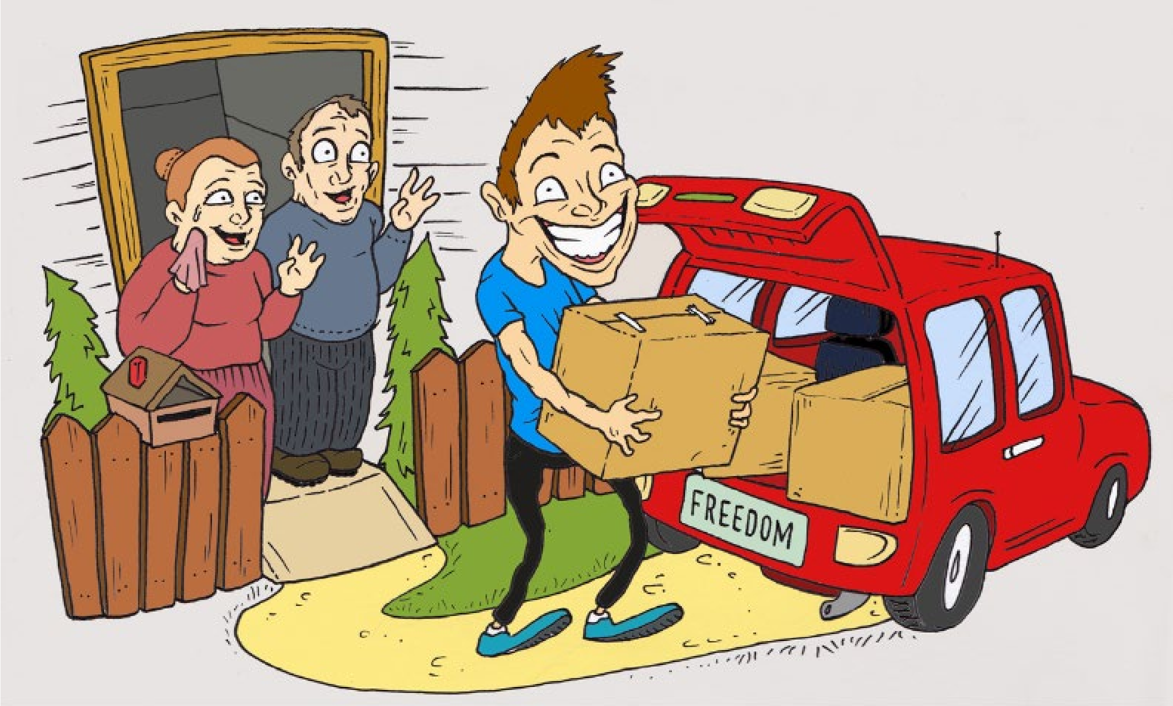
HOUSING AND SUPPORT FOR YOUNGER PEOPLE WITH DISABILITIES TRANSITIONING TO INDEPENDENT LIVING:

ELEMENTS FOR SUCCESS IN THE DESIGN AND IMPLEMENTATION OF DISABILITYCARE AUSTRALIA, A NATIONAL DISABILITY INSURANCE SCHEME



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YDAS
YOUTH DISABILITY ADVOCACY SERVICE

Housing and Support for Younger People with Disabilities Transitioning to Independent Living: Elements for Success in the Design and Implementation of DisabilityCare Australia, a National Disability Insurance Scheme

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Further copies of this publication are available by contacting YDAS: ydasmanager@yacvic.org.au

Electronic versions can be downloaded from www.ydas.org.au

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CONTENTS

EXECUTIVE SUMMARY

Young people with disabilities wanting to make the transition from living with their families to a place of their own face many challenges. These relate to their level of confidence in their ability to live independently, the confronting concerns held by family, friends and carers about their safety and survival, and the difficulty involved in securing flexible supports. This project provided an opportunity for the voice of younger people with disabilities to be heard in shaping policy and practice with respect to housing and support in a new disability funding paradigm, DisabilityCare Australia, a National Disability Insurance Scheme.

This research involved a multi-pronged approach to data collection. It included:

- a systemic meta-review of the literature containing empirical evidence in relation to independent living arrangements for people with disabilities,
- a review of the grey literature that identified research documents and reports that are more associated with the work of practitioners in the field,
- an online survey with a separate questionnaire for people with disabilities and family members,
- qualitative research involving face to face interviews with people with disabilities and family members,
- focus groups with people with disabilities, family groups, advocates, and
- interviews with peak bodies and specialist agencies.

The literature review was clear in identifying that smaller scale dispersed housing consistently outperforms clustered and institutional settings on most outcome measures and that clustered and institutional settings do not appear to offer any consistent benefit over smaller dispersed housing settings. The review demonstrated that widely held beliefs that individualised approaches are too expensive are not validated by the evidence. It also challenges the idea that people with higher support needs need to be housed in group or congregate care settings.

The research found that while a single model of housing could not be identified as the most appropriate solution for everyone, there were key elements to effective housing and support for people with disabilities. These were accessible homes in central locations, homeliness and privacy, clear rights and responsibilities, consumer control, individualised arrangements, flexibility of support, protection and enhancement of informal relationships, a sense of belonging to a community, responsive services and personal safeguards

We also found examples of good services and exemplary practice that are delivering on the kind of outcomes that people with disabilities and families desire, enough to show that it can be done well. There is an opportunity under the DisabilityCare Australia to expand these approaches across the country.

We have learnt that people with disabilities and their families and supporters are an untapped creative resource. DisabilityCare will need to know how it can best support co-design and co-production that will bring this experience and passion to the table.

Consultations across different jurisdictions highlight a common demand for trustworthy information. Many consumers of disability services complained about the lack of good information and support from their current service provider and are increasingly wary of the competing and conflicting interests between provider and consumer. They would like to see peer support structures, independent advocacy and information resources that encourage consumer empowerment and informed decision-making.

Furthermore, there is clearly a need for a choice of dwelling types in a variety of locations that are both accessible and affordable. While the provision of housing rests with housing authorities and urban planning arms of government, we argue that DisabilityCare needs to be active in lobbying for a greater investment by governments in housing in both the social housing and private housing markets.

There is also a strong challenge to DisabilityCare to establish effective policies and procedures for the administration of personal budgets under the scheme. This report calls for a paradigm shift in the relationship between the funder and the person receiving the funding that trusts individuals to know what works best for them, and that allows participants in the scheme to research what works best by taking risks, trying new things and being allowed to make mistakes.

The development of disability support strategies that encourage a mix of paid formal supports with the informal and natural supports within our communities is a key recommendation of this report. This work requires expertise and skills and must be done in a developmental manner. Investment in this area needs to be seen as having a potential positive benefit to the financial bottom line of DisabilityCare.

The report highlights some key issues for consideration as DisabilityCare is rolled out across the launch sites in the coming months. The pressures to set up and establish the new disability support framework will be a consuming process. Through our consultations, we discovered that there are good ideas and motivated people who want to engage with the design and development of DisabilityCare and its operation in their local communities.

INTRODUCTION

"A person's home is a sanctuary, a place for rest, for socialising with friends and sharing life with significant others. It is an important platform for life in the community."

The Youth Disability Advocacy Service (YDAS) is a state-wide advocacy service for young people with disabilities aged between 12 and 25. YDAS works alongside young people with disabilities to raise awareness of their rights and to support them to achieve what they want. YDAS is funded by the State Government of Victoria.

YDAS, through a grant from the City of Melbourne, ran a forum in December 2012 called *Moving on Out - A Housing and Independent Living Forum for People with Disabilities, Families and Disability Sector Workers*. There was a strong response to this forum and many issues were raised by participants, which are addressed in this report.

The current research was funded by the Australian Government, through the Practical Design Fund, to investigate how younger people with disabilities' housing and support needs can best be met in the design of DisabilityCare Australia, a National Disability Insurance Scheme. It considers what is needed to enable younger people with disability support needs to transition from the family home or an institutional-style arrangement to an independent life in the community. This report is an example of YDAS's commitment to respond to the needs and aspirations expressed by people with disabilities, their families and other experts in the field to improve housing and independent living options.

Until recent reforms, disability service delivery trends and dominant practice have revolved around segregated, congregate care models for people with disabilities. The development of individualised approaches and packages of support in some Australian states and territories has provided new stimulus for the development of service and support arrangements that offer more individualised and more inclusive living options for people with a disability who rely on funded support for their activities of daily living. The commitment by the Australian Government to deliver a National Disability Insurance Scheme (now called DisabilityCare) in which there is a strong commitment to entitlement to disability supports and individualised, consumer-directed approaches to funding, sets the scene for new and more diverse housing and support arrangements.

Research methodology

The research involved a multi-pronged approach to data collection. It included:

- systemic meta-review of the literature containing empirical evidence in relation to independent living arrangements for people with disabilities,
- a review of the grey literature that identified research documents and reports that are more associated with the work of practitioners in the field,

- an online survey with a separate questionnaire for people with disabilities and family members,
- qualitative research involving face to face interviews with people with disabilities and family members,
- focus groups with people with disabilities, family groups, advocates, and
- interviews with peak bodies and specialist agencies.

Research Team

A diverse team of researches carried out this project:

- *Dr George Taleporos* – the Manager of the Youth Disability Advocacy Service, experienced advocate with a doctorate in psychology. He has lived experience of disability and expertise in self directed and individualised supports.
- *David Craig* – A disability consultant with extensive experience in community development, advocacy, leadership and management within both disability service provision and independent disability advocacy organisations.
- *Mark Brown* – Researcher and Deakin University PhD candidate, with lived experience of disability and recent experience of moving out of his family home.
- *Cath McNamara* – Project officer at FIELD (Furthering Inclusive Learning and Development) and holder of a Masters in Social Science. She has extensive experience in the development of attendant support schemes, promoting independent living and direct family experience from her life with late husband (a well-known disability rights activist and advocate).
- *Sarah Forbes* – A community development worker with a strong background in person-centred service development and a recipient of an Ethel Temby scholarship to research leading international and national practice in community inclusion.

A systematic meta-review of academic empirical evidence

Living options for people with disabilities have been addressed in a variety of literatures, including medical, allied health, and sociological literatures. It was apparent from an initial search of academic citation databases that there were over 3000 journal articles, books, and other publications that in some way concerned living options for people with disabilities. In the past 15 years, several systematic reviews have been conducted into the outcomes associated with different housing and living arrangements for people with disabilities. To efficiently gain an understanding of what has been well-established by empirical studies, we undertook a systematic meta-review (a systematic review of systematic reviews) with regard to disability and living arrangements.

Systematic reviews (also referred to as meta-analyses or meta-studies) are increasingly used in academic disciplines where there are large bodies of evidence that might be relevant to answering important questions. The premise of systematic reviews is that, because any one study can be affected by biases of the researchers, characteristics of the methodology, idiosyncrasies of the local context, or indeed, by mere random chance occurrences, a systematic process that integrates all available high quality evidence provides the most reliable and valid picture. Because systematic reviews report the methodology used to identifying, filter, and synthesise data, there is a basis for evaluating the validity of the conclusions drawn by the review authors.

The aim of this systematic meta-review was to investigate:
1) What are the well-established findings regarding what does and does not work in the provision of living options for people with disabilities?
2) How and to what extent does this apply to young people with disabilities transitioning to adult living options?

Methodology

A systematic search was conducted in February 2013 of 17 academic citation databases. The databases searched and the search terms employed are described in Appendix A. The titles and abstracts were then manually screened to identify duplicates and non-relevant publications. A record was deemed relevant if it was focused on any aspect of housing arrangements or transitions for any group with a disability, impairment, or illness, and employed a systematic process for reviewing empirical literature. (Reviews dealing primarily with elderly populations were excluded). The search was supplemented by manual searches of the reference lists of selected key publications. At the end of these processes, 16 systematic reviews were identified. The full text of one of these reviews (Felce, 2000) could not be obtained, and therefore was not considered in this review. Another three reviews (Chilvers, Macdonald & Hayes, 2010; Leff et al, 2009; Newman, 2001) concerned housing and people with psychiatric disabilities (i.e. long-term mental illness). These reviews drew few conclusions, however, and are therefore not discussed further in this report.

The remaining 12 reviews fell into three categories:

- 8 were systematic reviews of studies on outcomes associated with different living arrangements for individuals with intellectual disabilities

- 4 were systematic reviews seeking to identify factors associated with “successful transition” to adulthood of young people with disabilities.

Outcomes for people with intellectual disabilities

The success of deinstitutionalisation

Five systematic reviews examined ‘deinstitutionalisation’ studies - studies that followed people with intellectual disabilities who were living in an institutional setting as they transitioned to a community living arrangement. Such studies compare residents’ scores on outcome measures across time (pre-transition and post-transition), or between those who did make the transition and those who remained in institutions.

A consensus finding of these reviews was that, on most outcome measures employed, and across countries, deinstitutionalisation has typically had positive effects. In a review of 33 US studies conducted between 1980 and 1990 that met inclusion criteria, Kim, Larson, and Lakin (2001) found almost all studies demonstrated a statistically significant association between improvements in ‘adaptive behaviours’. Young, Sigafoos, Suttie, Ashman, and Grevell (1998) found a similar pattern in 13 Australian studies identified in the academic literature.

Kozma, Mansell, and Beadle-Brown (2009) more recently reviewed 68 international studies conducted between 1997 and 2007. This review found that community-based living is typically associated with better adaptive behaviour, but also improved community participation, social networks and friends, family contact, self determination and choice, quality of life, and greater satisfaction for residents and their families.

Lemay (2009) drew similar conclusions from a review of 37 studies, with inclusion criteria similar to Kozma, Mansell, and Beadle-Brown. The most recent systematic review identified, that of Walsh, Emerson, Lobb, Hatton, Bradley, et al. (2010), also drew similar conclusions from 37 deinstitutionalisation studies published between 1995 and 2005.

Overwhelmingly, then, the evidence points to community settings being preferable to institutional ones for most individuals with an intellectual disability.

What is it about living ‘in the community’ that produces the improved outcomes of deinstitutionalisation? On this question these studies did not provide an entirely clear picture. Definitions of ‘community living’ varied greatly within this literature. Community settings examined in deinstitutionalisation studies included group homes, clustered housing, dispersed single person dwellings, and involved a variety of different support service arrangements (Kozma, Mansell, and Beadle-Brown, 2009; Walsh et al., 2010).

Nevertheless, it seems likely that the size and scale of arrangements is an important factor. Whereas institutions typically house 20 - 100 individuals under the same roof, community living arrangements see much smaller numbers in the same dwelling. It is noteworthy that it is not merely the early studies of the 1970s and ‘80s that support deinstitutionalisation. Reviews limited to more recent studies reach similar conclusions. One might expect that, in response to early evidence of the problems associated with institutions, those institutions that continued to operate would have sought to make improvements. That recent studies show significant benefits of deinstitutionalisation may suggest that there is something fundamentally problematic about highly congregate living, not easily addressed by changes to management practices of institutions.

Comparisons of different non-institutional settings

Review authors note that there is considerable variability in outcomes in non-institutional settings. Simply living in a smaller setting does not seem to, of itself, guarantee good outcomes. Clearly, the specifics of a community living arrangement impact its success for people with intellectual disabilities.

There were two systematic reviews of studies that compared different types of non-institutional settings. Mansell and Beadle-Brown (2009) reviewed research comparing clustered housing, residential campuses, and village communities, with more dispersed housing. From 10 studies in the international literature which met inclusion criteria, it was concluded that dispersed housing is either superior to, or no worse than, clustered settings on most quality of life indicators. These indicators included measures related to social inclusion, interpersonal relations, material well-being, emotional well-being, and physical well-being. (A notable exception, however, was a single study on village communities for people with less severe disabilities; this study found some benefits associated with the particular village community studied.)

Walsh et al.'s (2010) systematic review also considered 30 studies comparing different community settings. From these, they concluded that choice and self-determination were more available, and that greater participation in community activities occurred, in "smaller, less institutional settings". With regard to other outcome measures (including personal skills, material well-being, social networks and friendships, employment, emotional well-being, challenging behaviours, physical health, and life satisfaction), they concluded that little empirical evidence exists, or that results are inconsistent. The article does not, however, clearly detail the criteria used to reach these conclusions; these conclusions should accordingly be given less weight.[1]

The findings of these systematic reviews further suggest a fundamental problem with arrangements that cluster individuals with intellectual disabilities. As Mansell and Beadle-Brown (2009) point out, "If exemplary clustered settings, comprehensively outperforming dispersed housing, did exist it seems likely that they would by now have appeared in the research literature." Beyond this, however, the specific characteristics that produce good outcomes are not well established. We return to discuss why this may be so in subsequent sections.

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[1] There was a third systematic review (van Blarikom, Tan, Aldenkamp, & van Gennep, 2006) concerning people with intellectual disabilities who also experience epilepsy. It concluded that there was insufficient evidence to draw conclusions with regard to this sub-population.

- For individuals with intellectual disabilities, smaller scale dispersed housing consistently outperforms clustered and institutional settings on most outcome measures
- Clustered and institutional settings do not appear to offer any consistent benefit over smaller dispersed

Young people with disabilities and transition

None of the systematic reviews or meta-analyses discussed thus far were focused on young people with disabilities, nor did they specific address the applicability of their findings to young people. However, there were foursystematic reviews identified that concerned the broad topic of young people with disabilities and their transitions to adulthood. Although none aimed to address transitions involving housing, they were considered for any broader lessons on transition management.

Algozzine, Browder, Karvonen, Test, and Wood, (2001) conducted a systematic literature review of the effectiveness of interventions intended to develop various 'self-determination' abilities in individuals with disabilities on the basis that fostering these skills may facilitate a better transition to adulthood. The great majority of the 22 studies that met inclusion criteria involved young people with intellectual disabilities. From these studies, the authors concluded that there was "strong evidence" that young people with intellectual disabilities can learn to make choices and solve problems, and "modest evidence" for the efficacy of teaching self-advocacy skills. The studies drawn on to reach these conclusions, however, involved a range of definitions and measures of the target abilities, such that the results aggregated do not provide a clear picture of what specifically should be taught and how. Moreover, these authors note that little research has sought to actually demonstrate a link between the self-determination abilities that are taught, and broader quality of life outcomes for individuals. Thus, this 'self determination' literature appears to be in its infancy.

Betz (2004) conducted a systematic review seeking to identify what is known about how adolescents with disabilities or chronic diseases transition from paediatric to adult health care services. The 43 relevant studies identified varied greatly in the issues addressed and the characteristics of participants, and it was noted that most studies employed problematic methodologies or failed to report the methodology in sufficient detail. Nevertheless, several common sense principles that were commonly suggested by participants of such studies as being 'good practices' for transition were noted. These included: formal plans and coordination of transition between health care services, treating youth as mature individuals, counseling and advocacy support, services for families. The main conclusion drawn, however, was that health care transition research is also only in its early stages, with a larger and higher quality evidence base needed.

A similar conclusion was also in a systematic review by While et al., (2004). These authors identified 126 studies or reviews on the topic of the transition from paediatric to adult health care services. Numerous suggestions for 'good practice' were noted. The most common suggestions were intra and interagency agreements, transitional teams or workers, and specific communication systems during transition. However, among these 126 studies, only three were deemed to provide any strong evidence for practice. Given this paucity of robust evidence the authors did not draw any conclusions about specific practices, but rather urged for further research.

The most recent systematic review identified on transition - that of Crowley, Wolfe, Lock, and McKee (2011) - suggests that there is still little robust empirical evidence available.

- Research on young people with disabilities and transition is limited by methodological problems
- Specific transition services and programs, and the teaching of self-determination skills, are commonly cited strategies for transition management

Implications of the empirical literature

The systematic review literature shows what is well established by empirical evidence and where there are gaps. Although there are likely new areas of evidence emerging, these do not appear to have been subjected to rigorous systematic evaluation and review, and it is beyond the scope of this report to do so.

The evidence suggests that there is no basis for selecting any particular models as best practice. Claims that model X is suitable for Y population should be viewed with scepticism in the absence of substantial evidence. Of course, academic research moves slowly, and governments and disability organisations do not have the luxury of waiting for the evidence base to mature. However, there is a strong case to be made that good outcomes are more likely to the extent that people with disabilities can have living situations that are customised to meet their needs as an individual. We suspect this will be especially true for young people with disabilities in a period of transition to adulthood.

The literature pertaining to people with intellectual disabilities indicates that scale matters. Larger scale arrangements which cluster people with intellectual disabilities consistently perform worse than smaller, dispersed arrangements on almost all outcome domains. One factor may that large scale, clustered settings promote a stigma about people with disabilities and become a barrier to community inclusion. Another explanation may be that scale *necessarily* limits freedom, choice, and individuality. To the extent that any individuals share a resource, they must compromise on its use when their needs or desires for it do not align. For example, able-bodied friends living together must compromise on who watches a shared television if they wish to watch different programs.

Co-residents cannot have complete freedom over that common resource. However, in such an arrangement, such a trivial compromise is likely well offset by the many benefits of living with a good friend, such as company, support and economies of shared expenses.

People with more severe disabilities, however, typically share resources linked to their core human needs when living in congregate arrangements. For example, to the extent that someone shares support staff with others, they may have to compromise on when and how often they can eat, sleep, use the toilet, relieve pain, socialise, work, study, engage in activities meaningful to them, receive medical care, or receive advocacy support; and they must compromise on which staff are hired and how they are selected. Sharing an environment or equipment will also involve similar compromises: for instance, what makes a kitchen well adapted to one person's disability may make it more inaccessible for their housemate; having the heating turned up may bring comfort to some and discomfort to others. Moreover, if individuals are very dependent on shared resources, then it becomes difficult to accommodate an individual's changing needs without this impacting the others using those shared resources.

Of course, some compromise is a part of life, and on a small scale, resource sharing may have a negligible effect. However, when an individual must compromise on core human needs, objective and subjective quality of life will inevitably be diminished. One would expect that this principle would generalise beyond intellectual disabilities, to people with any disability.

To what extent could congregate living arrangements (e.g. group homes or clustered housing) be improved by better management practices, for example, having more caring, smarter, or more qualified support staff, higher staff to client ratios, innovative building designs or different approaches to creating a compatible mix of residents? As Mansell and Beadle-Brown (2009) point out, "If exemplary clustered settings, comprehensively out-performing dispersed housing, did exist it seems likely that they would by now have appeared in the literature". It seems more likely that congregate living is fundamentally problematic.

What then constitutes 'best practice' for the design of small scale, dispersed living options? Again, the only assumption that appears warranted is that needs vary greatly for each individual. The systematic review literature does not point to any particular model or model element as universally important. This may be because the support and housing needs of a person with a disability are determined not just by their diagnosis, but in complex interaction with their individual characteristics and desires: personality, gender, sexual orientation, culture, ambitions, social networks, and past experience, among other factors. In Australia, the current generation of young people with disabilities (many who have experienced mainstream education) may not identify particularly strongly as 'a person with a disability', but rather as a unique individual who merely happens to have a disability. For many of this generation, the prospect of 'fitting into' any disability housing model, other than one tailor-made for them, is likely to represent a relinquishing of their individuality.

If anything is to be deemed ‘best practice’ it ought be a *process* for designing and trialing individualised options. This notion of designing supports to meet an individual’s needs is not new. It has been referred to as ‘person-centered planning’ or ‘individualised supports’, and has been recommended in numerous reports and policy documents (e.g., Bleasdale, 2007; Parmenter and Arnold, 2008). Although frequently cited as a guiding principle of service provision, the experience of our research team in the disability sector is that there is a subtle but constant temptation to give lip service to person-centered planning but in practice adopt ‘one-size-fits-many’ solutions. We suspect that, in the absence of robust evidence for ‘best practice’, policy makers, case managers, families, and some young people with disabilities themselves, seek to minimise risk and settle for living options that are familiar, quickly implemented, or have anecdotally appeared to work for someone else. Truly individualising living options requires creativity, experimentation, and persistence.

- Congregate living may be fundamentally problematic.
- There does not appear to be a basis for selecting any particular models as best-practice; rather, options should be designed to meet each individual’s needs.

GREY LITERATURE REVIEW

Introduction

The systemic meta-review undertaken for this project shows that:

- Clustered and institutional settings do not appear to offer any consistent benefit over smaller dispersed housing;
- Congregate living may be fundamentally problematic;
- There does not appear to be a basis for selecting any particular models as best practice; rather, options should be designed to meet each individual's needs.

With this research in mind, the following section provides an overview of various 'Grey Literature' sources including reports, discussion papers, submissions to government inquiries and journal articles from Australia and overseas that examine the methods and options that people with a disability are using to live in their own homes with supports. The supports that people currently use are explained briefly, followed by a summary of the elements of providing housing and supports that make it possible for people with a disability to live in their own home.

In the past 30 to 40 years, disability policy has changed so that almost all of Australia's large residential institutions have closed and their former residents have moved into smaller, group or congregate accommodation or into a home of their own (Fisher, Parker, Purcal, Thaler, and Abelson, 2008; Bigby, and Fyffe, 2006). In Australia in the 1980's and 1990's, individuals with a disability, their family members and allies, and progressive disability service organisations, began creating innovative models of support which allowed people with a disability to live in the community and avoid institutional care (Fisher et al., 2008). This has allowed people with a range of support needs to live in their own homes with individualised support. Furthermore, community expectations have changed so that today most young people with a disability expect to leave their parents' home around the same age as young people without disabilities, and move into a living arrangement typical of other young people (PricewaterhouseCoopers, 2011).

The launch and implementation of DisabilityCare provides a unique opportunity to reconsider the effectiveness of current models of disability accommodation support, and to design DisabilityCare so that it provides ways for *all* people with a disability, regardless of the severity of their impairments, to utilise contemporary and innovative practices for living in ways typical of other citizens.

Housing and supports

There are two separate but intrinsically connected elements that are likely to produce successful living arrangements for people with a disability: 1) Quality housing, 2) Quality supports.

It is relatively simple to understand and assess *housing quality* given there is broad agreement about minimum living standards in Australia. These would include consideration for the living environment (i.e. weatherproof, connected to hot and cold water, adequate heating and cooling), safety (i.e. structurally sound, lockable windows, deadlocks on external doors) and affordability (i.e. cost-efficient to run heating, cooking and other appliances) (VCOSS, 2008). Additional considerations, particularly important in the context of the history of accommodation provided for people with a disability, include security of tenure and the right to move house when desired; the right to privacy; the right to choose who to live with; the right to choose who comes into the home; proximity of housing to community infrastructure and services; proximity to the individual's own important social relationships; and physical accessibility (Parker, and Fisher, 2010).

Quality supports, as they relate to housing, are more complex to design and to evaluate. There are a combination of factors which work together to provide for high quality supports; particularly that the service user has control over the supports provided and that supports are individually tailored and flexible (Bigby, 2000; Cocks and Boaden, 2009; Fisher et al., 2008). Where supports include paid assistance in the home, it is critical that staff respect and preserve the person's home environment (O'Brien, 1994; Kendrick, 2009). The 'elements' which ensure that any person with a disability can live in their own home with individualised supports will be described in more detail below.

The following section focuses on contemporary approaches to living arrangements that make it possible for people with disabilities to live in their own home with individualised supports.

Current approaches

In Australia, service provision in accommodation for people who need ongoing support remains concentrated on group homes and other small, congregate models of care (e.g. Cluster Villages) (Fisher et al., 2008). However an increasing number of disability service organisations in Australia and internationally have moved away from group-based models and are providing support for people with a disability to live in their own home, even where people have severe disabilities, have significant ‘behaviours of concern’, and need 24/7 support (Kendrick, 2009). Most of the well-known examples of these 'service transformations' have taken place in the US. For example, Jay Nolan Community Services in California has closed all group homes and now assists 97 clients, many of whom have autism and a considerable number who require 24/7 assistance, to live in their own home with individualised supports (http://www.jaynolan.org/about.php). Other examples include Onondaga Community Living in New York State (http://www.oclinc.org/residential/residential%20_index.htm) and Total Living Concept in Washington (http://www.totallivingconcept.org/supported_living.htm). These organisations made the transition from providing group-based accommodation to individualised options without additional funding from government using creative and innovative methods (Kendrick, 2009).

There are many more disability service organisations, including in the UK and in Europe, that are currently transitioning from providing group-based accommodation to a service model that assists each client to develop an individualised arrangement of their choice. The positive results seen by these agencies suggest there are multiple benefits in abandoning group-based accommodation models in Australia in favour of models which assist people to live in their own homes with tailored supports. There are very few agencies in Australia that exclusively support individualised living arrangements for people with a disability, however there are some examples including My Place in Western Australia (http://www.myplace.org.au/welcome/index.html) and Lifestyle Options in Queensland (http://www.lifestyleoptionsinc.org/).

There are also multiple examples in Australia and overseas of individuals with severe disabilities utilising 'user-controlled arrangements' whereby they have moved into their own home with tailored supports. Some of these arrangements are run by collectives of people with a disability and/or other families where they share ideas and some paid resources, for example Homes West in Queensland (http://www.homeswest.org.au/) and Living Distinctive Lives in Victoria (http://www.livingdistinctivelives.org/).

Current approaches used by people with a disability living in their own home can be grouped under these categories:

- **Service-supported;**
- **Service-hosted; and,**
- **User-controlled.**

Service-supported arrangements are where a disability service organisation works with each individual to determine where and how the person would like to live (i.e. the housing stock itself, location, who they would like to live with, etc.) and creates a personalised and highly-tailored support structure designed for that person. The disability service organisation coordinates the aspects of the arrangement according to an agreement between the two parties which outlines their roles and responsibilities. Each person lives in housing stock typical of people without a disability - private rental accommodation, a home they have purchased or in social housing. The disability service organisation typically provides ongoing assistance and coordination as required and support staff may be provided by the organisation or employed through the organisation at the direction of the individual themselves.

Service-hosted arrangements are where an individual with a disability and/or their family and allies, make all key decisions and coordinate the arrangement themselves but utilise the administrative and legal functions of a disability service organisation to host their individual funding package . The disability service organisation may legally employ the support staff on behalf of the individual, and provides a mechanism for accountability to service standards as required by relevant government agencies. Some host agencies provide additional services to the individual for a fee, for example, assisting the person or their family to set up a Circle of Support or to learn how to recruit support staff (e.g. Staffing Options, Queensland).

User-controlled arrangements are where the individual themselves, and/or their family and allies, receive individualised funding directly (e.g. Direct Payments in Victoria). They are accountable to the relevant government agencies for all expenditure and in some cases, hire staff directly (e.g. Direct Employment in Victoria). Many of these arrangements include an additional decision-making or support structure around the person such as a Circle of Support or Microboard. Some of these arrangements operate without government funding, relying on family finances and unpaid supporters.

People with a disability, their families and allies and disability service providers have developed innovative methods for ensuring that people with a disability can live in their own home with the supports they need. Many of these arrangements were created because people were either unwilling to enter into group-based accommodation on offer, or were unable to obtain services because of the complexity of their support needs (i.e. service providers were unable to provide support due to complex 'behaviours of concern') (Homes West, 2007).

Methods for support

People with a disability use a range of supports to live in their own home, for example they may enlist paid support workers to assist with personal care, utilise assistive technology and receive unpaid assistance from family, friends and neighbours. The following list is an inventory of types of support *structures (ways of coordinating supports)* and *methods (ways of providing support)* currently being used in Australia, North America and the UK which are currently considered innovative.

Structures

Key Ring or Link supports: a small number of people (usually between 4 and 10) who live in a specific geographical region utilise the shared resource of a paid supporter who lives nearby. This model is usually overseen by a disability service organisation that either provides agency-owned homes for people to live in, or assists each individual to move into their own home by securing the lease agreement for a suitable private rental property or by providing administrative and practical assistance for the person to purchase their own home (e.g. Northern Support Services, Victoria). In Australia, these programs are typically offered only to people with lower support needs, but can be used where people have high support needs if the paid supporter acts as a coordinator for each individual's live-in supporters.

Consumer-governed supports: individuals with a disability set up an incorporated enterprise that provides a mechanism to host and administer individualised funding packages (e.g. Lifestyle Options Inc., Queensland).

Family-governed supports: a group of 4-8 families (usually parents and siblings of a person with a disability) either contribute a portion of individualised funding budgets or receive grant funding for coordination of the supports for each individual to live in their own home. Most Family-Governed models employ a paid coordinator who assists individuals and families with planning, funding applications, recruitment of support staff and managing their funding (e.g. Homes West, Queensland).

Circles of Support and Microboards: a group of committed, unpaid individuals oversee the living arrangement (and usually other aspects of the person's life) in partnership with a person with a disability. Circles of Support are usually less formal and Microboards are typically an incorporated entity and more formalised (e.g. Vela Microboards, Western Australia).

Methods

Attendant support: an individual purchases the services of support workers to assist with personal care and assistance with everyday tasks in the home and relating to home. Some people employ support workers directly which can afford the individual greater control over who they employ and how the support is provided (e.g. Direct Employment in Victoria).

Co-tenancy / supportive housemate supports: a person with a disability shares their home with a housemate/s without a disability, usually in a private rental home or their own home. The housemate/s provides specific supports (e.g. to be home overnight most nights, assistance with cooking and cleaning) in exchange for reduced rent or free rent. Most people enter into a written agreement which outlines the support to be provided and grievance processes. The individual utilises individualised funding to pay for the service (e.g. Homeshare Program, Independent Disability Services, Victoria) and any additional support that may be needed to maintain the relationship.

Good neighbour supports: individuals with a disability utilise assistance from one or more of their neighbours in exchange for an agreed financial contribution from their individualised funding package. This arrangement is sometimes brokered by a disability service organisation (e.g. Midwest Community Living Association, Western Australia).

Host family and adult fostering supports: the person with a disability lives with a family other than their own as a boarder/co-resident and pays a financial contribution for support provided by the family from their individualised funding package (My Place, Western Australia).

Rostering informal supporters: the person with a disability utilises the support of family and friends who each provide some assistance on a regular basis. For example, 10 people each bring a meal to the person's home once a month to share together as a way of providing regular meals where the person is unable to do so themselves.

Assistive technology: people with a disability utilise technologies as supports in their home including emergency assistance systems, automated timers and doors, remote keyless entry systems, reminder systems, automated medication dispensers, climate control systems and home robotics. A significant number of people also rely on assistance animals in their home for flipping light switches, picking up objects and alerting the person to visitors and alarms.

Indicators of quality for living in your own home

A review of a range of journal articles, reports and submissions makes it clear that there are common themes identified by researchers and advocates for determining the quality of housing and supports for people with a disability.

Kozma, Mansell, and Beadle-Brown (2009) conducted a systematic review using the following 'domains' to assess overall quality of various living situations for people with a disability: *1) Community presence and participation, 2) Social networks and friendships, 3) Family contact, 4) Self-determination/choice, 5) Quality of life, 6) Adaptive behaviour, 7) Challenging behaviour, 8) Psychotropic medication, 9) Health, risk factors and mortality, 10) User and family views and satisfaction.*

A report published in 2008 by the University of New South Wales, "Effectiveness of Supported Living in Relation to Shared Accommodation", offered a comprehensive framework for evaluating the quality of 'effective accommodation support' focusing on *1) Outcomes and goals, 2) Administrative systems, 3) Service viability and 4) Formal and informal support* (pages 56-58).

The 'Personalised Residential Supports Project' completed by Curtin University in 2009 included an extensive literature review, focus group discussions, surveys of people experienced in developing individualised living arrangements and followed six individualised arrangements over 18 months. The project recommended nine 'themes' including: *1) Assumptions, 2) Leadership, 3) My home, 4) One person at a time, 5) Planning, 6) Control, 7) Support, 8) Thriving, 9) Social inclusion,* (pages 17-19).

A discussion paper prepared for the ACROD Accommodation Think Tank in Western Australia in 2006, "Innovation in Accommodation Support in WA: A Discussion Paper", which also included a literature review, summarised quality accommodation supports as including: 1) *Support staff, 2) Using a person-centred approach, 3) Location, 4) Structure* *of supports, 5) Service culture, 6) Safeguards, 7) Service management, 8) Control afforded to individuals, 9) Homeliness, 10) Builds on and supports informal networks, 11) Interconnected with local neighbourhood, 12) Provides safety.*

Bigby (2000) has described quality housing and support as including: 1) a house which is appropriate in its design, 2) affordable and where tenure is secure, 3) access to required supported services (formal or informal) that are available when needed, and provided in a way that meets individual needs and circumstances. Disability advocacy group, Action for More Independence & Dignity in Accommodation (1997), outline the key criteria of what people with disability see as making a house a ‘home’: 1) homes have a real address rather than the names of facilities or group, 2) leaving is by choice, 3) the people who live there have expectations of permanence, 4) tenure is by a lease or ownership, 5) people have control over who can visit or stay, 6) people have control over their physical environment.

Elements for success

Common themes arise from the literature reviewed. It is proposed that these themes be considered 'Elements' for how DisabilityCare can build a framework for understanding how to plan for quality housing and quality supports so that all people with a disability can live in their own home.

These elements offer guidance for understanding whether or not an individual with a disability, regardless of the severity of their impairments, is living in a situation where they have both quality housing and quality support:

<u>Quality housing:</u> housing stock must be of a good quality, physically accessible to the individual and their social network (i.e. visitable), in a location of the individual's choice, affordable, and typical of the housing choices available to all citizens. People with a disability should have access to the private rental market, home ownership and social housing.

<u>Homeliness:</u> the individual's home should remain a private space, suited to their preferences and tastes, and free of the demands of formal service regulations that compromise the individual's sovereignty in their home.

<u>Rights and responsibilities:</u> people with a disability must be afforded typical tenancy rights and responsibilities. All people should choose who they live with and should not be forced to live with others for the sake of cost-efficiency or service provider convenience.

<u>Control:</u> the individual, and where desired or required by the person, their family, friends, advocates and allies, must make the ultimate decisions about the living and support arrangements without fear of services being removed.

Individualised arrangements: each person's housing and support arrangements must be individually tailored to their preferences and needs and not based on service 'models' or programs.

Flexibility of supports: each person should determine the supports they want, how they will be provided and have the right to change these arrangements when they choose.

Protecting and enhancing informal relationships: housing and support should be provided in ways that maximise opportunities for the individual to build and maintain strong relationships with a spouse, family, friends and other relationships as they choose.

Community belonging: housing and supports provided should concentrate carefully on ensuring the individual has connection to their local community in ways that they choose to.

Responsive service systems: service providers must provide individualised arrangements as determined by the preferences and needs of the service user with a clear focus on supporting typical community living for service users.

Safeguards: the individual should have personal safeguards for their well-being which are provided separately from a housing service provider.

Cost-effectiveness

Policy-makers will be rightly concerned with the possible cost implications of providing each person with a disability in Australia with supports to live in their own home. However, while group-based, congregate care for people with a disability appears on the surface to provide cost-efficiencies, research in the past 20 years in Australia, the UK and in North America has shown that the cost of congregate models (including small group homes) invariably rise over time, whereas the cost of providing individualised support stabilises, and in some instances, declines over time (Felce, Perry, Romeo, Robertson, Meek, Emerson, & Knapp, 2008). Many people who are currently living in group-based accommodation could have a better quality of life and require less expensive supports if they were living in their own home in the community (Mansell & Beadle-Brown, 2009).

There is no evidence that individualised models of care are inherently more costly than congregate models "once the comparison is made on the basis of comparable needs of residents and comparable quality of care" (Mansell & Beadle-Brown, 2009, pg.2). Research in Australia and in the UK demonstrates that where people with a disability (or family members where the person is unable to) have control over the funding they need to live in their own home, savings to government range between 10% and 45% of the cost of current models of congregate care (Leadbeater, Bartlett & Gallagher, 2008). Further, where people with a disability have individualised supports to live in their own home, there are direct financial savings to the broader health and public services system by avoiding the need for expensive crisis responses (e.g. hospitalisation).There are also benefits from improving the individual's ability to become more engaged in paid employment and civic and voluntary roles in the community (Leadbeater et al., 2008).

It is important to note that disability service organisations in the US and UK that have successfully moved away from providing group-based, congregate models for accommodation and support to providing individualised supports for each person to live in their own home, even in cases where service users have very complex support needs, have done so while maintaining a balanced budget. They have completed the task without additional funding for individualisation of services (Kendrick, 2009). It should therefore be feasible for disability service organisations in Australia to do the same.

Of course it is possible for disability service organisations to provide individualised supports in ways that do not provide high quality outcomes. Therefore, it is imperative that services providing assistance for people to live in their own homes under DisabilityCare are well managed, guided by evidence of international best practice, are committed to assisting each service user to live a typical life in their community, and are focused on the specific needs of each individual being supported (Mansell & Beadle-Brown, 2009; Kendrick, 2009).

Conclusion

Research consistently shows that people with a disability who are supported to live in their own home with individualised and flexible supports have a better quality of life and their supports cost less when compared with congregate models of care. All people with a disability can be supported to live in their own home, even people with complex medical needs, people with severe intellectual disabilities, and people who need significant behavioural supports. There is no one 'model' of service which guarantees success however there are a set of 'Elements' that can guide good service provision. The implementation of DisabilityCare in Australia offers government a unique opportunity to invest in high quality individualised supports for people with a disability so that they can live in their own home, avoiding outdated models of congregate care, including group homes and cluster villages.

CONSULTATIONS

ONLINE SURVEYS

As a supplement to the interviews and focus groups, two online surveys were created. One version was intended for people with a disability to complete with regard to their own thoughts about their future living arrangements. The other was intended for parents (or guardians) of people with a disability to complete with regard to their own thoughts about their child's future living arrangements. The questions posed concerned location, household composition, support needs, rights, obstacles, equipment needs, and timeframes for change. 53 people with disabilities and 114 parents from across Australia responded to the survey. The details of the methodology and the full results are presented in Appendix B, but several interesting trends warrant summarising here.

Most participants favoured small households. Participants with disabilities typically wished to live with just one other person, and were against living with more than three others. Parents typically preferred their child live with 2-3 others, but most were against more than 5. Amongst participants with disabilities, there was a common desire to live with one's (current or hypothetical) partner. Differences between people with disabilities and parents on issues of household size and composition raise some interesting questions. Does this merely reflect differences in the disabilities of those who responded themselves versus those whose parents responded? For example, intellectual disabilities were more common for the children whose parents participated. Or do attitude differences between the two samples reflect differences in perspective that go with having a disability versus being a parent of someone with a disability? Future research might usefully pursue this issue.

Among participants' ratings of support needs, there were substantial proportions of people with disabilities and parents who desired what are currently uncommon types of disability support: support to develop romantic or sexual relationships, and support provided by a trained animal (e.g. assistance dog).

There was a notably strong desire from both people with disabilities and parents for a range of tenancy rights, in particular, rights to privacy, to decide who you live with, to have secure tenure, and to personalise the home.

With regard to timeframes for change, parents living with an adult child with a disability typically expected it would take longer for their child to move out than was ideal, often much longer. Almost entirely absent from the sample, were people with disabilities or parents who feared that they or their child would need to move earlier than desired. This suggests that support to move from the family home is a pressing need.

INTERVIEWS AND FOCUS GROUPS

In addition to the on-line survey we conducted face to face and phone interviews with a number of individuals and organisations. Altogether, we interviewed 28 individuals, conducted 10 focus groups (with between 3 to 12 participants in each group) and consulted with 10 peak bodies and disability agencies. The individual interviews and focus groups included both people with disabilities and parents or family members of a person with a disability.

Despite the short time frame and budget constraints for the project, we managed to consult with individuals in Queensland, Tasmania, Victoria, South Australia and ACT in face to face interviews and focus groups.

A significant number of participants in the consultations knew little about the National Disability Insurance Scheme (now DisabilityCare). Consequently, consultations also involved clarifying the core aspects of the scheme for participants in order to encourage more aspirational and creative thinking about preferred disability support and housing arrangements.

The following themes and recommendations emerged from these consultations.

KEY THEMES AND ISSUES EMERGING FROM CONSULTATIONS

Housing and disability support arrangements

The original aim of the consultations was to identify the effectiveness of various housing models. It seems that the notion of models is a very attractive idea to many because they are an attempt to simplify and codify services and structures for the convenience and efficiency of managers and administrators. Grouping ideas and categorising them also makes it easier to convey information about matters that cover a spectrum of diversity and complexity. The attraction of models for bureaucracies stems from a need for rationalisation and reduction of complexity to products and services that can fit into simple funding formulas and matching unit costs.

In his book, *The McDonaldisation of Society,* George Ritzer describes the manner in which rationalisation and scientific business management principles have spawned chains of franchised fast food outlets. Applying these principles to housing and support arrangements for people with disabilities demonstrates how the 'McDonaldised' view of models has served to limit creativity and diversity in design and delivery of these services. Models of service delivery in accommodation and support across Australia have offered up a range of 3 distinct types – large institutions (the ultimate warehouse approach), group homes (usually shared houses for 4 to 6 residents) and community living arrangements in which a person lives alone or with others of their choice in a single dwelling. In the early phase of deinstitutionalisation, the group home was intended as the transition home for people moving out of larger institutions on the way to more personalised living arrangements in a house or a unit. Given that funding arrangements and investment in services have been largely directed through state and territory administrations, the structures we have now are built around an uncritically accepted rationale that suggests certain models or levels of congregate care settings are specifically beneficial to people with certain types of disability support needs. Consequently, the idea that a person with 24/7 support needs can only live in a group home or even larger scale housing arrangements is widespread.

Both the literature review and our consultations with people with disabilities and their families strongly challenge this adherence to model-based thinking. A report by AHURI into housing and disability support (Bleasdale, 2010) also encourages policy makers to eschew the model based thinking, suggesting that the development of creative solutions with a range of diverse social partners is more likely to expand real housing options. We quickly moved from the idea of models that can be replicated in various settings - the 'Macdonalds' analysis with 3 basic models - Big Mac (institutions), Quarter Pounder (group home) and Junior Burger (living alone in a flat or unit with attendant support package). Instead we preferred the analogy of the "Sandwich Bar" menu where you get a choice of bread (housing type), choice of formal disability support arrangements (the fillings) and choice of people you live with and invite into your home and into your life (the dressing and condiments). Such an approach allows for individual needs to be met in a manner that supports normal human aspirations and needs and reflects much more of what people with disabilities and families we spoke with are wanting.

In summary, we found that individuals want to have a menu to choose from that allows them to pick and combine different elements that match their needs and aspirations. They do not want to be locked into a particular house/room with nowhere else to go. People we consulted want a 'home' that is personally tailored to their needs. Achieving cost efficiencies through some form of co-location of individuals or the proximity of housing always needs to be balanced against the benefits of dispersed housing and design that promotes maximum opportunities for social integration and inclusion in neighbourhood and local community life. Such decisions need to be informed by research evidence that points to the benefits of more personalised approaches and these decisions are best made by the individual and their supporters.

Despite a service system that the Productivity Commission report described as broken and significantly underfunded, we discovered that some individuals, with the support of families and strong advocacy, have been able to create more individually relevant housing and support options. Among those who had already moved out of home we discovered stories of positive achievements by individuals and their families in setting up a home and supports that match expectations being promoted under DisabilityCare. Some examples we came across in our research include:

> *Three families that have lobbied, planned and co-designed a 25 unit social housing co-operative in which all residents make a commitment to intentional community and mutual support arrangements, acceptance of the 3 young men as part of this community, and creative formal and informal support arrangements for the 3 young men who are residents in this housing project and each live in their own unit. It has been achieved with a great deal of hard work over 11 years to create an inclusive living arrangement that is tailored to the individual needs of each of the 3 young men including two of them who require 24/7 support.*
>
> *The mother of a son with severe and multiple disabilities arranged for him to move into a group home with several other adults with disability. When it became clear that his nutrition was being neglected and his freedom to go out with his support worker restricted without good reason, his mother obtained advocacy support to challenge the government to provide a better accommodation and support solution. She was successful in getting a new house set up, designed to better meet his needs, with a more flexible and responsible service provider. He was able to involve his parents in the decision about who moved in and to have a house that was located in the community in which he had grown up and gone to school. He was given a key to his own home having been denied this right by his previous service provider.*
>
> *One young woman, having had the chance to test out independent living in a 'training flat', moved into a unit with two other young women, have a say in who she lived with, and then relocate to a site with two units so that another friend could live next door. She said:*
>
> > ***"Having the chance to try living independently in the training flat gave me the confidence to move out. Then I talked two other friends into leaving home and joining me."***
>
> *Despite not having enough hours of disability support, this arrangement has enabled some resource pooling and creative thinking that has ensured that they have control over their lives and enjoy a secure and happy home life. This example stands out against other shared housing arrangements where residents are forced to share with people they would not choose to live with, and in some cases where another resident could create constant misery or even the daily threat of assault.*

A mix of participants who are still living in the family home and those who have moved out were interviewed. Some of those who had moved out had been forced by the inadequacies of the current system to accept a place in a group home but were keen to move on to something that offered more freedom and choice of housemates. Several families interviewed spoke about the trauma associated with “relinquishment”, where families desperate for a funding package would drop their son or daughter off at a respite facility and then refuse to come and pick them up. In each case, the government came up with an arrangement for emergency accommodation and support but not the kind of arrangement that was good or attuned to individual needs.

Of those people with disabilities who were still living at home with their parents, most wanted to move out into a place of their own, expressing a desire for greater freedom and control and a chance to grow up and live like an adult. One young women in her early 20s captured by saying:

> ***“I don’t want to live out of town anymore. I want to live in the city. I’ve got ideas in my head now about what I would like to do, but mum still treats me like a 3 year old.”***

A number of young adults who relied on parents for a significant level of their personal care at home were particularly motivated to move out and live more independently. The normal tensions that can emerge between young adults living at home with parents were stated as a motivation for wanting to move on. The desire to move in with a partner or girlfriend/boyfriend was also mentioned by a number of participants and the need for a home with private space and control over who can come or stay over was an important part of this.

There were a smaller number of young adults still living at home with their parents who indicated that they were happy at present to stay there, a situation that is also quite common among adult children without disabilities who are staying home longer or returning home after a period of living independently. In a number of these situations, the parents were planning for and motivated to see their adult son or daughter move into a place of their own. Some expressed this as a desire to see their adult child established independently with appropriate home and supports before they were no longer in a position to provide this support. Parents of younger adults with disabilities were usually more likely to support the desire of their son or daughter to move out as their other adult children have done.

Of the people with disabilities we spoke to who lived in group homes or larger congregate care settings all were very keen to move out to a place of their own. There was also a strong preference to move in to areas where they could easily get to shops, leisure facilities, health services and good public transport.

Housing choices

The importance of a good home

While housing is not specifically the domain of DisabilityCare, ensuring that participants in this scheme have appropriate housing and a place to call home underpins the success of

DisabilityCare to meet is goals and objectives. Quoting one of our researchers, ‘home is the base camp for a good life’. Home is the launch pad for an individual’s participation in work, recreation, cultural activities and education in their chosen community. It is a place for the quiet enjoyment of one’s personal and private space with friends, intimates and neighbours. It provides a haven from the tough challenges and barriers many people with disabilities face in finding acceptance and a sense of welcome in their communities.

Access to a range of housing types

Providing a range of dispersed housing that can accommodate the needs of those who want to live alone through to a variety of housing designs that allow for two to five people to share a home is critical to ensure people have a choice of housing. Our consultations highlighted some differences between individuals with a disability and their parents in respect to numbers of people living together. Young adults with disabilities indicated a preference to live alone, with a partner or with 1 or 2 other compatible people. Parents tended to indicate a preference for more people living together although not all parents supported group home models. This difference was nicely captured by one young woman who said:

> ***“Group homes are for parents but they don’t have to live in one***"

There was evidence that some families have come together with plans to set up co-located group homes believing that this offers economies of scale, security of tenure and a guarantee of 24/7 managed care. To many people with disabilities and families this is a worrying trend as it assumes that this model of housing will always be in demand beyond the life span of their son or daughter. Research evidence cited in the literature reviews concerning outcomes for residents in congregate care settings and cluster housing would suggest that governments should avoid investments in these kinds of housing models.

Recognition of value of normal housing careers

Planning and allocation of packages needs to take into account the idea that people with disabilities have a right to the same housing careers and pathways available to other citizens. The capacity to move between different housing types with a flexible disability support package that makes it possible to move from sharing a home with others to living alone, then perhaps with a partner or spouse. This reflects the kind of housing careers experienced by other citizens. Without this freedom to move from one type of setting to another and from one location to another, housing choice does not really exist. One young man who had a spinal cord injury from a motor vehicle accident described his ideal home said:

> ***“I want to get out of this group house. Some of these guys are driving me crazy. I want a duplex so I can live on my own but have some other people who can keep a bit of an eye on me. I need a garage to work on an old car I got before my accident”***

Affordability of housing

A number of participants in our consultations identified housing affordability as the main reason why they had either not been able to move out of the family home or have had to return to living with their parents (or end up homeless) as there were no other foreseeable options. Governments must address the issue of demand for social housing and engage more effectively with the private rental market to increase the availability of homes that are affordable and accessible and that do not place vulnerable people with disabilities in unsafe situations. A comment from a woman who had to move back home was:

> ***"I couldn't afford to pay rent so had to move back in with my mum. I hate not having the freedom to live the way I want to. Mum expects me to live like she does – keep things tidy."***

Housing availability

In a context where social housing is a major problem and where housing stock for this purpose has long waiting lists, DisabilityCare will need to become a strong player in pushing for accessible and affordable housing stock to be developed in line with demands identified in the individual plans of participants in this scheme. While some people with disabilities and their families have developed creative solutions to the problem of finding appropriate housing, most people we spoke to were struggling to identify suitable housing options that facilitate the promise of choice, community integration, safety and social connectedness.

Flexibility of disability support arrangements

Flexible plans

Plans need to be flexible to allow for the dynamic nature of the ups and downs of life, growth and changing circumstances. There is a risk that bureaucratisation of individual plans will limit and restrict choice. Plans are an important guide to what an individual wants from their package and a vehicle for guiding service providers and ensuring they are accountable to person-centred support practices. They should not however, be used to limit flexibility, prevent natural development and growth, nor preclude responding to events and changes that were not anticipated at the time the plan was put in writing. Individuals and their families we spoke to, particularly those who had taken control over their decision-making, indicated that reflective practices and dynamic planning processes produce the best outcomes.

Flexible staffing

In our consultations we heard about some of the flexibility that already exists in some jurisdictions that allow individuals and their families to tailor arrangements with support workers and/or agencies to enable greater freedom of choice and flexibility in how and when support is delivered. For consumers of disability support services, key concerns about more independent and individualised arrangements relate to reliability and quality of support workers. The experience of people who have developed expertise from living in their own home suggests that there needs to be flexibility for individuals to negotiate, for example, hourly rates and minimum shift times for support workers to ensure that they can purchase the right kind of support to meet their needs in particular situations. There is a risk that these kinds of supports could be over-regulated under DisabilityCare and that administrators alone will decide what gives the 'best bang for the buck'.

Flexibility in public housing regulations

A number of participants in our research who live in public housing highlighted problems they have had when they try to organise live-in care arrangements. Public housing authorities have regulations that require tenants to pay extra rent if they have extra persons living-in on a regular basis. This creates an unnecessary barrier to the kind of live-in arrangements that suit some people with disabilities best.

Choice and freedom

Choice of who you live with

Many people with disabilities have been forced into co-tenancy arrangements in institutions and group homes where they have little or no say in who they live with. Given the lack of privacy and open designs in most of these facilities, many people with disabilities are compelled to share housing with people they not only don't get on with or like, but who can also be a source of anxiety, stress and threat. State authorities, faced with an extreme shortage of accommodation places, often place people with disabilities in co-residency arrangements that would not be tolerated anywhere else in the community.

The choice of who we share our homes with is most likely the highest order decision we make in determining our own quality of life. There appears to be little evidence that this right is respected in existing institutions or group homes or that there is awareness about the level of trauma and suffering experienced by many of those who are placed in the position of sharing a home with people not of their choice. In this context, it is vital that the existing residents are supported to have a say in who fills any vacancies in the same manner that non-disabled adults in shared housing make such a decision. Residents are entitled to discover enough about the person who is coming into the house to determine whether their quality of life is going to be unfairly compromised. There was strong support from participants in our research, both individuals with disabilities and family members, for residents in shared housing to be empowered to choose who they live with. The right of residents to know information about the people they share their home with needs to be respected by providers of this form of housing.

Ease of movement from one home to a new home

While the practice of 'forced co-tenancy' in shared housing arrangements can provide some groupings where residents get along well and are compatible, there is no assurance that when a vacancy is filled that this situation will not change dramatically. It is important that when an individual is no longer happy with the living situation they are in and want to move on, that there are pathways into a variety of other living arrangements. People moving out of the family home are often encouraged or coerced into accepting a group home setting. Our research clearly indicates that the typical 5 to 6 bedroom facilities are larger than individuals with a disability prefer. At some stage it is likely that a person may wish to try some other form of housing arrangement, choosing to live with fewer people, specific friends or by themselves. Every effort must be made to ensure that such movements and capacity to make change are available.

Choice of support staff

Consultations indicated that the capacity to choose their own support staff rates very highly with people with disabilities and their families. Situations where the individual and their family have had the capacity to recruit and train their own staff reflected a great deal of satisfaction with support arrangements. For many people with disability, quality of life is increased when staff with expertise in the person's own support needs are readily available and have made long-term commitments to the job. Freedom to develop job designs and conditions of employment that are mutually beneficial is important for staff continuity and service quality.

No long term lock-in contracts with service providers

Concerns were expressed about the possibility that service providers might offer services on a contract basis similar to mobile telephone contracts where the consumer is locked into a contract for 2 years. While the market model is meant to benefit consumer choice and the development of more individually responsive services, it is also a place where vulnerable consumers may be easily exploited.

Maximising independence

"Raising the bar" – the power of having to act in your own interests

A number of adults with disabilities interviewed highlighted the issue of how hard it is to be independent when living at home with parents or to gauge whether they could survive the move to independent living. One young man planning to move out with his girlfriend put it like this:

> ***"Based on what I am like at home, I know my mum probably doesn't think that I could survive if I moved out of home. But I know that if I was in my own place I would raise the bar."***

It is not until the young person moves out of their parent's home that they discover what it takes to live independently. For those who have moved out this was a common experience. Young adults with disabilities are not different from their non-disabled peers in the sense that they are not always going to live the way the parents want them to when they move out. Skills in managing the home emerge with practice and encouragement over time.

The process of transitional or phased steps towards living independently

A significant number of respondents indicated that the chance to experiment with independent living and to have trials was an important step in the process. Some had been given the chance to live in an 'independence training flat" before moving out. Others were supported to set up a separate living space within the family home and others moved into a 'granny flat' at the rear of the family home as a step towards eventual independence.

> *The mother of one young man who lives with a severe form of autism, exhibits "behaviours of concern" and had experienced traumatic neglect in a state run care facility, told us of the journey she was now taking with her son towards independent living in the community. The family had found their son his own house and were working closely with staff from a service provider to develop a lifestyle that allowed for his need to be free to come and go as he pleased. When in state care his habit of 'escaping from care' to go on long walks had been perceived as 'absconding' and led to confinement in secure institutional settings. His family now see that being able to go on long walks is an essential freedom for him that meets important needs. He has been known to call into a local supermarket while out on a walk, collect several items of confectionery and leave without paying. Where once the shop owners would have called police to have him charged with shop lifting, leading to police involvement that would traumatise this young man, his mother is now working with business owners and police to handle him in a more appropriate manner. He moved into his own rental property 3 years ago with support at certain times of the day, including staff or family sleeping over with him except for one night a week when he stays on his own to gradually build his independence. His mother describes it as "a work in progress", as he adjusts to living in the community and coping with the impact of the trauma of the past.*

Another creative solution using funding to support transition to independent living has made use of a motel room to provide immediate and available accommodation for a living away from home trial.

> *A young man from a Torres Strait Islander background, who is living 30 minutes away from the rural town where he goes to work and likes to enjoy a range of recreation and cultural activities, has secured some funding to try out living in town. The funding has been flexible enough to allow him to live in a motel room 2 nights a week and the rest of the time back at home with his mother. He feels that if he can do this for 6 months he will know if it will work out in the longer term. He needed 8 hours for a support worker at first but as he has settled in and begun to use the natural supports of his mates he only needs 4 hours of paid support. In the longer term he may*

> *only need monitoring and occasional drop-in support. During this transition, the funding that supports him and his mother as his carer will need to be increased to cover his weekly rent at both locations. The extra funding that has been used to make this happen has required some creative work by the support agency. How does this young man feel about this? "Yes, motel is great! Love it! I do my stuff." When asked how he feels about moving out of home into a place of his own in the town he says, "Nervous and excited...worried."*

Such transitions can require more funding up front to provide an effective transition and experimentation to find what works best. Creating flexible options for people to more slowly transition into living in their own home (e.g. low cost flats for part-time use) could be a better long term investment by the funding agency to enable individuals to make a success of moving into a longer term home that best suits that individual. A number of people we interviewed indicated that once new arrangements are in place and are working, the cost of disability support can sometimes be reduced. Supporting the individual to feel in control through this transition, and to experiment until they get it right, could lead to positive longer-term outcomes for the funding agency.

The right to explore, experiment and taste various lifestyle options

Many adults with disability have little opportunity to experience a range of housing and support arrangements so may find it hard to know what choices are possible and what might suit them. While there are some programs offering transition support and skill development for people with a disability moving into their own home (e.g. Independent Living Support Initiative in NSW, Yooralla Community Learning and Living program in Victoria), availability is very limited.

A peak body representing Indigenous people with disabilities highlighted the need for people with disabilities living in remote rural settings who rarely experienced life outside their communities, to experience what life is like in other kinds of settings. The opportunity to explore other lifestyles in urban settings and rural cities, and to support them to develop a sense of where they may wish to pursue other avenues and opportunities, would be important to them. While decision-making is done in a collective way with families and communities, support (i.e. good advice and trustworthy information) is needed to find the balance between meeting specific needs and aspirations of the individual with their obligations to community. Similar parallels exist for people with disabilities from Culturally and Linguistically Diverse communities. Research by the Ethnic Communities Council of Victoria (2013) highlights the tension between belonging to and benefitting from the cultural life and values shared with others from a similar ethnic background, alongside the need to address or escape from stigmatising and damaging attitudes to disability within some cultures. In the shift towards greater individualisation and self-determination under Disability Care, there needs to be sensitivity to how collective thinking and engagement with family and community may at times be at odds with the individual's own aspirations to pursue a different course for themselves.

The importance of strong informal and natural community supports

The literature is very clear on the importance of family, friendship and natural community supports as the best protection vulnerable individuals have. A strong theme that emerged from our interviews with family members was a sense that they were solely responsible for the care and welfare of adult children with disabilities for the duration of their life. The idea that neighbours and other members of the community might provide some support and share some of the care responsibilities seemed to be an unreasonable ask. Parents even expressed concern about asking their other adult children to take up any of this responsibility.

While there is a wealth of examples of people with a disability benefitting from the natural and informal supports of the community, good practice in disability support of this type operates at the fringes and is rarely core business for service providers.

Healthy family relationships

There were a significant number of parents and people with disabilities who reported that the quality of ongoing relationships between both parties improved when they each lived in their own separate homes. However, it was a common view that adults with disabilities who move out into their own home are better off if they live near family members and can easily access support in an emergency. This does not exclude individual differences such as one person who indicated that their need to move further away was a direct result of the overprotective attitude of the person’s parents. A number of people described this as the challenge of finding the right distance that provides some degree of self-reliance and independence but also being near enough in an emergency situation.

Friendships and social networks

Too many individuals and their families expressed frustration about the lack of friendships and social networks experienced by many people with disabilities. Confidence in moving out and living independently is strongly connected to the level of informal social supports and friendships available to any individual. Social isolation and loneliness are significant issues for many people with disabilities who have moved out of their home or from an institutional setting. Many have few relationships with unpaid people other than with immediate family or parents. One young woman captured this issue like this:

> ***“I don’t really have any friends except I like some of my support staff. I think I would be more confident to go out places more if I could go out with some friends. I used to live in a normal shared house but the others didn’t understand my disability so I got thrown out. I get a lot of depression now.”***

Access to high quality facilitation expertise to increase social connectedness

There was significant dissatisfaction with many of the current programs offered by disability service providers through day services. Programs tend to operate group outings and activities but struggle to provide support for engagement of the person with a disability in personally relevant interests. While there has been some development of frameworks such as ‘Circles of Support’ that are specifically targeted at this need, there are very few services that support this need in an effective manner.

People with a disability have a strong interest in having access to expert support to facilitate friendship networks and local engagement with neighbours and community life in general. Very few agencies seem to offer this kind of support. The manager of one agency whose core purpose is to support communities to be places where citizens with disabilities experience full inclusion suggests that workers that seek to “plug people into clubs and structured programs are taking the easier path. The work that makes a difference supports the establishment of strong mutual bonds between a person with a disability and others around shared interests and true friendship.” This one agency uses a list of characteristics arising out of good leisure (developed by NICAN) as a guide for their practice including:

- Belonging to and being a part of communities
- Adventure and challenge
- Companionship, increased social networks, new and stronger friendships
- Interdependence
- Sense of freedom
- Control and power over one’s own lifestyle
- Improved self-image through achievement of personal goals
- Hope and enthusiasm for the future
- Feelings of achievement.

The majority of people we spoke to indicated that they were dissatisfied with the programmed menu of day activity and ‘community access’ trips that were the main fare offered by traditional services. There is a clear demand for something that is more personal, more satisfying and more self-directed.

DisabilityCare will need to consider how funding arrangements foster and encourage the development of disability supports that bring this level of expertise and commitment into the market place, as they may not emerge from market demand when consumers have had limited or no previous experience of the this kind of support agency.

Supporting right to develop intimate relationships, co-habitation and parenting

There was a strong indication by many young adults with disabilities that they would like to share their home with a girlfriend, boyfriend or partner. For some this was an existing relationship and for others a future ambition. Lack of consideration for the privacy needed for such intimate relationships was evident in the design of many of the current shared house arrangements. A young woman living in Hobart expressed a view that many young people expressed in consultations:

> ***"I want to move out of the group home to live with my boyfriend but my dad won't let me have a boyfriend."***

Peer support networks

While most of the people participating in this research support the move away from congregate care settings and group programs that are based on economies of scale, there remains a strong belief that peer support plays a crucial role in promoting good outcomes for people who rely on disability supports. Good quality peer support is where people come together to share information, provide mutual supports and to obtain some collective bargaining power in the design and delivery of services. Our research identified an emerging interest in peer support as a feature of disability support arrangements that offer individualised funding and promote self-determination.

- Some *ISP Support Networks* have been established by and for people with disabilities and their families who are using Individual Support Packages in Victoriaas a vehicle for sharing information, providing support and advice and promoting awareness about rights and responsibilities. Groups advertise their meetings and have blogs through an online 'Meet Up' site.

- A number of agencies have established a Key Ring model that has been adapted from a program in the UK. The model provides for a central worker who has a service coordinator role and encourages and supports peer support between a group of individuals living independently in their own homes and who live in the same neighbourhood.

- Small groups of family members, people with disabilities and their supporters are coming together in informal and more formal groups to plan, lobby and share information relevant to their concerns about future housing options. These networks, if connected and supported have the potential to play an important role in pressuring local authorities and state governments to open up new housing options that provide a variety of local accommodation options. The 25 unit social housing development in Woden, ACT is an example of a good outcome of local collectives of people with disabilities and their families.

- There are nearly 500 Centres for Independent Living across the USA that are consumer controlled, community based, cross-disability, non-residential, non-

> profit agencies that provide a range of independent living services that include information and referral, independent living skills training, individual and systemic advocacy and peer counselling. We detected a growing anxiety among many people with disabilities and their families about how disability support arrangements will operate under DisabilityCare and how they can access reliable, trustworthy information to empower their decision-making. These concerns are being fed by the activities of many service providers as they gear up to compete with each other for clients within the context of the new funding arrangements.

Consideration should be given to trialling the Centres for Independent Living concept in one or more of the launch sites. It is critical that such centres are controlled by people with disabilities and their representatives, independent of service provision and specifically resourced to support and empower participants to get best value for their money.

Pets

Having a companion / assistance dog or other pet or was important to many of the young adults we interviewed. Some wanted companion and assistance dogs that are trained to provide some basic assistance such as picking up the phone and bringing it to the owner, retrieving things that are dropped and other chores relevant to the situation. Others sought the companionship and personal security that a pet dog or cat can provide, particularly those who have chosen to live alone. Many of the social housing options and private rental properties that people with disabilities are likely to reside in do not allow residents to have pets. Three young adults living a 19 unit complex for people with disabilities who could live independently complained about not being able to keep pets:

> ***"We would like to have a pet dog or cat but the manager says that if we all had cats and dogs it wouldn't work. A dog would help me feel safe when I go out."***

Risk, safety and security

The dignity of adventurous living

In his well-known book, "*Watership Down*", Richard Adams tells the story about an encounter between a wild rabbit called Hazel and a group of rabbits living in hutches at Nuthanger Farm. In the process of enticing the hutch rabbits to escape their safe but dull captive life on the farm to join him and friends in the wild, Hazel reflects that "*these rabbits have never had to act to save their lives or even to find a meal, so may need more time to think about this choice.*" This story very closely parallels the tension between the adventure of independent living against the secure safe settings many families have chosen for their sons and daughters with disabilities. Anxiety about what might happen to a more vulnerable person living in the community leads to housing and support arrangements that offer security and care that can stifle personal growth and development and severely limit opportunities for social connections and relationships with other members of the community.

Research around housing and disability supports by the Transport Accident Commission in Victoria is promoting the idea of ‘co-design’. The concept of co-production is taking the process further to promote the idea that the gifts, capacities and latent potential of each individual need to be developed and supported at all stages of design, implementation and review of service development and delivery. The dominant ‘care’ paradigm experienced by people with disabilities and their families can suppress this potential and encourage traits of life-long learned dependence. There was strong support from both people with disabilities and their families that making a contribution to society and living a purposeful life is important.

Difference between person with disability and their family

Our consultations and online survey highlight that one of the key differences between parents and their adult children with disabilities is the issue of safety and security. These differences fell into two basic groups:

- One group consists of young adults who wanted to move out of the family home into a home of their own or with one two others but families were anxious about their safety and indicated a preference for a larger group home or cluster arrangements.

- The other group included parents or family members who were keen to encourage their adult son or daughter to move out into their own place, but reported that there was little interest in moving on as the person with a disability felt quite safe and comfortable. This closely matches the trend of non-disabled adults who are moving out of the family home much later than in previous generations.

The need for early support and good information for parents of children with disabilities

Disability advocates we consulted highlighted the need for parents and families of a person with disabilities to have access to information and support at the earliest stages to promote the importance of thinking and planning ahead for the adult life of their child. Advocates also observed that families have a significant influence on the expectations and aspirations of adults with disabilities. Where families have ‘typical’ expectations for their children regardless of disability, they have raised their children to be strong, resilient, as independent as possible and with strong connections to siblings, friends and community groups and organisations. Children with disabilities raised in this manner are much better prepared to make good choices and to enjoy greater freedoms in adult life. It also increases the range of choice they can make about housing and supports because of the confidence they have to live independently.

Many older parents we talked with indicated they were not given good information and support in how to promote independence and promote the capacities and strengths of their child with a disability. Some who are in their 80s were struggling to know how they should raise the matter with their son or daughter and other children. Keeping an adult son or daughter with disability at home has been seen as a way of ensuring their protection and well-being however in many cases has had the reverse effect of making them more vulnerable as the parents' capacity to provide care diminishes. Many have pushed for larger congregate care settings with the idea that there is safety in numbers but have not had access to good advice and information about the shortfalls in congregate care and the impact on a range of well-being indicators identified in the literature.

Risk management and dignity of risk

Excessive risk management strategies employed within this sector were the source of many complaints from participants in this research project. While not wishing injury or trauma to any support workers in the course of doing their jobs, it was felt that many policies and practices employed by service providers made a nonsense of the idea of 'service' provision. Many felt that a lot of the current risk management practices placed management interests over the interest of those they claim to serve. Many people with disabilities and their families expressed frustration about rigid risk management regimes and management practices that resort to the easy path of risk avoidance over common sense and a balanced management of risk.

Quality of disability support service provision

Parents fears about leaving their son or daughter to the care of services that seem not to care enough about the quality of support necessary for a decent life was a strong theme in our consultations. Concerns included service providers' lack of commitment to good nutrition, maintaining independence skills, supporting good hygiene, providing or organising appropriate physical therapies for people with limited mobility.

Advocates we spoke with discussed some of the individuals they support who have complex support needs and, in some cases, have packages close to a $1M and yet service providers fail to provide positive outcomes and often withdraw from provision of care to these individuals. Advocates with expertise in working with people who have very complex support needs believe that DisabilityCare will need to research and invest in best international practice in this area.

During consultations participants were asked to share examples of good practice in disability support arrangements and housing options. It was clear that exemplary practice occurs in isolated pockets and people with disabilities and their families do not have easy access to this information. There was a strong demand for an online database where interested individuals could access examples of exemplary practice in:

- Housing models

- Disability support arrangements
- Strategies for building capacity of natural and community supports like ‘Circles of Support’, etc.
- Recreation and social network development
- Work and vocational initiatives
- Education and development of independent living skills
- Self-advocacy and empowerment.

Location of housing

In consultations with a number of individuals that took place in their shared accommodation settings, it became clear that governments have many of these facilities in locations that are remote from the hub of community life and often entailed expensive taxi trips to access shops, services, work and further education. While land packages in these locations would have been attractive to the funding authorities, the long term costs to individuals and the need for higher support packages would suggest that future investments should be made in more central locations despite the initial higher capital investments required.

Location was important to most of the people who participated in this research. Reasons given included:

- In the neighbourhood where a person has grown up and has existing social networks
- Proximity to community facilities, shops, health services and public transport
- Places where a person could keep pets.

Local and state governments need to play a leadership role in urban housing and planning to ensure the needs of people with disabilities who have mobility impairments are considered when zoning and planning for community housing.

Emerging importance of assistive technologies

Cost saving potential of assistive technologies

The development of a variety of assistive technologies is providing greater capacity for independent living for people who rely on disability supports. From remote door locking systems, to movement monitoring devices and personal alarm systems, technology promises to offer new avenues for security, safety independence. While upfront capital purchase costs might seem high, there is significant potential for important longer term savings on personal care salary costs for some individuals. One person we interviewed spoke about getting approval to import a turning bed that cost $40,000. In his application he was able to demonstrate that this would remove the need for active overnight shifts and provide savings over a fixed period of time. Furthermore, it provided a more reliable solution than one that required overnight staff.

Technologies for monitoring (more widely used for supporting older people to remain in their homes longer and maintain their independence) need to be considered as part of the support strategies that expand the choice of housing and support arrangements.

Security and safety

Consultation with the Metropolitan Fire and Emergency Services Board and Country Fire Authority in Victoria highlighted emergency management issues facing people with disabilities in various kinds of emergencies. They have been active in developing alarm systems and personalised emergency action planning resources that take into account the specific needs of people with different kinds of impairments. They are keen to see that new housing and support arrangements and service plans include a standardised reference to emergency management planning. Regular training and information sessions need to be conducted for people with disabilities, their families and their support providers to maximise preparation for any possible emergency.

Communication equipment

There was evidence amongst the people we interviewed who are living independently that tablets, iPads and mobile phones were being used increasingly. Such devices have the capacity to incorporate a range of generic and disability specific apps that increase the ease of communication and connection for those who would prefer to live on their own. They are becoming critical equipment for many individuals who may not be literate but can access audio features offered by these devices. One young woman we met who lives on her own uses an Ipad for video calls using an app called Facetime. It allows her to be seen and see who she is talking to. She uses the audio features on the tablet to speak as she is not able to communicate verbally. She said:

> ***"I can ring friends on my Ipad and keep in touch. My care hours were cut back and they tried to make me move into a group home but I refused. At the moment my friends are helping out while I try to get more funding for support hours. My mum and friends can contact me on Facetime to see if I am ok."***

Independent advocacy and information

Access to independent advocacy support

People who participated in this research project highlighted concerns about current quality of disability support services, lack of transparency with individualised funding packages and concerns about the lack of choice of services. While many individuals were unaware that they could access independent disability advocacy support funded by government, others reported on how strong, independent advocacy support had been crucial in overturning decisions that had led to negative outcomes for their family member with a disability. There was strong support for all participants in DisabilityCare to be made aware of their rights to advocacy support and to have knowledge of how to access an advocate when needed.

Access to independent and trustworthy information

A concern that was expressed by many people interviewed was that, in a new 'market model' paradigm, it would be difficult to get access to reliable and trustworthy information about services and what they offer. Access to advocacy agencies will be critical as a resource to ensure that individuals and their families are aware of their rights, have access to good information to support informed decision-making and have access to support to negotiate problems and complaints against the service provider or the funding agency. One parent complained:

> ***"My son's service provider won't tell us how much funding we have and what choice we have to change how the money is used. We need a one-stop-shop, somewhere you can get advice you can trust."***

Economic value of trust

Control over funding = lower costs to agency over time

People we spoke to who had been allowed more control over how they used their funding to purchase services, support and equipment, reported greater satisfaction with the outcomes. The greater the flexibility and scope for self-determination the disability funding arrangements allowed, the greater the likelihood that individuals would not always need all the funding allocated. At the initial stage of moving out into a new home and location people may require a higher level of funding. However when people are settled into an independent setting, have an appropriate mix of formal and informal supports in place and are working to a person centred agenda, the level of funding needed may reduce. One family with a son with very complex support needs and supported by a high cost package were able to return $40,000 in a particular year. However, this was only achieved after the family took over management of the support package from a service provider that had not only used the full funding package but had still failed to deliver positive outcomes for their client.

'Light touch' approach by administration of disability support

Research indicates that letting individuals decide how best to spend available funding package and promoting the practice of co-design and co-production within person-centred planning and implementation produce more satisfying outcomes and perhaps less lower longer term costs. DisabilityCare Agency administrators will need to avoid the natural tendency of bureaucracies to micro-manage and apply rigid rules and guidelines to how packages are used by individuals.

Banking funds

A number of individuals with experience of self-managed individual support packages supported the need for packages to allow for a reasonable level of banked funding which enables them to manage unplanned contingencies, purchase a piece of equipment that saves ongoing costs, etc.

Several individuals who were currently using individual support packages argued that the capacity to bank some of the funding and trust by the funding body to manage this sensibly engenders a greater sense of responsibility to spend available funds carefully and wisely. As one person on an individual support package put it:

> ***"If we were able to keep a small reserve for emergencies, I might not feel like I had to spend up my unspent funding at the end of the year for fear of losing it. Someone should look at how this might even save some money if people could bank a small amount."***

Eligibility for support for people with disabilities with lower support needs

A significant issue raised during our consultations was the concern for those people with disabilities with lower support needs who may not be eligible for a support package through DisabilityCare. Specifically, people were fearful that if people with lower support needs were not eligible for funds, individuals would end up needing higher levels of support at a later stage. This highlights the need for support where there is a monitoring role by the support agency and where peer supports and voluntary relationships are given attention and development to maintain ongoing independence of these individuals. Failure to provide this level of support can mean that individuals are increasingly at risk and eventually end up needing much higher levels of care, a situation that could have been prevented by low supports offered in a flexible and timely manner. One agency referred to this approach as a 'light touch' approach in which intervention and engagement are on an as-needed basis. A little support in a timely manner goes a long way.

Disposable income

Many people with disabilities and families stated that low income (from pensions or other forms of social security) and limited or no access to paid employment meant that the cost of living independently was a major barrier to moving out of the family home. More needs to be done to address income security issues and provision of affordable, accessible housing if individuals with disabilities who rely on disability supports are to move into a home of their own.

SUMMARY OF FINDINGS AND CONCLUSIONS

This project brings together the findings of the research literature with the voices of people with disabilities and their families at an important time of change in disability support arrangements across Australia.

The review of academic literature concentrated on the meta-studies around the topic of independent living and self-determination for those people with disabilities seeking to move into a home of their own. In this process we set out to identify the various models of housing and disability support that we could compare to identify the strengths and weaknesses of each model. While the literature clearly indicated that congregate care settings and clustered models of housing were limiting and less successful than more dispersed forms of housing and support, it was clear that we should abandon the idea of models in favour of a consideration of the key elements that allow for more individualised choice and personal benefit.

The academic research in this area revealed as many gaps as it did useful guidance on what arrangements of housing and disability support are most appropriate. However research on deinstitutionalisation provided clear evidence that dispersed forms of housing and support offer better outcomes on most quality of life indicators.

The grey literature encompassing more of the work documented by practitioners provided a rich and consistent message about the factors that make life better for people with disabilities. The key themes emerging from this review included the quality of housing, accessibility of house and its proximity to the hub of community facilities and transport infrastructure. It also highlighted the importance of services that were flexible, responsive, individualised and respectful of a person’s rights and supportive of their responsibilities and put the individual in control of their own life. This area of the literature also stressed the vital role that connection to community makes for individuals with disabilities and the need for an integration of funded disability support with informal support.

This literature emphasises ways in which funded support can enhance the capacity of community support for the individual as well as promoting the capacities and contributions of the individual. This is very different from the ‘tack on’ approach often employed where voluntary relationships are diminished in value by disability professionals and made subservient to the role of the paid worker. The research shows that voluntary relationships and friendships play an important safeguarding role for people with disabilities and are needed to counter the vulnerability of people with disability living in the community.

The grey literature challenges the view, widely held by administrators and many family members and even people with disabilities themselves, that people who require 24/7 support need to live in congregate care settings due to the economies of scale. There is sufficient evidence to show that putting together the right elements of support for an individual opens up the options and choices of housing and support arrangements that will work best for that individual.

Research consistently shows that people with a disability who are supported to live in their own home with individualised and flexible supports have a better quality of life and their supports cost less when compared with congregate models of care. All people with a disability can be supported to live in their own home, even people with complex medical needs, people with severe intellectual disabilities, and people who need significant behavioural supports. There is no one 'model' of service which guarantees success however there are a set of 'elements' that can guide good service provision. The implementation of DisabilityCare in Australia offers government a unique opportunity to invest in high quality individualised supports for people with a disability so that they can live in their own home, avoiding outdated models of congregate care, including group homes and cluster villages.

While there were limitations of funding and time to travel to meet with individuals and groups face to face, the online survey encouraged participation by people with disabilities and family members around the nation. The survey was intended to be explorative, rather than test any particular hypothesis or theory about participant views.The survey results strengthened the results of face to face interviews and focus groups. In particular, the survey highlighted that people with disabilities who responded preferred the options of living with one other or alone while family responses favoured 2 to 3 others. When it came to 5 or more living together, there was a unanimous view that this was undesirable.

Proximity to family, friends, shops, transport and community facilities were rated as important aspects of location of housing. Rights to have control, choose who you live with and who supports you were all rated highly. Obstacles to moving out related mainly to lack of income, affordability of housing and limitation of disability supports. Families also referenced lack of supported accommodation places in their responses.

The current research highlighted the diversity of experience, insight and perspective among people with disabilities and family members across the country. At one end of the spectrum we discovered individuals, and small groups of people who had achieved rewarding outcomes in terms of housing and disability support arrangements that were personalised and allowed greater freedom and quality of life. It again reinforced the idea that ‘models thinking’ in relation to what works best was too limiting to encompass the creativity and capacity for personalisation some people have achieved.

Characteristics of these early adopters of change showed that they had a dream or vision of what they thought would work best, they were prepared to move heaven and earth to get it and they were very persistent. “I am living the dream” was how one such person described her achievements.

In addition to situations where individuals had moved into a place of their own, including some individuals with high support needs and 24/7 care requirements, there was a strong theme of individuals living near others using disability supports to get some advantages from sharing staff, keeping an eye on each other and creating the potential for live-in care arrangements. These arrangements included people with a range of different support needs and were about striking a balance between having your own personal home space but still getting some of the synergies and benefits from shared support. There were also individuals who had collaborated with others in a similar predicament to share information and develop collective strength to find appropriate housing and support.

A key issue highlighted by this research is the importance of friendship and social connections for people with disabilities. There were exceptional stories about families and their adult son or daughter with a disability that have created a network of supports through extended family, neighbours and friends that provides social connection, safeguards and confidence for individuals to live in their own home in the community. Our research discovered that while many would love to have something similar as part of their support arrangements, there are very few services that think and act beyond providing paid support staff. Much needs to be done to foster the natural supports of our communities to rise to this challenge.

The demand for community inclusion will require the development of a skilled workforce that can facilitate social inclusion. While there are some current programs that work with community clubs and structured community programs, there is almost no support to develop more informal relationships and friendships. Programs that do this well are isolated and little is done to encourage this work under current funding models.

The top down administration of disability services has produced a system of support that is not working for many people with disabilities and their families. As a result, people with disabilities, families and increasingly more service providers and jurisdictions are beginning to generate emerging services that may eventually replace the old services.

A grass roots approach to tackling problems and finding solutions should draw greater attention from DisabilityCare. Many people with disabilities and families expressed disenchantment with what is offered by many service providers. It is vital that emerging services receive encouragement and support as much as existing providers are being supported to re-orientate their services.

Support for local peer support structures and the need for local consumer-governed resource centres to support consumer groups is one of the clear demands arising from our research. In the market place paradigm that is taking shape now, service providers are organising themselves to ensure their ongoing viability. Peer support to protect vulnerable consumers in this market place will be critical. Safeguarding consumer protection with independent advocacy should also be a priority to balance the power between providers and consumers.

Finally, and most importantly, the evidence across all the research in this project says very loudly that if we get the policy settings and strategies right individualised approaches will not cost more than grouped and segregated models that people don’t really want.

RECOMMENDATIONS

ACCESS TO HOUSING CHOICE

The evidence from this research highlights the importance of access to a range of housing types to meet the different needs of individuals with disabilities at different stages of life and the need to accommodate changes in circumstances over a life time. However, research evidence strongly argues against congregate housing and cluster housing models in terms of the longer term outcomes for people with disabilities. Many older parents who have been waiting for an accommodation option for their son or daughter have only seen institutions, group homes and perhaps some experience of in-home supports through respite support programs. In this context some are lobbying and/or planning for 'cluster housing' developments that resemble small institutions. Interestingly, this model has no appeal for younger people with disabilities when offered a choice. Governments need to heed what the research says about appropriate housing and support arrangements. DisabilityCare needs to provide leadership with other governments agencies in this area.

Recommendation 1

- That DisabilityCare engage with state and territory housing bodies to identify gaps between demand for housing by people with disabilities and availability of appropriate affordable and accessible housing stock as a first step towards development of an action plan for housing for people with disabilities.

Recommendation 2

- That current supported accommodation arrangements (operating in some state and territory jurisdictions) that prevent residents moving out and taking their share of funding with them are changed to allow costs to be individualised and housing and disability support to be separately costed. This costing should be used to enable the person to receive an individualised funding package that reflects the cost of their housing and support.This package could be used to purchase housing and support in the free market.

Recommendation 3

- That DisabilityCare fund further research into a range of housing and support arrangements that are being employed successfully to support independent community based living for people with disabilities and make this information available to people with disabilities and their families to support creative thinking and good practice across all jurisdictions.

Recommendation 4

- That people with disabilities are provided with access to a range of housing options that support them to have housing careers that recognise changing needs and circumstances over a lifespan and support the same freedom of movement to choose where they live available to other citizens in Australia.

TENANCY RIGHTS

There was a very strong response from people with disabilities and many of their parents against the current group home model that gives residents very little or no choice of who they live with. While some believed that the group home was working well when all co-residents were compatible, the lack of protection for residents against a vacancy being filled by someone desperate for a place but perhaps a very poor match in terms of compatibility highlights the lack of recognition of this most important right – the right to the quiet enjoyment of your own home. This matter needs to be taken seriously and tenancy conditions and regulations strengthened to give individuals choice, but more importantly, to offer more personalised living arrangements that avoid the issue some participants described as forced co-tenancy.

Recommendation 5

- That people with disabilities living in shared housing arrangements be guaranteed choice in who they share their home with in line with the wider community expectations and practices where adults choose to live in shared housing.

Recommendation 6

- That people with disabilities are accorded the same tenancy rights and security of tenure as other citizens living in rental properties. An important factor here is the separation of the housing provider from the provider of supports ie. housing should not be provided by the same entity that provides support.

LOCATION OF HOUSING

The location of housing has too often been based on top down decision-making by government administrators keen to obtain property at the lowest cost possible. The longer term costs for taxpayers and the impact on participation and community inclusion for those who are housed away from community and business activity hubs in towns and suburbs need to also be considered when developing social housing projects. Town planning needs to consider where housing can be set aside that meets the needs of those with limited mobility without building congregate care sites or villages.

Recommendation 7

- That DisabilityCare engage with state and territory governments, peak local government associations and urban planning professionals to develop an action plan to develop adaptive and visitable housing within planning schemes that give priority to people with disabilities with mobility restrictions in and around business, community and cultural activity hubs.

FLEXIBILITY OF DISABILITY SUPPORTS

Many we spoke to had no experience of consumer directed funding arrangements and had not had access to the right level of funding to meet basic needs, so it was difficult for them to imagine how someone needing 24/7 support could live anywhere but a congregate care facility. The international research and some good domestic examples demonstrate that people with complex support needs can live in their own home. DisabilityCare will need to ensure that staff involved in planning and linking people with disabilities to services are knowledgeable and skilled in facilitating good choices.

Recommendation 8

- That people with disabilities with support packages be supported to develop creative and flexible disability support arrangements suited to the particular needs of the individual at any given time.

Recommendation 9

- That the assessment of support needs and individual plans for those eligible for a disability support package take into account the need for transitional supports and funding when individuals are seeking to move out of the family home into a place of their own.

Recommendation 10

- That service agreements between service providers and their clients not permit long term, lock-in contracts.

Recommendation 11

- That DisabilityCare negotiates arrangements with all State and Territory public housing authorities to ensure that live-in support arrangements for people with disabilities who require this support do not incur additional financial costs to the individual.

Recommendation 12

- That DisabilityCare ensures that operational guidelines for individual planning promote plans as living documents that serve the purpose of empowering and supporting self determination of the individual.

DEVELOPMENT OF NATURAL AND INFORMAL SUPPORTS

There is a tendency of 'top down' developed systems of funding and administration to focus on unit cost funding arrangements and what funding will purchase. In this 'marketised' service system, social capital and the informal and natural supports of community are not only underestimated and ignored, but can be actively undermined. A system of funding and supporting people with disabilities to live in a more inclusive society relies heavily on the capacity of individuals, their families and the communities they inhabit to find a more effective blending of paid formal supports with the informal natural resources of the community. This will require thoughtful investment and a 'grassroots up' design and development process to maximise good outcomes for people with disabilities who rely on disability supports for their activities of daily living.

Recommendation 13

- That DisabilityCare invest funding into community capacity building initiatives that are dedicated to the development of friendships, social connections and a range of voluntary support arrangements that provide safety and protection against exploitation and loneliness.

Recommendation 14

- That research be undertaken to identify the relationship between the development of natural and informal supports, different housing and support arrangements, the outcomes for individuals and their families and the impact on need for paid support.

Recommendation 15

- That planners and planning tools used to create individualised plans take into account the rights of people with disabilities to have intimate relationships, partnerships and having a family and include necessary supports for this in the plan.

PEER SUPPORT NETWORKS

DisabilityCare will need to invest in initiatives that build community capacity, provide good information, encourage empowerment and choice and promote innovative development of disability support strategies that are life enhancing and value adding for people using individual budgets. In the course of the project we met different groups of people with disabilities and family members who had come together to try to develop better services and options in housing, disability support arrangements, employment, recreation and social connections. They expressed a need for good information, trustworthy advice from sources that were independent of funding bodies and service providers and some basic support and resourcing to develop new initiatives. DisabilityCare will gain much from supporting these grassroots action groups.

In areas where 'the market' cannot respond effectively, specific development of supports may be necessary. The development of regional/local disability resource centres (along the lines of Centres for Independent Living in the US) managed and operated by people with disabilities and their organisations was suggested as a possible structure for doing this work. These disability resource centres might also play a role in stimulating and supporting informal supports of families, friends and neighbours within local communities.

Recommendation 16

- That Local Area Coordinators are required to support and resource a range of peer support strategies that enable people with disabilities, their families and supporters to be proactive in planning and service development and design. These might include:
    - Housing action groups
    - Research-based approaches to employment
    - Development of social support and inclusive recreation options.

Recommendation 17

- That DisabilityCare fund a trial of a consumer-governed Centre for Independent Living in one or more of the launch sites as a one-stop-shop for independent information and advice, referrals to advocacy and disability supports, counselling and skills training.

Recommendation 18

- That the importance of pets, companion animals and assistance dogs be incorporated into the individual planning process and planning tools in recognition of the valuable role they play in providing security, companionship and support.

RISK MANAGEMENT AND DIGNITY OF RISK

The researchers encountered significant anger and frustration stemming from the manner in which most service providers manage risk and duty of care. People with disabilities and their families feel that perceived risks are poorly managed and that service users are the victims of excessive protection of organisational interests. It would seem that this is an area of great wastefulness and service dysfunction that is worthy of investigation.

Recommendation 19

- That DisabilityCare commissions research into the impacts of risk management practices employed by disability support agencies. The research should identify the extent of these practices, their impact on the cost and quality of support to people with disabilities and their families and determine whether a more balanced approach between protecting support workers and meeting needs of consumer can be developed.

GOOD PRACTICE IN SERVICE PROVISION

In a new service funding paradigm, people with disabilities and their families are desperate to hear about good practice and exemplary service options to enable them to make good choices and to get to work on developing similar initiatives in their local area. Access to such information is not easy to access and the good practices we discovered in this process are often operating out of the limelight. Support for the development of communities of practice for service providers, service planners and community capacity builders should be an important task for workforce development activities under DisabilityCare.

Recommendation 20

- That DisabilityCare fund the development of a website and /or information service for this sector that is tasked with the responsibility of gathering and publishing information on exemplary practices in a range of areas including: housing initiatives; flexible disability support arrangements; creative employment; inclusive recreation, friendship and social connections; and assistive technology applications.

ACCESS TO INDEPENDENT ADVOCACY SUPPORT

While the Productivity Commission described the current disability funding arrangements as dysfunctional and under-funded, it clearly accepted that the shift to consumer directed funding and entitlement to disability support would not change the need for strong and effective advocacy support that is independent of service provision and service funding functions. Signs that service providers are preparing for this new market paradigm strengthen the need for a boosted investment in a range and mix of independent advocacy support agencies that are accessible to people with disabilities across Australia.

Recommendation 21

- That independent disability advocacy received a matching increase in funding to that being invested in disability support to ensure that people with disabilities and their families are properly supported to operate in the new market place environment.

Recommendation 22

- That funding for both individual and systemic advocacy, is independent of service provision, to minimise potential for conflict of interest.

INVESTMENT IN TRUST

Francis Fukuyama's text *Trust,* in which he explores the economic value of systems that are built on trust, speaks directly to one of the key issues that DisabilityCare must address. How much can we trust participants in scheme to use their funding wisely? What safeguards need to be built in to protect taxpayer interests against misuse of funding? The research evidence on this matter very strongly supports investing in trust, which has been found to lead to cost savings in many instances. A system of regulation and micro-managed control of decisions about how funding will be spent by the administrators will only rob funds holders of much needed resources. The cultural change required among administrators will be a key task for change management.

Recommendation 23

- That policies and operating rules and guidelines be solidly based on a premise that people with disabilities and their families are co-designers and co-producers of a workable and efficient DisabilityCare scheme. Further, that the Agency adopt a position that an investment in trusting clients to be the experts on what they need and what works best for them will reduce inefficient and wasteful churn of valuable funding in over-administration and micro-management.

Recommendation 24

- That DisabilityCare research the benefits to individuals and the viability of allowing individuals to bank some of their funding as a reserve or contingency fund to provide a measure of protection and confidence for individuals as well as a means of reducing administrative overload of having to be reassessed every time there is a change of circumstances.

SUPPORT TO PEOPLE WITH LOWER SUPPORT NEEDS

Many participants in this project expressed concern about being left out because DisabilityCare may not consider them eligible for support. Demand management targets by government often lead to rationalising funding in a way that those who fall just outside the eligibility criteria end up falling through the cracks. The interface between what responsibilities fall to DisabilityCare and what responsibilities need to be taken up by other sections of government administration will be an important space for further work to prevent people with disabilities with lower support needs falling into a policy vacuum.

Recommendation 25

- That DisabilityCare consider how the intention of Tier 2 support identified in the Productivity Commission Report can be developed by the agency to provide effective light touch community based supports and resources that ensure the needs of this group of people receive appropriate attention in a timely manner.

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APPENDIX A – META-REVIEW SEARCH PARAMETERS

Databases searched

PsycINFO
PsycARTICLES
PsycBooks
PsycEXTRA
Psychology and Behavioural Sciences Collection
Social Work Abstracts
SocINDEX
MEDLINE
CINAHL
Health Policy Reference Center
Academic Search Complete
eBook Academic Collection (EBSCOhost)
eBook Collection (EBSCOhost)
Health Source: Nursing/Academic
EBSCO e-journals
ERIC
Education Research Complete

Initial search criteria

The search was conducted using the EBSCOhost.com web interface. No limit was imposed on the date of publication. (Note: * specifies that any ending to the word stem was permitted, # specifies that single additional letter is permitted to allow for alternative spellings, N5 specifies that search terms must be less than five words apart, W3 specifies that the second search term must be within five words of the first, and terms within inverted commas required exact matching).

Title contains any of:
- housing
- “group home*”
- “nursing home*”
- residential
- living N5 (arrangement* OR circumstance* OR community OR option* OR independ* OR environment*)
- resettl*
- relocat*
- community W3 (placements OR settings OR care)
- institutionali#ed

institutionali#ation
deinstitution*
“moving out”
transition* AND (independ* OR adult* OR community)
accommodation
respite N5 (care* OR program* OR residential)

AND title contains any of (within 7 words of previous criteria):
disab*
ill*
supported
managed
impair*
disor*
handicap*
“special needs”

AND title or abstract or keywords contain any of:
review*
meta-analysis
meta-study
overview

APPENDIX B – ONLINE SURVEY RESULTS

As a supplement to the interviews and focus groups, two online surveys were created. One version was intended for people with a disability (PWDs) to complete with regard to their own thoughts about their future living arrangements. The other was intended for parents (or guardians) of PWDs to complete with regard to theirown thoughts about their child's future living arrangements.

Methodology

PWDs and parents of PWDs were invited to complete the version of the survey relevant to them. Web links to both surveys were distributed to various disability organisations across Australia, along with a description of the research project; these organisations were asked to distribute the information within their respective networks. Potential participants were told that five people who completed the survey and left contact details would be randomly selected to receive a $50 gift voucher.

For both surveys, some questions required choosing an option on a rating scale; other questions allowed participants to enter text in a free-response format. In order to make the survey easy to complete, there were no mandatory questions, nor was there a minimum number of questions requiring a response.

Although the central focus of the research was on 'younger' people with disabilities who live with their parents, no one was excluded from completing the survey on the basis of their (or their child's) age or current living arrangements. This decision was made on the basis that older people who have moved (or their families) might provide useful insights from their experience of transition.

The surveys were intended to be explorative, rather than test any particular hypothesis or theory about participant views. The statistics presented are therefore intended to summarise responses of the sample; no attempt has been made to evaluate statistical significance or draw broader inferences to the population of Australians with disabilities.

Demographics and current living arrangements

53 PWDs and 114 parents responded to the survey. PWDs were asked to report their own age, gender, and postcode; parents were asked to give the age, gender, and postcode of their child with a disability. Postcodes were used to identify the locations. Table 1 summarises these characteristics. Note that, all of the statistics in Table 1 describe PWDs. For the PWD survey, this information was self-reported, whereas parents provided their child's age, gender, and location in completing the parent survey. Parents were not asked to report on their own demographic characteristics.

Table 1. Demographic characteristics of PWDs as reported by themselves or their parent.

	PWD Survey	Parent Survey
Location (state)		
ACT	2 (4%)	10 (9%)
NSW	6 (11%)	14 (12%)
QLD	5 (9%)	6 (5%)
TAS	5 (9%)	1 (1%)
VIC	26 (49%)	68 (60%)
WA	1 (2%)	2 (2%)
Postcode Not Reported	8 (15%)	2 (2%)
Location (remoteness)[a]		
Major City	32 (60%)	79 (69%)
Inner Regional	13 (25%)	21 (18%)
Outer Regional	0 (0%)	1 (1%)
Postcode Not Reported	8 (15%)	2 (2%)
Gender		
Male	20 (38%)	72 (63%)
Female	32 (60%)	31 (27%)
Not Reported	1 (2%)	0 (0%)
Age		
Mean	32.80 years	22.10 years
Standard Deviation	12.06 years	8.32 years
Under 18	1 (2%)	27 (24%)
18-24	16 (30%)	38 (33%)
25-29	5 (9%)	20 (18%)
30-39	15 (28%)	14 (12%)
40+	14 (26%)	3 (3%)
Not Reported	2 (4%)	1 (1%)

[a] Derived from postcodes using ABS (2013) postcode to remoteness area correspondence table.

Participants also reported, in a free-response format, what their (or their child's) disability is called. Responses were categorised based on the main diagnosis reported, as shown in Table 2.

Table 2. Disabilities as described by PWDs or their parents.

Disability	PWD Survey	Parent Survey
Autism Spectrum or related disorder	4 (8%)	26 (23%)
Unspecified intellectual disability or global developmental delay	3 (6%)	21 (18%)
Cerebral Palsy	4 (8%)	11 (10%)
Down Syndrome	5 (9%)	11 (10%)
Acquired Brain Injury	2 (4%)	7 (6%)
Prader Willi Syndrome	0 (0%)	5 (4%)
Fragile X Syndrome	0 (0%)	3 (3%)
Other chromosome disorder	0 (0%)	4 (4%)
Other genetic (non-chromosome) disorder	2 (4%)	6 (5%)
Spinal Cord Injury	4 (8%)	0 (0%)
Spina Bifida	4 (8%)	0 (0%)
Multiple Sclerosis	2 (4%)	0 (0%)
Arthritis	2 (4%)	0 (0%)
Other	4 (8%)	5 (4%)
Unknown or no response	15 (28%)	4 (4%)

To get a sense of the current living situations, participants were asked to report how many people they (or their child) currently lives with, and to select from a checklist the nature of the relationships with co-residents.

Table 3. Current household composition

	PWD Survey	Parent Survey
"Who currently lives with you (your child)?"		
Living alone	7 (13%)	7 (6%)
Living with a child[a]	9[a] (17%)	4[a] (4%)
Living with a grandchild	0 (0%)	1 (1%)
Living with a parent	26 (49%)	73(64%)
Living with a sibling	8 (15%)	35(31%)
Living with a roommate/housemate	2 (4%)	10(9%)
Living with a romantic partner	11 (21%)	2 (2%)
Other	2(4%)	4(4%)
"How many people currently live with you (your child)?"		
0	8 (8%)	7 (6%)
1	11 (21%)	12 (11%)
2	17 (32%)	27 (24%)
3	4 (8%)	22 (19%)
4	4 (8%)	20 (17%)
5	1 (2%)	6 (5%)
6 - 10	0 (0%)	2 (2%)
Over 10	0 (0%)	2 (2%)
Not reported	7 (13%)	5 (4%)
Mean (responses > 10 excluded)	1.73	2.69
Standard Deviation (responses > 10 excluded)	1.25	1.54

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[a] This checkbox item was intended to assess how many PWDs lived with their own children. However, it was apparent in analysis that some PWDs likely selected this checkbox item merely on the basis that the household included someone under 18. The ambiguity of this option means it must be interpreted with caution.

For the PWD Survey, participants were also asked "Did someone help you complete this survey?" 12 (23%) responded "yes", 33 (62%) responded "no"; 7 (13%) gave no response.

Attitudes to location characteristics

To understand factors that participants thought were important to choosing a location, and the degree of variation between people on this issue, participants were presented with several possible features of a living location. They were asked, “If you moved, where would you like (your child) to live?”. Participants rated each of the options on a 5-point scale ranging from “Strongly Dislike” to “Strongly Like”. Participants were also given an opportunity to describe other factors important to them, but none did so.

Table 4 summarises responses for the 53 PWD. It presents the features in order of how strongly they appealed to the average participant. The range of responses encompassing the middle 90% of responses (the ‘trimmed range’), and number of participants who did not provide a response is also indicated. Despite the diversity of participants, the great majority of PWDs favoured living near to public transport, friends, shops and other facilities. Participants varied most greatly on whether they wanted to live in an urban, suburban, or rural area. Only one participant entered an extra option in the ‘other’ box that was not covered by the presented features; this individual reported wishing to live near a particular ‘carer’ described as being the only one they trusted.

Table 4. PWDs’ ratings of location features.

“If you moved, where would you like to live?”	**Mean (SD)**	**Trimmed (90%) range**	**No Response**
near to public transport	4.43 (0.67)	4 - 5	10
near to your friends	4.4 (0.76)	4 - 5	9
near to shops, entertainment, and other facilities	4.38 (0.73)	4 - 5	10
near to your family	4.24 (0.83)	3 - 5	7
near to your current work/school/university	4.15 (0.92)	3 - 5	12
near to the groups they're currently part of (e.g., sport group, church or other religious group)	3.87 (0.81)	3 - 5	14
near to people your age	3.68 (0.74)	3 - 4	14
near to people from your culture	3.51 (0.77)	3 - 5	15
in a suburb	3.51 (1.31)	2 - 5	11
in the country (in a rural area)	3.32 (1.45)	1 - 5	15
in a city	3.23 (1.56)	1 - 5	13
near to people with a similar disability	3.19 (0.84)	3 - 4	15
near to people with a dissimilar disability	2.97 (0.79)	2 - 4	17

Note: 1 = strongly dislike, 2 = dislike, 3 = neither like nor dislike, 4 = like, 5 = strongly like. SD = Standard Deviation

Table 5 summarises responses for the 114 parents. It is seen that the great majority of parents strongly endorsed the notion of their child living in proximity to themselves, family, shops and other facilities, and near their friends. Parents varied most on whether they wanted their child to live in a city or a rural area, or near to people with a similar or dissimilar disability. Two parents reported being 'near health/medical care' as an important additional feature; another reported that the 'safety' of the local area was important.

Table 5. Parents' ratings of location features.

"If your child moved, where would you like them to live?"	**Mean (SD)**	**Trimmed (90%) range**	**No Response**
near to me	4.7 (0.57)	4 - 5	9
near to family	4.69 (0.56)	4 - 5	13
near to shops, entertainment, and other facilities	4.57 (0.7)	4 - 5	14
near to their friends	4.53 (0.74)	4 - 5	20
near to public transport	4.49 (0.85)	3 - 5	19
near to people their age	4.42 (0.8)	3 - 5	16
near to the groups they're currently part of (e.g., sport group, church or other religious group)	4.39 (0.77)	3 - 5	20
near to current work / school / university	4.3 (0.93)	3 - 5	17
in a suburb	4.06 (1)	3 - 5	20
near to people from their culture	3.69 (0.84)	3 - 5	23
near to people with a similar disability	3.62 (1.19)	2 - 5	17
in a city	3.08 (1.2)	1 - 5	26
near to people with a dissimilar disability	3.03 (1.04)	2 - 5	21
in the country (in a rural area)	2.79 (1.27)	1 - 4	24

Note: 1 = strongly dislike, 2 = dislike, 3 = neither like nor dislike, 4 = like, 5 = strongly like. SD = Standard Deviation

Attitudes to household characteristics

Participants were asked how many people they would like to live with, or how many people they would like their child to live with, in an ideal situation. They were asked to rate each of seven options on a 5-point scale. Table 6 presents a summary of responses for PWDs, and Table 7 presents the summary for parents.

On average, PWDs most strongly endorsed the notion of living with one other person. Living with 2-3 others, or living alone were the next most strongly endorsed, on average, although PWDs varied considerably in their responses to these options. Living with any more than three others was viewed unfavourably by most PWDs. Parents, by contrast, preferred slightly larger household sizes, on average. 2-3 people was the most strongly endorsed option by parents, and living with more than five others was viewed as undesirable by most parents. However, parents tended to vary more in their views on household size than did PWDs.

A large proportion of participants gave no response to one or more of the options. However, examination of the data revealed that most of these participants rated at least one option, and typically rated it 5 ("strongly like"). It would therefore appear that a number of PWDs indicated their ideal household size, but did not wish to discriminate between their non-ideal options.

Table 6. PWDs' ratings of desired number of co-residents.

"If you moved, how many people would you like to live with?"	**Mean (SD)**	**Trimmed (90%) range**	**No Response**
none (living on your own)	3.33 (1.49)	1 - 5	25
1	4.33 (0.96)	3 - 5	19
2-3	3.43 (1.28)	2 - 5	15
3-5	2.11 (1.34)	1 - 4	25
5-10	1.4 (0.76)	1 - 3	27
10-20	1.35 (0.63)	1 - 2	26
more than 20	1.41 (0.8)	1 - 2	25

Note: 1 = strongly dislike, 2 = dislike, 3 = neither like nor dislike, 4 = like, 5 = strongly like. SD = Standard Deviation

Table 7. Parents ratings of desired number of co-residents.

“If your child moved, how many people would you like them to live with?”	**Mean (SD)**	**Trimmed (90%) range**	**No Response**
none (living on their own)	2.48 (1.6)	1 - 5	43
1	3.2 (1.35)	1 - 5	43
2-3	3.93 (1.22)	2 - 5	31
3-5	3.14 (1.5)	1 - 5	41
5-10	2.01 (1.29)	1 - 4	43
10-20	1.58 (1)	1 - 3	42
more than 20	1.42 (0.97)	1 - 3	43

Note: 1 = strongly dislike, 2 = dislike, 3 = neither like nor dislike, 4 = like, 5 = strongly like. SD = Standard Deviation

Participants were asked about the desired characteristics of people they might live with. They were asked to rate a set of co-resident characteristics on a 5-point scale. Tables 8 and 9 summarise the results for PWDs and parents respectively. For PWDs, the most appealing option, on average, was to live with one's (current or hypothetical) partner; PWDs tended to vary considerably in how they rated the remaining options, however 'with your parent(s)' was the least desired option. There was more consensus among parents, most wanting their child to live with 'someone their age', 'someone paid to provide support', or 'a friend of theirs'.

Table 8. PWDs ratings of co-resident characteristics.

"If you moved and did live with others, who would you like to live with?"	**Mean (SD)**	**Trimmed (90%) range**	**No Response**
with your partner (boyfriend, girlfriend, spouse)	4.38 (0.98)	3 - 5	20
with your child or children	3.81 (1.25)	2 - 5	31
with someone your age	3.7 (0.81)	3 - 4	19
with a friend	3.57 (0.95)	2 - 4	17
with someone who does not have a disability	3.52 (1.03)	2 - 5	21
with someone who has a similar disability to you	3.14 (1.14)	1 - 4	17
with someone who volunteers to provide some support who also lives with you	3.06 (1.34)	1 - 5	21
with someone paid to provide some support who also lives with you	3.03 (1.28)	1 - 4	21
with someone younger than you	3.03 (0.95)	2 - 4	19
with someone older than you	3 (1)	1 - 4	23
with your sibling(s)	2.75 (1.39)	1 - 5	20
with someone who has a different disability to you	2.74 (1.12)	1 - 4	21
with your parent(s)	2.52 (1.23)	1 - 4	21

Note: 1 = strongly dislike, 2 = dislike, 3 = neither like nor dislike, 4 = like, 5 = strongly like. SD = Standard Deviation

Table 9. Parents' ratings of co-resident features.

"If your child moved and did live with others, who would you like them to live with?"	**Mean (SD)**	**Trimmed (90%) range**	**No Response**
with someone their age	4.51 (0.65)	4 - 5	29
with someone paid to provide some support who also lives with them	4.21 (0.92)	3 - 5	28
with a friend of theirs	4.12 (0.99)	3 - 5	38
with someone who does not have a disability	3.95 (0.97)	3 - 5	33
with someone who volunteers to provide some support who also lives with them	3.94 (0.99)	3 - 5	37
with their partner (boyfriend, girlfriend, spouse)	3.82 (1.02)	3 - 5	59
with someone who has a similar disability	3.68 (1.13)	2 - 5	29
with someone older than them	3.34 (0.93)	2 - 5	28
with someone who has a different disability	3.27 (1.06)	2 - 5	28
with someone younger than them	3.18 (0.86)	2 - 4	32
with their child or children	2.84 (1.22)	1 - 5	82
with me	2.72 (1.38)	1 - 5	42
with extended family members	2.71 (1.19)	1 - 4	48
with a parent	2.62 (1.31)	1 - 4	45
with their sibling(s)	2.62 (1.28)	1 - 4	41

Note: 1 = strongly dislike, 2 = dislike, 3 = neither like nor dislike, 4 = like, 5 = strongly like. SD = Standard Deviation

Perceptions of support needs

In this report, the term 'support' is used to refer to any kind of assistance that is provided and has some relation to a person's disability. This may be provided by a volunteer, family member, friend, or someone paid to do so. Participants were presented with ten categories of support and were asked to rate how much of each they would ideally like. Ratings were made on a 5-point scale, with the options labelled 'not at all', 'occasionally', 'some of the time', 'most of the time', and 'all of the time'. The participants who indicated they would like at least some of that support type were identified; means, standard deviations, and trimmed ranges, were then calculated based on the ratings of these participants. Tables 10 and 11 summarise the results for PWDs and parents, respectively.

A majority of PWDs reported wanting someone to ‘clean or take care of’ the residence, someone to ‘be around just in case’, and someone to ‘provide physical supports’; sizeable minorities desired the other categories of support. PWDs varied, however, in how much of each type of support they wanted.

For all but one category (assistance animals), a majority of parents reported wanting some degree of that support for their child. On average, parents tended to want a greater amount of these support types than did PWDs. This may reflect the differences in disabilities between PWDs who completed a survey and those whose parents did so. Two parents referenced support outside the house as an additional need in the ‘other’ box; another referenced various types of physical therapy.

Interestingly, although assistance animals were the least commonly endorsed need, it was nevertheless of interest to a sizeable minority of PWDs and parents. One might expect interest to rise even further if there were greater awareness in Australia of the variety of ways animals (typically dogs) can assist people with disabilities.

Table 10. PWDs' ratings of support needs.

"If you moved, what kind of supports would you like?"	**Number wanting some of support type (% of sample)**	**Mean (SD)**	**Trimmed (90%) range**
Someone to clean or take care of the house/unit/apartment	36 (68%)	3.69 (0.93)	3 - 5
Someone to be around "just in case" to make sure you're OK	36 (68%)	3.17 (0.98)	2 - 5
Someone to provide physical supports (e.g., personal care, assistance with meals)	28 (53%)	3.59 (1.08)	2 - 5
Someone to provide advocacy support	25 (47%)	2.92 (1.06)	2 - 4
Someone to help you learn or practice new skills	24 (45%)	3.48 (1.24)	2 - 5
Someone to help you make plans and decisions	23 (43%)	3.5 (1.06)	2 - 5
Someone to coordinate and organise support staff/volunteers	23 (43%)	3.14 (1.17)	2 - 5
Someone to help you make new friends	20 (38%)	3.16 (0.96)	2 - 4
Someone to help you develop romantic or sexual relationships	15 (28%)	2.93 (0.92)	2 - 4
An animal trained to assist you (e.g. assistance dog)	13 (25%)	3.58 (1)	2 - 5

Note: 1 = not at all, 2 = occasionally, 3 = some of the time, 4 = most of the time, 5 = all of the time. SD = Standard Deviation

Table 11. Parents' ratings of support needs.

"If your child moved, what kind of supports would you like them to have?"	Number wanting some of support type (% of sample)	Mean (SD)	Trimmed (90%) range
Someone to clean or take care of the house/unit/apartment	96 (84%)	4.03 (0.98)	3 - 5
Someone to help them learn or practice new skills	95 (83%)	4.12 (0.89)	3 - 5
Someone to coordinate and organise support staff/volunteers	94 (82%)	4.12 (1)	3 - 5
Someone to provide physical supports (e.g., personal care, assistance with meals)	92 (81%)	4.22 (0.9)	3 - 5
Someone to provide advocacy support	92 (81%)	3.85 (1.08)	2 - 5
Someone to help them make plans and decisions	91 (80%)	3.99 (0.91)	3 - 5
Someone to be around "just in case" to make sure they're OK	89 (78%)	4.2 (0.86)	3 - 5
Someone to help them make new friends	89 (78%)	4.08 (0.96)	3 - 5
Someone to help them develop romantic or sexual relationships	58 (51%)	3.23 (1)	2 - 5
An animal trained to assist them (e.g., assistance dog)	46 (40%)	3.78 (1.08)	2 - 5

Note: 1 = not at all, 2 = occasionally, 3 = some of the time, 4 = most of the time, 5 = all of the time. SD = Standard Deviation

Perceptions of equipment needs

To get a general sense of equipment needs, participants were provided with an opportunity to list, in a free-response format, the equipment they (or their child) would "like or need" to have if they moved. Participants' responses were diverse, such that there were too many items to list all of them in this report, and few that were listed by more than 5% of PWDs or parents. Interestingly, with the exception of hoists and lifting machines, the other five most commonly listed items (computers, internet access, iPads and telephones) were not specialist medical or disability equipment. This suggests mainstream technology can be particularly important for people with disabilities to live more independently.

Attitudes to rights

Participants were asked to rate the importance of a set of possible rights. It was assumed that most participants would not object to having (or their child having) any given right respected, but that they would nevertheless value certain rights over others. Therefore, participants made ratings on a 5-point ‘importance’ scale, with options ranging from “not at all important” to “essential”. Table 12 and 13 summarise the results for PWDs and parents, respectively. It is seen that, overall, rights appear to be highly valued by both PWDs and parents.

Table 12. PWDs' ratings of the importance of rights.

"If you moved, what rights would be important for you?	Mean (SD)	Trimmed (90%) range	No Response
To privacy	4.49 (0.82)	4 - 5	13
To decide who you live with	4.43 (0.68)	4 - 5	12
To come and go as you please	4.39 (0.86)	4 - 5	14
To decide who comes into your home and on what terms	4.38 (0.86)	4 - 5	15
To personalise your home to your liking	4.38 (0.86)	4 - 5	15
To decide where you live	4.38 (0.74)	4 - 5	12
To live there as long as you like	4.26 (0.72)	3 - 5	13
To choose what supports you receive	4.22 (0.96)	3 - 5	16
To move from there when you choose	4.22 (0.9)	3 - 5	16
To have friends or family stay with you	4.11 (0.97)	3 - 5	15
To choose which organisations provide you with supports	4.1 (0.75)	3 - 5	13
To choose what days and what times you receive supports	3.97 (1.13)	3 - 5	14
To choose which staff or volunteers work with you	3.92 (0.98)	3 - 5	13
To alter the building into the future (e.g. ramps built, doors widened, kitchen altered)	3.77 (1.11)	2 - 5	17
To trial different living and support options until you find what works for you	3.54 (1.39)	2 - 5	15
To have sex or intimacy with someone you choose in your home	3.53 (1.32)	2 - 5	16
To receive supports from more than one organisation	3.51 (1.29)	2 - 5	17

Note: 1 = Not at all important, 2 = not very important, 3 = somewhat important, 4 = very important, 5 = essential. SD = Standard Deviation

Table 13. Parents' ratings of the importance of rights.

"If your child moved, what rights would be important for them to have?	**Mean (SD)**	**Trimmed (90%) range**	**No Response**
To live there as long as they like	4.67 (0.66)	4 - 5	27
To privacy	4.56 (0.73)	3 - 5	28
To personalise their home to their liking	4.54 (0.77)	4 - 5	27
To have friends or family visit or stay with them	4.44 (0.89)	3 - 5	28
To decide who comes into their home and on what terms	4.44 (0.85)	3 - 5	28
To choose which staff or volunteers work with them	4.41 (0.73)	3 - 5	28
To decide who you they live with	4.39 (0.9)	3 - 5	29
To choose what days and what times they receive supports	4.36 (0.87)	3 - 5	29
To choose what supports they receive	4.36 (0.82)	3 - 5	28
To trial different living and support options until they find what works for they	4.28 (0.91)	3 - 5	27
To move from there when they choose	4.26 (0.98)	3 - 5	29
To decide where they live	4.23 (0.94)	3 - 5	27
To choose which organisations provide them with supports	4.16 (0.93)	3 - 5	28
To come and go as they please	4.05 (1.15)	3 - 5	31
To alter the building into the future (e.g. ramps built, doors widened, kitchen altered)	3.76 (1.36)	1 - 5	30
To receive supports from more than one organisation	3.6 (1.03)	2 - 5	28
To have sex or intimacy with someone they choose in their home	2.96 (1.53)	1 - 5	30

Note: 1 = Not at all important, 2 = not very important, 3 = somewhat important, 4 = very important, 5 = essential. SD = Standard Deviation

Interest in skills development

To gauge participants' perceptions of how their (or their child's) skills could be developed, participants were asked to indicate which of nine categories they saw as areas for development. Table 14 presents the proportion of PWDs' and parents who endorsed each category. It is noteworthy that there was some interest in all the areas of skill development.

Table 14. Participants perceived areas for skill development.

"What skills would you like to (hope they could) learn or develop?"	**Individuals (%)**	**Parents (%)**
Cooking	18 (34%)	75 (66%)
Household tasks, e.g. cleaning, shopping, etc.	21 (40%)	77 (68%)
Travel, getting around in community	13 (25%)	70 (61%)
Planning, decision-making	8 (15%)	69 (61%)
Self-care, e.g. hygiene, health	18 (34%)	77 (68%)
Building / looking after relationships	10 (19%)	72 (63%)
Assertiveness, self advocacy	14 (26%)	66 (58%)
Money management – budgeting, paying bills, etc.	13 (25%)	53 (46%)
Managing / directing support workers	18 (34%)	49 (43%)

Perceived obstacles to change

To help understand participants' perceptions of obstacles, they were asked, "What are or would be the obstacles to you (your child) moving from your current living arrangement to something closer to your (your child's) ideal? Answers were provided in a free-response format.

The nature of the responses made them difficult to categorise and summarise quantitatively, however some common themes were apparent. Participants most typically referenced 'financial' obstacles, sometimes referring to low income, lack of employment, unaffordability of housing, or lack of disability funding as obstacles. Often participants merely referenced 'money' or 'finances' in a general sense. Parents also often referred to a lack of supported accommodation places.

Participants also commonly referenced the suitability of housing and services in some way, referring to the difficulty of finding the "right place", "somewhere suitable", or somewhere accessible. Some parents remarked that the quality of support provided by service providers is not sufficient for their child. Interestingly, only a few participants mentioned a psychological factor as an obstacle, although a sense of fear or worry was often implicit in participants' responses.

Time-frames for change

In both surveys, participants were asked two questions about the timeframe within which a change in living arrangements might occur. The first of these questions asked, “Ideally, approximately how soon would you like (your child) to move from where you are now to a new living arrangement?” Participants were presented with eight time-frames to choose from, ranging from 1-6 months to “never”. The following question asked, “Approximately how soon do you think it will actually be before you (they) move?” Participants were presented with the same eight time-frames to choose from.

Figure 1 presents the proportions of PWDs and parents who chose each option as their ideal timeframe for change; it also indicates the proportions who did not respond to the question. 2 - 5 years was the most common response for both PWDs and parents, however, shorter and longer timeframes were also well represented.

Figures 2 and 3 depict (for PWDs and parents, respectively) the differences between ideal and expected timeframes; these data are categorised by whether the person with a disability currently lives with a parent. In these figures, the horizontal axis represents the ideal timeframe, and the vertical axis represents the expected time. Therefore, markers in the shaded area represent participants whose ideal and expected timeframes match. Markers above the shaded area, meanwhile, represent participants who expect change will take longer than they would like; markers below, represent those who expect change will occur sooner than they would like.

As seen in Figure 2, only one PWD who currently lives with a parent expected change to occur sooner than they would like; the remainder expected change to occur within or longer than their ideal time-frame. Individuals who were not living with a parent were more evenly distributed above and below the shaded area. In Figure 3, it is seen that a majority of parents whose child lives with them (or another parent) expected change to take longer than their ideal, often expecting it to be considerably longer. Almost entirely absent were responses from parents fearing that their child would have to move away from them sooner than they desired: only two parents were in this category.

Figure 1. Participants' ideal timeframe for moving to a new living arrangement

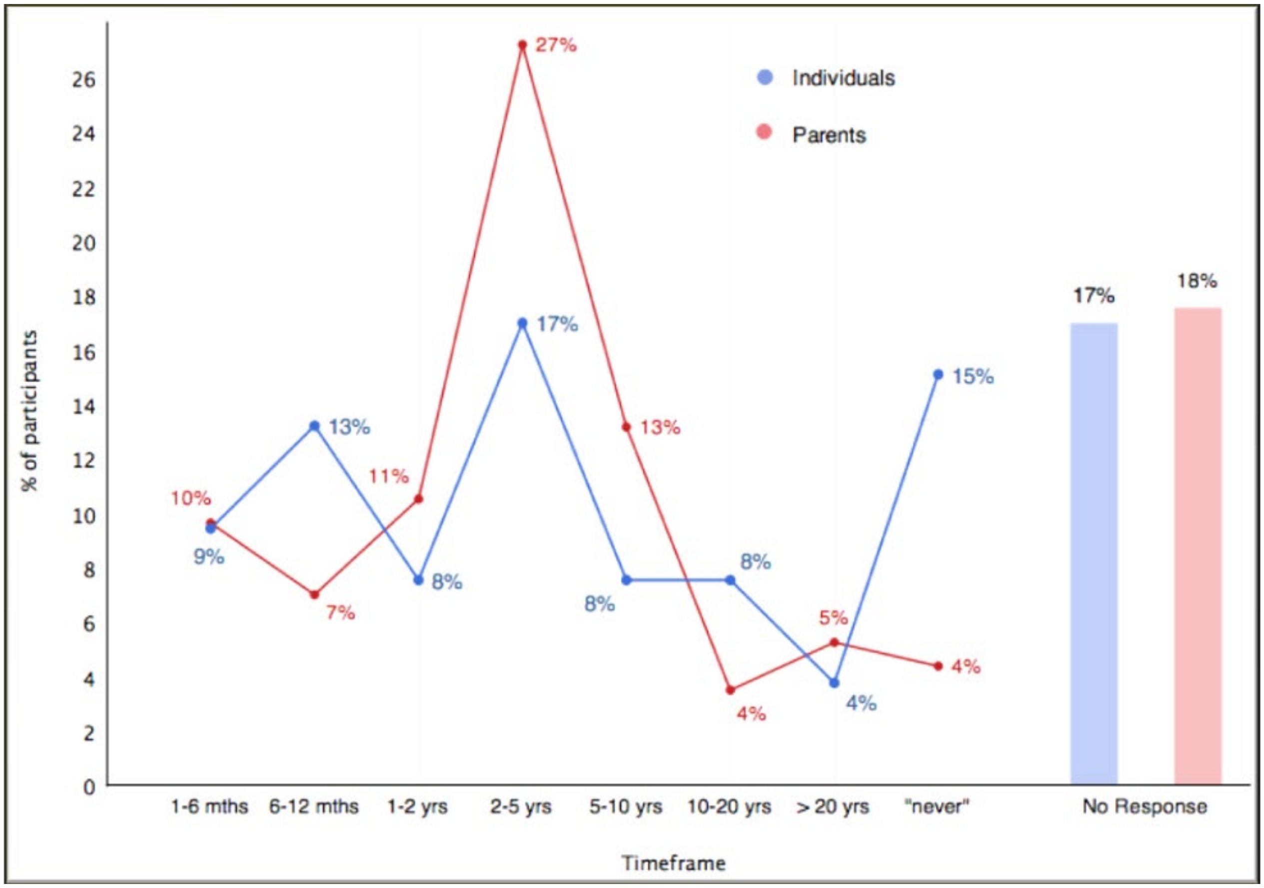
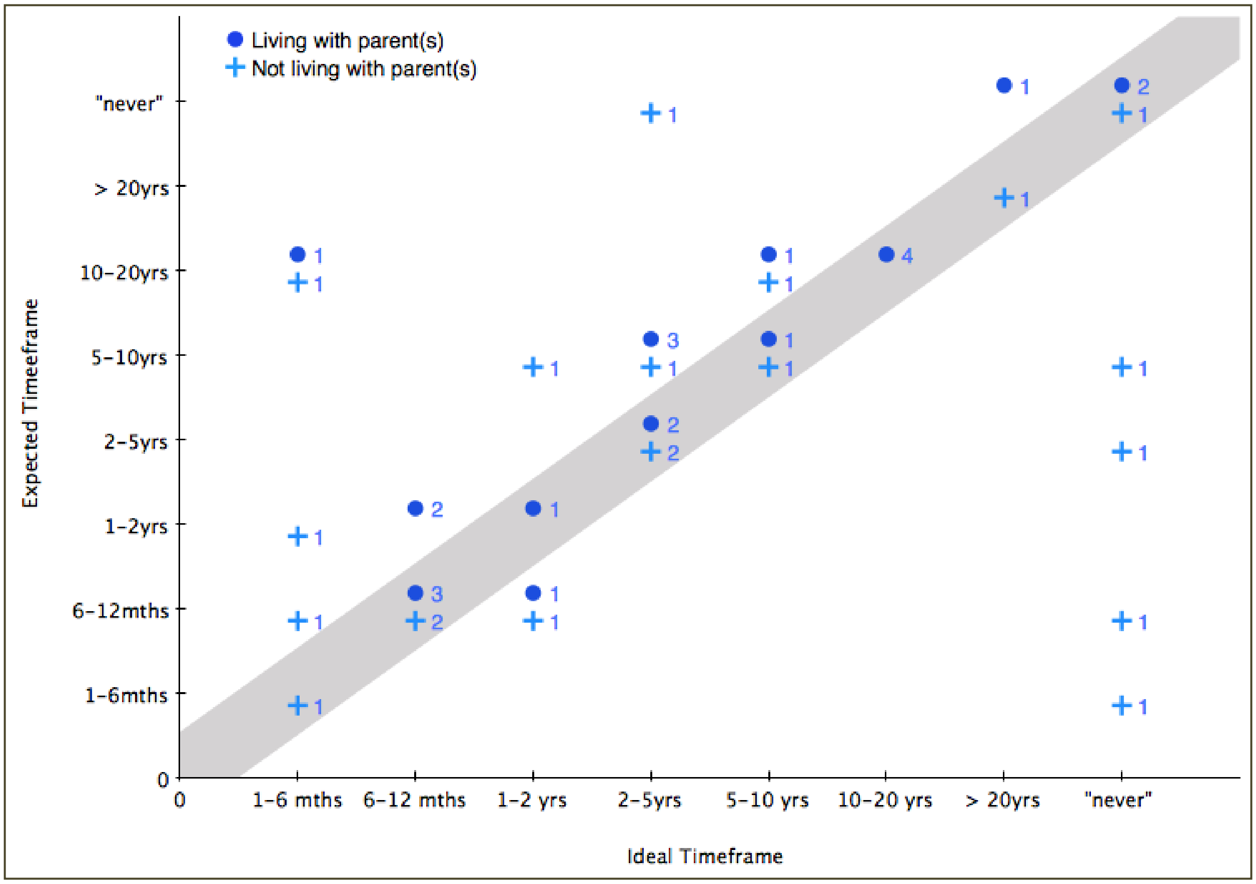
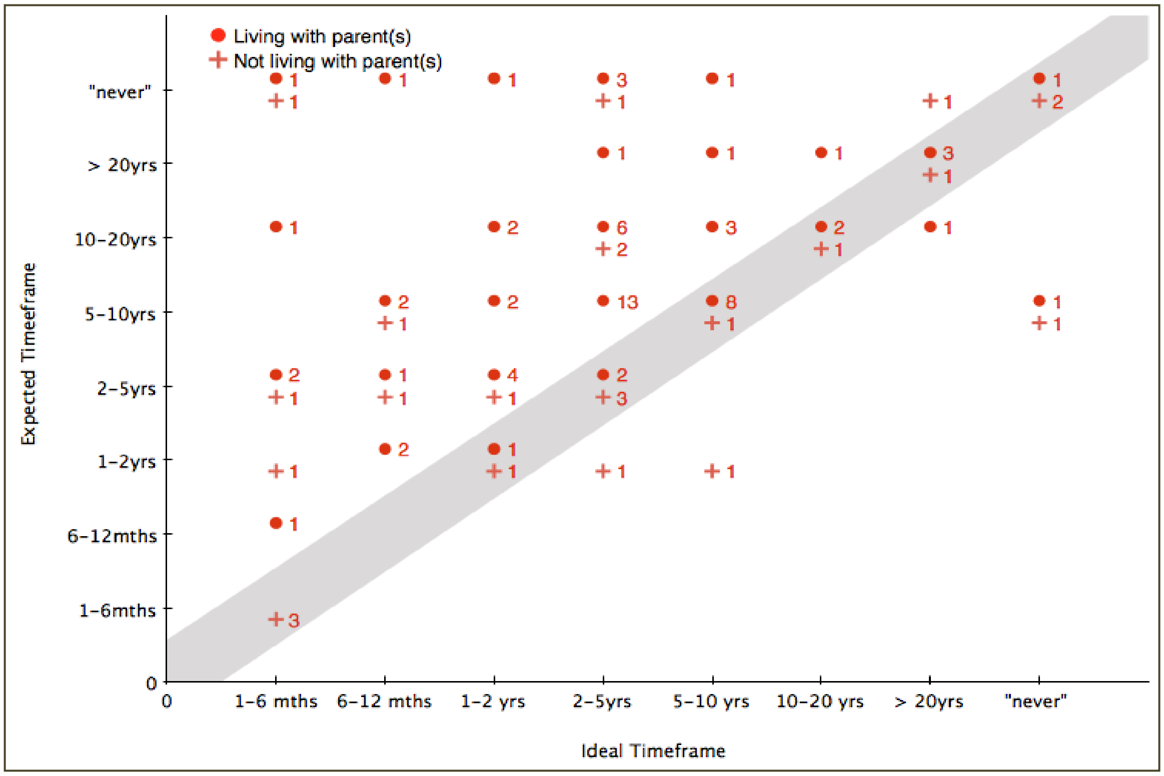


Figure 2. PWDs' ideal versus expected timeframe for change (categorised by living with parent status).



Note: The number of participants represented by each marker is indicated by its adjacent numeral.

Figure 3. Parents' ideal versus expected timeframe for change (categorised by living with parent status).



Note: The number of participants represented by each marker is indicated by its adjacent numeral.