the actions of a forceful entrepreneur are at the centre of 'change in economic life' (Swedberg 1976, p. xi). Schumpeter's theory of action complemented studies of the economy as something separate to social activity (Swedberg 2000). Recent literature and research built upon the early work of Schumpeter and other theorists to contribute to the study and evaluation of social entrepreneurship and social innovation through the initiatives of citizens tackling social issues important to them. In discussing this field, the researcher recognises that entrepreneurship and social entrepreneurship are overlapping concepts that are not mutually exclusive.

The development of key ideas in this expanding area recognises the social entrepreneur as carrying out new combinations of already existing materials and forces to address social need in new ways. For example, the modern-day social entrepreneur can quickly combine, adapt and use a mix of business, charity and social movement models (Nicholls 2006, p. 2). This is enabled by state-governed regulatory systems, the internet and other technology, enabling the quick incorporation of different types of entities and faster connection of people seeking change together. The distinctions between the concepts of entrepreneurship v. social entrepreneurship, enterprise v. social enterprise, and innovation v. social innovation from the literature are briefly outlined in this section to illuminate these developments.

### **6.2.1 Entrepreneurship v. social entrepreneurship**

Schumpeter (1934) defined entrepreneurship as making innovations or new combinations of existing labour and materials (Swedberg 2000, p. 15) as distinct from predetermined or habitual combinations in the normal flow of economic processes. French economist Jean-Baptiste Say identified that entrepreneurs create economic value (Dees 1998). Low and Macmillan (1988, p. 141) acknowledged that entrepreneurship is a multifaceted phenomenon but writers had failed to agree upon a common definition. Low and Macmillan argued that different definitions 'hampered research progress' (p. 141) and, to illustrate their point, they cited Stevenson, Roberts and Grousbeck's (1985) suggestion that entrepreneurship is driven by the perception of opportunity (to acquire resources) (p. 140) and Gartner's (1985) definition of entrepreneurship as the creation of new organisations (pp. 140–1). Low and Macmillan proposed that entrepreneurship is the 'creation of new enterprise' in order to establish a common definition (p. 141). Their definition was a synthesis of Schumpeter's (1934) innovations perspective, the economic actor perspective that requires accepting significant economic risk (Cantillon cited by Jarillo & Stevenson 1990; Blaug 2000) and the emerging organisation perspective (Katz & Gartner 1988).

Like entrepreneurship, the concept of social entrepreneurship is a composite or 'cluster' of dimensions (Choi & Majumdar 2014), including the creation of new social organisation or new social enterprise that creates social value (Choi & Majumdar 2014; Mair & Marti 2006; Seelos & Mair 2005), the role of social entrepreneur as change agent, and the presence of social innovation in social and economic life. Entrepreneurs who pursue resources and other opportunities to provide housing for adults outside existing housing and disability service systems is social entrepreneurship. It is not a necessary requirement that more housing options for more adults are achieved, or that established housing and service systems support or replicate these changes. But these are outcomes that families and NGOs may want. The two case studies in this chapter present examples of the activities, decisions and transactions of families, friends and NGOs who collaborated and worked together to combine and organise a mix of different resources and other inputs to assist adults with disability to live in their own home. Each case study presents examples of entrepreneurship (pursuing

opportunities and resources held by another, and creating new social enterprises together) and social entrepreneurship (organising and combining social resources to enable new homes, while seeking to replicate them for more adults).

The concepts of social enterprise and social innovation are described later in this section. Social value and social entrepreneur are described next.

#### **6.2.1.1 Social value**

Young (2006, pp. 57–8) emphasised that social value is subjective, negotiated between stakeholders and contingent. Its elements are not easily aggregated for measure by a single metric, and ideas of ‘justice, self-determination, and respect’ are inherent to the generation of social value. Notwithstanding these contested features, it is accepted that social value is created when reasonable social issues or problems are addressed (Alvord, Brown & Letts 2004; Light 2006; Young 2006), social needs are met (Mair & Marti 2006; Seelos & Mair 2005) or social change is accomplished (Choi & Majumdar 2014, p. 364 citing Dees 1998). Martin and Osberg (2007) required large-scale social change for social entrepreneurship to be present. The researcher disagrees with this view because it favours scalable innovation over grassroots social innovation, which addresses social need but on a smaller scale. In the field of housing, the social value of creating the adult’s own home will not reflect a system-level measure like reducing the public housing waiting list or reducing homelessness. Instead, value reflects the disabled adult’s experience and whether, as Young (2006, p. 57) described, they feel ‘empowered or disempowered’. The value of the adult’s own home will also depend on ‘how it is delivered as well as on objective outcomes’ (Young 2006, p. 57). In disability, the human rights framework (UNCRPD) and people with disability (Cook & Miller 2012) agree that ‘how’ housing is delivered requires the person to choose and control where they live and who they live with. They want to live in their own home where they have autonomy (Every Australian Counts 2015).



### 6.2.1.2 Social entrepreneur

The presence of a social entrepreneur as ‘hero’ is another dimension of social entrepreneurship in the literature. Dees (1998, pp. 3–4) offered an idealised definition of social entrepreneurship, describing social entrepreneurs as change agents who exemplify the characteristics listed in Table 13.

**Table 13: Defining social entrepreneurship (Dees 1998)**

- |   |
|---|
| <ul style="list-style-type: none"> <li>• Adopting a mission to create and sustain social value (not just private value).</li> <li>• Recognising and relentlessly pursuing new opportunities to serve that mission.</li> <li>• Engaging in a process of continuous innovation, adaptation and learning.</li> <li>• Acting boldly without being limited by resources currently in hand.</li> <li>• Exhibiting heightened accountability to the constituencies served and for the outcomes created.</li> </ul> |
|---|

Dees (1998) explained that the above characteristics combine ‘an emphasis on discipline and accountability with the notions of value creation taken from Say, innovation and change agents from Schumpeter, pursuit of opportunity from Drucker, and resourcefulness from Stevenson’ (p. 3).

The above characteristics identify the social entrepreneur as an individual or group of actors who pursue resources or other opportunities to create social value through better social outcomes for others. To that end, these characteristics are identified in both case studies. The families, friends and NGOs involved in each model were therefore social entrepreneurs who enabled the adults to leave the family home and live independently. The NGOs, families and friends developed processes separately and together, adapting the models to reflect agreed roles and responsibilities, and using the skills and resources they respectively brought to each social enterprise, namely, the Enabled Housing Model in Case #1 and the Co-resident Support Model in Case #2. Families, friends and NGOs entered each new social enterprise boldly.

In some situations, depending on the number and variety of enterprises working to achieve shared outcomes together, an entrepreneurial network (including partners across a network) may exist. Leadbeater’s (2006) study of entrepreneurial networks is described next.

### **6.2.1.3 Entrepreneurial networks**

Several authors have offered an alternative view from the 'hero' entrepreneur approach. Leadbeater (2006) described the city of Curitiba in Brazil as entrepreneurial because it creates impactful social value through a network of collaborators and partners led by the city's council. He concluded that the network of actors increased the effect of 'the range of resources that can be brought to bear on an issue, and multiplied the number of experiments and innovations, allowing solutions to be tailored to particular circumstances' (Leadbeater 2006, p. 240). Importantly, the council's network mobilised resources in households and civil society in addition to the private sector (Leadbeater 2006, p. 240). Mulgan (2006) located social entrepreneurship within a broader movement to expand the influence of organised activity by people, organisations and groups based on values, consent and mutual commitment. Nicholls and Cho (2006) defined social entrepreneurship as 'a dynamically evolving phenomenon that engages a broad range of stakeholders and is articulated across different organisational approaches' (p. 99). They contended a similar view — namely, that social entrepreneurship is an umbrella term for an international phenomenon of organised activities for social purposes at the intersection of civil society, market and state.

### **6.2.1.4 Enterprise v. social enterprise**

Schumpeter's (1934) focus was the activity of a person or organisation as entrepreneur. But his writings did not restrict enterprise as activity to a business venture or to an entity trading for profit (Swedberg 2000, pp. 15–7). In a similar way, social enterprise denotes continuous activity (Peredo & McLean 2006) and new initiatives launched by a person, organisation or group. Like entrepreneurship and social entrepreneurship, social enterprise has been defined as a composite or 'cluster' of dimensions. The EMES<sup>20</sup> European Research Network's study of social enterprises presented a list of nine dimensions and characteristics of a social enterprise (see Table 14). But not all

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<sup>20</sup> EMES was formed as a network of European academics with European Union funding. It was named after its first research program on 'the emergence of social enterprises in Europe', although the research network studies the third sector more broadly (Murdock 2010).

of these economic and social characteristics are required, and some will not be present (Defourny 2014).

**Table 14: EMES social enterprise indicators**

<b>Economic and entrepreneurial dimensions</b>	<b>Social dimensions or characteristics</b>
<ul style="list-style-type: none"> <li>• A continuous activity producing goods and/or selling services.</li> <li>• A high degree of autonomy.</li> <li>• A significant level of economic risk.</li> <li>• A minimum amount of paid work.</li> </ul>	<ul style="list-style-type: none"> <li>• An explicit aim to benefit the community.</li> <li>• An initiative launched by a group of citizens.</li> <li>• Decision-making power not based on capital ownership.</li> <li>• A participatory nature that involves various parties affected by the activity.</li> <li>• Limited profit distribution.</li> </ul>

The recognition that not all of the above characteristics are required is inconsistent with literature that uses the term ‘social enterprise’ to only describe legal entities that are incorporated to operate trading activities in a market producing goods or selling services for a social purpose, or using their ‘revenue and/or business model to further a community or public purpose’ (Justice Connect 2017, p. 5). However, to require a trading enterprise for a social, public or community benefit is a narrow view that overlooks multiple different versions and combinations of activities that comprise social enterprises across society (Steyaert & Hjorth 2006). This trading perspective excludes types of social enterprise with characteristics described by EMES (Table 14) that are initiated in resource-constrained communities but are not in trade or commerce for a social purpose. Indeed, a requirement for incorporation (which can be necessary to produce goods or sell services) may be beyond the reach of some communities. The preferred view is that a social enterprise is any initiative *with continuous activity* to create a community or other public benefit. A public benefit can include addressing a social problem or meeting a social need such as housing for people with disabilities. In particular, an alternative provider of housing for such people is a social enterprise whether or not it, she, he or they are incorporated, and whether or not they are a trading enterprise, although *continuous activity* for that social purpose (i.e. to address the housing need) is necessary. Regardless of

the adopted definition, social innovation has a broader meaning (The Young Foundation 2012, p. 7) that is discussed below.

### **6.2.2 Innovation v. social innovation**

Social innovation is central to the concept of social entrepreneurship in the same way that innovation is central to the concept of entrepreneurship as a broader concept. However, it is helpful to distinguish between the terms ‘innovation’ and ‘social innovation’ because they have different meanings.

#### **6.2.2.1 Types of innovation**

Schumpeter’s five types of innovative entrepreneurial behaviour that influence the literature and research on entrepreneurship and innovation are summarised by Swedberg (2000, pp. 15–6) as:

*(1) the introduction of a new good; (2) the introduction of a new method of production; (3) the opening of a new market; (4) the conquest of a new source of supply of raw material; and (5) the creation of a new organisation of an industry.*

Types of innovation have been developed and expanded further. For example, the Organisation for Economic Co-operation and Development’s (2015) Oslo Manual offered a broader list of four types of innovation: (i) product innovation; (ii) process innovation; (iii) marketing innovation; and (iv) organisational innovation. The more recent OECD/Eurostat (2018) Oslo Manual compared the types of innovation described in previous Oslo Manual editions with a more granular explanation of innovation. Further, Cuerva, Triguero-Canoz and Córcoles (2014) contributed ideas, structures, behaviours and practices as additional types. The next section introduces a significant research program that defined social innovation in Europe.

#### **6.2.2.2 Types of social innovation**

TEPSIE was a collaborative research project funded by the European Union between 2012 and 2015. TEPSIE developed a working definition of social innovation to achieve consistency and coherence in its research programs. TEPSIE (2014) defined social innovation as:

*new approaches to addressing social needs. They are social in their means and in their ends. They engage and mobilise the beneficiaries and help to transform social relations by improving beneficiaries' access to power and resources. (p. 9)*

TEPSIE's definition was developed from a comprehensive literature review (The Young Foundation 2012) and its large-scale research programs, so it is arguably 'the most empirically grounded definition' (McNeill 2017). TEPSIE's definition of social innovations confirms that the way such innovations are developed or used (the means) is just as important as the innovations or social outcomes from it (the solution or ends). Murray, Caulier-Grice and Mulgan (2010, p. 30) explained the importance of requiring both elements together:

*the way an innovation is developed is just as important as the innovation itself. The two are linked: the process will have an impact on the kind of innovation developed. In most cases the success of innovation will rest on the participation and involvement of a wide variety of interests — the users and beneficiaries of the innovation as well as the producers and suppliers.*

TEPSIE (2014) identified five types of social innovations (see Table 15), observing that some 'social innovations might cut across more than one type' (p. 10). This study presents multiple examples of each type of social innovation identified by TEPSIE. New services or products included new homes that did not previously exist. New practices were required for both models presented in this chapter (e.g. pooling the resources of families, friends and NGOs to expand their effect). New processes included the financial assessment of applicants to determine their eligibility for rent supplementation in the Enabled Housing Model, and performance reviews of co-residents providing paid support as a role shared by the NGO and parents in the Co-resident Support Model. New rules and regulations included rules developed specifically for each model, such as the change to ACT public housing policy to enable the co-resident carer to live rent-free in public housing in the ACT. New organisational forms included collaborative governance to deliver new models, and the alliance between families, friends and NGOs to deliver services together.

**Table 15: Five types of social innovations (TEPSIE 2014, p. 10)**

<b>New services and products</b>	For example, new interventions or programs to meet social needs
<b>New practices</b>	For example, new services that require new professional roles or relationships
<b>New processes</b>	For example, co-production of new services
<b>New rules and regulations</b>	For example, the creation of new laws or new entitlements <sup>21</sup>
<b>New organisational forms</b>	For example, hybrid organisational forms such as social enterprises

There is no social enterprise definition in TEPSIE's (2014) guide titled 'Doing Social Innovation'. Instead, TEPSIE provided an example of social enterprise and distinguished charities, community and voluntary sector organisations as different (TEPSIE 2014, p. 15). TEPSIE communicated its meaning of social enterprise by including an example of a legal corporation, which is the social equivalent of a commercial business trading for profit. TEPSIE chose Belu Water, a UK drinks company that sells ethically sourced bottled water and donates 100% of its profits to WaterAid. WaterAid is an international not-for-profit and charity, which Belu Water is not. In Australia, social enterprises like the Big Issue and SILC are also registered not-for-profits and registered charities that sell a service or product. SILC provides low-cost NDIS SIL services, which fund person-to-person assistance for adults with a disability. As charities, the Big Issue and SILC can accept donations that are tax-deductible for the donor (<https://www.thebigissue.org.au/support-the-big-issue/donate/>). SILC is a hybrid model as a registered not-for-profit, registered charity and registered NDIS service provider in order to have standing and eligibility for all available resources for its social purposes. In addition, the governing body of SILC comprises volunteers drawn from a community of parents of children with autism. SILC is therefore a social enterprise that is a charity, community and voluntary sector hybrid organisation.

<sup>21</sup> TEPSIE included the example of personal budgets in this category, which is a UK model for individual funding of a range of human services, including disability support. This was a transformational change enabled by government funding policy and other rules. NDIS individual funding is also supported by new policy and rules.

In an earlier paper, the Young Foundation (2012) expressly defined social enterprises as the social equivalent of a commercial business trading for profit:

*Social enterprises are businesses with primarily social objectives whose surpluses are principally reinvested for that purpose.* (p. 7)

However, in the same paper, the Young Foundation (2012, p. 7) acknowledged that the definition of social enterprises is debated because a social enterprise can take various legal forms in different countries. The concept of social innovation is broader but can overlap with either or both social enterprises and social entrepreneurship (The Young Foundation 2012, p. 7). As stated earlier, this researcher does not agree with the exclusion of *non-trading* social purpose enterprises from the definition, whether incorporated or unincorporated, provided they are continuously active in seeking or achieving social benefit or social change. It is therefore the researcher's view that the unincorporated joint venture in Case #1 and the host agency model that enables the co-resident support in Case #2 are social enterprises. This is consistent with Schumpeter's approach to the definition of entrepreneur, which did not require the entrepreneur's activities to be tied to an entity or a business, whether a commercial or social business.

Table 16 summarises the literature and highlights the differences between social enterprise, social entrepreneurship and social innovations outlined in this section.

**Table 16: Definitions of social enterprise, social entrepreneurship and social innovations**

<b>Social enterprise</b>	Social enterprise is a continuous activity or new initiative of an organisation, individual person, group or other collective to achieve a social goal. Social goals include meeting a social need. Social need includes a need for housing, support or care.
<b>Social entrepreneurship</b>	Social entrepreneurship is a dynamically evolving phenomenon that engages a broad range of stakeholders in the pursuit of solutions using new approaches, social innovation and social value creation (Nicholls & Cho 2006). Social entrepreneurship includes not seeing or accepting restrictions that may stop activities to achieve social goals (Dees 1998).
<b>Social innovations</b>	Social innovations are new approaches to meeting social needs by using social means that engage and mobilise beneficiaries, transform social relations and improve beneficiaries' access to power and resources (TEPSIE 2014).

### 6.3 CASE STUDIES

Purposive and convenience sampling were used to select the two NGO case studies presented in this chapter. The two case studies were selected from a larger sample of six family case studies and five NGO case studies in a larger body of research. These were the only two NGOs in the larger sample that provided disability support services in accommodation before the introduction of the NDIS, which began in Australia in July 2013. The two case studies are identified as Hartley Case #9 and JewishCare Case #10 in Chapter 3, but are identified in this chapter (in reverse order) as Case #1, which introduces the Enabled Housing Model from JewishCare's perspective, and Case #2, which introduces the Co-resident Support Model from Hartley's perspective. Case #1 studies the collaboration and joint venture between families, friends and JewishCare to develop and deliver the Enabled Housing rent supplementation model (Enabled Housing Model) to create more housing for an unlimited number of adults and their co-resident housemates. The JewishCare interview was conducted in the first year of the three-year pilot project of the Enabled Housing Model. Case #2 studies the collaboration and partnership between parents and Hartley Lifecare (Hartley) to host, develop and deliver a co-resident model of support with an employed housemate (Co-resident Support Model). The Co-resident Support Model is a new model of care and support for three adults.



JewishCare is a NSW-based not-for-profit NGO and a registered charity. It delivers person-centred services for individuals and families, young people and older people. Its disability services include NDIS-funded support for a person with disability in their own home, but it is not a housing provider. A group of seven family members and friends approached JewishCare with their ideas to enable adults with a disability to move into their own home close to their existing social networks. A means-tested rental subsidy would be made available to each eligible adult and their co-resident housemate from philanthropic donations raised or donated by members of the group of seven. JewishCare contributed its knowledge, experience, skills, attitudes, systems and practices from its operations in the not-for-profit sector and the disability service system.

JewishCare's participation in the Enabled Housing project and the implementation of the Enabled Housing Model in Case #1 was at two levels: it provided representative participants to the project's governing board, called the Joint Operating Committee (JOC); and it administered the initial process for evaluating the eligibility of families to sign a private lease agreement. At a third level — the household level — JewishCare was a registered NDIS service provider that could provide NDIS-funded services to adults in a household enabled by rent supplementation if chosen, and it was a service provider to one household at the date of their interview.

Hartley is an ACT-based not-for-profit NGO and a registered charity. Hartley was supporting 88 people in 36 houses across Canberra in the year ending June 2020 (Hartley Lifecare Annual Report 2019–2020, pp. 4, 30). Like JewishCare, Hartley is not a housing provider; it does not own the houses it provides support to. In Case #2, Hartley collaborated and worked with parents acting as the Getting a Life family governing group to deliver the Co-resident Support Model for their sons in their own home. Hartley was invited to participate in this research because it was the host agency under a memorandum of understanding it entered into with the parents to implement the Co-resident Support Model for their sons living in the Benambra Intentional Community in a suburb of Canberra. The Benambra Intentional Community was established by the parents acting as the Getting a Life family governing group with the assistance of the ACT Government and ACT Housing. Like JewishCare in Case #1, Hartley contributed

its knowledge, experience, skills, systems, practices and attitudes to the lived experience of the adults who chose to live with co-residents.

Hartley's participation in the Co-resident Support Model operated at different levels. Hartley was a registered NDIS service provider that employed the co-residents who lived with each adult to provide paid support. The co-residents were chosen by the sons and their parents with input from Hartley, which also interviewed the co-residents. The relevant parent, relevant co-resident and Hartley engaged in annual performance reviews for each co-resident together. Each co-resident also provided their perspective on their experience as a co-resident at each review.

## **6.4 RESEARCH METHODOLOGY**

### **6.4.1 Units of analysis**

Engeström's (2001) cultural–historical activity theory was used to examine the process of a group of actors learning to implement two different co-resident housemate models to enable independent living arrangements for adults with a disability that were innovative. The primary unit of analysis was the 'activity' of the NGOs collaborating, co-learning and working with families and friends to implement the Enabled Housing Model in Case #1 or the Co-resident Support Model in Case #2. Activity included collaboration and working together through a specific legal framework or mechanism such as partnership, joint venture, host agency and/or family governance. Activity included families and friends from the family, household or volunteer sector working with the NGOs from the not-for-profit and, in this case, the disability service sector. The parties contributed their respective inputs from these different sectors to enable the new individual living arrangements. The secondary unit of analysis was the 'actor' or 'subject' whose perspective was adopted in relation to the collaboration, co-learning, working together or working with. In this chapter, the NGOs' perspective was adopted.

### **6.4.2 Procedure**

Data were gathered using a combination of document analysis, website reviews and semi-structured interviews with the Manager of Disability Services with JewishCare in Case #1 and the Chief Executive Officer of Hartley in Case #2. Semi-structured interviews were used in both case studies. The Disability

Services Manager for JewishCare, Ms Suzi Parker in Case #1, and the Chief Executive Officer of Hartley, Mr Eric Thauvette in Case #2, were interviewed for approximately one and a half hours on one occasion in relation to their respective models. In addition to the interview with Mr Thauvette, two parents who designed the Co-Resident Support Model were interviewed as a separate family case study. Documentary evidence was available from the Getting a Life publication (Richards & West 2014) and Hartley's website for Case #2.

In relation to Case #1, the researcher received a copy of an independent review of the Enabled Housing Model prepared in 2019. The researcher is treating the independent review as confidential to JewishCare and the group of seven. Because it is not possible to unread the independent review, the researcher used the review to verify and validate the interview data to the extent they were relevant. Ms Parker was interviewed on a second occasion, but that interview was outside the scope of this chapter.

Adults and co-residents were not interviewed because system-level activity was the focus of the study. In addition, there were ethical issues, which are discussed in the next section.

#### **6.4.3 Exploratory study**

The Enabled Housing project aimed to help adults find private rental housing, find a housemate and enable the payment of rent by the adult and their housemate through rent supplementation. The group of seven had given or raised philanthropic donations to fund a means-tested rent subsidy for successful applicants. JewishCare co-delivered the allocation of the rent subsidy in partnership with the group of seven through membership of a JOC structure governing the pilot project for the model:

*NGO Parker, Case #1: We have partnered with a group of concerned parents and friends in the Jewish community who are fundraising to provide rental supplementation to enable people to move out of home.*

Families, friends, adults and co-residents were not approached to participate in the research. The pilot project was launched in 2017 (Zinn 2019, p. 2) and was in the first year of its three-year term when Ms Parker of JewishCare was

interviewed. A three-year period is a short period to make progress in enabling multiple new homes for adults given the opportunity to leave their family home for the first time. This was evident in the slower establishment of family governed homes in the separate SILC Case #7 study when SILC was first established.

This innovative pilot was a first-time project in the field of housing for the group of seven. Housing for people with disability is fraught with multiple barriers and challenges. Seeking to interview the group of seven, or the adults and co-residents who were eligible for the rent subsidy, while they confronted new challenges in housing and real estate was difficult. The researcher had developed some experience in approaching families to participate in this research. A high level of trust must be established first; however, the researcher did not have a relationship with the group of seven and was not known to them. The researcher also found that families must be at a stage in their progress in setting up new homes to be willing to speak freely about that experience.

Seeking to interview the adults or co-residents participating in the Enabled Housing project was also difficult for other reasons. The need for applicants to satisfy a means test meant that the take-up rate was slow, the new homes that were established were small in number, and the residents who were means-tested could be vulnerable. It is also necessary to safeguard a person who is unwilling to participate in research but unable or uncomfortable expressing that view. There were additional ethical issues if the co-resident housemates had recently met and were in the process of forming their relationship and learning to live together. These new living arrangements were important.

It was also anticipated that the interviews with families or adults who had established new homes would develop into additional, spin-off case studies outside the joint venture arrangement, because JewishCare's role did not extend to establishing the new homes themselves. Additional case studies were beyond the scope and timeframe of this research.

In relation to Case #2, interviews with the first co-residents are on Hartley's website and YouTube (<https://www.youtube.com/watch?v=TfwgjhMXnz4>). Ultimately, the adults and housemates in the Enabled Housing Model and the

Co-Resident Support Model are not known to the researcher, the researcher is a stranger to them, and the interview process did not include them.

#### **6.4.4 Ethics approval**

Ethics approval for the research was given by the UTS HREC in 2017. The Committee agreed that the application for approval met the requirements of the National Statement on Ethical Conduct in Human Research 2007 (National Health and Medical Research Council 2007). The approval number is UTS HREC REF No. ETH17-1412.

#### **6.4.5 Activity theory for data analysis**

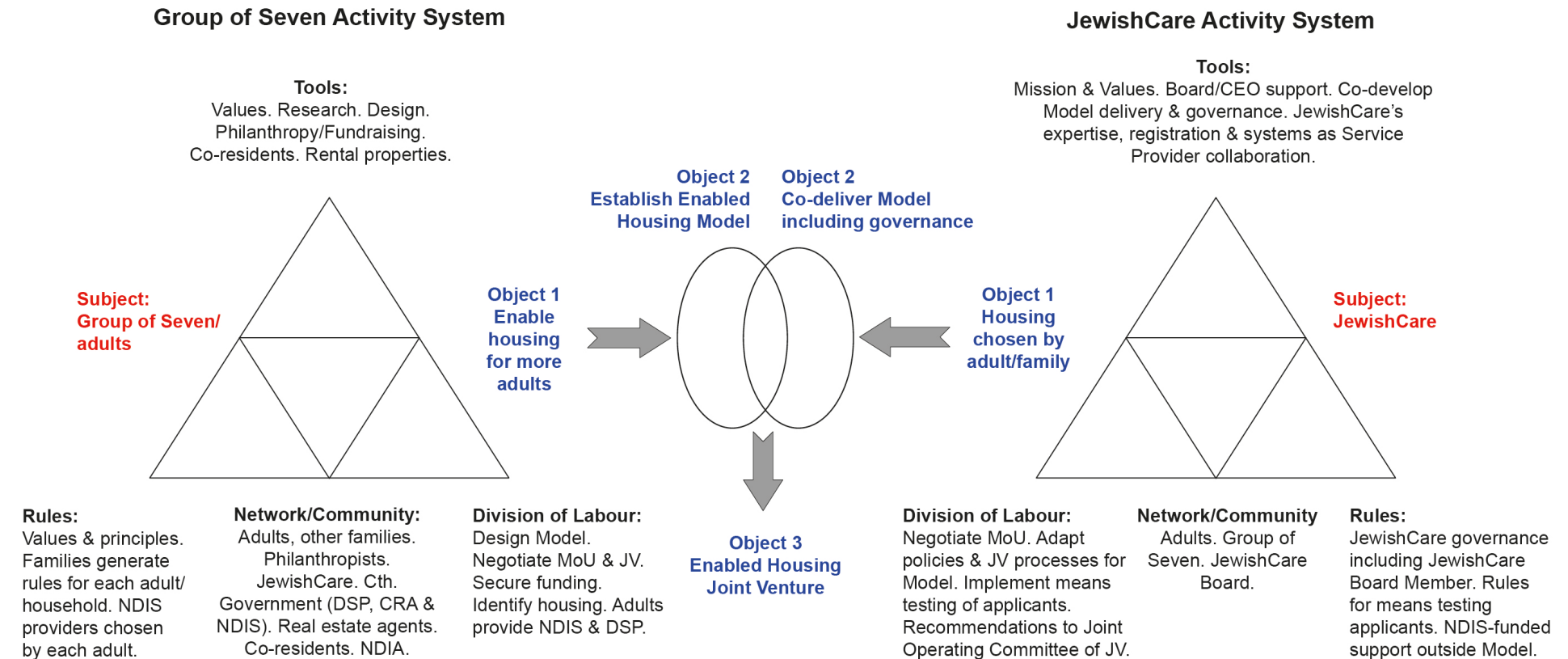
Engeström (2001, p. 136) developed activity theory to examine multiple interacting activity systems. Analysis of multiple interacting activity systems is a framework for expansive learning whereby the interaction of multiple activity systems increases the capacity of the individual activity systems (Engeström 2001, pp. 135–6). For this reason, activity theory was used in this chapter to analyse the interacting activity systems in the Enabled Housing Model and the Co-resident Support Model to understand the horizontal networks of activity by family, friends and NGOs, and to investigate the pooling, combining and applying of resources from different sectors and the boundary crossing by different actors (Engeström, Engeström & Kärkkäinen 1995). These interacting activity systems explained the hybrid models created when different actors contributed different resources from different sectors in the two models in this chapter. Engeström (2001, p. 136) recognised that interacting systems are a source of innovation, and The Young Foundation (2012) identified cross-sectoral activity as a feature of social innovation.

Analysis of multiple interacting activity systems in the two models in this chapter investigated the inputs to those activity systems from the NGOs' perspective. Figure 12 presents the interaction between the activity system depicting JewishCare's contribution to the Enabled Housing pilot project and the activity system depicting the contribution of families and friends. Those NGOs, families and friends crossed family and service sector boundaries when their activity systems interacted. Figure 13 presents the NGO's contribution to the Co-resident Support Model from Hartley's perspective. Additional activities to attain housing

for the Co-resident Support Model were analysed in Chapter 4. Future analysis of the Enabled Housing pilot project could include the separate interacting activity systems to attain housing, find co-residents and negotiate paid support, which are outside the scope of this thesis.

**Figure 12: Enabled Housing Model #1**

**ENABLED HOUSING MODEL #1**



#### **6.4.6 Concepts from theory**

The analytic framework applied the conceptual elements identified in the literature regarding entrepreneurship, social entrepreneurship, social enterprise, social value and social innovation. The pursuit of resources and opportunities, shared learning, new ways of working together and implementing innovations (joint venture and host agency, with new policies and processes), as well as sharing power and resources using new systems (family governance) and values (control and choice), are examples consistent with the meaning of these concepts in their practical application. Differences in each case study informed the exploration of continuous activities to execute each innovation in different ways. The case studies are described in more detail in Sections 6.5 and 6.6.

### **6.5 DISCUSSION**

As a consequence of the families and friends controlling and choosing the innovative design of their model, as well as their choice of NGO as partner for the implementation, there was no conflict and no known disagreement in the delivery of either innovation. Indeed, there were three common features.

First, the families, friends and NGOs shared experience in disability and their respective communities. In Case #1, the families, friends and JewishCare shared membership of the Jewish community. In both case studies, each group of actors shared knowledge, experience and understanding of the unmet housing need and a concern for where adults with disability would live in the future. Ms Parker of JewishCare had a lived experience of disability with a sibling, and Mr Thauvette of Hartley had a background working in a person-centred service organisation in Canada.

Second, in a general sense, the families, friends and NGOs had equal standing. Although families and friends were innovators who designed each model and instigated the collaboration, the terms of the relationship for implementing these innovative models were formalised on mutually acceptable terms. In Case #1, families, friends and JewishCare adopted an unincorporated joint venture structure and a JOC for governance of the model's implementation as a three-year pilot project under a negotiated memorandum of understanding (MOU). In Case #2, parents had power over the model through family governance and the



Getting a Life family governing group. Hartley's role as host agency was also formalised under an MOU on terms acceptable to the parents and Hartley.

Third, the adults and/or their representatives exercised control and choice with the support of JewishCare and Hartley. In Case #1, the provision of paid support was outside the Enabled Housing Model. JewishCare was chosen to provide NDIS-funded support in only one household established through the Enabled Housing project. In Case #2, the parents chose Hartley as the host agency. In each case study, families, including the family member with a disability, retained control and choice regarding the selection of the co-resident and the co-resident's role.

Other similarities and differences between the two case studies are identified in the next section.

## **6.6 FINDINGS**

The eight features of social innovation identified by The Young Foundation at the commencement of the TEPSIE research project in the European Union (2012, pp. 21–4) were found in each case study. The eight features of social innovation are:

- cross-sectoral
- open and collaborative
- grassroots and bottom-up
- pro-sumption and co-production
- mutualism
- creates new roles and relationships
- better use of assets and resources
- develops assets and capabilities.

These features of social innovation are discussed below. Section 6.6.1 answers research question RQ1. Sections 6.6.1 and 6.6.6 answer research question RQ2. Sections 6.6.1, 6.6.3 and 6.6.7 answer research question RQ3. Sections 6.6.1–6.6.7 answer research question RQ4.

### **6.6.1 Cross-sectoral**

Each model was produced by cross-sectoral activity and collaboration between actors combining resources from three or more sectors: the family or household sector with its volunteering and philanthropy; the community sector for philanthropy and fundraising; the not-for-profit sector with the skills, experience, systems and registrations to deliver or govern disability services; and the government sector for individual funding for paid support, the DSP, which contributes to rent, and Commonwealth Rent Assistance towards the cost of private rental where adults or co-residents were eligible.

In both case studies, families and friends secured housing for their model. In Case #1, private rental properties were secured using real estate agents in the private sector. In Case #2, after years of advocacy by parents, the ACT Government built public housing for the Benambra Intentional Community, which three sons and their co-residents live in. The security of tenure under the leases with ACT Housing in Case #2 enables a more secure, long-term housing arrangement in contrast with the lease agreements with private landlords in Case #1.

### **6.6.2 Open and collaborative**

Families, friends and NGOs were open and collaborative in the contribution of their respective resources to the development, implementation and operation of each model. Each NGO shared their knowledge and expertise regarding the cost to deliver housing, support and service options. Further, they used existing organisational systems and contributed their compliance and administrative infrastructure to help the families and friends implement their model. Specific examples of open and collaborative efforts are described in this section.

#### **6.6.2.1 Enabled Housing Model #1**

JewishCare contributed to the development of the objectives and activities of the group of seven. Originally, the group of seven intended to buy houses or build them. JewishCare discouraged the group from buying houses or building, at least initially, until they had the capacity to fund building maintenance. In addition, the original aim of the group of seven was to assist adults personally known to them.

However, only one person who was a friend had moved into his own place.<sup>22</sup> So, the group of seven collaborated with JewishCare to enable housing for adults not previously known to them, but who were identified and introduced by JewishCare. Membership of the Jewish community, and serving members with a housing need, unified the purposes of JewishCare and the group of seven.

#### **6.6.2.2 Co-resident Support Model #2**

Hartley worked closely with the parents to implement their Co-resident Support Model. Hartley offered its organisation, systems, processes and staff to maintain the arrangement, meet compliance requirements and perform some administrative functions:

*NGO Thauvette, Case #2: When they approached me, they were wanting to be set up as a company themselves, to have full control over what was being done. And they asked my opinion. I suggested to them that we can take away all the complicated things that they wouldn't want to deal with, such as insurances, liability, workers compensation and the other things that you have to have. I said with the recruitment of employees and the technical side of things, 'You guys can be in full control of how that gets managed, the model, the support and everything'. So, they really liked the idea.*

Hartley's own philosophies recognised, valued and empowered the control and choice of the person with disability, their parents, siblings, guardians, advocates and others. Hartley recognised that these relationships are frequently best placed to understand the level of support required for the person (Hartley 2020, p. 2).

#### **6.6.3 Grassroots and bottom-up**

Both models are grassroots, bottom-up initiatives led by families and friends. Chatterton (2015, pp. 13–4) elaborated on the meaning of grassroots as a concept:

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<sup>22</sup> A larger sample of case studies for this research, but outside the scope of this thesis, confirmed that adults may not be ready to move, or parents may not be ready for their children to move, even when activities to prepare for the move begin. There can be various reasons for this.

*Grassroots projects are self-initiated and people-led. Their main feature is that they are healthily removed from the influence and motives of governments, large institutions or big business ... In this sense, they are more like social movements seeking paradigmatic shifts to overturn the status quo.*

Although adults with a disability who need paid support and a co-resident housemate may not achieve complete self-sufficiency, it made sense for adults, families and friends to meet their own social needs from within their own community (Chatterton 2015, p. 12). Chatterton (2015) argued that self-reliance 'leads naturally ... [to] valuing the grassroots' (p. 13).

#### **6.6.3.1 Enabled Housing Model #1**

In Case #1, the Enabled Housing Model would subsidise rent in suburbs that were otherwise too expensive for applicants to live in. In doing so, the applicants were enabled to bring together all of the elements needed to establish their own home. Working from the grassroots up, these elements included finding co-resident housemates, finding appropriate housing and finding a new home to rent. The Enabled Housing Model offered the means for adults to find appropriate housing when there was no other pathway to achieve their own home. From JewishCare's perspective, in relation to people it supported outside the model and the pilot project:

*We're not aware of another 30 or 40 people specifically looking to live in group homes. But we are aware of those kinds of numbers of people who have ageing parents. We need to be looking at alternative sources of accommodation.*

#### **6.6.3.2 Co-resident Support Model #2**

In Case #2, both parents separately visited a range of models to develop their ideas around *how* their sons might live in their own home in the future. One of the parents, Ms Richards, visited the Onondaga Community Living organisation in Syracuse, New York, when her son was young. Onondaga had a housemate model whereby people lived rent-free and provided some level of support to the person in the house. In relation to group homes, Ms Pat Fratangelo, who ran Onondaga at the time, said to Ms Richards:

*Parent Richards, Case #2: It's not about dismantling group homes, because some of the group homes work very well, people have been living together for a long time, and they like each other. It's about finding the right home for a person, whatever that is.*

The other parent, Ms Connaughton, separately visited an organisation in Queensland, also when her son was young. She visited a home where the parents of a young woman had done some really nice work around the social aspects of her living arrangement, including the organisation of friends to visit her home for dinner once a week. Ms Richards and Ms Connaughton each thought differently about the future home of their son. They knew that the social characteristics and social configuration of the person's own home would be key to its success. Back in the ACT, both parents separately realised they would have to create a model themselves. Eventually, working together, the parents selected and adapted a Co-resident Support Model after developing ideas they had seen in operation elsewhere. From Hartley's perspective, the co-resident support model, host agency and intentional community where the sons live were the parents' vision. Hartley helped make the co-residency possible by stepping in to help fill any gaps.

#### **6.6.4 Pro-sumption and co-production**

There were stakeholders who were both producer and consumer or beneficiary of each model. This is described as pro-sumption and co-production (The Young Foundation 2012). Families and friends designed each model, and the NGOs provided input into the design for implementation. Families, friends and NGOs produced or delivered their respective models with different roles and responsibilities. Each adult and co-resident was involved in the delivery or production of the co-residency, and they were 'consumers' or beneficiaries of the companionship, or paid support, from their housemate.

##### **6.6.4.1 Enabled Housing Model #1**

Families, friends and JewishCare adopted new roles. Families and friends were the designer and funder of the Enabled Housing Model, as well as the producer and partner of JewishCare in the implementation and governance of the approval of applications and the allocation of the rent subsidy. Families were hands-on in

designing and setting up their child's household, which was outside the role of the group of seven and JewishCare. In the process of implementation, there was certainly some co-learning or learning together:

*NGO Parker, Case #1: The co-residency is called enabled housing, so that's very much about co-design. Well, not really co-design because the model is the model, but how it looks for every individual is slightly different.*

Also in Case #1, the design and operation of the governance for the Enabled Housing project involved multiple boards of directors. The Enabled Housing project had a JOC as its governance board, and JewishCare's board supported JewishCare's participation in the Enabled Housing pilot. Members of the JOC were two JewishCare representatives, two representatives from the group of seven (one a family member and one a concerned friend) and an independent director who was the chairperson. Ms Parker, Disability Services Manager, and a JewishCare board member were both on the JOC of the unincorporated joint venture for the duration of the pilot. The JOC was a shared governance body that became a form of boundary crossing in its structure and operation. This was illustrated in Figure 12 in Section 6.4.5.

#### **6.6.4.2 Co-Resident Support Model #2**

The parents and Hartley adopted new roles, and board approval was obtained in Case #2. Mr Thauvette, Hartley's CEO, was enthusiastic in his support for the Co-resident Support Model. The parents acting as Getting a Life were also key to securing the support of Hartley's board:

*NGO Thauvette, Case #2: Our Board is an excellent board. So, I'm one person able to advocate for certain types of models. I think my enthusiasm helped, when I was explaining this model. But when I got the families in to present to the Board, they were all for it.*

#### **6.6.5 Mutualism**

Collaboration and cooperation in the case studies had mutual-aid characteristics. There are many examples of the tendency for association when families and people with disability connect for mutual support, navigate service systems

together and share collective objectives. In addition to the mutual support and comradery between families and friends, the two case studies were examples of cross-sectoral mutual support. The models were initiated and led by families and friends, who invited the NGOs to deliver and support each model. In doing so, the NGOs were partners in delivering new types of living arrangements in new ways. Hence, it is critical for NGOs to cultivate grassroots, bottom-up initiatives if they want to participate in, and contribute to, changing models and innovation. Conversely, families and friends relied on the institutional support of the NGOs, including their established reputation within the service system, their registration as a disability service provider if needed, their administrative infrastructure, and their understanding and management of risk regarding compliance, insurance and other matters that were important for the management of their model.

#### ***6.6.6 Creates new roles and relationships***

Families and friends designed each model, and the NGOs co-produced them. In turn, the models enabled each adult's new role as home 'owner'. For the first time, adults could experience a sense of proprietorship, learn to live independently from their family and learn to live with new housemates. These new roles shaped and changed their relationships with each other.

##### ***6.6.6.1 Enabled Housing Model #1***

In Case #1, the group of seven provided the funding they donated or raised as philanthropists, thereby becoming financier and funder. The adults or their representatives retained power through individual control and choice of the provider of the NDIS-funded paid support the adults needed, thereby becoming tenant and service user. The Enabled Housing Model was an innovative way of contributing resources to establish more homes for more adults, subject to identifying eligible adults.

##### ***6.6.6.2 Co-resident Support Model #2***

In Case #2, each co-resident was employed by Hartley, which provided them with some training. However, the parents interviewed and selected each co-resident with Hartley. The sons had a say and needed to like their co-resident. Parents described their expectations for the role of the co-resident and the co-

resident's relationship with their son, which varied according to the specific needs of each adult:

*Parent Connaughton, Case #2: In Dan's case, the co-resident's role is to be home by the agreed time each night and ensure Dan has a proper meal. The co-resident can go out at night, but we want someone to be present in the house so Dan is not lonely. Dan puts his washing on, but the co-resident is responsible for making sure the washing is done ... The other thing we do differently is we encourage Dan to be part of the co-resident's family and for the co-resident to be part of Dan's family. For example, if the co-resident is going to see his parents one night for dinner, he might take Dan along.*

The house is also the co-resident's home, but the tenancy and lease agreement are in the name of each son. The co-resident will no longer live in the home when his employment ceases. In Case #2, the employment relationship is innovative, the Co-resident Support Model that the parents developed with pieces of information from other models is innovative, and the role and relationship between the parents and Hartley as host agency is innovative. All of these roles are regulated through the exercise of control and choice of the sons or their parents as their representative and family governance.

#### **6.6.7 Better use of assets and resources**

Both models combined and leveraged government funding with other resources that the adult with a disability or their housemate had or could garner. In both models, the DSP was used to cover the rent.

##### **6.6.7.1 Enabled Housing Model #1**

Unlike Case #2, rent supplementation was combined with the DSP and Commonwealth Rent Assistance in Case #1, and NDIS-funded support was arranged outside the Enabled Housing Model. JewishCare observed that this offered an opportunity to use sources of funding differently:

*Parker NGO, Case #1: The way we have formulated our Enabled Housing Model is that people must have the funded support around*



*them before they're eligible for Enabled Housing, because Enabled Housing is about rental supplementation and the co-resident. It's not about support. The community is not going to provide support. That's the government's role. That's why NDIS has allowed us to think a bit differently about all of this.*

#### **6.6.7.2 Co-resident Support Model #2**

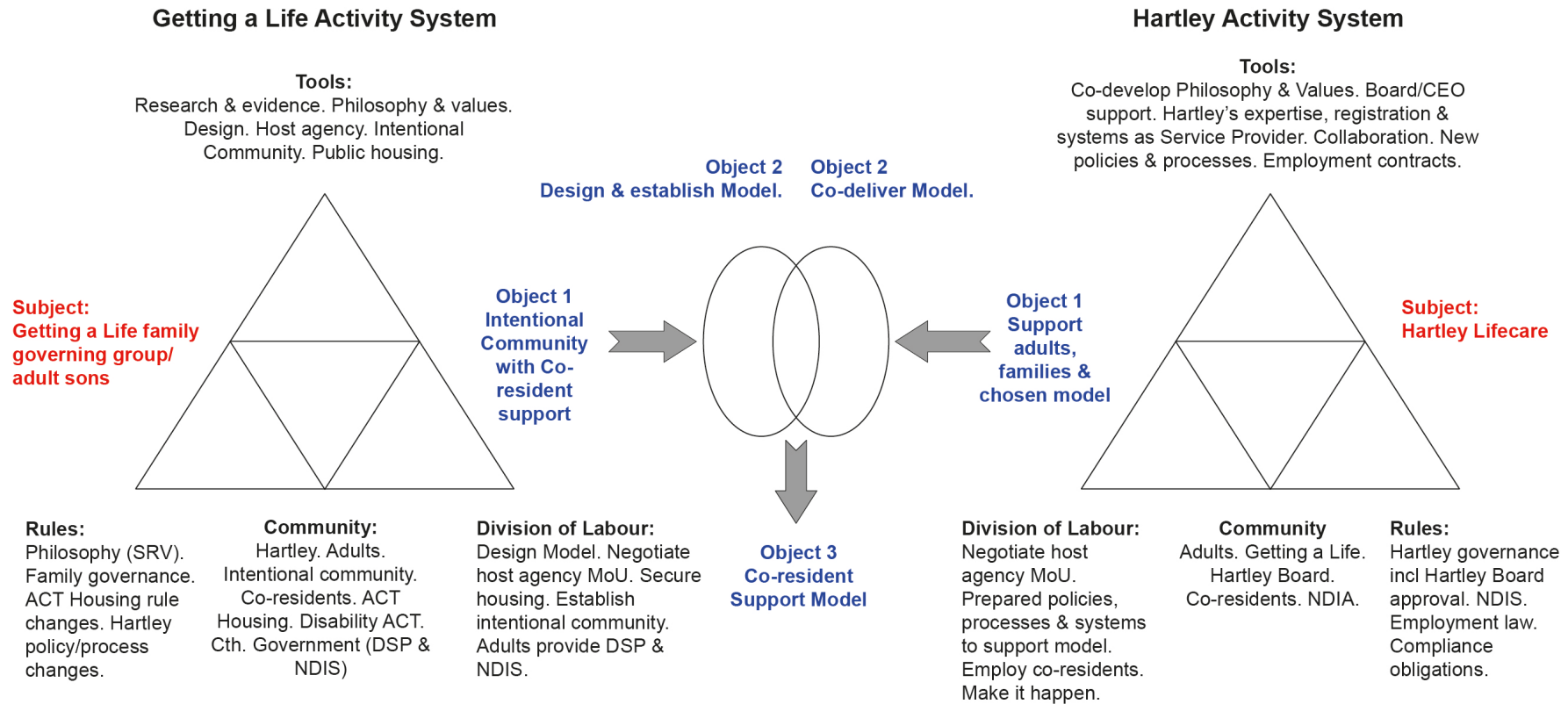
Conversely, the role of the co-resident in Case #2 was to provide NDIS-funded support as well as friendship and companionship. That is, the provision of paid support by a co-resident was the purpose of the model. But in Case #2, the Co-resident Support Model was one of three interrelated key elements. The intentional community where the men and their co-residents lived was really innovative, and the partnership with Hartley made the arrangement sustainable:

*Thauvette NGO, Case #2: Some people would think absolutely no, it would never have happened in their lifetime. But it's incredible what he's doing. The fact that he lives on his own, or with a co-resident, and has a community around him too. And for the other two also of course. But that is really the outcome you would want at the beginning. So the evaluation is based on how well they're doing, I guess. That's hard to quantify. It always is.*

As a consequence of the different support needs of each son, the co-residents possess different attributes appropriate to their different roles. Figure 13 illustrates the contribution of assets and resources in Case #2.

**Figure 13: Co-resident Support Model #2**

**CO-RESIDENT SUPPORT MODEL #2**



Key differences between the Enabled Housing Model in Case #1 and the Co-resident Support Model in Case #2 are summarised in Table 17.

**Table 17: Key differences between the models**

Enabled Housing Model #1	Co-resident Support Model #2
Family and friends raised funding to supplement the cost of rent in the private rental market.	Public housing is provided separately to the Co-resident Support Model.
Paid support to enable the adults to live independently is provided separately to the Enabled Housing Model.	The Co-resident Support Model provides a model of paid support.
Although they provide company for the adult in their home, the co-resident housemate is not an employee and can leave at any time.	The co-resident cares about the adult as a housemate, may share their social network and will provide paid support. The co-resident carer is therefore an employee of the NGO. But parents also interview, select and govern the arrangement in collaboration with the NGO.
The objective of the Enabled Housing Model is to meet the housing needs of both the adults and the co-resident housemates. The co-resident has their own lease.	Although the housing is the co-resident's home as well, the lease is in the adult's name, and the co-resident occupies the adult's home as a term of their employment contract with the NGO.
Roles shared between families, friends and NGOs at different levels and for different purposes.	

### **6.6.8 Develop assets and capabilities**

TEPSIE's (2014, p. 9) definition of social innovations incorporated five criteria. In meeting such criteria, assets and capabilities are developed. These criteria were evident in each case study. First, the social innovation must be 'new to the context in which it appears. It might not be entirely new but it must be new to those involved in its implementation'. The Enabled Housing Model in Case #1 and the Co-resident Support Model in Case #2 were new ways of enabling adults to live independently in their own home. Both models were new ideas. Each group of actors adopted new roles and relationships for the first time. Elements of the models may be taken from elsewhere but used differently and in new ways. Second, the innovation must address 'a social need in a positive or beneficial way'. Both case studies demonstrated that adults with high support needs are no

longer confined to group homes. In Case #1, the Enabled Housing Model enabled adults with the highest support needs to live independently, provided that NDIS funding for paid support is appropriate and sufficient:

*NGO Parker, Case #1: In terms of enabled housing, I had always envisaged co-residency would be for people with low support needs. But our first person who is in this model actually has very high support needs. Again, I imagined one person with a disability and one co-resident. But this young man has three co-residents living in a four-bedroom house. And each co-resident is working, or is co-residenting, two nights a week.*

Third, social innovations are ‘ideas that have been put into practice’. That is, after ideas are developed, they must be implemented and tested. As stated previously, an independent review of the Enabled Housing Model was completed at the end of the pilot project. In addition to implementation, the objectives and outcomes were independently checked. In Case #2, both parents had collected evidence of positive outcomes in independent living arrangements for decades. They shared what they learned and the evidence they collected with the ACT Government through presentations to agencies, bureaucrats and ministers.

Fourth, beneficiaries must be ‘involved or engaged in the development of the social innovation or in its governance ... either directly, or through ... actors who themselves have direct contact to the beneficiaries’. Adults, co-residents and families who benefited from the model were involved in its design and development. Family governance of each model existed at the system level and the household level. At the household level, the role was slightly different each time. Thus, each model met the wishes and needs of the adults and parents as they chose to implement them.

Fifth, social innovations ‘transform social relations by improving access to power and resources of specific target groups’. Like the Enabled Housing Model in Case #1, it is possible to replicate the Co-Resident Support Model for more adults in the community:

*NGO Thauvette, Case #2: We’ve replicated the co-resident model, which we didn’t do before we started with those three men. Not the*

*intentional community model, but the co-resident model itself with other individuals in different houses in three other locations. It stays within the envelope of funding. And it's only for certain people because you create a relationship between the co-resident and the family to work really well together.*

Recognising and valuing all non-financial and financial assets and capabilities made each model possible.

## **6.7 CONCLUSION**

Families, friends and NGOs partnered to provide or enable housing for adults to leave the family home through both models. The Enabled Housing pilot project sought to address the problem of housing supply by providing the financial means for adults and their co-residents to access private rental properties. Housing supply is a first step; however, it is only one element that adults need to have in place to assert their independence. Sustainable housing is an important second step, unless a sustainable arrangement is achieved with their first move. The activity theory framework and cross-case comparison was used to identify and understand what additional resources were needed to sustain these grassroots initiatives.

The adults who adopted the Co-resident Support Model lived in public housing. This type of government assistance — namely, security of tenure under the terms of a public housing lease and capped rental costs — addresses the real need for sustainable housing. Private rental arrangements will always be tenuous for financial and other reasons because the investor landlord will respond to changing incentives in the private rental market, the opportunity or desire to sell the rental property, and changes in the landlord's circumstances over time.

The Enabled Housing pilot project is a missed opportunity for the federal, state and local governments and the NDIA to partner and offer adults with mixed types of disability security of tenure in order to leverage the philanthropy of and donations raised by family members and friends. If the community housing sector in NSW does not have the capacity to offer such arrangements, then a government initiative to offer a new type of rental model that guarantees security of tenure and capped rental costs is needed.

In 2019, the NDIA, which administers the NDIS, stated that it would study 'individual living options' (ILO) that are created in the community (McInnes 2019). In that announcement, the NDIA identified four types of ILOs of interest: living alone, co-residency, host arrangements and living together. These examples described ILOs as a configuration of social relationships (e.g. 'living alone' or 'living together'). The NDIA did not use the label 'ILO' to denote housing type (e.g. rented or ownership), housing design (e.g. cluster or house v. unit) or source of funding. NDIA research of individual living arrangements provides an opportunity to identify missing resources in order to sustain living arrangements that families and friends may be willing to co-fund. The NDIA may be open to funding a wider range of models for people eligible for the NDIS in financial partnership with families and friends. However, new approaches to addressing housing needs in this way must offer exit options for families and friends to withdraw their contribution as their circumstances change. It is also recommended that the NDIA partner with state and territory governments to undertake such research so those governments can develop other models for adults who are not eligible for the NDIS. In doing so, those governments will be better equipped to leverage family resources, partner with the community and meet housing needs quickly.

## **7 BUILDING PERSON-CENTRED HOMES**

This chapter is the fourth paper prepared for publication. It presents a single case study of more than 15 families ('family group') who chose a cluster development to establish a new home for their adult daughters and sons with an intellectual disability. This chapter describes their design of the built environment, which includes housing and the home environment (Rapoport 1985). The purpose of the design of both was to meet the individual choice of each intended resident who would live in the cluster, as well as their preferences as a group living together. This chapter explores the family group's desired design of the cluster to achieve a person-centred design and home. Knowing the preferences of their children, their parents set about engaging in activities to help attain them.

They challenged the beliefs, attitudes, interpretations and practices<sup>23</sup> of the building professionals who designed and built the cluster, and of the bureaucrats who instructed the builder. Parents challenged the application of institution- or facility-like characteristics to the selection of the land, the design of the cluster and the construction of the houses. In the end, the family group created a home for their children as residents, with security of place. They achieved an attractive dwelling with good key workers who are present 24 hours a day, seven days a week, or overnight.

### **7.1 INTRODUCTION**

The three principal elements of 'where a person lives' identify separate places that the person will occupy, control or use: first, the built environment; second, the home environment (Rapoport 1985); and third, the concept of home (Annison 2000), which is the space controlled by the person living there, into which others are invited. The research and literature confirm that control and choice of the built and home environment are important for people with a disability (Annison 2000; Cook & Miller 2012; O'Brien 1994). The human rights framework requires control and choice. In terms of the home environment, Rapoport (1985) offered

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<sup>23</sup> A person's behaviour is determined by their ideologies, which refers to the combination of beliefs, attitudes and interpretations of reality derived from the person's experiences, knowledge and values (Wolfensberger 1972, p. 7).

a conceptual framework<sup>24</sup> predicated on choice, contending that characteristics of the home environment that are ‘not chosen ... are not home’. However, an imposed setting can become home through ‘increasing congruence ... with needs and preferences’ (Rapoport 1985, p. 256). Where services intersect with day-to-day living, research has established that people with disability who exercise choice of services are more satisfied (Glendinning et al. 2008).

For the exercise of choice, research has established that ‘living where you want’, ‘having a say’, including a say in who you live with, ensuring you are ‘listened to’ and ‘treated with respect’, and having a choice of key workers providing paid support in the home are desired outcomes of people with disability (Cook & Miller 2012, p. 12; Miller et al. 2008 p. 152). To encapsulate the essential features of home for people with an intellectual disability, O’Brien (1994) emphasised a sense of place, control over the home and necessary paid support for living there. Security of place is achieved through valued roles such as tenancy a ownership (Annison 2000, p. 253).

When a home is to be built, choice by the intended resident requires their participation in the design and fit-out processes. When their home is built, the household and home environment are maintained with good key workers supporting the residents’ needs, as well as their activities within and outside that setting. For people who are eligible, Australia’s NDIS should provide sufficient funding for key workers who provide person-to-person assistance (paid support).

Conversely, choice and control over the physical aspects of the home environment, including type of housing and design, are more difficult to achieve when a person with a disability does not have the financial capacity to rent, buy or build their own house. Historically, people with a disability have not been included in decision-making processes regarding the purchase or construction of the government-funded housing they will live in. These processes were controlled by bureaucrats or agency staff who did not recognise the disabled

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<sup>24</sup> Rapoport (1985) explained that ‘conceptual frameworks are neither *models* nor *theories*. Although these latter terms are used in many different and often contradictory ways ... *models describe* how things work, whereas *theories explain* phenomena. Conceptual frameworks do neither; rather they help to think about phenomena, to order material, revealing patterns — and pattern recognition leads to *models* and *theories*’ (p. 256). Independent living, intentional communities and cluster housing are different *models* for combining housing, tenancy and support in the field of disability housing. A range of property designs can be used for any of these models, including shared living arrangements, split housing with shared facilities and unit housing under a single roof (DHCS ACT 2010, p. 2).



person as a client of their agency or of a housing provider, architect or builder. This contrasts with people who buy or build their own house with their own funding. This second group has control over where to build or buy their house. If a person is building their own home, they are able to choose, engage and instruct an architect and builder to complete and deliver their house. As the 'client', they have as much input into the design and oversight of the building work as they choose or as their budget permits. In contrast, a person who does not have the financial capacity to rent, buy or build their own house will have less control and less choice. This is problematic when houses are built for people with different disabilities and different individual requirements. It is therefore important for a person with disability, or a representative who has knowledge of their needs and preferences, to have input into the design process. In addition, the importance of a participatory design process to balance individual wishes and needs has been acknowledged for group living in a cohousing model, along with the preferences of a group who will live together, the characteristics of the site, the building rules and the project's budget before building begins. (Durrett 2009, p. 137). Similarly, participation in building processes when construction commences is important to ensure that the needs and priorities of the intended resident continue to be understood and will be met.

To elaborate on these matters, this chapter presents a case study that is unusual because the family group supported 15 adults to move from their respective family homes to live in their own place for the first time in their lives. The case study is one of three case studies from a larger sample in which housing was built with government funding. It is the only case study in that sample to establish government-funded cohousing with a cluster design. In the other two case studies, the concept designs for the built environment prepared by parents (with the assistance of architects) were not used to build their housing. In one of the two case studies, a villa design that had not been chosen by the families was adopted because the sites purchased at the chosen location were too small for their design.

In the case study, neighbours welcomed the group of 15 women and men into their neighbourhood. However, it was a battle for their parents to have their choice of design recognised by the government agency that controlled the

funding. When the NSW Minister for Disability asked bureaucrats to execute the project, neither the parents nor the intended residents were recognised as 'clients'. The agency contracted and instructed project managers, a draftsman and a builder. Agency staff controlled the release of funding for the purchase of the land, the building design and the construction or build. The parents therefore had no choice but to intervene in the design process and assert their ideas. They adopted new roles to monitor building activity, invited themselves to build meetings and enforced their aesthetic and design standards to achieve the design they had discussed with their children and agreed with the family group. What could have been achieved more efficiently, with less conflict, if the family group had been brought into the decision-making process, is now a moot point. However, it is necessary to include the intended residents as clients for future housing developments, especially as the building sector builds more housing for more people with disability.

This chapter starts with a brief overview of the literature that has developed in disability and housing as separate fields of study. The literature includes studies of residential care services in accommodation that are institution-like in form or function. The literature suggests that society maintains a self-perpetuating cycle of residential institutions. Indeed, the design of these homes can be devoid of outside perspectives, devoid of input from intended residents or devoid of innovation. As a consequence, new homes for people with disability are similar to the old ones. This chapter then describes the design choice made by the intended residents and their parents. This is followed by a discussion of the desired outcomes in the case study, the findings and the conclusion.

## **7.2 LITERATURE REVIEW**

Different areas of literature are relevant to this study. Bostock et al. (2004) highlighted the tendency of the literature on community care and supported accommodation to focus on the quality of support services and care outcomes. Less attention has been paid to exploring the fundamental role of housing and housing policy frameworks for people with disability. Similarly, the housing literature has focused on housing needs, housing supply and affordability (Bostock et al. 2004). In this literature, people with disability are viewed as one

among other disadvantaged groups who need housing. Bostock et al. (2004) contended that these different areas of focus have left a gap in the study of the housing aspects of human service policies when moving disabled people out of institutions.

There are separate areas of literature that explore new housing models. For example, there have been efforts to synthesise alternative housing options, like cohousing, with traditional housing concerns, like affordability (Holtzman 2010). Cohousing has been adopted by different groups of people for different purposes — for example, university students needing somewhere to live and elderly people who are lonely in their own homes. There are other purposes for which a cohousing model is used. Intergenerational cohousing is used in Europe and North America. Durrett (2009) provided a guide on how to plan and implement cohousing communities on a larger scale to enable ageing in place. Cluster housing is another innovative model; it was originally developed to focus on land management for the sustainable use of community resources and the effective sharing of space and assets. Deutscher (2013) encouraged architects to continue experimentation with cluster housing to address the housing need with houses built to a size that communities can more easily accommodate.

The term 'cluster housing' has also been used to describe larger, campus-style arrangements for people with a disability (studied and written about by Emerson 2004 in the UK and Bigby 2004 in Australia). Emerson's (2004) research identified negative features of the cluster housing he studied, including support from fewer staff than in other settings, the predominantly short-term use of accommodation by residents, a greater use of casual staff, more restrictive practices, more sedentary lives, less home-like settings and a restricted range of leisure, social and friendship activities. Emerson (2004, p. 195) warned that the results of his study needed to be treated with caution. Indeed, 60% of the people in his sample were located in socially deprived districts in England, and support was received from traditional service providers who owned, controlled or were tied to the housing. Nonetheless, Emerson (2004) and Bigby's (2004) interest in past models of so-called cluster housing as a service or care model is important. Such studies hold funding bodies and service providers to account. Those studies would ensure that service providers discharge their duty of care to people

who live in housing they do not own and who receive paid support they may not control from support workers they may not choose.

In the case study, the parents acting as RASAIID designed a small cluster of houses to be built in the same location. The purpose of the cluster design was to build homes for the community of women and men to live together and independently as they requested, and achieve the housing outcomes desired by the parents. The concept of person-centred in this context means a personalised design and home determined by the person's decisions within the limits imposed by their ability and budget (Productivity Commission 2011, p. 344). Person-centred decisions in housing include decisions by the person about 'where they might live' and 'who they would like to live with' (Productivity Commission 2011, p. 345). Person-centred is distinguished from person-centred support (FACS 2015; Garner & Dietz 1996), person-centred planning, and a service-centred approach, which traditional group homes have adopted.

However, advocates and bureaucrats were critical of RASAIID's cluster before it was built. They told the parents that, in their opinion, RASAIID was trying to create an institution. In the disability literature, the term 'institution' refers to an institution-like residential setting for long-term accommodation. Institution as a residential setting is a composite concept, although the literature identifies a range of different characteristics pertaining to the built form, the staffing model, the function and the experience of people living in such places, usually described as negative. Historically, in the US and elsewhere, negative characteristics of residential institutions included overcrowding, understaffing and underfinancing (Kugel 1969, p. 1). Other problems have included the location of those settings in 'out of the way' communities, which created a problem with the recruitment and retention of qualified staff (Kugel 1969, p. 2). Other institution-like features have included 'obsolete architecture and design' (Kugel 1969, p. 4), a lack of facilities and a lack of comfort — for example, a lack of air conditioning for climate control, which has health outcomes (Kugel 1969).

Segregation, lack of choice and regimentation of living arrangements devalue people with disability and are the focus of disability studies. Although barriers are not limited to these features, the choice of where to live and who to live with is the starting point for resolving these problems. The United Nations (2006)

Convention on the Rights of Persons with Disabilities, article 19, recognised choice of where to live as a human right. Article 19 required parties to:

*recognize the equal right of all persons with disability to live in the community, with choices equal to others ... ensuring that: a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement.*

This chapter therefore views only one model approach to housing with paid support as institutional. This model can be described as the 'being done to, being looked after, having no choice path' (Ms Richards, research participant). In contrast, the RASAIID cluster was an innovative, first-of-its-kind model for NSW. It was chosen by the families, including their daughters and sons. The cluster was made possible through individual funding for paid support and financial assistance for the capital cost from the state and federal governments. However, when the parents sought to communicate their plan for the cluster to the relevant government agency, agency staff criticised and contradicted their choice. They told the parents that they had to build group homes for their children. This raised questions for the cluster development: 'Who is the client?', 'Who controls the design or form of what is built?' and 'Who controls the function of purpose for which the resident's home is used?'

The rest of this section selects literature that explains the factors that influence the tendency to create or recreate residential institutions in form or function, notwithstanding attempts to do things differently throughout history. In Australia, adherence to the use of the group home model drives the lack of choice and control over where people with disability will live, contrary to the human rights framework. This is described in the next section.

### **7.2.1 Lack of choice**

In an Australian context, government bureaucrats, government-appointed experts and funding rules have determined where people with disability can live, the type of buildings they can live in, the purpose or function of their accommodation and the number of people they should live with, as well as the role, organisation and activities of staff. This was the case before and after

deinstitutionalisation, which is the term used to describe governments moving people from large residential institutions into smaller living arrangements, with the large residential institutions then closed or repurposed. In NSW, this has remained the situation since the policy to close large residential institutions was formally adopted in 1983. The Richmond Report (Richmond 1983b) in NSW contained a recommendation for people with disability to live with their family or otherwise in the community in 'normal' houses (Recommendation Part 1, rec. 3(ii); Part 2, p. 41). However, it has been government agencies or their agents that have decided which houses and which streets. Community was something 'out there' in which people would be placed. Other government reports grappled with the quality of housing services or supported accommodation in a care context, acknowledging the growing demand for control and diversity of choice in both housing and paid support (NSW Government 2006). In general terms, where people have needed supported living, the NSW Government was slow to offer choice.

In Australia, deinstitutionalisation is still underway. Following the adoption of the 1983 Richmond Report recommendation to close large institutions, state and territory governments in Australia commenced funding smaller models in the community to which people with disability were moved. The group home model became the dominant model for this purpose, but this model has been relatively static and resistant to change. It has been described as a community care or service model whereby housing is bundled with staff who provide paid support to people living in those homes (Clement & Bigby 2010, p. 15). Clement and Bigby (2010) defined group homes more broadly 'as accommodation for between four and six people, where *extensive* or *pervasive* paid staff support is provided to the residents both in the home and when leaving it to use community-based settings' (p. 15). Important research overseas and in Australia has studied the culture of organisations operating group homes (Bigby & Beadle-Brown 2016; Bigby et al. 2014), the attitudes and practices of people providing paid support, and the outcomes for people living in accommodation they have not chosen.

Literature has also studied the outcomes for people living in housing they control and choose. In Control in the UK developed a system of self-directed support as 'a way of supporting disabled people to have real power and responsibility' (Poll

et al. 2006, p. 6). The goal of their pilot was to ‘put control over funding and support close to the disabled person’ (Poll et al. 2006, p. 9). In Control’s evaluation of Self-Directed Support at six pilot sites found that the disabled people in their study wanted to live like everybody else (Poll et al. 2006). Reports for Australian governments have identified the same desires (NSW Government 2006; Sach and Associates, Miller & Burke 1991).

Simon Duffy was a member of the group that evaluated the In Control pilot. Duffy (2013) expressed concerns that the design of the NDIS in Australia is a hyper-centralised bureaucratic model. Duffy recommended that the NDIS harness the efficiencies that come from shifting responsibility to citizens and making resources flexible; otherwise, the quality of support and the sustainability of the NDIS model will suffer (2013, p. 10). Notwithstanding the concern that a rule-driven centralisation of control-limiting choice may come to pass, the parents in the case study were optimistic that separation of funding for paid support from the provision of housing increased choice, assuming access to housing was achieved and funding was sufficient.

### ***7.2.2 Institution as structure or function***

Landesman (1988) explained that there are at least two ways to think about institutionalisation in the context of living arrangements: ‘one is to focus on structural features; the other is to consider functional features’ (p. 107; see Kozma, Mansell & Beadle-Brown 2009; Stancliffe, Emerson & Lakin 2004). Landesman (1988, p. 107) identified four broad categories of ‘negative functional features that make residential settings institutional in nature’ to the detriment of the people who live in those settings: ‘1) rigid administrative organisation, 2) behaviour of direct care staff toward residents, 3) resource utilisation, and 4) their relationships with others outside the residence’. He noted that institutions with the same structural features may function differently, but ‘what happens from day to day is what matters the most for residents’ (Landesman 1988, p. 107).

Sarason (1969) sought to understand why the pattern of residential care with professional and nonprofessional staff had been so consistent in the US, even when efforts were made to change it. He suggested that one reason was ‘the failure explicitly and systematically to list and evaluate the universe of

alternatives in regard to residential care' when planning what would be built and how to resource it (Sarason 1969, p. 351). Although an old study, Sarason asked individuals who were responsible for creating institutions at the time to think about other possibilities. In that experiment, he found that those individuals would develop new approaches to residential care that they had not considered previously (Sarason 1969, p. 352). Sarason concluded that the way the person leading the design and construction initially thought about and planned the setting contained the seeds as to whether a different setting would be created, or whether something the same as past settings would be built.

Sarason (1969) also contended that enlargement occurs when more actors with different objectives become involved in the same project. That is, the setting quickly becomes 'a highly differentiated one in which the parts are maladaptively related and the overall purposes of the setting become secondary to the purpose of its component parts' (p. 347). He argued that the seeds for later success or failure are sown in the beginning, when planning for the setting to be built (Sarason 1969, p. 348). Landesman and Sarason's contributions are important. Further insight could be provided by studies of bureaucracy within the systems or organisations that control, organise, standardise and govern the implementation and administration of housing and paid support. Bureaucracy is a rigid mode of organisation, and some writers have observed that it is incapable of change. This is the situation observed when government funding is used with agency oversight.

Mansell and Ericsson (1996) also suggested that 'institutions have been a remarkably durable and resilient form of social organization and there must be at least the possibility that new services in the community come to recreate institutional practices' (p. 242). Researchers continue to study the extent to which smaller residential settings and the group home model can become a form of institutional care or possess characteristics that are 'institution-like' (Cocks et al. 2014). It may be that ways of thinking about housing as a care service were at least one obstacle to changing the 'only one' model that tied housing to paid support and was preferred by government. This is different to the purpose that housing and assistance in our own home offers the rest of us. Other obstacles can include the control of the bureaucracy within the funding agency over how



funding for people with disability can be used. Practices, policies and other rules can reflect out-of-date, discriminatory beliefs and attitudes regarding the type of housing people with disability can live in. The next section briefly describes historical beliefs, attitudes, practices and rules that have been applied to housing with paid support.

### **7.2.3 Negative attitudes, practices and rules**

Wolfensberger (1983) enunciated the risk that people with disability may be devalued and badly treated. He described living in a segregated manner and receiving services in 'settings that look forbidding and fortress-like ... far removed from the rest of society' (Wolfensberger 1983, p. 235) as examples of discrimination and disadvantage. Modern-day examples of segregated living include locating the residence of people with disability in an industrial or commercial area, or a significant distance from friends or family members who would otherwise remain in their lives and keep an eye out for them. The location of housing can also isolate people with disability by locating them away from other citizens, shops and services. As a consequence, mobility and opportunity to live and move about among other people with more independence are impeded. People with disability are also segregated when government-funded housing is not designed, configured or located to empower the person to live with their friends, children or siblings.<sup>25</sup> Other institution- or facility-like practices include the use of design or symbols that are stigmatic and signal that the person who lives there, or the function of their house, is different. The use of features designed for industrial and commercial purposes that are institution- or facility-like include the green 'running man' exit signage in a person's home. It is important to understand the role and application of building rules that apply to accommodation for people with disability from their perspective. A decision to use such signage in the cluster was successfully challenged through the parents' advocacy.

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<sup>25</sup> In June 2020, the minister for the NDIS proposed a policy change to recognise the need for choice and flexibility to live with family, friends and partners in SDA housing funded under the NDIS.

#### **7.2.4 Building rules in Australia**

Building rules reflect the interaction between form and function, purpose or use. Franz et al. (2014, pp. 13–5) described the building rules that affect the design and construction of buildings in Australia, including the following brief list. First, the National Construction Code (NCC), which includes the Building Code of Australia and the Plumbing Code of Australia, is the minimum building code. Second, the national Disability (Access to Premises — Buildings) Standards 2010 ('Premises Standards'), made under the *Commonwealth Disability Discrimination Act 1992*, commenced in May 2011 to improve non-discriminatory access to new and certain upgraded buildings (not private housing) (Australian Building Codes Board 2018, p. 9). Third, the Australian Standard (AS) 1428.1-2009 (Design for access and mobility — General requirements for access — New building work) specifies the design requirements for new building work required by the NCC and the Premises Standards.

An understanding of these rules and the actors who apply and regulate them is needed before design and construction begins. First, Australia's NCC assigns a classification to buildings on the basis of their function and use. The classification will determine which provisions of the NCC and which technical requirements apply to that building or building work. These provisions and requirements include fire ratings, provision of escape in an emergency and acoustic separation between bedrooms and shared living space. In turn, designers, architects and builders design and construct buildings to comply with the description of function and use for a particular class, the relevant technical standards that apply to that class, and local environmental planning instruments based on classification by function and use.

To illustrate this, Class 1a is the classification for standalone single dwellings of a domestic or residential nature, such as houses, townhouses and row houses. Class 1b is the classification for a boarding house, guest house or hostel with a floor area of less than 300 m<sup>2</sup> and ordinarily fewer than 12 residents. Class 2 is the classification for residential apartment buildings. Classes 3–9 are used for a range of different types of commercial and public-nature buildings. From these categories, Classes 1a, 1b, 2 or 3 can be chosen as the appropriate classification for different types of accommodation for people with disability, ranging from a

single home domestic dwelling to shared living arrangements like group homes, clusters and cohousing. To be distinguished from a domestic dwelling, Class 3 is a category for residential buildings for long-term accommodation in a care context, or transient living for unrelated people in any of the following:

- a boarding house, guest house, hostel for more than 12 people (if fewer than 12 they are classified as Class 1b) and a lodging house or backpacker accommodation
- a residential part of a hotel or motel
- a residential part of a school
- accommodation for the aged, children or people with disability
- a residential part of a healthcare building that accommodates members of staff
- a residential part of a detention centre
- a residential care building.

Although there is nothing in the language of Class 3 that requires an architect or builder to design or build accommodation that is institution- or facility-like, building professionals may be influenced to adopt an institution- or facility-like approach because of the nature of the other types of accommodation listed in Class 3. Perhaps the challenge for the architect and builder of accommodation is the fact that their client is not actually the resident. Therefore, future residents are not given an opportunity to provide input into the concept design or changes during the building process. Architects and builders may adapt the design of other buildings previously built in the same building class for the same purpose. They may replicate features that are institution- or facility-like.

In NSW, the classification system outlined above interacts with local environmental planning (LEP) instruments issued by each local council. LEP instruments restrict the types of houses or dwellings that can be built in an area for a particular use. To comply with these planning instruments, it is necessary to determine the design concept of the residence to be built (e.g. a domestic dwelling or a cluster of individual homes). Then, before the site is purchased, it is necessary to determine whether the relevant planning instrument permit

construction of the design concept or operation of the accommodation for the particular use on that site.

It is possible for the relevant planning instrument to permit multiple dwellings to be built on a single site without formally subdividing it. It is also possible to build different types of housing with different classifications on the same site if the planning instrument permits this approach. These matters are an important consideration for people who want to build a cluster of houses on the same site — assuming that policy-makers will permit people with disability to make this choice.

In the case study, the parents understood that their property was zoned differently to permit more houses on a single site. But the researcher has not identified the classifications of the houses in the case study or the applicable planning instruments. Further, the draftsman, builder, certifier and owner or manager of the houses were not interviewed, although the design of the houses and cluster as a whole are on the RASAIID website. The houses in the case study were domestic dwellings. Designed as a cluster of separate houses on the same site, they comprised six sole-occupancy units, a standalone house with two two-bedroom units and a house with bedrooms and separate ensuite bathrooms for five adults. Thus, there may be multiple classifications within the cluster (e.g. a combination of Class 1a, 1b and/or Class 2 building types).

### ***7.2.5 Livable Housing Design Guidelines***

At the time the houses in the case study were built, there were no specialist design standards to ensure the built environment and fit-out features would meet the individual needs of people with particular disabilities. Instead, the organisations and people instructing the draftsman and builder used an early edition of the Livable Housing Design (LHD) Guidelines, which were developed by a partnership of representatives from the residential building and property industry, the disability and ageing sectors, and government. The LHD Guidelines were intended to guide the adoption of minimum access features to support ageing in place. They require levels of accessibility that reflect the assumption that physical disabilities increase with age. Subsequent editions of the LHD Guidelines have been published since the cluster was constructed. The LHD

Guidelines contain 15 liveable housing design elements pertaining to different levels of specification for accessible housing. Seven core liveable housing design elements must be satisfied to achieve a silver-level specification for minimum accessibility. Additional design elements must be satisfied to achieve a gold-level specification for enhanced accessibility. All 15 design elements are featured in a platinum-level specification for full accessibility.

Although most housing authorities are only using silver- or gold-level specifications (Australian Building Codes Board 2018), RASAIID was informed that the design and construction of the houses in their cluster would be built in accordance with the platinum-level specifications because the source of funding was government funding. Aspects of the LHD Guidelines were unclear at that time, and interpretation of the platinum-level design elements was contested during construction. In October 2019, after the houses in the cluster were built, the NDIS issued an SDA Design Standard (2019),<sup>26</sup> which would have been the relevant design standard for the cluster if it had existed at that time. This is discussed in the next section.

#### **7.2.6 NDIS SDA Design Standard**

People with disabilities are eligible for SDA funding to live in SDA housing if they have an 'extreme functional impairment' or 'very high support needs' (NDIS SDA Rules 2020, section 11), subject to other criteria. SDA Design Standard 2019 specified the minimum design requirements for four separate design categories to ensure SDA housing is built to meet the particular needs of the person with a particular type of disability. SDA Design Standard 2019 and the NDIS Price Guide 2019–20 require SDA housing to comply with the requirements of the applicable design category. There are four design categories to choose from, and some requirements apply to more than one design category. The four design categories are improved liveability, robust, fully accessible and high physical support.

As an example, SDA housing for high physical support requires a provision for power and an inbuilt structure capable of installation of a ceiling hoist (SDA Design Standard 2019, p. 70). The owner/investor who has built or is planning to

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<sup>26</sup> SDA Design Standard (Edition 1.1 Issue Date 25 October 2019).

build SDA housing can do so before they identify the people who will choose to live in that house. The owner/investor may seek to future-proof their investment and build SDA housing that complies with all design categories in order to offer their SDA housing to the maximum number of permitted residents (up to five) and maximise the revenue they will earn from their investment. The Summer Foundation and Housing Hub (2021, p. 2) found that a large number of SDA housing planned for construction in the future will accommodate only one resident. However, people who are eligible for SDA funding may not want to live where new SDA housing is built, and they may prefer to live with people without disability. The interaction between building practices, building design and SDA funding rules must be flexible to ensure the design responds to the choice of the intended residents.

## **7.3 METHODOLOGY**

### ***7.3.1 Units of analysis***

This research used a case study approach to focus on two units of analysis. The primary unit of analysis was the ‘activity’ to create the adults’ own home in their own community — a community living within a cluster design in a community. The secondary unit of analysis was the ‘actor’ who undertook the activity to create the new homes, whether acting alone or in a group. The actor in the case study is the family group acting collectively as RASAIID and the RASAIID parents. The case is the activity of RASAIID and the RASAIID parents who created the cluster together. The boundaries of the case are the six elements of the activity theory framework:

- 1) What is the desired goal? The object.
- 2) Who desired the goal? The subject.
- 3) Who worked with the subject to achieve the desired goal? Their network and community of actors.
- 4) What resources, strategies and other tools, methods or approaches were used to achieve the desired goal? The tools.
- 5) Who did what? The division of labour.

- 6) What rules, professional conduct, routines, norms or attitudes supported or constrained what people did to achieve the desired goal? The rules. (Leadbetter 2008; Martin 2008; Villeneuve 2011)

There are separate, interconnecting activity systems, including the appointment of the registered service provider, supporting the adults in their own home, but this is outside the scope of this research.

### **7.3.2 Research questions**

The research questions this chapter aims to answer are:

- RQ1: What type of home did parents choose for their daughters and sons with an intellectual disability?
- RQ2: What home did they achieve?
- RQ3: How did they accomplish that home?

### **7.3.3 Sample of research participants**

The primary criterion for inclusion in this research was that parents had achieved housing by taking action themselves. RASAID was identified as a potential case study when one of the parents spoke publicly at a 2015 parent-led symposium for parents who were interested in building supported accommodation. At that symposium, RASAID spoke about the person-centred homes they had created for children in the community of RASAID families with government funding before the NDIS commenced.

Ethics approval for the research was given by the UTS (HREC REF No. ETH17-1412) in 2017. RASAID as a separate legal entity gave organisational consent to each parent's participation in the research in accordance with the requirements of the ethics approval. The three RASAID parents who were research participants each gave consent, as well as written consent to be identified.

The researcher invited the former Disability Minister who assisted the parents to participate in the research and sent the ethics documents to him with his consent. The Hon. Andrew Constance is a serving minister in the current NSW Government and was unable to participate in the study.

#### **7.3.4 Procedure**

Data were collected using semi-structured interviews with three parents directly involved in the design and delivery of the cluster. The three parents were interviewed twice. Semi-structured interviews with probing questions were used to gain a deeper understanding of the meaning, perspectives and experiences that relate to the activities to create these new homes from the perspective of the parents. Additional ad hoc, one-off questions were asked to clarify interview data for cross-case comparison with other case studies from a larger sample for thesis research. All interviews were recorded, transcribed and then managed using NVivo qualitative data analysis software.

#### **7.3.5 Activity theory for data analysis**

While thematic analysis is often used to analyse data in case study research, this study used Engeström's (2001) cultural–historical activity theory, which provided the framework to study contradictions within and between activity systems where the values, priorities and objectives of actors attempting to work together were inconsistent or incompatible. The researcher had assumed that the commitment of government funding to build the cluster of houses meant that agency staff, the architect, builder and housing provider would collaborate and cooperate with the RASAIID parents to deliver the cluster, albeit with some differences of opinion. But it was not anticipated that agency staff would object to the cluster design after it had been approved and funded. Collaboration, cooperation and learning together (or co-learning) was limited to the RASAIID parents and their children. Activity theory offered some understanding of the relationship between pushing back and the parents attaining their housing objectives in the context of contradicting objectives and conflict.

#### **7.3.6 Concepts from theory**

Data analysis applied the concepts of accommodation, housing, home, care and institutions identified in the deinstitutionalisation literature, community living studies, supported accommodation studies, group home literature and research of individual living arrangements. Concepts identified in the power literature were also used. Beliefs, attitudes and practices of bureaucrats and building rules were identified as obstacles and barriers to the attainment of houses and the home environment in a cluster design that reflected the choice and preferences of the



adults. Tools and strategies used by parents to mitigate or overcome obstacles and barriers were studied, along with the relationship between their activities, strategies and decisions with the housing outcomes achieved. Ultimately, parents pushed back and refused to accept any compromise to their vision.

#### **7.4 FINDINGS**

RASAID comprised a strongly motivated, cohesive group of families. Their activities were driven by a shared philosophy, whereby residents in the RASAID community would live together as a community within a community. This was a person-centred project from the perspective of the RASAID parents. The parents identified and agreed upon the housing and care outcomes they desired for the adults, both individually and as a collective. The RASAID families had many meetings ‘to discuss what they wanted as a group and singly’ (Parent Shields, research participant). PATH (planning alternative tomorrows with hope) is a tool for person-centred thinking, planning and practice. The parents had external people visit them to conduct a PATH plan with each person:

*Parent Poole: We did ask each individual that was going to move in where they wanted to live. We built the place for the people that were going to live there, as they requested it.*

As it developed, the cluster design reflected the individual choice of each adult and their preferences as a group. Every adult had a friend or knew someone who would live in the cluster:

*Parent Shields: It became a philosophical thing. Because the advocates and then [the agency] were saying there’s only one appropriate model. But we were saying ‘People in religious institutions can live together, and people in boarding schools can live together. Why can’t we?’*

The researcher had assumed that the study would explore the partnership and collaboration between the parents and government to deliver the cluster model of houses because the disability minister had supported the parents and the NSW Government had committed part of the funding. It was not anticipated that agency staff would object to the construction of the cluster. They told the parents

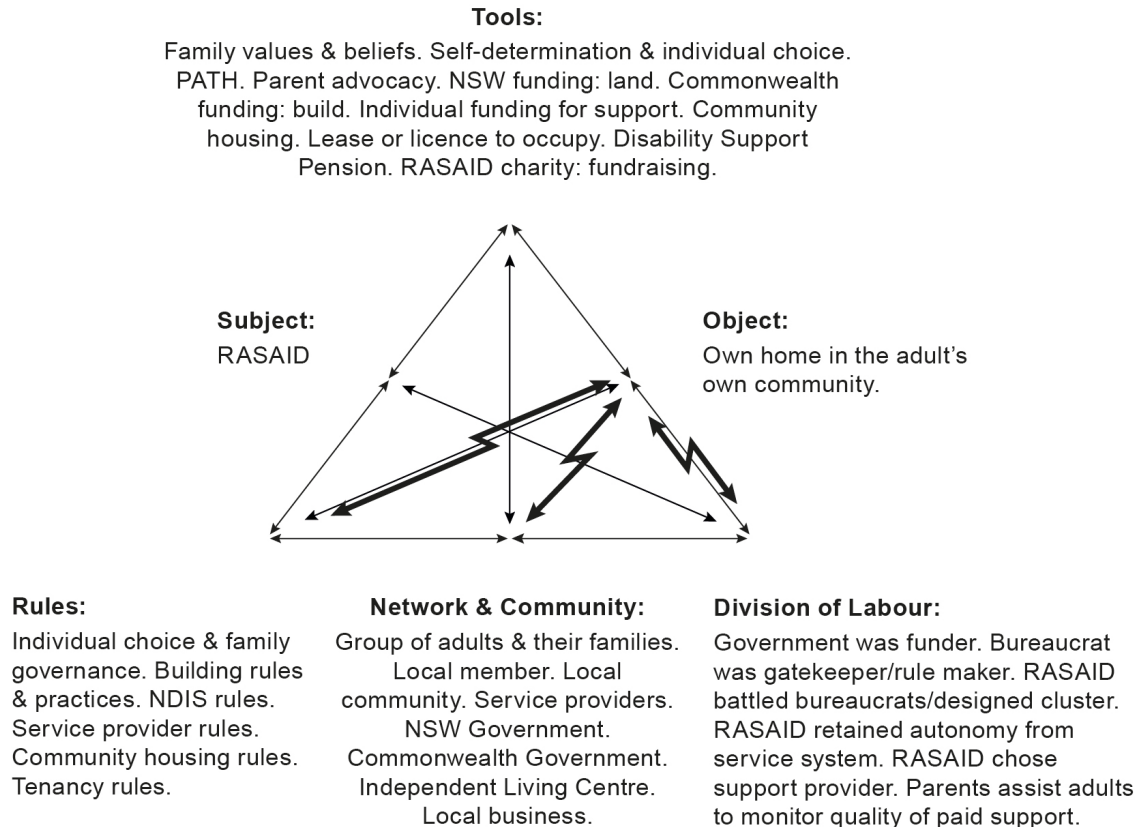
that a group home was the only model the adults could have. As a consequence, collaboration and cooperation between the parents and agency staff was limited. But the RASAIID parents had the power to constrain agency staff and reject the group home model because the families had developed a collective plan and knew what the individuals wanted for their new home within that plan (Parent Rollo). The RASAIID parents were able to communicate the needs and wishes of the adults to the agency, the draftsman, the builder and all project managers on site.

The RASAIID parents accomplished their model because they challenged and pushed back against the lack of understanding of the design and build requirements of the RASAIID parents. During construction, the parents hired the Independent Living Centre to assist them as an expert in building, disability housing and disability. The builder from the centre had a physical disability and used a wheelchair; he was therefore able to provide a knowledgeable, practical demonstration of the aspects of the design, building work, fixtures and fittings that were not required, did not work or could not be used in the manner they were installed. In accordance with the development of activity theory by Engeström (2001), the builder crossed over the boundary between disability expert and building expert.

The tension and incongruence between the conflicting objectives, attitudes and rules created the momentum for change. The parents adapted to the challenges they confronted when agency staff would not give up control or share decision-making power with the adults or parents. The leadership of two parents emerged during the build process. Together, they adapted their role (Heifetz & Laurie 1997) and learned to navigate the community of actors who controlled the funding and the contractors, and they invited themselves into the design, build and fit-out processes. They took action to intervene when the design and building work was inconsistent with their vision of the aesthetic and functional elements of their desired home. In accordance with the development of activity theory by Engeström (2001), the parents straddled the role of advocate and unpaid project manager to oversee the construction project on behalf of the adults and the RASAIID parents.

Engeström (2001) also developed activity theory to accommodate analysis of activity in its social and historical context. The conflict between the opinion and perspectives of parents and agency staff was investigated in that context. For decades, it had been the agency's role to allocate supported accommodation (typically group homes) funded by government. In turn, agency staff determined where adults would live, which is not to say that efforts were not made to find housing locally if possible. It was also the agency's role to manage the group home model as built and funded by the NSW Government. If adults abandoned the group home model by declining to live in them, those housing assets would become vacant, stranded assets that the NSW Government would need to repurpose. Figure 14 depicts the tension and incongruence between RASAIID's desired objectives and the attitudes held or rules applied by government actors with conflicting objectives. This tension and incongruence between the conflicting objectives created the momentum for change in the model for new homes described in this thesis.

**Figure 14: RASAIID contradictions**



## 7.5 DISCUSSION

### 7.5.1 Contradictory objectives

Although the agency had told the RASAIID parents that they were rebuilding institutions with their cluster model, it was politicians, bureaucrats and other people who suggested building the houses in areas that were inappropriate:

*Parent Rollo: Some of their ideas were less than enthusiastically received by us. People were looking for big blocks of land only in industrial areas. So we found the land.*

The location of housing close to the family home and remaining family members, work and other daytime activities was important for these adults who were ageing and could not drive:

*RASAIID: The person with a disability [must] remain close to work or day programs, thereby reducing the necessity for long and expensive travel across the city as now often happens.*

The parents were adamant and persistent in selecting an attractive location in an ordinary residential street. They located multiple blocks of land for purchase, including the block they selected. Finally, the housing provider that held the government funding in their bank account had a look at the land the parents had selected and approved it for purchase. It was a level block, so access issues were not a problem prior to construction (although unnatural levels were unfortunately created during the building work).

Once the land was purchased, the cluster design was the next battle. The RASAIID parents had advocated for a cluster of houses to politicians of the NSW Government. They submitted the concept in their application for SAIF funding from the Australian Government, which agreed to fund construction of the model. After the parents received the funding, agency staff insisted on the group home model:

*Parent 1: We had these advocates and [the agency] saying 'There's only one appropriate model'.*

*Parent 2: [The agency] said everybody has to have their own gate, their own letterbox, their own parking space. And we said, 'But*

*none of them drive'. And they said, 'Well, let's look at the design'. So they prepared this mock design. And in it, everybody had a letterbox, front gate and a car space. And there was no yard. The house, what was then a four-bedroom house, had no windows. You had a front door, a back door, and no windows. So then we said, 'No, look, we're going to have to design it'.*

The cluster was a philosophical choice. In terms of the housing itself, the RASAIID families asked their children what they wanted and then designed it:

*Parent Shields: I always thought my son would want to live in the five-bedroom house. I thought he would need that level of support. But one night we had the plan set up on the kitchen table. And my son said very clearly, 'I want to be by myself'. And so that was the right thing for him.*

This particular group of parents had sufficient motivation, confidence and stamina to contradict and reject the agency's opinion:

*Parents 1 & 3: We had many, many meetings.*

*Parent 1: How many project plans did we have?*

*Parent 3: Twenty concept plans.*

*Parent 2: And finally, in the end, we said, 'No stop. Clear it'. We went over to the draftsman's office and said, 'This is what we want'. We were there for two hours. And we got this basic plan of what we wanted.*

The parents assisted the draftsman to prepare the design of a small-scale cluster of self-contained houses to create each home. In the design, a kitchen, dining area and laundry facilities would be shared space. So the new design would reflect the collective agreement of the RASAIID families for the social configuration of the home environment. However, the agency did not want to build a common room:

*Parent 1: The agency were determined that we weren't going to have a common room.*

*Parent 3: That was a big fight.*

*Interviewer: Yes. It has come up in other case studies; and I don't quite understand. It doesn't really drive the cost. I mean, if you've got the land, the size of the land is the size of the land.*

*Parent 3: It wasn't that. It was that other people's homes don't have common rooms.*

Although the parents approved the final design, the views of everyone else continued to be barriers. Further, there was no process to include the parents during construction:

*Parent 2: Although they had our money, we had our collective plan of what we wanted. We knew what individuals needed within that plan. We said, 'It's our place, so we're coming to your meetings'.*

### **7.5.2 Implementation of the model**

The RASAIID parents invited themselves to build meetings with the builders and the housing provider to ensure their plan for the cluster was built. They faced two problems during the building work. The first was in relation to complying with the platinum-level specification in the LHD Guidelines. The second reflected the multitude of actors involved in the project who were beginning to contribute features that were institution- or facility-like. Both problems are discussed below.

#### **7.5.2.1 LHD Guidelines (Platinum Standard)**

The platinum-level specification to build and fit out the home environment for ageing in place under the LHD Guidelines was unclear and difficult to apply to housing for people with different types of disability and their individual needs and wants:

*Parent 1: The housing provider, and the people overseeing the build, said everything had to be the platinum standard. But everybody's definition of platinum was different. They said everything had to be wheelchair-accessible. They were putting in basins too low, toilets too high and benches were the wrong height.*

*Parent 2: There were no kitchen cupboards.*

*Parent 1: That's right. We weren't going to have kitchen cupboards because we had to have wheelchair-accessible sinks and things. But we said our guys are not in wheelchairs.*

*Parent 3: Two in wheelchairs.*

*Interviewer: Their idea of disability was physical disability?*

*Parent 1: Absolutely. So then we got [the expert] from the Independent Living Centre involved. Fantastic man. He was a builder. And he had an accident so now he's in a wheelchair.*

*Parent 3: He was a gem.*

*Parent 1: So he came around when we'd started building. And he'd say, 'The toilet's too high. I can't go across on to it'.*

*Parent 3: And he was a builder himself.*

*Parent 1: And the basins were too low. And then he'd drive his wheelchair up the paths. He was fantastic.*

The multitude of actors on the building project were prepared to listen to the expert from the Independent Living Centre engaged by the RASAIID parents. That expert was a builder who could interpret the relevant building code, technical rules and design guidelines from the perspective of a person with a disability. As a building expert, he also knew when, why and how to apply the relevant building rules. As a builder with a physical disability, he could demonstrate the incorrect interpretation of building rules on site and demonstrate when something did not work.

#### **7.5.2.2 Signage and other symbols**

It was still a constant battle to prevent the use of facility-like signage and other institution-like features. Some of these were attributed to an interpretation of the platinum-level specification in the LHD Guidelines, and some of these may pertain to the interpretation of the NCC and related technical standards. The adoption of these features and interpretations reflected beliefs, attitudes, practices and rules that singled out disability housing and made it look different. Those interpretations and features would have transformed what had been chosen as a domestic setting into something institution- or facility-like. For

example, the builder was going to install green 'running man' exit signs on every door in the home. Then, one day, wheelchair access stencils arrived for application to the concrete driveway:

*Parent 1: To show them where to park the bus. Like it was a council car park or something. But we said 'no'. And we were able to get the Independent Living Centre on site to tell them this was not needed.*

Eventually, the parents achieved the desired home. It looks like any other place in the same street:

*Parent 3: It looks like a normal place in a normal street.*

*Parent 2: Because we didn't have the cattle grids out the front.*

*Parent 3: That was the other thing. If you have a camber, a ramp of a certain degree, it's got to have rails under the platinum standards. So when it was designed, we made sure that all of the paths up to the front doors and everything else were at the right level so we didn't have to have railings. We drove past one day and they'd put all these railings in.*

*Parent 1: Another stage they put in see-through glass doors for the front doors. We made them take out all the glass doors.*

*Parent 2: And all the rails.*

*Parent 3: They were saying, 'they had to be in because of this'. We said, 'but that was not in the design'. So we ended up getting [the Independent Living Centre] out again. The only way we could get around having the railings [because they had installed the ramps incorrectly] was by not having a gate to every front door which we didn't need. So they had to be filled in.*

*Parent 2: And the paths were re-designed so we didn't have to [have the railings].*

The RASAIID families aimed to deinstitutionalise the appearance of the built and home environment, which would become home to the men and women who now live there:



*Parent 2: It was a deliberate attempt to deinstitutionalise it. Make it look like any house in the street. That was our aim and we actually achieved that. Because you can look around at any houses and you can pick out the disability houses, but you can't do that with RASAIID.*

### **7.5.3 Community within a community**

Social connection with the broader community was also important. Thoughtful activities of the RASAIID parents included the neighbours. For example, RASAIID invited the community to the sod-turning ceremony, and when the houses were built, they invited the neighbours to visit and have a look around. Neighbours who were relatives of the lady who previously lived on the same property were delighted to find that the parents had put that lady's iceberg roses, which had been growing up to the front door of the old house, in pots and back on site. One parent had also made a wooden plaque with the idiom, 'peace in this house', which the previous owner had used to welcome people into her home. The plaque hangs at the front door of the main house.

### **7.5.4 Individual choice**

In relation to choice, these adult women and men have chosen their own home. There were a number of levels where they exercised choice, including the PATH process. Choice became a reality in the case study for the three sons of the research participants. Each family took a slightly different approach to the same process.

One of the young men 'hates change of any sort'. So he started with a single night as a trial. When his parents asked him how it was, he answered, 'not sure'. He returned to the cluster for a second trial night, which was intended to be 'just overnight'. But their son has not been back to sleep at the family home since:

*Parent 1: As soon as he understood this was his place, he said, 'this is my place'. They say of all of them, my son is the most proprietorial. And sometimes he'll tell a staff person, 'this is my place. I don't want you'. I think it is good.*

A second son was meant to move into his new home gradually:

*Parent 3: He went for two nights and he was actually ok. Now, he'll only come home [to the family household] for Christmas and Easter.*

*Interviewer: Otherwise he won't come home?*

*Parent 3: No. He loves it.*

*Parent 1: And he's changed a lot. He's become much more vocal.*

*Parent 3: Vocal, outgoing and again he will say, 'I don't want to do that'. He's completely changed.*

*Parent 1: He's also sort of taken over the role of the tour guide.*

The third son was also meant to have a slow transition. As with the other two men, he visited the cluster when it was being built. His mother chose the cluster for him because she felt he would be safer. But it is also important for him to have people to interact with, because he is used to having a lot of family around:

*Parent 2: He knew this was where he was going to live. I was really afraid that he wouldn't transition well. So I took him there for his first night thinking he would be back home the second night. He hasn't been home since.*

*Interviewer: Why's that?*

*Parent 2: Because that's his house.*

*Parent 3: Actually he would not put his shoes on so he couldn't get in the bus.*

In relation to the home environment, the design and selection of the fit-out was controlled by the parents to the extent they were able to do so. The home environment is person-centred and tailored to the needs of each person living there. Each bathroom is individualised in design, and each adult has chosen their own feature tile for their bathroom. Some of the vanity units reach the floor, and the combination of baths and showers (handheld or fixed) are chosen according to each person. It was important for those with showers to have shower screens, which offer privacy, instead of a single wet room without screens or other fittings.

A couple of the parents persisted in their efforts to have a purpose-built wardrobe for their daughter or son because they have to fit all of their belongings in their room, including linen. Each person also chose the colour of the paint for a coloured feature wall in their bedroom. Air conditioners and fans have been used to get the temperature right. In addition to individual needs, aesthetically attractive features were added to the home environment, including plantation shutters, which the parents maintain. The parents created a home environment that is comfortable, welcoming, attractive and easy to use with their attention to aesthetic and functional detail.

Key workers were not forgotten. Each of the three areas in the cluster has a separate, fully equipped office with a separate bedroom for the paid carer, if required. And, of course, the women and men share the kitchen and the common room, both of which are features in ordinary houses and a characteristic of shared cohousing.

## **7.6 DESIRED OUTCOMES**

The parents were aiming to achieve four objectives irrespective of the design of the house and the home environment. First, some of the parents were in their 80s, so the RASAIID parents were determined to create housing for the adults before their parents died. It was a priority for the family group to manage the transition from living with the family to living in their own home in a planned, timely and orderly way. It came to pass that the mother of one of the men who now lives in the cluster died when she was close to 90. Although her son had lived with her for 50 years, he is very happy in his own home. He is said to be one of the more talkative members in the cluster.

Second, although agency staff wanted RASAIID to build a group home, the RASAIID parents were adamant that these women and men would live in an aesthetically attractive home. The parents were determined to achieve houses that were in sympathy with the street setting where their neighbours live. The objective was to ensure that people driving or walking past the house could not pick them as different. Indeed, as institution-like features were added during the building process, the parents insisted that the builders remove them. The

parents' efforts were a deliberate attempt to deinstitutionalise the home, which they achieved:

*Parent 3: And our place looks like any other place in the street. It looks a bit like villas. In fact, some people came and wanted to know if they could buy some of the villas. Or buy a villa.*

Third, the parents were determined that their children would not be lonely and would live in a community that was welcoming. This social purpose for the home was reflected in the design of the built environment, as well as the social configuration of the home environment:

*Parent 1: We used to say that we hoped that we would be a model that could be used by other people. It was just a pipe dream of ours. It was really like pushing social change. And we didn't know if it was going to be successful. We just thought we were all good friends. The kids didn't all know each other, but they all knew somebody. There wasn't anyone going in without any links at all ... What we didn't understand at the time was how well it was going to work.*

Fourth, it was not the purpose of this living arrangement to increase individual dependence on paid support. Nor was the model a congregate model of care as the bureaucrats viewed it, or a staffing model, which is the basis of the design of the group home model. The parents adopted a new approach. They engaged a non-traditional provider to provide the paid support, and the parents live nearby to provide assistance when needed. As their children established confidence and became more vocal, the parents reduced their oversight role.

## **7.7 UNEXPECTED OUTCOMES**

The parents described the cluster model best:

*Parent 2: It's our way of including our people in the local community; as well as including the local community in their lives where they live.*

Most importantly, their daughters and sons chose what they wanted as home and what they wanted in their home:

*Parent 1: The people that are in single units are in them because they wanted to live in their own unit. We built the place for the people that were going to live there, as they requested it.*

In addition to RASAIID's purposes and the aims of the parents, the cluster residents have a sense of place, control over their home and a sense of ownership. In 2019, the parents flagged a possible opportunity for the adults to move around a bit in the cluster, but a reallocation of their rooms was rejected. None of the women and men wanted to move because they had become very attached to their own space. The parents have described this learning:

*Parent 1: They've attained ownership of their own little place.*

*Interviewer: Did you envisage that?*

*Parent 3: No.*

*Parent 1: They couldn't ever have ownership before.*

*Parent 2: It's a really positive outcome, because they're very house-proud.*

## **7.8 CONCLUSION**

The RASAIID parents defied the view and belief that their children should not live together in a group of 15 adults. They withstood criticism of the cluster housing model by bureaucrats and funded advocacy organisations who told the parents that the cluster of houses for 15 adults would rebuild institutions. Institutions create barriers to community participation, social connection and person-centred supports. The parents argued that if other people are permitted to live together in groups, the RASAIID adults who knew each other should be permitted to live in their group. In any case, smaller groups of up to five people living in group homes that are controlled by service providers can be institution-like. RASAIID demonstrated that the social outcomes for the residents in the cluster were positive in ways the residents and parents could not anticipate. The design of the cluster — as a built and social form — has achieved individual, person-centred homes for residents who are proud to live there. The cluster housing model offers a model for existing groups of people who have strong community ties or who choose to live together because of the nature of their community (The

Cromehurst Foundation 2005). The model is individually designed to provide SIL for groups of people with intellectual disabilities. As such, this is a model that other people with disabilities, and their families or carers, can replicate.

The experience of the RASAIID residents demonstrates that the social benefits of individual and group living require further study. There are 20 families in the RASAIID community of families, with 15 adults from those families living in the cluster. Some of the remaining adults in the RASAIID group are on the waiting list for the cluster. Of the 15 residents, three *chose* to live in the cluster after having tried living in an alternative housing option. This transpired when four of the original 20 adults were offered brand new, individual housing commission or public housing flats after Housing NSW heard about the RASAIID group in the media. The four adults chose to accept the offer and moved into those flats before the cluster was ready. Ms Estelle Shields described their experience:

*Three of them were not happy. They didn't like it. It was too isolating. So, they came into the cluster when we built it. But one of the four is still there.*

A future area of research includes investigating and developing a deeper understanding of living arrangement models from a social relationship perspective. Developing this area of knowledge would improve the design of communities in public and other social housing, thereby enabling better social and housing outcomes for residents.

There is also no research evidence establishing the optimal size of a group home for people with disability, nor any evidence establishing a limit on the size of a group of friends who want to live together. Rules regarding the number of people who can live together must be flexible and accommodate opportunities for stronger social connections, different types of community, choice of location and choice of housemates. Government attempts to do things differently can fail at the beginning if housing policy requires segregated living or limits the group size for people with disability. The NDIS SDA Innovation Plan released in 2019 (NDIA 2019) anticipates that innovation in SDA design will promote independence, community inclusion and transform government-funded housing to move away from high numbers of residents living together. The RASAIID parents offer an

example of this kind of innovation through their alternative approach to housing. The NDIS will fund innovation when government is open to new ideas.

As a model of paid support, the parents reported that the NDIS has driven positive changes within the cluster by ensuring that a sufficient number of key workers who support the residents are funded; this is something that the parents had not anticipated. Although there are issues with the flexibility of SIL funding, and the NDIS provides different levels of individual funding to each adult, the combined funding model ensures that there are three awake workers who are present to assist the residents each night. Any resident can immediately access a key worker in their home 24 hours a day, seven days a week, if they need help.

Finally, an institution is not just about the form of the house, the number of residents or the number of key workers. The parents acknowledge that it is possible to make an institution out of any model. They ensure that household activities are not rigidly organised, and that individual activities and individual relationships with service providers are respected. That is, relationships, activities and routines are individual rather than organised, and they are undertaken for the group. But residents spend time with one another and do things together when they choose.

## **8 CONCLUSION, CONTRIBUTION AND RECOMMENDATIONS**

This thesis presented an exploratory study into how families and NGOs created new homes for adults with disabilities. This chapter summarises the contributions of this research to the practice of institutional entrepreneurship, the field of the study of power, the discipline of social entrepreneurship and innovation in building person-centred homes. It then discusses the contribution to theory and practice.

One contribution of this research is recognition that there are alternative activities and strategies to create pathways for people with disability to live in their own home. Parents and NGOs chose to undertake action and create new homes instead of waiting for unresponsive housing systems to include adults on their waiting list or to allocate housing to them, as there was no assurance that this would occur. A further contribution of this research is investigating innovation as a way or means to bring about change in the housing status quo for ageing adults living with ageing caregivers. Understanding that innovation was not the purpose of the activities and strategies, at least initially, is an important consideration. Innovative models of home or ways to achieve them were related to families and NGOs making do with limited resources. Parents and NGOs were innovative entrepreneurs creating new homes in new ways for adults when housing was essential and there was no other way of achieving it. Innovation was therefore a matter of necessity.

The new models of housing, support and (in the family case studies) family governance evolved through the activities of parents and NGOs irrespective of policy and funding boundaries around housing systems and service systems. How traditional housing systems should respond to these bottom-up initiatives and whether traditional models of supported accommodation will adopt aspects of these new models to achieve positive housing outcomes for more adults are issues for other NGOs and policy-makers to consider. Alternatively, traditional housing systems and service systems can remain closed and unresponsive to new ideas and changing models of home. However, investigating the characteristics chosen for different elements of these new types of living arrangements, and the resources required to achieve such characteristics, is the



next step for caregivers, NGOs, policy-makers and others who want to address the gaps and limitations in housing supply using these new models.

## **8.1 STRUCTURE OF THIS CHAPTER**

In this final chapter, the contributions and policy recommendations of the thesis are outlined, the limitations of the research are identified, achievement of the study aims is demonstrated, areas for future research are highlighted and final conclusions from the research are presented.

## **8.2 CONTRIBUTIONS TO THE DISCIPLINE OF INSTITUTIONAL ENTREPRENEURSHIP**

This thesis applied the theories of institutional entrepreneurship and social innovation to the study of family and NGO activities and strategies to investigate new models of home for adult children with high support needs. Institutional entrepreneurship and social innovation are theories of action that explain the role of families and NGOs as advocates and change agents who achieved better housing and household outcomes for the adults. Using activity theory for data analysis, the research established the relationship between system-level activities and strategies, which persuaded government actors to support new models of home, and family and/or NGO activities, which pulled resources and other inputs together at the system, community and household levels with government support. Seeking to assist their children to live independently, the parents achieved new models of home by choosing, organising and controlling the location of the home, key workers and housemates.

The theories of institutional entrepreneurship and social innovation also explained how effective (powerful) family governance drove institutional change and social innovation to meet housing needs in a non-market (family) and quasi-market (not-for-profit) context. Families and NGOs created new pathways into those new homes instead of waiting for approval to join a housing waiting list. This meant that the adults with high support needs were no longer confined to the family home or segregated group homes.

Table 18 lists the diverse sources and ownership of the housing used in the case studies. The research confirmed the expansion of the disaggregated housing

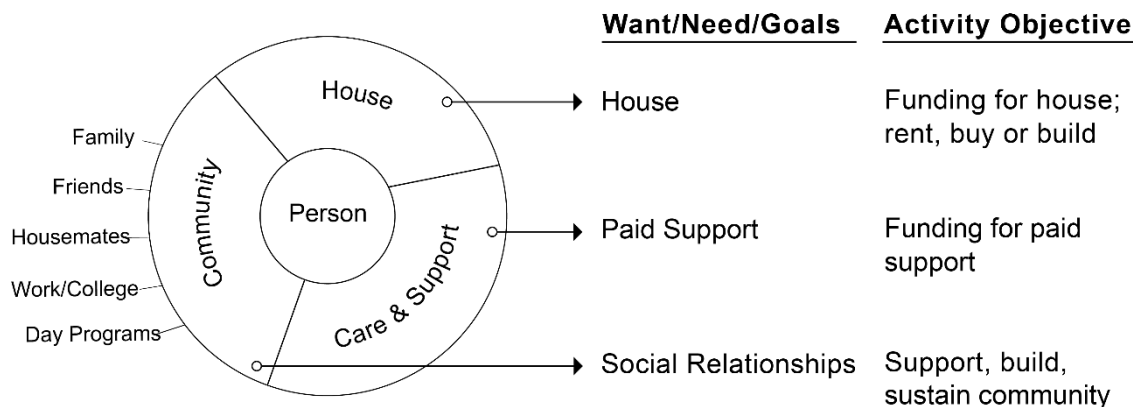
and disability service systems occurring in Australia to meet housing needs (Sach and Associates, Miller & Burke 1991).

**Table 18: Types of housing**

Case studies	Source of housing
Case #1	Own home
Case #2	Public housing rental
Case #3	Private rental
Cases #4 and #5	Community housing rental x 2
Case #6	Houses owned by Waverley Council or rented from a community housing provider by Waverley Council
Case #7	Hartley is not a housing provider
Case #8	SILC is not a housing provider
Case #9	JewishCare is not a housing provider
Case #10	Newly built SDA housing
Case #11	Housing or land to build it not yet attained.

Each research participant identified care and paid support, community, and housing (see Figure 15) as the three core housing objectives that support the social inclusion of their adult children.

**Figure 15: Three elements of home — pre-NDIS**



These three core elements align with the emerging map of connected, interdependent activity systems illustrated in Figure 3 (Chapter 4). The depiction of the connected, interdependent activity systems in Figure 3 unifies action research, activity theory and theory of change in this thesis. Institutional entrepreneurship is a theory of social change and institutional change, namely, more housing for adults with disabilities, and new models of home created by parent and NGO activity.

### **8.3 CONTRIBUTIONS TO THE FIELD OF POWER**

This thesis applied theories of power to understand and explain the experience of families with system-level barriers that prevented the adults accessing government-funded housing or paid support. The research established the relationship between system-level activities and strategies that developed organisational and relational power with politicians and governments as allies, and community-level activities and strategies to mobilise community support and exercise power-over, power-to, power-within and power-with. Entrepreneurial bricolage was the field of literature that explained the pattern of behaviour that families were observed to engage in when resources were limited. Parents were advocates and bricoleurs, using their limited resources to develop and exercise four sources of power to achieve their housing objectives: organisational power, community power, relational power and personal power. Entrepreneurial bricolage explained how the four types of power were developed and used. Parents built community support and power in their own communities and developed power-to achieve housing outcomes by working with different levels of government in partnership with political allies and voting citizens.

Parents achieved better housing and support outcomes for the adults by combining limited resources in new ways for new purposes. They worked within, around and across traditional housing and service system boundaries to secure resources and create new homes where existing housing and service systems had not done so. The parents joined or formed organisations to build a larger platform for their advocacy to reach voting citizens, and they took action with other families to attain housing with paid support for their adult children. The parents mobilised community support by running campaigns and public meetings and ensuring that politicians were invited and present. Their political strategies built political support for the housing objectives of these parent advocates and relational power with politicians as allies. Parents achieved new homes through their determination and perseverance. Parents and other advocates achieved system change through the reform of disability policy and individual funding. Power as a theory of action explains how parents exercised the power-to mitigate or overcome barriers to achieve their housing objectives.

## **8.4 CONTRIBUTIONS TO THE DISCIPLINE OF SOCIAL ENTREPRENEURSHIP**

This thesis developed an emerging map of institutional entrepreneurship, social innovation and social entrepreneurship as overlapping areas in each field when social means were used to meet the housing need and collaborative innovation was achieved. Key concepts from the literature and theory of social entrepreneurship and social innovation were applied to investigate the collaborative effort of families, friends and NGOs using activity theory for data analysis. These concepts included social enterprise and social value. In this thesis, social enterprise was continuous activity by families, friends and NGOs to achieve new homes for adults with disabilities and, in some case studies, co-residents who chose to live with them. Social value was created when housing needs were met by the social enterprise of families, friends and NGOs. Social entrepreneurship is a theory of action and a theory of social change that explains resource-seeking activities in innovative ways or that explains innovative ends to achieve a public, community or other social benefit.

The means or ways in which the social need for housing was met were important. Acting as social entrepreneurs, families, friends and NGOs combined their respective resources to create impactful social value (Leadbeater 2006) as partners and collaborators. Grassroots, family led initiatives for new homes were implemented at the intersection of the family or household sector, the not-for-profit sector, the public or government sector, and the market sector for private rental properties or building work. These initiatives and the social innovations that emerged from the unfolding activities included the changing roles performed by families, friends and NGOs, their changing relationships with each other, and the empowerment of disabled adults to live in their own home when their access to power and resources improved (TEPSIE 2014, p. 9). The families and friends had autonomy in decision-making and choice-making in the family case studies, and like-minded NGOs shared power and responsibility for decision-making when designing, delivering or operating new models with parents.

The eight features of social innovation identified by TEPSIE (2014), and the earlier work of The Young Foundation (2012), were found to be present in the

case studies. Research by TEPSIE (2014, p. 12) also identified five stages of a social innovation lifecycle:

- prompts — where the need becomes apparent
- proposals — where ideas are developed
- prototyping — where ideas are tested in practice
- sustaining — when the idea becomes everyday practice
- scaling — growing and spreading social innovations.

The Enabled Housing pilot project (Chapter 6) was a prototype in the testing stage of the social innovation lifecycle. In contrast, the Co-resident Support Model (Chapters 4 and 6) was in the sustaining stage of the social innovation lifecycle because it had been operating since 2013 for a smaller group of three adults. SILC's co-operative of family governed households (Chapter 4) had received seed funding from the government for the purpose of achieving scale, namely, helping other families establish their own family governed household so that more adults could achieve their own home. Consequently, SILC is in the scaling stage of the social innovation lifecycle. However, more government assistance with the housing element is required — specifically, government-funded housing — in order to test more innovative ideas in practice, sustain innovative ideas day to day and achieve scale in new living arrangements for more adults.

## **8.5 CONTRIBUTIONS TO INNOVATION IN BUILDING PERSON-CENTRED HOMES**

This thesis applied the concepts and themes in the literature and research regarding deinstitutionalisation, community living and models of housing with paid support in a modern context. This was research regarding the vision for building or creating better housing, better care and support, and other positive outcomes that were sustainable for ageing adults living with ageing parent caregivers. The research offered an opportunity to present the type of home that adults and parents wanted, including a social configuration that accommodated friends living together as a community within a community. The desired housing objectives also included an attractive house in an ordinary street that did not look

like an institution- or facility-type residential setting for people with disabilities. This thesis combined theories of action, action research and activity theory to contribute a synthesis of home, caregiving and service systems in relation to which the roles of families, NGOs and governments are changing. In the new living arrangements that have been established, caregiving is shared, and planning for children to live locally before their parents die, or are no longer able to provide caregiving, is implemented.

## **8.6 EXPLANATION OF BARRIERS AND SUCCESSES**

### ***8.6.1 Housing as a barrier***

The case studies confirmed that the barriers to attaining new homes for adults included the cost of housing, the cost of land to build housing and the cost of rental properties. For parents and NGOs, limited social housing was a system barrier, and the cost of land and housing was a resource barrier. Three of the 11 case studies (Intentional Community Case #2, Sutherland Shire Independent Living Case #4 and Ryde Cluster Case #5) secured newly built houses through government-funded construction for which land was also acquired. When completed, housing for the Benambra intentional community in Case #2 was allocated to the ACT's public housing system. Housing for the two large family groups in Cases #4 and #5 was allocated to the community housing system in NSW before they were built. Both housing systems had previously excluded these adults, although it is not known whether their exclusion from government-funded housing systems was related to a lack of housing, the need for live-in support or other factors.

Challenge Southern Highlands Case #10 was the only case study in the sample of 11 case studies in which an NGO taking the initiative to create or support new homes both built and retained ownership of new housing for adults who wanted to live locally. It was also the only NGO in the sample for this research to secure land donated by a local council. The starting point for this housing success was the advocacy of Mr Tony McElhinney, General Manager of Challenge Southern Highlands and the support of the Board of Challenge Southern Highlands for this initiative. Mr McElhinney and a parent presented a persuasive case to their local council, requesting the donation of land to build Challenge House. When Mr

McElhinney was informed that the land would be transferred to Challenge Southern Highlands, he lodged a successful expression of interest for a NSW Government grant that would fund the construction of Challenge House. Philanthropy and donations from the local community enabled Challenge House to open and operate until the vacancies were filled. Challenge Southern Highlands is among a group of first-time SDA housing providers that have joined the growing NDIS-funded SDA housing market in Australia.

HOME Case #11 was an unsuccessful case study because it did not acquire land to build homes for adults with a mild to moderate intellectual disability, which was HOME's vision. When HOME lobbied the NSW Government and a local council to support their model, there was a good response. HOME received government funding to complete a design and feasibility study, which they based on land in Sydney that they had reason to believe they could access. HOME completed the feasibility study but, ultimately, could not secure the land. HOME then negotiated to purchase some of the units in a proposed property development. This plan fell through when the developer sold his land to a new developer who had no interest in HOME's model or concept. Attempts to lobby the local council for land both then and subsequently have been unsuccessful. HOME cannot proceed with its plans until land is forthcoming. The review of the HOME case study confirms the experience of families in the successful case studies, namely, that the gateway barrier to acquire land and fund construction is high, and more government assistance to overcome this barrier is needed from all levels of government.

### **8.6.2 Limited involvement of NGO service providers**

Historically, NGO service providers in the disability service system that provide care in supported accommodation did not describe themselves (and were not registered as) housing providers. Typically, the housing that NGO service providers have used to provide care in group homes or other supported accommodation was government-owned, rented, family owned or donated by the community or government for that purpose only.

However, NGOs were important allies for the parents. In PaRA Co-operative Case #3, two third-party NGOs were critical allies because they organised a meeting between the most senior bureaucrat and Mr Anthony, which they also

attended. This gave Mr Anthony an opportunity to propose his family governed model, which the CEOs of those NGOs also supported. One of the NGOs was the first service provider for the PaRA home when it was set up, although that NGO was later replaced by the PaRA Co-operative, with the approval of the government. In Cases #2, #4 and #5, NGO service providers did not provide housing but provided paid support when the adults moved in. In two other case studies, NGOs were established by parents and friends (SILC Case #7 and HOME Case #11). JewishCare is not a housing provider and did not provide housing for the Enabled Housing pilot project, but it was an important partner, collaborator and supporter of that social enterprise.

SILC is an NGO that is not a housing provider and does not provide housing for the family governed households that are members of SILC. Hartley (Hartley Case #8) supported the three men in the Benambra Intentional Community, but the houses for the intentional community were built by ACT Housing. HOME Case #11 has been unsuccessful so far, but it has sought to partner with a housing provider or developer who will build housing privately. Challenge Southern Highlands is the exception among the NGOs in the sample because it built Challenge House. Challenge Southern Highlands was also unique within the sample of case studies for this research because it was an Australian 'disability enterprise' that provided employment for people with disability. Challenge Southern Highlands has expanded its social purpose to include the provision of SDA housing and SIL-funded support.

Although the NGO service providers were not a critical factor in the attainment of government-funded housing in the family case studies, the success of the parent/NGO partnerships in Intentional Community Case #2, Hartley Case #8, (Sutherland Shire Case #4) and RASAID Cluster Case #5 enabled the parents to remove themselves from the day-to-day high support needs of their children. In Cases #3 and #7, SILC as NGO will provide critical institutional support as parents get older, although the parents running family governed households are still highly involved in the lives of their children.

Eastern Suburbs Case #6 was a unique case study within the sample of case studies because Waverley Council (which is not an NGO) had the foresight, capacity and social-mindedness to establish the Waverley Community Living



Program for people with disabilities living locally. The mother in Case #6 has had important partnerships with organisations that employ or otherwise support her daughter. The mother and daughter have worked closely together for the daughter to achieve independence and live alone if she chooses this option. Eastern Suburbs Case #6 was similar to the other family case studies because the partnership with the Waverley Community Living Program was only part of the story of the success achieved through the continuum of the parents' caregiving over their child's lifetime.

### ***8.6.3 Determination and persistence of parents***

In every case study, success was preceded by a significant effort from the parents to engage politicians. That is, the living arrangements that the families achieved required determination, persistence and 'dogged perseverance' (Parent Shields, Case #5). A handful of empathetic, supportive and at times opportunistic politicians in NSW, the ACT and federally helped families attain new homes for their adult children in response to the parents' determination and persistence. The parents' political strategies required meeting politicians at every level of government: politicians in power and in opposition. Politicians in the newly elected Commonwealth Government and the NSW Government implemented policy change in disability when voting citizens and communities across Australia agreed that public funding must deliver long-term, high-quality care and support for people with significant disabilities and high support needs. People with disabilities, families, other caregivers and advocates had reached a consensus for the NDIS in parallel with the activities of parents and NGOs in this research. The RASAIID case study was unusual in that the Commonwealth Government helped fund construction of the innovative cluster by awarding a grant for innovative housing, even though state and territory governments were responsible for the provision of housing at that time. This occurred when the federal, state and territory governments were renegotiating their respective responsibilities to deliver a national disability scheme across the country. It also confirmed the changing political agenda and that community attitudes can either contribute to housing success or block it.

#### **8.6.4 Least cost to government**

It is arguable that the family governed home model in its various forms had NSW Government support in Cases #1 (Own Home), #3 (PaRA) and #7 (SILC) because it was a lower-cost model for the government to fund than the traditional group home model, which the parents did not choose anyway. The continuing involvement of families overseeing the quality of paid support, as well as the safety, wellbeing and happiness of the adults and their key workers, was a significant (unpaid) contribution made by parents. In turn, the replacement of traditional service providers with unpaid family governance or low-cost SIL services from like-minded or family governed NGOs removed or controlled and reduced the overhead costs of a traditional service provider's management structure that the government had previously funded. Cases #1 and #3 demonstrated these savings at the time the parent participants were interviewed. After the interviews, the parent in Case #1 engaged a like-minded service provider when housemates joined her daughter in her own home. The families in Case #3 engaged the family governed SILC as a low-cost SIL provider and cancelled PaRA's registration as a service provider. In addition, the family owned apartment in Case #1 (Own Home) and rental housing in Cases #3 (PaRA) and #7 (SILC) delayed the government's contribution to the capital cost of housing for those adults.

From the family's perspective, any model with rented housing should be quick to execute (if the NDIA processes applications for NDIS SIL funding quickly, as required) compared with a waiting list system. Where families organise rented housing, the transaction costs are also lower for the government because agencies do not need or employ the staff or skills to organise the rental properties. In effect, governments have outsourced the cost and activity of the organisation of rented accommodation to parents who have taken on the role of pulling the bits and pieces of each model together. In turn, parents with their children have control and choice over the elements and characteristics of the adult's home.

The families and NGOs who designed and/or delivered new models have evaluated the outcomes of their design in practice. They possess a significant body of knowledge they have learned by taking action and setting up new homes:

*Parent Anthony, Case #3: My view is that, when the government says, 'We'll do something different, if it's demonstrated by experience', it denies you the ability to do anything different. A lot of government policy says, 'We want an evidence base'. But our view is, 'Let's work out how to do it, and we'll collect evidence along the way. But don't wait. You're not going to find the evidence if you can't do it differently'. Where there's a reason then that's enough of a reason to do it. Then you can find out whether the method you employed achieved the objective or not.*

The NSW Government has issued industry benchmarking documents to inspire and guide building innovation and better social housing (NSW Land and Housing Corporation 2020a, 2020b). SDA housing is an example of government doing something differently to address housing needs, and SDA housing providers (which include the NSW community housing providers for whom those benchmarking documents were issued) must also deliver building innovation and better housing outcomes for residents and neighbourhoods. This research demonstrates that building innovation, better housing outcomes and more housing for adults can be achieved by all housing providers, whether they are community housing providers, other NGOs or parents responsible for housing that is state government-funded or NDIS-funded. The contributions of this research to theory and practice and policy recommendations are discussed in the next section.

## **8.7 CONTRIBUTIONS AND RECOMMENDATIONS**

This section delineates the theory contribution, practice contribution and policy recommendations of this research.

### **8.7.1 Theory contribution**

As discussed above, this thesis applies the theories of institutional entrepreneurship, social entrepreneurship and social innovation to the study of family and NGO activities and strategies to achieve housing objectives. Institutional entrepreneurship, social entrepreneurship and innovation are theories that are usually applied to explain resource-seeking innovations in for-profit markets. A growing body of social entrepreneurship literature also explains

social enterprise and social entrepreneurship in a for-profit market context. However, market actors and governments have failed to address housing needs when left to their own devices. These theories were therefore combined and applied to family and NGO not-for-profit activities and strategies to explain how effective (powerful) family governance and innovative initiatives of families and NGOs drove institutional change and social innovation to meet housing needs in a non-market and quasi-market (not-for-profit) context. In a resource-constrained environment, the application of these theories to family and NGO activity is timely and important.

Battilana, Leca and Boxenbaum (2009) identified that there is limited discussion in the literature about the intersection between institutional entrepreneurship, social entrepreneurship and social innovation. As discussed above, this thesis contributes an emerging map of overlapping areas in these separate fields when social means are used to meet social need and resources are limited. The theory of power, the concepts of power-over, power-to, power-within and power-with, and the use of activity theory for data analysis also unified the study of institutional entrepreneurship, social entrepreneurship and social innovation as theories of action. This confirms the view that new initiatives at the intersection of different institutional fields (e.g. the family, the state and the not-for-profit sector) are 'more likely to spawn institutional entrepreneurship' (Battilana, Leca & Boxenbaum 2009, p. 76).

The use of activity theory is a methodological contribution of this thesis. Activity theory was used to organise cross-case data and apply theory to action research as an alternative to process analysis (Battilana, Leca & Boxenbaum 2009) and an alternative to input, output and outcome theory of change thinking (Center for Theory of Change 2021). The activity theory diagrams are an innovation that unify action research, activity theory and theory of change.

### **8.7.2 Practice contribution**

The practice of families partnering with not-for-profit NGOs and different levels of government to address gaps and limitations in housing supply can be undertaken by more people with disabilities and their caregivers. It can take some years to develop ideas and a vision for home, collect evidence from

existing models, and locate and mobilise allies with the authority and power to assist people or caregivers to achieve housing. Thus, it is recommended that people and caregivers in search of housing start taking action early, before housing is required, and develop specific choice-making and decision-making strategies that align with and develop individual and collective housing objectives. The practice of identifying or creating opportunities to secure housing or paid support, and being prepared to compromise or change the desired housing objectives over time, can require knowledge and skills that are learned by taking action first.

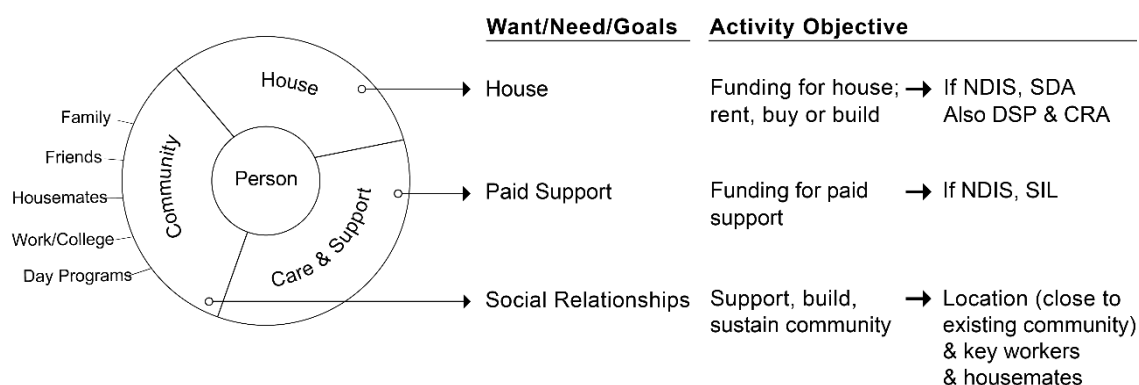
The practice of families seeking to partner with not-for-profit NGOs and government will be required to address NGOs' and governments' usual practice of and preference for working in partnership with each other to deliver government-funded services or assets (Shergold 2016), rather than in partnership or collaboration with the service user including, in this case, residents with disabilities who need or want to live in social housing. NGOs in the not-for-profit sector have limited resources, so it is timely for more NGOs to investigate different opportunities, partnerships with potential service users and social value that can be created when people with disabilities are located at the centre of government investment to meet housing needs rather than market interests.

The research confirmed that the practice of advocacy by parents and NGOs to achieve housing change occurred along two dimensions: horizontal and vertical (Mathie & Gaventa 2015, p. 5). As horizontal activity, parents and NGOs actively engaged with other families and communities to solve housing needs using local, community and family resources. As vertical activity, parents and NGOs engaged in organised action 'oriented towards claiming rights and shaping decisions of the state' (Mathie & Gaventa 2015, p. 7). Activity theory provided the framework to study the practice of advocacy, organisation and collective action along both dimensions. This thesis is a reminder for people with disabilities and their caregivers to be most strategic when politicians have no authority or power to change the housing status quo. Community campaigns and connecting with others to develop power-within, power-to and power-with is critical in this scenario. The research also demonstrated the importance of context and complementary collective and individual processes when taking action. Parents

learned advocacy, organisation and political strategies together and from each other. Family practices included working with family groups as a collective to achieve individual goals for each adult.

Last, the SDA framework under the NDIS is a pathway framework that was not available for the adults in the family case studies at the time their parents created their new homes. That framework should now operate to provide SDA housing applicants with the information they need and the administrative infrastructure to assist with their application, including how to apply for SIL or SDA funding, what happens when an application is lodged, what happens when it is approved, and how approved SIL and SDA funding must be spent. This pathway framework should also offer certainty of an outcome for eligible people and a transparent process with eligibility criteria that apply equally to applicants for funding, regardless of whether SDA housing is the applicant’s preferred choice. Figure 16 illustrates the pathway to SDA funding for housing and SIL funding for paid support for eligible adults.

**Figure 16: Housing pathway elements — post NDIS**



Legend: NDIS = National Disability Insurance Scheme; SDA = Specialist Disability Support Accommodation payment; DSP = Disability Support Pension; CRA = Commonwealth Rent Assistance; SIL = Supported Individual Living payment.

**8.7.3 Policy recommendations**

This section contributes and reinforces seven policy recommendations, some of which governments, NGOs, families, advocates, peak bodies and researchers have suggested previously or may be underway.

First, individual housing systems that use public funding must be appropriately resourced to meet the housing needs of adults with disabilities. Reliable data on housing demand are required to quantify housing needs generally, and in planning to meet housing demand in appropriate locations specifically for adults

with disabilities. Housing waiting lists have missing data, out-of-date data and recording errors (AIHW 2020). Therefore, the AIHW or another body that is independent of state and territory governments must share with those governments the role and responsibility of more actively improving the recording and public reporting of general housing demand data and specific housing demand or housing need data for people with disabilities. Housing need, the location of housing need and the cost for meeting housing demand in the locations required by people with disabilities (buying, renting and/or building) can be identified from better-quality datasets from multiple sources. Adequate government funding is then demonstrated when the supply of all types of housing for people who need it is increased. Housing need on a large scale will not be met if the government's response is tied to a specific housing system, its rules and its waiting list.

Second, the cost to meet the housing need must be calculated, budgeted and expended over time. Housing systems also require regular investment for maintenance and growth or they will decline and dissipate. Governments should identify initiatives that will reduce the cost and delay in the construction of government-funded housing. Future research may include a comparison of the cost to build for private use with the cost that building professionals charge government development projects and the basis for any higher building costs. Funding saved from reduced building and project costs across housing systems can be reallocated to buy real estate in areas where land is expensive but more appropriate for the intended residents.

Third, demand data are needed by relevant market actors who will increase the housing supply if they have better information.<sup>27</sup> That is, data regarding the number of people who need housing, and the location and type of housing they need, must be available to investors, developers, builders and housing providers. An independent national coordinator of planning must be appointed to aggregate, report and share housing demand data for different types of housing. This will safeguard the consistent operation of all housing systems to achieve better outcomes for people with disabilities as a shared objective. SDA demand

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<sup>27</sup> The NDIA has always expressed its commitment to report the data it collects to support the creation of a market in NDIS-funded services.

data supplied by the NDIA measures only one category of housing demand because SDA is only part of the whole housing system.

Fourth, people with disabilities want to choose from a diverse range of housing options like everyone else. But the policy boundary between particular housing systems (like public housing and SDA housing) can hinder movement between systems as housing needs change. A pathway framework and processes that will assist people with disabilities to move if they choose, and to achieve equitable and efficient access to housing of their choice in any system, must be developed. The need to move between housing systems can be driven by changing location requirements and changing relationships with housemates, neighbours or friends over time. Indeed, an objective of the NDIS was mobility, so that people would be able to cross over jurisdictional borders (from one state or territory to another) and take their NDIS funding with them. In a similar way, people with disabilities must be mobile between housing systems and remain eligible for NDIS SDA funding if they choose to leave the SDA housing system. That is, if a person with a disability is eligible for SDA funding at one point in time, they should be eligible in the future. Rules and other structural safeguards are required to ensure that providers of SDA housing will enable the mobility of their tenants between houses and housing systems.

Fifth, to bring demand and supply together, a formal pathway system with supporting processes must be established to support people with disability (with or without NDIS funding) to navigate between all housing options in all systems, including private rental, private housing available for cohousing, boarding houses, public housing and community housing. A national system with performance objectives similar to those stated to exist for the NSW Government's Housing Pathways system is a starting point (FACS 2020), with one exception. A single waiting list is not recommended because it has not been demonstrated to be efficient or effective in the allocation of housing. In NSW, the waiting list has become, or has always been, a priority waiting list. The case studies highlight the risk that a register or waiting list can give administrators or systems the power to exclude housing applicants. Other important initiatives in the not-for-profit sector offer additional pathways, all of which can be located within a holistic framework. These initiatives include the 'NEST' domain.com.au-



style website and its listings of available housing, launched in May 2018. The Summer Foundation's 'The Housing Hub' website is a similar initiative that began as a pilot project in 2017 and includes SDA housing built by Summer Housing among its advertised vacancies. DisabilityHousing.com.au advertises properties for sale and for rent, and also provides an 'accommodation wanted' section for would-be occupants. Opting out of these initiatives would give housing providers power-over people with disabilities in need of housing, limit the choice of applicants and increase the choice and control of housing providers.

Sixth, incentives to encourage families to invest in housing for their children should be considered. Anecdotally, successive politicians in the NSW Government have been approached for relief from stamp duty and land tax as potential incentives. These approaches have been unsuccessful to date. However, the NSW Government may now want to provide assistance that increases flexibility and choice for families to opt in and out of a property investment model using incentives of this kind.

Finally, default providers of SDA housing must be appointed in local government areas where a sufficient number of different types of SDA housing are not built. Default providers of SDA housing must be appointed by a government minister or agency to ensure public transparency and public accountability. Default providers must be appointed for a single (and reasonable) term that is fixed to reduce the risk of fraud, complacency, overcharging and monopoly status of a default provider. The objectives of a default provider scheme must include increasing the number of providers of appropriately designed, good-quality SDA housing in local areas to ensure eligible people with disability do not miss out.

## **8.8 LIMITATIONS**

This research has methodological and scoping limitations. It was an aim of the research to understand the perspective of parents who worked hard to establish their daughter or son's own home, but there are other perspectives. The bureaucrats and politicians who interacted with the research participants have mostly left their roles. ADHC no longer exists, which means that approval to interview agency staff was not available, and it would be difficult to locate former staff. In any case, it was a conscious decision not to attempt to reconcile

conflicting recollections and perspectives. The key NSW politician who helped the families in two case studies is a serving minister of the current NSW Government and was not available to participate. One former bureaucrat was interviewed on the condition of confidentiality, so his information has not been disclosed. NGO staff who had worked closely with some parent research participants had left the employment of those NGOs, and current NGO CEOs were not CEOs at the relevant time. In any case, it would be unethical to adversely affect the working relationship between families and those NGOs today.

The research design was changed to include institutional actors other than families to expand the voices heard and the perspectives analysed for the study to some degree. But there were scoping limitations in the approach adopted. While the research question was amended to ask how NGOs, as well as families, created new homes, it was a limitation of the study not to extend the research question to ask how government or agencies created new homes for other people with disabilities over the same period. Governments may want to present the spectrum of their innovative initiatives across Australia in a separate study. The NDIS SDA Innovation Plan 2019 is an opportunity to document and report on some of those efforts.

The criteria for joining the case study sample and the requirement that the family member or NGO was seeking or had achieved new homes was a methodological limitation to including more NGO case studies in the sample. Conversely, the sample and the study of the activities and strategies of this group of actors addressed a gap in the literature and offered a way to present new ways of working between families and NGOs. This is an important area of focus because not-for-profit NGOs generally do not have sufficient funding to meet the growing housing need. This is not a criticism of those NGOs, but an aspect of the constraints on how government funding works in the social housing sector in Australia.

## **8.9 ACHIEVEMENT OF STUDY AIMS**

The study and research findings met the five aims of the study described in the preface.

The role of families and NGOs as advocates and change agents was investigated. The thesis shared examples of the changes achieved through individual and collective housing advocacy, community support, individual funding, and new roles and relationships between families and NGOs who designed and/or delivered housing solutions together. The mixing and matching of resources from different sectors and actors enabled new models of home. Whether the NDIS will drive or limit such activities in the future is an area for future research.

The activities and strategies undertaken by families and NGOs as allies of the adults in the case studies were explored (see Chapters 4–7). NGOs and families were found to work closely together in the co-design and co-delivery of services. In their case studies, these allies shared decision-making power, pooled their resources and executed housing projects together.

The interpretivist approach, the interview method, the selection of families and NGOs as ‘subjects’, and the use of activity theory in the data analysis ensured that the study listened to the voices of families and NGOs, presented their perspectives and demonstrated their contribution to achieving more housing.

This study presented the service-providing and caregiving role of parents, other family members and friends who continue to monitor, oversee and support the new living arrangements they established. The research shares the lessons learned by parents and NGOs<sup>28</sup> about what worked and what did not, and the importance of the communities they formed. Access to fit-for-purpose housing and housing systems that accommodate the diverse range of housing needs in our society remain a costly barrier to housing solutions. The housing and paid support models that were established require institutional support to be sustainable into the future, and to be replicated. Governments also want to innovate, offer choice and fund better housing and paid support models. The study demonstrated that governments could engage with and support these initiatives to address the housing need more quickly.

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<sup>28</sup> They developed new, stronger tactics when their polite requests for assistance and better services failed (Panitch 2008).

## 8.10 FUTURE RESEARCH

Areas for future research were identified in the thesis. These include interviewing the residents who moved into their own home to establish their satisfaction with their home and, separately, the quality-of-life outcomes for both the parents and their adult children. The role and contribution of other actors across the disabled person's network of social relationships and service providers is another important study topic. This may capture the role of key workers and the relationship between positive outcomes, including the length of time they have spent working with an adult. It would be significant to investigate the effect of grassroots activity and innovative initiatives on broader system change over time. This includes changes in the design and operation of existing group homes, and the pressure to change those traditional models to keep up with family led initiatives. It is important to understand whether the NDIS is driving or limiting innovation and whether it mitigates or overcomes resource and system barriers in different housing systems. Families may contribute feedback on their experience with SDA housing as a funding model and housing system from a demand perspective. Future research must include this feedback when it evaluates the effectiveness and efficiency of the SDA and SIL framework, including delays in the approval and payment of these funding streams.

This study provided baseline data on existing government support for the sustainability or replication of the models in the case studies. There are potential case studies for future research that could be spin-off case studies. For example, the 11 other household members of the SILC Co-operative (Case #7) could be spin-off case studies if they agreed to participate in future research. Hartley Lifecare (Case #8) uses the Co-resident Support Model for people other than the three men who live in the intentional community (Case #2). The use of the co-resident innovation for more families by Hartley or other providers could form spin-off case studies if they agreed to participate in future research.

Ms Parker is the Disability Services Manager for JewishCare and the research participant for JewishCare Case #9. She spoke highly of her brother's friendly neighbour model in an intentional unit block in Glasgow, which she would like to replicate in Australia. A study of her brother's experience of home and his unique model in Glasgow could be a future spin-off case study with the brother's

consent. Ms Carter was a research participant who is known to or worked with parent advocates in Cases #1, #4 and #5. She provided a thick description of her activities supporting her son to attain his own home. Ms Carter is also part of a significant network of parent advocates working with other families. A study of her achievements for her son and other adults or caregivers could be a spin-off case study with her consent.

The number and different types of living arrangements needed for adults who are not NDIS-eligible is a related area for future study. Anecdotally, a large number of families build granny flats to create homes for their daughters and sons in the yard of the family home. An understanding of the number of these arrangements could support government planning and assist families to prepare to replace these arrangements in the future e.g. when parents die, siblings inherit the home or the family home is sold to fund retirement. The economic value of these arrangements, including savings to government, should be measured and valued as a contribution by the people living in those arrangements and their caregivers. Future research should evaluate the extent to which innovative initiatives in the case studies are capable of replication for people with disability who are not eligible for the NDIS. After all, this group of people with either mild or moderate disability and low support needs lack NDIS funding and are dependent on effective and efficient access to appropriate, good-quality public housing or community housing where they must be able to live without fear of bullying, discrimination or abuse.

## **8.11 CONCLUSION**

Families and NGOs have improved the housing options for adults with disability. They have established new homes and put in place paid support, and they have achieved this without the resources to do it on their own. How? By making allies of those who could help the families and their adult children obtain the necessary resources — politicians, bureaucrats, NGOs and their own communities. The study described how families and NGOs found and made allies, and how they harnessed community support to secure improved housing options in NSW and the ACT.

In identifying and describing these matters, the study revealed and explained limits in the capacity of politicians, bureaucrats and NGOs to commit resources and limits in the capacity of traditional housing systems and service systems to offer more housing and paid support. One limit is whether the political ally has been voted into office — that is, holds political power. This opens the prospect of the politician activating the levers of governmental power to give effect to commitments they may have given to the families. Some bureaucrats and agency staff were constrained by their role and government rules, even when they wanted to assist more people with disability and caregivers. In addition, there were attitudinal barriers and a lack of understanding of the need to change the traditional model of supported accommodation that governments had adopted as the standard model. Other factors that limited the prospects of attaining the desired new homes for the adults were the cost of housing, land and construction, as well as the institutional reluctance of multiple actors to consider dealing with these challenges in a different way.

The models of home, support and the role of the community in assisting the adults to live independently are a different matter. Although governments and their agencies were slow to innovate, and the group home model of supported accommodation has been slow to change, governments were found to be willing to learn from these grassroots innovators. Governments shared power and resources with the families and NGOs because those governments and their agencies could not meet the need for housing with better models of paid support on their own. Further, families could not achieve housing efficiently without government support. Families, NGOs and governments must continue to work with people with disability to test and sustain future social innovation in social housing with paid support.

This study should prove helpful to families and NGOs who are seeking better housing options for adults with disability. The learnings should also assist people with disability who need housing but do not have family members, advocates or NGOs assisting them.

## REFERENCES

- Access Economics 2005, *The economic value of informal care*, Report for Carers Australia, Access Economics and Carers Australia, Canberra.
- Access Economics 2010, *The economic value of informal care in 2010*, Report for Carers Australia, Access Economics and Carers Australia, Canberra.
- Allen, A. 1999, *The power of feminist theory: domination, resistance, solidarity*, Westview Press, Boulder, CO.
- Altman, B.M. 2001, 'Disability definitions, models, classification schemes, and applications', in G.L. Albrecht, K.D. Seelman & M. Bury (eds.), *Handbook of disability studies*, Sage, Thousand Oaks, CA, pp. 97–122.
- Alvesson, N. & Sköldbberg, K. 2009, *Reflexive methodology: new vistas for qualitative research*, Sage, Thousand Oaks, CA.
- Alvord, S.H., Brown, L.D. & Letts, C.W. 2004, 'Social entrepreneurship and societal transformation: an exploratory study', *The Journal of Applied Behavioral Science*, vol. 40, no. 3, pp. 260–82, viewed 9 July 2018, <<https://doi.org/10.1177/0021886304266847>>.
- Amado, A., Stancliffe, R.J., McCarron, M. & McCallion, P. 2013, 'Social inclusion and community participation of individuals with intellectual/developmental disabilities', *Intellectual and Developmental Disabilities*, vol. 51, no. 5, pp. 360–75, viewed 14 March 2021, <<https://doi.org/10.1352/1934-9556-51.5.360>>.
- Anderson, P. 1976–1977, 'The antinomies of Antonio Gramsci', *New Left Review*, vol. 100, pp. 5–78.
- Anderson, U.L., Head, M.J., Ramamoorti, S., Riddle, C., Salamasick, M. & Sobel, P. 2017, *Internal auditing*, Internal Audit Foundation, Lake Mary, FL.
- Annison, J.E. 2000, 'Towards a clearer understanding of the meaning of "home"', *Journal of Intellectual & Developmental Disability*, vol. 25, no. 4, pp. 251–62, viewed 4 November 2016, <<https://doi.org/10.1080/13668250020019566-1>>.

- Association for Children with a Disability NSW 2010, *Submission No. 96. Inquiry into services provided or funded by the Department of Ageing, Disability and Home Care*, Association for Children with a Disability NSW, Sydney.
- Association for Children with a Disability NSW 2014, *Through the maze*, 5th edn, Association for Children with a Disability, Sydney.
- Attorney General's Department 2008, *Capacity toolkit*, New South Wales Government, Sydney.
- Australian Building Codes Board 2018, *Accessible housing options paper September 2018*, Australian Building Codes Board, Canberra.
- Australian Bureau of Statistics 2018, *Disability, ageing and carers, Australia: Summary of findings, Australia*, Australian Bureau of Statistics, Canberra, viewed 15 February 2020, <<https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release?>>.
- Bachrach, P. & Baratz, M.S. 1970, *Power and poverty: theory and practice*, Oxford University Press, New York.
- Baker, T. & Nelson, R.E. 2005, 'Creating something from nothing: resource construction through entrepreneurial bricolage', *Administrative Science Quarterly*, vol. 50, no. 3, pp. 329–66, viewed 9 July 2018, <<https://doi.org/10.2189/asqu.2005.50.3.329>>.
- Bank-Mikkelsen, N.E. 1969, 'A metropolitan area in Denmark: Copenhagen', in R. Kugel & W. Wolfensberger (eds.), *Changing patterns in residential services for the mentally retarded*, Report to the President's Committee on Mental Retardation, US Government Printing Office, Washington, DC, pp. 227–54.
- Barnartt, S., Schriener, K. & Scotch, R. 2001, 'Advocacy and political action', in G.L. Albrecht, K.D. Seelman & M. Bury (eds.), *Handbook of disability studies*, Sage, Thousand Oaks, CA, pp. 430–49.
- Barnes, C. & Mercer, G. (eds.) 1996, *Exploring the divide: illness and disability*, The Disability Press, University of Leeds, Leeds.



- Barnes, C. & Mercer, G. 1997, 'Breaking the mould? An introduction to doing disability research', in C. Barnes & G. Mercer (eds.), *Doing disability research*, The Disability Press, University of Leeds, Leeds, pp. 1–14.
- Barnes, C., Mercer, G. & Shakespeare, T. 1999, *Exploring disability: a sociological introduction*, Polity Press in association with Blackwell Publishers, Cambridge.
- Barraket, J. 2008, 'Introduction', in J. Barraket (ed.), *Strategic issues for the not-for-profit sector*, University of New South Wales Press, Sydney, pp. 1–13.
- Battilana, J., Leca, B. & Boxenbaum, E. 2009, '2 How actors change institutions: towards a theory of institutional entrepreneurship', *Academy of Management Annals*, vol. 3, no. 1, pp. 65–107, viewed 2 May 2017, <<https://doi.org/10.5465/19416520903053598>>.
- Bhattacharyya, J. 1995, 'Solidarity and agency: rethinking community development', *Human Organisation*, vol. 54, no. 1, pp. 60–9.
- Bigby, C. 2004, 'But why are these questions being asked? A commentary on Emerson (2004)', *Journal of Intellectual and Developmental Disability*, vol. 29, no. 3, pp. 202–5, viewed 12 December 2019, <<https://www.tandfonline.com/doi/abs/10.1080/13668250412331285181>>.
- Bigby, C. 2019, *Transcript — 6 December*, Disability Royal Commission, Brisbane, pp. 381–447, viewed 12 December 2019, <<https://disability.royalcommission.gov.au/publications/transcript-6-december-2019>>.
- Bigby, C. & Beadle-Brown, J. 2016, 'Culture in better group homes for people with intellectual disability at severe levels', *Journal of Intellectual and Developmental Disability*, vol. 54, no. 5, pp. 316–31, viewed 12 December 2019, <<https://doi.org/10.1352/1934-9556-54.5.316>>.
- Bigby, C., Knox, M., Beadle-Brown, J. & Bould, E. 2014, 'Identifying good group homes: qualitative indicators using a quality of life framework', *Intellectual and Developmental Disabilities*, vol. 52, no. 5, pp. 348–66, viewed 12 December 2019, <<https://doi.org/10.1352/1934-9556-52.5.348>>.

- Bigby, C. & Ozanne, E. 2001, 'Shifts in the model of service delivery in intellectual disability in Victoria', *Journal of Intellectual Disability*, vol. 26, no. 2, pp. 177–90, viewed 4 January 2018, <<https://doi.org/10.1080/13668250020054495>>.
- Blair, T. 1999, 'Beveridge revisited: a welfare state for the 21st century', in R. Walker (ed.), *Ending child poverty*, The Policy Press, Bristol, pp. 7–18.
- Blaug, M. 2000, 'Entrepreneurship before and after Schumpeter', in R. Swedberg (ed.), *Entrepreneurship: the social science view*, Oxford University Press, Oxford, pp. 76–88.
- Bonyhady, B. 2013, *The National Disability Insurance Scheme: supporting participants to gain appropriate housing with quality support*, presentation slides, National Disability Insurance Agency Board, Canberra.
- Bostock, L., Gleeson, B., McPherson, A. & Pang, L. 2001, *Deinstitutionalisation and housing futures: final report*, Australian Housing and Urban Research Institute, Melbourne, viewed 29 October 2015, <<https://www.ahuri.edu.au/research/final-reports/2>>.
- Bostock, L., Gleeson, B., McPherson, A. & Pang, L. 2004, 'Contested housing landscapes? Social inclusion, deinstitutionalisation and housing policy in Australia', *Australian Journal of Social Issues*, vol. 39, no. 1, pp. 41–62, viewed 29 October 2015, <<https://doi.org/10.1002/j.1839-4655.2004.tb01162.x>>.
- Bourne, J. 2010, "Mad as Hell" about disabilities', *RN Breakfast*, radio program, Radio National, Sydney, 29 March, viewed 7 October 2018, <<https://www.abc.net.au/radionational/programs/breakfast/mad-as-hell-about-disabilities/3112332>>.
- Bryman, A. 2016, *Social research methods*, Oxford University Press, Oxford.
- Burns, D., Williams, C.C. & Windebank, J. 2004, *Community self-help*, Palgrave Macmillan, New York.
- Business Council of Co-operatives and Mutuals 2014, *Public service mutuals: a third way for delivering public services in Australia*, White Paper, Business Council of Co-operatives and Mutuals, Canberra, viewed 29 April 2018,

- <[http://bccm.coop/wp/wp-content/uploads/2014/09/WhitePaper\\_PSM\\_LR1.pdf](http://bccm.coop/wp/wp-content/uploads/2014/09/WhitePaper_PSM_LR1.pdf)>.
- Carers Australia 2021, *Who is a carer?*, ACT, viewed 6 January 2021, <<https://www.carersaustralia.com.au/about-carers/who-is-a-carer/>>.
- Carnemolla, P. 2020, 'Individualized apartment accommodation for people with intellectual disability: protocol for a qualitative study examining the well-being and support outcomes linking house and health', *JMIR Research Protocols*, vol. 9, no. 8, viewed 8 June 2020, <<https://doi.org/10.2196/18248>>.
- Carney, T. & Keyzer, P. 2007, 'Planning for the future: Arrangements for the assistance of people planning for the future of people with impaired capacity', *QUT Law Review*, vol. 7 no. 2, viewed 23 October 2016, <<https://doi.org/10.5204/qutlr.v7i2.135>>.
- Carter, M.L. 2014, *National Conference 2014—Mary Lou Carter (Carers Alliance)*, videorecording, YouTube, viewed 28 September 2020, <<https://www.youtube.com/watch?v=HxolQmv8xw0>>.
- Center for Theory of Change 2021, *What is theory of change?*, viewed 29 June 2021, <<https://www.theoryofchange.org/what-is-theory-of-change/>>.
- Chatterton, P. 2015, *Low impact living*, Routledge, New York.
- Choi, N. & Majumdar, S. 2014, 'Social entrepreneurship as an essentially contested concept: opening a new avenue for systematic future research', *Journal of Business Venturing*, vol. 29, no. 3, pp. 363–76, viewed 21 August 2018, <<https://doi.org/10.1016/j.jbusvent.2013.05.001>>.
- Christensen, P. 2012, 'Key strategies of sustainable real estate decision-making in the United States: a Delphi study of the stakeholders', PhD thesis, Clemson University, Clemson.
- Church, C. & Rogers, M.M. 2006, *Designing for results: integrating monitoring and evaluation in conflict transformation programs*, Search for Common Ground, Washington, DC, viewed 30 March 2020, <<https://www.sfcg.org/Documents/manualpart1.pdf>>.

- Clapham, D. 2002, 'Housing pathways: a post modern analytical framework', *Housing, Theory and Society*, vol. 19, no. 2, pp. 57–68, viewed 10 September 2016, <<https://doi.org/10.1080/140360902760385565>>.
- Clement, T. & Bigby, C. 2010, *Group homes for people with intellectual disabilities: encouraging inclusion and participation*, Jessica Kingsley Publishers, London.
- Cocks, E., Thoresen, S., Williamson, M. & Boaden, R. 2014, 'The individual supported living (ISL) manual: a planning and review instrument for individual supported living arrangements for adults with intellectual and developmental disabilities', *Journal of Intellectual Disability Research*, vol. 58, no. 7, pp. 614–24, viewed 4 November 2016, <<https://doi.org/10.1111/jir.12059>>.
- Collings, S., Dew, A. & Dowse, L. 2016, 'Support planning with people with intellectual disability and complex support needs in the Australian National Disability Insurance Scheme', *Journal of Intellectual and Developmental Disability*, vol. 41, no. 3, pp. 272–6, viewed 12 December 2019, <<http://www.tandfonline.com/doi/abs/10.3109/13668250.2016.1151864>>.
- Commissioner Sackville 2019, *Transcript — 2 December*, Disability Royal Commission, Brisbane, pp. 1–68, viewed 12 December 2019, <<https://disability.royalcommission.gov.au/publications/transcript-2-december-2019>>.
- Commonwealth Letters Patent 2019, Disability Royal Commission, signed by the Governor-General of the Commonwealth of Australia 4 April 2019, viewed 12 December 2019, <<https://disability.royalcommission.gov.au/letters-patent>>.
- Conroy, J.W., Fullerton, A. & Brown, M. 2002, *Final outcomes of the 3 year California Quality Tracking Project*, report no. 6, Center for Outcome Analysis, Narberth, PA.
- Cook, A. & Miller, E. 2012, *Talking points personal outcomes approach: a practical guide for organisations*, Joint Improvement Team, Edinburgh.

- Cornwall, A. & Gaventa, J. 2000, 'From users and choosers to makers and shapers: re-positioning participation in social policy', *IDS Bulletin*, vol. 31, no. 4, pp. 50–62, viewed 18 April 2021, <<https://doi.org/10.1111/j.1759-5436.2000.mp31004006.x>>.
- Craig, G. 2007, 'Community capacity building: something old, something new...?', *Critical Social Policy*, vol. 27, no. 3, pp. 335–59, viewed 22 April 2021, <<https://doi.org/10.1177/0261018307078846>>.
- Cresswell, J.W. 2007, *Qualitative inquiry and research design*, Sage, Thousand Oaks, CA.
- Crotty, M. 1998, *The foundations of social research: meaning and perspective in the research process*, Taylor and Francis, London.
- Cuerva, M.C., Triguero-Cano, Á., & Córcoles, D. 2014, 'Drivers of green and non-green innovation: empirical evidence in Low-Tech SMEs', *Journal of Cleaner Production*, vol. 68, pp. 104–13, viewed 12 May 2018, <<https://doi.org/10.1016/j.jclepro.2013.10.049>>.
- Curryer, B., Stancliffe, R.J. & Dew, A. 2015, 'Self-determination: adults with intellectual disability and their family', *Journal of Intellectual and Developmental Disability*, vol. 40, no. 4, pp. 394–9, viewed 1 August 2019, <<https://doi.org/10.3109/13668250.2015.1029883>>.
- Dahl, R. A. 1961, *Who governs? Democracy and power in an American city*, Yale University Press, New Haven, CT.
- Daly, K. 1992, 'The fit between qualitative research and characteristics of families', in J.F. Gilgun, K. Daly & G. Handel (eds.), *Qualitative methods in family research*, Sage, Thousand Oaks, CA, pp. 3–11.
- Davis Smith, J. 2000, 'Volunteering and social development', *Voluntary Action*, vol. 3, no. 1, Winter, pp. 9–23.
- Davy, L., Fisher, K.R., Wehbe, A., Purcal, C., Robinson, S., Kayess, R. & Santos, D. 2019, *Review of implementation of the National Disability Strategy 2010–2020: final report (SPRC Report 4/19)*, Social Policy Research Centre, University of New South Wales, Sydney, viewed 7 March 2020, <<https://doi.org/10.26190/5c7494b61edc4>>.

- Dees, J.G. 1998, *The meaning of 'social entrepreneurship'*, Center for Social Innovation, Graduate School of Business, Kauffman Center for Entrepreneurial Leadership, Ewin Marion Kauffman Foundation, Stanford University, viewed 12 May 2018, <[https://centers.fuqua.duke.edu/case/wp-content/uploads/sites/7/2015/03/Article\\_Deess\\_MeaningofSocialEntrepreneurship\\_2001.pdf](https://centers.fuqua.duke.edu/case/wp-content/uploads/sites/7/2015/03/Article_Deess_MeaningofSocialEntrepreneurship_2001.pdf)>.
- Defourny, J. 2014, 'From third sector to social enterprise: a European research trajectory', in J. Defourny, L. Hulgard & V. Pestoff (eds.), *Social enterprise and the third sector: changing European landscapes in a comparative perspective*, Routledge, Abingdon, pp. 17–41.
- Deloitte Access Economics 2013, *Resource allocation for specialist homelessness services (final report for FACS)*, Deloitte Access Economics, Sydney.
- Deloitte Access Economics 2015, *The economic value of informal care in Australia in 2015*, Carers Australia, Canberra, viewed 30 May 2018, <<https://www.carersaustralia.com.au/submissions-reports/research-reports/>>.
- Deloitte Access Economics 2018, *Modelling the value of unpaid work and care*, Report for the Office for Women, formerly of the Department of Health and Human Services, Canberra.
- Deloitte Access Economics 2020, *The value of informal care in 2020*, Deloitte Access Economics, Sydney.
- Department of Disability, Housing and Community Services (DHCS) ACT (2010), *From house to home: housing, tenancy and support for people with complex needs related to their disability*, DHCS ACT, Canberra.
- Department of Social Services 2014, *Supported Accommodation Innovation Fund (SAIF)*, viewed 24 October 2017, <<https://www.dss.gov.au/our-responsibilities/disability-and-carers/program-services/for-service-providers/supported-accommodation-innovation-fund-saif>>.

- Department of Social Services 2019, *National Disability Strategy 2010-2020*, viewed 9 November 2019, <<https://www.dss.gov.au/our-responsibilities/disability-and-carers/publications-articles/policy-research/national-disability-strategy-2010-2020>>.
- Desa, G. 2012, 'Resource mobilization in international social entrepreneurship: bricolage as a mechanism of institutional transformation', *Entrepreneurship Theory and Practice*, vol. 36, no.4, pp. 727–51, viewed 2 February 2019, <<https://doi.org/10.1111/j.1540-6520.2010.00430.x>>.
- Deutscher, R. 2013, 'It's time to revisit cluster housing', *Planning News*, vol. 39, no. 6, pp. 12 & 21.
- DiMaggio, P. 1988, 'Interest and agency in institutional theory', in L.G. Zucker (ed.), *Institutional patterns and organisations: culture and environment*, Ballinger, Cambridge, MA, pp. 3–21.
- DiMaggio, P. & Powell, W. 1983, 'The iron cage revisited: institutional isomorphism and collective rationality in organizational fields', *American Sociological Review*, vol. 48, no. 2, pp. 147–60, <<https://doi.org/10.2307/2095101>>.
- DiMaggio, P. & Powell, W. 1991, 'Introduction', in W. Powell & P. DiMaggio (eds.), *The new institutionalism in organisational analysis*, University of Chicago, Chicago, pp. 1–38.
- Disability Housing Futures Working Group 2016, *Disability Housing Futures Working Group final report February 2016*, sponsored by the National Affordable Housing Consortium, viewed 17 March 2019, <[nahc.org.au/documents/DHF\\_Final\\_Report\\_February\\_2016.pdf](http://nahc.org.au/documents/DHF_Final_Report_February_2016.pdf)>.
- Disability Housing Futures Working Group 2017a, *Disability housing futures: modelling the disability housing gap and its impact on lifetime support costs. Report 2 September 2017*, Disability Housing Futures Working Group, sponsored by the National Affordable Housing Consortium.
- Disability Housing Futures Working Group 2017b, *People with disability living in inadequate housing: prevalence, trends, and health and workforce participation outcomes. Report 1 April 2017*, Disability Housing Futures

- Working Group, viewed 17 March 2019,  
<[https://nahc.org.au/documents/DHF\\_Report\\_April\\_2017.pdf](https://nahc.org.au/documents/DHF_Report_April_2017.pdf)>.
- Duffy, S. 2013, *Designing NDIS: an international perspective on individual funding systems*, The Centre for Welfare Reform, viewed 29 October 2015,  
<<http://www.centreforwelfarereform.org/uploads/attachment/360/designing-ndis.pdf>>.
- Durrett, C. 2009, *The senior cohousing handbook: a community approach to independent living*, New Society Publishers, Canada.
- Earl, D. 2007, 'Caring for their children. Forever. Parent-run organisations for children with disabilities in New South Wales, 1950–1968', Bachelor's thesis, The University of Sydney, Sydney, viewed 20 November 2016,  
<[https://docs.google.com/file/d/0BxJ40rvOKOpBYjJIZTBkNGMtZmEzMy00Mzc5LWI5YjEtMzA0ZWUxM2U5ZjI0/edit?pli=1&hl=en\\_GB#>](https://docs.google.com/file/d/0BxJ40rvOKOpBYjJIZTBkNGMtZmEzMy00Mzc5LWI5YjEtMzA0ZWUxM2U5ZjI0/edit?pli=1&hl=en_GB#>).
- Eastman, K. & Kayess, R. 2019, *Transcript — 6 December*, Disability Royal Commission, Brisbane, pp. 386–7 & 393, viewed 12 December 2019,  
<<https://disability.royalcommission.gov.au/publications/transcript-6-december-2019>>.
- Eisenstadt, S.N. 1980, 'Cultural orientations, institutional entrepreneurs, and social change: comparative analysis of traditional civilizations', *American Journal of Sociology*, vol. 85, no. 4, pp. 840–69, viewed 15 December 2018, <<https://doi.org/10.1086/227091>>.
- Elster, J. 2015, *Explaining social behavior: more nuts and bolts for the social sciences*, Cambridge University Press, Cambridge.
- Emerson, E. 2004, 'Cluster housing for adults with intellectual disabilities', *Journal of Intellectual and Developmental Disability*, vol. 29, no. 3, pp. 187–97, viewed 13 October 2019,  
<<https://doi.org/10.1080/13668250412331285208>>.
- Engeström, Y. 1987, *Learning by expanding*, Oriental-Konsultit, Helsinki.



- Engeström, Y. 1999, 'Activity theory and individual and social transformation', in Y. Engeström, R. Miettinen & R. Punamäki (eds.), *Perspectives on activity theory*, Cambridge University Press, Cambridge, pp. 19–38.
- Engeström, Y. 2000, 'Activity theory as a framework for analyzing and redesigning work', *Ergonomics*, vol. 43, no. 7, pp. 960–74, viewed 2 April 2019, <<http://www.tandfonline.com/doi/abs/10.1080/001401300409143>>.
- Engeström, Y. 2001, 'Expansive learning at work: toward an activity theoretical reconceptualization', *Journal of Education and Work*, vol. 14, no. 1, pp. 133–56, viewed 20 April 2020, <<https://doi.org/10.1080/13639080020028747>>.
- Every Australian Counts 2015, *A place I can proudly call home*, viewed 24 October 2015, <[everyaustraliancounts.com.au](http://everyaustraliancounts.com.au)>.
- Eyler, P. 2005, *Out-of-home—not out of the family: rethinking the care of children with profound disabilities*, Disability Advocacy Service Hunter, Newcastle.
- Family and Community Services 2015, *Accommodation support policy*, Ageing, Disability & Home Care Department, Family and Community Services, Sydney.
- Family and Community Services 2018, About Housing Pathways factsheet, Sydney, viewed 29 June 2021, <<https://www.facs.nsw.gov.au/housing/help/ways/about-housing-pathways-factsheet>>.
- Femia, J. 1981, *Gramsci's political thought: hegemony, consciousness and the revolutionary process*, Clarendon Press, Oxford.
- Flanagan, K., Levin, I., Tually, S., Varadharajan, M., Verdouw, J., Faulkner, D., Meltzer, A. & Vreugdenhil, A. 2010, *Understanding the experience of social housing pathways*, AHURI Final Report No. 324, Australian Housing and Urban Research Institute, Melbourne.
- Follett, M.P. 1924, *Creative experience*, Longmans, Green & Co, New York.

- Follett, M.P. 2003, 'Power', in H.C. Metcalf & L. Urwick (eds.), *Dynamic administration: the collected papers of Mary Parker Follett*, Routledge, New York, pp. 95–116.
- Franz, J., Adkins, B., Petriwskyj, A., Bitner, G., Ward, M. & Rolfe, A. 2014, *Person-centred approaches to private housing for people with disability: impediments, difficulties and opportunities*, Queensland University of Technology and The University of Queensland for The Disability Policy and Research Working Group, Queensland.
- Friedland, R. & Alford, R.R. 1991, 'Bringing society back in: symbols, practices and institutional contradictions', in W.W. Powell & P.J. DiMaggio (eds.), *The new institutionalism in organisational analysis*, University of Chicago Press, Chicago, pp. 232–63.
- Garner, H. & Dietz, L. 1996, 'Person-centred planning: maps and paths to the future', *Four Runner*, vol. 11, no. 5, viewed 18 April 2021, <[ttac.odu.edu/Articles/person.html](http://ttac.odu.edu/Articles/person.html)>.
- Gartner, W.B. 1985, *Entrepreneurs and entrepreneurship: process versus content approaches*, unpublished manuscript, Georgetown University, Washington, DC.
- Garud, R., Hardy, C. & Maguire, S. 2007, 'Institutional entrepreneurship as embedded agency: an introduction to the special issue', *Organization Studies*, vol. 28, no. 7, pp. 957–69, viewed 2 April 2019, <<https://doi.org/10.1177/0170840607078958>>.
- Gaventa, J. 1980, *Power and powerlessness: quiescence and rebellion in an Appalachian valley*, University of Illinois Press, Springfield.
- Gaventa, J. 2006, 'Finding the spaces for change: a power analysis', *IDS Bulletin*, vol. 37, no. 6, pp. 23–33, viewed 16 June 2019, <<https://doi.org/10.1111/j.1759-5436.2006.tb00320.x>>.
- Gilchrist, D.J. & Butcher, J.R. 2016, 'Introduction', in J.R. Butcher & D.J. Gilchrist (eds.), *The three sector solution: delivering public policy in collaboration with not-for-profits and business*, ANU Press, The Australian National University, Canberra, pp. 3–21.

- Glendinning, C., Challis, D., Fernandez, J., Jacobs, S., Jones, K., Knapp, M., Manthorpe, J., Moran, N., Netten, A., Stevens, M. & Wilberforce, M. 2008, *Evaluation of the Individual Budgets pilot programme: final report*, Department of Health, London.
- Greene, J.C. 1993, 'The role of theory in qualitative program evaluation', in D.J. Flinders & G.E. Mills (eds.), *Theory and concepts in qualitative research: perspectives from the field*, Teachers College Press, New York, pp. 25–45.
- Grunewald, K. 1969, 'A rural county in Sweden: Malmohus County', in R. Kugel & W. Wolfensberger (eds.), *Changing patterns in residential services for the mentally retarded*, Report to the President's Committee on Mental Retardation, US Government Printing Office, Washington, DC, pp. 253–87.
- Hahn, H. 1985, 'Toward a politics of disability: definitions, disciplines, and policies', *The Social Science Journal*, vol. 22, no. 4, pp. 87–105.
- Hartley Lifecare 2020, *Annual Report 2019–20*, Canberra, viewed 14 March 2021, <<https://www.hartley.org.au/about-us/publications>>.
- Heifetz, R.A. & Laurie, D.L. 1997, 'The work of leadership', *Harvard Business Review*, 75, pp. 124–34.
- Hill, T., Thomson, C. & Cass, B. 2011, *The costs of caring and the living standards of carers*, Australian Government Department of Families, Housing, Community Services and Indigenous Affairs, Canberra, viewed 1 February 2019, <[www.dss.gov.au/sites/default/files/documents/05\\_2012/sprp\\_43.pdf](http://www.dss.gov.au/sites/default/files/documents/05_2012/sprp_43.pdf)>.
- Himmelweit, S. 2013, 'Care: feminist economic theory and policy challenges', *Journal of Gender Studies Ochanomizu University*, vol. 16, pp. 1–18, viewed 8 February 2020, <<http://oro.open.ac.uk/36454/>>.
- Holloway, I. 1997, *Basic concepts for qualitative research*, Wiley-Blackwell, Oxford.
- Holtzman, G. 2010, *Introduction to cohousing & the Australian context*, Sydney Choosing Group, Sydney.

- Institute of Internal Auditors 2017, *International Professional Practices Framework (IPPF)—glossary*, Institute of Internal Auditors, Lake Mary, FL.
- Institute of Public Administration 2012, *Public policy drift: why governments must replace 'policy on the run' and 'policy by fiat' with a 'business case' approach to regain public confidence*, IPAA Policy Paper, April, Institute of Public Administration Australia, Sydney.
- Jarillo, J.C. & Stevenson, H.H. 1990, 'A paradigm of entrepreneurship: entrepreneurial management', *Strategic Management Journal*, vol. 11, Special Issue: Corporate Entrepreneurship, pp. 17–27, viewed 3 October 2017, <<https://www.jstor.org/stable/2486667h>>.
- Johnson, D.P. 2008, *Contemporary sociological theory: an integrated multi-level approach*, Springer, New York.
- Justice Connect 2017, *Social enterprise guide: legal issues to consider when starting up a social enterprise*, Justice Connect Not-for-Profit Law, Melbourne, viewed 24 November 2017, <[https://www.nfplaw.org.au/sites/default/files/media/Social\\_Enterprise\\_Guide\\_Cth\\_1.pdf](https://www.nfplaw.org.au/sites/default/files/media/Social_Enterprise_Guide_Cth_1.pdf)>.
- Kaptelinin, V. n.d., 'Activity theory', *Encyclopedia of human computer interaction*, 2nd edn, viewed 30 January 2020, <<https://www.interaction-design.org/literature/book/the-encyclopedia-of-human-computer-interaction-2nd-ed/activity-theory>>.
- Katz, J. & Gartner, W.B. 1988, 'Properties of emerging organizations', *The Academy of Management Review*, vol. 13, no. 3, pp. 429–41, viewed 15 December 2018, <<https://doi.org/10.2307/258090>>.
- Kayess, R. & Sands, T. 2020, *Convention on the Rights of Persons with Disabilities: shining a light on social transformation*, Social Policy Research Centre, University of New South Wales, Sydney.
- Kendrick, M. 1996, 'The natural authority of families', *CRUCial Times*, vol. 6, no. 6, viewed 18 March 2021, <<https://cru.org.au/crucial-times-issue-6-natural-authority-of-families/>>.

- Kendrick, M. 2011, 'Empowerment and self direction relative to the design and governance of personalized service arrangements', *Journal of Human Development, Disability and Social Change*, vol. 19, no. 2, pp. 57–68, viewed 21 June 2020, <<https://s3-ap-southeast-2.amazonaws.com/activ8wanda/Pearl/1168/Empowerment%20%20Self%20Direction%20Governance-Pearl-1168.pdf>>.
- Koren, P.E., DeChillo, N. & Friesen, B. 1992, 'Measuring empowerment in families whose children have emotional disabilities: a brief questionnaire', *Rehabilitation Psychology*, vol. 37, no. 4, pp. 305–21, viewed 10 September 2016, <<https://doi.org/10.1037/h0079106>>.
- Kovacs Burns, K. & Gordon, G.L. 2010, 'Analyzing the impact of disability legislation in Canada and the United States', *Journal of Disability Policy Studies*, vol. 20, no. 4, pp. 205–18, viewed 9 March 2019, <<https://doi.org/10.1177/1044207309344562>>.
- Kozma, A., Mansell, J. & Beadle-Brown, J. 2009, 'Outcomes in different residential settings for people with intellectual disability: a systematic review', *American Journal on Intellectual and Developmental Disabilities*, vol. 114, no. 3, pp. 193–222, viewed 24 October 2015, <<https://pubmed.ncbi.nlm.nih.gov/19374466/>>.
- KPMG 2015, *Going home staying home post-implementation review: 2015 final report*, KPMG, Sydney, viewed 9 July 2015, <[https://www.housing.nsw.gov.au/\\_\\_data/assets/pdf\\_file/0008/340559/GH\\_SHPostImplementationReviewKPMG.pdf?fbclid=IwAR1RUXC9f9wTYwM4uXkKs675ce0k0KD8J76aCITukECYlclLflkFVgBFMuw](https://www.housing.nsw.gov.au/__data/assets/pdf_file/0008/340559/GH_SHPostImplementationReviewKPMG.pdf?fbclid=IwAR1RUXC9f9wTYwM4uXkKs675ce0k0KD8J76aCITukECYlclLflkFVgBFMuw)>.
- KPMG 2018, *Specialist Disability Accommodation Pricing and Payments Framework review: final report, 3 December 2018*, KPMG, Sydney, viewed 27 February 2019, <[https://www.dss.gov.au/sites/default/files/documents/02\\_2019/sda-framework-review-08022019.pdf](https://www.dss.gov.au/sites/default/files/documents/02_2019/sda-framework-review-08022019.pdf)>.
- Kretzmann, J.P. & McKnight, J.L. 1993, *Building communities from the inside out: a path toward finding and mobilizing a community's assets*, ACTA Publications, Chicago.

- Krlev, G., Anheier, H.K. & Mildenerberger, G. 2018, 'Introduction: social innovation—what is it and who makes it?', in H. Anheier, G. Krlev & G. Mildenerberger (eds.), *Social innovation comparative perspectives*, Routledge, New York, pp. 3–35. <<https://www.taylorfrancis.com/books/oa-edit/10.4324/9781315158020/social-innovation-helmut-anheier-gorgi-krlev-georg-mildenerberger>>.
- Kugel, R.B. 1969, 'Why innovative action?', in R. Kugel & W. Wolfensberger (eds.), *Changing patterns in residential services for the mentally retarded*, Report to the President's Committee on Mental Retardation, US Government Printing Office, Washington, DC, pp. 179–95.
- Landesman, S. 1988, 'Preventing "institutionalisation" in the community', in M.P. Janicki, M.W. Krauss & M.M. Seltzer (eds.), *Community residences for persons with developmental disabilities*, Paul H. Brookes Publishing Co, Baltimore, MD, pp. 105–16.
- Leadbeater, C. 2006, 'The socially entrepreneurial city', in A. Nicholls (ed.), *Social entrepreneurship: new models of sustainable social change*, Oxford University Press, Oxford, pp. 233–46.
- Leadbetter, J. 2008, 'Learning in and for interagency working: making links between practice development and structured reflection', *Learning in Health and Social Care*, vol. 7, no. 4, pp. 198–208, viewed 23 June 2018, <<https://doi.org/10.1111/j.1473-6861.2008.00198.x>>.
- Leininger M. 1994, 'Evaluation criteria and critique of qualitative research studies', in J.M. Morse (ed.), *Critical issues in qualitative research methods*, Sage, Thousand Oaks, CA, pp. 95-115.
- Leont'ev, A.N. 1978, *Activity, consciousness, and personality*, Prentice-Hall, Englewood Cliffs, NJ.
- Leont'ev, A.N. 1981, *Problems of the development of the mind*, trans. M. Kopylova, Progress, Moscow.
- Lévi-Strauss, C. 1972, *The savage mind*, Weidenfeld and Nicolson, London.
- Lewis, T., Millington, M. & Marini, I. 2015, 'Counseling in the context of family empowerment', in M. Millington & I. Marini (eds.), *Families in rehabilitation*

- counselling: a community-based rehabilitation approach*, Springer, New York, pp. 47–65.
- Light, P.C. 2006, 'Reshaping social entrepreneurship', *Stanford Social Innovation Review*, vol. 4, no. 3, pp. 47–51, viewed 12 November 2017, <<https://wagner.nyu.edu/files/performance/ReshapingSE.pdf>>.
- Lincoln, Y. & Guba, E. 1985, *Naturalistic inquiry*, Sage, Thousand Oaks, CA.
- Lister, R. 2010, *Understanding theories and concepts in social policy*, The Policy Press, Bristol.
- Llewellyn, G., Gething, L., Kendig, H. & Cant, R. 2003, *Invisible carers facing an uncertain future*, A report of a study conducted with funding from the National Health and Medical Research Council 2000–2002, Faculty of Health Sciences, University of Sydney, Sydney.
- Lord, J. & Hutchison, P. 2003, 'Individualised support and funding: building blocks for capacity building and inclusion', *Disability and Society*, vol. 18, no. 1, January, pp. 71–86, viewed 6 October 2019, <<https://doi.org/10.1080/713662196>>.
- Low, M.B. & MacMillan, I.C. 1988, 'Entrepreneurship: past research and future challenges', *Journal of Management*, vol. 14, no. 2, pp. 139–61, viewed 10 June 2019, <<https://doi.org/10.1177/014920638801400202>>.
- Lukes, S. 2005, *Power: a radical view*, Macmillan, London.
- Lyons, M. & Passey, A. 2006, 'Need public policy ignore the third sector? Government policy in Australia and the United Kingdom', *Australian Journal of Public Administration*, vol. 65, no. 3, pp. 90–102, viewed 7 December 2019, <<https://doi.org/10.1111/j.1467-8500.2006.00496a.x>>.
- Mair, J. & Marti, I. 2006, 'Social entrepreneurship research: a source of explanation, prediction and delight', *Journal of World Business*, vol. 41, no. 1, pp. 36–44, viewed 12 November 2017, <<https://doi.org/10.1016/j.jwb.2005.09.002>>.
- Mair, J. & Marti, I. 2009, 'Entrepreneurship in and around institutional voids: a case study from Bangladesh', *Journal of Business Venturing*, vol. 24, no.

- 5, pp. 419–35, viewed 12 November 2017,  
<<https://doi.org/10.1016/j.jbusvent.2008.04.006>>.
- Mansell, J. & Ericsson, K. 1996, 'Conclusion: integrating diverse experience', in J. Mansell & K. Ericsson (eds.), *Deinstitutionalization and community living: intellectual disability services in Britain, Scandinavia and the USA*, Chapman & Hall, London, pp. 241–53.
- Marshall, T.H. 1950, *Citizenship and social class*, Cambridge University Press, Cambridge.
- Martin, D. 2008, 'A new paradigm to inform inter-professional learning for integrating speech and language provision into secondary schools: a socio-cultural activity theory approach', *Child Language Teaching and Therapy*, vol. 24, no. 2, pp. 173–92, viewed 1 May 2019,  
<<https://doi.org/10.1177/0265659008090293>>.
- Martin, R.L. & Osberg, S. 2007, 'Social entrepreneurship: the case for definition', *Stanford Social Innovation Review*, vol. 5, no. 2, pp. 28–39, viewed 18 November 2017,  
<[https://ssir.org/articles/entry/social\\_entrepreneurship\\_the\\_case\\_for\\_definition](https://ssir.org/articles/entry/social_entrepreneurship_the_case_for_definition)>.
- Mathie, A. & Gaventa, J. 2015, 'Planting the seeds of a new economy: learning from citizen-led innovation', in A. Mathie & J. Gaventa (eds.), *Citizen-led innovation for a new economy*, Practical Action Publishing, Warwickshire, UK, pp. 1–27.
- McGowan, C.R. 2003, 'Systems, definitions and identity: the socio-political disability/illness identity triangle. "Who do you want me to be for me to get what I need? And how severe is enough?"', Master's thesis, University of Manitoba, Winnipeg.
- McInnes, T. 2019, 'Navigating successfully between the two systems: community housing & specialist disability accommodation', presentation slides, 19 November, Australasian Housing Institute Conference, CHPs and Disability, Sydney.



- McNeill, J. 2017, 'What is social innovation?', lecture notes, Social Enterprises and Co-operative Innovation, Newcastle Business School, University of Newcastle.
- Merriam, S.B. & Tisdell, E.J. 2016, *Qualitative research: a guide to design and implementation*, Jossey-Bass, San Francisco.
- Mertens, D.M. 2005, *Research and evaluation in education and psychology: integrating diversity with quantitative, qualitative, and mixed methods*, Sage, Thousand Oaks, CA.
- Microboards Australia n.d., 'What is a microboard?', viewed 21 May 2020, <[microboard.org.au/what-is-a-microboard/](http://microboard.org.au/what-is-a-microboard/)>.
- Miller, E., Cooper, S.A., Cook, A. & Petch, A., 2008, 'Outcomes important to people with intellectual disabilities', *Journal of Policy and Practice in Intellectual Disabilities*, vol. 5, no. 3, pp. 150–8, viewed 23 August 2017, <<https://doi.org/10.1111/j.1741-1130.2008.00167.x>>.
- Morris, A., Muir, K., Dadich, A., Abelló, D. & Bleasdale, M. 2005, *Housing and accommodation support initiative: evaluation report I*, SPRC Report 9/06, viewed 2 April 2019, <[http://www.sprc.unsw.edu.au/reports/HASI\\_ReportI/Summary.pdf](http://www.sprc.unsw.edu.au/reports/HASI_ReportI/Summary.pdf)>.
- Morse, J.M., Barnett, N., Mayan, M., Olson, K. & Spiers, J. 2002, 'Verification strategies for establishing reliability and validity in qualitative research', *International Journal of Qualitative Methods*, vol. 1, no. 2, pp. 13–22, viewed 6 February 2020, <<https://doi.org/10.1177/160940690200100202>>.
- Mulgan, G. 2006, 'Cultivating the other invisible hand of social entrepreneurship: comparative advantage, public policy and future research priorities', in A. Nicholls (ed.), *Social entrepreneurship: new models of sustainable social change*, Oxford University Press, Oxford, pp. 74–95.
- Murdock A. 2010, 'EMES—European Research Network', in H.K. Anheier & S. Toepler (eds.), *International encyclopedia of civil society*, Springer, New York, pp. 12–36, <<https://doi.org/10.1007/978-0-387-93996-4>>.

- Murray, J. & Adams, V. 2012, 'Counting the cost of Australia's care economy', *The Conversation*, 22 October, viewed 1 February 2019, <<https://theconversation.com/counting-the-cost-of-australias-care-economy-9946>>.
- Murray, R., Caulier-Grice, J. & Mulgan, G. 2010, *The open book of social innovation*, The Young Foundation and NESTA, viewed 10 October 2017, <<https://youngfoundation.org/wp-content/uploads/2012/10/The-Open-Book-of-Social-Innovation.pdf>>.
- Naples, N. (ed.) 1998, *Grassroots warriors: activist mothering, community work and the war on poverty*, Routledge, New York.
- National Disability Insurance Agency 2019, *SDA Innovation Plan*, viewed 26 June 2020, <<https://www.ndis.gov.au/providers/housing-and-living-supports-and-services/housing/specialist-disability-accommodation/sda-innovation-plan>>.
- National Disability Insurance Agency 2020, *Self-management*, viewed 1 September 2019, <<https://www.ndis.gov.au/participants/using-your-plan/self-management>>.
- National Health and Medical Research Council 2007, National Statement on Ethical Conduct in Human Research, <<https://www.nhmrc.gov.au/about-us/publications/national-statement-ethical-conduct-human-research-2007-updated-2018>>.
- National People with Disabilities and Carers Council 2009, *Shut out: the experience of people with disabilities and their families in Australia*, National Disability Strategy Consultation Report, Commonwealth of Australia, Canberra, viewed 12 June 2018, <[https://www.dss.gov.au/sites/default/files/documents/05\\_2012/nds\\_report.pdf](https://www.dss.gov.au/sites/default/files/documents/05_2012/nds_report.pdf)>.
- Nicholls, A. (ed.) 2006, *Social entrepreneurship: new models of sustainable social change*, Oxford University Press, Oxford.

- Nicholls, A. & Cho, A.H. 2006, 'Social entrepreneurship: the structuration of a field', in A. Nicholls (ed.), *Social entrepreneurship: new models of sustainable social change*, Oxford University Press, Oxford, pp. 99–118.
- Nirje, B. 1969, 'The normalization principle and its human management implications', in R. Kugel & W. Wolfensberger (eds.), *Changing patterns in residential services for the mentally retarded*, Report to the President's Committee on Mental Retardation, US Government Printing Office, Washington, DC, pp. 179–95.
- NSW Government 2006, *Accommodation and support paper*, NSW Government, Sydney.
- NSW Land and Housing Corporation (LAHC) 2020a, *Good design for social housing*, NSW LAHC and Government Architect NSW, Sydney, viewed 20 June 2021, <<https://www.dpie.nsw.gov.au/land-and-housing-corporation/plans-and-policies/good-design-for-social-housing>>.
- NSW Land and Housing Corporation (LAHC) 2020b, *Land and Housing Corporation dwelling requirements*, NSW LAHC and Government Architect NSW, Sydney, viewed 20 June 2021, <[https://www.dpie.nsw.gov.au/\\_\\_data/assets/pdf\\_file/0018/338112/LAHC-Dwelling-Requirements\\_September-2020\\_Access.pdf](https://www.dpie.nsw.gov.au/__data/assets/pdf_file/0018/338112/LAHC-Dwelling-Requirements_September-2020_Access.pdf)>.
- NSW Legislative Assembly 2008, 'Questions on Notice, 7 May 2008 and 11 June 2008', NSW Parliament, pp.2906-7, viewed 28 June 2021, <<https://www.parliament.nsw.gov.au/la/papers/Documents/2008/17-june-2008-questions-and-answers/073-QA-S.pdf>>.
- NSW Legislative Council Standing Committee on Social Issues 2010, *Services provided or funded by the Department of Ageing, Disability and Home Care*, Report No. 44, New South Wales Parliament, Legislative Council, Sydney.
- NSW Mental Health Commission 2014, *Reform—the story so far*, viewed 25 June 2020, <<https://nswmentalhealthcommission.com.au/reform-the-story-so-far>>.

- NSW Ombudsman 2004, *DADHC—the need to improve services for children, young people and their families*, a report arising from an investigation in the Department of Ageing, Disability and Home Care, NSW Ombudsman, Sydney.
- O'Brien, C.L. & O'Brien, J. 2000, *The origins of person-centered planning: a community of practice perspective*, Responsive Systems Associates, viewed 2 March 2021, <[https://www.nasddd.org/uploads/documents/The\\_Origins\\_of\\_Person\\_Centered\\_Planning\\_Obrien\\_and\\_Obrien.pdf](https://www.nasddd.org/uploads/documents/The_Origins_of_Person_Centered_Planning_Obrien_and_Obrien.pdf)>.
- O'Brien, J. 1994, 'Down stairs that are never your own: supporting people with developmental disabilities in their own home', *Mental Retardation*, vol. 32, no. 1, pp. 1–14, viewed 10 July 2016, <<https://eric.ed.gov/?id=ED342144>>.
- OECD & Eurostat 2018, *Oslo manual 2018: guidelines for collecting, reporting and using data on innovation*, 4th edition, OECD Publishing, Paris/Eurostat, Luxembourg, viewed 25 June 2020, <[doi.org/10.1787/9789264304604-en](https://doi.org/10.1787/9789264304604-en)>.
- O'Mallon & Osborne 2020, 'Social waiting housing list “decades long”', *The Young Witness*, 7 July, viewed 14 February 2021, <<https://www.youngwitness.com.au/story/6821860/social-housing-waiting-list-decades-long/>>.
- Oppenheimer, M. 2000, 'An overview of the voluntary principles in Australia: why the past matters', in J. Warburton & M. Oppenheimer (eds.), *Volunteers and volunteering*, The Federation Press, Leichhardt, pp. 9–18.
- Oppenheimer, M. & Warburton, J. 2000, 'Introduction', in J. Warburton & M. Oppenheimer (eds.), *Volunteers and volunteering*, The Federation Press, Leichhardt, pp. 1–8.
- Organisation for Economic Co-operation and Development 2015, *Oslo manual: guidelines for collecting and interpreting innovation data*, 3rd edition, OECD Publishing, Paris/Eurostat, Luxembourg.

- Pal, L.A. 1992, *Public policy analysis: an introduction*, 2nd edn, Nelson, Scarborough, Canada.
- Panitch, M. 2008, *Disability, mothers, and organisation: accidental activists*, Routledge, New York.
- Parmenter, T.R. 1999, 'Implications of social policy for service delivery: the promise and the reality "are we getting real?"', *Journal of Intellectual & Developmental Disability*, vol. 24, no. 4, pp. 321–31, viewed 7 December 2019, <<http://www.tandfonline.com/doi/abs/10.1080/13668259900034081>>.
- Peredo, A.M. & McLean, M. 2006, 'Social entrepreneurship: a critical review of the concept', *Journal of World Business*, vol. 41, no. 1, pp. 56–65, viewed 21 November 2017, <<https://doi.org/10.1016/j.jwb.2005.10.007>>.
- Poll, C., Duffy, S., Hatton, C., Sanderson, H. & Rutledge, M. 2006, *A report on In Control's first phase 2003–2005*, In Control Publications, London.
- Pringle, B. 2017, 'Steven Lukes and the "three-dimensional" power of neoliberal discourse: a case study of Australian documentation', Master's thesis, Western Sydney University, Sydney.
- Probst, B. & Berenson, L. 2014, 'The double arrow: how qualitative social work researchers use reflexivity', *Qualitative Social Work*, vol. 13, no. 6, pp. 813–27, viewed 30 March 2020, <<https://doi.org/10.1177/1473325013506248>>.
- Productivity Commission 2011, *Disability care and support*, report no. 54, 31 July, Productivity Commission, Canberra.
- Productivity Commission 2011a, *Disability care and support*, report no. 54, overview, 1 July 2011, pp. 1–63, Productivity Commission, Canberra.
- Qu, L., Edwards, B. & Gray, M. 2012, *Ageing parent carers of people with a disability*, Australian Institute of Family Services and Carers Victoria, Australian Government, viewed 20 May 2017, <<https://aifs.gov.au/publications/ageing-parent-carers-people-disability>>.

- Rapoport, A. 1985, 'Thinking about home environments: a conceptual framework', in I. Altman & C.M. Werner (eds.), *Home environments*, Plenum Press, New York.
- Ratner, C. 2002, 'Subjectivity and objectivity in qualitative methodology', *Forum: Qualitative Social Research*, vol. 3, no. 3, art. 16, viewed 10 April 2020, <<https://doaj.org/article/91fb3dc12036481b90ce70f6aeca2f9b>>.
- Raynor, K. & Coenen, L. 2021, 'Business model innovation and scalability in hybrid affordable housing organisations: empirical insights and conceptual reflections from Melbourne, Australia', *Journal of Housing and the Built Environment*, 25 March, Springer, <<https://doi.org/10.1007/s10901-021-09836-x>>.
- Richards, S. & West, T. 2014, *A place to call home: the story of the Benambra Intentional Community*, Getting a Life Family Governed Group, Canberra.
- Richmond, R.T. 1983a, *Inquiry into health services for the psychiatrically ill and developmentally disabled*, Department of Health NSW, Division of Planning and Research.
- Richmond, R.T. 1983b, *Inquiry into health services for the psychiatrically ill and developmentally disabled: Part 1*, NSW Parliament, Sydney.
- Robinson, S.A. 2019, *Transcript — 3 December*, Disability Royal Commission, Brisbane, pp. 69–153, viewed 12 December 2019, <<https://disability.royalcommission.gov.au/publications/transcript-3-december-2019>>.
- Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability 2019, *Terms of reference*, <<https://disability.royalcommission.gov.au/about-royal-commission/our-terms-reference>>.
- Rubin, H.J. & Rubin I.S. 1995, *Qualitative interviewing: the art of hearing data*, Sage, Thousand Oaks, CA.
- Rummery, K. 2007, 'Caring, citizenship and New Labour: dilemmas and contradictions for disabled and older women', in C. Annesley, F. Gains & K. Rummery (eds.), *Women and New Labour*, The Policy Press, Bristol.

- Sach and Associates, Miller, T. & Burke, T. 1991, *The housing needs of people with disabilities*, National Housing Strategy discussion paper, Australian Government Publishing Service, Canberra.
- Sanderson, H., Duffy, S., Poll, C. & Hatton, C. 2006, 'In Control: the story so far', *Journal of Integrated Care*, vol. 14, no. 4 pp. 3–13, viewed 13 March 2021, <<https://doi.org/10.1108/14769018200600025>>.
- Sarason, S.B. 1969, 'The creation of settings', in R. Kugel & W. Wolfensberger (eds.), *Changing patterns in residential services for the mentally retarded*, Report to the President's Committee on Mental Retardation, US Government Printing Office Washington, DC, pp. 341–57.
- Schumpeter, J.A. 1934, *The theory of economic development*, trans. M. Becker & T. Knudsen, Harvard University Press, Cambridge, MA.
- Seelos, C. & Mair, J. 2005, 'Social entrepreneurship: creating new business models to serve the poor', *Business Horizons*, vol. 48, no. 3, pp. 241–6, viewed 1 September 2018, <<https://doi.org/10.1016/j.bushor.2004.11.006>>.
- Seo, M.G. & Creed, W.D. 2002, 'Institutional contradictions, praxis, and institutional change: a dialectical perspective', *Academy of Management Review*, vol. 27, no. 2, pp. 222–47, viewed 7 April 2019, <<https://doi.org/10.5465/amr.2002.6588004>>.
- Shapiro, I. 2006, 'On the second edition of Lukes' Third Face', *Political Studies Review*, vol. 4, no. 2, pp. 146–55, viewed 11 November 2019, <<https://doi.org/10.1111/j.1478-9299.2006.000105.x>>.
- Shergold, P. 2016, 'The three sectors, one public purpose', in J.R. Butcher & D.J. Gilchrist (eds.), *The three sector solution: delivering public policy in collaboration with not-for-profits and business*, ANU Press, The Australian National University, Canberra, pp. 23–32.
- Smith, N., Lister, R., Middleton, S. & Cox, L. 2005, 'Young people as real citizens: towards an inclusionary understanding of citizenship', *Journal of Youth Studies*, vol. 8, no. 4, pp. 425–43, viewed 29 April 2021, <<https://doi.org/10.1080/13676260500431743>>.

- Somerville, P. 1998, 'Explanations of social exclusion: where does housing fit in?', *Housing Studies*, vol. 13, no. 6, pp. 761–80, viewed 17 February 2020, <<https://doi.org/10.1080/02673039883056>>.
- Stancliffe, R. 2001, 'Living with support in the community: predictors of choice and self-determination', *Mental Retardation and Developmental Disabilities Research Reviews*, vol. 7, no. 2, pp. 91–8.
- Stancliffe, R.J., Emerson, E. & Lakin, K.C. 2004, 'Residential supports', in E. Emerson, C. Hatton, T. Thompson & T. Parmenter (eds.), *International handbook of applied research in intellectual disabilities*, John Wiley & Sons, Chichester, pp. 459–78.
- Stancliffe, R.J., Lakin, K.C., Doljanac, R., Byun, S.Y., Taub, S. & Chiri, G. 2007, 'Loneliness and living arrangements', *Intellectual and Developmental Disabilities*, vol. 45, no. 6, pp. 380–90, viewed 12 June 2018, <[https://doi.org/10.1352/1934-9556\(2007\)45\[380:LALA\]2.0.CO;2](https://doi.org/10.1352/1934-9556(2007)45[380:LALA]2.0.CO;2)>.
- Stancliffe, R.J. & Whaite, A. 1997, *Watagan Project evaluation*, The University of Sydney, Centre for Developmental Disability Studies, Sydney.
- Stevenson, H.H. 2000, *Why entrepreneurship has won!*, Coleman White Paper, USASBE Plenary Address, 17 February, Graduate School of Business Administration, Harvard University, Cambridge, MA.
- Stevenson, H.H., Roberts, M.J. & Grousbeck, H.I. 1985, *New business ventures and the entrepreneur*, Irwin, Homewood, IL.
- Steyaert, C. & Hjorth, D. 2006, 'Introduction: what is social in social entrepreneurship?', in C. Steyaert & D. Hjorth (eds.), *Entrepreneurship as social change*, Edward Elgar, Cheltenham, UK, pp. 1–18.
- Stordy, P. 2012, 'Undergraduates' internet literacies', PhD thesis, University of Sheffield, Sheffield.
- Stout, M. 2018, 'Pursuing community change through radically democratic practice', in A. Eikenberry, B. Sandberg & R. Mirabella (eds.), *Reframing nonprofit management: democracy, inclusion and social change*, Melvin & Leigh, Irvine, CA.



- Summer Foundation & Housing Hub 2021, *Specialist disability accommodation supply in Australia: January 2021*, Summer Foundation and Housing Hub, Melbourne, viewed 21 April 2021, <<https://www.summerfoundation.org.au/resources/specialist-disability-accommodation-supply-in-australia/>>.
- Summer Foundation & Social Ventures Australia 2020, *Specialist disability accommodation — supply in Australia, March 2020*, Summer Foundation and Social Ventures Australia, Melbourne, viewed 21 April 2021, <<https://www.socialventures.com.au/assets/Specialist-Disability-Accommodation-Supply-in-Australia-March-2020-webres.pdf>>.
- Supporting Independent Living Co-operative (SILC) 2019, *PaRA Co-operative Limited*, viewed 7 July 2019, <<http://www.silc.coop/member-profiles/para-co-operative>>.
- Swedberg, R. 1976, 'Introduction', in J.A. Schumpeter (ed.), *Capitalism, socialism and democracy*, Routledge, New York, pp. ix–xxi.
- Swedberg, R. 2000, 'The social science view of entrepreneurship: introduction and practical applications', in R. Swedberg (ed.), *Entrepreneurship: the social science view*, Oxford University Press, Oxford, pp. 7–50.
- Sydney Morning Herald 2007, *Carers Alliance party to be launched*, viewed 21 April 2018, <<https://www.smh.com.au/national/carers-alliance-party-to-be-launched-20071005-12le.html>>.
- Tchida, C.V. 2018, *Toward an analytical framework for assessing power dynamics in university–community partnerships*, Master's thesis, Arizona State University, Tempe.
- TEPSIE 2014, *Doing social innovation: a guide for practitioners*, deliverable of the project: 'The theoretical, empirical and policy foundations for building social innovation in Europe' (TEPSIE), European Commission – 7th Framework Programme, European Commission, DG Research, Brussels.
- The Association of Genetic Support of Australasia 2005, *The Association of Genetic Support of Australasia Inc. Newsletter — September 2005*, no. 74, pp. 14–7.

- The Cromehurst Foundation 2005, *The Cromehurst Foundation Intentional Community Proposal, Response to DADHC Discussion Paper on Models of Supported Accommodation for People with Disability*, Sydney.
- The Oxford English Dictionary online*, 2000, Oxford University Press, <<https://www-oed-com.ezproxy.lib.uts.edu.au>>.
- The Young Foundation 2012, *Defining social innovation: Part 1*, 31 May 2012, deliverable 1.1 of the FP7-project: 'The theoretical, empirical and policy foundations for building social innovation in Europe' (TEPSIE), European Commission — 7th Framework Programme, European Commission, DG Research, Brussels, viewed 6 December 2019, <<https://youngfoundation.org/wp-content/uploads/2012/12/TEPSIE.D1.1.Report.DefiningSocialInnovation.Part-1-defining-social-innovation.pdf>>.
- Thomas, C. 2004, 'Disability and impairment', in J. Swain, S. French, C. Barnes & C. Thomas (eds.), *Disabling barriers—enabling environments*, Sage, London.
- Thornton, P.H., Ocasio, W. & Lounsbury, M. 2012, *The institutional logics perspective: a new approach to culture, structure, and process*, Oxford University Press, Oxford.
- Tilly, C. 1991, 'Domination, resistance, compliance ... discourse', *Sociological Forum*, vol. 6, no. 3, pp. 593–602, viewed 5 July 2019, <<https://doi.org/10.1007/BF01114480>>.
- Trochim, W. 2006, *Research methods knowledge base*, 3rd edn, Atomic Dog Publishing, Cincinnati, OH, viewed 30 March 2020, <[www.socialresearchmethods.net](http://www.socialresearchmethods.net)>.
- Tyler, T.R. 2011, *Why people cooperate: the role of social motivations*, Princeton University Press, Princeton, NJ.
- United Nations 2006, *Convention on the Rights of Persons with Disabilities*, Geneva, Switzerland.

- Villeneuve, M. 2011, 'Learning together: applying socio-cultural activity theory to collaborative consultation in school-based occupational therapy', PhD thesis, Queen's University, Kingston, Ontario.
- Vygotsky, L.S. 1978, *Mind in society: the development of higher psychological processes*, Harvard University Press, Cambridge.
- Warburton, J. & Oppenheimer, M. (eds.) 2000, *Volunteers and volunteering*, The Federation Press, Leichhardt, NSW.
- Wehmeyer, M.L. 2003, 'A functional theory of self-determination: definition and categorization', in M.L. Wehmeyer, B.H. Abery, D.E. Mithaug & R.J. Stancliffe (eds.), *Theory in self-determination: foundations for educational practice*, pp. 174–81, Charles C. Thomas, New York.
- Weiss, C. 1995, 'Nothing as practical as good theory: exploring theory-based evaluation for comprehensive community initiatives for children and families', in J.P. Connell, A.C. Kubisch, L.B. Schorr & C.H. Weiss (eds.), *New approaches to evaluating community initiatives*, The Aspen Institute, Washington, DC, pp. 65–92.
- Whitelaw, A. 2018, 'Ageing carers' experiences of planning housing transition for their adult child with disability: a qualitative study', Bachelor's thesis, Monash University, Melbourne.
- Wiesel, I. 2019, *Transcript — 3 December 2019*, Disability Royal Commission, Brisbane, pp. 72–82, viewed 12 December 2019, <<https://disability.royalcommission.gov.au/publications/transcript-3-december-2019>>.
- Wiesel, I., Easthope, H., Liu, E., Judd, B. & Hunter, E. 2012, *Pathways into and within social housing*, AHURI Final Report No. 186, Australian Housing and Urban Research Institute, Melbourne.
- Wiesel, I., Laragy, C., Gendera, S., Fisher, K., Jenkinson, S., Hill, T., Finch, K., Shaw, W. & Bridge, C. 2015, *Moving to my home: housing aspirations, transitions and outcomes of people with disability*, AHURI Final Report No. 246. Australian Housing and Research Institute, Melbourne.

- Williams, F. & Popay, J. 1999, 'Balancing polarities: developing a new framework for welfare research', in F. Williams, J. Popay & A. Oakley (eds.), *Welfare research: a critical review*, UCL Press, London.
- Williamson, O.E. 1996, *The mechanisms of governance*, Oxford University Press, New York.
- Wolf, J. 1990, 'Out of mind, out of sight? From housing discrimination to public accommodations legislation', *Journal of Disability Policy Studies*, vol. 1, no. 2, pp. 99–110, viewed 5 November 2019, <<https://doi.org/10.1177/104420739000100206>>.
- Wolfensberger, W. 1972, *The principles of normalization in human services*, National Institute on Mental Retardation, Toronto.
- Wolfensberger, W. 1983, 'Social role valorization: a proposed new term for the principle of normalization', *Mental Retardation*, vol. 21, no. 6, pp. 234–9. Re-published in 2011, *Intellectual and Developmental Disabilities*, vol. 49, no. 6, pp. 435–40, viewed 4 March 2018, <<https://doi.org/10.1352/1934-9556-49.6.435>>.
- Wolfensberger, W. 1998, *A brief introduction to social role valorization: a high-order concept for addressing the plight of societally devalued people, and for structuring human services* (3rd ed.), Training Institute for Human Service Planning, Leadership & Change Agency, Syracuse University, Syracuse, NY.
- World Health Organization 2001, *The International Classification of Functioning, Disability and Health (ICF)*, World Health Organization, Geneva, Switzerland, <<https://www.who.int/standards/classifications/international-classification-of-functioning-disability-and-health>>.
- Young, R. 2006, 'For what it is worth: social value and the future of social entrepreneurship', in A. Nicholls (ed.), *Social entrepreneurship: new models of sustainable social change*, Oxford University Press, Oxford, pp. 56–73.

Zames Fleischer, D. & Zames, F. 2001, *The disability rights movement: from charity to confrontation*, Temple University Press, Philadelphia, PA.

## **APPENDICES**

**APPENDIX A: STUDIES OF UNPAID CAREGIVING**

<b>Publication</b>	<b>Data</b>	<b>Method</b>	<b>Findings</b>
Access Economics 2005, <i>The economic value of informal care</i> .	Study of the economic value of unpaid/informal care for people with disability, chronic illness or old age. Unpaid carer data based on the ABS SDAC conducted in 2003.	Replacement valuation method was used to calculate the cost of buying replacement care services to be provided in the home by formal care providers.	2.6 million Australians estimated to be providing unpaid care (including 494,000 primary carers). Unpaid carers estimated to provide 1.2 billion hours of care (an average of 9 hours per week) at A\$25/hour. Replacement value estimated to be more than A\$30.5 billion.
Access Economics 2010, <i>The economic value of informal care</i> .	Study of the economic value of unpaid/informal care for people with disability, mental illness, chronic condition, terminal illness and the frail aged. Unpaid carer data based on the 2003 SDAC survey. The number of carers in 2003 was extrapolated to 2010. Assumed 5 hours per week for non-primary carers.	A replacement cost valuation was used to estimate the economic value of unpaid care in Australia in 2010.	2.9 million Australians estimated to be providing unpaid care. Unpaid carers estimated to provide 1.32 billion hours of care at A\$31/hour. This is 33% higher than 2005 data, attributed to the ageing population and related increase in the number who receive care. Replacement value estimated to be more than A\$40 billion.
Deloitte Access Economics 2015, <i>The economic value of informal care in Australia in 2015</i> .	Study of the economic value of unpaid/informal care for people with disability, mental illness, chronic condition, terminal illness and the frail aged. Unpaid carer data based on the	A replacement cost value was used to estimate the cost of services to replace unpaid care in Australia	2.86 million unpaid carers (including 825,000 primary carers) estimated to be providing unpaid care. Unpaid carers estimated to provide 1.9 billion hours of care at A\$31.36/hour. The number of

	2012 SDAC survey, and ABS population projections to estimate unpaid carers in 2015, including the 2011 Census of Population and Housing. Assumed 13 hours per week for each carer.	in 2015 if it was no longer available.	people with a profound or severe disability over 65 who were not living in supported accommodation was growing at a faster rate than the supply of informal carers. Replacement value estimated to be A\$60.3 billion.
Deloitte Access Economics 2020, <i>The value of informal care in 2020.</i>	Study of the economic value of unpaid/informal care for people with a disability, mental illness, chronic condition, terminal illness and the elderly. Unpaid carer data based on the 2018 SDAC survey and ABS population projection data to generate estimates for 2020. Assumed an average of 35.2 hours per week for primary carers and 5 hours of weekly care for non-primary carers.	A replacement cost method to estimate the cost of buying an equivalent amount of paid care to replace unpaid care if it was no longer available.	The replacement cost for unpaid care provided by 2.8 million unpaid carers (including 906,000 primary carers) estimated to be approx. A\$77.9 billion based on 2.2 billion hours of care at \$36.12/hour in 2020. Replacement value of unpaid care for people with a profound disability is \$51.6 billion, \$23.1 billion for people with a severe disability and \$2.6 billion for people with a moderate and mild disability (p. iv).



**APPENDIX B: ETHICS APPROVAL UTS HREC REF NO. ETH17-1412**

**Human Research Ethics Committee**  
 Ethics Secretariat  
 C/O Research Office  
 15 Broadway, Ultimo NSW 2007  
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 Research.Ethics@uts.edu.au

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UTS CRICOS PROVIDER CODE 00099F

8<sup>th</sup> August 2017

Ms Susan Margaret Bailey  
 School of Built Environment  
 UNIVERSITY OF TECHNOLOGY SYDNEY

Dear Susan,

**UTS HREC ETH17-1412 – CHRISTENSEN (for BAILEY) – “A place to call home for adult children with a disability: family action for institutional change”**

Thank you for your response to the Committee's comments for your project titled, "A place to call home for adult children with a disability: family action for institutional change". The Committee agreed that this application now meets the requirements of the National Statement on Ethical Conduct in Human Research (2007) and has been approved on that basis. You are therefore authorised to commence activities as outlined in your application.

You are reminded that this letter constitutes ethics approval only. This research project must also be undertaken in accordance with all UTS policies and guidelines including the Research Management Policy (<http://www.gsu.uts.edu.au/policies/research-management-policy.html>).

Your approval number is UTS HREC REF NO. ETH17-1412.

Approval will be for a period of five (5) years from the date of this correspondence subject to the submission of annual progress reports.

The following standard conditions apply to your approval:

- Your approval number must be included in all participant material and advertisements. Any advertisements on Staff Connect without an approval number will be removed.
- The Principal Investigator will immediately report anything that might warrant review of ethical approval of the project to the Ethics Secretariat ([Research.Ethics@uts.edu.au](mailto:Research.Ethics@uts.edu.au)).
- The Principal Investigator will notify the UTS HREC of any event that requires a modification to the protocol or other project documents, and submit any required amendments prior to implementation. Instructions can be found at <https://staff.uts.edu.au/topic/sub/Pages/Researching/Research%20Ethics%20and%20Integrity/Human%20research%20ethics/Post-approval/post-approval.aspx#tab2>.
- The Principal Investigator will promptly report adverse events to the Ethics Secretariat ([Research.Ethics@uts.edu.au](mailto:Research.Ethics@uts.edu.au)). An adverse event is any event (anticipated or otherwise) that has a negative impact on participants, researchers or the reputation of the University. Adverse events can also include privacy breaches, loss of data and damage to property.
- The Principal Investigator will report to the UTS HREC annually and notify the HREC when the project is completed at all sites. The Principal Investigator will notify the UTS HREC of any plan to extend the duration of the project past the approval period listed above through the progress report.

## **APPENDIX C: FAMILY CASE STUDY INTERVIEW QUESTIONS**

### **Introduction**

I would like to interview you about establishing [*insert name*]'s new home.

### **Vision**

1. What was/is your [vision/idea]?
2. How did the [vision/idea] develop?
3. How did the new living arrangement begin?
4. Did your [vision/idea] change? Why?
5. Do you think the vision/idea was important to persuading people to support your ideas? To achieve outcomes from that vision? What were the outcomes do you think?
6. Open questions will be used like: What makes you say that?

### **Collective action**

7. When did you start working with [your daughter/son]/[other families][NGO] and why?
8. Did you/when did you begin working with [a group of families]?
9. Did [he/she/they] share your vision/idea?
10. Did your [vision/idea] change when you began working with [x]/[the group of families]?
11. Did the group change over time and did the vision change as members of the group changed?
12. Can you describe the advantages or disadvantages of organising and working as a group?
13. What were the outcomes from working in a group?
14. Open questions will be used like: What makes you say that?

### **Leadership**

15. Who was important for the creation of the new living arrangement?
16. What action did they take?
17. What were obstacles you faced in establishing [*insert name*]'s new home?
18. What action did you take?
19. Who were the key people that helped you overcome those obstacles?

- 20. Did you share your [vision/idea] with them? How?
- 21. Did they share your [vision/idea]? What did they do to help?
- 22. Open questions will be used like: What makes you say that?

### **Planning**

- 23. How did you plan to create [*insert name*]'s new home?
- 24. What were your short- and long-term plans?
- 25. What planning formal or informal or both?
- 26. Did you document what you wanted? Can I see those documents?
- 27. Do you think the planning helped guide you on decisions you made, choices and in doing so or in any other way influence the outcomes?

### **Power**

- 28. How long did it take you to establish [*insert name*]'s new home?
- 29. What did you have and what did you need to achieve that vision/idea/objective or goal?
- 30. Where did you think you would get what you needed?
- 31. Did you have a strategy for getting what you needed?
- 32. What was it?
- 33. Can we look back over the [ten] years in terms of key milestones, significant events, opportunities and setbacks? Can you describe them for me?
- 34. How were those setbacks overcome? How did you get the power to do that?
- 35. Who were the key people that helped you overcome those setbacks?
- 36. Open questions will be used like: What makes you say that?

### **Institutions**

- 37. Can we discuss the institutional environment over that time?
- 38. You wanted housing and support for [*insert name*]. What were the options? Would you describe the range of services, organisations and rules as an institutional maze? Why/why not?
- 39. Did you attempt those options? Why/why not?
- 40. What institutions or organisations did you approach for assistance over that time?

41. What was their response?
42. Which organisations did you correspond with to secure the new home?
43. What was the tone of that correspondence?
44. Over what length of time did you correspond? Can I see that correspondence?
45. What organisations did you meet with to secure the new home?
46. Who were key people in the institution or organisation?
47. Did any create an opportunity or give you an idea that helped you?
48. Do you deal with any of those institutions or organisations today?
49. Making the case for change, your vision. Who did you make that case to?
50. How many people supported your vision, and what did they do to show that support? Do you have that support today?
51. Did they do anything to demonstrate their support? Did you mobilise them into action?
52. Do you think there are any permanent or currently existing changes that come from your dealings with organisations when establishing [*insert name*]'s home? For example, your arrangement has 10+ people living together but the government's current policy position is no more than 5 people with a disability living together. That's just one example but are there areas where organisations like government have changed to incorporate the way you went about setting up [*insert name*]'s home even how they deal with other families now? Is there any change following your work in that institutional maze we talked about?
53. Open questions will be used like: What makes you say that?

## **APPENDIX D: NGO CASE STUDY INTERVIEW QUESTIONS**

### **Introduction**

I would like to interview you about new living arrangements or home you are helping families to create. I am interested in understanding the strategies, activities, processes and actions that families have used to create the new home; understanding family action or activity to create housing from a provider perspective.

In relation to [insert organisation's name]:

### **Organisation**

1. What 'sector' or 'market' does [organisation] operate within?
2. What clients, members, people does [organisation] serve?

### **Services**

3. What services does [organisation] provide?
4. Does [organisation] provide housing for people with disability or manage it or secure, build or otherwise create it?

### **Mission and social purpose**

5. What is [organisation's] mission?
6. Please describe [organisation's] social purpose?

### **Goal congruence**

7. What is the vision of [organisation's] clients?
8. What are their objectives?
9. How does that vision or those objectives align with [organisation's] mission or purpose?
10. How are objectives or goals shared by [organisation] and its clients?

### **Group v. individual goals**

11. Does [organisation] act on behalf of groups of families or individual family members including the person with disability?
12. What are the family group's/family's common or shared collective interest, purpose or objective? What are the individual interests?

### **Working together**

13. How does [organisation] work with families to attain shared objectives or goals? Examples?

14. Whose interests are advanced? With whose resources?

### **Strategies**

15. What are [organisation's] strategies?

16. What strategies, activities, processes and actions have you observed families to use or create a new home?

17. How or when does [organisation] know or measure it is advancing the interests or achieving the purposes of the person, [organisation's] members, clients or their families?

### **Community**

18. What connects people to [organisation] and [organisation] to its community of clients? What is the nature and strength of the social connection e.g. shared identities? Common values? Community ties? Culture? Trust?

### **Empowerment**

An area of interest in this study is the concept of power: power-over, power-to and power-with. For example, the institutional environment may exercise power-over the person or families.

19. The person or families may acquire empowerment to attain their objectives by working with [organisation]. How does [organisation] work with families to attain empowerment?

20. Do you have organisational practices that drive or support these relationships of 'working with'?

### **Funding**

21. What funding systems does [organisation] access whether continuously or from time to time?

22. How important is individual funding, for example, to empower choice and self-determination?

### **Self-determination**

23. How are children with disability involved in action taken?

**APPENDIX E: NOTE OF MEETINGS OF S. RICHARDS, CASE #2**

<b>Work done to achieve a house for Jackson,</b>	
13/6/02	Housing ACT
24/7/02	Mr Bill Woods, ACT Minister for Disability
13/1/03	Housing ACT
6/3/03	Helen Hopper, Disability ACT
13/3/03	Mary Brookes, Disability ACT
29/4/03	Living in Networked Communities LINC
24/7/03	Canberra Co-Housing ACT
4/9/03	Canberra Co-Housing ACT
21/10/03	Mr Bill Woods, ACT Minister for Disability
30/3/04	Living in Networked Communities LINC
24/5/04	Louise Bromhead, Centacare
13/7/04	Kerrie Tucker, MLA
29/7/04	Housing ACT
2/8/04	Mr Bill Woods, ACT Minister for Disability
13/9/04	Canberra Co-Housing ACT
30/9/04	Sandra Lambert, CEO DHCS & Lois Ford ED DACT
4/11/04	Presentation on Rougemount Intentional Community to David Collett, Maureen Sheehan, Lois Ford et al
12/1/05	Ian McNeill, Disability advisor to John Hargreaves, Minister for Disability.
4/2/05	Jacqui Burke, MLA
22/3/05	Crisis in accommodation public meeting
29/3/05	Housing ACT
9/6/05	John Hargreaves, Minister for Disability & Sandra Lambert
14-15/06/05	Hosted Rougemount/Deohaeko in Canberra
4/7/05	Housing ACT
9/8/05	Presentation on Rougemount Intentional Community to HACC network
20/1/06	Housing ACT
7/2/06	Presentation to Housing Forum Legislative Assembly
27/2/06	Housing Forum Legislative Assembly
1/6/06	Simon Corbell, Minister for Land & Planning
3/8/06	Katy Gallagher, Minister for Disability
12/9/06	Housing meeting Hartley Lifecare
16/11/06	Katy Gallagher, Minister for Disability
28/3/06	Sandra Lambert, CEO DHCS
7/2/07	Meyer Brandenburg, Chair Hartley Lifecare
26/6/07	Maureen Sheehan ED Housing ACT
23/8/07	Garrett Purtill, Disability Advisor to Katy Gallagher
Aug-07	Housing submission written and distributed
23/10/07	Maureen Sheehan, ED Housing ACT

6/12/07	President and Vice-President of Canberra Community Housing, Maureen Sheen & David Matthews, Housing ACT
	<b>Karen and Cheryl join me</b>
6/2/08	Minister Katy Gallagher,
18/2/08	Maureen Sheehan, Andrew Whale, David Collett (with Karen C, Cheryl P, and husbands)
2/4/08	Guida, Moseley and Brown Architects (with Mac)
27/6/08	Bus trip to view housing examples (the three families)
31/7/08	Maureen Sheehan and Andrew Whale (with Karen C)
12/11/08	Housing ACT joint Champions Group (with Karen C)
13/1/09	Disability ACT and Housing ACT
15/1/09	ACT Minister for Disability and Housing, John Hargreaves
16/2/09	Housing ACT
5/2/09	Lois Ford, ED Disability ACT
17/2/09	Kim Fischer, Disability Advisor to Minister Hargreaves
13/3/09	Lois Ford, ED and Sarah King Individual Response Team, Disability ACT
14/4/09	Martin Hehir, David Collett, Bronwen Overton-Clark, (with Karen, Mac)
16/4/09	Stimulus package information session, MBA, Fyshwick
22/5/09	Kel Glover, Stimulus Package Advice (with Karen & Cheryl)
1/6/09	David Dawes, Chief Minister's Department with Ric Butt
	<b>Mac died the next day on 2r</b>
30/7/09	David Collett, Brown Overton-Clarke (with Duncan)
4/8/09	Neil Harrigan, CEO CatholicCare, Paula Chemello
10/8/09	David Collett, Andrew Whale, Josh Reinhart, Peter Johns
1/9/09	Craig Brennan, CEO CHC
9/9/09	Craig Brennan, Paula Chermello and Michael CHC
10/9/09	Andrew Whale, Peter Johns (with Karen)
14/9/09	Andrew Whale, Peter Johns, Josh Reinhart (with Karen, Cheryl)
21/10/09	Andrew Whale, Bronwen Overton-Clark, David Collett, Kel Glover, Michael (CHC), Neal Harrigan (with Karen, Cheryl)
14/12/09	Maureen Sheehan
24/3/10	LINC Meeting - no show on their part
31/3/10	Neil Finch Disability Advisor to Joy Burch (Karen & Johanne)
8/4/10	Amanda Bresnan, MLA (Karen)
17/5/10	LINC interview, CatholicCare
1/7/10	Jacque Lavis, GHD



- 28/7/10 Peter Johns, Jo Mitchell, Rob Thorman, Lesley Watson (LDA) (Karen, Cheryl, Johanne, Ian)
- 25/8/10 Joy Burch, Neil Finch, David Dawes, Joel (Chief of Staff) (Cheryl, Johanne, Tim)
- 17/9/10 Land viewing with Neil Finch Karen, Cheryl)
- 27/09/2010 Perth trip – Pinakarri, My Place, Vela Micrboards  
to Australia, Paul Antonelli, LACs and families. (with  
1/10/2010 Johanne, Karen and Cheryl)
- 8/10/2010. Faye Minty, Capital Community Housing
- 13/10/2010. Kel Glover, Community Housing Canberra (with Johanne)
- 21/10/10 Maureen Sheehan, Richard Baumgart, Peter Johns, Ian  
Ross (with Karen and Cheryl)
- 1/11/10 Eric Thauvette to discuss management and employment  
ideas
- 25/11/10 Ian Ross to discuss funding (with Karen, Cheryl and  
Johanne)
- 21/12/10 Ian to discuss funding
- 18/1/11 Richard Baumgart, Peter Johns, David Collett, (with  
Karen C )
- 14/2/11 Launch of the land/house development with Joy Burch,  
Neil Finch, Lois, David C, Peter J, Richard B, Kate Starrick  
(with Johanne, Karen)
- 15/2/11 Ric Butt (with Karen)
- 24/2/11 Ric Butt & AMC architects (with Karen and Johanne)
- 24/2/11 Karen & Sally met with Cheryl