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Person-Centred Approaches to Private Housing for People with Disability: Impediments, Difficulties and Opportunities

Final Report

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for

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Abbreviations

ABI	Acquired brain injury
ABCB	Australian Building Codes Board
ABS	Australian Bureau of Statistics
AHURI	Australian Housing and Urban Research Institute
AIHW	Australian Institute of Health and Welfare
AS	Australian Standard
COAG	Council of Australian Governments
CRPD	United Nations Convention on the Rights of People with Disabilities
CRA	Commonwealth Rent Assistance
CSO	Community Service Organisation
DDA	The Disability Discrimination Act 1992
DSA	Disability Services Act 1986
DSP	Disability Support Pension
DPRWG	The Disability Policy and Research Working Group
ILM	Independent Living Movement
NAHA	National Affordable Housing Agreement
NCC	National Construction Code
NDA	National Disability Agreement
NDIS	National Disability Insurance Scheme
NDS	National Disability Strategy
NDUHD	National Dialogue for Universal Housing Design
NPO	Non-profit organisation
NRAS	National Rental Affordability Scheme
OHS	Occupational Health and Safety
PCP	Person-centred Planning
RAC	Residential Aged Care
WHO	World Health Organisation

Glossary

Access	Access, in the context of this study, is defined as being in a situation where disability, or the consequences of or attitudes to disability are not barriers to, as stated in Article 19 of the Convention of the Rights of People with Disabilities (United Nations, 2007), "…choosing a place of residence and where and with whom to live on an equal basis with others".
Agency	Agency occurs when individuals or groups intentionally make things happen, and in this sense, agency enables people to consider, plan, act and adapt (Bandura, 2001). There is some thought that inanimate objects or non-physical social entities can have agency. While not being able to act in physical ways, they are influential by their mere existence (Robinson, 2011).
Disability and impairment	Disability is an umbrella term, covering impairments, activity limitations, and participation restrictions. Impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations.
Ecological perspective	From an ecological perspective there are multiple influences on behaviour (intrapersonal, interpersonal, organisational, community and policy) and that because of their interactive relationship demand multi-level intervention to effect change.
Housing careers	Housing careers are housing responses to people's needs through their life with consideration for their sense of identity and personal aspirations and situations.
Housing typologies	Housing typologies is a categorisation of housing type. For people with disability in Australia, these housing types are categorised in this project as: Private • private market housing (ownership and rental). Non -private • care facilities/care integrated housing ('supported accommodation'; 'residential care'; 'congregate care' facilities); and • social/public/community housing (subsidised housing). Hybrid • hybrid models integrating private with other typology characteristics (cluster models, intentional community models). Other 'accommodation' • hospitals and prisons; • crisis and transition accommodation; • respite and hospice accommodation; and • no fixed accommodation as in the case of homeless people.
Housing – private	As a base definition, this project uses the Australian Institute of Health and Welfare's (2012) definition that encompasses "housing that is owned or is in the process of being purchased by the occupant, or is privately rented by the occupant" (p. 2). 95% of the Australian population use private housing; 67% are home owners and purchasers; 25% rent privately, with a small percentage of alternative private-tenure types (3%). The rest (5%) use social

	housing (Australian Institute of Health and Welfare, 2013, p. 5).
Housing – social	Social housing is subsidised housing provided and managed by either government or the not-for-profit sector and is used by 5% of the Australian population (Australian Institute of Health and Welfare, 2013).
Inclusion	Both the CRPD (United Nations, 2007 Article 3 (c)) and the National Disability Insurance Scheme Act 2013, pp. Section 3, Clause (1)(g)), seek the full inclusion of people with disability in mainstream society. This study uses Chenoweth & Stehlik's (2004) definition that inclusion is where "people with disabilit[y] and families are fully accepted and are afforded the same opportunities for participation as non-disabled people" (p. 59).
Person-centred planning	Person-centred planning is an approach that aims for the person with disability, with family and friends as partners, to be the centre of a process to desire or imagine a better life, to develop a plan that reflects the person's capacities, needed supports, talents, dreams and priorities for their life (Rasheed, Fore, & Miller, 2006; van Dam, Ellis, & Sherwin, 2008).
Support – formal	Formal support is assistance provided to a person with disability by people who are paid.
Support – informal	Informal support is non-paid, usually voluntary assistance to a person with disability.
Tenure	Tenure can be briefly defined as "the holding or possessing" of home. Most people in Australia prefer the tenure of home-ownership, home-purchaser or private rental; however, there is an over-representation of people with disability in public, hybrid or alternative tenures.
Universal design	Universal design has two definitions: 1. "The design of products and environments to be usable by all people, to the greatest extent possible, without the need for adaptation or specialised design" (Mace, 1985). 2. "….design for human diversity, social inclusion, and equality" (Design for all Europe, 2004).
Visitability	"Visitability is a movement to change home construction practices so that virtually all new homes — not merely those custom-built for occupants who currently have disabilities — offer a few specific features making the home easier for mobility-impaired people to live in and visit."(Concrete Change, 2014)

Executive Summary

This Final Report presents the findings of a research project commissioned by the Disability Policy and Research Working Group (DPRWG) to explore the barriers and obstacles impeding a person-centred approach to planning and private housing for people with disability. More specifically, the research aimed to:

- review selected person-centred approaches to private housing securement for people with disability;
- map the context and identify the structural elements impeding attempts to implement person-centred approaches and access to housing in the private market for people with disability;
- provide recommendations on how the person-centred models studied can be refined to inform person-centred planning , individualised support and self-directed funding;
- explore the implications for access to and the design and provision of private housing for people with disability; and
- establish the basis for ongoing housing and disability research.

Despite growing recognition of the relationship between housing, health and wellbeing, and legislation that endorses the choice of housing as a basic human right, people with disability remain significantly under-represented in the private housing market and excluded from the opportunities afforded by private housing personally and socially. In order to understand what might be impeding access to private housing for people with disability, the project focussed initially on three organisations and their attempts to integrate innovative, and what they understand as person-centred models of housing, into the private housing market for people with disability. These were:

Case A

A community financial organisation working on behalf of individuals with disabilities (and/or their families) and associated not-for-profit service and housing providers to broker financial models that facilitate access to appropriate and affordable housing, including owner-occupied housing.

Case B

A not-for-profit foundation working on behalf of young people with disabilities at risk of being placed in or staying permanently in residential aged care facilities. To this end, the organisation works with state and federal government, housing associations, property developers, community service organisations, and financial institutions to produce a coordinated model of supported housing.

Case C

A community association working directly with families with an adult child with a disability, financial institutions, a planning organisation, local/state/federal government, a research institution, and a social enterprise housing provider to produce a private housing model to facilitate transition for the adult child currently living at home to their own privately owned home.

As the study of the three organisations progressed, it became apparent that these cases were cases of organisations acting *on behalf of* people with disability and their families, prompting the addition of a fourth (parent-led) case:

Case D
A family working with two other families, a family governance group, a community organisation and government, to secure housing of choice (in this case, social housing) for their adult children within an intentional community. The inclusion of a case of social housing connected integrally to the community challenged several preconceived notions including the study's original understanding of private housing.

In addition to the cases, individual participants, involving parents of adult children with disability, and individuals with disability, were also included to provide for a more diverse, inclusive and person-centred project.

During the initial interviews with participants, it became apparent that the issues they were dealing with involved multiple layers and levels interconnected in dynamic and sometimes incongruent ways. To understand this further, the project utilised an ecological theoretical framework recognising that: situations are informed/impacted by various external systemic factors interconnected across all systems in society; people have agency shaped by various factors including those of a personal, individual nature; and people and environment have a reciprocal relationship which changes over time.

Methodologically, the project involved explanation building using a multiple case study approach supported by a contextual study. It accessed multiple sources of data including documents, archived records, semi-structured interviews, and models developed by the case organisations. As well as helping to build a picture of causal relationships, the multiple sources and associated methods constituted corroborating strategies for strengthening research quality. Data collected were analysed by three researchers using an iterative process of comparing emerging findings against initial and emerging statements/propositions within and across organisations and individual cases. Overall, the process involved a gradual building of an explanation of the barriers and obstacles impeding access to private housing for people with disability, and of the policy and practice implications for government, organisations such as the case organisations and community organisations, the housing industry, people with disability, and families of people with disability.

In general, the project reveals a complex and challenging picture of access to private housing for people with disability and their families. A number of key issues are identified. First, challenges and impediments to access to private housing for people with disability are various, occur in all domains and across the ecology, and are interconnected. We refer to this as a mosaic. However, there is a siloed approach to planning and services, including housing that does not recognise the mosaic nature of the issues. Housing needs to be considered as an integral and priority issue within planning that is aligned, but not conflated with, other areas such as support services.

There is also a siloed approach to housing for people with disability which assumes and maintains a 'disability space'. While some will prefer to move within this space, a more mainstream approach to the issue of limited suitable stock (including regulation, education of the industry, promotion and advocacy by community organisations, and so on as listed in our recommendations) would facilitate greater inclusion as well as broader societal benefits. This will require significant changes, including a policy shift to support and facilitate movement between the 'disability' and 'mainstream' space, as well as within the 'mainstream' space. This also has implications for how housing assistance is provided and structured, and how funding models and financial services are regulated and supported to address affordability.

The focus on a 'disability space' and 'disability-focused solutions' also limits choice and movement along a housing pathway or career. Our suggested focus is on providing and opening up opportunities for people with disability within the mainstream space in an inclusive way that benefits the whole community, and not only people with disability and their families. The fundamental issue of availability of stock in the 'mainstream' space is significant in the ability of housing-related planning to be person-centred; at present, approaches that are designed to be person-centred are severely challenged by the lack of stock available and suitable for use. Additional recommendations relating to home modifications will have considerable implications in this regard.

The project further recognises the segmented and siloed nature of the broader policy/ legal/ funding environment which perpetuates the single-issue and disconnected or piecemeal approaches to which organisations have been restricted. Because of this segmented system, the ability of individuals and organisations to operate across the systems in the ecology and to span the issues that challenge access is severely restricted. Both the mosaic nature of challenges to access and the challenges for individuals and organisations to move between systems in the ecology highlight a need to adopt a holistic approach where systems are aligned and congruent.

Specifically, the report makes the following recommendations to government, the housing industry, individuals with disability, families/support networks/advocates, community organisations, and research institutions:

Recommendations for Government
The report recommends that:

With regard to the provision of housing—
1. minimum visitability requirements for all new and extensively modified housing are included in the National Construction Code;
2. mainstream housing supported under the National Rental Affordability Scheme, or using other government subsidies, provides Livable Housing Australia's Gold Level of access as a minimum;
3. incentives for the housing industry to build, and buyers to demand, Livable Housing Australia's Gold or Platinum level housing;

4. planning legislation to support the development of inclusive residential communities, including a mix of affordable housing types close to accessible transport, work opportunities, services and community amenities;

5. to be considered as a priority issue within planning that is aligned, and not conflated with, other areas such as support services; and

6. support for planning that is holistic and inclusive of housing that incorporates mainstream options and services.

With regard to housing assistance—

1. greater flexibility in assistance packages to support people with disability in choosing where and with whom they live, to develop a housing career, and to change, and develop their housing situation over time or as their situation changes. While this may be housing provided through the disability sector it should not preclude mainstream housing. Indeed, it should facilitate movement between the disability and mainstream spaces providing individuals with greater choice;

2. considers other related needs such as assistance in obtaining work;

3. explores additional mechanisms for attaining sustainable home-ownership such as shared equity, home loan assistance, or incentives for family investment; and

4. people with disability, regardless of their access requirements and support needs, are given the same opportunities to live in social housing as other people.

With regard to home modifications—

1. the government establishes a national adequately funded home modification program to assist people with disability and their families to remain in mainstream housing. This would require:
   - the development of national standards addressing construction quality, safety and OHS issues for paid staff;
   - consideration of the needs of both current and prospective users; and
   - the tracking of extensively modified housing for future use.

With regard to information and awareness—

1. the government provides illustrated examples of people with disability living successfully in a variety of mainstream housing; and

2. the government makes available timely information on housing assistance for people with disability and their families to encourage and support envisioning and planning a housing career supporting community inclusion, secure tenure and wealth creation.

Recommendations for the housing industry

The report recommends that:

1. the housing industry emphasises education and training of housing industry professionals with regard to the impact of good mainstream housing design on people's inclusion and participation in family and community life;

2. the housing industry supports education, training and incentive strategies of Livable Housing Australia for all housing sectors; and

3. the housing industry supports the regulation of visitability requirements for all new and extensively modified housing in the National Construction Code for national consistency and efficiency.

Recommendations for individuals with disability

The report recommends that:

1. people with disability take opportunities to imagine beyond current specialist disability housing solutions including seeking out other people who have established their own home in the mainstream community;

2. people with disability envision, and plan for their own home as part of their goals for a good life, and these plans reflect normative housing careers, including aspirations of home ownership, security of tenure, and wealth creation; and

3. when mainstream housing design is required to change to meet particular needs, people with disability seek their incorporation without compromising their individual style and preferences.

Recommendations for families, support networks and advocates

The report recommends that:

1. families, support networks and advocates assist the person with disability to envision, plan, find and maintain their own home by:
   - assisting them to seek out other people who have established their own home in the mainstream community as examples of what is possible;
   - using mainstream housing assistance strategies, including shared equity, home loan assistance and incentives for family investment that are available to encourage people with disability into sustainable home-ownership;
   - assisting people with disability to direct their support, and coordinate their transport, leisure and work opportunities so that they are able to participate and contribute to family and broader community life;
   - recognise the dignity of risk associated with independent living; and
   - promote individual potential for growth beyond current capabilities in living independently.

Recommendations for community organisations

The report recommends that:

1. community organisations in their support for people with disability and their families:
   - place the focus on the person before the disability;
   - ensure policies and practice follow the CRPD articles, including supporting people with disability to choose where and with whom they live, and their active participation and inclusion in community life;

- encourage mainstream housing opportunities; and
- facilitate their access to information and resources and demonstrations of best practice to people with disability and their families and support networks.

2. community organisations advocate for and promote community awareness of the benefits to society of visitable and inclusive housing.

Recommendations for future research

This project highlights the need and opportunities for substantial further research by government, universities, the housing industry, and community associations. Recommendations for future research that explicitly acknowledges the scale and temporal constraints of this project include but are not limited to:

1. longitudinal research that maps the experiences of people with disability over time as they move along housing pathways;
2. research that more extensively explores the experiences of people with disability across the range of housing and accommodation environments;
3. research that focuses on the relationship between type and level of disability and housing experience and opportunity;
4. research that considers cultural issues impacting choice and personal and family agency;
5. research that focusses on further understanding the complex nature of person-centredness and how housing can be effectively incorporated in person-centred planning; and
6. research that evaluates the outcomes and effectiveness of person-centred planning; and
7. research that further explores how to reconcile a person-centred philosophy with a holistic appreciation of the external and internal factors impacting private housing access for people with disability.

1 Introduction

1.1 Research Aims

This research project, commissioned by the Disability Policy and Research Working Group (DPRWG), focuses on the much-neglected area of housing and disability, in particular, private housing. As noted by Tually et. al. (2011), there is:

> ... a dearth of literature on housing and disability in Australia generally…This absence exists despite growing recognition of the importance of appropriate, stable and affordable housing in the health and wellbeing outcomes of all individuals. Housing is increasingly recognised as shaping access to/maintaining the services and support we all need for our sense of self- and community-worth and wellbeing (Tually, Beer, & McLoughlin, 2011b, p. 22).

In other words, suitable housing is fundamental to health and wellbeing, and choosing what this might entail is a basic human right. Unfortunately, for many people the ability to choose is seriously compromised by various factors. Significant in this respect is disability. The ratification of *The UN Convention of the Rights of Persons with Disabilities* is acknowledgement of disability as a human rights issue (Fronek, Chenoweth, & Clements, 2010, p. 7), and along with this, the need for models of funding and service provision that support people to make choices and have greater control over the funding and support they require to meet their needs and aspirations. In this respect, the Australian government launched The National Disability Insurance Scheme (NDIS), which aims to provide greater entitlement and capacity for individuals to plan and direct their support – sentiments reflected in the slogan for the 2013 NDIS conference 'My Choice, My Control, My Future'.

One of the main principles of the NDIS is a person-centred approach that engages the person with disability and/or their representative, in planning for and making decisions about their future – including where and with whom they live. Unfortunately, the limited range of housing options for people with disability is seriously out of step with the UN convention and related person-centred policies, with emphasis placed on group home and congregate care models. What this points to is the need for people with disability to have greater access to private housing, and for research to explore how such access may be facilitated through person-centred approaches. In response this research project asked:

> What are the barriers and obstacles currently impeding person-centred approaches to private housing for people with a disability?
>
> How might such knowledge contribute to the development and implementation of person-centred approaches to providing access to private housing for people with disability?

Specifically, the project aimed to:
- review selected person-centred approaches to private housing securement for people with disability;
- map the context and identify the elements impeding attempts to implement person-centred approaches and access to housing in the private market for people with disability;

- provide recommendations on how the person-centred models studied can be refined to inform person-centred planning, individualised support and self-directed funding;
- explore the implications of access to and the design and provision of private housing for people with disability; and
- establish the basis for ongoing housing and disability research.

This report addresses these aims, using an ecological framework that positions the issue of access within and across disability specific and mainstream systems.

1.2   Structure of the Report

The report begins in Section 2.0 with an overview of the current housing situation in Australia and against this backdrop highlights the private housing situation for people with disability. This is supported by an historical review of the disability and housing policy and regulatory context.

Section 3.0 presents the theoretical context of the project informed by literature relevant to access, inclusion and participation. It draws attention to personal, systemic and attitudinal factors impacting access to private housing and through this greater inclusion and participation in society for people with disability.

Section 4.0 follows with an outline of the ecological approach adopted by the project. It also includes detail of the case study methodology, how it was conceived and employed in line with the ecological framework.

Section 5.0 reports on the three primary cases, and attempts by the case organisations (who are positioned in different ecological systems), to implement what they regard as person-centred approaches to private housing for (on behalf of) people with disability. While the cases have much in common they differ in terms of the barriers they primarily attempt to address; for example, Case A focuses on financial barriers to private housing, Case B is concerned with relational barriers to do with information, communication and facilitation, and Case C shows concern for environmental barriers of housing design and location. As indicated, these cases describe attempts undertaken by organisations *on behalf of* people with disability and their families. Appreciating this, the study then included an additional case of an attempt *by* a mother to facilitate a housing outcome that met her vision of a meaningful life for her adult son with disability; and to enrich this further with the voices of other individuals and families and their personal experiences of attempting to access housing tenure of choice.

This parent-led case and additional individual experiences are described in Section 6.0. While the inclusion of this case and individual participants further revealed the systemic barriers to private housing for people with disability, it also revealed wider societal attitudinal barriers as well as more personal and individual barriers associated with people with disability themselves and their immediate family. The case descriptions presented in these sections are summarised versions of the full case reports presented in Appendix A of this report.

Using an ecological framework the cases are brought together in Section 7.0 to highlight key findings and their significance in relation to the aims of the project. The discussion informs Section 8.0 which follows and policy / practice implications and recommendations for government, organisations, the housing industry, people with disability, and their families.

2   Demographic/Policy Context

This section provides the demographic and policy context for the project. It starts from the current mainstream housing situation providing as recent statistics as possible of available housing stock and of the percentage of the population accessing this stock. This then provides a 'normative' benchmark for a comparative view of the current housing situation for people with disability and the tenure they most access. As the discussion will highlight, people with disability are underrepresented in the private ownership and rental market and overrepresented in the social and marginal markets; and as illustrated in the next part of the section this is despite various anti-discrimination conventions, policies, strategies, and legislation. The section concludes with a description of the housing stock categorised as private, non-private, hybrid and other accommodation.

2.1   Current mainstream housing situation

Housing demographics

The most recent statistics available from the Australian government show that just prior to 2013 95% of the Australian population used private housing; 67% were homeowners and purchasers; 25% rented privately, with a small percentage of alternative private-tenure types (3%), the remaining (5%) used social housing (Australian Institute of Health and Welfare, 2013, p. 3) (Figure 2.1).
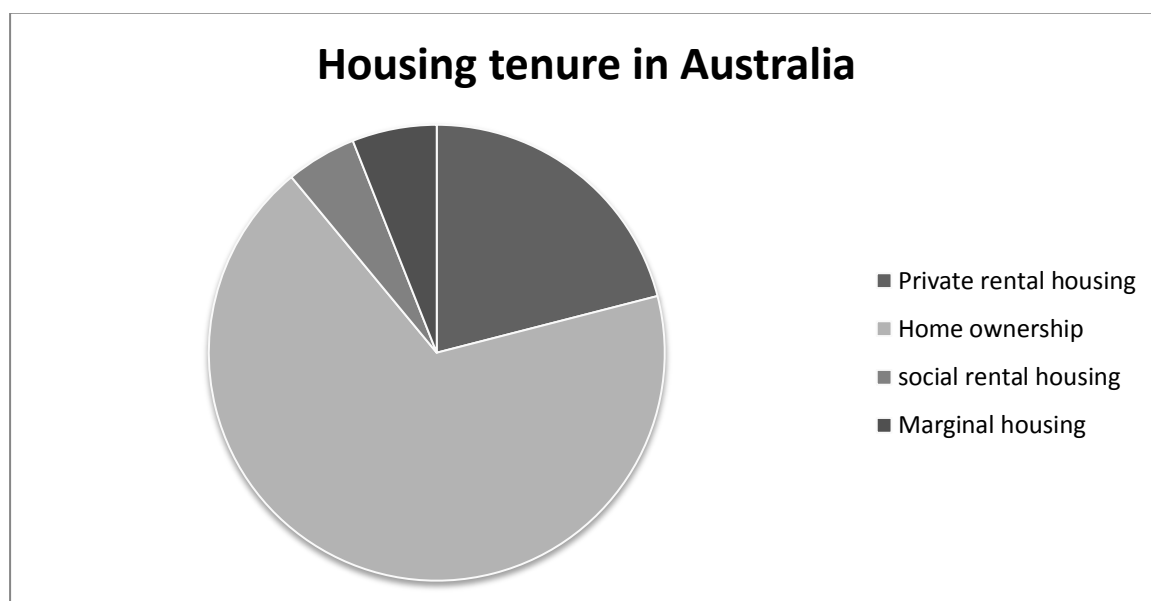
Figure 2.1: Housing stock in Australia, by tenure type
(Australian Institute of Health and Welfare, 2013, p. 3).

Housing tenure can be further delineated according to the legal and financial status of the occupant. Elements of legal status relate to rights of access, occupation, use and control. In Table 2.1 we have drawn on existing literature to summarise the criteria that delineate common housing tenure types in Australia.

In the last decade, the size of households has decreased and the average size of dwellings has increased, leading to an increase in the demand for the number of dwellings required to house the population (Australian Institute of Health and Welfare, 2013). Although the percentage of homeowners has remained steady, the percentage of people with a mortgage has risen from 30% in 1994 to 36% in 2009. 24% of households rented privately in 2009 compared with 18% in 1994. The increasing demand for private housing stock has seriously impacted housing supply with supply of new housing considered inadequate to sustain current choices of tenure (National Housing Supply Council, 2011, p. 54).

Table 2.1: Criteria for delineating housing tenure type in Australia
(Australian Institute of Health and Welfare, 2011; Hulse, 2008).

Housing tenure	Legal status	Financial status
Owner/ Purchaser	Legal rights to access, occupy, use and control; and buy/sell land and dwelling	If owned outright, no debt secured against the property. If purchasing, the debt secured against property giving rights to third parties in respect of sale of dwelling.
Private renter	Legal rights to access, occupy, and use dwelling and associated land through lease arrangements.	Payment of rent or other consideration for occupancy of dwelling to a private landlord
Public*[1] renter	Legal rights to access, occupy, and use dwelling and associated land through lease arrangements.	Payment of rent or other consideration for occupancy of dwelling to state or territory housing authority.
Marginal housing (caravan parks, boarding houses, residential facilities, nursing homes and institutions)	Various arrangements for defining residency rights and responsibilities.	Payment or other consideration to the residential facility for rental and perhaps other services.

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[1] *a number of government housing authorities are transferring the management and property to community housing NPOs and tenure may compare with other private rental tenure in terms of security.

Of relevance to this project, the statistics highlight how private ownership is the choice of a majority of people in Australia followed by private rental, and that access to private housing is likely to be increasingly competitive due to diminishing supply. This will further impact on people with disability wishing to access the private housing market, and will no doubt influence the statistics and research, such as that presented in the following section that indicate that people with disability, particularly younger people, experience greater barriers and impediments to private housing than the general Australian population. The fact that people with disability are more likely to have lower incomes than the general population (Australian Government, 2012) means that for this reason alone they are less likely to be home owners, and if they are home owners, more likely to experience housing stress. In all, they are more likely than the general population to be tenants, especially social housing tenants (Beer & Faulkner, 2008, p. vi) putting people with disability at further risk of exclusion from the preferred tenures of Australian households.

2.2 Current housing situation for people with disability

Disability and housing demographics

At the time these demographics were compiled nearly 23 million people in Australia, 4.1 million people (or 18.5% of the population) identified they have a disability (Australian Bureau of Statistics, 2010, p. 6). Around 3.7 million (or 16.3% of the population) reported a specific limitation or restriction; that is, an impairment restricting their ability to perform communication, mobility or self-care activities, or a restriction associated with schooling or employment. The prevalence of people with disability differs from State to State with 25% of people in Tasmania living with disability compared to Western Australia and Australian Capital Territory (16%) and the Northern Territory (12%). People with disability were more likely to be found in inner regional areas (22%) rather than the major cities (17%). **Indigenous Australians** experienced disability at around 2.2 times the rate of non-Indigenous Australians (Australian Bureau of Statistics, 2009).

There were 3.3 million **older people** in Australia with around 1.7million with a disability. This means around 40% of people with disability were over 65 years with this figure at the time expected to increase as the population ages (Australian Bureau of Statistics, 2012 Older people - key findings).

Around 2.7 million people (or 12% of the population) were **carers,** providing informal support to people with disability, with 770,000 people (or 3.4% of the population) primary carers. Most carers were female, and likely to be partners or parents of the person requiring support. Almost 75,000 carers were less than 15 years old. Around one third of primary carers had a disability themselves with around 18,600 male and 43,300 female primary carers themselves having a profound or severe core activity limitation (Australian Bureau of Statistics, 2012 Carers - key findings).

As recent as 2013, people with disability still were likely to have lower incomes than the general population, resulting in fewer housing options and a higher dependence on social housing and support services (Australian Government, 2012; Australian Institute of Health and Welfare, 2013; Beer & Faulkner, 2008). Households with a person with disability made up 40% of tenants in public

housing and approximately 37% per cent in community housing (Australian Institute of Health and Welfare, 2013, p. 40). Households with a person with disability, however, were held to be more likely than the broader population to own their own home (Australian Institute of Health and Welfare, 2013, p. 39). This was attributed to two factors: disability increases with aging—older households are more likely to own their own home, and families of people with disability assign priority to home ownership over other opportunities as secure tenure assists with caring responsibilities and reliable access to services (Beer & Faulkner, 2008, p. 40). As our project highlighted however, home ownership can be temporary for these households and does not guarantee the same type of tenure for the adult children once their ageing parents are no longer there or able to support them. In addition, many households with a person with disability identified that the onset of disability increased caring responsibilities and subsequent loss of income assisted their "fall-out" of home-ownership (Beer & Faulkner, 2008, p. 39).

In terms of people with disability in marginal housing the statistics are unreliable due to problems with identification of premises, the transience of the residents and self-reporting by proprietors. Recent research indicates many residents are ageing, have a disability, are unemployed and have high support needs (Goodman et al., 2013, p. 4). Goodman et al. argue that the supply and demand for marginal housing are directly related to levels of unemployment and retirement, and the availability of affordable private rental housing and social housing. Marginal rental housing has been considered a form of homelessness for people who cannot afford, are unable to sustain, or are excluded from normative housing (Goodman, et al., 2013).

Approximately .5% of Australians identified themselves as homeless; that is, living in:
- improvised dwellings, tents, sleepers out;
- supported accommodation for the homeless;
- temporarily with other households;
- boarding houses;
- other temporary lodging; and
- severely crowded dwellings (Australian Bureau of Statistics, 2006).

Of this group, 36% lived in boarding houses or residential services, and 35% lived in severely crowded housing. While it can be assumed a large percentage have a disability, Aboriginality, the remoteness of location and poor command of the English language were also evident as factors leading to homelessness (Australian Bureau of Statistics, 2006). In addition, there were approximately 6000 people under 65 years living in residential aged care facilities with around 700 of them under the age of 50 years (Winkler, Callaway, & Guthrie, 2013). They currently relied on aged care because appropriate housing and the level of disability support required were either not available or were inadequate in community settings (Winkler, Farnworth, Sloan, Brown, & Callaway, 2010).

In summary, the housing picture for people with disability and their families shows some specific patterns. In relation to the general population, Beer and Faulkner (Beer & Faulkner, 2008, p. vi) found that households with a member with disability:

- are more likely to report significantly lower incomes;
- are more likely to experience housing stress;
- are more likely to be tenants, especially public tenants;
- generally have less financial liquidity; and
- have made housing decisions based on the needs associated with a family member's disability or long-term health condition.

While the above has generalised the situation for people with disability, it is important to recognise that specific disabilities can impact in different ways on housing choice and experience. Within the limitations of their study, Beer and Faulkner (2008) identify a range of issues for people with particular disabilities:

People with psychiatric disability report the lowest incomes, few opportunities for full-time employment and greatest overall disadvantage. Most people are tenants, particularly of social housing. Their support needs are typically inadequately met. A higher number than average live on their own or with another person with disability, and the episodic nature of mental illness causes many to change their housing often, and to make them more vulnerable than the average person to homelessness (p. 30).

People with mobility impairment identified three particular difficulties: the first is low income, second is the lack of appropriately designed dwellings, and the third is the added cost of equipment and modifications. Once people with mobility impairment find and modify their dwelling and establish their support services and networks they are reluctant to move from that dwelling and neighbourhood (p. 33).

People with sensory disability also suffer loss of income, causing many to fall out of home-ownership. However, they appear to find appropriately designed dwellings more easily than those with other disabilities (p. 36).

People with cognitive disability currently have limited opportunities for full-time work. Many people live with family members well into middle age, and then move into shared supported-housing (such as, group homes or community residential units). In this sense, their housing options are more often defined by the availability of support (p. 36).

People with disability due to ageing have increasingly chosen to live in the community with only 6% living in residential aged care (Productivity Commission, 2011b, p. 13). They are more likely to own their own home, and those in rental are more likely to be in social housing than the general population (Judd, Olsberg, Quinn, & Demirbilek, 2010, p. 5).

Summary of main points

In summary:
- despite private ownership or rental being the main choice of most people in Australia people with disability accessing private ownership or rental are significantly underrepresented;
- the significance is critical considering that nearly 1 in 3 people in Australia have a disability or report a specific limitation or restriction. Of the 18.5% who identify as having a disability approximately 60% are under 65 years of age and while the percentage under 65 years of age is decreasing, the percentage of older people with disability is on the increase;

- when the impact on those supporting people with disability is considered, the extent of exclusion from mainstream housing escalates. Housing choices and careers of carers, families and other household members are also affected;

- for people with disability various external and internal factors affect access to their choice of housing, particularly private housing. The age when people acquire a disability as well as the type of disability will affect access to the choice of tenure and the type of housing that is needed;

- households with a younger person with disability are likely to have less income than the general population, due to lack of work opportunities, added costs of living, and caring responsibilities. These households are also likely to have fewer assets. They, therefore, are less likely to own or purchase their housing, and are more likely to be tenants, especially social housing tenants, than the general population;

- older people who acquire their disability later in life are likely to have acquired some assets, including housing, before they acquired a disability. This has implications for support including housing modification assistance in helping these people remain in their home and community; and

- beyond the specific access issues experienced by people with disability, and not withstanding issues of appropriate design and location, there is the issue of the availability of stock in general, with mainstream housing demand exceeding supply and competition for private housing further exacerbating the risk of exclusion for people with disability.

2.3   Private housing for people with disability: the policy and regulatory context

Historical overview in Australia

This section outlines the key initiatives that have shaped the provision of housing for people with disability in Australia in the last twenty-five years. The enactment of the *Disability Services Act 1986* and its State equivalents and the closure of most large institutions followed the emergence in the 1960s of the American Independent Living Movement (ILM) (Kendrick, 2012; Wolfensberger & Nirje, 1972) which drew a direct link between self-managed accessible housing and independent living and social inclusion (Hemingway, 2011, p. 19). Over the last twenty years or so, the Australian Government enacted a suite of anti-discrimination legislation with proactive strategies, capacity for standards and capacity for redress against discriminatory practices. The design of private housing was not addressed; however, the requirement for non-discriminatory access to housing assistance programs, in particular, social housing, required government and community housing providers to consider not only housing allocation processes but also the design of their housing stock.

Historically, housing policy has not treated vulnerable people well; the legacy is a social housing program, bearing the full brunt of housing need for people with disability. The private housing-market has made minimal concessions to the design and location needs of households who have little or no buying power, including people with disability (Troy, 2012, p. 285). The national regulatory scheme for construction has no access requirements for the internal spaces of housing.

Instead a variety of local requirements, advice and incentives has been used to encourage the housing industry to respond voluntarily—with little effect (Karol, 2008; Ward, Franz, & Adkins, 2012).

In 2008, the Australian Government sought advice from leaders in the private sector on innovative ideas that would increase private sector involvement and investment in the funding of disability services and related infrastructure (Disability Investment Group, 2009). With the establishment of National Disability Insurance Scheme (NDIS) as their first recommendation, they identified a direct link to the need for a response from the private housing sector. They suggested that, with the certainty of funded support, many people with disability and their families could now plan for the future in areas such as housing, in the same way that compulsory superannuation has encouraged additional private contributions to retirement savings (p. 4).

The purpose of the NDIS is "to support the independence and social and economic participation of people with disability" (National Disability Insurance Scheme Act 2013, p. 4). Any initiatives for the private housing industry to support the NDIS should align with this purpose. Current Australian Government regulatory and policy frameworks that are relevant to private housing are:
- Australia's human rights obligations;
- Disability Services Act (DSA) 1986 and de-institutionalisation;
- Australia's social inclusion agenda and urban policy framework; and
- Design and construction codes, guidelines and policies

Australia's human rights obligations

The Australian Human Rights Commission describes the purpose of human rights as recognising the inherent value of each person, regardless of background, where they live, what they look like, what they think or what they believe. Human rights are based on principles of dignity, equality and mutual respect, which are shared across cultures, religions and philosophies. They are about being treated fairly, treating others fairly and having the ability to make genuine choices in our daily lives (Australian Human Rights Commission, 2013). With regard to people with disability the Australian Human Rights Commission oversees the Australian Government's obligations in the *Disability Discrimination Act 1992* and the United Nations Convention on the Rights of People with Disabilities (CRPD).

> *The Disability Discrimination Act (DDA) 1992*

The *Disability Discrimination Act 1992* aims to eliminate, as far as possible, discrimination against people on the grounds of disability (*Disability Discrimination Act* 1992 Clause 3). This legislation works three ways: it offers a mechanism for individuals to seek redress against discriminatory behaviour (Clause 67); it encourages entities to develop action plans towards non-discriminatory practices (Clause 59); and it provides capacity to develop standards, which clarify what is discriminatory (Clause 31).

The Access to Premises Standard (Australian Government, 2010a) details what must be done to provide for non-discriminatory access to public buildings. With regard to housing, the standard does not apply to Class 1 (a) dwellings (detached houses) and the interiors of Class 2 dwellings (multi-dwelling complexes), however it does require apartment buildings with short-term rental to provide non-discriminatory access in the common areas and at least one floor containing sole occupancy units up to the entrance doorway of every sole occupancy unit located on that level (Australian Government, 2010a).

Convention on the Rights of People with Disabilities (CRPD)

The Australian Government's obligation under the CRPD is significant in relation to housing as it now recognises that people with disability have the right to "full and effective participation and inclusion in society" (Article 3) and people with disability should "have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others" (Article 19). The CRPD promotes the concept of universal design[2] in the development of standards and guidelines for (in this context) housing, in a way that requires "the minimum possible adaptation and the least cost to meet the specific needs of a person with disabilities" (Article 4). The Council of Australian Government's (COAG) National Disability Strategy (Australian Government, 2011a) provides the policy direction in response to these obligations, and aims for "improved provision of accessible and well-designed housing with choice for people with disability about where they live" (p. 32).

Disability Services Act (DSA) 1986 and de-institutionalisation

Australia, as in many Western countries, previously considered that people with significant disability were best cared for in facilities separate from the mainstream community. The emergence of parent groups after World War 2 and the influence of normalisation and social role valorisation theory (Wolfensberger & Nirje, 1972) led to a national change in policy direction resulting in the *Disability Services Act (DSA) 1986*. The DSA was considered revolutionary at the time because it guided services to be more flexible and responsive to the needs and aspirations of persons with disabilities and to assist them towards full participation as members of the community. This approach resulted in a gradual increase in acceptance of people with disability in work and community life and the closure of larger residential institutions. As previously highlighted, this in turn influenced the emergence of a range of housing/accommodation models including group homes and the like.

Since the DSA various policy and program advances have affected the provision of housing and support for people with disability:

- the *Disability Discrimination Act 1992* and its State equivalents offered people with disability equal access to housing assistance, public spaces and places and transport;
- increased funding through the State equivalents to the DSA and the Home and Community Care program offered a growing choice of community-based services;

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[2] The definition of "universal design" in the Convention is "the design of products, environments, programmes and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design" (United Nations, 2007, p. 4).

- increased awareness of universal housing design through voluntary codes of practice in the housing industry;
- increased interagency coordination to assist particular groups to establish, live and remain in their own home and community;
- funding developments – such as availability, flexibility and mobility of funding, and measure of unmet demand for support from people with no support or needing different support;
- focus on staff development with increased training, pay levels and work conditions;
- greater understanding of people from Indigenous or culturally or linguistically diverse backgrounds;
- greater understanding of working flexibly with and for the person and family; and
- increased understanding of the needs of carers of a person with disability – such as risk, safety, emotional or financial support (Fisher, Parker, & Purcal, 2009, p. 322).

Kendrick (2012) sums up the achievements since the DSA as a shift in values from low expectations and incarceration to considering people with disability as fully human, capable of learning and development and entitled to participatory lives in the community. There is a relative disappearance of the custodial large institutions, growth of public and community support for a better life for people with disability, and enough examples of people with disability living full lives that it is now harder to dispel this policy direction. Kendrick balances this picture with what he considers are the challenges ahead. People with disability continue to experience discrimination and negative community attitudes, many people with disability and their families do not receive the level of support they require, and many services are unable to respond in a manner that truly meets peoples' needs. He argues that many people with disability live in the community but are not included; they remain unable to participate or contribute as their fellow citizens.

National social inclusion agenda and urban policy framework

The Australian Government's social inclusion agenda is for "all Australians [to] have the opportunity and support they need to participate fully in the nation's economic and community life, develop their own potential and be treated with dignity and respect" (Australian Government, 2010b, p. 4). The national urban policy priorities are to facilitate the supply of appropriate mixed income housing, and to support affordable living choices:

> We will need diverse dwelling forms and sufficient affordable housing options across all tenures including home-ownership, private rentals, social housing and crisis accommodation, to accommodate people for short or longer periods at different points in their lives or 'housing careers' (Australian Government, 2011c, p. 55).

National Disability Insurance Scheme (NDIS)

The NDIS is a funding mechanism which is guided by a set of objectives and principles (National Disability Insurance Scheme Act 2013 Clauses 3-4). It differs from previous funding mechanisms, such as the *Disability Services Act 1986*, and its State equivalents in three fundamental ways:

- it provides an entitlement of support to people with significant disability, adopting an insurance-based approach (Clause 3 (2));
- it provides capacity for the individual to plan and direct how their support is provided (Clause 31). Anticipated outcomes are a much greater number of people will receive support, and services will need to respond to these individual plans;
- it levies every taxpayer in Australia, thus bringing the costs and anticipated outcomes to the general public's attention.

NDIS aims to:
- give effect to Australia's obligations under the CRPD, and other relevant human rights obligations;
- support the independence and social and economic participation of people with disability;
- enable people with disability to exercise choice and control in the pursuit of their goals and the planning and delivery of their supports;
- facilitate the development of a nationally consistent approach to access to, planning for, and funding of supports;
- promote high-quality and innovative supports that enable people with disability to maximise independent lifestyles and full inclusion in the mainstream community; and
- raise community awareness of the issues that affect the social and economic participation of people with disability, and facilitate greater community inclusion of people with disability (National Disability Insurance Scheme Act 2013 Clause 3).

Protagonists of the NDIS anticipate a system of entitlement for people who need support, services having to respond to these individual plans, market-forces elevating the quality and responsiveness of paid service, and the general public paying greater attention to how the funds are spent (Every Australian counts website). Others warn against expectations that a funding mechanism alone will change people's lives (Kendrick, 2011). This suggests that building an inclusive and meaningful life for people with disability is complex, and formal support services play a vital but limited role. The NDIS does not provide funding for housing or housing assistance. It does, however, consider home modifications, with equipment and vehicle modifications, as part of a person's support strategy (Australian Government, 2013).

Design and Construction codes, guidelines and policies

With regard to meeting the particular needs of people with disability in residential environments, the private housing industry has five main influences on its practice:
- the National Construction Code (NCC) and legislated requirements under the State building acts;
- requirements of funding mechanisms and development authorities;
- voluntary guidelines which encourage universal design;
- market-demand for universal design; and
- need for modification of existing housing.

These are now discussed.

National Construction Code

The National Construction Code (NCC), consisting of the Building Code of Australia and the Plumbing Code of Australia, is developed by the Australian Building Codes Board (ABCB) as a joint initiative of all three levels of government in Australia to address issues of safety and health, amenity and sustainability in the design, construction and performance of buildings. It is also a regulatory reform vehicle for COAG, and develops both effective regulatory systems and appropriate non-regulatory solutions (ABCB, 2011). The regulatory system stipulates the minimum requirements necessary to meet the needs of all stakeholders, and provide a consistent quality of building across Australia.

All state legislation must refer to the NCC as the minimum building code. With the enactment of the Access to Premises Standard in 2011, the NCC improved the standard to include non-discriminatory access to the common areas of all Class 2 buildings. This means a continuous accessible path of travel from the street boundary to the principle pedestrian entrance of the building. The entrance and doorway must meet Australian Standard (AS) 1428.1(2009) specifications. Further, the passageway and any doorways along that passageway that leads to the required apartments must also meet the requirements of AS1428.1 (2009). This pedestrian entrance is required to be accessible to at least one floor containing dwellings and to the entrance doorway of each dwelling located on that level.

Some states have enhanced the NCC by amending their building or planning legislation to require access requirements for the interior of housing. In South Australia, for example, Class 2 developments of twenty or more dwellings require five per cent of the total number to comply with AS 1428.1(2001) (Government of South Australia, 2002). Similarly, the ACT Government has a requirement for one in every ten dwellings of a Class 2 development to comply with AS 4299– Adaptable housing (ACT Government, 2013). New South Wales Government devolved the responsibility for the supply of accessible housing to local authorities resulting in a highly fragmented approach (Newman, 2010). This approach is currently being reviewed in the development of their new planning system.

In conjunction with the NCC are various standards. Standards Australia, a national non-government organisation, develops standards through a process where competing interests are considered and consensus is reached. These standards can be then incorporated into legislation (Standards Australia, 2013). The Australian standard for access and mobility – new building work: 1428.1 (2009) is referenced by the Access to Premises Standard (Australian Government, 2010a) and the National Construction Code. Standards Australia also developed the Adaptable Housing standard AS 4299 (1995), for mainstream housing that could be used by a wide range of people and could easily be adapted for specific needs if required. This has not been referenced in the National Construction Code; however, it has been used in many other guiding mechanisms.

Requirements of funding mechanisms and State development authorities

The Australian Government also requires housing funded under the National Rental Affordability Scheme (NRAS) to incorporate some universal design features (National Rental Affordability Scheme Regulations 2008 Schedule 1). NRAS seeks to address the shortage of rental housing and rapidly rising rents by offering an incentive to providers of new rental dwellings. The incentive is offered on the condition that dwellings are rented to eligible low and moderate income households at a rate that is at least 20 per cent below the prevailing market rate (Australian Government, 2011b, p. 7). The scheme's funding round No. 5 has advised proposals that incorporate the Gold Level of the Liveable Housing Design guidelines will be assessed more favourably (Livable Housing Australia, 2013a).

Most State development authorities require some accessible housing to be provided by developers within their mix of more affordable housing. For example, the Queensland Government requires at least ten per cent of its multi-residential developments to comply with their specific guidelines (Urban Land Development Authority, 2011, p. 3). The policy of New South Wales's equivalent, Landcom, suggests to developers that they provide accessible housing if it is appropriate and financially viable for them to do so (Landcom, 2008, p. 5).

Voluntary initiatives

There have been several comprehensive voluntary access guidelines developed in the last decade to encourage the private housing industry to expand their buying-market to people who need accessible housing (Building Commission Victoria, 2002; Department of Housing, 2001; Master Builders Association (ACT), 2001). Recent studies into the outcomes of a voluntary approach suggest little change has occurred as a result of these industry initiatives or market-demand (Colmar Brunton, 2004; Karol, 2008). Nevertheless, in 2010, the Australian Government encouraged housing industry and community leaders (National Dialogue for Universal Housing Design (NDUHD) to develop a national voluntary access guideline (Livable Housing Design Guidelines) and plan with an aspirational goal of all new housing providing minimum access features by 2020 (NDUHD, 2010a, 2010b). The signatories then gave carriage of this project to a non-government entity, Livable Housing Australia.

Livable Housing Australia's project differs from the previous voluntary initiatives in three ways: it takes a national focus; it stems from an agreement amongst a wide range of industry and community stakeholders; and it has been directed to meet a clear goal and agreed targets against which its progress can be measured. Livable Housing Design guidelines have three levels: Platinum Level providing full accessibility; Gold level, providing an enhanced accessibility; and Silver Level which provides minimum access with the following seven core features:
1. a safe continuous and step free path of travel from the street entrance and / or parking area to a dwelling entrance that is level;
2. at least one, level (step-free) entrance into the dwelling;

3. internal doors and corridors that facilitate comfortable and unimpeded movement between spaces;
4. a toilet on the ground (or entry) level that provides easy access;
5. a bathroom that contains a hob less (step-free) shower recess;
6. reinforced walls around the toilet, shower and bath to support the safe installation of grab rails at a later date; and
7. a continuous handrail on one side of any stairway where there is a rise of more than 1 metre (Livable Housing Australia, 2012, pp. 12-13).

Its key strategies are to encourage the housing industry to adopt the Livable Housing Design Guidelines, certify dwellings that demonstrate compliance with the guidelines, work with government, and community agencies to support Livable Housing Design Guidelines and provide education to practitioners and assessors (Livable Housing Australia, 2013b).

The agreed interim targets for the private housing industry are:
*   25 per cent to Silver level by 2013;
*   50 per cent to Silver level by 2015;
*   75 per cent to Silver level by 2018; and
*   100 per cent to Silver level by 2020 (NDUHD, 2010b, p. 7).

For social housing, the targets are more ambitious with all new social housing to reach Silver Level by 2011 and Gold Level by 2019 (p. 7).

By mid-2013, the take-up by the private housing industry has been slow with the majority of certified dwellings being either government funded residential facilities specifically for people with disability or retirement village dwellings catering for older people (personal communication, July 2013). Nevertheless, Livable Housing Australia appears to remain committed to reach the 2020 target. In a July 2014 report, the following statistics were released:
*   LHA have issued 294 certificates for dwellings either designed or built that comply with the Silver, Gold or Platinum Levels outlined in the Livable Housing Design Guidelines.
*   LHA has issued 24 as-built certificates but there are over 50 dwellings built. There is a time delay (for various reasons) between dwelling construction and certification.
*   There are over 500 other dwellings (either designed or built) that are registered for certification and are still going through the process.
*   LHA have identified over 1850 other dwellings that claim to have been designed/built to at least the Silver level of the Livable Housing Design Guidelines but are not currently registered for certification from LHA.
*   It is expected that there are many hundreds more dwellings delivered by government agencies and the private sector for the aged, retirement living, public-housing and housing for people with disabilities that would meet the Silver level.   (Australian Network for Universal Housing Design, July 2014, p. 16)

We continue to see growth in the number of downloads of the Livable Housing Design Guidelines from our website. Last month (April 2014) we had over 3,500 downloads of the Guidelines from our

website. Courses for registered assessors are well attended around the country. Enquiries through our website continue to grow as does our list of members.

Market-demand for universal design

The demand for newly built accessible housing in the private market appears to be low. Studies of the housing careers of older people in Australia suggest that this group tend not to move as frequently as other groups, and consider their wellbeing is contingent on staying in the community they know, near good public transport, services and their networks of support. If their housing becomes unsuitable, rather than moving, they prefer to modify their home (Beer & Faulkner, 2009; Judd, et al., 2010).

Families with younger people with disability experience similar housing issues. The study by Beer and Faulkner (2009) report that households with a person with disability typically earn less, own less, and have greater difficulty maintaining the tenure of their home. Because the wellbeing of these families is also dependent on accessing support services and networks, affordable transport and employment, they are also unlikely to move once they have a suitable dwelling and all these elements are in place.

Although imminent retirees or "baby-boomers" indicate they want to stay in the community, live well and for a long time (Ozanne, 2009) they also tend to consider their housing as an investment rather than a stable family base and are anticipated to be more mobile than the previous generation, changing their housing a number of times after they retire (Beer & Faulkner, 2009). Spanbroek and Karol (2006) observed in their West Australian study that while this group are likely to require accessible housing in the near future, they are not showing signs of planning for changing needs in later life, illness or disability, to care for an ageing or ill partner in their housing choices. Buyers who want new accessible housing experience some reluctance from project builders when changes to regular plans are requested (Bringolf, 2011, p. 157). This is likely to be due to the unanticipated extra costs, extra supervision and time delays that might occur in an already complex, formulaic, and interdependent industry (p. 47). In summary, people who need accessible housing are not part of the buying-market for new housing, and buyers of new housing do not identify a need for accessible housing.

The Australian Government also required the 20,000 dwellings funded by the fiscal stimulus initiatives during the Global Financial Crisis (Australian Government, 2009) to incorporate some arbitrary access features in all the dwellings, with twenty per cent reaching the Adaptable Housing Standard AS4299 (1995) Part C.

The National Rental Affordability Scheme, which seeks to address the shortage of private rental housing and rapidly rising rents by offering an incentive to providers of new rental dwellings, recently advised applicants that proposals meeting the Gold Level of the Livable Housing Design guidelines would be assessed more favourably (Livable Housing Australia, 2013a).

Home modifications

As mentioned previously, most people with disability and their families rely on home modifications to meet their particular access needs. However, the lack of a systemic approach has led to a number of shortcomings, such as:

- home modification services are not typically considered part of or linked to a broader housing strategy;
- there is a lack of adequate funding resulting in a dilution of service and delays;
- home modifications services are also not linked to health and disability objectives;
- assigning priority and eligibility is difficult;
- the standard of home modification solutions vary in the absence of legislated standards for access;
- variability in the quality of home modifications cause concerns for home owners, users, and occupational health and safety concerns for home-based workers; and
- changing an existing building attracts other regulatory issues; such as fire regulations, body corporate considerations and the handling of asbestos (Jones, de Jonge, & Phillips, 2008, p. 4).

The provision of home modifications in private rental housing raises some particular issues. Under the *Disability Discrimination Act 1992* tenants have the right to modify a rental property within reason; however they are obliged to remove the modifications at the end of their tenancy. Many tenants are unwilling to make this financial commitment without security of tenure and landlords have been found to be reluctant to agree to modifications to make the dwelling more appropriate, even though they are not obliged to pay for them (Beer & Faulkner, 2009, p. 163; Jones, et al., 2008, p. 137). Social housing providers have an additional onus to provide non-discriminatory access to their stock, and home modifications are often provided to overcome discrimination caused by the lack appropriate housing stock (Jones, et al., 2008).

In all, the Commonwealth and State governments through the National Affordable Housing Agreement has committed to the aspirational objective that "all Australians have access to affordable, safe and sustainable housing which will assist them to participate in the labour force and more broadly in the community"(COAG, 2012, pp. 3-4). The Commonwealth and the States have also committed to reform directions that will enhance housing programs and services, including by improving the:

- integration of homelessness services and other mainstream services, such as employment services;
- operational efficiency of public housing and the employment outcomes of public housing tenants; and
- efficiency in the supply of housing through planning reforms.

The anticipated outcomes are:

- people who are homeless or at risk of homelessness achieve sustainable housing and social inclusion;

- people are able to rent housing that meets their needs;
- people can purchase affordable housing; and
- people have access to housing through an efficient and responsive housing market.

Summary of main points

In summary:
- policy directions endorse the principles that people with disability have the opportunity to choose their tenancy, location and particular living arrangement; and that housing provision facilitates full inclusion, participation and contribution of people with disability in family, work and community life;
- in spite of unprecedented reforms and policies, people with disability largely remain excluded from private ownership and rental with the percentage of people with disability in housing stress expected to rise and their options diminish;
- although public spaces are now required to provide non-discriminatory access, there is no equivalent national requirement for private spaces in housing; and
- home modification is a flexible strategy to address to some extent the lack of accessibility in housing, however the funding is inadequate to meet the need, and there is a lack of standardisation and alignment among the many programs, as well as incentives for providers to support home modification strategies.

2.4 Housing typologies

Housing currently accessed by people with disability in Australia is categorised for this report into four broad typologies: These include: private, non-private, hybrid, and other 'accommodation' categories. These include:

Private
- private market housing (ownership and rental);

Non -private
- care facilities/care integrated housing ('supported accommodation'; 'residential care'; 'congregate care' facilities);
- social/public/community housing (subsidised housing);

Hybrid
- hybrid models integrating private with other typology characteristics (cluster models, intentional community models);

Other 'accommodation'
- hospitals and prisons;
- crisis and transition accommodation;
- respite and hospice accommodation; and
- no fixed accommodation as in the case of homeless people.

Private market housing

Houses, units (rented accommodation)

A form of housing that that is more integrated throughout the community, and accessed by the community in general, are houses and units owned by individuals or groups as a form of economic and, in some cases, social investment. However as pointed out briefly here and discussed more fully later on, access to this form of housing for people with disability is compromised by a range of factors.

A number of not-for-profit and private sector advocacy groups exist around the country that assist individuals with disability in the procurement of private rental housing as well as the coordination of support services. What is important to point out is that such services are reliant on the availability of good quality, affordable, accessible housing stock in order to successfully aid their clientele. Considering studies as far back as 2001 (Berry & Hall) have calculated that:

> …despite the rent-assistance program, low-income households in the general
> population cannot afford to rent average valued houses of any size in almost any
> suburb of metropolitan Melbourne..." (Ilan Vizel, 2008, p. 34)

Thus while person centred initiatives like rent assistance " may allow individuals more freedom to choose" (Ilan Vizel, 2008, p. 34) if there is not enough stock to choose from within the community they may end up being of little benefit to the individual.

While economic exclusion is of serious concern, this is exacerbated by exclusion due to houses or units being physically inaccessible. This challenge of a lack of universally designed or adaptable housing stock within the private sector is one that has been grappled with for some time. Ilan Vizel labels the inaccessibility of most of the available housing stock as a "…mechanism of exclusion…", though subtler than other forms such as community opposition, but he sees it as far more effective means of marginalization (Ilan Vizel, 2008, p. 35).

It is also important to keep in mind that, as an individual's needs change, if a private rental property is not able to be adapted to suit, the individual will be faced with forced relocation. Kroehn found a reluctance on the part of many landlords to allow home modifications to be undertaken and in some instances residents have been "harassed" (2007, p. 7) over modifications that they have personally undertaken and paid for.

Scotts & Saville-Smith have written about the issue of modified dwellings which become "…'lost' to the disabled market through on-selling to non-disabled consumers." (2007, p. 12). They have documented other countries attempts to redress this through the use of registers and databases of accessible housing stock. Their finding is that the most well established systems are supported by legislation. One example, the Massachusetts Accessible Housing Registry, known as Mass Access, operates in tandem with state law which mandates that accessible housing owners must allow information about their units to be made available to the public and that:

>Registered landlords and management companies are required to rent accessible housing to a person with a disability or hold the apartment for 15 days (while searching for a renter with a disability (Scotts, et al., 2007, p. 12).

While the Mass Access program is run on a modest budget (Gesson & Haynes, 2004) comparative studies have shown that similar programs in areas where there is no accompanying legislative component are not as successful (Cheek, 2004).

Other countries, such as Norway, further require some of their accessible and universal designed housing stock to be registered and checked for any repairs or maintenance that may be required (Scotts, et al., 2007, p. 12).

Houses, units (owner occupied or family owned)

Housing in this category is purchased by individuals from the private housing market. It also includes the form of housing in which a person lives usually as a family member. For people with disability many remain in their family homes being cared for as long as possible by parents or a parent.

Sixty-eight per cent of Australians own or are purchasing their own home. Home ownership is also the major source of wealth in Australia, and is the major source of debt. Twenty-one per cent of Australians are private renters with only five per cent having access to social housing (AIHW, 2011). As people with disability often have limited income and high costs of living, they face a significant challenge to find, obtain and maintain private housing, and resort to social housing or specialised facilities.

People with disability have particular challenges in planning and achieving a normative housing career; some issues include addressing the source, nature and type of disability, affordability issues, matching access needs with supply, coordinating support, transport and informal networks. These are discussed more fully in a following section.

For people with disability wishing to access private housing as well as those wishing to remain living in their home, either independently or being cared for by family members, the issue of home modifications is significant. In response to the lack of accessible private housing, most people with disability and their families rely on home modifications to meet their particular access needs. Across Australia, there are a range of home modification services without overarching policy objectives, or benchmarks of quality that regulate them (Jones, et al., 2008, p. 3). Home modifications services are typically well regarded; however, the lack of a systemic approach has led to a number of short-comings which are detailed later in this report.

Co-residency housing

A number of organisations have trialled, with varying levels of success, a form of 'co-residency' model where an individual with disability owns or leases a residence and then selects a non-disabled person to live with (or near) to care for them. Commonly, the non-disabled person provides an agreed amount of care and support in exchange for free accommodation and potentially subsidised

expenses. Examples of programs such as these have been cited within earlier studies such as the 'Good Neighbour' program associated with ACROD and WA Government public housing (at the time called Homes West) (Fisher et al., 2008, p. 12) and the "Lower Great Southern (LGS) Community Living Association" (Fisher & Purcal, 2010, p. 531). One feature that is critical to ensuring that these models remain person-centred is that ownership of the home (or lease) is maintained in the name of the individual with disability and that they have ultimate choice with whom they co-reside. The third and fourth cases in our project provide further detail on co-residency in social as well as private housing situations.

Hostels and boarding houses

Hostels and boarding houses constitute privately owned housing with rooms rented out on a short to long-term basis. Occupants are offered a range of services from basic accommodation, through to the provision of meals and in some cases limited support with daily activities. This form of housing has a chequered history of taking advantage of vulnerable residents, many having some form of disability, and providing inferior accommodation and support at the expense of taking all or most of their income. While recent reforms have resulted in the closure of some of these facilities, this form of housing with its variable quality of accommodation remains, often used as a stop-gap in instances where access to affordable more appropriate accommodation is not available (Bitner & Franz, 2011, p. 5)

Non-private

Care facilities/care integrated housing

While these types of 'housing' vary in scale and form, they are all integrally tied to the provision of care and the congregation of people with disability, in many cases sharing care provision or at the very least receiving care services from the same provider. In this respect, a service delivery model determines living arrangements and dictates where people with disability will live. Various models include:
- institutional settings (for example, aged care facilities – low to high care support);
- large residential settings (large group houses or semi-detached dwellings in a complex); and
- small group houses.

Institutional Settings

The early 1980's in Australia, like many western nations, saw the advent of a movement to close residential institutions for individuals with disabilities. Without this singular universal accommodation 'solution', a range of alternatives were utilised which situated the individual with disability, geographically at least, in the larger community. Baladin and Chapman point to the utilisation of "…. small group homes, hostels, boarding houses, and independently supported accommodation within the community (Intellectual Disability Services Council 1994)" (Baladin, 2001, p. 38.33) as a means of accommodating those displaced by these changes. Bostock and Gleeson

(2004) tried to quantify the progress of this "radical rehousing of people in care" (p.41) concluding that:

> ...deinstitutionalisation processes appear to be slowing in many jurisdictions across Australia. According to state and territory agencies, this slowing is attributable to a number of factors, in particular the fact that most current institutional residents have high support needs and are therefore 'harder' to place in community settings. Earlier phases of deinstitutionalisation in the 1980s and 1990s tended to involve the relocation of residents with lower support needs (p. 52).

It also needs to be recognised that in some areas there has been ardent support for retention (and redevelopment) of institutions. Kew Residential Service in Doncaster Victoria, is a public example of family members lobbying, and winning, to maintain and redevelop a facility that originally housed close to 500 individuals with disability (O'Connor, 2003). While the redeveloped site will only accommodate less than half of the original population (the rest have been rehoused within community based accommodation), the movement does serve to challenge the belief that institutionalisation is not just tolerated but in some instances the preferred model.

One of the most common forms of institutionalised housing for people with disability is the nursing home or aged care facility. Excluding those over 65 years who have a disability a significant number of the residents include young people with disability many having acquired brain injury (ABI) (Winkler, et al., 2013).

Large Residential Setting Models

Alternatives to institutionalised settings such as the aged care facility are residences located in the community specially designed to accommodate large numbers of people with disability together. These can be single large buildings or a complex of detached or semi-detached buildings. An example in Queensland is Young Care established in 2005 to provide more age appropriate accommodation for young individuals with high physical care needs who are wishing to avoid aged care facilities. Funded through a combination of government funding and private philanthropy, Young Care has gained much media attention locally and, as it grows rapidly, it is currently looking to extend past the local region into neighbouring states. As well as being able to reside with other individuals of similar ages to themselves, Young Care strives to provide more desirable living options. Pro-bono design involvement from local architects and designers has resulted in facilities that have features and aesthetic attention to detail normally not found in other high care facilities. Young Care developments currently comprise a number of living units closely co-located with areas of private as well as shared facility. This co-location helps in the sharing of care costs across the site.

Group Home Model

Regardless of the fact that a number of studies, both overseas and in Australia, have shown that in-community supported living costs are comparable or in some cases lower (Emerson et al., 2001; Felce et al., 2008; Howe, Horner, & Newton, 1998; Stancliffe & Keane, 2000), the group home has

emerged to become a dominant model in Australia for care and accommodation of individuals with disability. The idea of groups of individuals with disability (usually three residents) residing in a 'normal' looking family home situated in an established neighbourhood (Gleeson & Kearns, 2001) appears to align well with ideologies of 'normalisation' and, subsequently, 'social role valorisation'. Bostock and Gleeson see this trend linking with social policy where the "The realisation of normality for service users was the chief object of reform, a normality rooted in conventional notions of home and family life" (Bostock & Gleeson, 2004, p. 44).

While there is divergent discourse on the efficacy and appropriateness of this style of accommodation, advocacy groups have pointed to the model as a form of 'forced co-habitation' (Queensland Shelter, 2010) which contravenes the UN Charter (United Nations, 2007). Certainly commentators such as Ilan Vizel highlight some of the more problematic aspects of this model, specifically that it is often "...the default option for people with challenging behaviours because there are no alternatives, despite their evident difficulty to share a home with other residents." (Ilan Vizel, 2008, p. 36) . Vizel recommends:

> ...allowing people with challenging behaviours to move out of group homes to more individualised settings, with sufficient supports, may solve many of the compatibility problems which undermine quality of life for most residents in shared supported accommodation in Victoria. Group-homes may thus become more liveable homes (Ilan Vizel, 2008, p. 36).

In terms of further resistance to the group-housing model, Bostock and Gleeson put forward that some service users and advocacy groups are challenging this model "on the basis that such options are 'formulaic' and unable to suit the diversity of client and family needs (Ellis 1998)" (Bostock & Gleeson, 2004, p. 47). Others have gone further in claiming that the structures, routines and cultures of institutions have merely been transposed " out into the community settings where they stand in sharp contradiction to the goals of community living" and that "the large institutions have merely been turned into many smaller ones scattered throughout the community" (Chenoweth, 2000, p. 81; Taylor, Bogdan, & Racino, 1991). While the politics of this debate warrant further discussion outside of this study what is clear is that alternative models beyond the group home are being sought and developed (Bostock & Gleeson, 2004, p. 47).

Social/public/community housing

Academics and statisticians have pointed to a significant overrepresentation of individuals and families living with disability within the social and community housing sectors. (Australian Institute of Health and Welfare, 2011; Beer & Faulkner, 2008). A 2009 report created by the Australian Institute of Health and Welfare documented a sharp increase of individuals with disability living in public rental housing from 23% in 2004-5 to 40% in 2005-10. Various factors have been attributed to this near doubling of residents such as increased disability rates and decline in new places coupled with a greatest need assessment system (Australian Institute of Health and Welfare, 2011, pp. p12-13). The immediate impact of this large demographic shift is that areas of 'concentration' of people

with disability have been created, delimiting opportunities for inclusion and participation in the wider community (Tually, et al., 2011b, p. 3).

Given the sharp increase in the number of individuals with disability within social and community housing, it is also unsurprising that the stocks of disability appropriate housing are insufficient. If we consider this lack of options in conjunction with the "...lack of accessible housing in the private market.." which can be seen as placing further pressure on the "…dwindling social housing market" (Bleasdale, 2007, p. 61), a clear picture begins to emerge of exclusion and extremely limited choice. In addition, the outstripping of supply to demand, can result in individuals with disability, even when categorised as being in greatest need, waiting many years to obtain a social housing place (Saugeres, 2011, p. 7) during which time individuals may be forced to reside in unsuitable accommodation or even be at risk of homelessness.

Another difficulty faced by individuals with disability in social housing is that the lack of choice over location can have significant flow on impacts in key life areas such as formal and in informal support networks and employment options. Ilan Vizel points out that the housing of individuals within social housing dictates the need for both formal and informal care to centre around this location over which the individual rarely has control and is a defining feature of a 'place-centred' rather than 'person-centred' approach (Ilan Vizel, 2008, p. 33). Bleasedale confirms this problem, outlining:

> Public housing is the most affordable form of housing for clients, but it is not always available in the areas in which individuals need it, or at the time they need it (Bleasdale, 2007, p. 17).

Some non-government organisations have undertaken to provide their own stocks of affordable, accessible housing. The Julia Farr Housing Association in South Australia operates as a "…landlord for a range of accessible community housing, and works with its tenants and their support agencies on accommodation matters" (Julia Farr Association, 2013). While attempting to address a significant need, such initiatives can be seen on the spectrum as closer to 'place centred' than 'person centred'.

Hybrid housing

Centre-based/linked/cluster care models

Centre-based or cluster models involve the congregation of people with disabilities individually housed with a direct connection to a carer or a support network. One example is the KeyRing concept. KeyRing is the proprietary name for an organisation in the UK that is "based on the idea of 'living support networks'"(Simons, 1998). Designed around individuals with learning difficulties, networks of up to nine people are created in a location with each individual residence (social housing) within walking distance of the others. A tenth member, called a 'community living worker' is chosen and agrees to provide around 10-12 hours a week support in exchange for accommodation and some household bills being paid. This arrangement does not provide 'high care' levels of support

but if needed, it can be brought in to meet any unmet needs. Reviews of the initiative have pointed to the fact that on average a third of their tenants were previously in residential care, and besides the potential for better quality of life outcomes, the move from costly care to an expenditure of under £50 a week in an established network makes financial sense (Simons, 1998). Initiatives similar to this model have, and continue to be, developed within Australia. One example of an organisation utilising this model is Marillac, who have the 'Neighbourhood Connections' program (also referred to as a KeyRing) currently operating in three locales in Victoria, Armadale, Frankston and Rosebud.
In 2004, Bostock observed that irrespective of the model, supported living housing whether congregate or centred-based "…will remain a significant feature of disability and accommodation support services in Australia" (Bostock & Gleeson, 2004, p. 52). Nine years later this remains the case with access to social, community or private market housing remaining largely ignored.

This form of housing was empirically studied in greater detail through the first and second cases (Cases A and B) included in this project as well as through other examples identified through on-going review. At this stage there appears to be two main models. In general, there are models that attempt to integrate appropriately designed and located affordable private housing with, if necessary, care support. As an example, this may involve investors pooling resources to buy a small number of accessible units in an existing complex in the community. In some cases, the allocation of accessible units may be determined at the design stage. The selected units may then be leased to another party such as an NGO who assumes responsibility for their maintenance and occupation. If care support is needed this may be arranged privately by the occupant or accessed through on-site care provided by a service provider. Money generated through the lease arrangement is held in trust managed by a financial broker. Further to this are shared equity schemes, whereby the person with disability and another party share the mortgage repayments on a dwelling.

Intentional community/sheltered village/housing co-operative/family governed care model

The ideological drive towards individual agency and control over accommodation and care has resulted in a current trend towards:

> …sustainable combinations of formal and informal support that can respond to changes in the person's choices and needs. This contrasts with more traditional models of housing support where a number of beds for people with similar disabilities are available in a house with paid staff (Fisher & Purcal, 2010, p. 528).

One grass-roots model that is being championed both within Australia and internationally is the 'intentional community'. Bostock and Gleeson drew attention to this movement in their 2004 study when they described that families were using the term:

> ...intentional community' to describe the concept because they felt that they were 'intentionally' creating a range of formal and informal networks by designing an environment where those networks could be maximised and encouraged (Bostock & Gleeson, 2004, p. 45).

These communities are modelled on a 'village' or 'sheltered village' model that are designed as alternatives to "both large institutions and dispersed community care networks" (Bostock &

Gleeson, 2004; Gleeson & Kearns, 2001, p. 45) and serve to counter the group home and institutional models.

Within Australia, one example of an intentional community that has come to fruition is that comprising our fourth case study (Case D). While it remains to be seen what successes and difficulties this community will encounter, there are a good number of overseas examples that have utilised similar models, dating back as far as the 60's. The Camphill Village Trust (CVT), started in the UK in 1939 and founded on Steiner principles now is attributed with having 100 communities in 20 countries around the world. The oldest of these 'villages' is Botton Village in the UK, with a population of 280 (130 of whom have special needs) the village includes a health centre, community hall, church, school and 5 working farms which produce organic and biodynamic food and livestock (Camphill Village Trust, 2013). Outside the CVT, other examples of similar communities, villages and housing co-operatives can be found in Iceland (Solheimar Ecovillage, 2013), Denmark (European Commission Youth), Canada (Deohaeko Support Network, 2013), France (Maison Emmanuel Centre Éducatif, 2013).

Other 'accommodation'

This section is included to draw attention to the need to differentiate between housing and accommodation of a temporary or crisis nature. In addition, it acknowledges that people with disability often reside in places not considered housing as understood and accessed by the general community or they are grouped together in such large numbers that the emphasis is more on shelter and care support than other housing affordances including developing an existential attachment whereby house becomes home.

While it could be argued that aged care facilities or large residences are more accommodation in the sense just outlined, they have already been considered in the previous section. Rather this section calls attention to other institutional settings such as:

- hospitals and prisons;
- crisis and transition accommodation;
- respite and hospice accommodation; and
- no fixed accommodation as in the case of homeless people.

The term 'transinstitutionalisation' has been used to describe the phenomenon "whereby disabled people are moved from institutions without adequate supports and then enter other institutional settings such as shelters, prisons, nursing homes or psychiatric hospitals" (Bostock & Gleeson, 2004; Hudson, 1991). Others have found a relationship between increasing incidence of individuals with intellectual disability in the criminal justice system and the rate of deinstitutionalisation (Armstrong, 1997). In NSW, it was calculated that one in five prisoners was intellectually disabled (evidence presented to a state Parliamentary Committee, reported in the *Sydney Morning Herald,* 28 May 2000 p.5) in (Bostock & Gleeson, 2004).

While there is a paucity of statistical evidence to quantify the rates of homelessness among the disabled, it is understood that "persons with a disability are vulnerable both to, and within,

homelessness because of their many have low incomes, may have limited engagement with the labour market, and limited housing options." (Andrew Beer et al., 2011, p. 4). Thus to simply say that one has been 'deinstitutionalised' or is 'living in the community' does not necessarily mean that they are adequately housed and cared for. Lesley Chenoweth sums this up well with her observation that:

> … the quality of life for people in community settings, at best, could be judged variable. Many do have fuller lives with more choices. Yet, many are also victims of crime, exploitation, or have few options in limited services" (Chenoweth, 2000, p. 94).

In terms of respite accommodation, Australia Welfare Report 2009 draws attention to a "...considerable unmet need for respite care..."(Australian Institute of Health and Welfare, 2009, p. 7) at the same time as it recorded an under-utilisation of existing services.   This discrepancy was explained by the AIHW as potentially owing to a "a lack of appropriate respite services" (Australian Institute of Health and Welfare, 2009, p. xi). For parents of children with a disability, in some areas the only respite available is within institutions such as aged care facilities. As well as not being fully equipped to cater for younger people and their needs, these facilities are frequently so alien in comparison to the everyday home environments that they are seen to cause levels of distress and damage which carers find hard to justify in exchange for short term respite.

In addition to facility-based places, community and in-home respite options are now appearing more on the landscape through not-for-profit organisations. MAMRE (MAMRE Association Inc., 2013), Life Without Barriers (Life Without Barriers, 2013) and Coonamble Parent Support Host Family (NICAN, 2013) are examples of organisations that utilise host families within the community to provide non-facility based respite. This is one area that has the potential for rapid change with the introduction of the NDIS as individuals and families are empowered to arrange service and support that directly meet their needs.

2.5   Conclusion

Contrary to the major policy changes in the area of disability, **housing policy** traditionally has not attracted bipartisan support.   In Australia, social housing has never been considered a real alternative to private ownership and, from the beginning, was considered as a welfare-housing program (Troy, 2012, pp. 283-285). Troy argues there has been consistent policy failure, with a mix of poor leadership, missed opportunities, and lack of vision about the long-term benefits of secure, affordable and appropriate housing.   An additional factor has been a negative, uncooperative attitude from within the housing industry, leading to some direct and indirect subsidies in an effort to stimulate activity, and which ultimately benefitted the prospective homeowner. Troy argues:

> We have been unable, as a society, to develop a shared understanding or commitment to the development of a system of housing that meets the needs of all in an equitable manner. The pursuit of short-term private benefits, including the chimera of reduced public involvement and obligation, has led to the dominance of

the "market". This, in turn, has meant that those who saw the provision of a wide
range of what were once seen as public goods and were important components of
the notion of a just and fair society have simply lost out (Troy, 2012, p. 285).

This grim housing policy scenario together with the economic and social disadvantage experienced
by people with disability and their families has contributed to their over-representation in social
housing, their higher rate of falling out of home-ownership and their greater housing stress than
most Australians. However, while the number of households experiencing housing stress (spending
more than 30% of their income on housing costs) is increasing, there is only a slight increase in social
housing in response. Social housing has now become the response for people in greatest need
(people who are homeless, or whose life or safety is at risk, whose condition was aggravated by their
housing or who had very high rental costs) (Australian Institute of Health and Welfare, 2012, p. viii).

In terms of **private housing assistance**, the current COAG's National Affordable Housing Agreement
aims to ensure that "all Australians have access to affordable, safe and sustainable housing that
contributes to social and economic participation" (COAG, 2012, p. 3). With regard to people in the
private market, the anticipated outcomes are:

- people are able to rent housing that meets their needs;
- people can purchase affordable housing; and
- people have access to housing through an efficient and responsive housing market (p. 4).

Private rent assistance is limited to Commonwealth Rent Assistance (CRA), a demand-based subsidy
that aims to reduce rental stress, and State-funded one-off subsidies for bond loans and rental
grants, rental subsidies and payment of relocation expenses. For many people on low incomes, CRA
is considered inadequate in reducing housing stress (paying greater than 30% of their income in
rent) (Australian Institute of Health and Welfare, 2013, p. 40).

The Commonwealth home-ownership assistance focuses on First Home Owners grants, which have
had little impact on the buying capacity of households with a person with disability (Beer & Faulkner,
2008). The States and Territories provide a range of direct lending (including government loans,
shared equity and bridging loans), deposit assistance, interest rate assistance; and mortgage relief.
These vary significantly from state to state—the most significant assistance is offered in Western
Australia and South Australia through shared-equity programs (Australian Institute of Health and
Welfare, 2013, p. 81; Beer & Faulkner, 2008, p. 51).

Despite the last fifty years seeing unprecedented changes in community attitude to, and
opportunities for, people with disability (Kendrick, 2012), this has not been reflected to the same
degree in housing policy or provision. The United Nations' Convention on the Rights of People with
Disabilities (United Nations, 2007) states that people with disability have the right to "full and
effective participation and inclusion in society" (Article 3), and should "have the opportunity to
choose their place of residence and where and with whom they live on an equal basis with others"
(Article 19). The Convention promotes the concept of universal design in the development of
standards and guidelines for (in this context) housing, in a way that requires "the minimum possible

adaptation and the least cost to meet the specific needs of a person with disabilities" (Article 4). It was formally ratified by the Australian Government in 2011.

The Convention on the Rights of People with Disabilities complements and supports previous core human rights instruments:

> All human rights are indivisible, inter-dependent, and inter-related. Consequently, access to adequate housing is essential for the realisation of many other human rights. It may, for example, be essential for the realisation of the right to life and survival, the right to health, the right to privacy, the right to home and family, the right to security of the person, and the right to freedom from abuse, neglect and exploitation (People with Disability Australia, 2010, p. 10).

People with Disability Australia (2010) suggests the CRPD has the following implications for housing provision in Australia:

- all elements of Australian housing systems should conform to basic human rights standards;
- evidence that people with disability are deprived of basic housing rights, would mean that Australia is in violation; and
- Australia should clearly identify the 'baseline' position (or starting point) for its efforts to progressively realise housing rights within Australian housing systems.

3   Access to private housing for people with disability – theoretical context

This section references existing research and publication that informed the theoretical context for the project. It commences by focusing on the central concepts of access, inclusion and participation, as they connect with the fundamental concepts of person-centredness and agency. It then shifts to summarising from the literature the main external, internal and attitudinal impediments for people with disability in accessing private housing highlighting the need for a holistic approach philosophically aligned with a person-centred ideology.

3.1   Access, inclusion and participation

What do we mean by access, inclusion and participation, and integral to this, person centred approaches?

This section focuses on **access** in relation to private housing for people with disability. In the context of this project, access is defined as being in a situation where disability, or the consequences of or attitudes to disability are not barriers to people with disability choosing where and how they wish to live as do other people in society. While most responses focus on the individual and appropriate designed housing, less attention is given to the notion of **visitability** and its consideration in relation to 'access'.

Individual solutions may offer a person a presence in the community but do not provide for social inclusion or participation. Inclusion is a process through which people build valued roles in society, have opportunities to contribute and develop meaningful reciprocal relationships. The process of inclusion benefits not only the person with disability but also the broader community through a sense of belonging, mutual support, friendship, and intimacy (Uditsky, 1993). "Visitability" is a physical manifestation in housing which "ensures that a basic level of accessibility will be provided in all housing, and . . . opens opportunities for participation in community life" (Truesdale, Steinfeld, & Smith, 2002, pp. 8-9). Visitability has three principles: the first is that basic physical access to and within a dwelling should be a right, not a privilege; the second is that, through good design, this access can be provided at minimal cost; and the third is that assigning priority to the most important features will enhance its acceptance and provision (Maisel, 2006).

Visitability is central to the objective of assisting people with disability to be included as fully participating citizens in their communities, and to strengthen informal networks. Community and family activities often occur in other people's homes; at a family dinner, watching the football game with friends, or having a beer on a neighbour's back veranda. When housing design denies basic access for people with disability, inclusion is limited, social capital is lost and both the person with disability and the community are diminished (Chenoweth & Stehlik, 2004). This broader need for visitability in housing is rarely taken into account by individual builders or buyers of new housing, and results in a legacy of physical exclusion throughout the community and aspirations of a 'good life' afforded the general community.

The idea of a 'good life' is difficult to define; each person has an individual interpretation. The necessity for disability-specific human-rights instruments, anti-discrimination legislation and funding programs, however, indicate that people with disability experience less than 'good lives'; where basic entitlements are ignored, discrimination is rife, and many basic needs, let alone personal aspirations, are simply not met. A recent national consultation of people with disability and their families reports that:

> [people with disability] face a constant struggle to obtain what the rest of the community would consider to be an ordinary life. They do not want special treatment—they just want the barriers removed so they can get on with living (National People with Disabilities and Carer Council, 2009, p. iv).

Quality of life indicators, which can be both subjective (love, friendship and spiritual fulfilment) and objective (physical health), form a hierarchy of importance (control over choice), with the most fundamental indicators being relevant to all people, and secondary indicators that are more specific to the individual and their circumstance (Cummins, 2005). Cummins suggests that quality of life indicators should not be defined in terms of needs or opportunities—rather, in terms of positive outcomes for people. A 'good life', in this sense, is an attempt to integrate these subjective and objective indicators, to name what is fundamental to all people, what is specific for the individual person, and to identify these in terms of positive outcomes.

The notions of a 'good' or 'ordinary' life are integrally tied to those of **inclusion and participation** and the aim to:

> ...create places and social spaces within our communities, where people with disabilities and families are fully accepted and are afforded the same opportunities for participation as non-disabled people (Chenoweth & Stehlik, 2004, p. 59).

Inclusion and participation call for a process of building relationships and capacities over time—ultimately leading to citizenship and a sense of belonging (Uditsky, 1993; Ware, Hopper, Tugenberg, Dickey, & Fisher, 2007). What makes communities inclusive are hundreds of everyday reciprocal interactions where individuals contribute their social currency (skills, talents and attributes) towards the social capital of communities. For people with disability to contribute their social currency, it is important not only to be present, but also to participate, contribute and to reciprocate in ordinary ways (Chenoweth & Stehlik, 2004). The idea of inclusion therefore places a responsibility on society to provide environments that optimise these reciprocal interactions throughout people's lives (Hahn, 1986; Oliver, 1990).

Notions of participation, contribution and reciprocation also assume **agency** on the part of the individual. Agency occurs when individuals or groups intentionally make things happen, and in this sense, agency enables people to consider, plan, act, and adapt (Bandura, 2001). Agency is integrally linked to the person and to approaches that are **person-centred**. 'Person-centred' in relation to approaches that facilitate access to private housing is understood as those that place the individual with disability and their needs, capacities, aspirations and rights at the centre. This is succinctly captured in the editorial published by the Community Resources Unit (CRU) in their June 2013 newsletter where they highlight the difference between receiving support that is *called* person

centred and support that *is actually* centred on the person and what they want for their life. As stated, "The need for us to develop responses that are suited to; unique to and driven by the person and those close to them remains something that endures" (Rodgers, 2013, p. 2). Person-centred approaches see the person first, not the disability first.

Person-centredness is central to the NDIS (Productivity Commission, 2011b, p. 344). The Productivity Commission is clear that the person with disability is centre, not only to the planning, but also to the action—how the plan is implemented. It identified three steps:

- **person-centred planning**: planning that is personalised and directed by the individual with appropriate levels of support if needed due to the nature of their disability;
- **personalised funding**: resources that are allocated to individuals to provide supports based on needs and preferences identified through the planning process; and
- **person centred service delivery**: tailored service coordination and delivery which may involve a combination of formal and informal, public and privately provided services and supports, to deliver outcomes and meet goals for an individual.

The idea of "person-centred planning" (PCP) was first conceived in the 1980s (O'Brien & O'Brien, 2000) and can be described as "seeing [the person] first rather than relating to diagnostic labels . . . strengthening the voice of the person and those who know the person best in accounting for their history, evaluating their present conditions in terms of valued experiences, and defining desirable changes in their lives" (pp. 4-5).

Given that people and their situations change over time, **planning** should be dynamic rather than static. 'Futures planning' is widely recognised as important to ensure continued support and financial stability for people with disabilities who require care. Long-term plans for housing may mean, for example, a change in housing situation, putting arrangements in place for a future move or future home modifications, or legal and financial arrangements for continued ownership or occupancy. It is important to note, however, that while elements of planning and action on plans may be undertaken in pieces (for example, the writing of wills, setting up of trusts and appointment of enduring power of attorneys and so on), the broadly accepted approach to planning is an holistic model that considers aspects of the individual's life as interconnected. This supports the DPRWG's own approach, which states that "Future planning should adopt a comprehensive approach that encompasses a range of services and supports a person with disability requires to ensure their future needs are addressed at significant life stages. These include: financial; legal; health care; transport and mobility; employment; social; and accommodation and support needs." (Disability Policy Research Working Group, 2011, p. 5).

This is an important characteristic of planning, as recent work conducted by members of this research team (Petriwskyj, Franz, & Adkins, 2012) on the housing plans of parent carers and their children, indicates. Planning for housing for these families was related closely, and inextricably, with care, lifestyle, social outcomes, employment, and continuing education among other aspects of life. Many complex factors are interwoven in planning such as the child's needs including independence, safety, care provision, proximity to family, and social outcomes; the parents' needs including their

health, financial considerations and work and other commitments; the interface with services including government services; previous experiences with services and service providers; and access to representation. Thus, the research indicated that, planning needs to be holistic, flexible in meeting the needs of individual families and sensitive to the history and circumstances of the family. Families in the study were seeking a wide range of outcomes from their housing choices, and were considering a broad range of options. It is therefore important not to make judgements or assumptions about what will suit individual families.

The politics of planning – who is in control, who is involved, the processes of planning and what is encompassed in the planning – are key aspects of planning approaches. Planning processes have evolved over time, and person-centred planning is now the widely accepted approach. Person-centred planning is seen as being about inclusion and power sharing. It is an approach that essentially ensures that the individual is the centre of the process, with family and friends as partners, to develop a plan that reflects the person's capacities, needed supports, talents, dreams and priorities for their life in addition to services (Rasheed, et al., 2006; Trudy van Dam, Judith Ellis, & Jane Sherwin, 2008). It also incorporates community supports and mainstream services in addition to specialist disability services. It is an approach that, the literature argues, requires a rethinking of assumptions, processes and systems surrounding services, therefore going beyond individual planning. Services are required to adjust to the person's wishes, rather than requiring the individual to fit within existing service menus (van Dam, et al., 2008). PCP is an ongoing process of review and action (van Dam, et al., 2008). This is another key distinction in approaches to planning; that is, continuity of planning, rather than a focus on a fixed solution or single time point. In the language of housing, this is demonstrated in the focus on a housing career rather than a fixed housing solution, although the extent to which this is achieved in reality is questionable.

The outcomes that are a focus of planning may also be affected by the catalyst or reason for the plan (for example, NDIS-driven planning), as well as who is involved in and facilitates planning (such as not-for-profit organisations, services, government departments etc.). A risk of service-driven planning, for example, is that outcomes will also be service-driven and will not adequately consider the range of interconnected dimensions of planning.

There are a range of tools that are based on the PCP approach including the McGill Action Planning System, Personal Futures Planning, Essential Lifestyles Planning, Planning Alternative Tomorrows with Hope and Circles of Support among others. Tools differ in their focus, and to some extent the populations they are geared towards (Rasheed, et al., 2006) but all share the key values of PCP. McGill Action Planning System (MAPS), for example, is designed for students in the school environment and focuses on inclusion, participation and learning, bringing together students, staff and family members to create shared understanding. The school community serves as a resource for the individual (Vandercook et al., 1989, cited in Rasheed, et al., 2006). Essential Lifestyle Planning, on the other hand, focuses on the person's life in the present and their core values and preferences, identifying what supports need to be provided day-to-day (Rasheed, et al., 2006). Personal Futures Planning is also a future oriented approach, which harnesses the wisdom of the planning group and focuses on helping the person to move towards their desirable future. It does not assume equal

knowledge of the person on behalf of all participants, but focuses on discovery (Rasheed, et al., 2006). These are just some examples of PCP-based tools available.

There has been limited research evaluating the influences, outcomes and effectiveness of PCP. Despite this, however, this approach is generally considered to be effective. The research suggests that the development and implementation of plans may be affected by the particular range of difficulties the individual may have; however, the availability of training and supports has also been shown to be important (Robertson et al., 2007; Medora & Ledger, 2005 both cited in van Dam, et al., 2008). In a range of studies, PCP has been demonstrated to have positive outcomes in areas such as autonomy, daily activities, relationships and satisfaction (Robertson, 2007, cited in van Dam, et al., 2008) contact with friends and family, community activities, social networks and choice (Claes, Van Hove, Vandevelde, van Loon, & Schalock, 2010), improved knowledge in some areas, engagement in interactions and activities, and challenging behaviour (Claes, et al., 2010). Medora and Ledger (cited in van Dam, et al., 2008), also reported PCP to be helpful in transitions between living situations. However, Claes et al. (2010) in their review of effectiveness studies, identified less positive outcomes including no impact of PCP on a range of areas such as employment, length of employment or medications, and some negative changes, such as in emotional and behavioural needs and life satisfaction.

In their review of person-centred approaches, van Dam et al. (2008) identified a number of barriers to successful implementation of PCP approaches. They suggest that attention needs to be paid to: deepening understanding of the complex nature of person-centredness; fundamental changes to processes and structures; strong leadership of these approaches; support and education for people with disabilities and their families; systems and practices to support implementation of initiatives; and systemic leadership and support for development of initiatives by services and communities (pp. 34-35).

In all, the outcomes for people with disability often fall short of the person-centred rhetoric. The chronic shortage of either housing options or support services, or both, results in a lack of choice and control, and subsequent disempowerment of people with disability and their families (National People with Disabilities and Carer Council, 2009, p. 18). Further, the compromises depend on whether support services or housing become the lead agency. For example, if the support agency leads, there is a temptation to group people to simplify service delivery. Similarly, if the housing agency leads, there is a temptation to only offer what housing stock is available regardless of whether paid or informal supports are available (Bostock, Gleeson, McPherson, & Pang, 2001, pp. 45-46).

The Productivity Commission (Productivity Commission, 2011a, p. 343) identified that greater alignment between person-centred planning and implementation could be achieved by providing:
- the capacity for people with disability and their families to envision and plan a good life independent of services;
- funding for reasonable and necessary supports as an entitlement,

- the capacity for people with disability to choose how much control they wanted to exercise in managing their support; and
- the capacity for people with disability to change and develop over time.

Some people with disability already consider they direct their planning and service provision, and are empowered through similar strategies. Kendrick (2011) offers a framework to assess levels of empowerment and suggests that when services do their job well "the person [with disability] is so routinely making the vast majority of key decisions that they simply do not any longer believe that they have a meaningful empowerment issue" (p. 7). The NDIS, however, aims to address only the issue of support and the needs of 20% of people with disability. This study is concerned with housing. So what would a person centred approach for housing look like? Kendrick (2011) suggests that empowerment occurs when the person with disability "is actually . . . enabled to make a significant difference, *through their own actions"* (p. 6 author's emphasis), on the type, location and appropriateness of housing that is obtained.

This study suggests that, in relation to housing, a similar level of empowerment ideally would necessitate that:
- any housing solution would not be dependent or tied to a support service (so that the person can change either their housing or their support without affecting the other);
- people with disability would have the same rights of purchase or tenancy afforded to other people;
- the basic design, construction and location of housing would not preclude a person with disability living in the dwelling, or visiting others in the community; and
- people with disability would have the same choice as others of where and with whom they live.

Put simply, person centeredness is how people ordinarily make decisions. Most people have the chance to live their lives determined by where they have chosen to live, who they choose to have in their lives, and how they spend their time, within reasonable and socially-accepted constraints. The NDIS aims to address one barrier; the lack of reasonable and necessary support. This study aims to identify the barriers and impediments for people with disability to private housing, and as such, participation in society and a 'good life'. As the following discussion will show impediments can be personal, systemic, environmental, and attitudinal.

3.2   Impediments to accessing private housing

The importance of individual and household positions, dispositions and characteristics in housing access

Characteristics at individual and household levels tend to influence peoples capacity to participate in the field of housing and negotiate it with reference to their needs and requirements (Sullivan, 1994). A recent study documents the forms of 'capital' that need to be considered in conceptualising housing access. In addition to economic capital, people who succeed in negotiating housing of their choice employ capital including substantive knowledge of the field and of legal rights and processes,

'habitus' or dispositions suited to advancing their position, social connections, and informal supportive networks (Boterman, 2012).

With specific reference to the role of disability, Beer & Faulkner (2011) document the diverse circumstances encompassed in the term disability. However in spite of this significant variation, data suggest that as a whole people with disability and their households experience less options in negotiating housing fields and limited capacity to express their housing needs within the market place. In these households, housing affordability appears to be a major challenge, accompanied by limited capacity to relocate for the purposes of better or more appropriate housing (Beer & Faulkner, 2011). This has ongoing consequences for other life chances, where housing is integral to access to suitable transport, services and employment. In the context of 'housing access' frameworks, these data raise questions regarding the nature and extent of capitals required to enhance access to participation in housing markets on the part of these households.

Following from this, in the context of the focus on 'person-centred' services, the question arises as to what characteristics of 'person centred service' have the potential to make a difference to the capacity of these households to acquire and deploy these capitals in private housing markets.

Private housing markets and access to housing

In addition to the characteristics of households, there are properties of private housing markets that are also important in considering relationships of access. Limited options experienced by people with disabilities and their households cannot be explained solely with reference to the capitals possessed and deployed by the households. Characteristics of housing provision in the field of housing itself have been documented as having agency in housing access. This applies to physical and sensory features of the housing, as well as to broader issues of tenure, location and affordability.

In terms of provision of appropriate housing in the private rental market, there is a clear shortfall in the capacity of this market under present tenure management structures to provide housing that accommodates the specific needs of people with disabilities. Research by the Tenants Union of Victoria suggests that responsibility for the provision of appropriate housing can rest by default on landlords who, while sometimes quite positive about making minor modifications, do not necessarily see this as their role or expertise (Wallis Consulting Group, 2008). Anti-discrimination legislation requires landlords to allow for reasonable modifications; however, the onus is on the tenant to carry out the modifications and to "make-good" at the end of the tenancy. This is unattractive to both tenant and the landlord if the tenancy is not long-term.

The design and construction of mainstream private housing are not required to consider the physical access needs of people with mobility limitations, resulting in most dwellings being unsuitable for people with physical disability and needing some modification. This not only limits the options for people with disability to find housing within an established community but also renders them isolated, unable to visit neighbours and friends (Ward, et al., 2012).

In addition to specific features of the dwelling, access to appropriate housing for people with disabilities is also crucially related to its location: a key factor in access to support, services and community participation. The connections and opportunities that come from being present in a community and becoming known take time and are hard won, and rely on stable tenure through long-term tenancies or home-ownership within that chosen community.

With respect to access to private rental and home ownership, the gateways to entry to these tenures can be more complex for people with disabilities. In terms of more generic questions of access to home ownership and implications for security in Australia, Colic-Peisker and Johnson (2010) suggest that even for middle class households, the hoped-for stability in homeownership can be threatened through anxiety entailed in making a considerable financial commitment. Further, sometimes the commitment to 'anchor' oneself in a dwelling through home ownership presents problems for the increased requirements of many for flexibility in living arrangements. It is arguable that households where disability is present would be more exposed to these threats to security in the context of problems associated with changing health requirements and issues of affordability. Housing researchers in both Australia and the United States further document the greater difficulties of people with disability in gaining access to private rental or homeownership in the first place. In general, people with disabilities may experience inequality in terms of established requirements of tenure entry, described in the U.S study on home ownership as 'capacity, credit, capital and collateral'. Opportunities to have an official and independent credit history, for example is much more difficult when one is seeking to move to homeownership from more dependent circumstances (Hagner & Klein, 2005). In both the U.S and Australian context, people with intellectual disabilities were identified as experiencing the most serious barriers to tenure entry (Hagner & Klein, 2005; Wiesel & Fincher, 2009).

Nevertheless, it is the aspiration of most Australians to own their home; and for good reason; home-ownership provides the most secure and socially valued form of housing. People with disability would similarly benefit from the aspiration of home ownership. There is an argument, therefore, that home-ownership should be regarded as the most preferable housing tenure for people as they are most to likely suffer marginalisation and devaluation through less secure forms of housing tenure (Wolfensberger, 2000).

In terms of recent research, this very brief review has identified the central relationships at stake in processes of access to private housing fields, which should be understood in terms of both the properties of households, as well as features of housing, location, and processes of tenure entry. We can now 'frame' the discussion of person-centred approaches in the context of the way they apply to these relationships in the interests of enhancing access to private housing and ongoing positions in these fields. As such, this project investigates the roles, processes and challenges involved in person-centred approaches in intervening in circumstances and characteristics of households, the processes through which these characteristics might be deployed in the service of access to private housing, and in interventions in housing provision and tenure management in the field of private housing.

The review effectively frames the question of the nature of 'person-centred' approaches at stake in intervening in housing access on the part of people with disabilities. On the one hand, it raises questions regarding the capitals needed by households, and on the other, the interventions required in private housing fields and other related fields. Central to this is understanding the larger cultural context including values, expectations and attitudes.

Attitudinal issues relating to disability and housing

The main attitudinal issues relevant to this project are those relating to **disability** and those relating to **housing**, particularly those that fail to see housing as nothing more than a physical environment.

Disability, identity and housing

The project to date suggests that the way in which disability and a person with disability are understood and conceptualised can contribute to difficulties in relation to access to private housing. In a wider context, this has been recognised by the Disability Policy and Research Working Group (DPRWG) in its support of the need for in-depth exploration of the definitions used for 'person with disability' (Disability Policy and Research Working Group, 2011). *Australia's Initial Report under the Convention on the Rights of Persons with Disabilities* highlights the variability between even purely legislative definitions within Australia with no fewer than eleven listed between the eight states and territories (Australian Government, 2010c, pp. 62-67). In this case, definitions focus strictly on the individual and their 'incapacities' with the most commonly repeated terms being loss, impairment, disorder, disease, illness, deficit, disturbance, malformation and disfigurement (Australian Government, 2010c, pp. 62-67). This is mirrored by the Australian Institute of Health and Welfare and their definition of disability as "one or more of 17 limitations, restrictions or impairments which have lasted or are likely to last, for a period of six months or more, and which restrict a person's everyday activities". These limitations, restrictions and impairments include:

- loss of sight (not corrected by glasses or contact lenses);
- loss of hearing where communication is restricted, or an aid to assist with, or substitute for, hearing is used;
- speech difficulties;
- chronic or recurrent pain or discomfort causing restriction;
- shortness of breath or breathing difficulties causing restriction;
- blackout, fits, or loss of consciousness;
- difficulty learning or understanding;
- incomplete use of arms or fingers;
- incomplete use of feet or legs;
- nervous or emotional condition causing restriction;
- restriction in physical activities or in doing physical work;
- disfigurement or deformity;
- mental illness or condition requiring help or supervision;
- long-term effects of head injury, stroke or other brain damage causing restriction;

- receiving treatment or medication for any other long-term condition or ailment, and still restricted; and
- any other long-term condition resulting in a restriction (Australian Institute of Health and Welfare, 2013).

Again, 'loss', 'restriction', 'difficulty' and 'incomplete' appear in almost every category.

For the purpose of this study, we have drawn on the 2001 World Health Organisation definition, which states:

> Disability is an umbrella term, covering impairments, activity limitations, and participation restrictions. Impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations.

Disability is thus not just a health problem. It is a complex phenomenon, reflecting the interaction between features of a person's body and features of the society in which he or she lives. Overcoming the difficulties faced by people with disabilities requires interventions to remove environmental and social barriers (World Health Organisation, 2001, p. 550). The WHO has graphically mapped these elements, and their connections, in Figure 3.1 as follows:
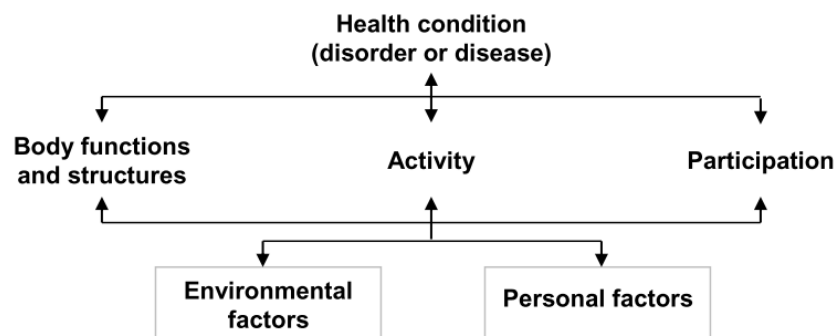
Figure 3.1: Conceptualisation of multi-dimensions of disability
(World Health Organisation, 2001)

This particular conceptualisation recognises the interrelationship between the individual and the physical and social context within which they are situated and interact. Of importance to this project is the inclusion of 'environmental factors', of which the built environment is a significant enabling as well as disabling element. In addition, the WHO definition recognises various forms of, and responses to, disability which can impact in different ways for people with disability in relation to housing. For example, Beer and Faulkner (2009) suggest that there are three key dimensions of disability that are pivotal in shaping the housing careers of people with disabilities. These are:

- extent of the disability;
- source of the disability; and
- type of disability.

Tually et al. point out that, "while some types of disability may have little, if any, impact on housing, others profoundly reshape the capacity of individuals and their household members to move through the housing market or gain access to housing assistance" (2011b, p. 25).

The description previously presented represents an attempt to reconcile two traditional models or constructs of disability: the 'social model'; and the 'individual/medical model'. Characteristics of the 'social model' include:

- an understanding that disability is socially constructed;
- a focus on human rights, social, and environmental barriers such as physically inaccessible housing;
- a concern for collective disadvantage within a socially, physically and economically unaccommodating environment;
- solutions sought through structural changes with policy and legislation targeting social and environmental barriers; and
- represents a valuable tool for collective action (adapted from Hemingway, 2011, pp. 51-65).

In contrast, the 'individual/medical model' supports the view that:

- impairment is the cause of disability, that is, it is understood that an individual has an impairment that can prevent them from doing something for themselves, or from fully participating in society and, as such, are therefore dependent on others. Associated with this are notions of personal tragedy, vulnerability and care against a benchmark of a supposed 'normality'; and
- policies tend to focus on rehabilitation or separate or specialised provision such as the provision of specially designed housing accommodating specific physical/functional needs (adapted from Hemingway, 2011, pp. 51-65).

Bridging these, in an attempt to adopt a holistic approach that recognises that there are both external, systemic barriers as well as internal, individual barriers, are models such as the 'social/relational' and 'biopsychosocial' and we would propose 'ecological' models, the latter adopted for this project as a theoretical and methodological framework.

Housing, home and tenure

The advocates' catchcry, "a bed in a house is not a home", serves to question many housing solutions for people with disability, which assign priority to the pragmatics of paid service delivery over individual needs, plans and aspirations (Epstein-Frisch, Van Dam, & Chenoweth, 2006). The concepts of 'sense of place', 'home' and 'tenure' are often not considered as important. This section explores these three concepts and how they can affect and engender the participation and social inclusion of people with disability and concludes with a list of assumptions which guide this project.

A **sense of place** can be stronger for some people than others, and expressed differently within various cultures and economic circumstances (Duncan & Duncan, 2001). It is generally agreed that places have no inherent meaning; rather, sense of place is a social construct and has three broad characteristics. Firstly, people's sense of place is natural and instinctual; secondly, it is a result of

people's interpretations of the meanings of their lives; and that thirdly, it is part of the politics of identity. A sense of place is no less or more important for a person because of disability or the type of level of support that is needed. Where and how people live, and with whom they live (and are connected to), will influence their sense of place in the world. How people interpret a sense of place will be influenced by whether they feel they belong; it will then impact on how they define themselves and others define them (Rose, 1995).

The inclusion and participation of people with disability will therefore be impacted, not only by their sense of place, but also how others perceive their own sense of place to include people with disability. Kakar (1996, p. 150) suggests that encounters of difference within communities can be both "exhilarating" and "painful". Once difference is recognised, it can lead to grouping, boundaries forming, and negative stereotyping. Rose (1995) suggests, however, that an increasingly mobile and changing world constantly challenges grouping behaviour, and that "ways of establishing senses of place and identity are merging which do not evoke Others, but instead handle difference in more respectful kinds of ways" (p. 116).

How people with disability and their families develop and maintain a sense of place, and how others consider the presence of people with disability, are critical to their successful inclusion and participation in communities. Easthope (2004) emphasises its importance: "One's sense of place (particularly one's home-place) is tied to one's identity . . . people have demonstrated incredible commitment to their places, so much so that they are willing to die for them" (p.132). This suggests the need for priority to be given to the notion of a sense of place within any housing strategy to overcome marginalisation and exclusion generally.

The idea of **home-place** can be differentiated from the broader sense of society-place; home is local, familiar and nurturing—society is expansive and conceptual (Tuan, 2001). Saunders and Williams (1988) argue that home is more than a house; it is a fusion of the physical structure and the social unit of a household, and cannot be considered separately. Further, "home is at the hub of a whole complex of relationships and in many ways is the crucial medium through which the society is structured" (p. 84). Psycho-social approaches to the concept of home suggest that this is where people's needs for identity, security, attachment and stimulation are best met (Dupuis & Thorns, 1998). Also, Somerville (1997) identifies the emotive significance of home as indispensable when attempting to explain the significance of home.

Easthope (2004) summarises: "Since 'home' is a term imbued with personal meanings, different people are likely to understand 'home' to mean different things at different times and in different contexts" (p. 135). The concept of home is not just a physical place; it is tied to the social, cultural, psychological and emotive worlds of people and is located in both time and space. There is an inextricable link between a person's well-being, and the manifestation of home. Homes are nodes for and within social networks of people who have significance for and influence on each other.

The concept of home described above challenges many housing solutions for people with disability, which may arbitrarily group and place people, and can compromise the development and

maintenance of individuals' natural social networks, and overlook the connections between sense of place and sense of home and how they can enhance the social, cultural and emotive worlds of individuals (Bigby, Knox, Beadle-Brown, Clement, & Mansell, 2012; Epstein-Frisch, et al., 2006). A starting point to consider home for people with disability is to understand how other people optimise their sense of place and sense of home through the different types of **tenure**.

For centuries, people have sought to control the physical environment of home to optimise their wellbeing and security (Hulse, 2008). The notion of tenure or "the holding or possessing" of home has developed over time from conditions of occupation and usage of land to a more fluid description of how people occupy and use housing. This section briefly considers this history, describes various accepted definitions of housing tenure and discusses current and future trends which challenge this understanding.

Tenure over land has been sought as an outcome of conflicting interests (for example, farming, mining and indigenous occupation). Ensuing rights of use and occupation are not mutually exclusive in many cases however, in Australia, owners of freehold land typically have the exclusive right to buy and sell their land. The right to occupy housing is governed by both federal and state legislation. Federal law regulates financial institutions who lend money for purchase of housing and land. State legislation has the constitutional responsibility for land management, including freehold, leasehold and licences to occupy. All states now have comparative legislation outlining the rights and responsibilities of landlords and tenants (Hulse, 2008). Hulse describes four basic housing tenure types, excluding marginal housing, in Table 3.1.

Table 3.1: Criteria for delineating housing tenure type in Australia
(Hulse, 2008)

Housing tenure	Legal status	Financial status
Owner	Legal rights to access, occupy, use and control; and buy/sell land and dwelling	No debt secured against the property giving rights to third parties
Purchaser	Legal rights to access, occupy, use and control, and buy/sell land and dwelling	Debt secured against property giving rights to third parties in respect of sale/disposal of dwelling
Private renter	Legal rights to access, occupy and use dwelling and associated land through lease arrangements	Payment of rent or other consideration for occupancy of dwelling to private landlord
Public*[3] renter	Legal rights to access, occupy and use dwelling and associated land through lease arrangements	Payment of rent or other consideration for occupancy of dwelling to state or territory housing authority

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[3] *a number of government housing authorities are transferring the management and property to community housing NPOs and tenure can no longer be distinguished from other rental tenure in terms of rights.

Hulse (2008) identifies some alternative tenure arrangements beyond these four major groups, which have emerged as a response to problems such as homelessness, lack of support, and unaffordability of housing. Some examples are rental-purchase and shared-equity arrangements, mobile-home and retirement-housing agreements where occupiers own the dwelling and rent the land, and licence to occupy non-private facilities such as boarding houses, group homes, institutions and residential aged care facilities (RACs). Further, special tenure arrangements have developed to cover employer-owned housing, indigenous communities, and short-term rental holiday accommodation. The four main private tenure types listed in Table 3.1 cover 89% of households, with 68% of households being home owners and purchasers and 21% as private renters; these are clearly the preferred tenures of Australian households (Australian Institute of Health and Welfare, 2011, p. 5). The 5% of households that are public and community housing tenants and the remaining 6% which have hybrid or alternative tenures have an over-representation of people with disability (p. 50).

According to Tually et al (2011a) although not socially-valued, public (and community housing) tenures currently offer greater security, better-designed housing, and more affordable options for households that are vulnerable in the private market. This, in turn, can assist people to enter the workforce and to better manage the complexities of their lives (Tually, et al., 2011b). Hybrid tenures such as rental-purchase and shared equity arrangements are under utilised in the Australian market and for this reason deserve further attention.

In a **shared equity** arrangement the purchaser part-owns a dwelling with a partner, usually a government agency or a financial institution. The primary aim is to assist low-income households to enter and remain in the housing market, by reducing the costs of deposits and ongoing mortgage payments; providing a safety net in times of financial stress, and offering capacity to invest further as the opportunity arises. Shared-equity products are attracting interest because house prices have been rising faster than incomes in most Western countries, making it increasingly difficult to purchase in the open market. Governments, in turn, are feeling increasing pressure to meet aspirations of their constituencies for homeownership, and to make any assistance go as far as possible (Whitehead & Yates, 2007).

Whitehead and Yates (2007) suggest that shared-equity products may have broader application involving other stakeholders beyond low-income households, for example, householders who wish to diversify the current investment that is tied up in their home to minimise risk in volatile financial times, older people who wish to realise part of their asset to supplement their pensions, and public developments that may wish to keep control over who gains access to affordable housing. In all, shared-equity products have potential benefits for a wide range of stakeholders; that is, investors, purchasers, and government.

The tenure of home-ownership has been found to have positive outcomes for both individual households and their communities, and that these are interdependent and mutually reinforcing (Rohe, Van Zandt, & McCarthy, 2002). This, however, may not have been the driver for home-ownership in Australia. The lack of support for private renters, a minimal social housing sector and

generous tax incentives for purchasers has made home-ownership of any kind the preferable option for the last half-century (Kemeny (1983) in Bourassa, Greig, & Troy, 1995).

Overseas research into the experience of users of shared-equity products identify the key benefits as increased opportunity to enter the housing-market and greater security in sustaining home-ownership. Secondary benefits are increased understanding of how the housing market worked, greater integration into 'better' neighbourhoods; their hope is that home-ownership will enhance the well-being and development of immediate household members, and will increase social and financial capital for future generations (Thaden, Greer, & Saegert, 2013). Shared-equity products have traditionally been seen to have complicated structures, higher transaction costs, and the potential for post-contractual difficulties, with the major concern being the prejudice against partial-ownership by the purchaser (Whitehead & Yates, 2007). Thaden, et al (2013) refute these concerns by reporting that purchasers consider they can manage these complexities once they are explained properly, and prefer part-ownership to renting or the stress of unsustainable mortgage payments.
Whitehead & Yates (2007) argue that governments also benefit from shared-equity products because they attract private finance into the housing market, reduce the number of people in the rental market, and ease the demand for housing by older householders who will have an asset they can realise in the future (a form of forced saving). Shared-equity products also offer opportunities for financial institutions to broaden their investment in the residential market beyond traditional home-ownership. In all, shared equity in housing potentially offers financial benefits for partners. Regardless, in Australia, shared-equity products have had limited success (Whitehead & Yates, 2007), and may present challenges should a person with disability choose to exit this kind of arrangement.

In Australia, shared-equity takes four forms. They are listed in order of capacity for choice and individual asset gain:
1. subsidy forgiveness
   Not traditionally considered a shared-equity product, "subsidy forgiveness", (or financial assistance requiring no repayment) for home-ownership (such as First Home Owner Grants, stamp duty concessions, interest rate subsidies) aims to encourage targeted low-income groups to enter the housing market or particular types of housing to be provided. In this context, subsidy forgiveness has been used to increase the supply of affordable rental housing (Australian Government, 2011b). This strategy assists purchasers to enter the housing market but does not address ongoing sustainability issues. With regard to people with disability, the Australian Government has yet to exploit this strategy to encourage purchasers to build or buy accessible housing; however, it has begun to consider access features as a condition for assisting the provision of affordable rental housing (Livable Housing Australia, 2013a);
2. shared-equity loans
   Shared-equity loans are the most common strategy. They comprise a first mortgage with the purchaser on a proportion of the full cost of the dwelling, and a second, subordinate loan (or a covenant deed) set against the remaining portion is taken out by a partner. The partner recoups this second share in capital appreciation at the time of sale. Financial return on the

partner's investment is dependent on the nature of the contract. The purchaser is encouraged and expected to "staircase" or buy further equity tranches over time towards full ownership. Shared-equity loans optimise individual asset gain, and offer some strategies for sustainability; however, they do not protect the broader affordability of housing stock over time;

3. shared ownership loans

   Shared-ownership loans are similar to shared-equity loans; however, the purchaser is required not only to make repayments on the first mortgage, but also to pay rent on the remaining portion. The partner also may take a stronger interest at the time of selling-on by determining the conditions of sale. Shared-ownership loans are less optimal with regard to asset gain or sustainability of home-ownership; however, they have some capacity to protect the broader affordability of housing stock over time; and

4. subsidy retention

   Subsidy retention is based on the principle of sharing the equity with the community rather than an individual and does this by providing housing to targeted low-income groups and limiting the resale value of properties through the use of a predetermined formula. Although the intention is to protect affordability of housing stock over time, this strategy limits the individual asset again and choice of housing for purchasers (Pinnegar, Easthope, Randolph, Williams, & Yates, 2009, pp. 19-20).

As the most common, the following section focusses on shared equity loans.

Shared-equity loans work best in markets that have steady, sustainable growth. To succeed they must carefully balance their policy aims and their viability in market contexts. They must also be able to respond to changes in government policy and financial markets in order to protect both the purchaser and the partner.

Partners traditionally are financial institutions and government agencies. Australian financial institutions traditionally have shown considerable caution before, during and after the Global Financial Crisis. In all, there has been very little real innovation or risk-taking; the private financial and housing market have yet to find a way to provide viable non-subsidised shared-equity products (Pinnegar, et al., 2009; Whitehead & Yates, 2007).

The alternative of government-agency backing has had some success, particularly in states where the housing prices are reasonable and predictable. In Western Australian and South Australia, shared-equity products are well-received and working-well. This is because they have guarantees and support measures in place, and the benefit of access to "cheap" government funding. They can, therefore, remain commercially viable with frameworks to manage risk and safety-nets for low-income purchasers. They have also found that they require arms-length operation from the broader government machine so that they can respond quickly to changes within the financial and housing-market (Pinnegar, et al., 2009, p. 77).

Pinnegar, et al (2009, pp. 89-95) suggest that the potential of shared-equity, in particular, shared-equity loans can be enhanced. Current successful State government shared-equity loans offer

lessons on what makes a program sustainable, including transitions by purchasers to private housing finance, and the necessary support and safety nets that are required. Further investigation on how governments can work with private financiers with the intention to integrate government loans into mainstream lending activity would also be helpful. Finally, programs should be within reasonable expectations and operations, while acknowledging their inherent complex structures. A sufficient number of purchasers must want to use them if they are to succeed. They also cannot meet everyone's needs for affordable housing. Shared-equity loans must, therefore, complement other housing assistance strategies to provide a continuum within the housing system.

Traditionally, the implementation of housing policy and housing finance has been a State-based matter. The considerable differences in housing prices among cities and between cities and regions has mitigated against a national shared-equity scheme. Nevertheless, in the context of major national policy initiatives affecting people with disability and their impact on private housing, a national approach is indicated. Pinnegar, et al (2009, p. 94) suggest that national policy aims and funding through a vehicle such as the National Affordable Housing Agreement can guide further development of state-based programs, although this raises further challenges in replication and comparison of key success indicators.

The details of how both levels of government can work together with the private sector are beyond this study; however, this section concludes that there appears to be a place for shared-equity products, in particular, those that assist people with disability and their families:

- to enter and sustain home-ownership;
- to find accessible housing through the mainstream market;
- to live within established communities and better access to mainstream facilities and services; and
- to have normative housing careers and opportunities for wealth creation similar to other people in Australian society.

In terms of other tenures such as boarding houses, residential facilities, and specialist disability housing, these often group people with disability together which has the potential to compromise the attainment of physical, social and emotional needs. Public, hybrid and alternative tenures emphasise the current barriers and impediments facing people with disability in accessing private housing and calls to question the efficacy of current housing policy in supporting people with disability "to maximise independent lifestyles and full inclusion in the mainstream community" and to "participate in and contribute to social and economic life" (National Disability Insurance Scheme Act 2013 Clauses 3.1(g), 4.2).

 The idea of tenure has typically connected one household to one dwelling. Hulse (2008) suggests this is not a complete picture, and that many households now challenge this established understanding. Some significant changes include the increased investment in rental properties by current home-owners; with around one in six households owning a residential property other than the dwelling they lived in. A significant number of home-owners or purchasers are also found to be occupying rental properties. Further, the consistent increase in multi-generational households over

the last twenty-five years "question[s] and extend[s] our current understanding of family values and family support, and particularly the degrees of flexibility and fluidity in which people apply when deciding their living arrangements" (Liu & Easthope, 2011, p. 27). Liu & Easthope argue this development should, in theory, challenge the rigidity of current housing design and how support is provided.

In addition, tenure is not a static phenomenon; people may choose or be compelled to accept different types of tenure at different stages in their lives. The notion of **housing careers or pathways** (where people go on a predictable linear trajectory matching housing need at various life stages) was first developed in the 1970's; however, this has been challenged by the idea of **'housing transition'**— a less linear trajectory affected by changes in the labour market, and personal and economic circumstances (Beer & Faulkner, 2009). For the broader Australian population housing transitions have become more a consequence of consumption aspirations rather than of need at different stages of life, and therefore the idea of 'home' is now more tied to people's sense of identity (p. 6). Noted earlier, this is less the case for people with disability and their families who are more likely to experience low incomes, housing stress and limited options with regard to location, design and affordability (Beer & Faulkner, 2009, p. vi). This study uses the term 'housing pathways' suggesting an intentional journey, which not only responds to people's needs through their life but can also respond to their sense of identity and personal aspirations.

This overview of the concepts of sense of place, home and tenure informing this study suggest the following assumptions can be made when considering the barriers and impediments people with disability face in the private market:

- where and how people live, and with whom they live and are connected to, will influence their sense of place in the world. How people interpret a sense of place will be influenced by whether they feel they belong, and it will then impact on how they define themselves and others define them;

- the concept of home is more than a physical place; it is tied to the social, cultural and emotive worlds of people and is located in both time and space. There is a documented link between a person's well-being, and their manifestation of home. The quality of home affects a person's well-being, and is a node for the social networks of people who have significance for and influence on the person;

- most people in Australia prefer the tenure of home-ownership, home-purchaser or private rental; however, there is an over-representation of people with disability in public, hybrid or alternative tenures;

- providing equitable access to all forms of tenure will assist people with disability towards independent lifestyles and full inclusion in the mainstream community and increase participation in and contribution to social and economic life; and

- the established idea of connecting one household to one tenure type is changing with housing now being used to enhance financial security, and to accommodate both formal and informal support arrangements.

3.3   Conclusion

This section has presented the theoretical context for the project drawn from existing research and publications that relate to its research questions and goals. Underpinning the project's focus on private housing is acknowledgement of its significant role in facilitating community inclusion and participation and through this access to an 'ordinary' or 'normative' life with the same opportunities as available to the wider community for leading 'a good life', that is, a life that is fulfilling and productive. Such aspirations, however, should not suggest that everyone conforms to some norm or that the same things contribute to a meaningful life. As with all people, people with disability have their own individual and household positions, dispositions and characteristics demanding planning for the future that sees the person first and that places their aspirations, capacities and rights at the centre.

One such right is the right to change housing as situations or goals change demanding that:
- people with disability have the same rights of purchase or tenancy afforded to other people;
- housing not be tied to a support service so as to provide for maximum flexibility and choice; and
- basic housing design, construction and location should not preclude a person with a disability living in the dwelling of choice or visiting others in the community.

Integral to the above, is:
- the capacity and capability for people with disability and their families to envision and plan a good life independent of services and that acknowledges the central role of the house or unit and its community as a home; that is as a place having fundamental social, cultural, emotional and existential significance; and
- the capacity of society (government, industry, organisations) to address systemic and attitudinal barriers impacting issues of housing availability, suitability and affordability.

In all, the literature suggests the need for research that can reconcile a person-centred philosophy with a holistic appreciation of the external and internal factors impacting private housing access for people with disability.

4 Theoretical and Methodological Approach

This section describes the ecological framework used to make sense of the complexity of the data collected from the case organisations and participants and to inform a more representative and comprehensive project.

4.1 Theoretical approach

While the literature reviewed for the project suggested the need for a holistic approach, this was not as apparent until we had collected initial data from the case organisations. During the process of interviewing key representatives of the case study organisations it became increasingly obvious that the issues they were dealing with involved multiple layers and levels, all interconnected in dynamic and for the most part incongruent ways. Some issues were more to do with individuals and their immediate context, while others stretched beyond individuals and their families to the broader community and society. It was at this point that we decided to adopt an ecological framework to theoretically guide and support the project.

Positioning the study theoretically

The concept 'ecologies' has several meanings, including the original Greek use in relation to a 'house' or 'dwelling' (Cooley, 2008). Given the focus of this study, it seemed appropriate to consider this as a fundamental generative concept acknowledging its potential to intervene in primary rather than just secondary ways. As is evident from a survey of the disability landscape and the empirical research to date, the primary intervention currently is a care based one with housing rarely considered as part of the service planning process. Where it is considered, this is generally in a supportive role as reflected in policies and practices described as 'housing assistance'. In Australia, housing support options for people with disabilities are most commonly crisis housing, social/public housing or community group housing (Australian Institute of Health and Welfare, 2013, p. 38). For private housing support there is some assistance for home purchase and private rental. In the main, housing is regarded as a form of social care intervention. An ecologies approach on the other hand invites consideration of housing for all people including people with disabilities as an existential intervention from which is generated other types of relationships – in contrast to its primary role now as a care intervention giving emphasis to the physical environment and how it supports the physical needs of the individual (and the carer).

Fundamentally, an ecological approach, as adopted for this project, draws attention to interconnectedness and interdependence, as opposed to the notion of evolutionary adaptation and "adjustment to rather than change in environmental conditions" (Gould, 1987, p. 43).

> From an ecological viewpoint, environment is multilayered and multifaceted. It has temporal dimensions as well as being both physical and social. Issues that at first glance appear to be localised will in fact be connected to broader environments crossing several borders and boundaries and into other areas....(Franz, 2010, p. 130)

Ecological models have a long history of development and application across a range of areas and for specific purposes. In the health area, ecological models have been used to understand the multiple, and interacting, factors influencing health behaviours by developing a combination of environmental, policy, social, and individual intervention strategies. From research in the United States, interventions based on ecological theory are understood to have contributed to major reductions in tobacco use since the 1960s (Sallis, Owen, & Fisher, 2008). Another area in which ecological models have played significant roles is education. Of particular note is the work of Urie Bronfenbrenner (1994) in terms of human development and his model that identifies various environments as contexts of development. Because this model has been used widely across various areas including disability (for example, Hogg 1997) it will be adopted here as a broad theoretical framework for the study. The model can be depicted graphically as conveyed in Figure 4.1.

Intra-personal
A person's characteristics

Micro-system
Family, friends, neighbours
and natural networks

Meso-system
Interactions between
operational services

Exo-system
The broader legislated,
policy and economic,
environment

Macro-system
Larger cultural context
including values,
expectations

Chrono-system
Time and change
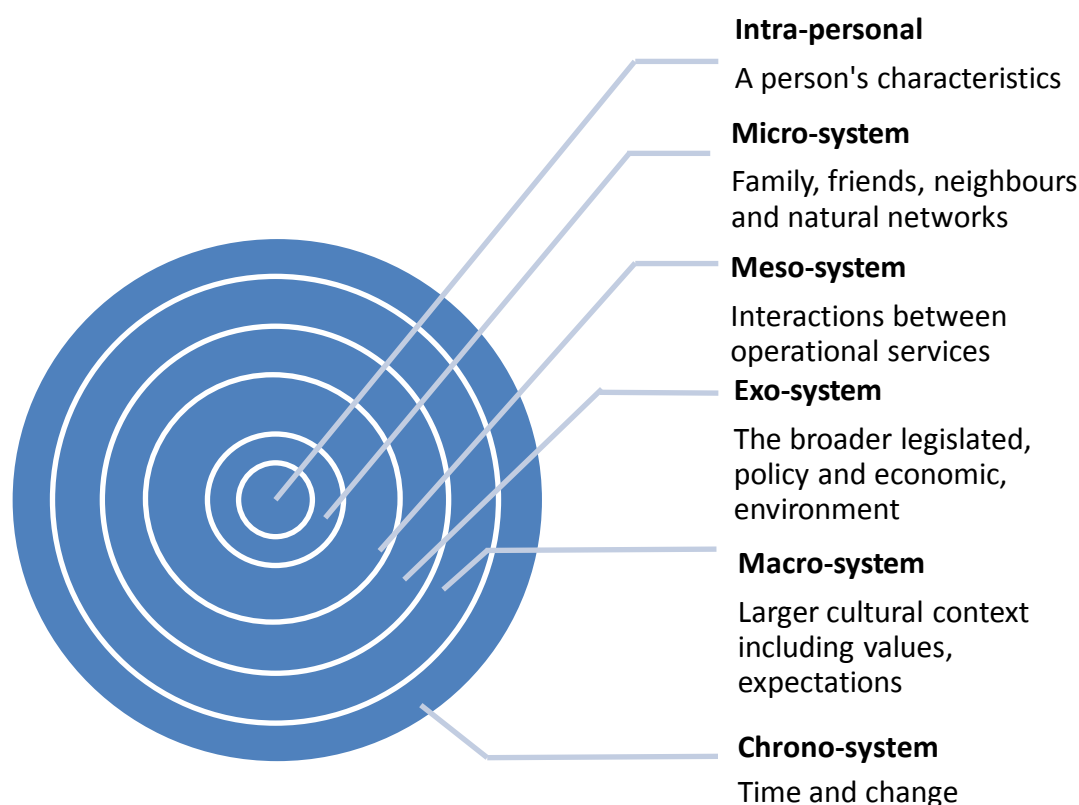
Figure 4.1: Ecological framework
(Adapted from Brymer and Davids, 2013; Bronfenbrenner, 1994)

As illustrated, the model consists of six levels. At the centre is the *individual* with their intrapersonal qualities including their biology, demographics, and family situation. In close proximity is the *micro-system* involving particular physical, social and symbolic features with which the individual comes into direct and immediate contact. These include certain settings such as school, health environments, workplace, neighbourhood, and associated people (for example, family, friends, and

carers) and activities (playing, visiting, learning, socialising). Connected to the micro-system is the *meso-system*, comprising the linkages and processes taking place between two or more settings accommodating the person (for example, the home/neighbourhood relationships; home/service provider relationships). Adjacent to this system is the *exo-system*, comprising various systems that have indirect influence such as the political system, the economic system, the housing industry, and so on. Extending out from the exo-system is the *macro-system* or the larger cultural context locating cultural values, social ideologies, and so forth. Situating all these systems and the individual in time and the process of change is the *chrono-system*.

For this study, the barriers/facilitators regarding access to private housing for individuals with disabilities will be located in relation to these systems. Interpreting Bronfenbrenner's model (1994) in relation to this study, transition to private housing for the individual with disability ought to occur when relationships between and across relevant systems are compatible or have contiguity. The conceptual development demanded then that the study be widened to produce a more representative overview of models aiming to provide people with disabilities with greater choice and independence through the provision of additional housing typologies. Added to this was the need to acknowledge a broader range of housing experiences including attempts by individuals or families to respond to their housing aspirations outside models developed by the not for profit organisations initially considered for this study.

4.2   Methodological approach

Research approach and methodology

Originally, the project involved three cases:

Case A

- A community financial organisation, working on behalf of both individuals with disabilities and/or their families and not-for-profit community organisations (including service and housing providers), to broker financial models that facilitate access to appropriate and affordable housing including owner-occupied housing.

Case B

- A not-for-profit foundation organisation, working on behalf of young people with disabilities at risk of being placed in or staying permanently in residential aged care facilities (RACs'). To this end, the organisation works with state and federal governments, housing associations, property developers, community service organisations and financial institutions to produce an integrated model of supported housing.

Case C

- A community association, working directly with: families with an adult child with a disability; a financial institution; a planning organisation; local/state/federal governments; a research institution; and a social enterprise housing provider to produce a financial, legal and regulatory model that would, through a particular private housing typology facilitate transition for the adult child to independent living.

The three cases were related because they represented different attempts to integrate innovative, and what they understood as person-centred, models of housing into the private housing market for people with disability. All three selected cases:

- have an explicit focus on housing for people with a disability;
- attempt to integrate housing for people with a disability into the private housing market;
- have encountered difficulties with and barriers to the implementation of their respective models;
- attempt to create an holistic approach to integrating other sectors/services into the process; and
- are attempting to develop and implement processes and models of housing that currently do not exist.

The following diagram (Figure 4.2) conveys the position of these organisations in relation to the ecological framework. It also positions a fourth case:

Case D

- A family working with two other families, a governance group and government to secure accessible social housing as part of an intentional community.

Intra-personal
A person's characteristics

Micro-system
Family, friends, neighbours and natural networks

Meso-system
Interactions between operational services

Exo-system
The broader legislated, policy and economic, environment

Macro-system
Larger cultural context including values, expectations and attitudes

Chrono-system
Time and Change
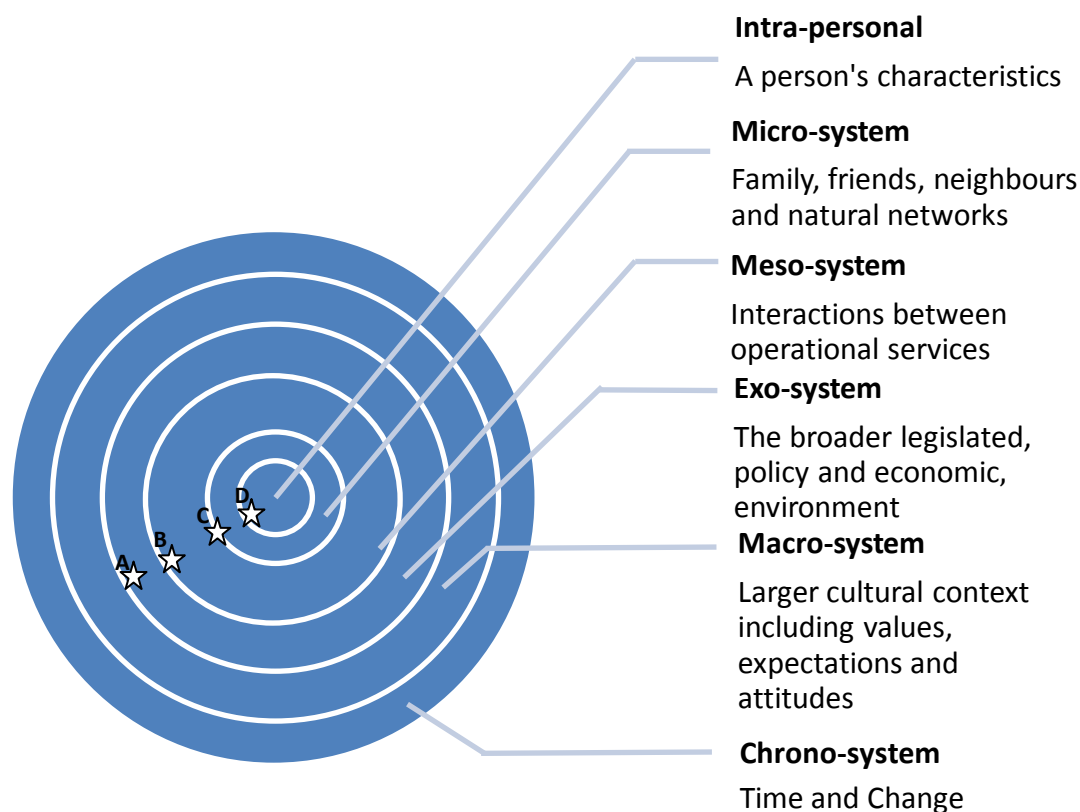
Figure 4.2: Position of cases in the ecological framework

As Figure 4.2 illustrates, cases A, B, C are located within and across various levels of the framework operating from their own specific perspectives and somewhat detached from direct connection with the person with disability or their families. In all cases there is heavy reliance on the service provider or other community associations to be the conduit to individuals and/or their families or those regarded as acting on their behalf. In other words, the case organisations are operating *on behalf of* people with disability. In contrast, in case D the main agent is the family itself and the immediate community. It involves an approach by the individuals themselves.

In talking to the representatives of cases A, B and C, it also became apparent that the relationships they had with not for profit organisations (NPOs'), and that the NPOs with people with disabilities or their families, were very selective, in that they tended to have relationships with individuals with specific types of disability and with those in receipt of special forms of individualised or block funding. As such, it became apparent for the study to be more inclusive of the diversity of personal housing experiences and interventions in relation to alternative housing models. In response, we also undertook interviews with the following individuals and family members:

- individuals and/or families who have been successful in accessing private housing (n=3);
- individuals and/or families who have tried to access private housing but have been unsuccessful (n=7);
- individuals/families who have experience of housing typologies not represented in the case studies (n=5); and
- individuals/families with greater diversity in terms of demographics, personal and family characteristics and circumstances, and so on (n=10)

As a whole then, the study has participants from organisations, families and individuals representing a diverse range of disabilities (physical, cognitive, mental, sensory, emotional and developmental) and housing experiences.

The original intention was to focus on each case in terms of the impediments and difficulties experienced by the case organisations and to bring these together through cross-case comparison. However, during the project our understanding of their role widened to also consider how they would contribute in descriptive, exploratory and explanatory ways to better understanding the overarching phenomenon of access to private housing for people with disability; a process enriched through the additional inclusion of the voices of people with disability and their families.

As conveyed in Figure 4.3, the research involved explanation-building, through a multiple case study approach supported by a contextual study to facilitate connection to and future research of the broader issue of community inclusion and participation for people with disability. It used multiple sources of data including documents, archived records, semi-structured interviews and the models developed by the organisations. As well as helping build a relational picture, the multiple sources and associated methods constituted corroborating strategies for strengthening research quality. Data collected were analysed using an iterative process of comparing emerging findings against initial and emerging statements/propositions within and across organisation and individual cases. Coding of interview transcripts was undertaken by three of the researchers and compared to ensure

a high level of research rigor and quality. Overall, the process involved a gradual building of an explanation of the barriers and obstacles impeding access to private housing for people with disability and of the policy and practice implications for government, organisations, the housing industry, people with disabilities and families of people with disability.
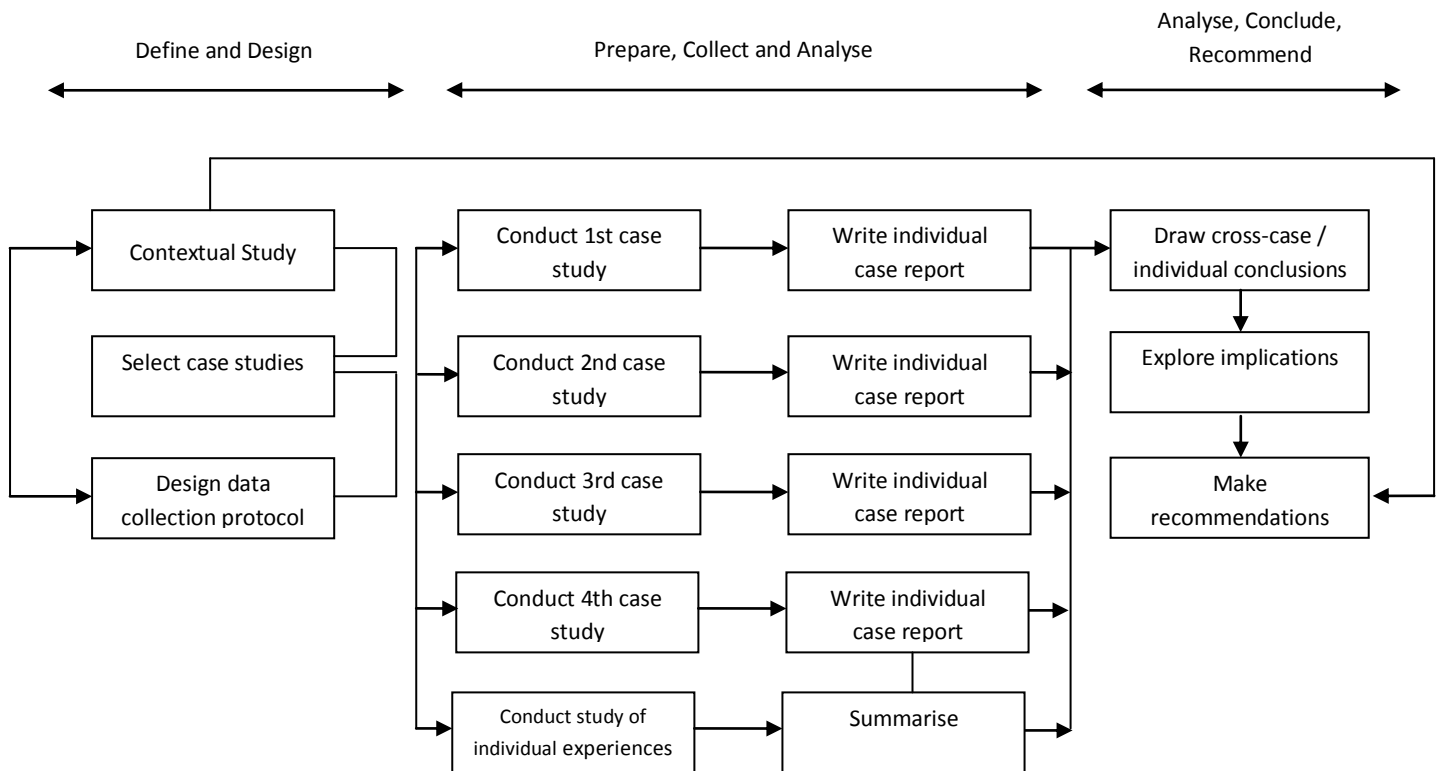
Figure 4.3: Multiple case study research approach
informed by (Yin, 2009).

The project also established a reference group of two individuals, both having worked in the disability field as well as personally having disabilities, who were invited to review critical stages of the project. The collection of data did not commence until full high risk ethical clearance was obtained.

4.3   Conclusion

This section has described the ecological framework used to position and guide the project. Detail has also been provided of the case study approach adopted by the project. The following sections contain summaries of the case reports leading then to a cross-case review in Section 7.0. The three sections constitute the findings of the project.

5 Organisational Agency and Housing: Attempts to implement person-centred approaches <u>on behalf of</u> people with disability

This section presents a summary of three case studies undertaken for the project that involve organisations and their attempts to improve access to private housing *on behalf of* people with disability. In-depth descriptions of the cases studies are presented in the appendix to this report.

While the organisations share a common concern for improving participation in society for people with disability and, in this regard, understand the significant role private housing and various structural and personal factors play in impeding participation, they differ in the nature of the agency they bring to this situation. For example, the first case study involves a Community Finance Organisation whose primary focus is addressing financial barriers; the second case organisation is a foundation concerned with information, communication and facilitation barriers; and the third case organisation is a not-for-profit community association attempting to work directly with environmental barriers, particularly inadequately designed housing. As the following summary will highlight, the difference is largely attributed to their organisational demographics and where they are positioned systemically in society. Despite their varying distance from the individual with disability and/or their family all organisations explicitly articulate support of the tenets of person-centredness in their planning and action.

5.1 Case Study A – the community finance organisation and attempts to address financial barriers

Organisational context

This case organisation involves what is known as a Community Finance Organisation. Established for approximately twenty years, the organisation operates as an independent organisation accessing community finance and social investment for those underserved, or excluded, from mainstream financial services (for example, individuals; groups including families and households; social/not for profit organisations (NPOs); social enterprises, social businesses, microenterprises). A member of wider international networks and institutions, its work, which can be described broadly as a brokering role, covers various areas including (among others), disability and disability services, housing and housing assistance. In this respect, it aims to build relationships among people with disability and their families, the peak bodies representing people with disability (for example, not-for-profit organisations particularly service providers; and local, state and federal government agencies), other emerging networks, social investors, and in some instances specific mainstream financial organisations that have a social focus. Central to this is enabling greater access to financial and social capital through social investment to fund appropriately located, well-designed, affordable housing providing a sustainable level of capital security and return on the investment.

Underpinning this is a mission to alleviate financial exclusion experienced by marginalised groups such as people with disability and not-for-profit organisations by focussing on people and communities being able to help themselves. As conveyed by the community finance organisation representative, it "…connects back to our friendly society history…and values centred on self-help, mutuality, and reciprocity", and, along with this, acknowledges that existing social structures and policies are failing many individuals and groups in society.

Factors identified by the Community Finance Organisation as influencing financial exclusion and sustainable use of financial products

While financial exclusion is normally considered in relation to individuals, the community finance organisation contends that exclusion also extends to groups such as NPOs and social and micro enterprise. As to how to address financial exclusion for individuals or groups, it argues that two factors, capability and market failure, need to be considered in combination with (both interconnecting with and across) various systems and issues in society. For example, in addition to factors relating to financial product promotion, communication, design and delivery, the community finance organisation identifies employment, lifelong financial planning and access to and maintenance of appropriate, long term affordable housing (the latter also associated with social and economic exclusion) as several factors contributing to financial barriers for people with disability. Exacerbating this further, they suggest, is a policy environment that remains largely disengaged from these emerging entities, their initiatives and the issues they are grappling with. As they point out, Community Service Organisations (CSOs) "…especially in the welfare and community sectors, are often placed in a situation of mitigating the worst effects of market failures on people who are marginalised and excluded in society" with banks and government departments failing to address the systemic causes of exclusion.

Over a period of six years the community finance organisation has attempted to respond to this though several models ranging from the more commercially oriented through to the more socially oriented. Despite their variation, all the models represent a concerted effort by the organisation to confront the financial market's preoccupation with the commercial imperatives of maximum return by adopting a 'low profit market' approach in which people with disability have access to housing subsidised by social investors, or a combination of social and public investors who receive a steady but below market return (the difference of which is off-set by their goal of a social return on their investment). The basic rationale for this then is to create financially viable options for independent living responding to the need to provide greater choice for people with disabilities and their families.

Attempts to implement person-centred approaches to private housing: the central role of finance

The community finance organisation's understanding of person-centredness in relation to housing is best conveyed through articulated principles that:

- housing provision should be centred on the person, connected to the support arrangements of the person in a way that ensures they remain connected to the relationships they have within their community; and
- planning for housing should take into account the physical environment as well as long-term issues associated with income and finances and decision-making beyond the life of the parent in the context of the broader family (reference withheld).

Differentiating private housing from other types of housing, the organisation defines it as housing not "…funded or built by the state". It is housing that "…may never be owned by the person with disability but it may have been created, secured or developed using money that is not money of the state but that comes from other private sources". In this respect, it is understood to include housing specifically built for people with disability (*appropriate housing*) funded either wholly or partly by (private) social investment (making it more *affordable housing*) not just (private) commercial investment. It is seen as additional to private housing available for purchase or rent on the open market, which, for many people with disability, is generally neither appropriate nor affordable; and, which, for the case community finance organisation has prompted them to explore alternative approaches. These are described in terms of the following models:

Model 1 – Brokering finance for home ownership through credit unions

This model represents one of the first initiatives attempted by the community finance organisation. Essentially it involved the institution brokering a home loan from a credit union for people with disability and/or their family. Under the Australian Credit Licence, lending authorities must have a supply of capital for residential home loan lending (which the organisation does not have) requiring them to engage with a financial organisation that does such as a credit union. This model has been abandoned for the time being.

Model 2 – Establishing and managing a property trust of houses leased directly to individuals with disability

Model 2 involves the community finance organisation in establishing and managing a property trust of houses leased directly to people with disability. This model has not been pursued.

Model 3 – Brokering finance for housing provision through a mortgage trust

Model 3 is concerned with establishing a mortgage trust backed by the state government with the capital raised to fund loans to housing disability service providers to purchase or build housing specifically for lease by people with disabilities. At the time of interviewing the organisation's representative this proposal was still before the state government.

Model 4 – Brokering and managing finance for housing provision through a charitable trust

Model 4 involves the establishment of a charitable trust with the community finance organisation as trustee to purchase several units in unit block developments using capital raised through predominantly social investment. The capital raised and managed by the organisation's subsidiary social investment company in the form of a non-profit community finance fund would be provided to the trust as an interest-only loan. The establishment of the trust as a charitable entity entitles the trust to apply for various tax exemptions such as stamp duty. The charitable trust provides a Head-Lease agreement to a service provider organisation, which sub-leases the units exclusively to individuals with disability or a family

with a member who has a disability. All units have two bedrooms apart from a one-bedroom unit designated as the carer hub providing twenty-four hour seven day a week carer support. The two bedroom units are viewed as allowing the possibility for supplementing support and providing companionship through parents or siblings staying over. This model is in the process of planning.

Implementation impediments and difficulties

Underpinning Model 1, as well as the other models, is a specific perspective on the social nature of financial inclusion/exclusion, and a view that even if the community finance organisation could go direct to the disability market, or even if mainstream financial institutions were interested in doing the same, both would have to rely on the non-profits to reach those comprising the disability market. Despite recognising the problems with service provider capability and capacity, they contend that they are still a significant mechanism due to their close relationship with people with disability and the interconnection of housing and care, "…the intersection is occurring between the needs and life circumstances of an individual and their connection to an organisation and that organisation's needs and ability to respond to the individual, so it's all tied in together".

In Model 2, the community finance organisation sees the NPO's involvement as an intermediary to help the organisation develop an appropriate fit relationship between housing and tenant. NPOs are also viewed as crucial in Models 3 and 4. In Model 3 state government funded loans are provided to not-for-profit disability housing service providers to purchase or build housing. One of the main complicating issues with this model has been the change of government with no response forthcoming from the new government. The reliance on government funding, as opposed to social invested funding, also differentiates this model from Models 2 and 4 moving it more into the realm of social housing and outside the domain of what the community finance organisation regards as private housing.

More than the other models, Model 4 highlights challenges in building relationships with investors as well NPOs, and having them commit to something that has not been undertaken before, that takes substantial time to put together, and that is reliant on a multitude of aspects coming together. In addition to deepening and widening investor relationships, the community finance organisation also regards as a challenge having the resources necessary to:

> "…go out and build [those] relationships into the non-profits and help them understand that actually this is something that could facilitate housing outcomes for some of the people [they] work with and their families. That's hard. There's all sorts of ideological barriers".

Challenges also exist in this model for the NPO. As noted earlier a major one is in trying to provide an appropriate level of care when the care is being shared among several individuals. Congregate care models such as this have built into them an 'economies of scale' rationale. From the community finance organisation's perspective, one of its most fundamental challenges was developing and implementing a process of due diligence to ensure selection of an NPO with experience, integrity

and a person-centred approach in working with their clients, for example, were they going to work from the person without assuming to know what they want.

The approaches devised by the community finance organisation offer a number of insights. In the main, they reflect a desire to implement a social model perspective of disability that also recognises the individual and their circumstances. In relation to housing, the organisation's work represents an attempt to address some of the economic and social disadvantage experienced by people with disability, and how various economic structures, including the principle of marketisation and institutional practices in particular, are barriers to social equality in the ways they restrict access to owner-occupied and private rental housing. One of the main factors here appears to be how financial institutions and rental authorities are allowed (as well as choose) to operate in relation to risk assessment. Associated with this are assumptions about, and the practices used to determine the capacity of the person with disability or their family to financially (and in some cases legally) sustain a mortgage or the lease. Added to this is the reality, as understood by the community finance organisation, that many individuals with disability or their families for a range of reasons (external and personal) just cannot afford to buy a property or rent in the mainstream market.   The impact of not being able to access mainstream housing, for whatever reason, is further compounded for many people with disability by a lack of accessible and appropriately located stock.

The models then developed by the community finance organisation are attempts to address these issues of affordability and appropriateness through the development of an alternative financial system primarily involving trusts and social investment or a mix of social investment and government/community funding. In facilitating access to the housing provided through this type of investment, the organisation sees a significant role for NPO support and housing providers and an existing system that for many individuals with disability ties them to particular service providers because of how various forms of funding support are provided by federal and state governments.

5.2 Case Study B – the Foundation organisation and attempts to address information, communication and facilitation barriers

Organisational context

Case B is a foundation not-for-profit organisation (NPO) working on behalf of young people with disabilities who are at risk of being placed in (or staying permanently in) residential aged care facilities (RACs). It was established in 2006 for the purpose of promoting the capacity of younger people with acquired disability and complex care needs to live in normative community settings. According to the foundation, its specific mission is "to foster the development of services and solutions that promote the health and well-being" of younger people with acquired disabilities and to empower them to participate in the community. It aims to do this by:
- supporting research to provide an evidence base for policy change;
- attempting to create a movement by supporting people with disability and their families to tell their own story, to envision and plan for themselves and keep the issue on the political agenda; and

- demonstrating what is possible, by working in partnership with housing and support organisations, and evaluate them with regard to the economic and human outcomes for this particular cohort (reference withheld).

Factors identified by the Foundation as influencing exclusion due to information, communication and facilitation barriers and the lack of exemplary models of appropriate housing

In general, then, the foundation's work emphasises a range of systemic and personal issues to do with information, communication and integrated facilitation, and how these, and housing, can be barriers to greater participation in society for people with acquired brain disability and complex needs. For the foundation, a planned approach to housing is central to these people leaving residential aged care facilities (RAC's) for without this it is impossible also to plan the equipment, disability support and health services that may be required. Unless a person already has their own home, the lack of accessible and affordable housing will limit the opportunities, and unless the issue of housing supply is resolved systemically, the pressure on acute health facilities to move people with acquired disability out will result in continuing placements in RACs.

With respect to the appropriateness of housing, the foundation points to inadequacies within the National Construction Code (NCC) and access guidelines for private housing spaces that are inadequate for adults with acquired disability, "There is a big difference between meeting standards and functional design for people with disabilities and the people that support them". Although there is some improvement in apartment building common areas due to the inclusion of the Access to Premises Code within the NCC, the representatives consider that it is still "not good enough for the 10% that sit above those 80- 90% [of people catered for in] most of those standards". Even when specially designed housing is available, according to the foundation, there is no guarantee that housing will be available to suit specific needs, with a mentality of slotting people into available projects regardless of their suitability. As they elaborate, specially designed housing also tends to be more expensive with significant gaps between funding strategies such as NRAS and rental assistance and the amount people with severe disability can typically afford. Another major barrier according to the foundation, is not knowing where appropriate housing could be found, and what compromises could be made.

In general, the foundation identified the need for:
- "broker" capacity to work with the various stakeholders, such as housing associations, disability and health service providers, and housing developers;
- processes to assist people with disability and families to envision their life and their future home, and actively plan how to obtain it; and
- facilitation to develop housing and support specific to the individual's needs: An interviewee said: "I guess I would sort of describe it as figuring out what their needs and preferences are, and wrapping housing and support around those rather than always trying to slot a person into a venue of options".

Attempts to implement person-centred approaches to private housing: the central role of information, communication and integrated implementation

The foundation's mission reveals a particular understanding of person-centredness and private housing and how the two are related. This can be summarised as:

- a vision for younger people with acquired disability having inherent value as members of society;
- a focus on workable solutions that address the complexities of bringing health services, disability support and housing together in a way that improves the health and wellbeing of this group;
- an understanding of the critical role families and informal networks play in people's health and wellbeing; and
- a realisation of the importance of the person, with their families and friends, to envision and plan a better life for themselves, and that their stories have the power to create a movement for change (references withheld).

In terms of housing, since 2009 the foundation has had two attempts at purchasing housing as demonstration projects within mixed mainstream housing development to rent (or sell) to people with acquired disability and complex care needs. To do this they are reliant on philanthropic funding: "we are using philanthropic funding to purchase housing. Without that it just wouldn't happen". Social enterprises, where a reasonable return for investors was expected, were considered non-viable when addressing the particular housing requirements of this group.

The capacity of individuals and families to plan for, and realise, a more independent and productive future was seen as critical, and closely aligned with this was the requirement to provide appropriate information, education and inspiration. This, for the case organisation, encapsulates a person-centred approach or what they describe as an individualised approach; one where housing and support packages are built in a coordinated manner around the individual rather than the individual being matched to housing that may not be close to family and informal networks and facilities; in some cases being pressured to accept inappropriately designed housing because of need to move from their present environment or through fear of not being considered in the future.

In addition to being able to live in an environment that supported individual physical needs, choice was also understood to be actualised through a tenancy arrangement that gave sole occupancy rights to the individual, in other words the right for the individual not to be forced to share with anyone else. Apart from this being a human rights and practical issue (with additional space being needed for equipment or a spouse/children and so on) the case organisation also sees it as "driving the wrong objectives" and not making financial sense to implement a model economically reliant on full occupation of multiple tenancies within the same dwelling. While they recognise the inadequacies of the Disability Support Pension, they prefer to subsidise this through additional (philanthropic) funding and to demonstrate over time potential reduced lifetime care costs for people with disabilities.

While housing provision that is financially viable and supports independent living is considered crucial in enhancing choice, the case organisation clearly recognises the need for other 'capitals' to be present in an integrated and individualised way to further enable choice – political, social and health, educational/informational, financial, legal and all the advantages that promote capacity for planning and expectations regarding independent and productive living.

Located in this broader field of choices, inclusively designed housing situated in mainstream communities is understood to have particular significance. Fundamentally, a small number of inclusively designed dedicated dwellings situated within a larger mix of social and/or private housing are seen to offer the person with disability greater possibility of a normative life – and the broader community the opportunity to develop more inclusive attitudes and for all residents to be seen as members of the same community providing informal support as the need arises through relationships of reciprocity. As expressed by one of the interviewees:

> …our goal for people living in these places is that if they were unwell or they hadn't been there for a week that somebody would actually notice and actually say – oh, where have you been, or that there would be people who would say hi to them and know them by name…and one of criteria for living there is that they [the individuals with disabilities] have the potential there to be good neighbours so that's about a reciprocal relationship.

For the broader community and the owners of the housing, which could be the case organisation, the inclusively designed housing is, for all intents and purposes, 'private' housing available for rent and providing the same (if not greater) tenancy rights as rental properties owned by private individuals. One of the interviewees also suggested the possibility of tenants having equity share in the dwelling. For the owners of the dwellings, the case organisation argues that given their specialised design and location within mainstream housing they be regarded as "…real assets that can be bought or sold" and that this makes more financial sense than owning group homes or lots of units that are often subject to vacancies and becoming "a white elephant".

While a dwelling may be dedicated to a support worker or service provider, they may or may not be providing direct support to the residents with disabilities. As described by one of the interviewees, the intent is for the model to be seen:

> …as being just like supporting someone who lived in the community – just because they [a support worker] happened to be co-located doesn't mean that it should be staffed or that the mentality should be like a shared supported accommodation service and that's been quite a shift.

As the other interviewee continues:

> Yeah, it's a foundation of thinking because when people see this sort of model they think ah shared supported accommodation, just different housing but we say no no no. Community living. Let's look at what we can do to actually get some synergy because they happen to be close together. Huge difference in the end how people approach that as being mindboggling.

The above discussion describes the defining features of the rationales, and perceived niche of this organisation and its role, and that of the housing industry, in facilitating greater choice for people with acquired and complex physical disabilities. However, there is another crucial layer of context that is central to the realisation of advantages and choices: the operational context of service and its relationship to the broader framing of service provision in terms of products and consumers. While not articulated to a large extent, the interview with the case organisation representatives did reveal acknowledgement of a role to be played by service providers and for them to in some cases be regarded as partners with housing providers, most likely in a housing management role.

Implementation impediments and difficulties

In terms of the two demonstration projects mentioned previously both attempts to secure housing by the foundation were unsuccessful. In the main, this was attributed to having insufficient time to what they understand as coordinating all facets and address each at crucial times in the projects. For instance, when working with a private project, the timeframe between the design stage and the apartments being sold off the plan did not allow for the due diligence process and access to finance required before purchase. In addition, when working from plans where design and engineering decisions have already been made, it became difficult to obtain the changes that were required to meet the particular access needs of the client group.

In summary, the foundation believes that housing projects are understood to be best influenced before the design stage if the access needs of people with large wheelchairs and equipment are to be considered, and for the units remain integrated in the development. The benefit of being able to influence the plans early in the project development stage is offset by the risk that the project might stall or not attract finance. In attempting to integrate housing solutions within regular communities, the foundation has had to manage the uncertainties of the mainstream housing market while trying to plan smooth transitions for people from RACs and coordinate appropriate disability and health services. "You sort of need to have a few irons in the fire and work closely but you need to know they are all not going to come to fruition or come to fruition in the timing you were hoping for". At the time of interviewing the organisation representatives, a project manager had been appointed to help address coordination and integration issues.

5.3   Case Study C – A not-for-profit community association and an attempt to address environmental barriers of access to private housing

Organisational context

This case involves a community association working directly with families with an adult child with a disability to facilitate transition for the adult child from the family home and the primary care of a parent or parents to independent living in a 'house' ideally owned and occupied by the adult child. The case organisation operates a number of community and family programs as well as disability and housing support services. Its vision is one of fairness, sustainability and belonging in the community. Through its work in the disability sector, the organisation came into contact with a considerable number of families with aging parents who were caring for their adult children with disability. These

families were part of a generation that had provided around the clock care for their children in the family home and now entering later life were facing a future where they were increasingly less able to continue to provide this level of care for their children.   Common to these families was a desire to avoid 'crisis' placement of their children, in the event that the family situation changed suddenly. These families felt that such a dramatic change in their child's life (particularly if their children were forced to suddenly relocate from a home and routine that they had known all of their lives, into an unknown arrangement that was likely to involve forced co-habitation with strangers) would have serious negative impacts on their children's, psychological, social, emotional and even physical well-being.

Factors identified by the Community Association as influencing exclusion due to environmental barriers

As understood by the community association there has been minimal response in relation to private housing which, as reflected in the following response by one of the organisation's representatives, they believe offers greater choice and opportunities for independence.

> You have a legacy um you know, when I pass on, if my child was living in next door or whatever the design incorporated, what I had was an asset, that my more independent living child or partner or whatever was able to say ok, I've passed on or had to go to a nursing home which there is another whole context in that argument, but I can rent that out, I can sell it and this is where we talked about strata titling, where we talked about townhouse, whether it's units, whether it's duplexes were involved because there could be a derived income to continue to support that person for the rest of their life so here was an asset that was realisable. That's what I call private.

Unfortunately, as they go on to elaborate, the private housing market makes few concessions to the design and location needs of households with people with disabilities. As such, in circumstances where ageing parents require new arrangements for the support of their adult son or daughter, many lacked viable choices:

> People in those circumstances, you don't know what you don't know … all they know is that they've got to do something but what's that something? What does that look like? How do you get to it? What's the path to get to it? No one was giving them a path.

In terms of design needs, the national regulatory scheme for construction has no access requirements for the internal spaces of housing and the Universal Design movement which is beginning to influence reforms in this area only focuses on general physical needs of accessing and using essential amenities. There is no consideration of the diverse nature of disability and of disabilities that are not easily visible such as vision impairment and intellectual disabilities to mention but a few.

> When they say accessible and disability adaptable homes, people picture wheelchairs. It isn't only about wheelchairs. That's one part of a disability sector but

that's what they think about. How do I get that wheelchair from A to B? How does it
turn in? There are so many other things um that we have to be cognisant about.

It was issues such as these then that influenced the community association in understanding the
problem and moving to a more individualised design approach for addressing these types of
environmental barriers. Also influential was an appreciation of the changing nature of life and of
their understanding of accessible individualised design being applicable to housing design more
generally: "the design that we looked at has to not only be for today but for the future and has to be
adaptable design".

Attempts to implement person-centred approaches to private housing: the central role of design and location

In exploring options for the families wanting to transition their son or daughter to their own home
and a more independent life, the case organisation began talking to various other organisations
including a university (accessing current knowledge of inclusive and consensus driven design) and a
professional design organisation (accessing architectural, interior, industrial, landscape and graphic
design expertise), the outcome of which was a collaborative research and design partnership
between all three organisations. Participation in this collective was based solely on pro-bono and in-
kind donations of time and other resources from all members and organisations.

Wanting to use the social and emotional relationships of the family and their adult child as well as
physical needs as drivers for environmental design, the project commenced by focusing on the
stories and lives of the families and working outwards from there. Whilst the ultimate hope was
that the model could be more widely applicable, it was never an initial goal to create a single model
regarded as a 'one size fits all' solution.

What has been termed the 'duplex' model soon emerged as a frontrunner for the initial case study
family. This model proposed two side-by-side or co-located privately owned dwellings, one occupied
by the parents and one by their adult child and a carer. The connection to the dwellings could be
modified to allow different levels of connection and separation associated with increasing support
provided by an external person who ultimately may be a co-resident living there rent free in return
for caring for the adult child.

With the need to accommodate a number of possible future scenarios, it became evident to the
collective that adaptability of the physical form was a key element. It also became clear to the group
that the social, political, legal, financial and care systems were inextricably linked to the housing and
this sparked a push to find solutions that addressed all of these factors. Initial financial and legal
modelling was undertaken using the situation of the case family as its basis. It was well understood
by the collective that the position of this family was not necessarily representative of the other
families and may even represent a marginal position. In this instance, immediate issues of
ownership were relatively straightforward (though still complicated because of different
government agencies and their assessments of the family's financial position); however planning for

a future where the parents no longer own the property was significantly more complex. As this arrangement was designed to be a 'home for life' for their child, the brief placed high importance on legal arrangements that protected the child's security of tenure. Legal consultation was employed to review how the family might manage the transfer of ownership to a child who would not be considered capable of administering the estate in the eyes of the law. Further consideration was given to how one of the dwellings might also be sold to help fund the child's care (if required), and allowing for this possibility added greater complexity. These investigations brought to the fore ever present issues of vulnerability regarding who might be trusted to always act in the child's best interest as well as help realise their aspirations for future independent living.

The issue of ownership also drew in questions of support. With this being a new model, there was no guarantee as to what level of physical separation was required between the dwellings in order for government agencies to consider the child to be living truly 'independently'. This is an example of one of the dilemmas of the strive for independence in a 'needs based assessment' system where while a child is being adequately cared for in the family home they are assessed as not in need, regardless of the fact that there is an impending greater need ahead for the family. In such instances families may find it necessary (particularly to avoid the crisis placement scenario) to proceed with creating the situation that may generate greater need and hope that their re-assessment is able to adequately assist.

Another financial component of the model, and its ultimate feasibility, related to the physical location of the duplex. The family was willing to sell their current home and re-build another to suit the new arrangements; however the ability to locate the new home in proximity to current informal (and formal) support networks was identified as key to its success. As such, cost and availability of land in the area required that a financial analysis be undertaken to weigh up the greater expenditure on a home in the right location as opposed to a cheaper location, which may have less upfront cost yet significantly greater ongoing costs associated with the need to substitute informal care with paid support.

The preceding discussion has highlighted the difficulty in avoiding addressing the issue of care in relation to the provision of person-centred private housing for individuals and families with disability. As a driving principle, the collective worked to, first and foremost, design a housing solution that helped achieve the family's goals and aspirations. In many ways the separation of these two areas was facilitated by the fact that there was little precedent available to predict how the organisations that fund and manage service and support might react to such a model. In addition, as mentioned earlier, there were no guarantees that the new arrangement would be considered truly 'independent' and that the family would receive the assistance needed to properly realise this new future.

The one perceived advantage of this new living arrangement however was that while the parents may still be forced to provide care until such time as a crisis is reached, the hope is that when that time does come, the child may not have to deal with the double trauma of losing their parent/s as well as being removed from their home. Again, this process involved designing with a number of

possible futures in mind, and trying to predict large portions of the equation that remained outside of the control of the family and the collective.

Implementation impediments and difficulties

Unfortunately after a concerted effort by all involved including external financial, planning and philanthropic organisations the community organisation was unable to produce an integrated package that would enable the private housing duplex model to be realised.

A significant factor in the case organisation's decision to discontinue with the model was lack of funding. In order for the case study organisation to continue to develop the model, given the often slow and complex work of trying to draw together the design, financial, legal and even support considerations (even though they are intentionally not tied together, they still remain relevant to each other), continuing resources were required. In the words of one representative, "we've done so much to this point, we needed funding to continue and there was just none around, everything was very, very tight".

In one interview where the case study representative reflected on the history of the project, the majority of the discussion centred around the issue of resources. As mentioned earlier, the social enterprise venture was created by the organisation in an attempt to generate an independent source of revenue ("alternative models outside of grant funding") and create some self-sufficiency, with any profits generated from the social enterprise re-invested in the not-for-profit arm. This desire came as a result of perceived "fiscal pressures" from both the government and philanthropic sectors and increasing competition for grant funding where "the dollars just are not there".

Although situated within the 'third sector', the organisation understands itself to be operating in an increasingly competitive environment, and that at the end of the day it keeps "coming back to economics". The creation of the social enterprise building arm brought increased pressures to the organisation from the private sector, as they were positioned alongside other builders and developers keenly seeking work in a post global financial crisis (GFC) setting. Operating within the private sector, the organisation felt "we're not competitive, we're too small" and referenced their vulnerability a number of times. This position was re-iterated also towards its position within the not-for-profit sector where the perception was that size was similarly important to government, who were seen as increasingly wanting to outsource their business and to "move all of that out to the big providers".

This continued focus on economic and business modelling also carries inherent in it the potential to create tension between, an organisations ideological goals of providing high quality, affordable, accessible housing (and support services), and their ability to deliver within a climate of scarcer resources. Questions also arose as to how a holistic approach such as this might be supported, with the organisation receiving "recognition from the government that the project was a good idea, but we don't know where it fits. Does it fit under housing? Does it fit under disabilities"? This problem of 'silos', while identified as being an issue within other sectors, is obvious here within the

government sector. One example given was of a recently disabled individual who was unable to return to their current home, and as a result cost the government "$1,000 a day to sit in a bed at the P.A. (Princess Alexandria Hospital)" where that money could be invested in finding or creating appropriate housing but is not able to be utilised for that purpose as it is seen as a 'housing' rather than 'health' problem.

Ultimately, access to resources proved to be the major barrier for all of the collective participants, including the families. In order for the case study family to confidently plan for their own and their family's future and weigh up what their best options are (i.e. spend more on housing in order to save on care or vice versa) they need access to information to be able to respond to such questions as:

- will this new model constitute 'independent living' as defined by the relevant agencies for their child?;
- will additional care funding be provided to help fill the gap between what they are currently receiving and what they will need as they are less able to care?;
- by undertaking this are they able to guarantee a home-for-life for their child? And what legal structures are available to protect this home and life for their child after they pass away?; and
- given that they are already of retirement age, what are the funding avenues available that would help them manage the difference between the value of their current home and the cost of purpose building the new co-located dwellings in the local area?

In the words of a representative of the organisation:

It's very one sided saying that every person has the right to choose but if they don't know what to choose then their decision, you can't make a decision if you don't know what to decide on, there's no communication, there's no education.

In an interview relating to their current position, the first case family were feeling "increasingly despondent" about their options and are seriously considering the existing options available to them (such as group homes and institutions) regardless of the fact that they know such environments and their associated stressors are likely to negatively impact on their child's social, emotional, psychological and even physical health. After dedicating their lives to providing a loving, caring and safe home the thought of their child being abruptly placed in an institution is "scary".

6   Personal Agency and Housing: Attempts to implement person centred approaches <u>by</u> people with disability and their families

The previous section presented examples of approaches by three different types of organisations to improve access to private housing <u>on behalf of</u> people with disability. In contrast, this section presents examples of approaches implemented <u>by</u> people with disability or their families. The first example involves an approach instigated by a mother with support from two other mothers all of whom have adult sons with different forms of impairment. The inclusion of this as a fourth case study is important to this study for several reasons. As the study will show, the case represents a response implemented by the family itself, not by an organisation on behalf of the family (and/or the person with disability). With reference to the ecological framework underpinning this study as a whole, the case is positioned at the heart of the ecology, that is, with the person and the people themselves. Specifically, it connects us intimately with what it means and takes to have personal agency; for one person to address not only the social barriers impacting on the issue of access and housing but also their own and their child's personal barriers and, in doing so, effect significant and enduring change.

Other personal stories are then presented which together with the case study fundamentally challenge assumptions and conceptions of private housing held by both the previous case participants and the researchers. These stories emphasise the more profound role of housing and home in personal growth and the exercise of choice and equal opportunities for participation in society by people with disability.

6.1   Case Study D – An individual approach in addressing social and individual personal barriers to housing of choice

Context

As indicated, this case describes a response to housing need instigated by a mother for her adult son with profound intellectual disability. Underpinning this is the mother's desire to safeguard her son while also enabling him and others with disability irrespective of severity to be included more in community and everyday life.

Central in this case story is a young man who is in his late 20's who we will call Robert*. Robert has a genetic condition that since birth has had a profound impact on him intellectually and to some extent physically. In his mother's words:

> He has never learnt to wave goodbye. He's never learnt to point. You know really basic things and he's never learnt to babble, so he's got no spoken language and I'd say he's got very little receptive language. He's completely dependent on people for every single thing in his life.

Apart for short periods of time when he was in respite or foster care, Robert has lived at home with his mother, father, and three brothers. Following the death of his father and his brothers moving away from home, his mother (Cathy*) has been his primary carer.

A person-centred approach in exercising the right to live in housing and community of choice: the central role of personal agency

Conscious of the need to consider a future where she could no longer be Robert's primary carer, Cathy began investigating ways that Robert could also have a home of his own. In this regard, she "pretty much was always stuck on an intentional community model". As Cathy elaborates:

> I never wanted him to be in congregate care, I never wanted him to live in a group house because he is really vulnerable. He's had the most horrible things happen to him when he's been with others, well staff who don't know him, and other people with a disability. And one of the best things about him moving into his own home, I thought, he never has to go to respite again. He never has to do that again, he will be safe, and he is safe too. Anyway, so I probably started the very, very hard work about the intentional community in about 2004.

Informing Cathy's work in relation to the intentional community was her research of existing intentional community models. In the early days, one of the most inspirational for her was the Rougemount Co-operative in Pickering, Canada established by the Deoaheko Support Network, a group of families with adult children with a developmental disability. Taking advantage of a federal and local government cost sharing arrangement, a 6-storey, 105-unit housing co-operative ensued, providing housing for a diverse group of people including the seven adult children of the support network.

At the heart of the model is the idea of a family governed approach "to building strong community" where people intentionally seek out ways to work together to be good neighbours for one another and for everyone, including the adult children with disability, that they "might live good, full, and contributing lives". As they emphatically state:

> …for our sons and daughters, and for ourselves, Rougemount is not a residential option. It is home. It is where people are hosts in their own home, co-operative members with rights and responsibilities, and good neighbours to one another. There is no support service within the building, and no office for the Deoaheko Support Network. Supporters work directly with people in their homes…We are not a service model, not an agency. Board members are family members. Paid supporters work for each family separately. Each person's life is very unique and is supported as an individual.

Also significant is how Rougemount can influence the wider community. In addition to supporting their own children, the Network families are conscious of:

> supporting, modelling and building a lifestyle in our community which touches a least a few hundred people – family, friends old and new, neighbours, co-workers, fellow volunteers, the artists and musicians with whom they share a passion, shopkeepers

and merchants, librarians and teachers, and many more – in ways that people say make a profound and positive difference in their own lives.

Implementation impediments and difficulties

Not having the resources to fund an intentional community privately and inspired by Rougemount which, as previously mentioned, was government funded, Cathy began lobbying senior government disability and housing bureaucrats that the intentional community model was worth pursuing as a public housing option. At the same time, Cathy also spearheaded the formation of a family governance group, comprising herself and two other mothers with adult children with disability. In 2006 the group set about actively working towards the implementation of the model for their sons.

After several frustrating years and many visits to various government ministers, the government eventually provided land and in 2010 agreed to fund the construction of a 25 dwelling public housing estate with 11 of the 25 units earmarked for the intentional community and 3 of the 11 units for the sons of the family governed group. Years earlier this would not have been an option for Robert, unless he was abandoned, homeless and on the crisis list. While later policies opened up the potential for Robert to secure public housing this is likely to have been unsuitable given his high support needs and his mother's vision for him to live in a supportive community close to his family and network of support.

While Cathy's original vision for the development was to be in a natural setting with units located around communal areas and facilities, she reluctantly accepted the argument that this was a public housing development demanding the most cost efficient design and use of the site for the building units. What she was adamant about however was that Robert's unit should have three bedrooms, one for him, one for his co-resident, and one for support staff when they relieve the co-resident. Co-residency is central to Cathy's vision of Robert receiving the extent and quality of support he needs and deserves. With the co-residency model, the co-resident is paid a salary as well as living rent-free. When the co-resident has time off, support workers provide the required 24hr care. As Cathy explains: "the co-residency position is a position like any other job in that you get a salary, you get a duty statement, you have conditions of service [such as forging new relationships for Robert]…he is a permanent full time employee".

To fund the required support, Robert receives an individualised funding package. The package is family governed and supported by a host NGO agency that employs the network's coordinator and takes care of the fiscal, administrative and legal processes. The host agency also employs Robert's courier van driver, with his wages coming from the earnings of the business.

In early 2012, construction began and in May 2013 Robert moved into his new home. As it turned out, Robert was offered a four-bedroom two-storey universally designed unit. Because Cathy remained actively involved in the project throughout, she was able to make suggestions and recommendations, many of which were accepted by the department. For example, she asked that one of the upstairs bedrooms be turned into a sitting area and office for the co-resident and support

workers. She was insistent that downstairs accommodating one of the bedrooms, bathroom, laundry, kitchen, dining and lounge areas adjoining the garage and outdoor courtyards was Robert's home and she did not want an office in his home for support workers. She also asked for added acoustic insulation in Robert's bedroom to minimise external noise but also help absorb growling sounds that Robert sometimes makes.

For the intentional community component of the public housing estate, Cathy argued that as for Rougemount residents would need to apply to live there and satisfy certain criteria such as excellent tenancy record, no history of alcohol abuse, and so on. Surprisingly for some people, the relevant department accepted her proposal undertaking information sessions and implementing a selection process that also required applicants to outline how they could contribute to the community and why they would like to live there.

The resultant community is diverse with young families, singles and married couples and people of different ages and ethnicity. In the course of six months the community has hosted concerts and barbeques. As Cathy comments: "The fact that all the people in the intentional community know each other and greet each other and talk to each other and go to each other's houses and borrow herbs from each other and plants you know that is, as I imagined. It's really good". And for Robert, "the number of people in his life has definitely expanded".

Despite the early signs that things are working well, Cathy acknowledges the crucial role she plays in keeping all parts working together, the family governance group, the intentional community, the host agency, disability housing around the needs and aspirations she has for her son. As she says: "none are enough on their own". To further safeguard then and for Cathy to be able to reclaim some of her life, she is now working to establish a micro board of five people governed by a constitution where members undertake to uphold her values and philosophy in the shared support of Robert as a unique and productive individual.

While this case reveals how people closest to those with disability can effect significant change, including at the policy level, it does not attribute this to personal agency alone, nor does it assume that everyone in a similar position has or should have the required capacity/capability. Rather, it highlights factors that contribute to personal agency and potential roles for the government and/or other organisations in relation to person-centred approaches and planning. In addition, it suggests the need for further exploration of how, even close family members, interpret aspirations, not just needs, for those with severe disability and how these can be understood as the son or daughter ages. With its focus on social housing, the case also challenges stereotypical views of social housing as standardised and inflexible, and invites further consideration of how continuing ontological vulnerability can be addressed through more secure tenancy arrangements.

6.2   Other personal experiences

The personal experiences of housing presented in this section are those of people with disability speaking for themselves, a parent or both parents together, and, in two cases in separate discussions a parent and their adult child with disability. There is also the voice of an advocate speaking from their experience of working with people with intellectual disabilities.

While the following sections will reveal similar and shared experiences for both family members and individuals with disability, there are instances where different issues are raised or, indeed, where there are differences of opinion.

In terms of the type of housing central to these experiences, this ranges from an adult child who still lives at home with her parents but where there is the desire to find a separate house or unit of her own in the private market; to adult children who have moved into private homes, rental, public housing, or supported accommodation.

The issues raised by the participants are grouped under three main categories constituting the following sub-sections:
- individual/family resources and characteristics;
- the interface between the individual/family, organisations, and services;
- experience and characteristics of housing.

Individual/family resources and characteristics

Roles and responsibility issues

The interviews with parents revealed a variety of issues to do with their son or daughter and the family as a whole in relation to housing. For several there was the tension between their desire to safeguard their child and the potential to enhance their child's life by facilitating and supporting their move out of home into a place of their own – and, in doing so, accepting greater risk. For the children this offered them the dignity of risk available to others without disability:

> Instead of enhancing his life, they would be trying to keep him safe, and wouldn't take the chance of him going out because he might get hurt, because they might have all this, they could be sued and whatever but we all take chances…. People have got to have a life, not just be locked up and safe haven't they?

In other cases, exploring other housing opportunities for their child was prompted by realisation of the emotional impact of caring for their child with disability and their responsibilities to other siblings as well as to each other. Conversely several participants with disability talked about how their own desires regarding housing choice were mitigated by an appreciation of their parents' needs and desires.

Resources and personal characteristics

A significant factor in considering housing options was the financial resources available to the family or individual to access their housing of choice. Integral to this was the type of care support needed and its associated cost and/or availability. All of the participants were fully or partially dependent on government support, with the majority accessing block funding allocated to various service providers and several undertaking self-directed funding. For several, this restricted their choice of housing because of direct relationships between community housing provision and community service provision; a situation also exacerbated by the family or individual's capacity or confidence in negotiating and managing individualised packages.

In some cases the cost of care support could be offset through informal care but this depended on the family or individual and the nature and extent of their social/community network. Many of the participants also noted a lack of awareness of the options or entitlement available to them for either or both care support and housing assistance. Connected with this was their capacity and capability to access information.

The participants also drew attention to the relationship between housing options and specific individual needs both physical and psychosocial. In some cases there was disparity between parents understanding of their child's needs and those expressed by the child themselves:

> My parents are very happy about this being an option for me because they feel it makes them feel secure about my safety and about there being somebody here at all hours of the day and night so to them, their concerns about me living independently have been allayed. I think it also matches a pattern they had chosen for themselves where for a long time now, they've had a plan to go into Independent Living and then whatever the next level of care is and then they would finally be able to go to a dementia unit or a palliative care unit on the same campus so that if one is well, and the other is declining they can still visit easily. So they've selected that kind of trajectory for themselves and I think based on that, they can't see why, I wouldn't be satisfied but given the freedom that I had in the rest of my life [in my unit where it is located], I'm finding it very confining and very restricting.

There was also a tendency for parents to focus firstly on meeting basic physical needs while their children were more aspirational in their responses.

While participants' stories revealed specific personal qualities central to their agency, for example, unconditional love, initiative, perseverance and courage, they also revealed emotional resistance and reluctance in moving to their own place or in supporting their child in the move away from home:

> ...well it was within our area here so it was close, but it was on a busy street, and really I mean it was very soon after we decided and I think we were probably just not quite psychologically ready to make a move either really.

Several stories highlight surprise on the part of parents in what their children were able to achieve in their own place having underestimated their potential for growth and independence:

[my daughter] is extremely happy there and she has really surprised us in some of the things that she's learnt how to do. I suppose when you've got kids at home and one of them is not as fast as doing things as the others you often find it's easier just to do it for them.

She was probably much more timid about saying you know what needs to be done and how to do it whereas now she's probably more assertive in saying what she needs.

He's got a really good life, but in saying that, he struggles everyday with his behaviour... but the difference in him is just phenomenal ...

Turning points and catalysts

Parents and individuals alike talked of certain stages in their lives that were the catalyst to changes in relation to housing or investigating alternative housing options. For parents looking after their child with disability from birth, retirement represented a major turning point when they were suddenly faced with the realisation that they were ageing and may not be able to continue to provide a home for life for their child. These participants also pointed to other times in life that prompted consideration of and decisions about housing, such as:

- the individual turning 18 and being eligible for different forms of government support including housing, care and/or various opportunities for employment. It is only in regard to relatively recent policy changes however that children being cared for at home have been eligible for public or social housing and have not had to be 'abandoned' to be eligible;

- greater exposure to examples of individuals with severe disabilities living independently in the community:

    I went to this place and it totally blew me away because I saw this person with pretty severe disability, intellectual disability, that was living in her own house, going back to her parent's place but living in her own unit and it, that was the start of when I really started to think well, there was a dream there in the back of my mind but I never thought it would happen.

- care support and services – ageing parents noted how the absence of support when their child was young contributed to their decisions to keep their child at home and how increasing support and services had provided more opportunities for living a more inclusive life;

- changes in the disability and associated health of individuals with disability prompting transition to more appropriately designed and located housing or to less independent forms of housing such as shared or congregate care housing. For the following participant the move from her own unit to supported accommodation in a large residential complex for people with disability was prompted by a lack of government funding to support additional care required due to her deteriorating condition:

    I was taken aback because I wasn't picturing that I would need that big a leap in care, I was simply really asking for an extra couple of hours. I was very happy living

> in my own home, happy living in the location where it was... good access to community, good access to public transport, good access to the things that I like... the Arts, movies that kind of thing, restaurants, library and good access via public transport to the city and the Arts precinct and my work. It's important to me to still work part time when I can so yes I was offered [this residential accommodation] and after getting over the shock I was under a little bit of pressure...

> Disability Services themselves assessed me for substantially more hours per day but they did not have the hours to offer. They rarely give people the funding packages now to go off and find their own services.

With the move has come a loss of empowerment and a less than normative environment and life:

> I like a sense that it's mine, it really is mine. I think that's the main thing and then it comes down to location. It doesn't matter whether it's private or public, or shared or rented or what, I do like the idea of having an anchor that can't be taken away from you at somebody else's behest or selling their property, terminate leases that kind of thing. I do like the idea of being self-directed that way.

> It's an unusual clustering of people of very high needs, both physically and intellectually, very demanding personalities. So it's an atypical cluster and so that brings out the best and more often the worst of everything so that bad traits get highlighted.

- the death of a primary carer impacting on the ability of the remaining spouse to provide adequate care;
- strain on the family;
- the emergence of other housing options and greater access to information on these such as the case with intentional communities;
- the desire of the individual to have a more independent and normative lifestyle:

> Well I guess soon after [my daughter] finished school, she started talking about you know, wanting to live in her own place and I suppose that we were also thinking well, you know, what's going to happen in the future when we're not around, and that her moving into her own place would be a step in the right direction from her point of view, and from ours so we just really started looking at different options.

including participation in the community:

> ...I'm keen to connect with my suburb to be part of a community so location of housing must not contribute to segregating people with disability.

> We tried very hard when she moved into meet the neighbours and for her to meet the neighbours and she does know them all and quite a few along the street as well.

and to be treated like others:

> ...think it's just him being treated like as normal as possible and having choices in his life and I really, I'm a big believer, I don't care who it is, if people respect you, you feel so much better about yourself and we all want to be respected don't we?

- the introduction of new policies or legislation (most recently the NDIS) that for the participants offers greater hope of appropriate individualised funding and agency in choosing where and with whom they lives. Other policy changes mentioned include: those to do with access in public spaces increasing the mobility of people with disability and their access to employment, education and social activities; as well as social housing and the provision of a percentage of universally design units within mainstream suburbs and communities. Although these changes were acknowledged favourably, there was also criticism of these not being sufficiently extensive; and

- integrated housing and care - this had contrasting responses such as decisions to use it because it was affordable and there appeared to be no other options; or to decisions to avoid it because of its congregated care approach and greater risk regarding personal safety and appropriate care:

  > You have no rights if you're in a group home.

  > I never wanted him to be in congregate care, I never wanted him to live in a group house because he's .... really vulnerable, he's had the most horrible things happen to him when he's been with other, well staff who don't know him, and other people with a disability, and one of the best things about him moving out into his own home, I thought, he never has to go to respite again.

The interface between the individual/family, organisations, and services

Government and support services

Many of the participants were critical of the government in terms of providing helpful information about options in relation to support services and housing and pointed to the distributed support approach as adding to the time and effort needed to locate, secure and coordinate appropriate services for a range of needs including housing. Several highlighted extensive and confusing paperwork and bureaucracy as complicating and compromising relationships with government departments. They noted instances of limited services and options available from the department and situations of receiving inadequate support or less than the assessed entitlement for care because the department was unable to afford to provide them with their full entitlement of care. In one instance highlighted previously this meant that an individual could not remain in the unit she owned instead being forced to accept an offer by the department to move into a large community run residence with other people with disability. Long application processing times and limited appropriately designed and located social or community housing meant that individuals could wait for long periods or felt pressured into accepting inappropriate housing for fear of being moved to the end of the line.

The relationship between the participants and respective community service providers also varied extensively. Several participants cited the management fees charged by the not-for-profit organisations (NPO) as being a source of additional financial burden. With some community organisations, participants were able to negotiate reductions of the management cost by taking over the activity themselves in lieu. Other issues with service providers included:

- limited choice and quality in relation to service providers and the services they offered which were generally untailored to specific needs and aspirations;
- an emphasis on need and care and de-emphasis of issues to do with personal development and growth; and
- staff behaviour including sexual assault, other forms of inappropriate behaviour such as dishonesty, lack of respect, favouritism, unreliability, prioritisation favouring the service provider over the client, failure to include the parent in decision-making concerning their child particularly that concerned with risk management.

Planning and access to housing experiences and challenges

In relation to housing access and associated planning participants mentioned, to varying degrees, disempowerment, discouragement and frustration. In addition to the availability of appropriate or adaptable stock and the provision of greater choice in both the private and social markets, legal issues to do with tenancy options were identified as being particularly restrictive and confusing. Added to this, there was very little, if any, assistance in understanding the relationship between housing and funding for other needs, and for some participants minimal if any attempts to allow their individual voice to be heard and for them to have greater autonomy in planning. Fundamental to the issue of planning is the decision to plan and undertake this as early as possible:

> ...we went to a few seminars and things early on before [our daughter] moved out and met some parents who were 75 and 80 with their child still at home, and worrying about what is going to happen when they fall off their perches, so we made a very conscious decision that we didn't want to be like that, that we had to do something at a stage where you are going to be around for a long time to make sure it works properly.

While access to relevant information is an important aspect of planning the qualities of those involved are also important including the preparedness to envision and imagine:

> It surprises me that people are so unimaginative about people's lives in general, you know, I know people get really tired, I mean, the thing is, anything you do is a lot of work, anything you do or if you have someone with a disability. I'm just talking about disability in particular, so everything I've done has been heaps of work and lots of thinking, but, when you've done the work, if you do the planning well, and you do the work well, I just maintain it, it just runs itself...

Experience and characteristics of housing

Housing

For all participants housing was understood as central to creating a 'normal' life. Integral to this was the ability to live on one's own in a house or unit catering for individual physical, psychosocial and existential needs currently and as they may change as the individual and their situation changes, for example, their condition deteriorates; they form a partnership, and so on:

> Really enjoy the space and opportunity to just have my own privacy.

> ...and we've given him the choice of .... what colours he wanted [to paint the house] and that sort of thing, and I think that's important you know so if you get the person who is going to live there to have a say...

> The builder built the entry path up to the level of the front door instead of having a step at the front door... unfortunately it was too late to pour the patio level up because they hadn't poured it as part of the original slab, so we had to retrospectively put a ramp in to get from inside to outside but I styled it so it was across the width of the open door so it just looked like.... the floor flowed through between one to the other. Progressively over the years as my abilities changed we had to change the ensuite, it's one of the new step free bathroom designs. We took out the shower enclosure that has a swing door on it but luckily it didn't have a very heavy bottom track so that just sawed off, sawed out and we just left the door off so there was just a single pane of glass there and that still works just fine and in the end I had to put a couple of rails in so instead of towel rails I've actually got grab rails so they also serve the purposes being towel rails...and very few other modifications. And in that time I've gone from walking very carefully through crutches and then walkers and then a small mobility scooter and a full wheelchair so it's seen me through all those transitions.

Private ownership aside, of fundamental importance was the provision of security of tenure in a general community location with appropriate access to services to support or cater for their health, care, social, work or education needs. While some sought the added security of ownership generally relying on their parents for the purchase of the unit or for loans to borrow in their own name, for others this was not an option making them dependent on social or community housing and at risk of compromising their safety and security, identity and privacy by having to share with others in a supported accommodation situation, or being in a vulnerable tenancy arrangement:

> I still have some, we all do, some fear I suppose that somebody might come along and say, what is this? You know, what is this? We need to stick two more people with disabilities here and two more here and two more here...

> I want my house to be safeguarded from any government trying to take it away, or turn it into a group home that deprives my rights.

> ...so he's a very, very lucky man, you know, because he's got this house... hopefully he'll keep it. I don't know with governments anymore how they're going to react to things...

Participants stressed the importance of being integrated with, rather than segregated from, the everyday community enabling them to engage with their neighbours and the local community.

For the participants, the appearance and use of the house as a home was understood to be potentially compromised by their need for support provided by visiting support workers or live-in support workers or co-residents. In this respect, they sought to hide or disguise elements not generally associated with 'normative' living:

> and I guess, you know like the importance in the housing is the, you can control the security without making a big deal of it, having things that look the least intrusive but are there to safeguard that person but not making it like it's a big deal...like [his] house just looks like a normal house, heaps of pictures around his bed but the security is there and everyone knows it.

> I think there's one thing I would hate to see is it looks like an institution. For me it's very important to look like a family home. Not have too many signs round about, do this, do that, you know, I think the more it looks like a family home, or a home of a person [the better]...

7 Implementing person-centred approaches to private housing for people with disability: Impediments, difficulties, and opportunities

This section presents a cross-case review of approaches adopted by the case organisations in attempting to facilitate greater access to private housing for people with disability. The discussion emphasises the impediments and difficulties both as they understood them as well as how this project views them when considered in a broader ecological context. The additional inclusion of a case involving a family and their adult child with a disability reflects this ecological consideration complementing the organisational focus and enabling a distinction to be made between approaches undertaken *on behalf of* people with disability and those undertaken *by* people with disability and/or their family. This individual and more personal representation is extended and enriched further through the inclusion of other families and individuals and their experiences of housing, providing the opportunity also to distinguish between parent experiences of disability and housing, and their adult child's experiences of disability and housing.

7.1 Impediments and difficulties as understood by the project participants

Each case organisation involved in this project has implemented approaches that have experienced various impediments and difficulties and have not been realised, or have not yet been realised. Notwithstanding experiencing impediments and difficulties, the personal story of the mother in Case D represent a personal success albeit not in relation to private housing but rather social housing and how it might afford the advantages normally associated with private housing. In all cases, the approaches were a response to what the organisations or individuals understood as problematic regarding access to [private] housing for people with disability.

Access and [private] housing as understood by the case participants

For the Community Finance Organisation (Case A), the lack of financial capital and the ability for individuals (and community organisations) to compete in the private market was viewed as one of the major barriers for people with disability in accessing appropriate housing and a 'normal' life in society; a situation understood to be exacerbated by various social factors including unemployment or low employment as well as the lack of accessible housing. For the foundation organisation (Case B), motivated by the goal to promote and help realise the potential of young people with acquired brain injury and complex needs as valued members of society, lack of an integrated approach around the individual and their health and care needs, and affordable and appropriate housing in the general community was seen as a major issue. The issue of appropriate housing for individuals with disability wanting to or in need of moving out of the family home to a more independent life constituted the focus for the a Not-for-Profit community organisation (Case C). The main concern for this organisation was the provision of housing designed and located to address both the transitional needs of individuals and families as well as specific individual social, emotional and physical and functional needs and aspirations of the person with disability.

Of the three cases, the community organisation can be seen as having the most direct and individualised relationship with people with disability and their families. Here the initiative was that of the community organisation rather than that of the family or the person with disability, as in the individual case (Case D), involving a case of a mother and son exploring for themselves and others opportunities for the person with disability to have a more independent, inclusive and productive life despite profound disability. In this case, the main impediments are understood as that of personal agency (for the mother) and community perceived personal agency (for the son), together with a lack of affordable and appropriate housing.

This issue of personal and perceived agency, including capability as well as capacity of both family members and individuals with disability, emerges vividly through the stories of other individuals included in our project. As highlighted in these stories and those of the case organisations, there are many external situations and structural elements that make it impossible or difficult for people with disability to access housing of choice. These have been found to encompass those of an economic and social nature, those to do with information, communication and facilitation, and issues that are environmental such as the physical characteristics of housing. Added to this are issues that are more individual and personal, for example, individual/ family resources, characteristics and history, personal attributes and values, that impact on many things including consideration of the need to plan, how to plan and what to plan for.

What is shared across the cases and individual stories however is a fundamental recognition of the central role of housing in locating people with disability in the wider community and if appropriately designed of offering the potential for personal independence, growth and wider attitudinal change. For the case organisations, impact and opportunity is understood to be most possible through private housing (as opposed to social and public housing and not including boarding houses, hostels, caravans, and shared accommodation). While private housing is normally defined as housing available in the private market for purchase or rental, the community finance organisation and the foundation organisation regard it also as including housing that is developed not through government funding but rather through private or social investment or philanthropic funding. So, for example, in the case of the community finance organisation, housing available for rent (possibly ownership) and provided through social investment and managed by a not-for-profit community organisations of the financial organisation itself is still considered as private housing. In contrast is the position of the community association, which regards private housing as exclusively that available in the private market and which is owned to be resided in or rented out. For this organisation, it is this form of housing that offers maximum choice and security (physically, emotionally, and financially not least through its provision for people with disabilities to have a housing career).

As pointed out, however, depending on personal circumstances there are families and individuals who just cannot afford to buy into or rent in the private market. In the financial community organisation and the foundation, this was approached by exploring how a subsidised form of 'private' housing might be possible. To date, such subsidisation has only been regarded as feasible

by adopting a service or congregate care approach involving clustering individual units together albeit located in the general community serviced if necessary by support workers accommodated in a separate but adjacent unit. What is not clear in these proposals is how much choice individual people have regarding support services and how suitable specific units would be for individuals. Given these issues and economic position there was no other option for the mother in the individual case study but to consider social housing and how this might be reconsidered to address specific needs and her vision for her son for a more personally secure and normative life. In this respect, the case also draws attention to the relationship between housing and tenancy and issues of choice, individual control and autonomy. In relation to housing, it is more about the type of tenancy associated with housing rather than the housing type per se.

The issue of tenure is also connected to something else that stands out in the community and individual case and that is how housing whether it be a unit or a house is regarded by the families and individuals in the project as having meaning beyond its physical characteristics and ability to cater for specific functional needs; how it is also a home with emotional, existential and symbolic meanings, not only in relation to it as a single entity but also extending beyond itself to the immediate community, its networks and amenity. As well as meaning for the occupants of the house or unit, the house or unit also says something to the community about the residents, for example, a typical looking house in a typical community encouraging a more normative view of the occupants.

Response to access and [private] housing issues by the case and individual participants

The responses by the case organisations reflect their organisational context, and from this position what they regard they can do to facilitate access to private housing for people with disability. For the community development finance organisation this involved developing models that sought to respond to individual and community sector capability and financial market failure in combination. In general, this was a brokering role involving in some cases mainstream financial institutions as well as social investors, government, and community associations representing specific groups of people with disability. As outlined, their response was in the form of several models ranging from one designed to facilitate access to privately owned housing through to the latest, a 'low-profit market approach' which uses a charitable trust to build or buy subsidised appropriately designed and located units within a mainstream housing complex that would be managed on behalf of the trust by a community organisation who would screen and select potential residents as well as provide service support accommodated in a separate unit in the complex. Problems with their first attempt in facilitating access to private housing they attribute to the mainstream financial market's preoccupation with maximum return and perceptions regarding risk in relation to the financial capacity of people with disability or their families' resistance. They also highlight difficulties coordinating all the parties and of the parties having the resources to address in a comprehensive and aligned way housing provision issues as well as the financial and legal issues associated with home ownership. These issues they have attempted to address through recognising a more central role for community organisations using social investment to implement a coordinated approach by the organisations to care and housing.

Although more understood in coordinated terms, the need for an aligned approach to better facilitate access to private housing for people with disability was also identified by the second foundation case organisation. For this research and advocacy organisation its main strategy is to model a successful approach supported by research and relevant information to produce appropriate and affordable housing for people with acquired brain disorders and complex behaviour. The model of housing proposed is similar to that previously described for the community finance organisation. Despite their appreciation of the need for a coordinated approach, initial attempts have failed due to the difficulty in undertaking this coordination. In particular, one difficulty was getting everything to come together at the appropriate time to inform the design of the units so that they were accessible and functional for this specific group of people with disability.

In the case of the third organisation we see an attempt to give priority to suitable housing design for adult children transitioning from their parent's home and an emerging appreciation of the need to also take account of other issues such as those of a financial and legal nature. Rather than consider the provision of multiple housing units as the other case organisations have, this approach focussed considerable resources on understanding, designing for and responding to the design needs and aspirations of an individual family in relation to their daughter with profound disability. While various structural issues were formidable barriers, in the end it was the organisation's inability to continue to fund their work in helping to develop a coordinated package for the family. Underpinning this (as noted by the community finance organisation) are systemic structural issues associated with new, emerging roles of community organisations and the lack of appropriate regulatory structures to enable them to resolve the operational and ideological tension of the coexistence not-for-profit community services and social enterprise ventures.

As highlighted previously, the approaches by the case organisations just described are ones developed *on behalf of* people with disability. By comparison, the story of an approach by mother for her son with severe intellectual disability is an example of approaches by people with disability and their families. Wanting him to live as normative a life as possible in the community, but also conscious of his vulnerability, as well as the family's financial situation, the mother undertook a family governed approach to building a strong community around her son living in a government provided unit designed to meet his specific needs of care, work and social interaction. Known as an intentional community, it comprises three units specifically designed for three individuals with disability, one of whom is the mother's son, located within a social housing community comprising eight units accommodating couples, families and individuals who have applied and been selected to live in a communally supportive way with the individuals with disability. This intentional community is itself located within a bigger social housing and mainstream housing community.

Faithful to her vision of this being a home for her son, the mother relentlessly advocated for the unit to have sufficient space to accommodate a co-resident paid through self-managed individualised funding to provide most of her son's 24hr care. Design wise it was also important for there to be an obvious separation between the co-resident's and relieving support workers' spaces and her son's with considerable effort given to making the unit look like any young man's unit. In achieving this, the mother experienced and overcame a multitude of impediments and difficulties at all levels

ranging from the broader social level and its values in relation to people with disability, through to the political and regulatory levels, across public and private housing and community service sectors, across time and changing governments and policies, down to the local community and its prejudices and views and ultimately to herself, her other sons, her son with disability and the family governance group and its values and intellectual and emotional capacity to develop a shared vision and implement it regardless of the barriers and impediments. For the mother, the main task now is to sustain the network and coordination needed to ensure now and when she no longer is able that all elements across all levels are aligned to the vision and that her son can continue to live in this home and because of this a "good, full and contributing life".

The stories of housing experience told by the individuals in the project reflect different stances when responding to their housing needs and aspirations. For some individuals, their parents are very proactive in securing or helping them secure private housing rental or ownership tenure. As well as financial support, they are also instrumental in helping sustain the occupancy through formal and informal support. Sometimes, however, individuals are forced out of a private housing situation into supported accommodation such as when their condition deteriorates requiring additional care that they can no longer afford, or when their parents can no longer provide the support, financial and/or physical. In these situations individuals with disability are largely dependent on what is available at that time through community organisations or social housing.

Summary of main points

Each organisation in this study has attempted to facilitate greater access to private housing for people with disability. Their approaches reflect specific understandings of the factors contributing to the barriers and difficulties experienced by people with disability. While the approaches adopted by the organisations have emphasised specific disabling factors, for example, *financial, environmental, and relational factors,* they also recognise that associated with these are various interconnected factors of a *social, political* nature. The fourth case involving a single parent and her son together with the other individual voices of the study shift the emphasis to individuals and their *personal* characteristics and qualities, and what they or their families are capable of in addressing housing needs and aspirations.

For all participants, their difficulties in some way can be attributed to various external and internal factors categorised as:
- financial (mainstream financial market's preoccupation with maximum return; lender processes of determining capacity and risk; low investor confidence in social investment; the individuals level of financial capital);
- regulatory (laws, regulations, policies impacting on organisations and their operation as well as individuals, their entitlements and rights);
- relational (inter-organisational coordination difficulties due to silo operation of various government departments; lack of an aligned approach involving individuals and relevant support organisations);

- temporal (the time it takes to develop and implement the models and associated resourcing implications; the need to synchronise with a range of agents);
- organisational (lack of capacity/capability; conflicting ideologies – for example, commercial versus non-profit);
- personal (capabilities/capacity of individuals/families – financial, intellectual, emotional); and
- environmental (the lack of affordable appropriate housing; the lack of appropriate information; rigid tenancy options).

7.2 Applying an ecological perspective

As previously described, an ecological perspective accepts that there is a dialectic relationship between the person and the environment and that a holistic appreciation of this interconnectedness is crucial when attempting to understand situations and effect change. For this project, it provides a framework to understand disability and housing and attempts to facilitate access to private housing in a mainstream context; first understanding what is normative and then what it requires from people and the environment to move towards achieving a normative outcome (Bronfenbrenner, 2000; Germain & Gitterman, 1995).

Implementing an ecological perspective recognises that:

- situations are explored using multiple understandings from individuals to groups operating in the various ecological systems regardless of their immediacy to the system. All systems are understood to have impact in some way with alignment across systems contributing to: a sense of belonging within a supportive informal network (relatedness); assumption by others of the person's capacity because of successful adaptation to the environment or environment to the person (competence); personal acknowledgement of one's capacity to adapt and to belong (self-esteem); the capacity to take control of one's life, to accept responsibility for one's decisions while respecting the rights and needs of others (self-direction);
- there is a temporal component; people, environments and their relationships are understood to change over time and time is integral in influencing person-environment fit and associated societal expectations and attitudes. Temporal concepts that can explain this further include: one's development through life from birth to death (life-course); individual interpretation of time; historical time (for example, generational difference regarding expectations of home ownership); and social time concerning the timing of personal, family and social events (for instance, the time when people normally leave home);
- there is a reciprocal relationship between the person and the environment. Interventions aimed at environmental change for instance will invariably impact personally and vice versa; and

- a person's characteristics, such as gender, level and type of disability, connectedness with others, and stage in life-course can shape the person's agency within the environment (Germain & Gitterman, 1995; Winkel, Saegert, & Evans, 2009).

Position in relation to the person with disability

As described, an ecological perspective acknowledges the interconnection of people and environment. It also acknowledges that individuals, those close to them and their personal situations, characteristics, attributes and aspirations are at the centre of effecting meaningful change. As conveyed in Figure 4.2, the case organisations are positioned at varying distances from the individuals with disability and while their approaches reveal a deep appreciation of the complexity of the situation and the need to understand and manage the multitude of external and internal factors impacting on access to private housing, and to do this in a person-centred way, our research shows that it is the position of the organisation in relation to the individual and broader systems that has compromised their approaches described in this project. It is also evident, as could be expected, that the more distant the organisation from the person, the greater the reliance on others to mediate the 'space' in between and to act on behalf of the person with disability or their family.

For the case organisations, not-for-profit community organisations are understood to be central because of their relationships with individuals and families through their service support roles; roles, which we propose, seriously impinge on their ability to see the person first rather than the disability, as well as the person first rather than housing.

Position within a specific ecological system

The focus of the community finance organisation on financial barriers to private housing aligns with the social model of disability and a concern for how socially created systems such as the economic system can be disabling for people with impairment, preventing them from realising normative expectations such as buying a house or renting privately if they so desire. The focus on financial capacity also explains why this organisation is reliant on the community groups that receive block and other funding from the government to provide care and other services to people with disability. With the foundation organisation we see a more direct attempt (because of the nature of the organisation and their position in the social ecology) to connect with the person and to appreciate how their specific impairment, in this case ABI, is responded to by society (for example, placement in residential care facilities) and, consequently, segregation from society and opportunities for a normative lifestyle. For the community organisation, their relationship particularly with aging parents has highlighted housing as a critical issue for their adult children in ensuring they continue to have their own home with the same security of tenure afforded by their parents privately owned housing. In the three cases just described, their responses on behalf of the individuals reflect emphases indicative of their organisation and its position within or spanning the macro, exo, meso and micro systems. In contrast is Case D a parent-led approach directed primarily by the families and their vision of a productive and meaningful life for their son and brothers.

System/value compatibility issues

While more apparent in the case of the foundation organisation, both the foundation organisation and the community finance organisation have attempted to reconcile a social model of disability with a medical/welfare model of disability; the latter reinforced through the involvement of service provider organisations and their service model approach to disability. The medical model of disability is based on the premise that an individual has an impairment, which prevents them from doing things for themselves and, as such, they are dependent on others for support. Such a view of disability goes hand in hand with the assumption as noted by Hemingway (2011) that the 'functional limitation' can be remedied through some intervention believed necessary for the transition of the individual to a more socially acceptable condition. For this project and its case organisations and participants, housing is regarded as one such intervention. In the case of the community financial organisation and the foundation organisation, however, this is informed by what Hemingway describes as "notions of supposed 'normality' where [despite the intentions of the organisations] people with disability are marked out as different from the norm" (p.52). This is inadvertently perpetuated through:

- the involvement in housing provision of organisations providing specialist services to people with disability, for example, community service providers; and
- the specialised approach to housing design, its financial subsidisation through welfare or mechanisms not normally available to the general community, the grouping of people with disability together albeit in separate units in a mainstream community or housing development; the grouping of such units around a designated care hub all of which distinguishes the house or unit and its occupants from other community residents reinforcing stereotypical views of disability and further perpetuating social exclusion.

The reality is that for many people with disability the current stock of private housing is unaffordable and inappropriately designed and located. And in this regard it is understandable that organisations involved with people with disability have attempted to address the situation as they have. With the third case organisation, the community association, we see a concerted effort to work with families on an individual basis to design and provide appropriately designed housing in locations with suitable infrastructure and connection to existing support networks. For this organisation, its lack of success is attributed to several factors including:

- an emphasis on housing design and location and a lack of attention to other related barriers such as those of a financial, legal, regulatory and personal agency nature;
- internal organisational issues to do with resourcing exacerbated by the need to extensively understand the needs and aspirations of the family as well as the individual with disability and to undertake its own research to develop appropriate knowledge to inform design;
- ideological and operational tension between the need to be commercially viable and its not-for-profit status;
- its inability to compete with the mainstream housing industry;
- the lack of appropriate regulatory and procedural systems and structures to support a new model of housing; and

- 'silo' responses from government/s hindering a holistic and coordinated approach to addressing issues of private housing access for people with disability.

Understanding of housing

For our project, the third case, involving the community organisation (Case C) was significant in its appreciation of housing as something more than a place of shelter and means of catering to specific physical and functional needs. As for all human beings it accepted that people with disability also have needs of belonging, esteem and self-actualisation (or rather that it should not be assumed regardless of the severity of the disability that this is not the case) and that one's home is a significant vehicle in responding to these needs. Unlike in the previous cases where an emphasis was more on apparent physical needs, in this case there was explicit recognition that like all people, people with disability "desire to flourish and not just survive" (Nelson & Stolterman, 2012, p. 110). In other words, they have aesthetic desires as well as functional, social and emotional needs.

Indeed, it could be argued that environments that provide for everything, or resist attempts to change them by the occupants themselves, are environments that provide little or no opportunity for creativity and growth. This was apparent in the stories of several of the individual participants recounting experiences of modifying, personalising and normalising their house or unit to better reflect who they are as a whole person, with some being particularly conscious of how spaces specially designed to cater for their disability put the disability first rather than the person, conspiring against attempts by the resident to make their place look 'normal' and fit in. Of course, there is another side to this and the potential risk as noted for the community finance organisation and the foundation organisation of putting the housing first and then trying to match the person and their disability to the house. As the community organisation and the individual case study emphasise, all people regardless of being diagnosed with the same disability, are unique and will grow and change in different ways over time. Housing needs and desires are not static and as such people with disability should be afforded the same opportunities as everyone else in determining their own housing pathway.

The notion of housing pathways or housing careers was explicitly addressed by the community organisation in the housing design for a family with an adult child and their desire (for their own as well as that of their child) to transition their child over a period of time to a more independent setting. The approach recognises that a personalised approach does not disregard the relationships that a person with disability has with significant others and of their needs and aspirations in facilitating the transition and the provision of an environment that would cater for changing care needs as well as future financial security through private ownership. Private ownership was also understood in this situation to provide maximum flexibility as well as control and ontological security.

Such an understanding however was challenged in our fourth individual case concerning social housing. Here, driven somewhat by financial constraints, there was a concerted attempt to explore the potential of the social housing system to be more flexible and responsive to the ontological

needs and aspirations, as they understood them for their adult children with severe disability. What this suggested for us was the need to give greater consideration to the issue of security of tenure (and tenure of choice), and as well as this, the possibility of there being more opportunities through government provided housing, than with private housing, particularly when the housing is not viewed in isolation but rather as integrally connected to community and its reciprocal role with housing in the creation of 'place'. While, to an extent, this was a consideration by the financial and foundation case organisations, for these cases the attempts were organisationally rather than individually led, compromising as we have seen genuine attempts to integrate people with disability in the wider community.

Unlike the organisations, the fourth case individual was also able to transgress the various system and sub-system boundaries in a more 'mainstream' way and coordinate them to better align with her vision for her son and of a more inclusive society. Unlike the organisations, she was also able to reconcile the tension between social and individual/medical conceptions of disability, implicitly conceptualising the situation ecologically or perhaps as described by (Thomas, 2004) 'biopsychosocially'. At the heart of this was a process of person-centred planning and of building a cohesive network of relationships and community that could be sustained over time. The notion of community expressed here is a heterogeneous one, one where inclusion is not about conformity and people with disability 'fitting in' and being tolerated but one where difference is celebrated and regarded as normative for productive and enriched lives, where all people can interact with each other and their environment in fluid and flexible ways. Significant in this is the provision of accessible and adaptable mainstream private and social housing and the alignment of support services rather than attempts to integrate or coordinate.

7.3   Impediments, difficulties – and opportunities: an ecological perspective

From an ecological perspective then, the impediments and difficulties experienced by the case organisations and individuals in attempting to implement person-centred approaches to private housing for people with disability are understood in relation to:

- **incompatibility of the relevant systems with purported values of person-centredness**
  Despite broad acceptance in policy of the need for person-centred approaches, the systems (financial, legal, service, health, and housing) are not set up to support person-centred approaches to housing for people with disability or their families. Disability-focused and welfare-focused systems appear in these cases to be restricting the emergence of more empowered approaches that allow for normative housing and living experiences. At the other end of the spectrum sit approaches that attempt to create opportunities within the broader competitive housing market, which face challenges from both sides – personal and family resources, and market pressures with lack of support and regulatory structures that protect the interests of not for profit (NFP) organisations and allow them to operate in this context. Despite the obvious importance of interactions between systems and institutions, the systems independently, and as a whole, are also seemingly unable to support or protect NFPs trying to coordinate approaches; nor do they support individuals with disabilities or

their families trying to determine their own vision and build appropriate capacity and capability;

- **failure to recognise issues as part of an interconnected ecology resulting in compartmentalisation of disability from the mainstream and discrete and segregating 'silo' responses**

  Further, despite broad acceptance of the interconnected nature of housing and aspects of life, albeit at a very basic level, and recognition of this in policy and government rhetoric to do with planning, the systems (again financial, legal, service and so on) are set up to operate only as silos. Where there has been some alignment, this has excluded housing. Where there are initiatives around housing, these have tended to separate housing from other aspects of life and living in a way that reduces it to mere physical space in which to exist (or co-exist) and receive support.

  The failure to recognise or respond to the 'mosaic' nature of challenges to private housing access is also a key challenge for organisations such as those represented in this project. Despite attempts to juggle multiple concerns, attempts invariably focus on one challenge at a time – stock, or money, or personal agency – rather than recognising that what challenges access is more of a mosaic of interlinked and even overlaid issues spanning the ecology. 'Solutions' in the form of models or approaches become piecemeal and ultimately are unable to respond to the issue in a fully acceptable way because they are trying to address what *they see* as the fundamental problem with access. In doing this they also tend to adopt a collective de-facto rather than individual personal approach where even person-centred approaches by the service organisations involved are designed to try to be as much as they can to as many people as possible and end up compromising and/or delivering more of the same.

  For the organisations involved in the project and those associated with them such as NPO service providers there is the challenge of bounded roles and philosophies. For organisations, particularly those closely involved with people with disability, there is a seeming inability to look past the 'disability space' in which they operate. However, given the current system this is possibly the only way they can operate. The policy and system itself has a 'mainstream space' and a 'disability space' that determines funding for anything these organisations might try to do. While the organisation might position themselves between the family or individual and the system, whether as a buffer, broker or conduit, in the end whatever they attempt to do ends up being shaped in much the same mould because that is all the system is capable of supporting;

- **lack of suitable housing stock and understanding of its fundamental role in society**

  As highlighted in the project, attempts to address the shortfall in appropriately designed and located housing has led to piecemeal, selective, even segregated, responses with very limited opportunity for people with disability. Irrespective of the type and level of disability, individuals with disability have an entitlement to choose their own place of residence and where and with whom they live on an equal basis, and for that housing to facilitate full inclusion, participation and contribution in family, work and community life. This suggests, then, that the issue of housing access and adaptability as well as community access be

understood as an issue for society as a whole, demanding a mainstream rather than disability-specific response in relation to the supply of new housing stock. At the very least this should entail that all new and extensively modified housing meet minimum visitability requirements with incentives for the housing industry to build Livable Housing Australia's Gold or Platinum level housing.

As the following section will highlight, it is only by adopting this ecological understanding of the impediments and difficulties, experienced by the case organisations and individual participants, that other arguably more sustainable opportunities become apparent. Responding to these opportunities does however have implications for broad systemic as well as personal change and agency.

8 Implications, Recommendations and Conclusions

8.1 Implications, policy challenges and recommendations

The project highlights the impediments and difficulties experienced by three different types of organisations attempting to address the shortfall in affordable and appropriate housing for people with disability. Despite a common goal of person-centred approaches for improving participation in the general community for people with disability through the provision of more accessible housing, attempts to do this (largely through the provision of specially designed rental properties) have been seriously compromised by their need to work with their existing community, social enterprise and service systems; systems that are not set up to effectively interconnect with or operate side-by-side with those involved in the provision of mainstream housing. While these alternative approaches may add to the existing stock, the findings of the project suggest that this will be minimal, exclusive, and will do little to provide greater options for people with varying levels and types of disability to choose where, how and with whom they wish to live. In fact, it may even perpetuate an 'us-and-them' mentality further alienating people with disability, albeit from within mainstream society. This leads us then to make the following overarching recommendation:

Address housing stock availability and suitability by adopting a mainstream approach rather than a disability-first/disability-specific approach

1. Housing first not disability first. Accessible, flexible, inclusive housing for all not just those with disability:
   - consideration of housing in relation to community and its physical infrastructure and design regarding access and services;
   - consideration also of community as systems of social networks including those of individuals;
   - housing design that adopts a whole of person, person/family first approach recognising how housing and communities are homes and places that inspire and support individual and family visions and aspirations for a good life and productive involvement as members of society – not just physical environments that support functional needs;
   - housing design that responds to changing needs and goals of individuals and families without major modification and cost;
   - housing design and tenancy options that recognise the various stages and situations of life and how housing options facilitate career pathways;
   - housing provision and tenancy options that blur the boundaries between social, community and private housing providing pathways across the housing sectors and opportunities for greater flexibility, choice and inclusion, as well as more heterogeneous appreciation of what is normative and mainstream; and

- social housing approaches that facilitate various tenancy/equity opportunities in relation to private housing for marginalised groups as well as social housing itself providing for greater security of tenure and/or ownership.

2. Housing at the beginning and the person as a whole at the centre:

   - housing that is given a separate focus for people with disability not secondary to or conflated with service support but rather aligned with it. This will challenge the silo approach adopted by government in responding to disability needs; and
   - housing planning that starts as early as possible not left until a crisis event occurs.

3. Housing that is affordable, achieved where possible through:

   - mainstream financial systems, communicating more effectively with people generally and using more flexible and individual procedures of risk assessment. Where this is not possible, alternative support may be provided through community financial systems working directly with people from a person-first rather than disability-first position to facilitate access to mainstream resources including housing;
   - housing affordability is also tied to other external systemic factors that require attention such as employment, financial entitlement and autonomy in decision-making about how the entitlement is used, and legal issues to do with ownership, all of which need to be considered first in relation to there being a diverse, heterogeneous society rather than those without disability and those with disability;
   - another factor affecting housing affordability is the additional cost of providing access features not normally provided in everyday housing. If such features were part of the expected norm and demonstrated to be achievable without any or substantial increase it is expected that such housing would not be appreciably more expensive than housing produced as it is currently; and
   - the lack of housing stock generally also contributes to affordability demanding attention by the housing industry and government to these wider issues of supply and demand.

4. Housing needs that are person and/or family driven:

   - from their vision for a meaningful life and where possible addressed through the person's or family's own agency – a person-centred approach that aligns fully with its inherent principles;
   - as in mainstream society, there is the assumption of competence with respect to the ability of people to be able to plan their life and the role of housing in this life. This is also the assumption of the disability sector but as our project reveals the ability of people with disability or their families to determine such a future varies for various systemic and personal reasons which may include a lack of belief in their own abilities, others' lack of belief in their rights and abilities, lack of access to relevant resources including knowledge and information;
   - as with the general population there is also a lack of explicit recognition of just how central and fundamental housing is to our lives from satisfying very basic needs of shelter through to enduring ones of belonging and self-actualisation; from housing being a house or unit through to it being a home; and
   - the issue then of empowerment, and of more fully capitalising on what housing affords, is a broader social issue as well as a more personal, individual issue. One might forecast

a specific role for the NDIS agency or an alternative intermediary government agency in ensuring that planning in relation to housing is given separate but aligned consideration with planning in relation to care/service support. There may also be a more acknowledged, government supported role for community organisations and family governance groups which are not service or housing providers and which can work directly and without conflict of interest with individuals in helping them develop capacity and agency.

Key challenges

Key policy challenges:

- addressing the failure of government systems to genuinely support the principles of person-centredness.

Key policy and organisational challenges:

- addressing failure to recognise the highly complex and interconnected nature of housing access and of the need for these reasons to look beyond the 'disability space' to the 'mainstream space' and to housing as a significant vehicle and catalyst for personal growth and social change.

Key policy and housing industry challenges:

- addressing failure to provide affordable, appropriate housing for people with disability within the mainstream marked.

Key personal challenges:

- addressing personal difficulties in informing, envisioning and planning where, how and with whom a person chooses to live, as a step in a housing career, which can change as the person changes over time.

Recommendations for Government

The report recommends that:

With regard to the provision of housing—

1. minimum visitability requirements for all new and extensively modified housing are included in the National Construction Code;
2. mainstream housing supported under the National Rental Affordability Scheme, or using other government subsidies, provides Livable Housing Australia's Gold Level of access as a minimum;
3. incentives for the housing industry to build, and buyers to demand, Livable Housing Australia's Gold or Platinum level housing;
4. planning legislation to support the development of inclusive residential communities, including a mix of affordable housing types close to accessible transport, work opportunities, services and community amenities;
5. to be considered as a priority issue within planning that is aligned and not conflated with other areas such as support services; and
6. support for planning that is holistic and inclusive of housing that incorporates mainstream options and services.

With regard to housing assistance—

1. greater flexibility in assistance packages to support people with disability in choosing where and with whom they live, to develop a housing career, and to change, and develop their housing situation over time or as their situation changes. While this may be housing provided through the disability sector it should not preclude mainstream housing. Indeed, it should facilitate movement between the disability and mainstream spaces providing individuals with greater choice;

2. considers other related needs such as assistance in obtaining work;

3. explores additional mechanisms for attaining sustainable home-ownership such as shared equity, home loan assistance, or incentives for family investment; and

4. people with disability, regardless of their access requirements and support needs, are given the same opportunities to live in social housing as other people.

With regard to home modifications—

1. the government establishes a national adequately funded home modification program to assist people with disability and their families to remain in mainstream housing. This would require:
   - the development of national standards addressing construction quality, safety and OHS issues for paid staff;
   - consideration of the needs of both current and prospective users; and
   - the tracking of extensively modified housing for future use.

With regard to information and awareness—

1. the government provides illustrated examples of people with disability living successfully in a variety of mainstream housing; and

2. the government makes available timely information on housing assistance for people with disability and their families to encourage and support envisioning and planning a housing career supporting community inclusion, secure tenure and wealth creation.

Recommendations for the housing industry

The report recommends that:

1. the housing industry emphasises the education and training of housing industry professionals with regard to the impact of good mainstream housing design on people's inclusion and participation in family and community life;

2. the housing industry supports education, training and incentive strategies of Livable Housing Australia, for all housing sectors; and

3. the housing industry supports the regulation of visitability requirements for all new and extensively modified housing in the National Construction Code for national consistency and efficiency.

Recommendations for individuals with disability

The report recommends that:

1. people with disability take opportunities to imagine beyond current specialist disability housing solutions including seeking out other people who have established their own home in the mainstream community;

2. people with disability envision, and plan for their own home as part of their plans goals for a good life, and these plans reflect normative housing careers, including aspirations of home ownership, security of tenure, and wealth creation; and

3. when mainstream housing design is required to change to meet particular needs, people with disability seek their incorporation without compromising their individual style and preferences.

Recommendations for families, support networks and advocates

The report recommends that:

1. families, support networks and advocates assist the person with disability to envision, plan, find and maintain their own home by:

   - assisting them to seek out other people who have established their own home in the mainstream community as examples of what is possible;

   - using mainstream housing assistance strategies, including shared equity, home loan assistance and incentives for family investment that are available to encourage people with disability into sustainable home-ownership;

   - assisting people with disability to direct their support, and coordinate their transport, leisure and work opportunities so that they are able to participate and contribute to family and broader community life;

   - recognise the dignity of risk associated with independent living; and

   - promote individual potential for growth beyond current capabilities in living independently.

Recommendations for community organisations

The report recommends that:

1. community organisations adopt a normative position regarding their support for people with disability and their families by:

   - placing the focus on the person before the disability;

   - ensuring policies and practice follow the CRPD articles, including supporting people with disability to choose where and with whom they live, and their active participation and inclusion in community life;

   - encouraging mainstream housing opportunities; and

   - facilitating their access to information and resources and demonstrations of best practice to people with disability and their families and support networks.

2. community organisations advocate for and promote community awareness of the benefits to society of visitable and inclusive housing.

Recommendations for future research

This project highlights the need and opportunities for substantial further research by government, universities, the housing industry, and community associations. Recommendations for future research that explicitly acknowledges the scale and temporal constraints of this project include but are not limited to:

1. longitudinal research that maps the experiences of people with disability over time as they move along housing pathways;
2. research that more extensively explores the experiences of people with disability across the range of housing and accommodation environments;
3. research that focuses on the relationship between type and level of disability and housing experience and opportunity;
4. research that considers cultural issues impacting choice and personal and family agency;
5. research that focusses on further understanding the complex nature of person-centredness and how housing can be effectively incorporated in person-centred planning;
6. research that evaluates the outcomes and effectiveness of person-centred planning; and
7. research that further explores how to reconcile a person-centred philosophy with a holistic appreciation of the external and internal factors impacting private housing access for people with disability.

8.2   Conclusion

This Final Report presents the findings of a research project commissioned by the Disability Policy and Research Working Group (DPRWG) to explore the barriers and obstacles impeding a person-centred approach to planning and housing for people with disability. Despite growing recognition of the relationship between housing, health and wellbeing, and legislation that endorses the choice of housing as a basic human right, people with disability remain significantly under-represented in the private housing market and excluded from the opportunities afforded by private housing personally and socially. In order to understand what might be impeding access to private housing for people with disability, the project explored the experiences of three organisations as well as individuals in their attempts to address their housing needs and aspirations.

Methodologically, the project involved explanation building using a multiple case study approach supported by a contextual study. It accessed multiple sources of data including documents, archived records, semi-structured interviews, and models developed by the case organisations. As well as helping to build a picture of causal relationships, the multiple sources and associated methods constituted corroborating strategies for strengthening research quality. Data collected were analysed by three researchers using an iterative process of comparing emerging findings against initial and emerging statements/propositions within and across organisations and individual cases. Overall, the process involved a gradual building of an explanation of the barriers and obstacles impeding access to private housing for people with disability, and of the policy and practice

implications for government, organisations such as the case organisations and community organisations, the housing industry, people with disability, and families of people with disability.

Using an ecological framework, the project found that:

- challenges exist within systems (such as the macro cultural, economic, regulatory systems through to local community, family and intra personal systems) as well as with the interaction between systems;
- reaching across systems is a key role for organisations and individuals but is very challenging with distance from the individual as well as from the policy/funding/service systems being a key aspect of the nature and extent by which they are challenged; and
- in the case of housing for people with disability a 'disability space' is assumed and maintained disparately within each system and is separate from the 'mainstream space' with the established policy, legal, funding structures making it difficult to move between the two spaces.

Overall, the project revealed a complex and challenging picture of access to private housing for people with disability and their families. A number of key issues were identified. First, challenges and impediments to access to private housing for people with disability are various, occur in all domains and across the ecology, and are interconnected. We refer to this as a mosaic. However, there is a siloed approach to planning and services including housing that does not recognise the mosaic nature of the issues. Housing needs to be considered as an integral and priority issue within planning that is aligned but not conflated with other areas such as support services.

There is also a siloed approach to housing for people with disability which assumes and maintains a 'disability space'. While some will prefer to move within this space, a more mainstream approach to the issue of limited suitable stock (including regulation, education of the industry, promotion and advocacy by community organisations, and so on as listed in our recommendations) would facilitate greater inclusion as well as broader societal benefits. This will require significant changes including a policy shift to support and facilitate movement between the 'disability' and 'mainstream' space and within the 'mainstream' space. This also has implications for how housing assistance is provided and structured, and how funding models and financial services are regulated and supported to address affordability.

The focus on a 'disability space' and 'disability-focused solutions' also limits choice and movement along a housing pathway or career. Our suggested focus is on providing and opening up opportunities for people with disability within the mainstream space in an inclusive way that benefits the whole community, and not only people with disability and their families. The fundamental issue of availability of stock in the 'mainstream' space is significant in the ability of housing-related planning to be person-centred; at present, approaches that are designed to be person-centred are severely challenged by the lack of stock available and suitable for use. Additional recommendations relating to home modifications will have considerable implications in this regard.

The project further recognises the segmented and siloed nature of the broader policy/ legal/ funding environment which perpetuates the single-issue and disconnected or piecemeal approaches to which organisations have been restricted. Because of this segmented system, the ability of individuals and organisations to operate across the systems in the ecology and to span the issues that challenge access is severely restricted. Both the mosaic nature of challenges to access and the challenges for individuals and organisations to move between systems in the ecology highlight a need to adopt a holistic approach where systems are aligned and congruent.

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Appendices

Appendix 1: Full Case Reports

Introduction

This appendix presents in full the reports of the three organisation cases and one individual case selected for the study, with the latter included to represent an attempt by three families to respond to housing aspirations for their adult sons with disability outside models developed by the not for profit organisations initially considered for this study. As with the summary reports, these case reports are de-identified, acknowledging our ethical undertaking to provide anonymity for all participants including the case organisations and their representatives.

The case descriptions which follow include:

Case A

- A community financial institution working on behalf of both individuals with disabilities and/or their families and not-for-profit community organisations (including service and housing providers) to broker financial models that facilitate access to appropriate and affordable housing including owner-occupied housing.

Case B

- A not-for-profit foundation organisation working on behalf of young people with disabilities at risk of being placed in or staying permanently in residential aged care facilities (RACs'). To this end, the organisation works with state and federal governments, housing associations, property developers, community service organisations and financial institutions to produce an integrated model of supported housing.

Case C

- A community association working directly with families with an adult child with a disability, a financial institution, a planning organisation, local/state/federal governments, a research institution, and a social enterprise housing provider to produce a financial, legal and regulatory model that would through a particular private housing typology facilitate transition for the adult child to independent living.

Case D

- A family working with two other families and government to secure accessible social housing as part of an intentional community.

1   Case Study A: A community finance organisation

The main unit of analysis for the project as a whole is access to private housing for people with disability. This case represents a sub-unit of analysis that focuses on financial access and the provision of housing for people with disability. The activities of the case organisation are understood as interventions (for the most part still in stages of planning or implementation) to facilitate access to capital for private individuals as well as for groups supporting individuals with disability. As the report will highlight attempts to implement these interventions have been challenging. A concern of the study then is in appreciating why this is the case and what this means in facilitating greater access to appropriate and affordable housing, particularly private housing, for people with disability.

The following section presents background information regarding the case organisation enabling a more contextualised understanding of attempts made by the organisation to increase the stock of affordable and appropriate housing for people with disability through community and social investment. In the main, this has involved a concern for housing provided and/or managed by not-for-profit organisations, which then sub-lease to individuals with disability.

1.1   Organisational context

Organisation type, philosophy, programs and services

The case organisation involves what is known as a community finance organisation. Established for approximately twenty years, they operate as an independent organisation accessing community finance and social investment for those underserved, or excluded, from mainstream financial services (for example, individuals; groups including families and households; social/not for profit organisations (NPOs); social enterprises, social businesses, microenterprises). A member of wider international networks and institutions, its work covers various areas including among others; disability and disability services, housing and housing assistance.

While financial exclusion is normally considered in relation to individuals, the community finance organisation contends that exclusion also extends to groups such as NPO's and social and micro enterprises. As to how to address financial exclusion for individuals or groups, it argues that two factors, capability and market failure, need to be considered in combination. Overall, it advocates for a definition of financial exclusion that includes 'usage' as well as 'access', and recognition that it has different forms in different socio-cultural situations. Based on the work of Corr (2006, pp. 10-13), they highlight the following dimensions to financial exclusion:
- geographical exclusion (poor service provision in certain areas);
- access exclusion (for example, due to a poor credit record/assessment);

- condition exclusion (where conditions attached to financial products cannot be met);
- price exclusion (because products are too costly for certain groups of people or have higher fees attached to them);
- marketing exclusion (where certain groups considered less profitable are excluded);
- self-exclusion (such as when people exclude themselves because they believe they will be discriminated against);
- resource exclusion (for example, where people do not have sufficient funds to be eligible to engage with the product); and
- electronic exclusion (due to an inability to access electronic financial systems).

Given acknowledgement of the above dimensions, the community finance organisation supports the following European Commission definition of financial exclusion:

> Financial exclusion refers to a process whereby people [and the community finance organisation would add, groups of people] encounter difficulties accessing and/or using financial services and products in the mainstream market that are appropriate to their needs and enable them to lead a normal social life in the society in which they belong (European Commission, 2008 in reference withheld).

In terms of specific individuals most subjected to financial exclusion, the community finance organisation identifies people living on low and fixed incomes, people with a poor credit history, people living in remote areas, people with disability [the latter of whom are for the most part living on low and fixed incomes (or entitlements), have a poor or nil credit history, and tend to live further away from a concentration of services due to the lower cost of accommodation]. Here, as they point out, is an inextricable link between financial and social exclusion with each potentially contributing to the other. In addition, individuals also tend to experience exclusion for a range of services and products including, as they highlight, transaction banking, credit, savings, insurance products, and superannuation.

Regarding NPOs, they highlight the following as contributing to their financial exclusion:
- lack of capital other than philanthropy and grant funding;
- lack of access to sources of investment capital and loan capital;
- lack of capital for asset development, growth capital and working capital; and
- questions around skills and capacities to engage with other forms of capital (reference withheld).

While they acknowledge there have been some changes in the Australian banking industry to open access to capital and investment in the non-profit sector, they also highlight how minimal this has been, constraining, among other things, the NPOs' ability to maximise their social impact.

Also providing services to those with disability, sometimes in support of NPOs, are various social enterprises. As noted by the community finance organisation, these are characterised by:
- social objectives as the core;
- limited distribution of profits where the majority are reinvested in the enterprise

and/or an associated social entity;

- mixture of capital inputs – grant, subsidised, earned; and
- generation of social return in addition to a financial return (reference withheld).

Along with microenterprises and social business, social enterprises constitute what the case organisation describes as the fourth sector overlapping with and connecting the public sector, the private sector and the third sector NPO groups. As they point out, attempts to raise capital by these enterprises is hampered by several factors including their legal status as neither a charity organisation nor a commercial business as well as by various internal issues to do with capacity and capability. Exacerbating this further they suggest is a policy environment that remains largely disengaged from these emerging entities, their initiatives and the issues they are grappling with. As they point out, Community Service Organisations (CSOs) "…especially in the welfare and community sectors, are often placed in a situation of mitigating the worst effects of market failures on people who are marginalised and excluded in society" with banks and government departments failing to address the systemic causes of exclusion. In this regard, the central role played by CSOs reinforces the perception "…that welfare responses are the only viable responses for addressing financial exclusion of individuals" taking the pressure off seeking alternative approaches or fully exploring emerging potentially innovative approaches or new sources of capital (reference withheld).

To explore what may be possible in terms of current approaches as ways of moving thinking beyond "new initiatives using old approaches", the community finance organisation acknowledges the work of Wold (2007) cited in a community finance publication (reference withheld) and proposes the following:

1. a 'no market' approach where market failure is attributed to the lack of a market [because the beneficiaries of the potential product or service are unable to pay for it, to convey what they desire or are unable to fully engage with the product necessitating the use of public funds or the provision of no/low cost products/services];
2. a 'limited market' approach involving the provision of specialist services subsidised by external funding with some nominal charge for the beneficiary; and
3. a 'low-profit market' approach in which beneficiaries are offered loans that attract a commercial rate of interest capitalised by social investors who receive a steady but below market return the difference of which is off-set by their goal of a social return on their investment. This is an emerging approach in Australia led by the community finance organisation.

To the above three, the community finance organisation adds a fourth approach:

4. an 'alternative market' approach involving situations where people pay "…extraordinary costs and endure difficult conditions in order to access credit and other financial services" (reference withheld).

In terms of the second and third approaches, they recommend addressing some of the shortcomings of current responses, such as:

- building investment scale for a diverse range of local organisations or concentrating it so a diverse range of needs can be met;

- providing a mechanism through policy and organisational structure for cross-sector partnerships that synthesises strengths and skills enabling new arrangements beyond the existing contract or service delivery arrangements;
- providing a structure or fourth sector organisation that can blend social and financial approaches;
- the capacity to advocate for an appropriate regulatory and enabling policy framework; and
- enabling the flow of new capital and investment to explore options for addressing financial exclusion across individuals, organisations and enterprises (reference withheld).

According to the case community finance organisation, community finance organisations are best placed to facilitate the responses just highlighted. As they elaborate:

> If CDFIs (community development finance organisations) were further developed in Australia, a range of market-based possibilities could be opened up that could complement the current welfare responses and the 'limited market' responses that have emerged from CSR and Corporate-Community partnerships around financial exclusion. This could also help to counter and provide a very real and scalable alternative to fringe markets that are often exploitive. It may even stimulate the mainstream financial institutions to engage more structurally and sustainably in addressing financial exclusion (reference withheld).

Providing the impetus for these changes in relation to disability is the newly introduced National Disability Insurance Scheme (NDIS) promising individuals with disability greater opportunity in exercising choice by being able to self-manage funds in an open market of service provision. In this regard the community finance organisation sees community finance and social investment as playing a critical role in providing access to capital to deliver quality services including housing that supports choice through it being more appropriate and affordable. Their recent responses build on a history of working with people disability, their families and various non-profit service providers. This experience has led them to develop the following principles:

- housing provision should be centred on the person, connected to the support arrangements of the person in a way that ensures they remain connected to the relationships they have within their community; and
- planning for housing should take into account the physical environment as well as long-term issues associated with income and finances and decision making beyond the life of the parent in the context of the broader family (reference withheld).

Underpinning these principles is acknowledgement that "people with disability and their carers are among the poorest in our community, and they experience the range of consequential negative impacts on housing security, physical and mental health, relationship breakdown and social and economic participation" (reference withheld).

While they claim "there is no definitive data on the number of people with disability and their families who experience financial exclusion" they suggest, "…it is not a stretch to

conclude that many of the 17.2% of Australians who are financially excluded also experience some form of disability". They also assert, "although financial hardship is a major driver of financial exclusion, it is also true that disability cuts across the socioeconomic experiences of people in Australian society. For some people with a disability and their families, income and financial hardship are not the major drivers of financial exclusion". In this regard, they highlight how high income families may still experience financial exclusion due to a lack of access to financial advice and planning particularly a lack of lifelong planning that takes into account the need for care beyond the life of primary carers such as parents.

From their research involving people with disability and their families, several factors were identified that appear to contribute to financial exclusion or make access to financial products difficult. These include:

- difficulty in understanding financial products particularly for people with cognitive and/or intellectual impairment;
- uncertainty as to who to ask for assistance in understanding the products.
- prioritisation of other matters over finances;
- lack of products tailored to the needs of the person with disability. Products that are considered inappropriate include: health insurance that does not take into account the specialised and enduring nature of health issues; credit products that do not provide flexible payment options; insurance products that fail to cover the cost of specialised equipment replacement;
- financial advice that does not take into account life-long needs beyond the life of the parent carers;
- product delivery that does not take into account the need for a carer or legal representative to be involved in decision-making with/for the person with disability; and
- a requirement by some banks for clients to have their own account for the receipt of income support necessitating for those with diminished capacity the appointment of a financial guardian; a situation that can be disruptive for families (Reference withheld).

In addition to these factors relating to **financial product promotion and communication, design, and delivery,** the research participants highlighted issues to do with **employment**, specifically:

- the challenges of gaining and maintaining employment and associated impact on accessing credit and finance and the goal of owning assets in their own right;
- reliance of inadequate pension support if no employment or family assistance is possible;
- care responsibilities that limit the ability of the family carer to work and receive an income; and
- no access to financial advice for long term life planning and the maintenance of a constant level of financial support (Reference withheld).

Housing was also identified as offering specific challenges such as:

- the lack of appropriate, long term affordable housing. Here appropriateness can relate to location and type of housing which if not suitable can affect social inclusion, employment participation and everyday functions;
- no financial capacity to experience stable tenure through home ownership creating reliance on social/community housing or the private rental market;
- inability to harness assets when appropriate and the adverse impact on a sustainable housing outcome;
- lack of knowledge about how to refinance assets and use the capital for other purposes;
- allowing for continuity in these assets financial arrangements beyond the lives of the family; and
- inability to appropriately involve family members and others in financial decisions over time (reference withheld).

In terms of **lifelong financial planning**, the participants identified the following as problematic:

- information about financial planning, the confidence to choose a financial planner, and the capacity to engage in relation to communication and decision-making;
- the tendency to limit planning to support needs; and
- a reliance on NPOs who may not have the skills or resources to adequately advise individuals and their families (Reference withheld).

Models to facilitate access to appropriate and affordable (private) housing for people with disability

Differentiating private housing from other types of housing, the community finance organisation defines it as housing not "…funded or built by the state". It is housing that "…may never be owned by the person with disability but it may have been created, secured or developed using money that is not money of the state but that comes from other private sources". In this respect, it is understood to include housing specifically built for people with disability (appropriate housing) funded either wholly or partly by (private) social investment (making it more affordable housing) not just (private) commercial investment. It is seen as additional to private housing available for purchase or rent on the open market, which, for many people with disability, is generally neither appropriate nor affordable; and, which, for the case community finance organisation has prompted them to explore alternative approaches.

The main intervention by the community finance organisation to help address issues of access to appropriate and affordable housing is a financial brokering role involving the development of relationships among people with disability and their families, the peak bodies representing people with disability (for example, not-for-profit organisations particularly service providers; and local, state and federal government agencies), other emerging networks, social investors, and in some instances specific mainstream financial organisations that have a social focus. Central to this is enabling greater access to financial

and social capital through social investment to fund appropriately located, well-designed, affordable housing providing a sustainable level of capital security and return on the investment.

Underpinning this is a mission to alleviate financial exclusion experienced by marginalised groups such as people with disability and not-for-profit organisations by focussing on people and communities being able to help themselves. As conveyed by the community finance organisation representative, it "…connects back to our friendly society history…and values centred on self-help, mutuality, and reciprocity", and, along with this, acknowledges that existing social structures and policies are failing many individuals and groups in society. For the organisation, this is particularly evident in the severe shortage of long-term stable and affordable housing for people with disability. Over a period of six years the community finance organisation has attempted to respond to this though several interventions ranging from the more commercially oriented through to the more socially oriented. Examples of the main interventions are outlined and illustrated in the following models.

Model 1 – Brokering finance for home ownership through credit unions

Model 1 represents one of the first initiatives attempted by the community finance organisation. Essentially it involved the institution brokering a home loan from a credit union for people with disability and/or their family. Under the Australian Credit Licence, lending authorities must have a supply of capital for residential home loan lending (which the organisation does not have) requiring them to engage with a financial organisation that does such as a credit union. As explained:

> …we've had a relationship with a national credit union and through that relationship they provided us with what you would call a loan mandate for the provision of home loans…so home loans to individuals or to families and that if we could originate projects around individuals they would provide the capital…the loans.

Unfortunately, this has not been pursued because:

> …we've not been able to secure the resources at the front end that would allow us to do the work that we would need to do to identify individuals and families so we've just parked that. We know the commitment is there and that sometime in the future we may be able to bring it to the fore.

The community finance organisation see the NPOs, who have a relationship with the people with disabilities and their families and understand their specific situation, as central to the future success of this model. Described as a "distribution channel", they regard their relationship with them as crucial in tailoring an appropriate loan package.

Model 2 – Establishing and managing a property trust of houses leased directly to individuals with disability

Model 2 involves the community finance organisation in establishing and managing a property trust of houses leased directly to people with disability. As they acknowledge this is their least preferred model because they attribute to themselves the added responsibility of ensuring that the individuals with disability bring with them appropriate ranges and levels of support. This, they recognise, is not within their area of expertise necessitating an intermediary role by service providers. Complicating this is the scenario of what to do if investors want their money back. Exit issues are presented as more complicated in this model because it is more commercially oriented.

Model 3 – Brokering finance for housing provision through a mortgage trust

Model 3 is concerned with establishing a mortgage trust backed by the state government with the capital raised to fund loans to housing disability service providers to purchase or build housing specifically for lease by people with disabilities. At the time this data were collected the proposal was still before the state government.

Model 4 – Brokering and managing finance for housing provision through a charitable trust

Model 4 involves the establishment of a charitable trust with the community finance organisation as trustee to purchase several units in unit block developments using capital raised through predominantly social investment. The capital raised and managed by the community finance organisation's social subsidiary social investment company in the form of a non-profit community finance fund would be provided to the trust as an interest-only loan. The establishment of the trust as a charitable entity entitles the trust to apply for various tax exemptions such as stamp duty. The charitable trust provides a Head-Lease agreement to a service provider organisation, which sub-leases the units exclusively to individuals with disability or a family with a member who has a disability. All units have two bedrooms apart from a one-bedroom unit designated as the carer hub providing twenty-four hour seven day a week carer support. The two bedroom units are viewed as allowing the possibility for supplementing support and providing companionship through parents or siblings staying over.

In selecting the service provider not-for-profit organisation (NPO), the community finance organisation undertakes rigorous financial and social due diligence regarding the NPO's capacity to meet the Head Lease commitment as well as the requirement to have a clear governance, policy, management and operational division between tenancy management and service delivery.

At the time of preparing this report, this model had yet to be fully implemented with funds still being raised to purchase six single level strata titled units already earmarked for the

35th level in a 40 level residential tower in an existing mixed-use development located close to transport services and a range of retail, entertainment, education and health facilities. Of the six units, five units would be sub-let to the NPO's clients with disabilities on a seven-year lease term basis with the option of a further seven-year lease. The NPO and/or the sub-tenants will have the first right of refusal to purchase at the end of the lease term. If the option is not taken up the lease would be renewed (the NPO will be responsible for building modifications required to suit the needs of the sub-tenants) or the units sold to the open market.

1.2   Positions and frameworks in access to (private) housing for people with disabilities

The central role of finance in promoting (private) housing options

As outlined previously, there are many reasons why people with disability are excluded from renting or buying housing of their choice, a major one being the availability of appropriate and affordable housing. The models just described are examples of different ways in which a community finance organisation has attempted to use community and social investment to intervene between individuals with disability and the more commercially oriented financial system. This aims to potentially provide more affordable and appropriately designed, and located, housing direct to individuals for lease at less than everyday market costs. Integral to this is fostering the social agendas of investors and their preparedness to offset maximum profit for social impact. In doing this, the community finance organisation is overtly confronting the financial market's preoccupation with the commercial imperatives of maximum return.

For this case organisation a key artefact is a financial entity that manages investment in a way that safeguards the financial and social interests of the investors through property (housing) providing at minimal cost a better life for people with disabilities, for example, a property trust as in Model 2; a mortgage trust as in Model 3; and a charitable trust as in Model 4. In developing these 'artefacts' the community finance organisation positions itself in a certain way, that is, as a community finance organisation as opposed to a bank, credit union or building society; a position enabling it to adopt a low-profit market approach involving brokering relationships with various systems and groups including government, mainstream financial institutions, and social investors, as well as not-for-profit community organisations. In some instances, as in Models 2 and 4, it envisages a more active role as a housing provider.

At a fundamental level, how the community finance organisation understands problems and issues is framed by its history as a friendly society with values centred on self-help, mutuality, and reciprocity and various goals informed by a human rights framework. These include:
- providing long-term stable and affordable housing;
- housing "… centred on the person, connected to the support arrangements of the

person in a way that ensures they remain connected to the relationships they have within their community". To this end, the community finance organisation is dependent on NPOs and an alignment of their mission with the vision of the community finance organisation;

- planning for housing that takes "into account the physical environment, as well as long term issues associated with income and finances and decision making beyond the life of the parent in the context of the broader family";
- providing access to capital through community finance and social investment to deliver housing that supports choice;
- "to bring about a strong and sustainable social sector that values social justice and human scale economy";
- "building the strength and independence of civil society organisations and in turn communities in which they exist";
- to ensure that "Everyone has the right to live in their own home, achieve their maximum potential and live the life of their choice";
- to "Provide flexible, individualised accommodation that is tailored to each person";
- "to ensure that people with disabilities can live integrated into the broader community, and have the same access to shops, services, transport and entertainment that all individuals have"; and
- to ensure "that people with disabilities have the freedom to make choices about their daily routines and social life, without the constraints of requiring carer support".

Attempting to honour the above values and address specific goals has not been without its challenges as highlighted in the previous descriptions of the models. In general, the challenges can be attributed to a range of market related structural issues and individual, group related capability/capacity issues, actual and perceptual. For example, with Model 1 these are summarised as:

- a financial regulatory context requiring a supply of capital for residential home lending necessitating the involvement of a mainstream financial institution and the development of a loan package according to commercial imperatives;
- clients' ability and resources for functionally and financially sustainable loan packages to be developed;
- the community finance organisation and their capacity and capability to help potential clients develop a sustainable loan package; and
- reliance on service providers having the expertise, resources and qualities to work with the community finance organisation in tailoring a loan package to meet the client's functional and financial needs.

Underpinning Model 1 and the other models is a specific perspective on the social nature of financial inclusion/exclusion and a view that even if the community finance organisation could go direct to the disability market or even if mainstream financial institutions were interested in doing the same both would have to rely on the non-profits to reach those comprising the disability market. Indeed, the organisation argues that the mainstream

banking sector would "...have even less capacity than we do to engage in the social dimensions of all of that because they're a commercial operator which is why organisations like this are valuable...is because ... we're not commercial and we're socially focussed and we can act as an intermediary...".

Despite recognising the problems with service provider capability and capacity then the community finance organisation contends that they are still a significant mechanism due to their close relationship with people with disability and the interconnection of housing and care; "...the intersection is occurring between the needs and life circumstances of an individual and their connection to an organisation and that organisation's needs and ability to respond to the individual, so it's all tied in together". An ideal situation would be "...where you get really high quality, exceptionally sophisticated organisational structures working well to respond to individuals, and communities and individuals who are highly empowered either through that experience or because of other experiences...".

In Model 2, the community finance organisation sees the NPOs involvement as an intermediary to help the community finance organisation develop an appropriate fit relationship between housing and tenant. NPOs are also viewed as crucial in Models 3 and 4. In Model 3 state government funded loans are provided to not-for-profit disability housing service providers to purchase or build housing. One of the main complicating issues with this model has been the change of government with no response forthcoming from the new government. The reliance on government funding, as opposed to social invested funding, also differentiates this model from Models 2 and 4 moving it more into the realm of social housing and outside the domain of what the community finance organisation regards as private housing.

More than the other models, Model 4 highlights challenges in building relationships with investors as well NPOs, and having them commit to something that has not been undertaken before, that takes substantial time to put together, and that is reliant on a multitude of aspects coming together. In addition to deepening and widening investor relationships, the community finance organisation also regards as a challenge having the resources necessary to, "...go out and build [those] relationships into the non-profits and help them understand that actually this is something that could facilitate housing outcomes for some of the people [they] work with and their families. That's hard. There's all sorts of ideological barriers".

Challenges also exist in this model for the NPO. As noted earlier, a major one is in trying to provide an appropriate level of care when the care is being shared among several individuals. Congregate care models such as this have built into them economies of scale rationale. From the community finance organisation's perspective, one of its most fundamental challenges was developing and implementing a process of due diligence to ensure selection of an NPO with experience, integrity and a person-centred approach in working with their clients, for example, were they going to work from the person without assuming to know what they want. This due diligence process is considered particularly important where an NPO is the service provider as well as the housing provider. Here the

community finance organisation undertook to ensure the lease agreement was not contingent or connected to the support arrangements.

As part of their due diligence, the community finance organisation also assumed responsibility for ensuring the apartments were of a high quality and located in an area with considerable public amenity and with sound capital security and investment return potential. "This is the challenge of our work, you know, you have to ask yourself the question…what degree do you add to your ordinary due diligence other criteria or levers that direct particular outcomes"? Also of concern to the community finance organisation were the demographics of the individuals with the desire not to have people all with high support needs congregated together but rather a mix of disabilities excluding those with severe intellectual disability who they consider to have higher risk than can be catered for in this model. In this respect, the community finance organisation is relying on the NPO to make a considered decision about who will live there while also acknowledging the limitations of having one carer and their ability to provide support for five individuals. Connected to this is the desire to have those with disability integrated in a natural way into the general apartment community.

Market niche, choice and 'private' housing

Creating a market

The issues just described precipitated the response by the community finance organisation to explore different ways in which to create a financial market to provide accessible and affordable housing to people with disability. As outlined, their main approach has been a 'low profit market' approach in which people with disability have access to housing subsidised by social investors, or a combination of social and public investors who receive a steady but below market return (the difference of which is off-set by their goal of a social return on their investment). The basic rationale for this then is to create financially viable options for independent living responding to the need to provide greater choice for people with disabilities and their families.

The provision of choice

For this case organisation the main actualisers of choice are financial structures that enable the provision of accessible and affordable housing for people with disabilities who are excluded for various social or personal reasons from accessing mainstream economic capital and, consequently, mainstream housing either to buy or rent. The community finance organisation also regards the NPO service provider as a significant actualiser in their role of working closely with individuals and families to help plan and manage service support. The provision of choice is understood to be further realised through housing designed and located to suit specific physical and social needs of people with disability. In this regard, expanding choice demands greater access to affordable, suitably designed, located and supported housing – as three of the four models involve housing directly linked to service provision; a situation which may delimit choice if housing and support are seen as mutually inclusive.

The approaches considered by the community finance organisation, specifically that of Model 4, invite further consideration in terms of their ability to fully align with the organisations vision and guiding principles to open up access and provide greater choice. Questions that can be asked include:

- is the reliance on service providers as gate keepers to housing for people with disability going to discriminate against certain groups of people with disability due to the tendency of service providers to support people with specific types and severity of disability?;

- does the reliance on service providers jeopardise the extent to which people with disability participate in decision-making about their own lives or learn to become more empowered and self-determining?;

- how much real choice do people have in supported accommodation? Can they and would they feel in a position to change their mind, either to change their service provider or move to another type of tenancy? ;

- are the due diligence processes reliable?;

- is profit (albeit less than in the general market) which is still important to social investors dictating a supported accommodation approach itself driven by an economic agenda based on the economic rationalisation of care?;

- is there a potential tension between structural measures of facilitating greater financial inclusion based on a social model of disability and the implementation of the model by service providers using a care model reflecting a medical perspective of disability?;

- despite the espoused aims of community inclusion, the supported accommodation interventions could be viewed as perpetuating a view of people with disability as special or different to the norm. How could systems particularly financial systems be restructured to provide greater access for people with disability to the normative housing culture or help inculcate a more inclusive housing culture (and society) based on difference rather than normalcy and conformity?;

- do the housing options and forms of tenancy related to the latter models afford the same degree of choice and opportunities for independence as those of owner occupation and private rental? If not, do they if desired by individuals offer opportunities for building capacity towards more independent forms of tenure?;

- will those NPOs holding head property leases actually adapt the accommodation to fit the individual or will there be a tendency to fit the resident to the unit and the changes they consider economically viable? Will this in turn perpetuate homogeneity as opposed to the desired heterogeneity?; and

- if most (if not all) of the residents have severe to profound disabilities will there be sufficient capital to tailor the physical environment to the individual? What are the implications if the property is to be sold to the open market in the future? What buyer attitudes will inform the perception and appreciation of the property?

The salience of supported housing in a private context

The questions posed in the previous section provide context for further exploring the notion of private housing and the extent to which the latter housing models proposed afford the

same or similar rights as the general community or opportunities to at a later stage gain access to more desirable housing. While the housing may be provided by private investment, albeit social investment, and located in the general community the central role played by the service provider raises serious questions about the ability of the resident to take their support package and move somewhere else or alternatively stay in the housing and use another service provider.

Realising the models in the 'market' of service provision

Central to the situation as described previously is the nature of service provision and how it is generally brokered and managed by various service providers in what is essentially a market where service providers compete against each other to secure funding and sustainable business through the support provided by governments or other external organisations to individuals with disabilities either directly or indirectly. The rolling in of the NDIS offers to disrupt existing market behaviour by giving individuals more individualised funding and greater control over how their support entitlements are used and managed. It does not however provide any direct assistance in relation to housing apart from home modifications. This suggests that planning involving those with moderate to profound disabilities in receipt of block or individualised funding will not address a wider range of housing options, and as such these people will remain dependent on government or community organisations for their housing. The need for community organisations and service providers to survive in this market also leads to greater attention being given to people with moderate to profound disabilities and their associated packages. There is less attention given to the housing needs of those with minor disabilities or those who will no longer receive the support of family in a private home situation and become fully dependent on the government for their support and housing. Attempts to address this situation in Model 1 reveal complex systemic difficulties in transferring ownership let alone gaining access to private housing as an owner/occupier.

The approaches devised by the community finance organisation offer a number of insights. In the main, they reflect a desire to implement a social model perspective of disability that also emphasises the individual and their circumstances. In relation to housing, the community finance organisation work represents an attempt to address some of the economic and social disadvantage experienced by people with disability and how various economic structures including the principle of marketisation and institutional practices in particular are barriers to social equality in the ways they restrict access to owner-occupied and private rental housing. One of the main factors here appears to be how financial institutions and rental authorities are allowed, as well as choose, to operate in relation to risk assessment. Associated with this are assumptions about and the practices used to determine the capacity of the person with disability or their family to financially (and in some cases legally) sustain the mortgage or the lease. Added to this is the reality as understood by the community finance organisation that many individuals with disability or their families for a range of structural reasons (external and personal) just cannot afford to buy a property or rent in the mainstream market. The impact of not being able to access mainstream housing for whatever reason is further compounded for many people with

disability by a lack of accessible and appropriately located stock.

The models then developed by the community finance organisation are attempts to address these issues of affordability and appropriateness through the development of an alternative financial system primarily involving trusts and social investment or a mix of social investment and government/community funding. In facilitating access to the housing provided through this type of investment, the organisation sees a significant role for NPO support and housing providers and an existing system that for many individuals with disability ties them to particular service providers because of how various forms of funding support are provided by federal and state governments.

2   Case Study B: A foundation

Case B is a not-for-profit foundation working on behalf of young people with disabilities at risk of being placed in or staying permanently in residential aged care facilities (RACs). To this end, the organisation works with state and federal governments, housing associations, property developers, community service organisations and financial institutions to produce an integrated model of supported housing.

2.1   Organisational context

Organisation type, philosophy, programs and services

Case study B is a company 'limited by guarantee' based in an Australian capital city. It was established in 2006 for the purpose of promoting the capacity of younger people with acquired disability and complex care needs to live in normative community settings and to avoid placement in residential aged care facilities. It envisages "that younger people with acquired and late onset disabilities and complex care needs will have inherent value as members of our society, with access to services and accommodation that support their health and wellbeing" (reference withheld). This case is of particular interest to the study as it involves people with disabilities normally marginalised by both health and disability services as well as housing providers.

To understand the case organisation contextually, we analysed its website, including videoed stories of individuals' housing and support arrangements, related published and unpublished documents, journal articles reporting on the research stemming from its work, its constitution, and transcripts from interviews with two of its representatives.

As noted in research undertaken by a member of the case organisation in association with several university researchers, in 2006, the prevalence of younger people residing in residential aged care facilities in Australia was one of the highest in the western world. This, in part, they attribute to an outcome of better medical intervention at the time of trauma resulting in younger people, particularly with head injuries, surviving. The placement of younger people in RACs is considered to be inappropriate because of the mismatch between

the support needs and aspirations of younger people, and inevitable focus within RACs on end of life. According to their research, they also report that most young people found they were effectively marginalised from their networks and community interests and that many experienced multiple secondary medical conditions, such as contractures, infections and pneumonia as well as depression (reference withheld).

Within its constitution, the foundation has the role of providing both direct and indirect services, including:
1. promoting the delivery of rehabilitation and allied health services to young people living in nursing homes, or at risk of admission to nursing homes;
2. promoting the development of transition arrangements from nursing homes to the community that incorporate consultation with young people and their families and significant others about community based accommodation and support choices;
3. promotion of research into the needs and service delivery options young people with Acquired Disabilities and complex care needs require;
4. development of innovative accommodation and support options that incorporate personalised care plans;
5. delivery of appropriate assessment tools for young people with Acquired Disabilities and complex care needs;
6. promoting improved integration of existing services in acute care, allied health, community services, housing, disability and nursing home services;
7. providing leadership to, and collaboration with, the disability, aged care, community, acute care and housing sectors to develop solutions for people with Acquired Disabilities and complex care needs; and
8. promoting development of self-advocacy skills in young Australians with Acquired Disabilities (reference withheld).

Its mission is "to foster the development of services and solutions that promote the health and well-being" of younger people with acquired disabilities and to empower them to participate in the community. It does this in three ways:
1. it supports research to provide an evidence base for policy change;
2. it attempts to create a movement by supporting people with disability and their families to tell their own story, to envision and plan for themselves and keep the issue on the political agenda; and
3. it aims to demonstrate what is possible, by working in partnership with housing and support organisations, and evaluate them with regard to the economic and human outcomes for this particular cohort (reference withheld).

The foundation's response to its mission appears to be shaped by a number of factors:
- its vision for younger people with acquired disability having inherent value as members of society;
- its focus on workable solutions that address the complexities of bringing health services, disability support and housing together in a way that improves the health and wellbeing of this group;
- its understanding of the critical role families and informal networks play in people's

health and wellbeing; and

- its realisation of the importance of the person, with their families and friends, to envision and plan a better life for themselves, and that their stories have the power to create a movement for change (references withheld).

The work of the foundation that particularly informs this study are their efforts to: influence the design of mainstream dwellings to meet the needs of people with significant physical disability; to increase the supply of housing so that people with disability can buy or rent them; and to empower people with disability and their families.

Facilitating access to housing (including private housing) for people with acquired disability at risk of entering or remaining in residential aged care facilities (RAC's)

For the foundation, its main concerns are providing a more suitable housing alternative for those people with acquired disability at risk of entering, or currently residing in residential aged care facilities; and finding alternatives that can inform policy by demonstrating economic benefit of less reliance on paid support by putting "more funding and capital into more appropriate living environments". The housing model pursued by the foundation since 2009 involves working with housing associations, or other NPOs, and purchasing a number of units scattered throughout a medium density private/social housing development, with a space on site for a disability support worker to provide outreach. Of central significance is the integration of people with disability in a mixed community and the design and location of the units that suits the physical needs of those with disabilities.

> The model [is] just like supporting someone who lived in the community. Just because they happen to be co-located doesn't mean that it should be staffed or that the mentality should be like a shared supported accommodation service.

This and other considerations are outlined as follows:
- having a planned approach to housing;
- appropriately designed housing;
- affordable housing;
- timely and informed involvement in housing design;
- matching people to housing rather than housing to people; and
- awareness of housing and ability to make informed decisions.

Planning an coordinated support approach

The foundation has identified that a planned approach to a housing solution is key to people leaving RACs; without this, it is impossible also to plan the equipment, disability support and health services that may be required. Unless a person already has their own home, the lack of accessible and affordable housing will, despite the NDIS, continue to be an impediment to social inclusion and participation, and unless the issue of housing supply is resolved systemically, the pressure on acute health facilities to move people with acquired disability out will result in continuing placements in RACs.

Appropriately designed housing

According to the foundation, access requirements within the National Construction Code (NCC) and access guidelines for private housing spaces are inadequate for adults with acquired disability. "There is a big difference between meeting standards and functional design for people with disabilities and the people that support them". Although there is some improvement in common areas due to the inclusion of the Access to Premises Code within the NCC, it is still "not good enough for the 10% that sit above those 80- 90% [of people catered for in] most of those standards".

Affordable housing

The foundation has identified that there is a significant gap between the cost of specially-designed housing, typical funding strategies (such as NRAS and rental assistance) and the amount people with severe disability can typically afford. Understanding that financial assistance for housing from families is the exception, and typical funding strategies for social and affordable housing do not include what is generally perceived as more expensive architecture.

Timely and informed involvement in housing design

The foundation has discovered a number of barriers in influencing the design and construction of mainstream private housing projects. For example:

- when social housing was included in the development, the allocation rules precluded a suitably located unit for support workers to reside in and provide support to people with disability in the complex.
- when working with a private project, the timeframe between the design stage and the apartments being sold off the plan did not allow for the due diligence process and access to finance required before purchase.
- when working from plans where design and engineering decisions have already been made, it became difficult to obtain the changes that were required to meet the particular access needs of the client group.

In summary, housing projects are understood to be best influenced before the design stage if the access needs of people with large wheelchairs and equipment are to be considered, and the units remain integrated in the development. The risk of being able to influence the plans early in the project development stage is offset by the risk that the project might stall or not attract finance. In attempting to integrate housing solutions within regular communities, the foundation has had to manage the uncertainties of the mainstream housing market while trying to plan smooth transitions for people from RACs and co-ordinate appropriate disability and health services. "You sort of need to have a few irons in the fire and work closely but you need to know they are all not going to come to fruition or come to fruition in the timing you were hoping for".

Matching people to housing rather than housing to people

As the foundation is aware, when access to suitable housing is difficult, there is a temptation to "slot" people with disability into available projects. The competing pressures from acute health care facilities and RACs for the person with acquired disability to leave, coupled with the desire for the person to find a suitable place to live, and the complexities of co-

ordinating support and health services inevitably leads to compromises:

> What typically happens now is that, um, there is a vacancy over this point and people are told here's a vacancy. We know it's not where you want; we know it's not near friends and family. . . It's not people you would choose to live with if you had a choice, but that's all we have, and if you don't take this option we don't know when we'll be able to offer you anything else.

Some of the issues highlighted by the foundation that arise when starting from a housing supply perspective are:

- people may be offered housing away from their social networks or familiar surroundings. One strategy was to offer housing only to people who came from the area; this then presented a challenge for the foundation to find people from a particular target group;
- people may be asked to share a two-bedroom apartment with another person with disability to optimise housing and support availability and minimise cost. For the foundation this is problematic as services reported that there were often vacancies due to incompatibility, and individual's living arrangements changed over time. "People might want a partner, they might want family there"; and
- when the housing solution was connected with a particular support package, the challenge was to find people who then would suit (and agree to use) that particular type of support.

Awareness of housing and ability to make informed decisions

Given the complexities previously outlined above, the foundation considered a barrier to finding appropriate housing was not knowing where suitable housing could be found and what compromises could be made. Professionals, people with disability and their families were becoming more aware of what was possible and the "trade-offs" that could be made. No project was going to be perfect so it was important to work out what was negotiable and non-negotiable for both the housing project and for the individual person. For example, living in a mainstream development may not result in the perfectly-designed dwelling; however, there was greater chance for inclusion and participation in the local community. Also, design and location decisions can accentuate or diminish a sense of "home".

In general, the foundation identified the need for:

- "broker" capacity to work with the various stakeholders, such as housing associations, disability and health service providers, and housing developers;
- processes to assist people with disability and families to envision their life and their future home, and actively plan how to obtain it; and
- facilitation to develop housing and support specific to the individual's needs: An interviewee said: "I guess I would sort of describe it as figuring out what their needs and preferences are, and wrapping housing and support around those rather than always trying to slot a person into a venue of options".

Since 2009, the foundation has had two attempts at purchasing housing as demonstration projects within mixed housing mainstream development to rent (or sell) to people with acquired disability and complex care needs. To do this they are reliant on philanthropic funding: "we are using philanthropic funding to purchase housing. Without that it just

wouldn't happen". Social enterprises, where a reasonable return for investors was expected, were considered non-viable when addressing the particular housing requirements of this group.

In both cases, however, attempts to secure housing by the foundation were unsuccessful due mainly to having insufficient time to coordinate all facets and address each at crucial times in the project. They did however provide learning opportunities for the foundation; experiences which are currently informing a new scoping exercise and the appointment of a project manager.

2.2 Positions and frameworks in access to appropriate and affordable housing

The central roles of design, research and education in promoting independent housing options

The background and model description just provided *clearly positions the perceived* imperative for the case organisation to prioritise design and location in housing as a means of enhancing choice available to young people with acquired disabilities and complex care needs, who would otherwise be confined to residential aged care facilities. As with case study A, a suitably designed and located residential environment is a key artefact in facilitating access to independent living and a healthier and more productive life.

In its plan to design and buy housing suitable to those with acquired disabilities or complex care needs, and to use such housing to demonstrate through its evaluation how it can be sustained economically, the organisation locates itself in certain ways involving various people, their knowledge and expertise and associated organisations. One way in which it regards itself is as a broker working with housing associations or service providers, housing developers and designers, disability and health service providers, philanthropists, people with disabilities and researchers, in a coordinated and programmed way to provide for specific individuals housing that suits their individual physical and social needs. Recognising the difficulty in making such specialised housing affordable, the organisation is also prepared to take on the role of housing provider where the housing is secured through philanthropic funding (as opposed to private or social investment funding which requires a higher rate of return). Added to this are other roles of educator, advocate and change agent. One fundamental aspect of the organisation's work is revealing and sharing people's stories of individualised planning around their housing and support needs that enables them to live where and how they want to live. The hope here is that these stories will inspire others to conceive of how they might plan for housing outcomes suitable to them. Recognising the need to provide evidence of cost benefits to facilitate policy change in social housing, which historically adopts a standardised economically conservative approach to housing, the organisation also sees its role as an evaluator and its projects as demonstration models. So, in all, the organisation positions itself in, and in relation to, various systems across the ecology of housing and independent living for people with disabilities.

In terms of how the case organisation understands the problems and issues, it appears that this is largely framed by knowledge of inadequacies in the system that allow large numbers of potentially productive people in their prime to waste away in environments that exclude them from mainstream society and that reinforce dependency and further threaten their physical and emotional well-being. Informing this is research that shows that people with acquired disabilities and complex care needs, who have little or no family or financial support, are at most risk of being confined to these forms of institutional environments, most often aged care facilities (reference withheld).

Despite the issue of people inappropriately placed in residential aged care facilities being a policy and funding priority since 2006 (Australian Government, 2006) with a three-pronged approach (finding community-based solutions so people can leave RACs; enhancing disability supports within the RACs; and minimising future admissions to RACs), progress has been slow with housing options restricted for the most part to shared accommodation. As recognised by the foundation, a major systemic inadequacy is the lack of housing that is designed to cater for specific physical and independent living needs, which is located near families and informal networks (that play a critical role in people's health and wellbeing), and is affordable. This situation, it suggests, is exacerbated by universal design principles that fail to address diverse and complex needs; by designers who have very little knowledge of inclusive design principles or how to work at the individualised level with the person with disabilities; and service providers, families and people with disability who have little idea about how to envision and plan for a more independent better life.

The NDIS's objectives for social inclusion and participation for all people with disability is understood by the case organisation as offering opportunities to address the issue of inadequate and inappropriate support; however, it highlights even further the limitations of the private housing market. Further, it challenges the current acceptance that some younger people might remain in RACs, and emphasises the importance of the other strategies of assisting people to leave RACs, and avoiding their placement in RACs in the first place.

Market niche, choice and specialised housing

Creating a market

The issues just described are understood as informing the need by the case organisation to establish a particular kind of housing niche for a specific (but large) group of people with disability; a housing niche that provides financially viable options for independent living that respond to the need to expand the choices available for people with acquired disabilities and/or complex needs many of whom historically would be destined to live in residential aged care facilities. The conception of choice in this case is based on this scenario of congregated care in an inappropriate environment for a younger person and its potential detrimental impact physically, socially and emotionally. The previous section highlighted in detail the central role of design, location and affordability in optimising independence as well as formal and informal care provision.

The provision of choice

The interviews and the organisation's published material identified a number of elements that were seen as essential for 'choice' to be actualised outside of the very limited aged care residential settings. Specifically, financial viability of alternatives; dispositions, knowledge and expectations regarding independence on the part of the person, their family, support services; the structures that facilitate and support viable housing provision, including, potentially the National Disability Insurance Scheme (NDIS) through more individualised planning and enhanced financial support; as well as housing and urban policy, legislation and design allowing for more accessible and usable residential environments.

The capacity of individuals and families to plan for and realise a more independent and productive future was seen as critical, and closely aligned with this was the requirement to provide appropriate information, education and inspiration. This, for the case organisation, encapsulates a person-centred approach or what they describe as an individualised approach; one where housing and support packages are built in, as they understand it, a coordinated manner around the individual rather than the individual being matched to housing that may not be close to family and informal networks and facilities; in some cases being pressured to accept inappropriately designed housing because of need to move from their present environment or through fear of not being considered in the future.

In addition to being able to live in an environment that supports individual physical needs, choice was also understood to be actualised through a tenancy arrangement that gave sole occupancy rights to the individual, in other words the right for the individual not to be forced to share with anyone else. Apart from this being a human rights and practical issue (with additional space being needed for equipment or a spouse/children and so on) the case organisation also sees it as "driving the wrong objectives" and not making financial sense to implement a model economically reliant on full occupation of multiple tenancies within the same dwelling. While they recognise the inadequacies of the Disability Support Pension, they prefer to subsidise this through additional (philanthropic) funding and to demonstrate over time potential reduced lifetime care costs for people with disabilities.

While housing provision that is financially viable and supports independent living is considered crucial in enhancing choice, the case organisation clearly recognises the need for other 'capitals' to be present in an integrated and individualised way to further enable choice – political, social and health, educational/informational, financial, legal and all the advantages that promote capacity for planning and expectations regarding independent and productive living.

The salience of inclusive mainstream housing

Located in this broader field of choices, inclusively designed housing situated in mainstream communities is understood to have particular significance. Fundamentally, a small number of inclusively designed dedicated dwellings situated within a larger mix of social and/or private housing are seen to offer the person with disability greater possibility of a normative life – and the broader community the opportunity to develop more inclusive attitudes and for all residents to be seen as members of the same community providing informal support as the need arises through relationships of reciprocity. As expressed by one of the

interviewees:

> …our goal for people living in these places is that if they were unwell or they hadn't been there for a week that somebody would actually notice and actually say – oh, where have you been, or that there would be people who would say hi to them and know them by name…and one of criteria for living there is that they [the individuals with disabilities] have the potential there to be good neighbours so that's about a reciprocal relationship.

For the broader community and the owners of the housing, which could be the case organisation, the inclusively designed housing is for all intents and purposes 'private' housing available for rent and providing the same (if not greater) tenancy rights as rental properties owned by private individuals. One of the interviewees also suggested the possibility of tenants having equity share in the dwelling. For the owners of the dwellings, the case organisation argues that given their specialised design and location within mainstream housing they be regarded as "…real assets that can be bought or sold" and that this makes more financial sense than owning group homes or lots of units that are often subject to vacancies and becoming "a white elephant".

While a dwelling may be dedicated to a support worker or service provider, they may or may not be providing direct support to the residents with disabilities. As described by one of the interviewees, the intent is for the model to be seen:

> …as being just like supporting someone who lived in the community – just because they [a support worker] happened to be co-located doesn't mean that it should be staffed or that the mentality should be like a shared supported accommodation service and that's been quite a shift.

As the other interviewee continues:

> Yeah, it's a foundation of thinking because when people see this sort of model they think ah shared supported accommodation, just different housing but we say no no no. Community living. Let's look at what we can do to actually get some synergy because they happen to be close together. Huge difference in the end how people approach that as being mindboggling.

The above discussion describes the defining features of the rationales and perceived niche of this organisation and its role and that of the housing industry in facilitating greater choice for people with acquired and complex physical disabilities. However, there is another crucial layer of context that is central to the realisation of advantages and choices: the operational context of service and its relationship to the broader framing of service provision in terms of products and consumers.

Realising the model in the 'market' of service provision

While not articulated to a large extent, the interview with the case organisation representatives did reveal acknowledgement of a role to be played by service providers which in some cases could be as housing providers but most likely as housing managers. Having said this there also appeared to be relief in recognition of the introduction of the NDIS and its promise of greater emphasis on the individual and the development of well-planned individualised support packages, offering recipients greater mobility and choice of

where, how and with whom to live; and, perhaps being the impetus for service providers to reconsider their approaches to support including housing support. If this is not the case it is likely for there to be tension between the ideals of the case organisation and the competitive, market driven reality of service provision, particularly if the service provider is managing the housing.

3   Case Study C: A not-for-profit community organisation

As highlighted previously this case involves a community association working directly with families with an adult child with a disability to facilitate a transition for the adult child from the family home (and the primary care of a parent or parents) to independent living in a 'house' ideally owned and occupied by the adult child. While the case gives emphasis to a particular private housing typology, it is also a case where there is recognition of the need to adopt an integrated, holistic approach working from the individual and family situation and circumstances.

3.1   Organisational context

Organisation type, philosophy, programs and services

The case organisation is a not-for-profit community organisation located in an outer suburb of a state capital. It operates a number of programs and services that can be described broadly as:

- community programs;
- disability support services;
- housing support service;
- foster and kinship care; and
- families change

The organisations vision concerns itself with fairness, sustainability and belonging in the community.

Through their work in the disability sector, the community organisation came in contact with a considerable number of families with aging parents, who were caring for their adult children with disability. These families were part of a generation that had provided around the clock care for their children in the family home, and now entering later life, were facing a future where they were increasingly less able to continue to provide this level of care for their children.   Common to these families was a desire to avoid 'crisis' placement of their children, in the event that the family situation changed suddenly. These families felt that such a dramatic change in their child's life (particularly if their children were forced to suddenly relocate from a home and routine that they had known all of their lives, into an unknown arrangement that was likely to involve forced co-habitation with strangers) would have serious negative impacts on their children's, psychological, social, emotional and even

physical well-being.

Models to facilitate access to private housing for people with disabilities

In exploring options for these families the community organisation began talking to various other organisations including a university and a professional design organisation, the outcome of which was a collaborative partnership between all three organisations. The following diagram captures the initial collective structure (Figure 3.1). Participation in the collective was based solely on pro-bono and in-kind donations of time from all of the individual members and organisations.
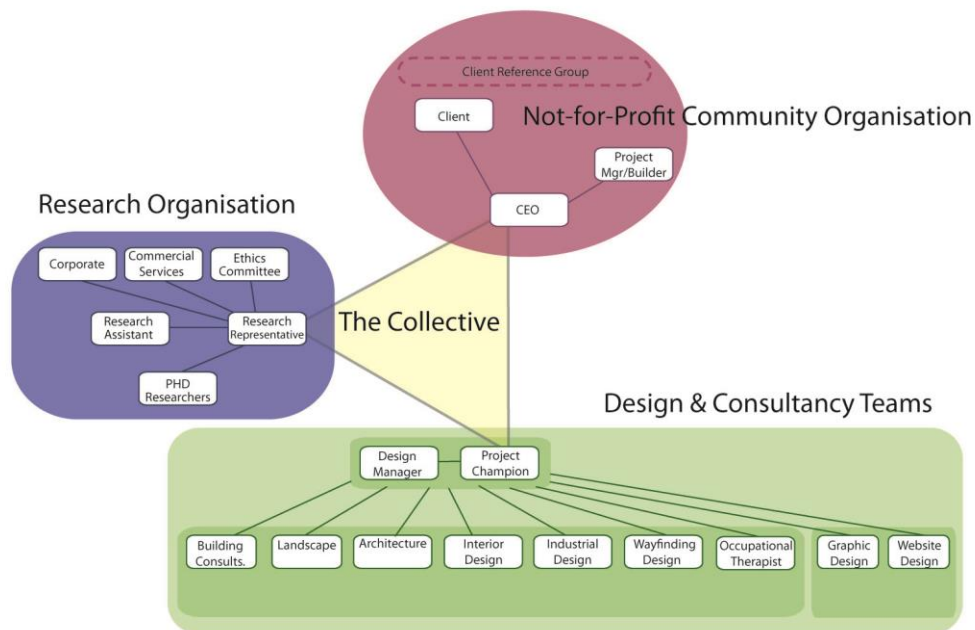
Figure 3.1: Collective Organisational Diagram

After early discussions, the collective agreed on the following overarching aims:
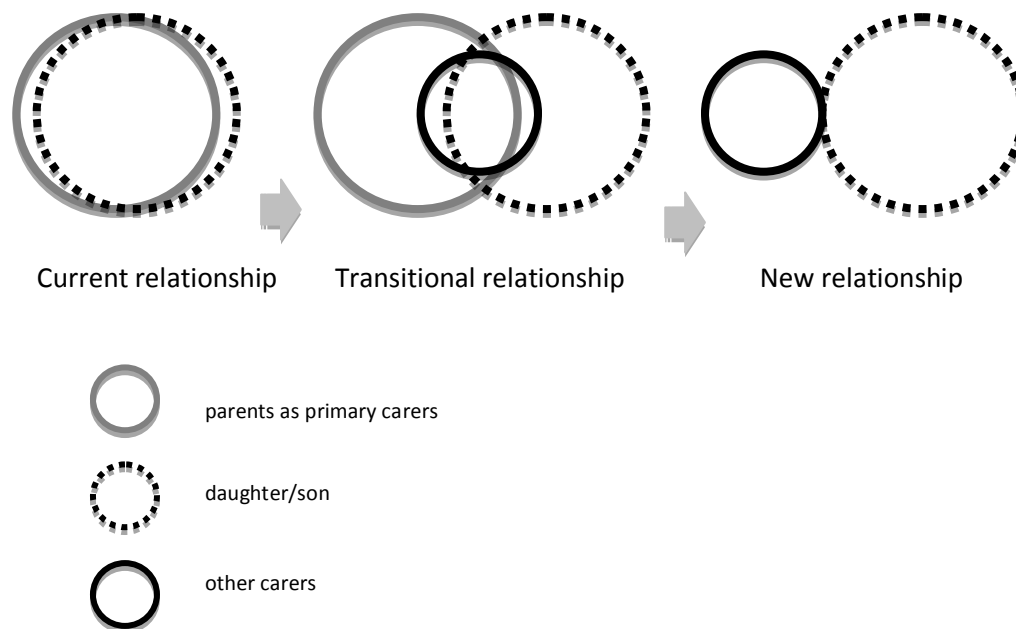
> A world's best practice of Universal Design for government and community to enact their hopes for an inclusive society and enshrined in human rights worldwide. The collective will achieve this through the development of a process and model of research, design and development that is collaborative, innovative, affordable and sustainable (reference withheld).

The concern of the group; to address the obligations of the UN Charter Convention on the Rights of Persons with Disabilities, specifically article 19a (where choice of living arrangement and full inclusion in the community is the ultimate goal), directed them to explore various independent living models for individuals and families. It was agreed within the collective that any such model needed to support families and individuals in making the transition to independent living in a manner and pace that promoted positive emotional, social, psychological and even physical growth. One family in particular generously volunteered a great deal of their time and personal information to participate as an

individual case for the development of an appropriate model. At this stage, the model was envisaged as a particular type of housing design.

Regular whole of group meetings, and focus groups, were conducted to shape and define the project. While these consultations were valuable in being able to utilise the wide range of multidisciplinary design expertise available within the group, it was also necessary to conduct smaller meetings and focus groups with more specific aims. As the project evolved, three clear streams of participation emerged, a steering group (comprising representatives of the three main participating groups) as well as a 'macro' and 'micro' group, which evolved in response to the growing awareness of the complexity of the issues being tackled.

The following diagram (Figure 3.2), illustrates conceptually the process proposed by the collective of transitioning families and their children from their current situations into new, more independent living arrangements.

| Current relationship | Transitional relationship | New relationship |

parents as primary carers

daughter/son

other carers

Figure 3.2: Conceptual model of transition to independence

This model used the social and emotional relationships of the individuals and families as drivers for the physical and functional design. In this sense the project started by focusing on the stories and lives of the families and working outwards from there. Whilst the ultimate hope was that the model could be more widely applicable, it was never an initial goal to create a single model that was then proffered as a 'one size fits all' solution.

In the early days of the project a number of design 'charettes' and workshops were held where the group developed and tested various house design proposals against the project's aims and goals as well as against other models existing nationally and internationally. These sessions were unique in that they drew together researchers, designers and other participants, including occupational therapists, all contributing in a democratic manner

described as consensus design. Many design participants reported that this style of designing represented a large (and desirable) shift for them, in that they were free to tackle the problem with autonomy and control, leaving aside many of the financial and political pressures associated with the paid work that they undertook in their daily lives.

What has been termed the 'duplex' model soon emerged as a frontrunner for the initial case study family. This model proposed two side-by-side or co-located privately owned dwellings, one occupied by the parents and one by their adult child and a carer. The connection to the dwellings could be modified to allow different levels of connection and separation associated with increasing support provided by an external person who ultimately may be a co-resident living there rent free in return for caring for the adult child. With the need to accommodate a number of possible future scenarios, it became evident to the collective that adaptability of the physical form was a key element. It also became clear to the group that such consideration could not occur in isolation from various social, political, legal, financial and support factors.

The initial financial and legal modelling was undertaken using the situation of the case family as its basis. It was well understood by the collective that the position of this family was not necessarily representative of the other families and may even represent a marginal position. In this instance, immediate issues of ownership were relatively straightforward (though still complicated because of different government agencies and their assessments of the family's financial position); however planning for a future where the parents no longer own the property was significantly more complex. As this arrangement was designed to be a 'home for life' for their child, the brief placed high importance on legal arrangements that protected the child's security of tenure. Legal consultation was employed to review how the family might manage the transfer of ownership to a child who would not be considered capable of administering the estate in the eyes of the law. Further attention was given to the possibility of selling one of the dwellings in order to provide for on-going financial security. These investigations brought to the fore ever present issues of vulnerability regarding who might be trusted to always act in the child's best interest as well as help realise their aspirations for future independent living.

The issue of ownership also drew in questions of support. With this being a new model, there was no guarantee as to what level of physical separation was required between the dwellings in order for government agencies to consider the child to be living truly 'independently'. This is an example of one of the dilemmas of the strive for independence in a needs based assessment system. While a child is being adequately cared for in the family home they are assessed as not in need, regardless of the fact that there is an impending greater need ahead for the family. In such instances families may find it necessary (particularly to avoid the crisis placement scenario) to proceed with creating a situation that may generate greater need and hope that their re-assessment is able to adequately assist.

Another financial component of the model, and its ultimate feasibility, related to its physical location. The family was willing to sell their current home and re-build another to suit the new arrangements; however the ability to locate the new home in proximity to current

informal (and formal) support networks was identified as key to its success. As such, cost and availability of land in the area required that a financial analysis needed to be undertaken to weigh up the greater expenditure on a home in the right location as opposed to a cheaper location, which may have less upfront cost yet significantly greater ongoing costs associated with the need to substitute informal care with paid support.

The preceding discussion has highlighted the difficulty in avoiding addressing the issue of care in relation to the provision of person-centred private housing for individuals and families with disability. As a driving principle, the collective worked to first and foremost design a housing solution that helped achieve the family's goals and aspirations. In many ways the separation of these two areas was facilitated by the fact that there was little precedent available to predict how the organisations that fund and manage service and support might react to such a model. In addition, as mentioned earlier, there were no guarantees that the new arrangement would be considered truly 'independent' and that the family would receive the assistance needed to properly realise this new future.

The one perceived advantage of this new living arrangement however was that while the parents may still be forced to provide care until such time as a crisis is reached, the hope is that when that time does come, the child may not have to deal with the double trauma of losing their parent/s as well as being removed from their home. Again, this process involved designing with a number of possible futures in mind, and trying to predict large portions of the equation that remained outside of the control of the family and the collective.

As mentioned earlier, the NPO was approached by families in their network who were grappling with this problem around planning housing for their future. As an organisation, they were in the process of establishing a social enterprise arm responsible for profit generating activities and re-investment back into the not-for-profit organisation. Prior to the establishment of the collective, the NPO had bought and renovated several houses that were then rented by different disadvantaged and marginalised groups. The desire to develop the social enterprise area of the organisation was in some ways a response to an emerging climate of increasing competition for ever scarcer government and philanthropic funding. Like many organisations, it was hoped that the move towards social enterprise would give the NPO greater capacity to respond to their community's needs.

Although there was in-house experience from their previous building projects, they identified additional value in bringing in outside expertise, in the form of architects, designers and researchers who would be able to focus specifically on design for disability. Relatively early in the project, the social enterprise building arm of the organisation was rebranded to better reflect the current focus on independent living. The original aim was that the building arm of the organisation would undertake to build the duplex following its conception and design by the collective. The case study representative described the goal of their organisation in this project as producing "affordable" and "functional" housing outcomes for families. To this end, the organisation committed resources to participate in the project with the goal of building homes and creating a business model that would establish themselves as a provider of person-centred private housing for these individuals

and families.

Unfortunately after a concerted effort by all involved including external financial, planning and philanthropic organisations the NPO was unable to produce an integrated package that would enable the private housing duplex model to be realised. Subsequently, the NPO has diverted its attention to the provision and management of supported accommodation for people with disabilities.

A significant factor in the case organisation's decision to discontinue with the model was lack of funding. In order for the case study organisation to continue to develop the model, given the often slow and complex work of trying to draw together the design, financial, legal and even support considerations (even though they are intentionally not tied together, they still remain relevant to each other), continuing resources were required. In the words of one representative, "we've done so much to this point, we needed funding to continue and there was just none around, everything was very, very tight".

In one interview where the case study representative reflected on the history of the project, the majority of the discussion centred around the issue of resources. As mentioned earlier, the social enterprise venture was created by the organisation in an attempt to generate an independent source of revenue ("alternative models outside of grant funding") and create some self-sufficiency, with any profits generated from the social enterprise re-invested in the not-for-profit arm. This desire came as a result of perceived "fiscal pressures" from both the government and philanthropic sectors and increasing competition for grant funding where "the dollars just are not there".

Although situated within the 'third sector', the organisation understands itself to be operating in an increasingly competitive environment, and that at the end of the day it keeps "coming back to economics". The creation of the social enterprise building arm brought increased pressures to the organisation from the private sector, as they were positioned alongside other builders and developers keenly seeking work in a post GFC setting. Operating within the private sector, the organisation felt "we're not competitive, we're too small" and referenced their vulnerability a number of times. This position was re-iterated also towards its position within the not-for-profit sector where the perception was that size was similarly important to government, who were seen as increasingly wanting to outsource their business and to "move all of that out to the big providers".

This continued focus on economic and business modelling also carries inherent in it the potential to create tension between an organisations ideological goals of providing high quality, affordable, accessible housing (and support services) and their ability to deliver within a climate of scarcer resources. Questions also arose as to how a holistic approach such as this might be supported, with the organisation receiving "recognition from the government that the project was a good idea, but we don't know where it fits. Does it fit under housing? Does it fit under disabilities"? This problem of 'silos', while identified as being an issue within other sectors, is obvious here within the government sector. One example given was of a recently disabled individual who was unable to return to their

current home, and as a result cost the government "$1,000 a day to sit in a bed at the P.A. (Princess Alexandria Hospital)" where that money could be invested in finding or creating appropriate housing but is not able to be utilised for that purpose as it is seen as a 'housing' rather than 'health' problem.

Ultimately, access to resources proved to be the major barrier for all of the collective participants, including the families. In order for the case study family to confidently plan for their own and their family's future and weigh up what their best options are (i.e. spend more on housing in order to save on care or vice versa) they need access to information to be able to respond to such questions as:

- will this new model constitute 'independent living' as defined by the relevant agencies for their child?;
- will additional care funding be provided to help fill the gap between what they are currently receiving and what they will need as they are less able to care?;
- by undertaking this are they able to guarantee a home-for-life for their child? And what legal structures are available to protect this home and life for their child after they are pass away?; and
- given that they are already of retirement age, what are the funding avenues available that would help them manage the difference between the value of their current home and the cost of purpose building the new co-located dwellings in the local area?

In an interview relating to their current position, the family were feeling "increasingly despondent" about their options and are seriously considering the existing options available to them (such as group homes and institutions) regardless of the fact that they know such environments and their associated stressors are likely to negatively impact on their child's social, emotional, psychological and even physical health. After dedicating their lives to providing a loving, caring and safe home the thought of their child being abruptly placed in an institution is "scary".

A common theme that has emerged from all the participants in this case is the high relative importance of housing for these families. To direct quote one family, "housing has to be at the beginning". The organisation still sees a "gap" in the market with many in need and a distinct "absence of choice" available to them, how that need is met, and importantly, what resources are used to meet it, is still an uncertainty.

While this section has provided background information of the case organisation and description of the development and attempted implementation of a model by the NPO for facilitating access to private housing, the following section adopts a more critical theoretical perspective exploring the case in terms of its positions and frameworks as they relate to access to private housing for people with disabilities.

3.2 Positions and frameworks in access to private housing for people with disabilities for Case C

The central role of design in promoting private housing options

The background and model description just provided clearly positions the perceived imperative for the case organisation to prioritise the qualities of the built environment in private housing as a means of enhancing the choice available to people with disabilities, particularly in this case, the options available to families wanting to transition to a more independent and secure future for their adult child when they can no longer care for them in their family home. In other words, suitably designed and located residential environments were understood as a key aspect for access to and continued occupation of private housing for people with disability. To this end, the case organisation located itself in a certain way as part of a move to "understand that design can play a major part in giving people a home, a home for life and understanding the needs of the people to contribute to what they have". One of the initiatives was to involve various 'actors', their 'knowledge' and associated 'organisations'; for example: researchers from a university with knowledge of inclusive, universal and consensus driven design; designers (architects, interior designers, industrial designers, landscape architects, graphic designers) from a professional design organisation with knowledge in their respective areas and a desire to make a pro-bono contribution to marginalised groups through design; specialist disability consultants such as occupational therapists and their knowledge of the physical needs and capacities of individuals with specific disabilities. Influencing this emphasis on design were particular initiatives on the part of the relevant state government that were seen as: "using some innovation and I remember some of the places we visited…and there were some good design ideas there but it was basic. It was really basic stuff".

At a fundamental level, how the case organisation understood the problems and issues was framed by events at a broader macro and historical level. Both the vision statement of the case organisation and the design collective reflect influence from the Human Rights Movement and principles as outlined in relevant charters and anti-discrimination legislation. Of primary influence was the United Nations' Convention on the Rights of People with Disabilities (UN, 2007) that states that people with disability have the right to "full and effective participation in society" (Article 3), and should "have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others" (Article 19). Also influential in terms of housing for people with disabilities was the de-institutionalisation movement and increasing emphasis after World War 2 on normalisation, social valorisation theory and policy change through the enactment of the Disability Services Act (DSA) (1986).

In all, however, the community organisation took the view that there has been minimal response in relation to private housing (which they believe offers greater choice and opportunities for independence), with the private housing market making few concessions

to the design and location needs of households with people with disabilities. For instance, the National Construction Code has no access requirements for the internal spaces of housing and the Universal Design movement which is beginning to influence reforms in this area only focuses on general physical needs of accessing and using essential amenities. There is no consideration of the diverse nature of disability and of disabilities that are not easily visible such as vision impairment and intellectual disabilities to mention but a couple. It was issues such as these then that influenced the community organisation in understanding the problem and moving to a more individualised design approach.

Also influential was an appreciation of the changing nature of life and of their understanding of accessible individualised design being applicable to housing design more generally: "the design that we looked at has to not only be for today but for the future and has to be adaptable design". The model developed in line with these principles was, according to interviewees, seen by government as a "damn good idea". However, as previously mentioned, they faced the formidable challenge of finding the funding required to continue the work in a context where everything was "very, very tight", and where they were in danger of being caught between the kinds of funding sources that were seen as appropriate.

Market Niche, Choice and 'Private' Housing

Creating a market

These issues identified previously were understood as central to the evolution of the current position and model of this organisation. In particular, they precipitated the perceived requirement to establish a housing niche of their own and alternative funding sources: "How do we create a market? There's a need, a gap. How do we create it"? The basic rationale for this market was this organisation's attempt to create financially viable options for independent living that responded to the need to expand the choices available for people with disabilities and their families. The conception of choice in this case is based on scenarios of the way families in these circumstances negotiate their options as the adult son or daughter moves to more independent living. The previous section described in detail the central role of design in promoting housing options that optimised family proximity in care provision but also attended to independence. The interviews underlined the significance of these options for a field that increasingly emphasises choice. In circumstances where ageing parents require new arrangements for the support of their adult son or daughter, many lacked viable choices:

> People in those circumstances, you don't know what you don't know … all they know is that they've got to do something but what's that something? What does that look like? How do you get to it? What's the path to get to it? No one was giving them a path.

Many were unable to access public housing and thus, it was observed: "the options were they had to stay where they were and do the best that they can".

The provision of choice

The interviews identified a number of elements that were seen as essential for 'choice' to be actualised outside of the very limited public housing options. The service provided by the

organisation was central to these discussions, where their emphasis on the financial viability of housing options, and design that promotes independent living, care relationships and accessibility were seen as crucial contributions to choice. Their model also entailed an emphasis on broadening understandings and applications of principles of accessibility:

> When they say accessible and disability adaptable homes, people picture wheelchairs. It isn't only about wheelchairs. That's one part of a disability sector but that's what they think about. How do I get that wheelchair from A to B? How does it turn in? There are so many other things um that we have to be cognisant about.

However, in addition to the organisation's perceived contribution to peoples' choices, there was also a vital focus on other domains and practices of choice that needed to attend to those offered by their service in order for people to realise access to private housing. These included dispositions and expectations regarding independence on the part of the person with a disability, and, given the envisaged enhanced financial support under disability care, the ongoing external structures and factors that influence the provision of viable housing models.

The capacity of families to foresee their needs and options into the future was also seen as critical, and, closely aligned with this, was the requirement to provide sufficient communication and education to promote the capacity for future planning and expectations regarding independent living::

> It's very one sided saying that every person has the right to choose but if they don't know what to choose then their decision, you can't make a decision if you don't know what to decide on, there's no communication, there's no education.

The salience of 'private' housing

Located in this broader field of choices, private housing appears to have a number of interconnected meanings and salience. First, it provides options beyond the limitations of public housing. Further, however, there is a sense here of the importance of 'private' provision of housing – the market niche achieved by this organisation allowed for the development of new models that incorporated innovative design as a component of the relationships enabling independence, and a social enterprise model of sustaining this provision. Private housing also refers to the centrality of acquiring assets for the ongoing achievement of life chances and independence. The following extract illustrates the way this is seen as a central 'capital' as both housing choice but also the capacity to convert assets into other economic choices:

> You have a legacy um you know, when I pass on, if my child was living in next door or whatever the design incorporated, what I had was an asset, that my more independent living child or partner or whatever was able to say ok, I've passed on or had to go to a nursing home which there is another whole context in that argument, but I can rent that out, I can sell it and this is where we talked about strata titling, where we talked about townhouse, whether it's units, whether it's duplexes were involved because there could be a derived income to continue to

support that person for the rest of their life so here was an asset that was realisable. That's what I call private.

The above discussion describes the defining features of the rationales and perceived niche of this organisation and its role in the centrality of choice for people with disabilities and their families. However, there is another crucial layer of context that is central to the realisation of advantages and choices: the operational context of service and its relationship the broader framing of service provision in terms of products and consumers.

Realising the model in the 'market' of service provision

The organisation located the challenge of providing viable housing choices for people with disabilities in changing concepts of care and service provision associated with market relationships and competition. At the operational level, the challenge was also described in terms of the financial viability of the service, which rested on the capacity to identify, measure, and demonstrate outcomes and thus a return on investment.

The notion of 'caring' as integral to relationships of access to housing was discussed in terms of the diverse forms and roles of care that need to be ready for the NDIS framework. There were many different parts of care that now need to be understood and applied more coherently:

> 'Carers' is an interesting term because it covers so many different things. I refer to things like - even some of the therapies that are needed. They're all part of that whole group that does care for that person. There's a primary of course but there is all that range of different groups so I think we're going to struggle. I think, there's a lot of missing parts to it. I don't think under Disability Care we're ready. I don't know if our work force is going to be ready when they do the big wholesale change because what we are going to be asking you to do is provide a competitive market to the client.

Access to private housing now must be delivered and negotiated through a market based concept of service, one that requires a new coherence and readiness on the part of service providers, but also a cultural requirement for people with disabilities to perform as consumers. This amounts to the capacity of service users to choose their service, but also opens up a domain in which additional skills and dispositions are now explicitly required:

> The person with a disability is now a consumer. There's now competitiveness so what they're going to do is... how do I get to choose who's the best? How do I find out who's the best carer to look after me? Whether it's respite care. Whether it's Blue Care all those sorts of things.

Under the NDIS, the idea of choice becomes attached to the 'person' more prominently as integral to 'person-centred planning'. The framing of choice in terms of market relationships thus adds to the list of capitals required to enter the field of negotiations for viable housing access: understandings, perceptions and agency in making choices.

In addition to the requirements for organisations to orient to a market of service and for consumers to access the capital required for agency and efficacy in practices of choice, this organisation saw the ongoing production of viable housing as crucial for exercising choice, following the principle of providing options "that gives a person with a disability the same levels of choice as somebody without a disability". This is seen as an important component of 'person-centred planning'. In addition to the "vision around being sort of person centred in terms of looking at the service provision and the care side of things" lie the challenges of providing viable housing choices. In relation to this principle the organisation envisaged significant challenges into the future, in generating the capital to provide these choices. In this context, frameworks of service and choice are firmly set in terms of economic models:

> If you look at our broader societal directions and priorities, pretty much everything is driven economically. Like I even think in the aged you know, the aged equation is going to be driven by economics. It hasn't been driven by ideology to say that as we age we're entitled to make choices and stay in our own homes. They get driven economically.

The organisation's response to this is to consider models entailing social impact bonds, requiring demonstration of outcomes in terms of tangible benefits of the service provision and demonstrating returns on investment. This presents the possibility of maintaining a focus on rights and social outcomes overlaid and supported by economic models:

> If you look at rights like there's no other sector that's more based in rights, you know. That's been pushed for a long, long time but I think it's the economic imperatives or economic modellings that will actually help achieve that.

4   Case Study D: An Intentional Community

This case describes a response to housing need instigated by a mother for her adult son with profound intellectual disability. Underpinning this is the mother's desire to safeguard her son while also enabling him and others with disability to be included more in community and everyday life.

4.1   Context

In the previous cases this section provided background information of the case organisations in terms of their type, philosophy, programs and services. In contrast, for this case there is no organisation as such but rather individuals and groups working together to create and sustain a housing model integrally linked to the notion of community and the opportunity for people with disability irrespective of severity to live as full a life as possible.

Background

As indicated, the case described here revolves around a particular person, a young man now

27 years of age who we will call Robert. Robert has a genetic condition that since birth has had a profound impact on him intellectually and to some extent physically. In his mother's words:

> He has never learnt to wave goodbye. He's never learnt to point. You know really basic things and he's never learnt to babble, so he's got no spoken language and I'd say he's got very little receptive language. He's completely dependent on people for every single thing in his life.

Apart for short periods of time when he was in respite or foster care, Robert has lived at home with his mother, father, and three brothers. Following the death of his father and his brothers moving away from home, his mother (Cathy) has been his primary carer. In doing this, one of Cathy's most constant struggles has been to have Robert included in life, whatever aspect of life that is. What she has learnt over the years is that "he is always, nearly always ignored. People don't, they often don't look at him; they don't greet him; they don't address him. He's not really ever included in anything". In an attempt to have Robert more included in life, and for that life to be productive and regarded as having value, Cathy established a mail courier business in his name. Every workday Robert in his van with a driver delivers parcels in the neighbouring suburbs.

Conscious of the need to consider a future where she could no longer be Robert's primary carer, Cathy began investigating ways that Robert could also have a home of his own. And in this regard, she "pretty much was always stuck on an intentional community model". As Cathy elaborates:

> I never wanted him to be in congregate care, I never wanted him to live in a group house because he is really vulnerable. He's had the most horrible things happen to him when he's been with others, well staff who don't know him, and other people with a disability. And one of the best things about him moving into his own home, I thought, he never has to go to respite again. He never has to do that again, he will be safe, and he is safe too. Anyway, so I probably started the very, very hard work about the intentional community in about 2004.

The intentional community model

Informing Cathy's work in relation to the intentional community was considerable research of existing intentional community models. In the early days, one of the most inspirational was the Rougemount Co-operative in Pickering, Canada established by the Deoaheko Support Network, a group of families with adult children with a developmental disability. Taking advantage of a federal and local government cost sharing arrangement, a 6-storey, 105-unit housing co-operative ensued providing housing for a diverse group of people including the seven adult children of the support network.

At the heart of the model is the idea of a family governed approach "to building strong community" where people intentionally seek out ways to work together to be good neighbours for one another and for everyone, including the adult children with disability, that they "might live good, full, and contributing lives". As they emphatically state:

> for our sons and daughters, and for ourselves, Rougemount is not a residential

> option. It is home. It is where people are hosts in their own home, co-operative members with rights and responsibilities, and good neighbours to one another. There is no support service within the building, and no office for the Deoaheko Support Network. Supporters work directly with people in their homes…We are not a service model, not an agency. Board members are family members. Paid Supporters work for each family separately. Each person's life is very unique and is supported as an individual.

Also significant is how Rougemount can influence the wider community. In addition to supporting their own children, the Network families are conscious of:

> supporting, modelling and building a lifestyle in our community which touches a least a few hundred people – family, friends old and new, neighbours, co-workers, fellow volunteers, the artists and musicians with whom they share a passion, shopkeepers and merchants, librarians and teachers, and many more – in ways that people say make a profound and positive difference in their own lives.

Not having the resources to fund an intentional community privately and inspired by Rougemount which, as previously mentioned, was government funded, Cathy began lobbying senior government disability and housing bureaucrats that the intentional community model was worth pursuing as a public housing option. At the same time, Cathy also spearheaded the formation of a family governance group comprising herself and two other mothers with adult children with disability and in 2006 the group set about actively working towards the implementation of the model for their sons.

After several frustrating years and many visits to various government ministers, the government eventually provided land and in 2010 agreed to fund the construction of a 25 dwelling public housing estate with 11 of the 25 units earmarked for the intentional community and 3 of the 11 units for the sons of the family governed group. Years earlier this would not have been an option for Robert, unless he was abandoned, homeless and on the crisis list. While later policies opened up the potential for Robert to secure public housing this is likely to have been unsuitable given his high support needs and his mother's vision for him to live in a supportive community close to his family and network of support.

While Cathy's original vision for the development was to be in a natural setting with units located around communal areas and facilities, she reluctantly accepted the argument that this was a public housing development demanding the most cost efficient design and use of the site for the building units. What she was adamant about however was that Robert's unit should have three bedrooms, one for him, one for his co-resident, and one for support staff when they relieve the co-resident. Co-residency is central to Cathy's vision of Robert receiving the extent and quality of support he needs and deserves. With the co-residency model, the co-resident is paid a salary as well as living rent-free. When the co-resident has time off, support workers provide the required 24hr care. As Cathy explains: "the co-residency position is a position like any other job in that you get a salary, you get a duty

statement, you have conditions of service [such as forging new relationships for Robert]…he is a permanent full time employee”.

To fund the required support, Robert receives an individualised funding package. The package is family governed and supported by a host NGO agency that employs the network's coordinator and takes care of the fiscal, administrative and legal processes. The host agency also employs Robert's courier driver with his wages coming from the earnings of the business.

In early 2012, construction began and in May 2013 Robert moved into his new home. As it turned out, Robert was offered a four-bedroom two-storey unit designed in line with universal design principles for wheelchair access and mobility. Because Cathy remained actively involved in the project throughout, she was able to make suggestions and recommendations many of which were accepted by the department. For example, she asked that one of the upstairs bedrooms be turned into a sitting area and office for the co-resident and support workers. She was insistent that downstairs accommodating one of the bedroom's, bathroom, laundry, kitchen, dining and lounge areas adjoining the garage and outdoor courtyards was Robert's home and she did not want an office in his home for the support workers. She also asked for added acoustic insulation in Robert's bedroom to minimise external noise but also help absorb growling sounds that Robert sometimes makes.

For the intentional community component of the public housing estate, Cathy argued that as for Rougemount residents would need to apply to live there and satisfy certain criteria such as excellent tenancy record, no history of alcohol abuse, and so on. Surprisingly for some people, the relevant department accepted her proposal undertaking information sessions and implementing a selection process that also required applicants to outline how they could contribute to the community and why they would like to live there.

The resultant community is diverse; comprising young families, singles and married couples and people of different ages and ethnicity. In the course of six months the community has hosted concerts and barbeques. As Cathy comments: “The fact that all the people in the intentional community know each other and greet each other and talk to each other and go to each other's houses and borrow herbs from each other and plants you know that is, as I imagined. It's really good”. And for Robert, “the number of people in his life has definitely expanded”.

Despite the early signs that things are working well, Cathy acknowledges the crucial role she plays in keeping all parts working together, the family governance group, the intentional community, the host agency, disability housing around the needs and aspirations she has for her son. As she says: “none are enough on their own”. To further safeguard then and for Cathy to be able to reclaim some of her life, she is now working to establish a micro board of five people governed by a constitution where members undertake to uphold her values and philosophy in the shared support of Robert as a unique and productive individual.

Positions and frameworks in access to housing by people with disabilities

The central role of attitudes about disability and the potential of people with disability to live "good, full and contributing lives"

The approach by Cathy just described has as its central driving force, the desire for her son, despite his dependency on 24hr support, to experience a full life and a community lifestyle in which he is supported and acknowledged as a unique and productive individual. Central to this is housing that is his home located in a safe, inclusive community comprising a small number of other people with disability as well as people without disability. For the intentional community model, housing is not seen as independent from the community but rather as the hub of an immediate and wider social network. Underpinning this more fundamentally is the notion of personal agency, both Cathy's and Cathy's belief in Robert's agency. Added to this is Cathy's acknowledgement of the agency of the house in which Robert resides in the general community and its potential, together with Robert having his business and leaving and arriving home every work day, to challenge and change discriminatory beliefs and behaviour.

The approach adopted by Cathy reveals her agency acting from the centre out; from her understanding of her son's and her needs and aspirations, to the immediate community as well as to society more broadly where she actively challenged existing disability support and housing policies. In all, Cathy's approach reflects an understanding of disability that recognises both its socially constructed nature and as well as the influence of her son's individual needs and her aspirations for him.

Market niche, choice and 'private' housing

Creating a market

While not a market in the private market sense, Cathy's approach involved establishing support of the need to develop an alternative approach in the provision of social housing for people with disability; an approach that recognised the need for specially designed affordable, appropriately located housing that suited individual needs physically, psychosocially and existentially.

Remaining for Cathy is some uncertainty about Robert's tenure situation and ontological security particularly if she is no longer there to represent him. While he has a head lease in his name, there is the potential risk of him being forced to move or to share his house with another tenant given that it is three-bedroom house.

The provision of choice

In Cathy's case the main actualisers of choice are structures and systems across the ecological framework all working in alignment to support the individual with disability and their right to live in the housing type and tenure of choice. So, for example, in terms of financial barriers these were addressed by focusing attention on what might be possible within the social housing and disability support sectors. Supplementing this is some private income generated by Robert's mail courier business. As Cathy mentioned, had she had

access to more funds she may have considered developing a private intentional community. This aside she acknowledges being inspired by other examples of intentional communities particularly international examples supported by local and federal governments.

In identifying the intentional community as a possible option and then realising it, Cathy had to also overcome quite significant information, communication and facilitation barriers. In many ways this was addressed through her own research to understand options and potential barriers, her involvement in various community groups and the development of supportive relationships, her ability as a communicator, her personal commitment to and belief in her son, and supporting this her many personal traits particularly her resilience.

From an environmental perspective there was the challenge of convincing the Department of Housing to provide a house specifically designed for her son's needs including accommodating a co-resident and relief support workers in a way that did not impose on her son's living space and make it look anything less than a normal home. Social barriers were addressed by designing the community around the housing and situating it with other social housing and the general community. In terms of support, Robert receives a family governed individualised funding package.

To coordinate all the various facets – the family governance group, the intentional community, the host agency and the various government departments, demands considerable effort by Cathy. Appreciating the risk and wanting to further safeguard Robert's quality of life she is, as indicated previously, in the process of establishing a micro board to share the support of Robert in a way that reflects her values and philosophies.

The salience of home

Rather than the concern being restricted to affordable and physically appropriate housing, this case demonstrates an appreciation of housing and its meaning beyond that as a building merely providing shelter or accommodation. For Cathy, Robert's house is integral to him living as full as a life as is possible. The case demonstrates what is possible with social housing in responding to individual situations, needs and aspirations normally associated with private housing ownership albeit with a tenancy structure somewhat like private rental that makes Robert more vulnerable to external factors than that provided through private ownership. In other ways of course, particularly through the house's design and connection to the intentional community, it provides someone like Robert with profound disability with affordable access to greater security and opportunities for community involvement and participation.

Realising the model in the 'market' of service provision

In terms of service provision, this model makes a clear distinction between housing and service provision while also recognising the need for each to be considered as part of a holistic approach. Rather than a changing cohort of support workers, the support in this model is provided through a co-resident who is paid a wage and lives permanently with Robert who holds the head lease. Essentially, Cathy manages the services on an individual basis with some administrative support provided by a host agency chosen by Cathy. With respect to the intentional community collective, it is managed by the main stakeholders

including the residents and their family governance group.

While this case reveals how people closest to those with disability can effect significant change, including at the policy level, it does not attribute this to personal agency alone, nor does it assume that everyone in a similar position has or should have the required capacity/capability. Rather, it highlights factors that contribute to personal agency and potential roles for the government and/or other organisations in relation to person-centred approaches and planning. In addition, it suggests the need for further exploration of how, even close family members, interpret aspirations, not just needs, for those with severe disability and how these can be understood as the son or daughter ages. With its focus on social housing, the case also challenges stereotypical views of social housing as standardised and inflexible, and invites further consideration of how continuing ontological vulnerability can be addressed through more secure tenancy arrangements.

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