LIVING LIKE EVERYONE ELSE

RE-THINKING 24 HOUR SUPPORT

A GUIDE TO NEW OPPORTUNITIES FOR SUPPORTING PEOPLE WITH DISABILITIES AND COMPLEX NEEDS TO LIVE IN THEIR OWN HOMES

DECEMBER 2016

SUMMER FOUNDATION

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Project brief: The Summer Foundation has been funded by NDIS to explore ideas of 24 hour support for people with disability and complex support needs, living in housing models that are innovative. The Summer Foundation's work is primarily with young people living in, or at risk of entry to Residential Aged Care (nursing homes). This project isn't limited to that group. The emphasis is on exploring possibilities that are emerging because of the development of the NDIS, most particularly through the lens of 'choice and control', which underpins the Scheme.

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SPECIFIC EXAMPLES OF NEW HOUSING AND SUPPORT ARRANGEMENTS:

NSW: Hunter project (Summer Foundation and Ability Options)

SOUTH AUSTRALIA: Woodville project (CARA)

TASMANIA: Queens Walk, Nexus Independent Living Program, Hobart (Nexus Inc. and HCA)

VICTORIA: Abbotsford apartment project (Summer Foundation, TAC RIPL, annecto, CEHL)

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OVERVIEW OF THE GUIDE

OVERVIEW OF THE GUIDE

Rethinking 24 hour support requires attention to many factors and issues. Living like everyone else incorporates independent housing arrangements, whereby housing is developed separately from support possibilities. With independent housing the individual decides to rent or own their own home, perhaps with others and in a location of their choice. Support in an individual's own home is an alternative to moving to a facility or group home[1].

Fundamental to the Guide is the identification of eleven implementation strategies which contribute to people with disabilities and complex needs being able to live like everyone else. These strategies are inter related but are often not relevant in the same way for different people with disabilities, families and different organisations. This overview to the Guide outlines the features of the guide and provides quick reference points for the reader wanting to explore the strategies and associated activities in the detail needed for successful implementation. A feature of the Guide is practical examples of how people with disabilities and complex needs are living in independent housing and descriptions of the models of support implemented by service providers.

BACKGROUND

The Summer Foundation was contracted by the NDIS through its Community Integration and Capacity Building (CICD) initiative to "undertake a series of activities aimed at researching best practice in the provision of 24 hour support services to people with high levels of support need, such as young people currently living in residential aged care".

The project started with the question:

WHAT IS 24 HOUR SUPPORT AND WHO IS IT FOR?

We now consider a more appropriate question to be

WHAT LEVEL AND TYPE OF SUPPORT DOES EACH PERSON NEED TO LIVE IN THEIR OWN HOME?

1. The terms 'group home' and 'shared supported accommodation' are used interchangeably depending on the context to refer to staffed houses which are typically for 4-6 residents.

INITIAL FINDINGS

- '24 hour support' incorporates a broad range of ideas including location, design, modifications, technology; and people including family, friends, community members and staff. 24-hour physical staff presence is but one option in the array of support choices within 24 hour support. Some people with disabilities and complex needs will be best supported through 24 hour physical staff presence – but an assumption of 24 hour physical staff presence should not be the starting point for planning living like everyone else.
- Many people with disabilities are consistently offered, or insist on, 24 hour physical staff presence (or 18 hours plus 6 hours of day support). Whether that is optimal often remains unexplored, because of the history of inflexible funding and assumptions and myths about risk and the need for protection.
- There is no single model of 24 hour support effective for all people with disabilities and complex needs living in their own homes. Evidence shows that people with disabilities are now living in circumstances not previously expected possible, and we are all continuing to learn how to benefit from this new world. However because not everyone has experienced these opportunities, or appreciates what might be possible, there remains a risk of replicating outdated and inflexible approaches to housing and support.
- For community living to become a successful reality attention must be given to rights, values and attitudes, reciprocal relationships, and understanding how each person with a disability can receive 'reasonable and necessary' support throughout life. These directions are consistent with enabling people with disabilities to live in their own homes and maximising the long-term sustainability of NDIS support funding.
- A climate of change creates the opportunity for innovative and improved responses to the support needs of people with disabilities. With the advent of the NDIS, the time is right to explore how people with disability and complex needs who are living in their own homes, can re-conceptualise and implement responses to their individual needs and preferences.
- Providers of support and housing, and individual and families, need to do their own re-thinking in response to new possibilities. Responsive and adaptable operational guidelines and procedures for the personnel involved in implementing new directions for living like everyone else are needed.

THIS PROJECT IS THEREFORE ABOUT LIVING, NOT HOUSING. THAT IS, HOW PEOPLE WITH DISABILITIES CAN

LIVE LIKE EVERYONE ELSE.

DIRECTION TAKEN IN THIS PROJECT:

The aims of the project were to:

- Describe the difference between '24 hour support' and '24 hour physical staff presence'.
- Investigate the range of strategies needed to develop support arrangements so that individuals with disabilities can live like anyone else.
- Examine practical examples of how these implementation strategies are currently working for people with disabilities and complex needs, acknowledging the variance arising from people's different histories and support needs.
- Outline the obstacles and challenges faced and explore ways to meet them.

The project team identified the need to document and describe strategies that best answer our new questions in a contemporary landscape influenced by the introduction of the National Disability Insurance Scheme (NDIS).

Eleven implementation strategies were identified through a series of interviews and consultations, based on successful initiatives that have enabled people with disabilities to live like everyone else in their own way in their community. These strategies are described in detail in this Guide. Case examples illustrate some of the challenges of implementing these strategies. While the implementation strategies are interdependent, they are not sequential and have varying timelines. Reducing the strategies to a summary form risks a 'tick box' approach, which contradicts our goal of thoroughly re-imagining how life can be after the introduction of the NDIS.

The strategies are designed to keep expectations about possibilities open and evolving, and to review and question accompanying implementation processes. They also raise important re-framed questions, which facilitate choice and control, independence and community participation.

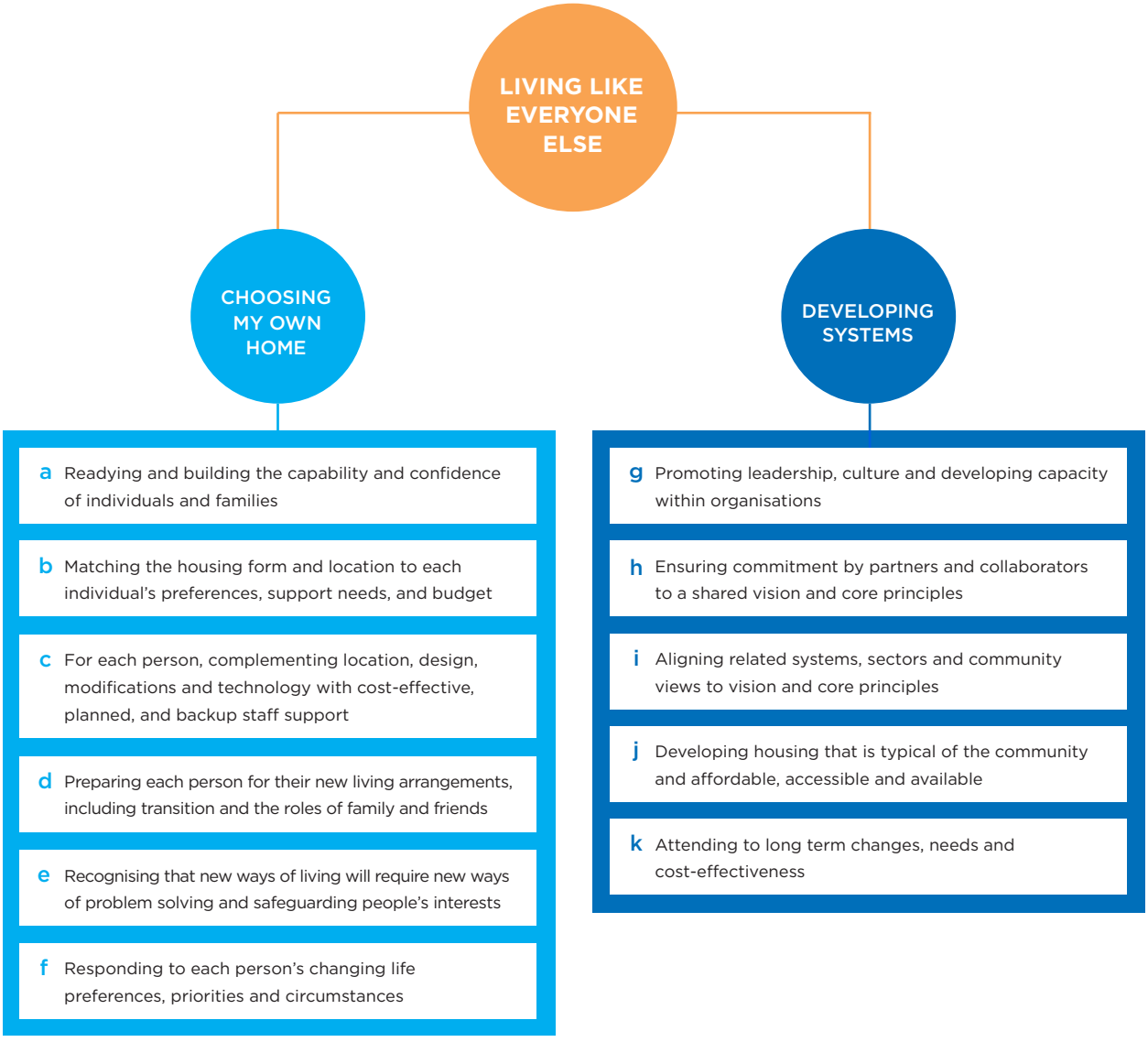
QUESTIONS INCLUDE:

- For people with disabilities, including those with complex needs: "How do I want to live?"
- For families: "Is information available about possibilities?"
- For staff support: "What is effective staff support practice, what does it look like?"
- For research domains: "Are we asking the right questions of researchers?"
- For policy: "What are the overarching policies and what are the trade-offs?"

Some implementation strategies and activities will be relevant to individuals, families, support providers, planners and support coordinators; or to systems, partnerships and collaborations, depending on each situation. Examples from the project describe how 24 hour support is being provided, and the learnings from each of them. What works well in one instance may not be replicable to another setting – even if implementation strategies and activities are the same.

ABOUT THE IMPLEMENTATION STRATEGIES

Eleven implementation strategies were identified from consultations and successful initiatives which have enabled people with disabilities to live like everyone else. The implementation strategies are divided into two groups: "Choosing my own home", and "Developing systems".



These strategies have implications for individuals and families planning individual living, and for systemic developments that enable sufficient well-designed and located housing to be available for individuals and families. It is not enough for each individual with disability to plan how they want to live. The absence of systemic developments will hinder the aspirations of people with disability.

The guide provides a framework from which relevant implementation strategies and activities ('what can be done') can be identified and refined. Initiatives and decision-making arising from these implementation strategies can produce concerted effort towards living like everyone else.

CHOOSING MY OWN HOME

The focus for this group of strategies is the individual choosing where, how and with whom to live, and how to be supported.

a Readying and building the capability and confidence of individuals and families

Learnings so far reveal that individuals and families have to want independent housing arrangements and see independent living as achievable. In order to take full advantage of the NDIS, exploratory and experiential processes are needed to inform family (parents, spouse or extended family), the individual, and, at times to prepare service providers and their support staff.

Examples of what can be done:

- Have the expectation from the start (from early childhood or post an accident) that independent housing will happen.
- Encourage individuals and families to imagine how life could be.
- Provide ongoing information, challenging expectations and stereotypes and promoting different ways of living available for individual, families, organisations and their staff and the wider community.

For more information about this strategy, associated issues and what to do, go to PAGE 28

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b Matching the housing form and location to each individual's preferences, support needs, and budget

Personal preferences about housing form and location arise from many variables: where someone wants to live, with whom; who the person wants to live near and how close or in what community, and what is available and affordable in that locality. How much personal space the person prefers or needs can be relevant when considering apartment living, suburban house, units or rural housing. Some people will already have a home and established way of living they wish to continue with after their accident or illness, or because it is the family home.

Examples of what can be done

- Plan carefully with each individual and family consistent with person's preferred lifestyle. Identify trade-offs, compromises and priorities.
- Develop incentives for people to become more independent.
- Recognise that individuals with disabilities and families need practical and emotional support.
- Ensure decisions about housing form and location precede decisions about support.

For more information about this strategy, associated issues and what to do, go to PAGE 33

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c For each person, complementing location, design, modifications and technology with cost-effective, planned, and backup staff support

Formal and informal support are not mutually exclusive and can all make a contribution in someone's life - just as the person with a disability can make contributions in the lives of others.

Staff support complements optimum use of design, modifications and technology. Staff support can vary over time in intensity, frequency and type and can include planned support as well as backup support for emergencies, and the unexpected. Different staff roles require different skill sets.

Examples of what can be done:

- Coordinate various formal and informal support arrangements.
- Understand the possibilities and limitations of technology.
- Explore cost-effectiveness of support by careful analysis of individual patterns of daily life.
- Find the right balance between planned staffing and backup staffing.

For more information about this strategy, associated issues and what to do, go to PAGE 38

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d Preparing each person for their new living arrangements, including transition and the roles of family and friends

Preparing to move is the point when an individual has decided to move (or moving is inevitable due to changing circumstances) and additional opportunities to exercise independence or the requirement for increased support are considered. Transition is the stage of actually moving in and being ready for the reality of new support arrangements.

Examples of what can be done

- Explore each person's new roles and responsibilities.
- Develop staff teams around each person.
- Assist individuals and families to plan, change and make transitions.

For more information about this strategy, associated issues and what to do, go to PAGE 49

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e Recognising that new ways of living will require new ways of problem solving and safeguarding people's interests

New ways of supporting people to live like everyone else will generate new problems to be solved and risks to be ameliorated.

Organisational and individual preparedness to be flexible and keep learning is essential.

Examples of what can be done:

- Assess risks and possibilities for each individual in the context of their preferred way of living.
- Develop a culture of learning and reflection rather than blame and punishment, and develop an enabling approach to emergencies.
- Recognise the vital safeguarding role of friends, family and community members.
- Anticipate that the unexpected will occur with new ways of living.
- Keep the goal in sight.

For more information about this strategy, associated issues and what to do, go to PAGE 53

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f Responding to each person's changing life preferences, priorities and circumstances

Establishing responsive support options means more than regular reviews. People with disabilities and complex needs living like everyone else will have ongoing requirements for 24 hour support, and the intensity and nature of support will vary over the years. People's lives change in both predictable and unexpected ways. Some changes happen suddenly, some need to be planned for, and sometimes an individual may wish to move house because of increased capabilities, new relationships or the desire for a fresh start.

Examples of what can be done:

- Ensure individuals remain central to decision-making effecting their lives.
- Establish ways to plan and monitor in the future.
- Keep building personal capability and flexibility central to support provider roles.

For more information about this strategy, associated issues and what to do, go to PAGE 60

DEVELOPING SYSTEMS

This group of implementation strategies notes the system-level changes required to further the proposed directions needed for each individual when choosing their home.

g Promoting leadership, culture and developing capacity within organisations

An approach which asks organisations and staff to work collaboratively with people with disabilities is more challenging to implement. It takes time and leadership for organisations, boards and staff groups to develop their culture and mission before new staff approaches and different styles of support can be implemented in the home of each person with a disability.

Examples of what can be done:

- Confirm the core principles of individualised service within the mission of the organisation.
- Create incentives for organisations and staff to promote independence, not dependence.
- Explore new ways to structure organisations consistent with the core principles.

For more information about this strategy, associated issues and what to do, go to PAGE 64

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h Ensuring commitment by partners and collaborators to a shared vision and core principles

Any development of housing for people with disabilities and complex needs includes many individuals, whether the housing development is large scale or housing that has been developed or modified for the individual with their family. Input from specialists in design, technology and modification is important to small and large scale developments.

A shared vision and core principles between partners and collaborators means everyone is committed to the same direction, while recognising the different contributions and perspectives. Each perspective in the partnership brings a different 'bottom line' which must be reconciled with the shared vision. Shared core principles focus attention to avoid inadvertently amplifying dependence, or failing to enable more independence.

Examples of what can be done

- Develop the vision.
- Coordinate the development of housing with the model of support through collaboration.
- Talk and explore to ensure clarity in the roles and responsibilities of partners including the individuals and family.
- Identify critical questions for collaborators to discuss and resolve.

For more information about this strategy, associated issues and what to do, go to PAGE 67

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i Aligning related systems, sectors and community views to vision and core principles

People with disability, like all citizens, rely on public sector information and services such as health, education, transport and justice. Along with members of the wider community, the values of these sectors can vary in their vision and expectations for people with disability and complex needs. Less progressive approaches can undermine the vision of increasing individual choice and control in their own lives for people with disabilities. New possibilities for risk reduction (through improving personal capability and social connectedness) are often not understood. Ongoing attention needs to be paid to building bridges and understanding with related sectors about the vision to "live like everyone else".

Examples of what can be done:

- Recognise everyone involved. This environment is increasingly complex for stakeholders to navigate.
- Develop cross-sector protocols around an individual with systematic, agreed in advance management of steps for contingency planning.
- Challenge government if needed: highlight possibilities and limits of what policy allows.

For more information about this strategy, associated issues and what to do, go to PAGE 72

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j Developing housing that is typical of the community and affordable, accessible and available

Access to housing is a recognised human right. Location is critically important to how someone wants to live. People with disabilities should expect to live in affordable forms of housing typical of the general community in each local metropolitan, regional or rural/ remote community. Forms of housing may include large-scale housing developments, to individuals and families making personal arrangements or working with community service organisations who are developing housing such as units or houses.

Examples of what can be done:

- Aim for support delivered in integrated and non-identifiable housing consistent with the local neighbourhood.
- Recognise that different housing forms suit different people.

For more information about this strategy, associated issues and what to do, go to PAGE 75

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k Attending to long term changes, needs and cost-effectiveness

Affordable, accessible and available housing options for people with disabilities and complex needs must contribute to people living well and be cost-effective for the long term.

Examples of what can be done:

- Recognise that people with disabilities and complex needs will experience changing circumstances over time.
- Look for opportunities to save costs by including innovation in the build, versus retrofitting.
- Explore ways to establish sustainable long term costs of support.
- Gather data about long term outcomes.

For more information about this strategy, associated issues and what to do, go to PAGE 81

HOW THE INFORMATION WAS COMPILED

This Guide has been developed through a twofold process comprising a review of contemporary relevant literature, and consultations with a number of individuals and groups reflecting various perspectives about housing and support for people with disabilities:

- The literature review provides a brief critical snapshot of research published or made available in the last decade by academic, community and industry bodies. The review was conducted around the eleven implementation strategies identified in the Living Like Everyone Else report.
- Consultations extended across 2016 involving families, carers, and experienced support providers, people with policy development knowledge at a state (SA, ACT, Tasmania, NSW, and Victoria) and national level, and those representing and advocating on issues for people with specific acquired and developmental disabilities (such as acquired brain injury, intellectual disability, progressive neurological conditions, physical disabilities, challenging behaviours and complex medical needs).

  Through their feedback, respondents made substantial contributions to progressive iterations of the guide and helped to ensure the guide represented a wide range of perspectives across state and national jurisdictions.

The learnings and achievements gleaned from those implementing different approaches to 24 hour support in the homes of people with disabilities and complex needs, are described in detail. The Summer Foundation is focused on young people living in, or at risk of entry to residential aged care. This project isn't limited to that group, it focuses on ideas of 24 hour support for people with disability and complex support needs living in innovative housing models. The emphasis is on exploring possibilities that are emerging because of the development of the NDIS, most particularly through the lens of 'choice and control' which underpins the Scheme

This work is challenging: flexibility and innovation require different approaches for different people across various circumstances and settings; and require practice that can adapt to changing requirements. The Guide challenges the reader to:

- Think beyond the typical ways that people with disabilities have lived, to how people with disabilities (including those with complex needs) might like to live, and then what is needed to make this possible. Taking this perspective means not assuming that 24 hour physical staff presence is the starting point for planning support in someone's home.
- Recognise that 24 hour support refers not just to staff, but includes the combinations of location, design and technology, as well as friends and family.
- Understand that some people with disabilities and complex needs are not able to be alone except for brief periods. But the requirement for 24 hour physical staff presence does not preclude people from more independent housing with a consideration of new and additional approaches to support.
- Aim to maximise the personal responsibility of people with disabilities and complex needs in ways that lead to greater independence and interdependence.
- Explore new and developing directions in support in people's homes that are possible, and already being implemented consistent with the principles embedded in the NDIS.

WHO THE GUIDE IS FOR

- Those working to maximise capabilities and opportunities for people with disability, their family members and friends; planners; Local Area Coordinators (LACs); service coordinators and advocates who are investigating and planning where to live or to continue living.
- Providers of support who want to review and pursue ideas and models of service that were previously not possible.
- Funding and policy bodies like NDIS, Lifetime Care and Support (NSW) and Transport Accident Commission (Victoria) that encourage affordable and sustainable variations in housing and support consistent with their public policies.

While this guide is relevant for people with disability and families including those who are self-managing their support arrangements, further development is needed with the materials to make it most useful for this perspective.

Contemporary examples of people with disability living in innovative ways in their own homes are included. For reasons of confidentiality and privacy these examples may be composites of actual situations and all personally identifying information has been changed.

Web links are provided for the examples of policy materials and resources cited in the main report.

Respondents' comments and service provider examples are used for illustration purposes throughout the report.

HISTORICAL AND CONCEPTUAL CONSIDERATIONS

HISTORICAL AND CONCEPTUAL CONSIDERATIONS

Contemporary approaches to housing for people with disability start with the belief that people with disabilities can live like everyone else in the community.

Living like everyone else means living arrangements that resemble those of other community members. That is, people with disability are not required to live in circumstances that would not be typical in the wider community. In order for this to happen, attention must be paid to matters considered in the decision-making common to all citizens: choice and control, civic responsibilities, personal priorities and security, the assessment and consideration of financial and personal risk, affordability, trade-offs and compromise.

A commitment to people with disability and complex needs having lives and housing like everyone else means a commitment to the diversity of housing typical across the community and an emphasis on staff engagement that focuses on developing personal and social capability, independence and social inclusion. Decisions about location, and tailored technology, design and modifications may be considered, in conjunction with staff support.

Some distinguishing features of living like everyone else are home ownership or tenancy rights through a lease or rental agreement. Living in one's own home means others do not have automatic right of entry; levels of support, including staff support, are negotiated depending on how the individuals wants to live and what degree of risk is acceptable to them; and there are opportunities for each person to develop their capability and lifestyle.

Living like everyone else incorporates independent housing arrangements, whereby housing is developed separately from support possibilities. With independent housing the individual decides to rent or own their own home, perhaps with others and in a location of their choice. Support in an individual's own home is an alternative to moving to a facility or group home[2] to get support.

BRIEF HISTORY OF 24 HOUR PHYSICAL STAFF PRESENCE

Many people with disability have always lived in the community; however, support has not always been flexibly available to people in their own homes. Family and friends may have provided support until someone's needs were judged too demanding for unpaid or informal support (such as support needs arising from regular overnight turning; seizures; or behaviours which disrupt sleep of others at home). This situation usually precipitated the person moving to a facility-based living arrangement with 24 hour physical staff presence, regardless of the person's other support needs, preferences and life goals. Facility-based living conditions can differ greatly from how other members of the community live and are not a "home". In the usual sense "home" is a part of the wider community. Larger residential facilities and smaller group homes commonly mean:

- Getting the required support is only possible in predetermined living arrangements.
- People with disability have no choice about who they live with.
- People live within the parameters designated by the organisation and make small decisions within the overall organisational operations. The living routine is largely determined by the facility or the household.

2. The terms 'group home' and 'shared supported accommodation' are used interchangeably depending on the context to refer to staffed houses which are typically for 4-6 residents.

- Staffing is integrally linked to the building and not to specific individuals. Constant staff presence means that some people may have more support than is needed – and some have less. There has often been an impetus to 'balance' staff attention equally in order to address possible perceptions of favouring one or another resident, even when levels of support needs can vary considerably.
- There is difficulty accommodating staffing arrangements for just one person. If someone does have high support needs, all members of the household are likely to experience more intensive or restrictive support (e.g. locked cupboards or doors, set schedules of the day).
- People are 'placed' and the viability of the setting depends on quickly replacing each person if they move on or pass away.

In these arrangements families, individuals and staff come to expect or assume the need for staff presence. Constant staff presence can be an important aspect of responding well to someone. However, constant staff presence can:

- Reinforce assumptions about each individual's dependency. The individual learns that problem solving means "ask the staff" so they experience reduced expectations. People with disability can lose skills, and have less opportunities to manage their daily lives.
- Disrupt relationships between the person, their family and the wider community. Staff can become the sole source of social interaction.

Many people with disability are consistently offered, or insist on, 24 hour physical staff presence (or 18 hours plus 6 hours of support during the day). Whether that is optimal remains unexplored, because of the history of inflexible funding and assumptions and myths about risk and the need for protection. Staff presence has seemingly provided blanket reassurance for government, organisations, people with disability and families, implying any challenges and risks will be covered. In this approach, protection rather than enablement is the driver shaping support. If staff and support organisations emphasise protection there is less attention to building personal capability or independence, participation and contribution, and social relationships with other community members. Ironically, the result is people with disability can be less protected due to social isolation, dependence and reliance solely on relationships with staff.

The difference between 24 hour support and 24 hour physical staff presence

24 hour support refers to support available in individual housing arrangements, comprising contributions from location, design, technology and various planned and backup staff roles. 24 hour support arrangements for someone could include, but are not be limited to, 24 hour physical staff presence.

24 hour physical staff presence describes one way to organise staff, whereby staff are rostered to the house or facility, physically close and able to observe and to respond appropriately to every/any situation arising.

WHO HAS BEEN ROUTINELY OFFERED 24 HOUR PHYSICAL STAFF PRESENCE

24 hour physical staff presence is often recommended in the following situations:

- **People with disability who are not safe to live on their own or to continue living in their own homes. In particular,**
  - People with medical conditions, including those with high risk condition(s) such as: uncontrolled epilepsy; high risk of choking or falls, inability to move; insulin dependent diabetes; dementia, disrupted sleep; or multiple complex conditions (for example, someone with diabetes, multiple sclerosis and epilepsy)
  - People who can't initiate a response themselves, particularly people with cognitive impairments (ABI or intellectual disability) who 'stay in their chair' and are not engaged without staff/others; people dependent on others for daily living tasks, emergencies, personal care and engagement; people with severe cognitive impairment who can't make their own decisions or who consistently make poor decisions, and where optimising the person's choice requires advocates/ representatives
  - People with behavioural and social support issues, such as people with challenging behaviours (including related to mental illness) that can lead to conflict with others; those who put themselves or others in the community at risk by making poor choices as they are not able to anticipate, appreciate or plan for the consequences
- **People with a disability who are anxious and in need of reassurance, including those who withdraw, are highly anxious, or with mental illness.** Anxiety and the need for reassurance can also be a factor in decision-making by family members, and their perceptions of what are the best living arrangements.
- **People with disability whose informal supports are not available or exhausted,** such as those disenfranchised from family and where it is not an option to stay home. This can be particularly difficult for youth with episodic conditions who often cannot access age- appropriate services.
- **People with disabilities who have experienced social or economic disadvantage and related issues**, such as having a non-English speaking background, or who have only ever experienced institutional settings.
- **People who are physically and/ or socially vulnerable and so at risk of being taken advantage of – including being robbed, exploited, abused.** These people can be active in the community but are vulnerable because of poor decision-making, including overuse of alcohol, drugs and gambling. Some of these people with disabilities may not be eligible for individual funding through the NDIS.

These descriptions imply different support requirements, some of which are static, some are changing, and some are episodic. The guide responds to the challenge of articulating practical examples which are sensitive to these many factors: an individual's impairments and capabilities; beliefs about what is possible from individuals, families and organisations; limitations and constraints; the importance of protection and risk minimisation; and the impact of someone's life course, life stage and social and economic experiences.

RE-THINKING 24 HOUR SUPPORT

Several significant and related developments in Australia and worldwide are reframing what is meant by 24 hour support and enabling greater personal autonomy, responsibility and flexibility in the lives of people with disability.

There is an overall movement to support people with complex needs in their own homes, particularly from older people and the aged care sector, but also in health, mental health and palliative services. This involves more use and promotion of home-based technology for monitoring health and wellbeing, and enabling an emergency response if required. Increasingly, people with support needs are expressing a preference to be in their own homes. Exploration of housing and support possibilities does not mean abandoning the support each person needs to manage their daily life; or failing to plan to maximise safety to support independent living; or that people with disabilities all have to live alone or together. Frequently, people with disabilities and complex needs do need housing with carefully planned staff support options spanning 24 hours of each day to maintain and enrich their quality of life and to avoid potential risk to the person, staff and the support provider organisations.

Individualised funding allocated to the person rather than to organisations. This development is occurring across human services, from aged care and disability to criminal justice. It offers the opportunity for different forms of funding for support, from mainstream, specialist disability, housing and health and personal providers. While individual planning can be a feature of block funding, individualised funding has the following features:

- Individuals and families can take more control of their lives by designing, choosing and monitoring support arrangements.
- Market forces are beginning to operate. Funding is portable and stays with the individual even if the person moves house. This development has implications for how support staff are employed, what is a 'workplace', and what happens to organisations who don't respond to what people want. Non-responsive organisations will lose income and therefore staff. This result is already occurring with the NDIS.

CASE STUDY

Lisa is 31 years of age and was only nine years old at the time of her accident where she sustained a severe acquired brain injury. Lisa lives at home with her Mum, Dad and two siblings. Her Mum manages her individualised funding budget which means that she receives a monthly payment from the Transport Accident Commission, Victoria (TAC) so that she can find and purchase the services that she needs.

Before individualised funding, there were a number of frustrations for Lisa and her family receiving support from TAC, particularly around the timeliness of approvals, being able to change providers, and dealing with a lot of red tape to order even a small piece of equipment.

Lisa has thrived with access to individualised funding. The flexibility to access more services has allowed her to obtain equipment more promptly without having to ask for TAC approval.

Lisa's Mum commented that individualised funding has made it easier to plan a family holiday like any other family, without having to get an occupational therapist report. As a result, the family felt that they were in control and had more choice.

Recognition that people with disabilities have been asked to live in ways unlike the rest of the community has resulted in housing careers for people with disabilities that have not resembled the wider community as they progress from childhood or post injury/ illness to older age.

Attention to increasing personal capability and social connectedness is challenging previous assumptions of dependence and the understanding of protection for people with disabilities. New understandings of personal risk management emphasise the importance of independence/ interdependence, community connections, and social relationships to quality of life, mental and physical health and community safeguarding.

The National Disability Insurance Scheme is signalling a change in thinking around new ways of providing support. There is now recognition that before NDIS, providers and individuals and families have been limited by state government policies, funded programs and procedures which restricted housing and support options – often in response to the need to ration limited resources. To an extent the disability sector has always attempted innovation, but with the NDIS funding model there is greater opportunity to explore new ways to deliver support.

National Disability Insurance Scheme (NDIS)

Much has been learned about new ways of providing housing and support for people with disabilities including those with complex needs. The NDIS emphasises individual choice and control, enabling a more flexible and varied understanding of support funding, and contributing to specialist housing through Specialist Disability Accommodation (SDA). These directions are consistent with the UN Convention on the Rights of Persons with Disabilities (2006) (http://www.un.org/disabilities/convention/conventionfull.shtml), and the Australian Law Reform Commission (2014) (https://www.alrc.gov.au/publications/equality-capacity-disability-report-124). The NDIS offers flexibility for 'reasonable and necessary' support funding, and emphasises the long term sustainability of the support funding for the individual, and for the scheme overall. The NDIS provides opportunities for individuals and families to be more informed about potential options. This guide helps to illustrate some of those options and initiatives.

'The NDIS exists to support people with disability to live an ordinary life. Affordable, stable and appropriate housing is integral to that vision.' (https://myplace.ndis.gov.au/ndisstorefront/specialist-disability-accommodation.html)

The NDIS Specialist Disability Accommodation (SDA) initiative is a welcome addition to this context 'for NDIS participants who require specialist housing solutions to assist with the delivery of supports that cater for their significant functional impairment and/or very high support needs.'

Support is being re-framed as a more mainstream concept sourced from multiple providers, not just what was previously termed 'disability support'. Developments in specialised and mainstream housing design, technology ('smart homes') and equipment are enabling greater personal independence and capability. Such developments contribute to more personalised support and challenge those considerations of safety which do not further independent living.

Rapid technological change increasingly caters for greater personal capability and security, for example, switch/ Bluetooth/ wi-fi access to light switch controls, heating and appliances; opening/ closing doors, windows and curtains; keyless entry; and remote monitoring.

CHALLENGES BEYOND THE SCOPE OF THIS GUIDE

Many forces have shaped how people with disabilities have been asked to live: community and family values, industrial agreements, government program guidelines and funding restrictions (such as vacancy management), service providers' ways of working, and the continuing shortfalls in affordable housing. Lack of housing options has meant that the goal for individuals and families has been to find somewhere – or anywhere – to live. It's not yet fully appreciated how some of these forces will affect the new opportunities coinciding with the introduction of the NDIS.

Systemic issues remain to challenge new directions in providing 24 hour support in people's homes:

- **There is an acknowledged shortage of housing.** More social housing depends on state and federal initiatives. There is growing recognition of the importance of the role for well-designed and located social housing which will be relevant for many NDIS participants.
- **Inconsistent allocation of funds to develop and sustain the individual's preferred support arrangements.** Even under a social insurance scheme such as the NDIS, there will likely be a focus on cutting costs and debate about what constitutes "reasonable and necessary" support.
- **The lack of flexibility or capacity to effectively alter elements of existing models of housing and support, particularly in relation to group homes.** For example, leaving an established group home or resolving conflicts can be complex and jeopardise the entire household; finances, lifestyle and relationships can be jeopardised.
- **A lack of understanding about the best mechanisms for coordination and collaboration** between providers of housing and providers of support, and amongst providers of supports. Sometimes a combination of options fails to lead to a coordinated whole for the individual. People with disabilities and complex needs can be very vulnerable to disjointed program boundaries even when they can manage their own supports. This is not to say that all aspects of someone's support needs to be shared with everyone. For example, house cleaning and personal care may not need much coordination.
- **When change is required over time, support arrangements that are too rigid** and subject to constraints can prevent timely reviews.
- **Industrial wage constraints which are reflected in the pricing/ funding offered to deliver support** (during day or evening/ night) can hamper flexibility.
- **Gaps in support available to people who can't make their own decisions**, and don't have supportive family or advocates. Where staff or family members are asked to make decisions which do not reflect the will and preference of the individual with a disability – this can also unnecessarily restrict privacy, confidentiality and choice or control.

INNOVATIVE APPROACHES TO LIVING LIKE EVERYONE ELSE

New housing and support projects are demonstrating new learnings about community living. Social relationships and links to the community are critical to living like everyone else and for avoiding social isolation. Experience shows people with disabilities can make different uses of ongoing direct staff input; that many people with a disability can be supported to live like everyone else; and that assuming 24 hour physical staff presence as the starting point for planning support for housing is a remnant of past approaches.

One model of housing and support is not relevant to all situations, and yet this is what group homes or residential aged care have become. Past approaches have (sometimes inadvertently) emphasised difference, paternalism and separation from civic participation in the wider community. Developing responses tailored for each individual necessarily requires flexibility in implementation.

This guide challenges the reader to rethink what contributes to planning and implementing housing and support. No single formula exists for developing support arrangements for people with disabilities and complex needs living in their own homes.

Eleven implementation strategies emerged from consultations and the literature review conducted for this project. The strategies are not sequential, involve different timelines and interdependencies and contributors and become more or less important in different settings and for different people.

The implementation strategies are divided into two groups: 'Choosing my own home', and 'Developing systems'. These strategies have implications for individuals and families planning individual living, and for systemic developments to enable sufficient well-designed and located housing to be available for individuals and families. The absence of systemic developments will hinder the aspirations of individuals with disabilities.

IMPLEMENTATION STRATEGIES

Eleven implementation strategies were identified from successful initiatives which have enabled people with disabilities to live like everyone else in their own way in their community. The implementation strategies are divided into two groups:

Choosing my own home

The focus for this group of strategies is the individual choosing where, how and with whom to live, and how to be supported.

PAGES 27-61

Developing systems

This group of implementation strategies notes the system level changes required to further the proposed directions needed for each individual when choosing their home.

PAGES 63-85

The implementation strategies are for living, not for the development of housing.

CHOOSING MY OWN HOME

a Readying and building the capability and confidence of individuals and families

Informing and readying individuals with disabilities and families is the foundation to making decisions about where to live. One of the biggest obstacles to the directions proposed in this Guide is a belief that there are limited ways that people with disabilities and complex needs can live. Individuals and families require information and practical examples to become ready and confident.

Early and repeated access to information is useful for individuals and families new to the disability system; and to those already living in the family home, shared supported accommodation or nursing home arrangements, or anyone who would like to live differently.

Although it can be daunting for any individual to realise their potential and move from the familiar to the unfamiliar, it is possible. In the past, people with disabilities and families did not have the opportunities offered by the National Disability Insurance Agency (NDIA). There is a significant difference for those individuals considering a transition from a long established group house or nursing home setting, to those able to plan a new housing arrangement.

An approach which asks individuals to be tenants, neighbours, responsible for bills – as much as they can and with only targeted and as needed assistance – requires effort from individuals and families. Learnings so far reveal that individuals and families have to want independent housing arrangements – a home of their own – and see it as achievable. Families may default to wanting 24 hour physical staff presence as the only option because of not knowing other examples and possibilities, because their particular situation is pressing to be resolved or because of limiting beliefs.

Under the NDIS, it is increasingly anticipated that people will direct or manage their own support arrangements. This too requires knowledge about possibilities and preferences, or the limited responses of the past will be re-created. It's very hard to explore options of where else to live, if other possibilities have never been available or discussed. Exploratory and experiential processes are needed, to inform family (parents, spouse or extended family), the individual, and, at times, to prepare support staff. For individuals with higher support needs, who could live independently of family members, a systematic approach is the key to develop confidence and acquire skills and to generate interests and expectations of independent living.

CASE STUDY

CHANGING PEOPLE'S EXPECTATIONS DEPENDS ON RECEIVING TIMELY INFORMATION

ANNA has a spinal cord injury and is moving from residential aged care to her own home. She said she only needed a personal care staff member every third day. After discussion, it became apparent that she was used to having a shower every three days. Her expectations changed when she understood she could have a daily shower.

LORETTA is the mother of six year old Jodie, who has multiple disabilities. Loretta assumed that the only place her daughter would be able to live in the future, if not with the family, was a group home. She had made that assumption based on advice from various early intervention health and education professionals. No one involved knew that there were alternatives.

JAMES lived with his family prior to moving to independent living. James was receiving some 1:1 attendant care support and his family was providing personal care at home. The move to independent living revealed that he required a much higher level of support to meet his needs, and to ensure the safety of support staff. For example, it was determined two people were required to ensure safe transfers from wheelchair to bed or between chairs, which was not possible with the level of support he received in the family home. This level of support had previously been considered adequate.

Maybe families can be the biggest barrier to our children's independence ...we don't even think that our kids can do things for themselves...
(PARENT)

WHAT CAN BE DONE

Have the expectation from the start (from early childhood or post an accident) that independent living will happen. Readying and firming expectations can take years. With preparation and time for comparison and reflection, individuals and families will be ready to consider different housing opportunities when they become available. Such readying sets the scene for NDIS preplanning and planning as part of individual plan development.

Encourage individuals and families to imagine how life could be. Encourage them to think about where they want to live without the parameters of the disability world. Respondents stressed the importance of "doing normal things". Examples of new housing with support possibilities will encourage individuals and families to want to be more independent and take more control and responsibility for how they live their life.

- Begin a discussion about preferred lifestyles with the opportunity for changes to daily life patterns, to encourage using local services and public spaces and inclusion in the social, economic and spiritual life of the local community.
- Recognise that people change their minds. Discussion groups, information sessions and formal and informal networks allow individuals and families to discuss their concerns and ideas.
- Anticipate that planning takes longer than initially expected.
- Discuss assumptions about dependency and protection and compare these with ideas about supporting people to live in their own home "like anyone else." Discuss risk side-by-side with life possibilities, in order to maximise quality of life and personal wellbeing. Some people with disabilities and families may view constant staff presence as essential – maybe an entitlement – and may never have thought about other options.
- Highlight the advantages of a capability-focus for individuals with disabilities and families. Identify the advantages for individuals in terms of choice and control, improved wellbeing and ability to manage the unexpected through building capability and relationships with more people. Increasing personal confidence is essential.
- Discuss new, distinct and emerging staff roles arising from more flexible approaches to 24 hour support, such as planners and facilitators, direct support staff involved with physical assistance, problem solving and / or skills development.

Involve a skilled facilitator to raise awareness of myths and draw out needs and possibilities for each person. A facilitator can negotiate individual plans for each person about how they want to live, and with whom, to enable improved quality of life with reasonable risk. They can explore possibilities to increase personal responsibility and capability and consider when support is needed for decision-making.

Recognise the varying capacity of individuals with disability, friends and family. Who is in this person's life to care about them? Some individuals have many people, others few. Informal networks of support can blend/ work cooperatively with paid support. Sometimes a family member needs support to continue their carer role.

- There are particular issues for people who can't readily communicate their preferences. Are staff or trusted others better able to detect someone's vulnerability? When are staff/ organisations obliged to do this?
- Whatever the arrangements, personal support networks do break down from time to time and backup is needed.
- For some individuals a relationship is needed with at least one person outside the service system who can help raise issues of concern and be involved in decision-making (for example, with people without family and friends). Independent advocates can be important when the individual and their family have different priorities.
- Explore options for people with disability with no family support. Consider advocates, circles of support, support for decision-making.

Provide ongoing public and targeted information, challenging expectations and stereotypes and promoting different ways of living available for individual, families, organisations and their staff and the wider community.

- Understand that many families and people with disabilities, and the wider community, view 24 hour physical staff presence as an inevitable arrangement for people with disabilities when families can no longer cope. For some people, considering how individuals with disabilities can live like anyone else is a significant change, and many will need time (perhaps even years) to appreciate the implications and possibilities of this direction.
- Find opportunities to talk with others – support networks and families of individuals –gathering information and sharing knowledge. Look for ways individuals and families can get in touch to identify ways to share/ work together without the family having to do all the work.
- Provide opportunities for people with disabilities and families to "see" alternatives and build from the experiences of others. Such opportunities can be provided through "virtual tour" walk-throughs of homes and interviews with people already living in new models of housing and support. Plan ways for individuals and families to visit/ see other housing arrangements, talk to people with different experiences.
- Try living in a home for a while by house sitting or staying for an extended period in a serviced apartment. This experience helps the individual with a disability, family and support providers to understand more clearly what level of support is required and to have open discussions before longer term housing commitments are made.

CASE STUDY

EXPLORING INDIVIDUALS' EXPERIENCES OF BEING ALONE WITHOUT FAMILY OR STAFF

JORGE has an intellectual disability and had always lived with his parents Nina and Alfredo. He was 22 when Nina died suddenly. Nina had done everything around the house; Jorge could not cook, use public transport, shop or use money. Alfredo could not cook either. Jorge's siblings assumed he would need to move somewhere with 24 hour staff presence but Alfredo wanted him to stay at home with him. Jorge could read and have a conversation about current affairs. With some staff support Jorge learned to cook for himself and his father. Since then Alfredo has died. Jorge continued living in the family home for a while. He now has friends, and is looking to share a flat with one other person.

SAMANTHA has a significant physical disability and had been living with her mother, who died suddenly. Friends of her mother banded together to roster people to be available to ensure Samantha was safe and "clean and tidy" in the family home, until other arrangements could be made. It soon became apparent constant presence was not needed. Samantha could maintain her daily routine – in fact she started to prompt the family friends about what to do next.

b Matching the housing form and location to each individual's preferences, support needs, and budget

The right choice of housing leads to a home: social relationships; links to various communities – cultural, physical and digital; access to work, education and interests; and with the right support and assistance, being as independent and capable as possible.

Think about the factors taken into account when anyone is deciding where to live: being close to work, family, transport, shops; as well as affordability. Final decisions about housing form and location may be a trade off between someone's preferences and options, and availability and affordability.

Personal preferences are important when it comes to housing form and location. Preferences are derived from many variables: where someone wants to live, with whom; who the person wants to live near to and how close, and what is available and affordable in that locality. Consider how much personal space the person prefers or needs (for instance for storage, friends staying over or wheelchairs) when considering apartment living, suburban house, units or rural housing. Some people will already have a home and established way of living they wish to continue with after their accident or illness, or may wish to return to the family home. .

WHAT CAN BE DONE

Describe the person's vision for living. People with disability must be able to choose who they live with. Agreements are then needed to normalise shared living: to negotiate shared effort, how people live together, house rules (such as what happens with friends who visit/ sleep over) and the financial implications of all arrangements including if someone moves out.

Plan carefully with each individual and family consistent with person's preferred lifestyle, including:

- Ensure support is focused on independence and that it goes beyond 'what people ask for', some people may choose not to do more for themselves, look after their health or learn how to problem solve but may be necessary areas to include in planning.

Make sharing work. Sharing is common in the wider community – but involves choice about who to live with and why. A person with a disability may share with another person with a disability, their spouse or family member, or someone without a disability who is not a relative. There may need to be agreements about how people live together. Lease agreements to determine who shares the rental costs may be needed. Sharing can also influence how much formal support is needed. There can be mutual support possibilities for people who are living together.

b CHOOSING MY OWN HOME

What is the goal?

For many people with complex needs, their support will include staff availability over 24 hours in order to:

- Live with who they want to
- Increase personal flexibility and quality of life
- Respond to emergencies and the unexpected
- Enable changes of home routine
- Allow for spontaneity
- Foster personal growth, development and sense of responsibility
- Minimise social isolation and loneliness
- Allow for peer/ mutual support which can be formal and informal, and can reduce anxiety, provide information, and be a source of information and advice
- Help people connect with neighbours and the wider community
- Attend to emotional support as well as physical support

Staff could be organised in many ways depending on the individual, and their family and community connections.

Develop incentives for people to become more independent

- Plan with the person to identify personal goals focused on greater independence.
- Don't assume support staff will do all of the everyday tasks.
- Recognise how housing location can build community connections, and save long term costs for transport and support.
- Explore how to meet support needed for independent living for specific individuals through capability building, location, neighbours, friends, family and community members and often (given enough freedom and opportunity) by the people with a disability themselves.
- Look for ways to support or extend ongoing involvement of family and friends and community.

Recognise that individuals with disabilities and families need practical and emotional support.
Challenge common assumptions about families. Currently the system works though individuals with disability may not acknowledge the role of families, particularly for people with cognitive disabilities. Issues are different for people with different disabilities who can direct their own decision-making and planning. Arrangements are needed that will continue after parents can no longer be involved.

- Help families recognise conflicts of interest and when family or staff can't separate their views from the perspective of the individual with a disability.

- Don't assume families automatically override a family member's wishes; or that involvement of family members is determined by how close people live to each other; or that all families are unable to represent their family member. Acknowledge that families face difficult decisions, are tired and uncertain at times, have mixed and changing views, have strengths and shortcomings.
- Be careful of being an advocate against family: families are the most likely to be consistent in the long term in the life of each person with disability. In contrast, staff frequently change employment and move away from people's lives.

Ensure decisions about housing form and location precede decisions about support. Tailor arrangements in order to maximise opportunities for living like everyone else through personalisation, independence, community inclusion and participation.

- Encourage individuals to think about the form of housing best suited to how they want to live.
- When a person with disability is still living in the family home, a group home or in residential aged care home, use small NDIS pre-planning packages to explore possibilities.

Questions to consider before deciding where to live

- Do I need help to plan housing and support needs, now and over time when things change? Who can do this with me? Family, friends, a case manager or other staff member? Is a circle of support a possibility?
- Who do I want to live with? Friends, family, people with a common interest or alone?
- Where do I want to live and in which community? What types of housing are preferred and can be afforded? Is it one house or an apartment in a complex? Which communities are familiar to me? Are there communities and social networks I should avoid or move on from?
- How much personal support do I need? Can I be without support for parts of the day? Are friends and family about regularly, as needed, for emergencies or for big decisions?
- What aids, design, technology and equipment do I need to be as independent as possible (for example, universal physical access plumbing fittings, electronic doors and appliances, alarms, appliances which 'talk'; assistance dogs, electronic diary, touch switches)?
- What are the best ways to organise staff support? Live in, drop in, rostered across several households, on call, week days only? How will this be resourced? Will family, friends, volunteers and community members be part of my regular support plan?
- Do I have enough income to do what I want? What is most important to me if resources are limited?
- How will the quality of staff be monitored? What can I do if I am unhappy with the support I have? What can my family or advocate do if they are not happy?

See also: Housing Toolkit, Summer Foundation (2013) **www.summerfoundation.org.au/resources/the-housing-toolkit/**

Assist person with trade-offs, compromise and priority setting. Trade-offs, prioritisation and compromise are inevitably part of all decision-making; it's the same for people with disability.

- Housing choice involves many trade-offs associated with decisions about renting versus buying; own home versus sharing with friends or those with a common interest; and location versus cost.
- Staff presence has advantages and also disadvantages which each person will want to weigh up. Staff presence can be reassuring and maximise the likelihood of intensive and rapid support if needed. Disadvantages arising from constant staff presence have been identified, such as changing expectations of personal capability and dependence. The person with a disability can feel staff act as a babysitter and the person experiences no sense of freedom. Some individuals may yearn for time alone, others may enjoy constant company. Tension can arise from staff coming into a home where several people live.
- Individuals may need support, information and opportunity to identify aspects of housing and support they are prepared to trade off and compromise in order to maintain their goals for living. This is linked to the level of risk each person with a disability and their family accept and how this agreement is reached.

CASE STUDY

WEIGHING IT UP: ADVANTAGES AND DISADVANTAGES OF CONSTANT STAFF PRESENCE & PRIORITIES FOR SUPPORT

JOANNE is a young woman with disability and complex needs living in the family home with her parents, Brian and Maree. Staff were coming into the home on a 24/7 basis. Brian and Maree came to realise that they rarely had a conversation without the presence of staff. This realisation prompted discussions about different ways their daughter could be supported.

TONY is a successful writer, living with his wife. He has developed multiple sclerosis in middle age and now finds he has less energy to get through the day, in addition to some physical limitations. Tony could put his energy into completing all his household chores but it means he is too tired to work, which is his highest priority. Initially support staff thought their role was to encourage Tony to do his household chores or leave his wife to do them, as that was their understanding of maximising his independence. However, Tony prompted further discussion and staff realised that providing assistance to Tony by completing his house work meant that Tony would be able to spend time with his wife and continue participation and contribution in the wider community, as well as maintain his network of writing and publishing colleagues.

Questions for people with disability: Do I want to live here?

- What do I want my life to look like? What will I be doing during the day and at night and on weekends? What support will I want and need?
- Will this housing suit how and where I want to live?
- Will there be enough space for my things?
- Will I be able to get on with people?
- Will it be noisy?
- What rules will there be?
- Can visitors come to any common areas inside and outside?
- Will I have a say in how flats/ apartments are run?
- Will I be able to easily continue my interests (religious, work, education, leisure)?
- Will I be able to easily get to the community facilities I use (such as the bank, library)?
- Will I be able to easily visit friends and family? Will they be able to visit me?

See also: Housing Toolkit, Summer Foundation (2013) **www.summerfoundation.org.au/resources/the-housing-toolkit/**

C For each person, complementing location, design, modifications and technology with cost-effective, planned and backup staff support

"Support" has become a vague term that needs to be unpacked to identify the various components that contribute to enabling a person with disability to live how they choose.

Staff support complements optimum use of design, modifications and technology. Staff support can vary over time in intensity, frequency and type and includes planned support as well as backup support. Backup support refers to emergencies, the unexpected and contingencies – from technology problems to lost house keys, long term illness, accidents, and evacuations due to natural disasters.

Support can be provided through friends, family, neighbours (often termed informal support) or paid staff (such as community access staff, community health staff, interpreters or financial counsellors), or through assistance dogs. The contributions from formal paid staff and informal friends and family supports are inter-related and the balance will vary for each person with a disability. Formal and informal support[3] are not mutually exclusive and can all make a contribution in someone's life - just as the person with a disability can make contributions in the lives of others.

Different staff roles require different skill sets. The nature of the direct support varies with an individual's priorities and capacities.

Relationships with staff

Staff can be very important in people's lives. Relationships with staff can involve emotion and empathy. It is not desirable for a worker or employer to have a relationship which is devoid of attachment and care.

However, there are different roles for staff and friends. Staff can be allies and companions but this is not the same as friendship. It is important not to misconstrue relationships with staff and not to downgrade them either.

Staff can help or impede the development of relationships between the person with a disability and their friends, family and community members. Staff can keep oversight of social connectedness (especially for people who struggle to connect to the community) but need to know when to withdraw or to stay and not be over-caring – thereby getting in the way of social relationships forming.

Relationships with staff can be significant for people with disabilities. These relationships can be long term where people know each other well. However, if the only relationships in the person's life are with staff, the individual can become isolated and vulnerable when staff leave. (http://www.gcss.org.au/category/news/2013)

3. See strategy A for more discussion about the importance of engaging informal supporters, such as friends and family

WHAT CAN BE DONE

Incorporate opportunities for individuals to demonstrate choice and control, such as

- Enabling a person's independent decision (with support as required) to move into housing in the preferred location with the preferred design and associated possibilities for staff support.
- Supporting a person's use of technology.
- Encouraging tenant involvement in selecting individual staff who will provide practical and personal support in line with their individual plans.

Align tailored modifications and technology with individual needs and preferences

- Emphasising strategies to ensure location, design, technology, aids and equipment and staff roles maximise independence, initially and over time.
- Seeking opportunities to include assistive technology, equipment and housing design and modification as an intentional element of support across 24 hours, rather than relying exclusively on staff or informal carers.

Investigate reliable and specific technologies that can transform how staff support is provided
How independently can residents live? How can privacy be maintained while still having access to 24 hour on-call support? Technology can be automatic and in the background or require active initiation. Technology can enable internal and external access in a building; streamline and improve reliability in staff rostering; and enable access for new staff at any time, such as emergencies.

- Have information sessions for support staff about new ways of providing support. Support staff will often be the point of reference for individuals and families seeking advice. Is their advice current?

Understand the possibilities and limitations of technology. Consider that technology:

- Changes rapidly
- Presents opportunities for increasing personal capability and a sense of security
- Varies in cost, purpose and complexity: from buzzers and phones, to computers and communication, to requiring active or passive involvement of the householder
- Changes the role of staff, rather than replacing staff. Staff are needed to ensure technology is used effectively and maintained optimally.

- People vary in their uptake of technology. Some staff, family, and people with disabilities don't like using technology – this will hinder uptake if use is assumed. Staff sometimes find it easier to "just use technology for someone – and that's what the person with a disability requests too". This seemingly easy way out can precipitate long term issues of dependency and lack of capability when staff are absent. However sometimes it's important not to dismiss an individual variation that works well. It is important to understand when and why variations in the adoption of technology occur.

Technology:

- May not reduce long term support costs, installing technology will require greater upfront costs and ongoing maintenance
- Must be reliable, with backup in case of power failure or system crash
- Can provide background monitoring; to ensure appliances are secure and/or to check a person hasn't fallen. Monitoring someone's status with technology reduces direct carer intervention until necessary and doesn't require the individual to engage with the technology.

SERVICES' PERSPECTIVE: EVALUATING AND MONITORING DESIGN CHANGES

The Institute for Safety, Compensation and Recovery Research (ISCRR), at the request of TAC Victoria, undertook a post-occupancy (building and technology) design evaluation in 2016. A survey of residents and support staff and anecdotal feedback from families pointed to issues with system malfunctions and failures, maintenance and response times in the first year of project delivery.

Necessary back-up systems have since been provided. Maintenance calls for the assistive technology installation have reduced over time. Improved data capture was advised in order to review system performance, existing technology usage and future specifications.

Explore cost-effectiveness of support by careful analysis of individual patterns of daily life

- Undertake a detailed analysis of each person's day to determine which different staff skills are required at different times. Pay attention to small-scale practical changes to enable individuals to add capability in their daily routines and avoid accumulated staff support hours and costs over many years.
- Analyse tenant appliance use and install appropriate equipment and supplies. Research what it takes for each tenant to get food from fridge to microwave, have a meal, and stack the dishwasher and turn it on. Purchase superior kitchen equipment (such as ovens with telescopic shelves) to enable personal capability; customise low cost household supplies (such as replacing laundry powder or liquid with capsules for tenants who find it difficult to measure or add detergent to the washing machine).

CASE STUDY

KATHRYN has a spinal cord injury and is living at one of the TAC Victoria RIPL sites. She has been able to maximise her independence by using the design and technology in her unit to independently use the kitchen, open and close the blinds and doors, and operate the heating and cooling. The location of the units means Kathryn is able to travel independently by train to university. Previously Kathryn used one-to-one staff assistance to travel to a bible study class, but now the church pastor drives her, which saves staff time and involves Kathryn more directly and independently in the community.

MIRANDA lives at a TAC Victoria RIPL apartment. She requires support for planning, organising and remembering day-to-day activities. Miranda frequently tired of the staff presence in her home and how this impinged on her privacy. She requested support be provided via text messaging to and from the support provider, rather than using face-to-face staff. Miranda has created the space and freedom she desires (no staff coming into her home), and still receives the support she requires.

Small changes can increase personal capability and deliver savings. For example:

- Close location to the community minimises transport costs.
- Minor household adaptations can improve quality of life and reduce long term health costs.
- Build volunteer, social, cultural and political opportunities for each individual to strengthen long term social networks.
- Create incentives for organisations to work with individuals and families to reduce support costs over time while still emphasising personal outcomes and independence.

Develop different approaches to staff roles and management to build personal capability and cost-effectiveness

- How can staff be organised to spend less time in the individual's living space, and instead be on call, drop in, or nearby?
- Develop support staff teams for each individual and vary the intensity of staff involvement. Encourage appropriate staff training, support and supervision to maximise interactions and develop independence for individuals. Train staff to support people to achieve their goals and to restrain themselves from "doing things for" individuals.

Distinguish between direct support (flexible, planned) and backup support for contingencies, emergencies and the unexpected. Most people have direct support at set times (for example for personal care or meal preparation) and support for problem solving or engagement, if needed. Ensure organisational systems for back up contingency support can work in harmony with planned support.

- Pool staff to ensure sharing of staff and regular staff availability; plan for staff to have time away from the same living space as the person.
- Determine the flexibility of the support provider to withdraw or reduce dependency if networks develop.

Determine the intensity, frequency and proximity of support each person needs and prefers

- Determine when and why staff presence is needed and how quickly. When is it necessary for staff to be in the same space as the person? Is backup support becoming regular when it should only be for emergencies?
- If staff are not present in the person's home, the reliability of 24 hour backup staff and technology becomes critical. Backup options include buzzers, sleep over staffing, drop in staffing (after hours – planned and emergency) and other members of a household checking in. For some people technology may not provide enough support and they will need active and trained night staff for example, people who need others doing things physically for them, people whose behaviour is dangerous to self or others or people with severe cognitive impairment who can't initiate engagement.
- Consider ways to respond to people with disabilities who can't speak. Backup support can be triggered by phone. Other options are alert buzzers, email and live online chat.

How prior experience with or expectations of the system may have shaped willingness to modify support arrangements. Such expectations can act against building independence.

- Consider how the system has taught families and people with disabilities to be cynical and distrustful. For example, "Don't give up any support, you might need it," or, "Don't give up the worker for the travel training [or other offers] in case you might need it." Such expectations can act against building independence. Low expectations can do the same.

> We (parents) ask for one-to-one staff overnight because that's all that's on offer – we don't think it's needed either... (PARENT)

ANNECTO AT ABBOTSFORD APARTMENT PROJECT, VICTORIA

Specific staff roles (Community Inclusion Facilitator, Inclusion Support Facilitators and After Hours staff)

The annecto staff support model features a dedicated staff member (termed the community inclusion facilitator) for transition and facilitation planning, as well as direct support workers (termed inclusion support facilitators), plus the use of the assistive technology to establish links to annecto's existing After Hours service.

The community inclusion facilitator supports collaboration between each tenant and their family and friends – to plan personal goals, maintain and develop networks, and provide the practical support needed for each tenant to live well in their own apartment and local community. This role supports people in managing the real life situations which emerge when people start to live more independently in the community, such as tensions which may arise between tenants and staff, among neighbours, or with the owners' corporation.

The community inclusion facilitator arranged many meetings with each tenant (and their family/ friends) for up to eight weeks before the decision to move in to the apartment, and then in the process of moving in, in order to get to know each person and understand how they wished to live. This process required planning and decisions to be tailored to each individual arising from the location, and design and technology for each tenant. The planning considered the roles and communication styles of paid staff, family and community members, and included 24 hour on call and emergency support.

Tenants phone the after-hours support team for two reasons: to manage their planned support arrangements, such as replace staff, shifts and timing of planned support for the next day; or to trigger the assessment of an emergency or unexpected situation which may be resolved by discussion, follow up the next day, involvement of emergency services and/ or response from nearby field officers (e.g. if someone has fallen out of bed). Tenants ring the after-hours service and do not go directly to the nearby staff.

Tenants are supported to be active rather than passive in their daily lives. For example, tenants were involved in selecting their inclusion support facilitators and training them about their needs and wishes.

Inclusion support facilitators are expected to encourage tenant initiation and assist with 'only what people can't do'. Staff understand the relationship between each tenant's independence and maximising the use of technology and design features. Staff also understand the importance of not just "doing things" for tenants – for example, it is the staff role to maximise each tenant's use of the technology, not to use the technology instead of the tenant.

> Remember if it's not someone's job it probably won't happen. This particularly applies to community development and building social relationships.
> (SUPPORT PROVIDER)

Identify staff roles and associated skills. New staff roles may be identified. All staff support roles require models of practice which are enabling – "doing with" rather than "doing for". Potential roles include:

- Direct physical care and assistance
- Coordination of support
- Advocacy
- Maximising personal development, skills and capability; for example, financial management, travel training, planning the day, modelling and problem solving
- Minimising anxiety and increasing emotional resilience for individuals and families, including supporting people to self-manage anxiety
- Preventing and monitoring for example health, food, cleanliness and medication, development and independence, behavioural issues
- Supervision, surveillance and monitoring regarding specific high risk issues
- Support to family to alleviate family carer roles
- Assisting the involvement of family, friends and community members and fostering new relationships.

Coordinate various formal and informal support arrangements. In general terms, but not always, there are some things which belong best with informal supports (for example, long term advocacy and representation) or with formal supports (for example, long term provision of intimate personal care).

- Some support is shared between formal and informal supports over a person's life time.
- Consider how design, modifications, equipment, technology can complement staff support for each person.
- Recognise the role for paid staff in building and maintaining informal relationships – facilitating communication, contact, visits, arranging "trouble shooting" sessions, arranging social contact – indirect (birthday cards etc.) and direct. Staff also have a role in monitoring – being aware if key relationships are dropping away for any reason.
- Identify roles for different staff which are planned, and how to respond with backup staff to emergencies.

Staff roles and scheduling are very different depending how support is delivered. If staff are responding, rather than simply present, a different skill set is needed: not just to "save the day" but "what to do if this happens next time". Problem solving, scenario planning for who else could be involved and possible roles for family, friends, neighbours; pre-planning too. This is different from traditional staff roles with a list of tasks to do. (SUPPORT PROVIDER)

LEARNINGS: ABILITY OPTIONS NSW

Ability Options NSW provides 24/7 backup emergency support to people with disabilities and complex needs living in their own apartments in Hunter, NSW. This service was initially planned as 3 x 8 hour staff shifts with dedicated backup staff.

The backup emergency team and the planned support team roles reman distinct and are undertaken by the same staff.

Access to backup 24 hour support is a key component of the Hunter model because of the high support needs and potential vulnerability of project tenants. For example, some tenants will experience brain injury-associated "overwhelm"; or have underdeveloped problem solving skills; memory challenges; reduced planning capacity and rigid thinking patterns. Other tenants have high physical support needs which require regular and reliable assistance, but can also be unpredictable at times.

Experience is indicating that some tenants assume that access to 24 hour onsite support means they have staff "on-tap" to attend to minor needs that could wait till their next individual support session. They may not plan well for managing their needs because they expect there is someone to do things for them at the time when they want, or when an unexpected need occurs. On the other hand ease of access has been central to giving people confidence that their new independent living arrangements will work for them in a timely way. It is clear that many do need to access assistance to manage some unexpected or unpredicted issues.

Tenant expectations of planned and backup support roles can become blurred. It is important that tenants use backup staff for emergencies rather than, for example because they are feeling a bit lonely. The current delineation is that backup staff don't do regular tasks such as personal care, walk the dog or replace other planned support.

The potential of the backup staff to assist in situations a planned staff member cannot undertake alone (e.g. a two person lift) is under review.

Using specialist staff in backup roles is leading to more skilled and cost-effective responses. For tenants with complex physical and medical support needs, an experienced nurse available 24/7 in the backup role provides skilled emergency personal care; nursing/ medical assessment; and the capacity to respond to emergencies.

Ongoing review and reflection is essential. The support arrangements planned early in the project evolve as people's lives evolve and change.

Find the right balance between planned staffing and backup staffing. Staff support involves the right combination of planned staffing (for specific times, purposes or all the time) and backup staffing (for emergencies).

Planned support describes staff support for known, regular, activities and needs such as:

- Personal, physical and medical care requiring specific staff competencies (e.g. epilepsy, PEG feeding)
- Increasing engagement and participation in preferred activities
- Building natural support arrangements between nearby friends/ tenants
- Helping people connect socially with neighbours (e.g. support staff regularly ringing, dropping in) and community networks. Building relationships, with friends, family and extended family, flatmates and other community members and volunteers
- Seeking opportunities to develop mutual support arrangements (e.g. bringing in the neighbours' rubbish bins).

Before **backup support** commences, the urgency of the issue requiring backup is assessed:

- The person with a disability makes phone contact with backup support staff, or alerts support staff via technology to begin the process of problem solving and deciding options with backup support (e.g. poorly cooked meal versus a medical emergency).
- If necessary, a decision is made to trigger contact to emergency services or nominated friends and family, or to deliver an immediate staff response.
- Staff responders are located near the home of the individual with disability. Proximity is based on the likely urgency of the backup or emergency and may include staff based within the individual's living space – but this is not assumed from the start.
- Skilled staff are matched to the likely backup/ emergency roles. For example, a nurse with emergency experience rostered as backup staff for individuals with high medical care needs can manage more situations before calling the ambulance; a counsellor can talk by phone to someone with anxiety arising from mental illness. Backup staff are selected to ensure they have the skills and capability to respond to the diverse range of unpredictable needs across several tenants.

> Staff are working to increase personal capability and work cooperatively across different aspects of support to someone living in their own home need to: have values consistent with the goals of the support organisation; be able to build the skills of others and motivate others to achieve their goals; have specialised skills when needed – for example skills with epilepsy, peg feeding, and building relationships with different people; be prepared to work with different people and able to accept that sometimes the person chooses another staff member. (SUPPORT PROVIDER).

CASE STUDY

PLANNING SUPPORT OVER 24 HOURS WHERE SUPPORT IS PROVIDED BY STAFF AND OTHERS

JOANNE has a progressive neurological condition and is living in her own home.

Planned staff support is arranged daily for getting up and going to bed, at mealtimes and to set up Joanne's environment for the day, (i.e. preparing what Joanne likes to do each day – to be able to turn on TV or computer; reach a drink; or make a phone call). The close placement of the right environmental control devices with large buttons means Joanne is independent for the rest of the day and does not need staff to be present.

Backup support is for the unexpected and emergencies. Joanne has a personal alarm to an attendant care agency if needed – if she fell out of bed or was incontinent. The Royal District Nursing Service would be contacted if nominated friends and family were not contactable. Joanne has a coded lock box so that nominated friends, family and backup staff can get into her home.

Match staff orientation, training, supervision and roles with different job requirements.

- Recognise staff skills need to be tailored for different target groups of people. For example, different staff practices are needed when staff teach skills and engage with people with an intellectual disability compared with adults with acquired neurological disorders.
- Clarify staff responsible for management, meeting OH&S requirements, and discipline.
- Organisations need new ways to roster staff that acknowledge different locations staff work in; travel time; and how many people can be supported by one travelling staff member. Different responses are likely in rural, remote and metro settings.
- Take steps to create viable jobs that staff want to do – and not a continuation of "on call plus call out" employment conditions as the foundation to backup support. The challenge is to balance good employment conditions for staff and a good life for the person with disability. Be prepared to restructure organisations and to question how staff are employed.
- Set up contracts and rosters that maintain response flexibility and still attract good staff

> Poor support can be provided in a model that does not provide 24 hour physical staff presence; and good support in traditional 24 hour group home support. The success is related to staff's understanding about why they support people and the skills they have to do that.
> (SUPPORT PROVIDER)

NEXUS INDEPENDENT LIVING PROGRAM AT QUEENS WALK, HOBART, TASMANIA: DIFFERENT ROLES OF SUPPORT STAFF

With family: Provide information, reassurance; support to families to allow more independence; and emotional support during transition and change

Between family and tenant: Support the development and maintenance of effective relationships

With landlord: Support (rather than stand in for) interactions between tenant and landlord

With a young person with a disability:

- Skill development/ capability building: financial, budgeting; travel training
- Task analysis and teaching new tasks and responses; modelling
- Reinforcing routines; prompting the person to be active from morning
- Monitoring food and medication etc.
- Planning: meals, shopping
- Case management: connecting/ coordinating services; developing new services
- Prevention: information, problem solving, conflict resolution and verbal negotiation (for example if someone changed computer password)
- Debriefing, reducing and managing stress and anxiety
- Building relationships
- Review

Roles of others:

CEO and senior staff: Commitment to maximising the independence of each person being supported

Tenancy management: Clarifying what attracts person with disability to this setting; what living in this setting will mean in terms of daily lifestyle and responsibilities of a tenant, and what their reaction may be to other residents, noise etc.

Part of the reason Queens Walk has worked is because of strong family involvement. Families are involved with finances, advocacy, emotional support to the tenant, for the "long haul". They provide a "check and balance" with staff.
(SUPPORT PROVIDER, NEXUS INDEPENDENT LIVING PROGRAM)

d Preparing each person for their new living arrangements, including transition and the roles of family and friends

Preparing to move is the point when an individual has decided to move (or moving is inevitable due to changing circumstances) and additional capability or independence skills or support that may be needed are considered. Transition is the stage of move planning and actually moving in – and being ready for the reality of new support arrangements.

The transition into a new rental property household may involve a tenancy support function. The tenant is required to pay the rent, keep the apartment tidy and be neighbourly (respectful, not too loud). The tenancy manager does not need to know about support delivery details.

For many people with disabilities, the role of the tenancy manager will be the same as it is for any other tenant. The tenancy management role for people with complex needs and disabilities will not always be the same, for example, prompt maintenance can be essential for daily life where there are complex needs.

WHAT CAN BE DONE

Explore each person's new roles and responsibilities. People with disabilities and complex needs require support in relation to general living tasks rather than their disability. These include how to leave the family home for the first time, how to be a neighbour, a tenant, and community member.

- Explore the implications of new roles and responsibilities for people living in their own homes: as a tenant, as a neighbour and as a citizen in the local community. There will be new responsibilities for some people with disability.
- Support people who have never learned independent living skills and foster the sense of responsibility needed for living in their own home.
- Affirm the role of the person with a disability beyond the person 'to be cared for' in the family, such as companion or brother. Affirm the role of family member beyond their carer role, such as spouse, counsel or parent.
- Pay particular attention during transition to people who have been living in facilities with rostered staff (such shared supported accommodation or nursing homes). Some people with disabilities have learnt to be extremely passive – this can create a major safety risk.

SUMMER FOUNDATION, TAC RIPL, ABBOTSFORD APARTMENT PROJECT

Most tenants have come from living environments with continuous access to someone else close by in the event of an emergency or need for unplanned assistance (when living with family, in a nursing home or shared supported accommodation). The transition to living with less immediate access to staff, and coping with that adjustment, can be complex for tenants and family members (where available).

A key learning from the Summer Foundation/TAC RIPL Abbotsford apartment project has been that there is a higher level of anxiety when tenants first move in than originally anticipated. This response resulted in the need for more unplanned support in the early stages. The project has demonstrated that participants take varying lengths of time to become confident with living in their new home and accustomed to and competent with using technology tailored to support their safety and independence. Prior familiarity with technology, cognitive capacity, and the ability to think clearly when stressed can influence this – something typical of the general population, but with greater consequences for this group. The reliability of technology and staff's confidence and competence with it also added to complexity during the first few months of the project.

The experience of the project has highlighted that a growing confidence in living independently can unravel quickly for a tenant. Swift and effective support is needed when new tenants are confronted with challenges to ensure such events are not associated with high anxiety for tenants in their new home.

Develop staff teams around each person

- Recruit specifically for each person and develop staff roles consistent with how the person wants to live. For example, build/ look for staff knowledge about the local community to increase the likelihood of community linkages.
- Coordinate support around the person with a disability only when needed. Look to strengthen privacy for the person, and confidentiality between workers and with other aspects of support. Clarify when/ if staff may need to debrief or problem solve without the person with disability being present.
- Reinforce a model of staff practice associated with building independence and social communication. Supervise, coach, model, mentor – help staff understand how their interactions promote independence and engagement. Staff "doing nothing" might be the best response in some situations. How staff provide general, enabling support is not determined by whether staff are physically present with people with disability, or away from people's homes; or whether staff are funded by block funding or individual funds.

> It's not the model of accommodation that determines great staff support but the quality of the staff *and* the model of staff practice and supervision
> (SUPPORT PROVIDER)

CARA, WOODVILLE, SA – CONCIERGE MODEL

These apartments suit people who don't need someone all the time but do need a sense of security due to illness or risk.

People who require active night staff will not be well supported with this approach, for example people with challenging behaviour who are awake at night; people with deteriorating neurological conditions.

Transition to the new household

- Transition can begin before finalising a person's housing decision. Explore preliminary opportunities to try out certain arrangements, to thoroughly identify someone's support needs particularly those which may not be apparent in the previous/ current setting.
- Understand the detail of how the person with disability wants to live. Small details can jeopardise the success of living arrangements (e.g. a large TV and large sofas can prohibit comfortable TV watching from a bulky wheelchair; high cupboards reduce opportunities for independence; soap holders carefully placed enable a person to wash unassisted).
- Transition to a new home and providing assistance to move and settle in involves immediate responses and time-limited responses for each person and new location. Initial questions like "Is the power connected?" can be followed by household skills development – about how appliances work, what are the housekeeping arrangements (rental and utilities payments), and finding the way around the neighbourhood, as well as problem solving and monitoring of household supplies and budget.
- Transition involves trying out how the home is set up; ensuring best use of appliances and products; practising emergency arrangements; and emotionally and practically preparing for relying on new staff and technology support arrangements.
- Ensure new support options are flexible. This task may be intense in the initial transition period but will reduce in intensity as skills, familiarity and confidence increase.

Assist individuals and families to change and make transitions

- Be sensitive to people's anxieties, and their emotional adjustment to living alone without staff always present. Many people have never been alone in their lives, or since their accident. Once living in their own apartment, they are reliant on technology and on-call staff. People who had lived in staffed settings seem to find this transition more difficult. Support for this may require more resources initially.
- Recognise that times of high anxiety for tenants (such as housing transition, ill heath, return to work) will lead to short term support cost increases, as transition and facilitation workers set up new problem-solving strategies.
- Reassure family members, especially during transition and change.

CASE STUDY

TRANSITION TO NEW LIVING ARRANGEMENTS AND GROWING CONFIDENCE

John's support was funded by TAC Victoria following a spinal cord injury due to a vehicle accident. He was receiving active overnight care to provide assistance such as turning him or offering him a drink. Within three months of moving to one of the TAC Victoria RIPL properties, John was sleeping well. The support provider, after consulting with John, suggested that his morning shift commence a little earlier. This allowed adequate time for John to get ready for the day, and meant there was no requirement for active overnight worker presence. Now, if John needs assistance during the night he can contact the backup support staff with a call button. John felt increasingly safe and comfortable in his new unit, so he was able to make this transition shortly after moving in.

Technology available at RIPL

The assistive technology utilises an intuitive user interface that is fully customised to suit John's ability. A seamless/mesh Wi-Fi network allows tenants and support staff to utilise a tablet to control any assistive technology features seamlessly from any area of the site. Features that can be controlled through the use of the tablet include control of the air-conditioning unit, on/off and dimming function of all lighting throughout the unit, operation of the motorised window furnishings, use of the front door intercom and camera, and the ability to lock and unlock external doors. The assistive technology also incorporates a communication system that utilises speakers and microphones provided in every habitable room. This allows two-way voice communication from John's unit to the support unit via phone and tablet. The system also includes a red/amber/green alert system for John seeking assistance from support staff. The system incorporates a process for support staff to acknowledge receipt of the alert via the tablet, so that John has positive confirmation that a call for assistance has been received.

e Recognising that new ways of living will require new ways of problem solving and safeguarding people's interests

New ways of supporting people to live like everyone else will generate new problems to be solved and risks to be ameliorated. Organisational and individual preparedness to be flexible and keep learning is essential. Assuming dependency and prioritising protection above all else means potentially jeopardising possibilities for a rich, meaningful life – including the unexpected twists and turns or opportunities to learn from mistakes and negative experiences encountered by all members of the community.

Processes are needed to explore each person's level of reasonable risk given the life they want to live. Legislation, standards, and concerns about litigation can act to reinforce the assumption that it is not possible for people with disabilities to begin to explore and undertake normal housing responsibilities. Organisations are wary of being "blamed" for negative events in people's lives, as if all potential threats to people can be anticipated and negated and must be controlled or avoided.

Learning from mistakes is often termed "the dignity of risk" but this does not mean people with disabilities being exposed to situations with inadequate support and information. Staff presence has provided blanket reassurance for some organisations, people with disabilities and families.

Recognise that no one can be 100% safe, and that greater personal capability increases control over daily life and that trying to eliminate risk situations reduces the capacity to handle them when they inevitably occur.

> 24 hour staffed support gives a false sense of security ... 24 hour physical staff presence is the "easy" response: can "blame" staff when something goes wrong.
> (ALLIED HEALTH PROFESSIONAL)

WHAT CAN BE DONE

Assess risks and possibilities for each individual in context of their preferred way of living. From the start, emphasise greater personal independence and responsibility for how each person wants to live. Align the analysis of risks with the person's goals so that the assessment of risk is embedded in a context.

- Reach agreement about the level of risk acceptable to the person and family – formalise these agreements if needed. Explore options with staff – they too need to be comfortable with the level of risk. If the person with a disability accepts a greater level of risk than staff would, discuss this with staff, the person with a disability and family members.

- Background technology is useful to make contact, check health status, signal possible injury or falling over. However like staff support, it may not be infallible. For example, a choking incident in the middle of the night for someone with a known medical condition, "Probably would not be picked up by sleep over staff anyway."
- Understand the additional responsibilities of living in one's own home in the community; in residential settings (shared supported accommodation)/ nursing homes) individuals are not responsible for purchasing food or paying power bills etc.
- Discuss at board and staff levels the changing implications for confidentiality, decision-making and risk when the individual is deciding how they want to live. Provide staff and board members with opportunities to explore possibilities, learn from other settings. Develop an organisational culture, industrial agreements and staff roles which emphasise enablement and independence. If providers focus on independence, choice and control as a means to reduce risk, this can assist individuals and families to do so too.

Resist the emergence of the "disability world" way of thinking. Maintain an emphasis on the real world – not the disability world. Individuals are tenants/ residents first and foremost with roles and responsibilities, and should have the freedom to make mistakes or change their mind.

What type of risks am I comfortable with?

The conclusions to these questions will vary across different people. Discuss why particular conclusions were reached.

- What level of risk is the person prepared to take and allowed to take by others (family, organisations)? This will vary for each individual and with "what level of anxiety is tolerable".
- How is a balance achieved between the chance to learn from new opportunities and the possible associated risks?
- How does the sense of risk vary at different life stages? For example, for younger people who have "lots of living ahead" versus older people; or the likelihood of specific risks at various life stages, such as financial or physical exploitation, or falls.
- How can the risk of financial, physical or sexual exploitation of people be ameliorated by building capability and social networks?
- Identify conflicts of interest. Conflicts of interest arise when there are different priorities. A support provider organisation may want to ensure their ongoing role and income from supporting the person with a disability; individuals with a disability can have different views to their parents or other family members. Recognising who has a conflict of interest and whether they can negotiate a change of view is an important aspect of risk management assessment.
- What if the person with a disability wants less responsibility or less independence?

CASE STUDY

TECHNOLOGY MAY BE A BETTER OPTION

James lives in a group home. He often has a seizure at night. If he wakes up, he is usually already in bed, or is able to return to bed if he is not. Sometimes he falls and hurts himself. If James became unconscious he could not rouse staff. His family discuss with him that technology seems a better option. An alarm could notify staff that he has not returned to bed after a certain time gap; and wrist technology/ watch would allow James to talk to backup staff. These staff need not be working from his house – if nearby, staff are able to move to respond as needed or change their pattern of work depending on what is required. Over time, overnight staff may be responding to people dotted throughout a community.

POTENTIAL FOR ORGANISATIONAL BARRIERS

Organisational responses to changes, backup and emergencies "can derail how people with disabilities want to live."

For example, Steven has autism and wants to go to the cinema, but he dislikes crowds and new places. What are the options? Change the goal and forget what Steven wanted to do? Or keep the goal and keep trying varying approaches, maybe for several years until a way is found for Steven to enjoy the cinema.

Rachel is usually driven about by her support worker, but the support worker loses his driving licence. What are the options? Rachel doesn't access the community as there is no one to drive her or Rachel learns to use public transport with the support worker.

There is no longer funding for transport, but staff have always driven George to the shops. What are the options? George can no longer go shopping as transport is unfunded or George does shopping in other ways; online, using closer local shops, or goes shopping with a friend.

Helpful and unhelpful concepts for new ways of thinking. Terms like "duty of care" and "dignity of risk" were framed in a past policy context. It can be argued that these concepts are not serving discussion well enough in a new world order pitched at increasing personal independence and capability rather than reinforcing dependence and protection of people with disabilities. How "duty of care" and "dignity of risk" are understood has implications for what choices and opportunities are considered.

Develop a culture of learning / reflection rather than blame/ punishment, and develop an enabling approach to emergencies. Reassure and debrief with families, individuals with disability and staff after challenging situations arise. For example, Sylvia lives alone. A mechanical fault meant she was unable to get out of her bed for several hours. Reflection time was needed to consider whether Sylvia was still comfortable with the level of risk and her goals for how she wanted to live and using real world thinking, how the likelihood of the incident recurring could be removed or reduced.

Reflect on how decisions are made. Sometimes decision-making or choice is reduced to just two options: "this or that"

- Time and effort is required to consider multiple variables, and the change and interactions they bring. What partial and variable contributions could be made towards the best solutions to the circumstances now? The contributions and circumstances may change in the future.
- Be aware that operational issues that exist or arise can distract us from the person's original goals and vision.
- Emphasise that housing is the person's home, and not a facility.

Commit to staff development and specialisation. Staff don't automatically know what to do without training, supervision and mentoring. Have ways for staff to get support for the unexpected and difficult (e.g. annecto's 24 hour support is available to people with disabilities and to support staff).

Develop staff incentives and mentoring to promote increased capability. Staff satisfaction in their role is important: not just "doing things for" the person with a disability, which for some staff "can initially feel like doing nothing".

- Reward staff for new ways of working: this may involve staff being less active or encouraging individuals to do things for themselves even when they direct anger and frustration at staff.
- Develop the flexibility to enable staff to carefully withdraw if someone's personal networks develop or to reduce dependency as confidence and capability grows.
- Recognise staff and family can be critical to reinforcing optimum use of technology and other assistive equipment.
- Ensure that building the capacity of individuals is the focus for all support workers. Staff involved in planning, support, and facilitation roles can all optimise design and technology use for greater independence and community inclusion.

> One of the biggest lessons was to help staff stand back and let the young person experience the highs and lows of living their own lives.
> (SERVICE PROVIDER)

When is too much support acceptable?

What if someone doesn't want to be more independent and would prefer to be cared for and protected? Some people will be more fearful and need reassurance, but what is reasonable if people do want staff support? For example, sometimes when staff ask individuals to do more they are rejected by the individual. If the person or their family prefers greater dependency who pays? Why are they making this choice – anxiety, a sense of entitlement, overprotection?

When is it OK "to do for"? When might staff do things for someone that they could do themselves with great effort? For example, where an individual has personal household tasks completed by others to leave energy for socialising. Unless someone else does the cleaning and cooking, the person with a disability has no energy to go out and participate in community activities. Personal independence must be understood as more than simply completing household tasks.

Can the person agree to take more responsibility and trade off risk for opportunity and other aspects of quality of life? For example, can the person agree to levels of personal safety recorded through an Advanced Care Planning process? (http://advancecareplanning.org.au/resources/victoria)

Recognise the vital safeguarding role of friends, family and community members

- Include building, nurturing and maintaining informal supports in support staff's roles.
- Work to strengthen the safeguarding role of families and other informal supporters, and plan for times when this is unavailable, either temporarily or permanently.
- Recognise the role of family or friends to monitor what is happening and/or to be consulted at key decision points.
- Identify external roles including advocates/ decision-makers for people without support from family.
- Be open with individuals and families about the approach to risk adopted by the support provider (e.g. what "natural consequences" might mean). Have a mechanism to debrief staff, family and individuals with disabilities and learn from any incidents.

Anticipate that the unexpected will occur with new ways of living. Many normal life issues will be new to people with complex needs who may not have the sets of skills and emotional experience required to be a typical citizen. Outline medical, behavioural or technological responses to known issues. Be prepared to:

- Provide reassurance and reduce anxiety for individuals and families.
- Inform, problem solve, advise, resolve conflict, undertake verbal negotiation.
- Minimise decisions made during crises and emergencies. Find time for reflection after the event.
- "Realise that we cannot anticipate each unexpected event" when people with disabilities experience more independence in the community (e.g. when alcohol is involved or independent travel to unexpected locations).

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e CHOOSING MY OWN HOME

The sleepover function reassures families. Families wouldn't have agreed to move without the sleepover staff member. In the first six months, the sleepover staff member only received three wake up calls, which were mainly for reassurance due to disorientation and confusion. There was nothing that required an emergency response.
(NEXUS INDEPENDENT LIVING PROJECT AT QUEENS WALK, HOBART, TASMANIA)

Keep the goal in sight

- Recognise discussion on 24 hour support can slide into unanalysed "what if's" and emphasise organisational risk.
- Be alert to blanket responses to risk and accountability. Some organisations respond by prioritising the consistency and uniformity of processes ahead of responding to individuals.
- Be aware of blanket responses that have been reinforced in industrial agreements that are now "out of touch with what is really required for flexible individualised service provision."

Practical Ways of Reducing Risk:

- Comprehensive fire management plan
- Use of tablets, phones and personal safety devices
- Use of tablets to find locations around the community
- Daily life contact with different people
- Identification of emergency phone numbers in easy to access forms (e.g. speed dial on the phone)
- Regular phone call to person, drop in
- Backup for technology
- Staff close by and able to respond as fast as needed
- Specific staff training
- Supportive role developed with neighbours
- Pre-planning agreements such as Advanced Care Plans
- External coded key lock to enable entry
- Credit cards with credit limits
- Learning to use public transport

Assessing risks and safeguards: NDIS Operational guidelines

People with disability should be supported to exercise choice, including in relation to taking reasonable risks, in the pursuit of their goals and the planning and delivery of their supports.

The NDIA will discuss safeguards with participants in the following ways: choice and control; risk-based and person-centred approach; and presumption of capacity.

The following safeguard levels can guide the development of appropriate measures:

- Individual level safeguards: include both informal and formal safeguards for participants.
- Informal safeguards: these acknowledge that participants are more likely to be safe when they are actively involved with their family and community. The things that make people safe are the same things needed to have a good life. For example, caring relationships and enhanced opportunities for participation in daily life.
- Individual formal safeguards: which include rules for restrictive practices and serious incident reporting.
- Service level safeguards: Service level safeguards include quality frameworks, complaints mechanisms and workforce requirements such as qualifications, recruitment practices and performance standards.
- System level safeguards: The NDIA will use existing system-level safeguards to safeguard participants. These include internal and external processes for making complaints, processes to have decisions reviewed by an independent body and statutory powers.
- Community based safeguards: The NDIA uses and operates in the context of existing community based safeguards that are not formally a part of the disability service system. These include advocacy organisations, community visitor schemes, public advocates or guardians, Ombudsman offices and discrimination commissioners. People with disability can also use a range of safeguards available to the community including anti-discrimination and consumer protection legislation.

Additional safeguards the NDIA can put in place through the participant's plan include: reviewing the participant's plan more frequently; setting out arrangements for regular contact between the NDIA and the participant; or providing funding for supports to assist participants to manage their own plans for example, budget training.

NDIS operational guidelines: https://www.ndis.gov.au/operational-guideline/planning/performing-needs-assessment.html#8.4

f Responding to each person's changing life preferences, priorities and circumstances

People with disabilities and complex needs living like everyone else will have ongoing requirements for 24 hour support, and the intensity and nature of support will vary over the years. People's lives change in predictable and unexpected ways. Over a lifetime, everyone needs different support for different reasons and at different times due to illness, new learning and opportunities, changed family life, older age etc.

Establishing responsive support options means more than regular reviews. Responsiveness is a product of the vision for the housing option and how each person wants to live. It is not simply a response to a short term problem. Responsive support requirements need to have the potential to be constant, variable (increasing or decreasing), episodic and fluctuating. Support needs may be affected by the different trajectories arising from different disabilities and impairments (for example, conditions that involve progressive deterioration or early ageing). Responsiveness requires personal and organisational persistence and trialling of new approaches.

> Responsiveness is not just being nice to people – this is a challenging life journey. Staff may be contactable for problem solving with the person, but can't do everything.
> (SERVICE PROVIDER)

WHAT CAN BE DONE

Ensure individuals remain central to decision-making affecting their lives

- Keep the person's goals alive. Consider circles of support, Advanced Care Plans (http://advancecareplanning.org.au/resources/victoria) or informal and formal advocacy.
- Emphasise the will and preference of people who can't easily or independently direct decision-making.
- Restrain others (such as family, providers, emergency workers) from overriding or disregarding the person's preferences.
- Incorporate ongoing learning.
- Gather feedback from individuals themselves via verbal communication, non-verbal communication (gestures, facial expression, postural changes) and behavioural changes.
- Determine whether individual outcomes are achieved and ensure individuals are satisfied with the outcome.

Establish ways to plan and monitor in the future

- Gather and review data about the progress towards individual outcomes and costs over time.
- Plan a recommended review schedule.

NEXUS INDEPENDENT LIVING PROGRAM NILP, QUEENS WALK, TASMANIA:

'Funded as shared supported housing but we are able to be more flexible than shared supported housing'.

Queens Walk incorporates four apartments for four people who otherwise would have been accommodated in shared supported housing arrangements. Nexus has a staff office apartment well away from the other four tenant's apartments, including a bedroom for sleepover. Tenants don't come to the office but use a buzzer to call staff. The funding is based on a 4 bedroom group-home.

Other features of Queens Walk:

- Each young person with a disability is responsible for their own home. Living arrangements are typical of anyone renting a home.
- Separate tenancy management function is provided from support provider.
- Individuals and staff are not all in the one location, with staff based away from where people live. Tenants come and go from their units without staff knowing, and vice versa.
- Individuals are largely responsible for their own lives, and staff don't have responsibility for a group of people at all times. The resulting interactions are usually one-to-one and focused on personalised support. There are no group-based housing arrangements and the only group activities are arranged by the tenants (e.g. two individuals gaming, or renting the common room to watch the football grand final). Many of these group activities happen without staff involvement and can include other tenants from the site.
- Staff are rostered from set shifts. Because tenants spend time alone, rostered staff may not be needed by tenants at times during a shift. Opportunities for residents to exercise independence are more frequent than with group-based living arrangements. Flexibility for tenants increases over time. Personal learnings and development: one tenant, for example, has chosen to live with someone so he has more company.
- Support staff don't do everything and are not responsible for the household. For example, support staff won't change light globes but will encourage the resident to problem-solve by asking, "What do you need to do?" None of the current residents have lived in group homes, they all moved from their family home. This background means there is not the expectation that staff fix things (but sometimes the expectation that family will). Staff emphasis is on "fault correction, not fault prevention".
- Natural links across the four NILP participants in Hobart have formed. They problem solve, share information, look at ways to interact; they also model interactions, including with other residents across site. Natural interactions are occurring in this social housing environment; other tenants "look out for" the young men.
- The families are given information and reassurance too.
- Episodic changes in need are factored into the NDIS plan and intense one-to-one support can be brought in when needed.
- The small number of four units means that systems are less likely to be organisation dominated.

DEVELOPING SYSTEMS

g Promoting leadership, culture and developing capacity within organisations

Organisations and the community need to be ready to work differently if people with disability and complex needs are to be supported to live like everyone else. An approach which asks organisations and staff to work collaboratively with people with disability, and asks families to be flexible and coordinate with other supporters is more challenging to implement.

Well-managed organisational development means organisations will be ready to extend existing finance, human resources, industrial relations systems, and develop new workforce skills and capacity (and sometimes new workforces) to work in someone's individualised home environment. Sometimes the readying process is a partnership, involving gradual exploration between a support provider and those receiving support, and their families and the local community.

Some organisations with structures built around a traditional model of accommodation support may see little incentive to adapt policy, procedures and staff training. Some providers of support will need convincing about the feasibility and commitment required to become more responsive to how individuals want to live; and to positively and actively support increasing independence. As the NDIS gains traction and individuals and families become more self-directing, the time to pursue organisational development may no longer be available to providers of support.

WHAT CAN BE DONE

Confirm the core principles of individualised service within the mission of the organisation.
The organisational goal of support that enables people with disabilities and complex needs to live like everyone else in their own home requires capability in the support provider to work with each individual as needed, to:

- Increase personal flexibility and quality of life
- Respond to emergencies and the unexpected
- Enable changes of home routine
- Allow for spontaneity
- Reduce social isolation and loneliness
- Foster formal and informal mutual support to reduce anxiety, provide information and be a source of advice
- Help people with disabilities connect with neighbours and the wider community
- Attend to emotional support for individuals as well as physical support, and learning and development.

Create incentives for organisations and staff to promote independence, not dependence.

- Incentives are needed for organisations to work with individuals and families to increase personal capability and reduce support costs over time where practicable. Incentives are not necessarily financial. Consider the effect on the organisation's reputation and brand and opportunities to specialise, grow and expand. Look at ways to further the mission of a not-for-profit organisation and disseminate good performance data.
- Promote organisations where the management and culture endorses personal outcomes: improving quality of life and maximising independence as a priority and embed personal capability building for individuals as an organisational imperative.

Discourage staff from doing tasks "the way we always do." Expose staff to different modes of providing support for people with disabilities to live like everyone else. Assess the different approaches needed for building capability for people with medical, physical, behavioural and/or cognitive needs, or developmental and acquired disabilities.

- Staff and organisations benefit from seeing, discussing and experiencing new ways of working and delivering support, structuring and monitoring staff groups. Discuss how to define staff roles, including in partnership with the individual and with families.
- Involve all departments. It was found that finance, industrial relations and human resource functions, and support staff can find flexibility challenging – at least at the start. Consider the important perspectives of unions and employers.

THE IMPORTANCE OF A SHARED VISION

A support provider in a group home aimed to provide personalised support which built people's independence and networking in their local community. However, the finance department's approach to purchasing contracts was to keep prices low. Bulk buying of provisions meant there was no opportunity for individuals living in the group home to plan requirements, shop and build relationships with local businesses. In the context of prioritising an organisational goal (increasing personal capability and independence), an emphasis on achieving lowest prices risks undermining the overall organisational goal.

Explore new ways to structure organisations

- Explore how to individualise support responses while maximising cost-effectiveness.
- Seek ways to cluster or share staff rosters without grouping staff in people's homes.

EXAMPLE OF INDIVIDUAL DELIVERY AND SHARED MANAGEMENT OF STAFF AT ABBOTSFORD APARTMENT PROJECT

From a tenant perspective, all staff support is individual and tailored. There are only individual responses, and no group-based staff responses. From an organisational perspective, support is delivered through 'individual' and 'shared' staff support elements. The 'shared' element enables 24/7 availability for responses to issues beyond the support provision developed from each person's individual goals. In addition, there is access to the annecto After Hours Service.

Develop principles and practices to work collaboratively with families and people with disabilities: recognise family members as interdependent not co-dependent.

- Recognise that some families will want to be very involved in an ongoing sense, others will want less involvement – so structures and expectations need to be flexible enough to cater for different families, different availability or changes over time.
- Explore backup for families whose ability to stay involved can vary and change.

Principles: Support providers and families working together (Office of the Disability Services Commissioner, Victoria)

http://www.odsc.vic.gov.au/resources/occasional-papers/

- People with a disability have a right to lead a life of their own choosing.
- Relationships are important in people's lives.
- "Family" means different things to different people.
- Both families and service providers contribute to a person's life.
- Differing views should be expressed and respected.

h Ensuring commitment by partners and collaborators to a shared vision and core principles

Any development of housing for people with disabilities and complex needs includes many individuals, especially if the development is large scale. Housing developers, specialists in design, technology and household adaptations, staff support providers, tenancy managers, funders, as well as individuals and families, may all be involved. Housing developed or modified for the individual may involve them and their family, and the owner/builder of the housing. Input from specialists in design, technology and modification is important to small scale developments too.

A shared vision and core principles between partners and collaborators means everyone is committed to the same direction, while recognising the different contributions and perspectives. Shared core principles focus attention to ensure staff and family strive not to inadvertently amplify dependence, or fail to enable more independence. Reducing dependence provides the opportunity to examine whether cost-saving features can reduce lifetime care costs.

Each perspective in the partnership brings a different "bottom line" which must be reconciled with the shared vision (such as staff roles, size of housing, numbers of people sharing or privacy). Agreed core principles provide the point of reference for later decision-making, and parameters of compromise and trade-offs which will emerge throughout the development of any housing option. Trade-offs, choice and diversity are part of normal living.

WHAT CAN BE DONE

Develop the vision

- Foster a diverse provider landscape in which there is a move away from leaders and managers who are accustomed to older institutional models of 24 hour physical staff presence.
- Look for opportunities to link all perspectives to maximise opportunities for independent living. Tailor the vision to the specific circumstances.

Ensure common understandings of terms underpinning the vision.

- A shared understanding of what it means for people with disabilities and complex needs to live like everyone else as a citizen is needed. Individual circumstances will vary in terms of the least restrictive alternative, the dignity of risk and a focus on increasing personal independence and responsibility; how individual and organisational risks are managed without reducing opportunities; and what an emphasis on "enabling not doing" means.
- Recognise that the vision can be undermined when different aspects of support are not integrated. Multi-component 24 hour support needs detailed planning around the relationship between technology, design and staff roles.
- Establish principles to guide decisions about location, housing form, technology and other adaptations. Consider attention to upfront versus long term costs and benefits.

ABBOTSFORD APARTMENT PROJECT (SUMMER FOUNDATION, TAC VICTORIA, ANNECTO, CEHL)

The core collaborators developed a shared vision for the Abbotsford apartment project about:

"...making a reality the long term impact of increasing independence, decreasing support hours, and maximising control for tenants." (Abbotsford apartment project documents).

The collaborators protected the long term vision and "guarded the outcomes wanted" based on clarity about what was being measured from the start; and "the group held everyone accountable". All collaborators were committed to learning about ways to maximise independence, choice and control for tenants living as community members in an inner city apartment complex. The guiding questions for the collaboration were:

"What does it take for all in the collaboration to think about tenants' long term independence?"

"How to enable greater individual capability at home and in the community?' 'How can each person be supported to do this?" (https://www.summerfoundation.org.au/resources/abbotsford-report/)

THE VISION

The partnership and the vision

The Abbotsford apartment model was developed through a collaborative process between four organisations (Summer Foundation; TAC RIPL; annecto; and Common Equity Housing Limited). The model aimed to enable people with complex support needs to each live in their own fully accessible apartment, with the same rights and responsibilities as other community members living in medium density, inner city housing. Tenants are expected to live as independently as possible in apartments that they rent and for which they are responsible. Tenants pay affordable rent based on their income.

Tenants have housing and tenancy obligations. There are tenancy and property management rules common to everyone living in the housing development for example, expectations via the building's owners' corporation regarding the smoking policy in public or shared spaces.

Always remember the vision – living like everyone else

To maximise privacy, consider where staff will be in someone's home in order to minimise staff "walk throughs". For example, if staff will work predominately in the bathroom, site bathroom near the front of the building.

Delineate staff areas from someone's home space. Ensure that provisions for staffing do not interfere with the house being a home (e.g. ensure staff / bus parking is not the main external feature; staff facilities and spaces for staff relaxation or congregation needs in the house should be separated from the residents' private living spaces).

HUNTER NSW APARTMENTS

Key design features of the Hunter NSW apartments were consistent with the vision to support people with disabilities to live in their own apartments, either alone or with a spouse, friends, or family, and:

- Allow for real life opportunities
- Be accessible
- Support dignity
- Have customisable features for individual needs
- Use home automation technology
- Incorporate safety features supporting independent living
- Minimise future costs

Identifying partners and collaborators

- Is this a large scale housing development or person-by-person housing development? Who leads the development of housing? Who leads the development of support?
- What partnerships are needed to achieve the vision? What are the respective roles and responsibilities? What processes will be adopted to enable collaboration?
- How can location, technology and design be part of the development of housing?
- Confirm that everyone involved is willing to explore and try new approaches, including to risk amelioration and problem solving.
- What are the responsibilities of people with disability and families? Ensure people with disability and families are drivers and advisors wherever possible.
- Who can live in this housing option? How will identification of potential individuals and referral processes be managed?

> People with profound disability can have the same tenancy agreements as their neighbours – the housing provider asks only three things: be neighbourly, pay the rent, and look after the property. The right support enables a person with disability to do this.
> (RESEARCHER)

h DEVELOPING SYSTEMS

Coordinate the development of housing with the model of support through collaboration. There are separate roles of housing owner/ manager and support providers. Tenancy management, while separate, can work with support providers and reduce the likelihood of eviction; support to help tenants reduce noise, keep the house tidy, and problem solve with neighbours will be important.

Talk and explore to ensure clarity in the roles and responsibilities of partners including the individuals and family:

- Families and individuals need to be able to distinguish what they do from others involved. Is there a role for advocacy?
- Recognise the wide range of mainstream and disability support providers contributing to support around each individual.
- Are all roles identified, coordinated and linked? When is coordination not needed?

Identify the core planning group members and establish a communication and coordination strategy with the individual, their family, social and community networks and other sectors, particularly health. The core planning group may be several individuals with disability or families.

- Develop protocols/ agreements for planning and communication; build in review as things develop and change; decide the level of formality/ informality for agreements.
- Expect and plan for how to respond to disagreements or problems.
- Rotate the lead agency or group chair depending on the stage of implementation. Individuals involved will change over time and will also change when housing is being developed by individuals and families.

Identify critical questions for collaborators to discuss and resolve

- For each collaborator: what are acceptable trade-offs? What cannot be compromised?

> The starting point is not that the developer has to live up to our expectations. Rather, what is the developer's perspective too? Developers already see they are providing a social service by building more housing: so why would they respond to the social conscience argument to include more variations? Negotiation is needed to find a shared solution.
> (ADVOCATE)

What level of risk is each partner and collaborator prepared to accept? This can be more straightforward for people without a cognitive impairment who have the recognised right to choose and refuse support even if risk is significant. For those with a cognitive impairment (such as intellectual disability, ABI, mental illness), more is needed to discuss and explore risk, and greater responsibility may be assigned to the support provider.

- Explore and discuss the implications of the directions proposed for existing program, industrial issues, funding and staff role boundaries.
- Decide what safety nets are needed. These options will vary for different people and different organisations, and over time as individual and organisational capability changes. The quality of support, safety and health require monitoring; so does the identification of abuse or exploitation. Recognise that families are often particularly interested in safety and security and that there will be important historical, cultural and gender issues within families and communities.
- Recognise the particular challenges which arise when people with complex needs do not have family support; are not readily able to communicate their preferences; or when family overrides the views of the individual.
- Keep family, friends and community networks well engaged as they can impact most on increasing or decreasing confidence of the individual, while staff will change.

Who decides if the person with a disability finds decision-making difficult?

- How can personal outcomes remain uppermost in priorities? Under what circumstances should families or staff override the wishes of the individual? What about people who can't direct their own lives? Who is in this person's life to care about them?
- When is a formal decision-maker needed (e.g. public guardian)?
- Do/ should low-incidence but high risk events take precedence in decision-making for the person and/or for the support organisation? For example, a blocked catheter or occasional but life-threatening seizure.
- How are these issues negotiated and monitored? How quickly do staff need to be able to respond? How physically close do staff need to be? When does staff proximity mitigate against someone taking more responsibility?
- How can pre-planning be maximised? When is not enough support a problem? Whose problem is this? Who judges that it is not enough? How is this negotiated? Has support been reduced too quickly or been insufficient to build capability and greater independence? Is decreasing support linked with increasing capability, dignity, comfort and independence?

i Aligning related systems, sectors and community views to vision and core principles

People with disabilities, like all citizens, rely on public sector information and services like health, education, transport, justice etc. These sectors can be less (or more) progressive in their vision and expectations for people with disability and complex needs. Less progressive approaches can undermine the vision of increasing individual choice and control in their own lives for people with disability. Possibilities for risk reduction are often not understood. Ongoing attention needs to be paid to building bridges and understanding across related sectors about the vision to live like everyone else.

WHAT CAN BE DONE

Pursue initiatives for systems development to occur in parallel with planning alongside a particular person who is moving such as,

- Building or liaising with real estate agents, property developers or financiers; coordinating access to support.
- Workshops initiated by GPs, allied health or community health about options for community living and individual priorities to initiate appropriate planning and relevant safeguards.
- Resourcing substitute decision-makers to understand what living like everyone else means for people with disability and complex needs.

Recognise everyone involved. This environment is increasingly complex for stakeholders to navigate, including:

- Individuals, their family and friends
- Funder (increasingly the NDIA, but also TAC, Lifetime Care)
- Professional input – for instance for people leaving acute care
- Planners, local area coordinators and service coordinators who act as intermediaries/advocates for the person
- Housing owners – which under NDIA will expand from social housing as the provider of last resort to institutional and private investors accessing Specialist Disability Accommodation (SDA) funding
- Specialist and mainstream support providers purchased with NDIS funds for example architect, builder, electrician, IT consultant, and occupational therapist
- Community members, neighbours, nearby homeowners or tenants
- Occupation health and safety, work cover, unions

Explore opportunities for coordination and note opportunities for cost saving. There are potential solutions across health, disability and the community whereby improved coordination would provide more opportunities for individuals and save costs. For instance providing a structure and support for the person to achieve and maintain optimal health and function maximises the person's capacity for independence and participation. It can also potentially decrease the number of crisis situations and the need for support and use of acute health services over time.

Develop information and options with other sectors in order to explore and understand respective roles and interrelationships. For example, options to have home nursing following a stay in hospital.

> If someone has been in hospital, they may need Hospital in the Home for a time (like any other community member), working with disability support staff – systems need to work together to meet the needs of the person.
> (HEALTH PROFESSIONAL)

Develop cross-sector protocols around an individual with systematic, agreed-in-advance management of steps for contingency planning: involving hospital, ambulance, fire brigade, general practitioner and pharmacist. Ongoing review of these agreements is needed to keep them current. All new staff should know the agreements in place in case of emergency.

- Look for ways to coordinate sectors around an individual, including systematic agreed steps for backup contingency planning. At an individual level it can be feasible to coordinate other sectors, such as district nurse, police, fire brigade general practitioner, pharmacist etc., guided by the individual's preferred way of living in their home.
- Develop protocols with the individual, their family, social and community network and other sectors particularly health.
- Use Advanced Care Plans (https://www.advancecareplanning.org.au/state-information) as a means to coordinate support around a person with clarity about what level of risk will be acceptable to the person and family.
    - Identify roles for advocates, guardians or those with power of attorney.
    - Ensure regular review when/if the person's circumstances change.
- Explore the balance between working in someone's home and workplace definitions where, for example, a workplace requires signs for wet floors, but a home would not.

Challenge government if needed: highlight possibilities and limits of what policy allows.

- Review industrial agreements for consistency with provision of flexible individualised service provision. Currently there are structural and funding barriers to implementing new ways of thinking about multi-component support. The distinction between planned and backup support is starting to challenge existing program, industrial, funding and staff role boundaries.
- It is essential to protect the rights of people with disabilities and the rights of workers and to get the correct balance so that workers' rights don't restrict the personal independence of people with disabilities, and staff are employed according to reasonable working agreements.
- Consider community values and legal requirements about risk and the need for protection. The perspective and role of the coroner is a critical reflection of community values. The coroner has the role of making judgements about defensible risk following death from fire, accident etc.

> In a bid to avoid criticism and blame, organisations, staff and families make decisions which can be pre-disposed to being overly-protective, perhaps restrictive of the life of the person with disabilities. Organisations can be "too risk averse at the expense of individual outcomes." Processes are needed to build and understand the confidence and capability of each person with a disability and to ascertain to what extent each person comprehends the implications of personal risk and taking personal responsibility. The intention of these discussions is to assist the individual with support from family, friends and support providers to decide, for example, "Yes, it's OK for me to have drop-in staff."
> (ALLIED HEALTH PROFESSIONAL)

j Developing housing that is typical of the community and affordable, accessible and available

People with disability should expect to live in the types of housing typical of the general community in each local metropolitan, regional or rural/ remote local community. This includes individuals and families making personal arrangements, perhaps between families, about the use of the family home or planning a new house; individuals who wish to stay in their own homes following accident, injury or illness; or families/ individuals working with community service organisations who are developing housing such as units or houses. Location is critically important to how someone wants to live. The development of housing has a long lead time, unless the person is building or modifying their own house.

Access to housing is a recognised human right

Every person has the right to an adequate standard of living, which includes the right to adequate housing (International Covenant on Economic, Social and Cultural Rights, ICESCR, article 11).

The right to housing is more than simply a right to shelter. It is a right to have somewhere to live that is adequate. Whether housing is adequate depends on a range of factors including:

- Legal security of tenure
- Availability of services, materials, facilities and infrastructure
- Affordability
- Accessibility
- Habitability
- Location
- Cultural adequacy.

https://www.humanrights.gov.au/our-work/rights-and-freedoms/projects/housing-homelessness-and-human-rights

HOUSING – BUILT FORM VARIABLES (FROM 2016 PROJECT CONSULTATIONS)

- Housing form: flat, unit, apartment, house to options such as bungalows and bedsits.
- Location: inner city, familiar locality, rural, regional, near family, work, interests. There will be different options in different locations, such as remote compared with inner city.
- Size, including considerations arising from who to live with; and/or other space requirements (such as personal space preferences, visitors staying over, hobbies).
- Capacity for ownership, rental or family/ private arrangements.
- Accessibility: inside the home; to the property and any opportunity for links to the wider community including transport.
- Affordability: Individual budget and income.
- Availability – options are rental and purchase. Some people will already be living in their own homes. Market rental may be an option for housing for people with disabilities depending on local availability, accessibility and affordability. Additional rental arrangements may arise through public rental, community housing organisations or other non-government agency or family purchase.

WHAT CAN BE DONE

Aim for support delivered in integrated and non-identifiable housing consistent with the local neighbourhood.

- There are significant advantages when the development of housing is influenced by considerations about all forms of support, including location, design, technology and the roles of various support staff. This principle applies to single housing and to larger scale development.
- Identify who is funding housing and any contribution from NDIS SDA funding. "Innovative" housing solutions can trap people into financial arrangements that will lose money or cause significant conflict for others, if they choose to move on. For example, say three families buy a house to accommodate their children in a shared living arrangement, but the individuals find that they don't get on, even though the parents assumed that they would.
- Avoid creating artificial conditions for housing away from, and different to, the rest of the community.
- Variations to housing design. Variations to group homes are developing. Housing and apartment design within an overall housing complex or neighbourhood, for people with disabilities (e.g. one and two bedroom apartments or a house plus a bungalow on a site rather than a five bedroom group home). These options with rostered 24 hour backup staff are introducing greater possibilities for personal space and individualised living arrangements, with staff rostered to enable responses to each person. These design features suit people with intellectual disabilities who don't require close staff presence and staff can act as backup to people living more independent lives in adjacent and nearby apartments/ flats. There are options for sharing so co-tenants may assist each other.

- Recognise that housing location is the foundation of support. Where someone lives determines how readily friends, family and the community can visit; how readily businesses and public spaces can be utilised; and the cost of transport. Location in a familiar community allowing friends and families to easily remain involved can be traded off against shortfalls in housing availability – especially where staff know the person as a community member. An accessible house, away from friends and families and a familiar community, can create significant social isolation.
- Establish the standard for each housing build in terms of technology, design and modifications, and what will be tailored to each individual.

SUMMER FOUNDATION HUNTER PROJECT, NSW

The Summer Foundation has purchased 10 fully accessible apartments for the Hunter Demonstration Project and one smaller apartment to provide a base for support staff. These apartments are peppered throughout a new five-storey private development of 110 apartments.

The Summer Foundation has worked closely with the developer at the design stage to ensure that all 10 apartments, parking, lifts, common area doors and the building security system will meet the needs of people with significant disability, a number of whom will use larger electric wheelchairs. Technology, design and location are integral to support planning. The apartments have one and two bedrooms.

NEXUS INDEPENDENT LIVING PROGRAM AT QUEENS WALK, HOBART, TASMANIA.

Housing Choices Australia (HCA) manages an ex-public housing property with 54 units across four three-storey blocks. The program uses four out of eight one bedroom accessible ground floor apartments, all other units have two bedrooms. The property is a re-development of a 1960's "old technology" public housing site with a reputation for drugs, violence and anti-social behaviour. The community housing model introduced was transformational, a mix of many residents including refugees, older residents, low income workers etc. Buildings have been upgraded but the basic design is not changed. There are no lifts. But the site offered many advantages such as being close to transport, work, recreation and shops. The innovation has not been in the physical fabric as it uses typical housing fabric, but in the core principle. Both the housing and disability agencies believe in the desire to provide a "transition model". In this case, innovation focuses on the flexibility of staff support at any one time and over time, and in how staff are structured and organised. The initial aim is for tenants to stay 12-18 months with these transition support arrangements and then to move to more independent living.

DESIGN AND TECHNOLOGY AT ABBOTSFORD HOUSING PROJECT

Through careful specification, each Abbotsford apartment emphasised quality household appliances, assistive technology, good design and adaptability to contribute to amenity, convenience, low cost maintenance, security and accessibility. All apartments were designed to maximise consistency with the Livable Housing Australia Platinum level requirements (http://www.livablehousingaustralia.org.au). There were a number of differences in the details of the design of the Abbotsford project apartments.

Apartments were designed to be aesthetically pleasing (i.e. "able to be sold later"), functional, and "accessible but not institutional". This focused the attention of the collaborators on the details of the fittings, finishes and style in each apartment, and the accessibility (doors and pathways) in the common areas within the apartment complex, both inside and outside the building. Adaptability in kitchen and bathroom areas proved critical for optimising personal independence.

Technology was pursued which could:

- Reinforce each tenant's sense of, and capacity for, independence, privacy and personal control (through control of, for example, light, blinds, temperature, door access).
- Reinforce each tenant's confidence and sense of security when they were alone.
- Create reliable communication, including arrangements for emergencies and contingencies, and simultaneously
- Reduce the need for "ever-present" support staff by increasing tenant independence.

The same core technology in each apartment allows each tenant to:

- Alert staff at any time in the event of an emergency or need for urgent backup assistance. Tenants use a range of devices (such as a pendant, wall alert button, tablet, watch or smart phone). In response to an alert, staff can make two-way voice contact with the tenant in their unit via ceiling microphones and speakers located in all major rooms in each unit.
- Via iPad or smart phone, tenants can operate the lighting, blinds and temperature controls in their units and open internal and external doors, including the door to the building to let visitors in.

This home automation technology is a mainstream product, with adaptations to fit the particular needs of the project.

Both the site entry gate and the building entry door are automated to interface with the home automation system. In addition, the lift in the building has been retrofitted to enable a remote control device to be used by any tenant who cannot operate normal lift control buttons.

Specific structural design features in individual units included:

- Highly accessible internal circulation spaces in each apartment with attention to door and corridor width, room lengths, and turning circles.
- Attractive design, similar to neighbouring units, using mainstream rather than disability-specific design and products wherever possible.
- Accessible bathrooms and kitchens with a number of adaptable features that can be tailored to individual requirements.
- Robust wall products to reduce damage from wheelchairs.

Tenants are responsible for supplying their own phone, television and entertainment systems.

TECHNOLOGY FOR INDEPENDENCE AND SAFETY

RIPL housing incorporates the Leviton security and home automation system as the base assistive technology platform. RIPL is now considering smart home technology. It is anticipated that this platform will increase independence and safety for the end user. It enables unobtrusive risk and abnormality detection, along with the ability to learn individual behaviours and patterns so that the technology can prompt end users when required, or alert nominated parties in an emergency. All of this can occur without conscious input.

> People living in these arrangements in their own flats are living quite independent lives – and there is staff backup if emergencies occur. Families are reassured. Families would not have agreed to more separate housing arrangements. (SERVICE PROVIDER)

Recognise that different housing forms suit different people. For example, who is comfortable being in a lift as part of living in an apartment? Is it easy to get in/out of the building and the apartment complex – not just access within the apartment? Who needs open space, quiet, and opportunity away from too many people? Who gets lonely living alone? Who likes to live near friends or family?

- Distinguish between a specific target group for housing relevant during the building and design phase and eligibility requirements for potential residents once the housing is completed. Development of housing involves long time frames and tends not to be planned for specific individuals, but may be planned for specific target groups of people (such as, people who want to be more independent with physical or medical support needs; or who are mobile with a cognitive impairment).

ELIGIBILITY CRITERIA, HUNTER PROJECT, SUMMER FOUNDATION

Consistent with the focus on supporting independence, people considered eligible for the Hunter project needed to be able to demonstrate the following:

- Strong desire to live independently; willingness to take responsibility for achieving this
- Willingness to use the technology provided in order to support and enhance independence
- Ability to live successfully in an apartment development, in close proximity to multiple neighbours
- Ability to understand and fulfil personal responsibilities associated with being a tenant with a Residential Tenancy Agreement (with support as required)
- Suited to and appropriate for the location – either the location supports ongoing connections with family, friends and interests, or it is suited to building a more independent lifestyle
- Willingness to participate actively in the evaluation of the project

Who will apartment and unit living suit?

Living alone in an apartment and unit will suit those people who prefer having their own homes but knowing that people are nearby (though not in the same living space).

"In an apartment/ unit you can have your privacy, can be independent and look after your own space. It's nice to live near other people without having to share your flat with them. It can be useful to have staff nearby without them running your home for you."

Apartment living will suit tenants who:

- Like the idea of being alone but with help or friends nearby
- Like to live close to others while having a space they identify as their own, where they control who enters
- Wish to share with others of their choice

Apartment/ unit living will not suit tenants who:

- Prefer more privacy and want their own garden and outdoor space
- Have particular individual lifestyle preferences not suited to close living, such as playing loud music, having a workshop or studio, having lots of visitors late at night
- Dislike living closely with people (or sharing a lift, outdoor space, corridor)

NEXUS INDEPENDENT LIVING PROGRAM AT QUEENS WALK, HOBART, TASMANIA

With the age-based rollout of the NDIS in Tasmania, this project has focused on young people aged 18-24 years. Nexus Inc approached HCA to explore ways that young people with an intellectual disability could more effectively engage in social housing. The advantage of the shared physical infrastructure is that it allows for some reduction in support, but people still live in their own units with few restrictions and integrated access to everyday social supports. The principal is that young people with a disability can develop skills in the social housing program and later move on to more independent living arrangements. The aim is for tenants to stay 12-18 months with these support arrangements.

Eligibility requirements for Queens Walk project

There are two selection processes for individuals who meet the eligibility criteria: one with Nexus Inc as the support provider, and one with Housing Choices Australia (HCA). Tenants have their own lease with HCA for the apartment so they must be able to afford rent, take on the responsibilities of tenants (such as tidy flats, pass inspections etc.) and conduct themselves in a pro-social way around other tenants. There is a contract between Nexus Inc and each individual for the provision and funding of support.

k Attending to long term changes, needs and cost-effectiveness

People's lives change over time. Long term support costs can be funded efficiently to prevent over-servicing when needs can reduce, as well as when they increase.

The challenge for housing with 24 hour support is not simply the pursuit of innovation in housing or in support. Reflection is needed about why some policy directions haven't progressed from the past. This lack of progression has contributed to the perception that service providers wish to maintain the status quo, and that resistance to innovation is the obstacle to progression.

WHAT CAN BE DONE

Recognise that people with disability and complex needs will experience changing circumstances over time. Their needs can be episodic; change with some increased skills; require more assistance when dealing with planning, problem solving and monitoring; and perhaps require different arrangements for physical support at times and mental health support at others.

- **Look for opportunities to save costs by including innovation in the build, versus retrofitting.** Recognise the time and cost to developers of varying specifications and timelines: housing development specifications are more expensive and difficult to change part-way through the process.

- **Explore ways to establish sustainable long term costs of support.** Data is needed about if, how and when pre-planning, capacity building, and contingency planning are able to reduce support costs over time and provide the lifestyle individuals want. Some support costs are currently not recognised by the NDIS (for example, emergency support is not funded in an individual package). The absence of this backup can mean individuals and families are less likely to try varied housing arrangements rather than shared supported housing which is predictable and known about.

NEXUS INDEPENDENT LIVING PROJECT AT QUEENS WALK, HOBART

Can increasing independence reduce long term support cost?

In this project, limited term 24 hour support focuses around an endpoint: the person moving out or staff withdrawing and thus reducing long term support costs. Already residents are more independent. For example, after six months three of the four tenants are getting their own breakfast; and all four travel independently by bus from the apartment block to the shops. The future prospects for independence are that support coordination continues in addition to 3-4 hours per week of personalised support because facilitators "don't know yet how little support people may need longer term."

In the initial skills assessments on residents moving into the project, many parents were aware of the skills the people had, but reported that at home they rarely used them – either through choice or lack of opportunity. Encouraging residents to display their skills in their own homes was as much about motivation as it was about allowing them to experience the logical consequences of inactivity (e.g. an adverse tenancy inspection report).

ANNECTO – 'LIGHT TOUCH' BACKUP OPTIONS CONTRIBUTING TO 24 HR SUPPORT

- Welfare checks: After hours staff work to individual plans for each resident: using drop in/ phone call checks. Staff have a checklist, and are sensitive to danger signs (e.g. depression, food shortage; responses to weather extremes; preparations when natural disasters threaten). Changes are better targeted through assessment by after hours staff than by more 'present' staff. Clear and consistent data gathered by staff who record scores in different life areas over time such as relationships, time in the community etc. Tenants can reflect on these scores to understand which areas need more focus.
- Staff can escalate situation to case manager.
- The annecto After Hours team is available to many organisations. Emphasis is on problem solving with the resident i.e. not "doing for".
- Assistive technology: Dedicated phone lines when individuals need urgent backup; speaker phones at home for residents to contact staff and vice versa.

Look for opportunities to pool staff support while maintaining individual flexibility, delivery and reasonable response times. Traditional approaches to rostering staff in shared supported accommodation has confounded staff presence and opportunities for pooling of staff for improving cost-effectiveness. Staff teams can be located nearby to the individual's home, as not everyone needs staff in the same room.

- Ensure response to individual is tailored to the individual first, regardless of funding levels and organisational capacity.
- Ensure rostered staff expect they will be working with different people, in different places, and that support intensity may increase or decrease.
- Recognise that any staffing arrangements can have built in rigidity or flexibility. There are examples of flexibility with shared supported accommodation and block funding (e.g. Queens Walk).

24 HOUR SUPPORT WITH CONCIERGE, CARA, WOODVILLE, SA

The project supports seven people in their own units spread across a general residential apartment block of 31 apartments. A dedicated concierge is available 24 hours via call system for the seven people with disability, in addition to a staff member who sleeps in a separate apartment and is available overnight to tenants if needed. Individuals have individually planned support package hours. The dedicated concierge is funded separately by CARA and the tenants do not contribute directly at this stage to the cost of the concierge.

Key learnings:

- Clarify that the concierge apartment is not for residents to congregate in if bored or lonely
- Important that pager equipment for concierge is working correctly
- Staff are not based in the residents' living spaces and this proactively encourages independence

The concierge enables:

- Residents to work on social connections. When residents first moved in the concierge emphasises establishing community connections, navigation, transport and shopping skills.
- Support role includes low level monitoring/ supervision and direct support if needed; and problem solving, working with resident on "how do you think you can solve this?"
- Cost-effective staffing: such as, situations requiring a second staff member to assist with a physical transfer, i.e. don't need a second staff member rostered for minimum time for a 10 minute task.
- Continuity of support: If support staff don't turn up or can't be replaced – concierge will cover shortfall initially until staff arrive. This includes assisting the person to get out of bed, help with some meal preparation, and medications oversight if needed.

Gather data about long term outcomes

- Assess the impact of short term economising when this negates the potential to reduce costs long term (for example, increasing people's capability/ skills or improving technology may be costly initially but costs will often reduce after the establishment stages). Data and experience is needed about the process of "scaling up" individual housing and support arrangements.
- Evaluate outcomes against pre-identified factors, such as support requirements before individuals move in; family support required in the initial stages; how individual is doing at various points in process. Specify frequency of evaluation.
- Be open to new learnings; understand who the evaluative process is for; build in reflective practice around each individual to review implementation; understand that not everything can be anticipated and build a dynamic learning culture between individual, family and providers. Be alert to individualised responses overwhelmed by institutional and government processes which can act against individualisation.
- Research and disseminate knowledge to describe outcomes and encourage others to learn and model from new developments. All contributors have a role with information dissemination: project partners, service providers, government funders and policy groups (especially NDIS, TAC), individuals with disabilities and advocacy groups.

HUNTER PROJECT UNDERTAKING FORMAL RESEARCH ON OUTCOMES FOR TENANTS

Undertaking formal research about tenant outcomes is a central element of this housing demonstration project. The most intensive outcomes evaluation will be undertaken across the first few years of the demonstration project. This research will provide critical insights into factors that contribute to or hinder good tenant outcomes. It will be central to determining the long-term efficacy of a reduced support approach and of the demonstration model itself. Having one support provider across the period of the Hunter project evaluation will enable greater clarity about the impact of the support approach. Having multiple support providers implementing different support philosophies and practices adds many variables and greatly dilutes the value of research findings.

The funding and policy dilemma: Policy directions are emphasising individualised funding. This risks increasing costs for support as many people require backup support but not constant staff presence. For backup support to be financially viable , a provision for individuals and families to contribute to a shared cost for the backup they require is important. It is proving difficult to establish shared funding arrangements – there are examples of housing being ready but not utilised because backup support is required, but cost-effective shared funding arrangements have not been developed. If people get more support than required, or if housing is developed but unoccupied because support arrangements cannot be devised, costs escalate. Some individuals, support providers and housing managers have overcome this by enabling:

- Tenants to move into a flat with a given support provider and tenancy manager, choice for the tenant revolves around monitoring the intent and outcomes from the package of support.
- Individuals contribute a small amount from their package to the cost of backup support.
- Support providers contract staff backup support, costs to backup system are less expensive than senior staff on call.

QUESTIONS FOR REFLECTION AND REVIEW

QUESTIONS FOR REFLECTION AND REVIEW

It takes effort for individuals and organisations to change, to move into the new and unknown. People can be apprehensive of "what may happen" because they are comfortable with "what happens now". An approach which asks individuals to be tenants, neighbours, responsible for bills – with only targeted and as needed assistance – is very challenging for some. For others, change might be much easier than staying where they are.

An approach which asks organisations and staff to be flexible and coordinated with others is also more challenging to implement. Implementation must be dynamic, evolving and adaptable enough to respond to different individuals now and throughout their lives.

Organisations often like to do things the same way. It was found that finance, industrial relations and human resources departments; in addition to support staff, can find flexibility difficult and initially time consuming, as new systematic approaches are required for their operations. The perspectives of unions, employers, and families are important and need consideration.

The following questions focus on issues critical to developing systems to support people with disability being able to choose their own home, without an inevitable assumption of 24 hour physical staff presence.

VALUES AND ASSUMPTIONS

- Is there pressure to maintain the status quo from individuals, families, board and staff?
- Are individuals and families willing to expend the effort, and organisations to try (and to persist with) new ways of thinking and responding?
- Are the key stakeholders committed to the proposed directions?
- Is the organisation committed to empowering individuals and families? How is this evidenced?
- Is there resistance in the organisation to new directions, arising from wanting to do things "the same way"?
- Is there a staff role to develop community links and build family participation?
- When staff operate under individualised funding, is it assumed that they know how to enable, rather than care for, the people with disabilities they are supporting?
- Does the support structure (even if innovative) have built into it an acknowledgement that for people with disability, as for other people in the community, ideas could change about where they want to live, and that aspects of their support could change over time?
- Is there a lack of motivation and/or process in place to review progress against the vision?
- Is it being assumed that implementation will occur automatically without being monitored?
- Is finance the main determinant of success over time with little attention to outcomes for individuals, that is, how people's lives are more like others in the community?

CHOOSING MY OWN HOME

Is the individual's will and preference central to decision-making, including when people can't readily express their views?

- Are the family or staff views dominating decision-making?
- Is support planning for someone in their own home distracted by operational issues arising, and by a failure to return to original goals and vision?
- Is there a good balance between industrial and staff priorities versus how each person wants to live? Do industrial priorities outweigh individual priorities, despite the shared vision and core principles of individuals, families, service providers and their staff, and housing organisations involved?
- Is there the opportunity to think about a range of solutions? Sometimes decision-making is reduced to just "this or that". Time and effort is required to consider multiple variables, how they interact and change and what could be partial and variable contributions to the ultimate solutions.
- Is too little attention being paid to the implications of someone's support needs?
- Is shared supported accommodation being seen as a response to someone's loneliness and lack of social connections, even though other approaches are possible?

PLANNING AND SYSTEM DEVELOPMENT

The core principles and vision for housing options need to be agreed to by everyone involved, documented and kept at the centre of all decision-making, compromises and trade-offs. This creates clarity for organisations and individuals about how the person wants to live and compromise (for example on staff roles, size of housing, numbers of people sharing). Understanding the vision gives meaning to discussions about risk, possibilities, choice and the purpose of support.

Assessment of risk also needs to be in context. If the starting point is risk to the organisation, then individualisation is diminished.

Living in the community in one's own home is challenging: in residential settings like shared supported accommodation or a nursing home, individuals don't have to think about purchasing food or issues such as the power being disconnected.

Some people will always have personal care and support staff-based requirements. Reviewing automatic 24 hour physical staff presence does not have to mean no staff support.

- Has the vision been replaced by discussions about risk and finances?
- Is there disagreement about core principles or about a vision for the housing?
- Does the organisational risk assessment process omit the assessment of risk to the person not having their preferred lifestyle?
- Are people assuming that 24 hour physical staff presence guarantees safety?
- Do safety features support independent living?
- Does risk to the organisation dominate decision-making?

- Do stereotypes about the dependency of people with disabilities and complex needs determine decision-making?
- Do individuals and families believe they are entitled to 24 hour physical staff presence?
- Is consistency and uniformity of process being pursued without assessing individual need? For example, introducing a routine of regular three hourly turning which may not be essential for everyone?

PEOPLE'S LIVES CHANGE OVER TIME: QUESTIONS TO CONSIDER

- Can long term paid support costs be funded through the NDIS?
- Is it assumed that 24 hour physical staff presence will be the most affordable?
- Is it assumed that 24 hour physical staff presence will be required forever and that the model is fixed – that is there will be no change in each individual's personal capability?
- Is it assumed that people's ideas and preferences about where they want to live can change?
- Is motivation built in, and are processes in place to review progress against the vision?
- Is it being assumed that implementation will occur automatically without being monitored?
- Is financial data the main data collected over time, with little attention to outcomes for individuals, i.e. so people can live like everyone else in the community?

CONCLUDING COMMENTS

This Guide is about living, not housing and the content has focused on a simple question: how can people with disabilities be supported to live like everyone else? The guide draws a distinction between "24 hour physical staff presence" and "24 hour support" comprising location, design, modifications, technology; family, friends, community members and staff roles. 24 hour physical staff presence is just one option in an array of support choices. Some people with disabilities and complex needs will be best supported through 24 hour physical staff presence – but an assumption of 24 hour physical staff presence is not the starting point for planning to live like everyone else.

The reader is urged to keep expectations about possibilities open and evolving, and to review and question accompanying implementation processes. Multiple perspectives are represented and implications have been considered for people with disabilities, including those with complex needs ("How do I want to live?"); for families ("Is information available about possibilities?"); for staff support practice ("What is effective staff support practice, what does it look like?"); for research domains ("Are we asking the right questions of researchers?"); and for policy ("What are the overarching policies and what are the trade-offs?").

The information in this Guide has the potential be used to develop many different support arrangements for different individuals with disabilities and complex needs. What all of these people have in common is the goal to live like everyone else.

ANNOTATED BIBLIOGRAPHY

PARAMETERS

A brief annotated snapshot of available research, including academic publications as well reports, papers, guides and the like produced by community and industry bodies.

Organised around the 2 elements (and 11 associated strategies) of housing and support, identified in the Living Like Everyone Else report: Choosing my own home; and Planning and system development.

Excluding literature already reviewed and cited in:

1. Summer Foundation (2016) Living Like Everyone Else
2. Disability Advisory Council Vic Research project (2004) Experiences of inappropriate accommodation support for people with a disability.
3. Summer Foundation 24 Hour Support CICD Project (2016) A Guide to Planning Support for People with Disability and Complex Needs Living in their Own Homes.

CHOOSING MY OWN HOME

Keywords: *Confidence – planning - Expectations – stepping outside disability land – where and how do I want to live? – design – location – community/neighbourhood –support – adaptability*

Implementation strategies:

a. Readying and building capability and confidence of individuals and families

b. Matching housing form and location to each individual's preferences, support needs and budget

c. For each person, complementing location, design, modifications and technology with staff planned and back up support.

d. Preparing each person for their new living arrangements, including transition and the role of family and friends

e. Recognising that new ways of living will require new ways of problem solving and safe guarding people's interests

f. Responding to each person's changing life preferences, priorities and circumstances.

Literature

"Building for Everyone: A Universal Design Approach" http://universaldesign.ie/Built-Environment/Building-for-Everyone/ http://universaldesign.ie/ Accessed 6/12/16.

Provides comprehensive best practice guidance on how to design, build and manage buildings and spaces so that they can be readily accessed and used by everyone, regardless of age, size ability or disability.

Barnes, S., Torrington, J., Darton, R., Holder, J., Lewis, A., McKee, K., Netten, A. and Orrell, A. (2012) 'Does the design of extra-care housing meet the needs of the residents? A focus group study', *Ageing and Society*, 32(7), pp. 1193–1214. doi: 10.1017/S0144686X11000791.

A qualitative study looking at physical design of "extra care" housing in England, through residents' and relatives' views and experience. Two key themes: how the building supports lifestyle and how the design of buildings affect useability. Authors look at how people with psychiatric or cognitive disability can be restricted by the building, resulting in reduced independence and social marginalisation. They advocate for "inclusive, flexible design" responsive to psychological, sensory and cognitive changes that happen as people age and lives change. A review of research undertaken as part of the study includes looking at the impact of living environments on quality of life and choice and control.

Broadhurst, S. and Mansell, J. (2007), Organizational and individual factors associated with breakdown of residential placements for people with intellectual disabilities. *Journal of Intellectual Disability Research,* 51: 293–301. doi:10.1111/j.1365-2788.2006.00876.x

Whilst the focus of this article is on "community placements" rather than housing more generally, it does analyse what's needed in terms of adequate and tailored support for people with challenging behaviours to live more successfully and sustainably in community settings. The study cites research identifying challenging social behaviour as being the main reason that community placements break down, and the central factor in why people with behavioural disabilities are typically the last to move out of institutional settings. The authors recommend that those developing housing and support for people with intellectual disability and behavioural issues ensure the technical competence of the setting (trained staff and professional advice) and the level of support it includes for staff (supervision, training, good leadership and management, and motivated culture).

Dewsbury, Guy; Rouncefield, Mark; Clarke, Karen & Sommerville, Ian (2004) Depending on digital design: extending inclusivity, *Housing Studies*, 19:5, 811-825, DOI: 10.1080/0267303042000249224.

Through the perception of people using technology, this study looks at the effectiveness of the design of smart-home technology as a means of enabling older people and people with a disability to maintain quality of life at home. The research focuses on domestic spaces and values, through observational studies, to gain insight into needs that would lead to more effective, appropriate, user-centred design. It explores the critical interface between technology and architectural design, and how for design to be inclusive it needs to be shaped by the person's real needs and preferences. Discussion covers universal design and the ways in which it can overlook individual needs. It looks at the different ways people use technology and advocates assessment of "system dependability" under the headings of trustworthiness, acceptability, fitness for purpose and adaptability.

Gibson, Barbara E.; Secker, Barbara; Rolfe, Debbie; Wagner, Frank; Parke, Bob; Mistry, Bhavnita "Disability and dignity-enabling home environments" *Social Science & Medicine* 74 (2012) 211e219 http://www.sciencedirect.com.ez.library.latrobe.edu.au/science/article/pii/S0277953611006472 Accessed 15/12/16.

A Canadian study focused on younger adults with a disability, exploring their experiences and views of home environments and how adequate they are. Applying an ethical lens of "social dignity", the authors identify "dignity-enabling" elements of home environments.

Green, D., and Sykes, d. (2007) Balancing rights, risks and protection of adults, in Bigby, C., Fyffe, C. and Ozanne, E. (eds) Planning and support for people with intellectual disabilities. Issues for case managers and other professionals, Sydney: UNSW, Chapter 3.

This chapter draws attention to the 'risk society' as a relatively new concept for service providers and staff and suggests that increasingly day-to-day operations of support staff and service providers are restricted by imperatives to avoid or manage risk. The intangible risks to the quality of life of people with disabilities are often accorded less weight than more tangible and easily measured risks or those associated with staff occupational health and safety. Practitioners and managers need to be aware of the tensions that arise in practice from the broader context in which they work if they are to have any chance of negotiating the impact of these at organisational and individual levels (Bigby, Fyffe and Ozanne, 2007, Page 19)

Heywood, Frances (2004) Understanding needs: a starting point for quality, *Housing Studies*, 19:5, 709-726, DOI: 10.1080/0267303042000249161 http://dx.doi.org/10.1080/0267303042000249161 Accessed 22/12/16.

Surveys current debates about housing quality for disabled people and the ways that understanding of housing need can determine whether adaptation or design work or not. Explores "good quality housing design" through the experience and views of people living in social housing adapted to their needs. Argues that broader "human needs" rather than material needs need to be the determinant of housing design and adaptation – good quality housing (and the process of reaching it) needs to enable dignity, control and play. Specifically it should be shaped by the need to: retain or restore dignity; have values recognised; have relief from pain discomfort and danger; minimise barriers to independence; have some element of choice; be communicated with and given clear information about building design in development; be able to take part in society; have light; and have space to grow, change, have visitors, have children.

Jenkins, P.; Scott, I.; Challen, A. Client Briefing: Eliciting Design Preferences from Building Users with Communication Impairments. *Buildings* 2012, 2, 83-106.

Reports on experience engaging with "building users" with communication difficulties as part of client briefings with architectural designers. Scottish based study involving people with a range of complex needs, predominantly learning difficulties, living in social housing. Engagement was about what people valued in their living environment. The aim was to convey the voice of people, and build awareness amongst design professionals, of their specialised needs and how these impact on design and on built places and spaces. The paper asserts that, in general, end-user engagement in design practice is long-established, but practitioners lack techniques to elicit preferences from people with communication disabilities. The study employs a picture-based communication system to obtain information from end-users with communication impairments. It has fed into a process for designing better briefs for architects and building contractors. The paper details the nature, use and challenges of the communication approach and its potential usefulness for clients and architects.

Kinsella, Peter "Supported Living, the Changing Paradigm: From Control to Freedom" http://www.family-advocacy.com/assets/Uploads/Downloadables/11288-Supported-Living-The-Changing-Paradigm.pdf Accessed 22/12/16.

Discusses the history and knowledge behind the notion of supported living for people with intellectual disability, person-centred approaches, and their foundation in beliefs about "every person [having] the right to lead their own life – determine how they live, who they live with, who provides them with support and how they live their lives". Defines what "supported living" means at a personal level and at a service/systems level. This includes, at service level, keeping the provision of housing and support separate, a culture or partnership and joint innovation/experimentation, ability to creatively work around systems, rules and other blockages, and a belief that change is possible.

Labbé, Delphine; Jutras, Sylvie; Jutras; Dominique (2016) "Housing priorities of persons with a spinal cord injury and their household members", *Disability and Rehabilitation* 38:17, pages 1716-1729.

Study aimed to identify housing priorities for people living with spinal cord injury and their households. Used a new tool (psycho-environmental housing priorities PEHP) to analyse housing needs and preferences. Concludes that while some housing needs were shown to be largely universal, (eg security and social contact) many are not, highlighting the importance of working one person (and one family) at a time in planning and decisions about housing. The study envisages rehabilitation professionals using the tool with families to plan housing modifications.

Milner, Paul & Kelly, Berni (2009) Community participation and inclusion: people with disabilities defining their place, Disability & Society, 24:1, 47-62, DOI: 10.1080/09687590802535410

New Zealand participatory action research project focussing on perceptions of 28 adults with a disability about place and belonging. A critical analysis of what inclusion means. Found that what mattered to people, what was most important to their sense of belonging, was where rather than how they participated, emphasising the importance of environment and place. Participants identified 5 key attributes of place as being important antecedents to a sense of "participatory membership" and belonging: self-determination; social identity; reciprocity and valued contribution; participatory expectations; and psychological safety. The article provides a useful tabulated comparison of "service and personal understandings of meaningful consumer participation", the latter described as "attributes of participation that seed a sense of belonging".

Muenchberger, Heidi; Ehrlich, Carolyn; Kendall, Elizabeth; Vit, Marina "Experience of place for young adults under 65 years with complex disabilities moving into purpose-built residential care" in *Social Science & Medicine*, Volume 75, Issue 12, December 2012, Pages 2151–2159.

Examines first person accounts of the significance of place for young adults (under 65) with complex disabilities moving into purpose built residential care. Participants included staff, family and residents. They reflected on the impact of the physical, care and social environment on their experience of place, and examined what factors promoted a healing environment. Five elements of experience were identified: freedom and self-expression; designing for disability; flexible and responsive care environment; establishing relationships; and defining spaces. Findings pointed to the need to appreciate the importance of place beyond the physical context for people with complex conditions to incorporate essential symbolic and relational concepts of value – "being of value (for family members), having value (for residents)".

The authors' intention is that the research will inform future planning and design of place, and who works and lives in the places that are built. Place-related themes revealed through the research included: Accessible user-friendly spaces; flexible and responsive care environment; establishing and maintaining relationships; defining space; and understanding place as considerably more than the built environment. The paper identifies "emergent design principles" based on participant experiences: healing environment; built environment; natural environment; symbolic environment; and social environment.

Orrell, A; McKee, K; Torrington, J; Barnes, S; Darton, R; Netten, A; and Lewis, A "The relationship between building design and residents' quality of life in extra care housing schemes", *Health & Place,* Volume 21, May 2013, Pages 52–64. http://www.sciencedirect.com.ez.library.latrobe.edu.au/science/article/pii/S1353829212002109 accessed 5/1/17.

UK study focussed on older people's living environments in "extra care housing schemes". Data collected on the connection between building design and quality of life. Building design was measured against 12 user-related domains using a tool developed in the EVOLVE (Evaluation of Older People's Living Environments) Project. These are tabulated and clearly defined, and include things such as "comfort and control", "dignity' and "working care" (extent to which the design provides an environment enabling staff to deliver high level care). Quality of life was assessed around the 4 domains of control, autonomy, self-realisation and pleasure.

The study found significant association between several aspects of building design and quality of life. It also found that the relationship between quality of life and building design varied with the level of independence of the person, so that

designing for the needs of a broad range of older people is problematic. The extra care housing being researched did not support those with higher needs as well as it did those with great independence.

The research produced a building evaluation tool based on evidence gleaned through the study (in this way connected with the research of Barnes et al), and piloted the tool in studying older people in extra care housing. Selected findings included that:

- elements of design related to accessibility, safety and working care were negatively associated with quality of life, while those related to security were positively associated with quality of life.
- building designers need to ensure features related to accessibility, safety and working care need to blend in, not creating an institutional feel, or signifying "old age" and frailty.
- the tool preformed well as a mechanism for evaluation across different types/designs of housing.

Phillips, N. and Rose, J. (2010), "Predicting Placement Breakdown: Individual and Environmental Factors Associated with the Success or Failure of Community Residential Placements for Adults with Intellectual Disabilities". *Journal of Applied Research in Intellectual Disabilities,* 23: 201–213. doi:10.1111/j.1468-3148.2009.00530.x

This study explores factors that are important in maintaining residential placement of people with intellectual disability and challenging behaviours. Predictive factors in the breakdown of placements included individuals being more self-sufficient in community (ability), individuals seen as having more control over their behaviour, and level of staff willingness to provide help and support with behaviour. Relevant organisational factors included low staff resources and energy levels, and poorer physical environment and administrative systems. The paper reviews past research about placement breakdown, intellectual disability and behavioural disability. It concludes with findings indicating that placement breakdown risk is a product of a number of individual and service factors and doesn't increase with the severity of the challenging behaviour. Implications are that there is much greater scope here for prevention and intervention in supporting people to live in the community. For example, the research suggests that the risk of placement breakdown would be reduced by increasing the competence and robustness of support services around the person.

Smith, D. and Macdonald, J. (2015), "Design as a Rehabilitative Tool for People with Acquired Brain Injury: Mapping the Field". *Journal of Interior Design*, 40: 21–38. doi:10.1111/joid.12048

Maps and summarises literature that involves or might inform design of "facilities for people with ABI". Although focus is more on facilities than home or domestic settings, design issues discussed are translatable to both settings. The research recognises that a person lives their life through his or her relationship with the physical environment, and that designers, who have particular perspectives on physical environments, offer alternative ways of seeing and can broaden possibilities for the creation of rehabilitation environments. It looks at the combination of empirical knowledge of health and rehabilitation with creative thinking through design, and how it can expand design capacity and effectiveness in areas such as: sensory quality; designing with colour; designing with light; nature, views and windows; layout; and exits and entries. The authors argue that through particular knowledge, designers can shape social concepts into built forms and spaces, which can then have a positive effect on human experiences and relationships. The review incorporated in the study shows the connection between designed environments and health and wellbeing, and highlights the potential of collaborative and co-design processes between designers and community/tenants. The authors conclude by listing what an environment can enable and facilitate for a person with ABI.

Tamas, D., Glumbic, N., & Golubovic, S. (2016). "Correlation Between Aggressive Behaviour and Stress in People with Intellectual Disability in Relation to the Type of Housing". *The Journal of Special Education and Rehabilitation*, 17(3/4), 46-61.

This research aimed to determine levels of aggressive behaviour found among individuals with intellectual disability (ID) living in different housing conditions, examine levels of stress experienced as a result of housing conditions, and explore relationships between aggressive behaviours and stressful experiences among individuals with ID living in

different housing types. The study revealed a connection between housing types and the levels and forms of aggressive behaviour and stress experienced by individuals. The research reviews past research on the role of environmental factors in expression of behavioural problems among people with ID, and influence of housing conditions on their stress levels. The results of the research showed correlation between various stress factors and aggressive behaviours among people with ID depending on the type of housing they lived in. Supported housing was shown to be the least frustrating environment, users showing lowest levels of aggressive behaviour. Implications for practice include: prevention of exposure to stressors; strengthening stress-coping mechanisms and family relationships; staff education about recognition of stress and causes of behaviour; and provision of stimulating environments with possibility for social exchange and inclusion.

Wiesel, I., Laragy, C., Gendera, S., Fisher, K.R., Jenkinson, S., Hill, T., Finch, K., Shaw, W. and Bridge, C. (2015) *Moving to my home: housing aspirations, transitions and outcomes of people with disability,* AHURI Final Report No.246. Melbourne: Australian Housing and Urban Research Institute. Available from: http://www.ahuri.edu.au/publications/projects/p71040 [6/12/2016].

Provides comprehensive background of housing and disability in Australia. Study undertaken in context of incoming NDIS, and its potential to enable more people to access supports needed to live independently in the community if affordable and suitable housing is available and can be secured. Focussed on people receiving individualised funding pre-NDIS, the study looks at: the expected impact of the roll-out of the NDIS on housing demand; when and how people with a disability secure their preferred housing (barriers to and enablers of access to various tenure types); the "shelter and non-shelter outcomes" for people with disability who move to their preferred home; and policy implications in preparation for the NDIS (new housing supply that's affordable, secure and well-located; tenant-directed design; home-sharing that enables choice and ensures privacy through design; sufficient NDIS support to enable decisions about housing, and to find and maintain it; and programs that build people's capacity to expand social networks).

Wright, C.J., Zeeman, H. & Whitty, J.A. J *Hous and the Built Environ* (2016). doi:10.1007/s10901-016-9517-2 "Design principles in housing for people with complex physical and cognitive disability: towards an integrated framework for practice".

The authors set out to develop a research-based framework for designing and building homes for people with complex disability. Based on review and synthesis of available research, they present a set of design features that are conducive to quality of life and social and psychological wellness of residents. The paper asserts that, for people with a complex disability, housing design and development need to take account of physical, social, natural, symbolic (eg a homey feel, a sense of place, restorative spaces) and care environments when determining design, location, and neighbourhood. The authors base their analysis on an "interactional understanding of the housing context and its influence on individuals' wellness outcomes". They offer a housing design and development framework intended as a practical tool or minimum standard for housing design and development decisions and processes. The paper provides usefully tabulated indicators of housing, location and neighbourhood (eg distance to CBD; noise levels; sense of community; socio-economic status of neighbourhood) and lists research supporting each one.

Zeeman, H., Kendall, E., Whitty, J.A. et al. *BMC Public Health* (2016) 16: 261. doi:10.1186/s12889-016-2936-x "Study protocol: developing a decision system for inclusive housing: applying a systematic, mixed-method quasi-experimental design".

Research focused on identified absence of practice and research about housing preferences of people with complex disabilities, and methodologies for practically and systematically involving people with complex disabilities in design and development of housing. It looks at how the Australian housing market can achieve this whilst also meeting corporate goals. Foundational research, spanning three years, sought to quantify the housing preferences of consumers and carers along with the development priorities of key stakeholders. Research aimed, through the process, to develop and test a tool to guide decisions about inclusive housing – the AHP (Analytical hierarchical process) methodology. This methodology aims to provide a consumer-led decision making process that enables competing and complex

choices, and various stakeholder priorities, to be effectively explored, negotiated and managed. Authors' anticipated results include: developing a tool for integrated decision making that will expedite development of inclusive housing , a tool for use across the public-private divide; integrating traditionally disparate sectors and coming up with a cross-sectoral response; examining the decision priorities of the various stakeholders and, drawing on the perspectives and experiences of young people at risk of entry into nursing homes, enabling the development of a value-based decision process that can underpin policy and practice in this area; and providing stakeholders with an approach for working through choices together, with consumer preferences, affordability and quality all being considered.

Zeeman, H., Wright, C.J. & Hellyer, T. J *Hous and the Built Environ* (2016) 31: 761. doi:10.1007/s10901-016-9499-0 "Developing design guidelines for inclusive housing: a multi-stakeholder approach using a Delphi method".

The project detailed in this paper aimed to bring together a multi-disciplinary design team and develop a set of principles and design features to inform inclusive housing guidelines - a foundation for developing "a more robust understanding of what works in supported housing design". It provides an overview of work to date (and gaps in that work) in the area of people with health and support needs engaging in processes of housing design. The authors talk about an "inclusion paradox", where " people who have the most to gain from housing development (people with complex disabilities) have the least opportunity to contribute to finding solutions, and those who have the most to contribute to new solutions (the private construction and housing sector) are usually the least engaged to do so".

The research looks at unmet needs and gaps in the housing sector, limited design diversity, low housing availability and limited availability of accessible housing and in-home care. It seeks, through a multi-stakeholder approach called the Delphi method, to identify important design features and core principles for supported housing. Analysis draws on consumer perspectives and evidence-based design research, as well as the body of knowledge about healing environments. It looks towards a more inclusive approach to housing where "people with complex disabilities are able to choose their place of belonging that is at an equal or better standard than the general population". The paper includes a review of literature about: the relationship between built environments and quality of life; care, support and building design; and the contribution of evidence-based design.

The authors demonstrate a multi-disciplinary approach to inclusive housing design. They identify viability and investment considerations including: design commitment to shared vs private floor space; efficiencies of care workforce working in the space; adaptability of the building to changing uses and care needs over time; cost efficiencies of materials; and eco-friendly heating/electrical. They point out that there are always trade-offs in choice and preferences amongst stakeholders. Most stakeholders compromise at least 2 of their interests. Multi-disciplinary involvement, however, enriches the breadth of ideas and perspectives in the design mix, leading to better decisions.

APPROACHES TO PLANNING

The following selected publications articulate approaches to planning that share a focus on an individual's capacities and potential and the capacities and potential of their communities – our collective capacity to 'imagine better'.

Literature

Coulson, Stephen (2006) *The big plan: a good life after school* Stephen Coulson and Heather Simmons, Inclusion Press, Canada http://www.inclusion.com/books/bigplanexcerpt.pdf and http://www.inclusionwa.org.au/documents/public/The_Big_Plan.pdf

Kendrick, M J (2010) Three day workshop, course handouts "Addressing the Leadership Challenges of Individual and Agency Transformation: Getting Good Lives 'One Person at a Time'", November 29 - December 1, 2010.

PLAN: Planned Lifetime Advocacy Network, Canada, http://newsite.plan.ca/future-planning/

Sherwin, Jane (2010) "Leadership for social inclusion in the lives of people with disabilities" International Journal of Leadership in Public Services" Volume 6 supplement, pp 84-93, accessed January 2014 via http://www.belongingmatters.org/#!free-resources/c12dz

Online tools and information

The following is a selected list of online tools and information for people with a disability and families about planning and supported decision making.

Advocacy for Inclusion Supported Decision Making app http://www.advocacyforinclusion.org/index.php/resources/supported-decision-making-app Accessed 22/12/16.

David Wetherow "From a Four-Bed Placement to a New Life" http://www.communityworks.info/articles/4bed.htm.

By way of advice to a parent, this article provides a series of questions to guide the exploration of design (rather than 'housing') in order to build a picture of who the person is and what would be wonderful for them, and find a home that is defined by relationship and contribution, not by 'taking care of'. Accessed 22/12/16.

Family Advocacy http://www.family-advocacy.com/assets/Uploads/Downloadables/11075-Learning-to-Listen-The-Key-to-Supported-Living.pdf Accessed 22/12/16.

Several papers and resources for families supporting people to choose and secure the home they want. For example: "Learning to Listen" by Scott Shepard and Cheryl Mayfield

A Place to Call Home, a guide for planning where to live, Pave the Way: Vision to Action Through Planning https://www.pavetheway.org.au/sites/pavetheway.org.au/files/documents/A%20Place%20to%20Call%20Home%20-%202013.pdf Accessed 22/12/16.

A resources for planning future living and what life might be possible. Starting with the concept of home, provides a framework for imagining, planning and decision making.

Peer Connect http://www.peerconnect.org.au/resources/me-and-my-choices/planning/ Accessed 18/12/16.

Picture my Future http://picturemyfuture.com/

The Picture My Future approach has been developed by Deakin University. Researchers worked with people with disability to develop an approach that supports people to talk to planners about what is important to them so that they have meaningful involvement in the planning process. It is picture and photo-based. The site includes online animated training modules, and visual and descriptive guides about talking to people with an intellectual disability, asking questions when exploring goals and making plans, and choosing someone to be a supporter. Accessed 22/12/16.

Ramcharan, P, Leighton, D, Moors, R, Laragy, C, Despott, N & Guven, N 2013, *It's My Choice! Toolkit*, Inclusion Melbourne/RMIT University, Melbourne http://www.inclusion.melbourne/wp-content/uploads/2013/06/Its_My_Choice_Vol2_web.pdf Accessed 22/12/16.

A guide for people with a disability and family, friends and advocates to explore and make choices, lifestyle choices as well as day to day choices.

SYSTEM DEVELOPMENT

Key words: *making it work (trust, relationships, interests, benefits) – agreement – commitment – partnerships – collective effort – collective good – shared values – creativity – problem-solving – person first, organisations second*

Implementation strategies:

g. Promoting leadership, culture and developing capacity within organisations

h. Ensuring commitment by partners and collaborators to a shared vision and core principles

i. Aligning related systems, sectors and community views to vision and core principles

j. Developing housing form which is typical of the community and affordable, accessible and available

k. Attending to long term changes in peoples' lives, needs and cost effectiveness

Literature

Austin, J and Seitanidi, M "Collaborative Value Creation: A Review of Partnering Between Nonprofits and Businesses: Part I. Value Creation Spectrum and Collaboration Stages" *Nonprofit and Voluntary Sector Quarterly* Vol 41, Issue 5, 2012. http://journals.sagepub.com.ez.library.latrobe.edu.au/doi/pdf/10.1177/0899764012450777 Accessed 22/12/16.

> A focused review of nonprofit/business collaboration and literature related to corporate responsibility. Review highlighted complexities and problems in the area of values-creation. Authors start with the premise that "creating value is the central justification for cross sector partnering". Focuses on development of a framework through which to evaluate, better understand and strengthen value co-creation. The framework is intended to provide a means to address the research question: "How can collaboration between businesses and NPOs most effectively co-create significant economic, social, and environmental value for society, organizations, and individuals?" It "enables a deeper understanding of partnerships as multidimensional and multilevel value creation vehicles" (p.74). The authors articulate and build on a collaboration continuum and a value creation spectrum as a way of understanding these processes.

Barroso-Mendez, María Jesús; Galera-Casquet, Clementina; Seitanidi, May; Valero-Amaro, Víctor "Cross-sector social partnership success: A process perspective on the role of relational factors" European management Journal Volume 34, Issue 6, December 2016, Pages 674–685.

> Evaluates the role of shared values, the process of developing these shared values, and the contribution of this process to trust and commitment in relationships between business and non-profit organisations.

Brown, L. David. "Bridge-building for social transformation." *Stanford Social Innovation Review* 13.1 (2015): 34-39. Brown examines partnership work and cooperation across organisational, sectoral and social boundaries, focussing on projects carried out across five countries.

> This article discusses how multi-stakeholder initiatives yield positive impact, and long term systemic change. Through mobilizing energy, such initiatives have potential to resolve complex, intractable, multi-level problems. They enable: change at multiple levels (individual, interpersonal, organisational and inter-organisational); social transformation that connects organisations, sectors and levels of society; and significant and positive shifts in social boundaries, communication patterns and levels of cooperation. Through a process of "multi-stakeholder workshops", relationships are built across system boundaries, a shared sense of purpose is created, and new ways of thinking and working are promoted. Workshops are adapted to fit the local context and local concerns.
>
> Looking at the successes and challenges of those projects that undertake this multi-stakeholder process, Brown identifies five elements associated with social transformation:

- Compelling, locally generated goals (local actors come together to articulate shared purpose & pursue joint action);
- Cross-boundary leadership systems (uses what's called the U process to create cross-boundary leadership systems, providing an "institutional base" for change. Initial coalitions identify, explore perceptions, reflect on assumptions, articulate purpose and commitment, generate new things.
- Generative theories of change (innovation as coming from deep understanding of complex problems, creative insight, setting expectations, keeping participants accountable, learning from deviations and developing new implementation strategies).
- Systems that enable and protect innovation (Differing interests, capacities and values can make working together challenging. "protecting innovations", creating a setting where differences are explored, goals agreed on, analysis shared, and the fledgling project/process is protected from outside interests or premature criticism).
- Investing in institutional change (ensuring longevity even though leaders may come and go. Need "insiders who can adapt outside ideas to fit local realities and legitimize new institutional arrangements".

Bryson, J. M., Crosby, B. C. and Stone, M. M. (2006), The Design and Implementation of Cross-Sector Collaborations: Propositions from the Literature. Public Administration Review, 66: 44–55. doi:10.1111/j.1540-6210.2006.00665.x

The work behind this paper is based on the belief that multiple sectors of democratic society must collaborate to deal effectively and humanely with contemporary challenges. It presents a review of literature on collaboration, and offers an inventory of the conditions affecting formation of collaborations, process, structural and governance components, constrains and contingencies, outcomes and issues of accountability. Cross-sector collaboration is defined as partnerships between government, business, non-profits, philanthropies, communities, or the public as a whole: "the linking or sharing of information, resources, activities and capabilities by organizations in two or more sectors to achieve jointly an outcome that could not be achieved by organizations in one sector separately". The authors provide a useful diagrammatic framework for understanding cross-sector collaboration. They emphasise the complexity of such collaborations, and that "they are difficult to sustain because so much must be in place and work well for them to succeed". "Leadership" is identified as the most challenging factor. Leadership needs to happen at multiple levels and successful leadership is necessary for the creation of public value.

Whilst acknowledging the enormous complexity of such collaborations, the paper does offer propositions related to collaboration outcomes and success. It highlights 3 critical components of cross-sector collaboration:

- Appreciation of uniqueness and differential strengths and weaknesses of governments, non profits, businesses and communities.
- Ongoing process dimensions, including leadership in the broadest sense.
- The dynamic nature of collaborative investment.

The paper asserts that the two research approaches to analysing collaborations, one drawing on network theory (focused on structural variables), the other on collective action theory (focussed on process), need to be brought together in future research in order to truly understand the complexity of cross-sector collaboration.

Fyffe, C., Bigby, C., Douglas, J., and Miller, C. (2014), Quality Systems and Outcomes Measurement project
http://dcsi.sa.gov.au/services/disability-sa/disability-sa-publications/quality-systems-and-outcomes-measurement-project

Disability SA established the Quality Systems and Outcomes Measurement Project in December 2013 in response to the question: How can individuals, families and funders know that disability support services are effective in achieving outcomes?

The project has produced a Service Effectiveness Framework (the framework). The framework uses tailored organisational effectiveness indicators to measure and monitor the performance of disability service providers in providing support that makes a difference in people's lives.

This unifying framework enables:

- Individuals and families: to have additional information to compare between, or reflect on, the performance of providers in areas of importance to them, as well as information gained from their informal networks and personal preferences.
- Providers: to review and monitor their service delivery, which provides a basis for supervising direct support practice and reporting about service delivery performance to the people they support and to their Board and Chief Executive Officer.
- Funders and external reviewers: to review and critique the service delivery outcomes of providers consistent with regulations, standards or other accountability requirements.

The framework is derived from four core individual outcome domains. The service effectiveness indicators (the indicators) reflect how well each provider responds to the people being supported, given their service model/s, business model and program logic. These indicators can be used by organisations to identify and measure service outcomes within their organisation and by individuals and families to guide their own enquiries and observations of organisation.

Implementation will not follow a uniform path – but depends on each provider developing measures of their effectiveness in making a difference in the lives of people that they support.

Imrie, Rob Disability, embodiment and the meaning of the home Housing Studies Vol. 19 , Iss. 5,2004 http://www.tandfonline.com/doi/full/10.1080/0267303042000249189?src=recsys Accessed 22/12/16.

Looks at explorations of the meaning of 'home', and housing studies in general, and how these often omit considerations of the body and impairment and its interaction with domestic space. The paper explores and advocates for the idea that a person's feelings about a home, and their experiences of it, are inextricably linked to "their corporeality or the organic matter and material of the body". Therefore, the quality of domestic life and of housing has to be understood with reference to the body and conceptions of corporeality. The authors explore what literature says about the disconnection between design of dwellings and needs of people with mobility impairments. In extreme situations design can prevent self-management or exacerbate conditions. That is, experiences of home of people with a disability are often at odds with ideal conceptions of home as haven, place of privacy, security, independence and control. Design conceptions have in part failed to conceive of impairment, illness or disease as part of domestic environments: "The impaired body is rarely a subject of comment or analysis" in housing studies and debates about the meaning of home. The paper goes on to explore : the "embodiment of the home"; disability, domestic design and home environment; and impairment and destabilizing the meaning of home.

Murphy, M; Perrot, F; and Rivera-Santos, M "New perspectives on learning and innovation in cross-sector collaborations" *Journal of Business Research* Volume 65, Issue 12, December 2012, Pages 1700–1709.

Focusses on learning and innovation and how this takes place in cross-sector alliances. Examines concept of absorptive capacity (an important concept in research on learning and innovation in partnerships in the corporate sector), looks at its relevance to cross-sector alliances, and presents a more applicable concept of relational capacity in the context of social innovation in alliances between profit and not for profit organisations. The relational capacity framework, one that responds better to differences in the type of partners and their goals, aims to aid understanding of inter-partner learning and innovation in such partnerships. It also enables insight into co-creation and co-innovation in "markets characterised by poverty" – that is, areas of development and change where disadvantage is a significant factor.

Sakarya, Sema; Bodur, Muzaffer; Yildirim-Öktem, Özlem; Selekler-Göksen, Nisan "Social alliances: Business and social enterprise collaboration for social transformation" *Journal of Business Research* Volume 65, Issue 12, December 2012, Pages 1710–1720.

Drawing on case studies, the paper reports on research exploring the question of "Why and with what consequences do business and social enterprises establish alliances?". Discusses patterns across the studies projects in setting and prioritising of objectives for the collaboration, resources provision by partners, the intended breadth and impact of collaborative work, and how results are measured.

Seitanidi, M. May, and James E. Austin. Creating Value in Nonprofit-Business Collaborations: New Thinking and Practice, edited by M. May Seitanidi, and James E. Austin, John Wiley & Sons, Incorporated, 2014. ProQuest Ebook Central, http://ebookcentral.proquest.com/lib/latrobe/detail.action?docID=1632619.

"... we are witnessing fundamental shifts in ways society and business and nonprofit managers are thinking about value. The concept of economic value creation has never been more hotly debated. From viewing value as hierarchical, with economic value at the top, we are moving toward equal priority for social and environmental value. From a single value associated with a particular sector, that is economic value from businesses and social value from nonprofits, we are moving toward the concept of multiple value production from each sector. From the dominant logic of value coming through transactional exchanges, we are moving toward recognising the greater value that can emanate from fused partnering relationships. The spotlight that used to shine on sole creation of value now shines on co-creation of value. The most productive pathway to progress is through strategic alliances across sectors" (p.3).

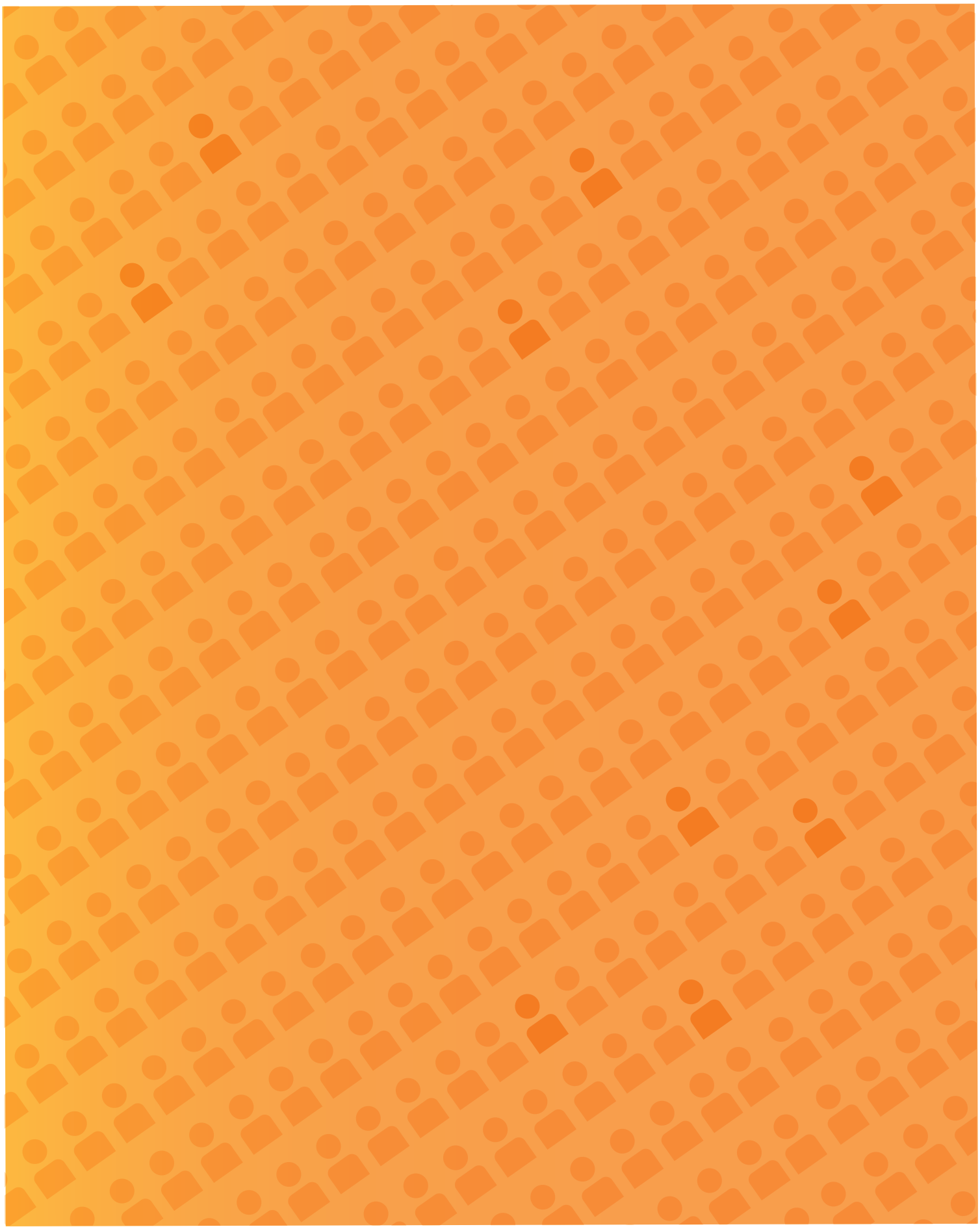
Publication describes the CVC Framework, a new way of viewing and analysing value and its co-creation, then elaborates on each of the five interconnected components of the framework: The collaborative value creation spectrum; Collaborative value mindset; Collaboration stages; Collaboration processes; and Collaboration outcome.

Wright, C., Muenchberger, H., & Whitty, J. (2015). The choice agenda in the Australian supported housing context: A timely reflection. *Disability & Society,* 30(6), 834-848.

Explores housing sector developments in Australia over the last three decades for people with a disability. Critiques key actions of housing and disability sectors, and finds a disconnection between housing choice policy and practice. Looks at the bias of livable housing design guidelines towards the functional (physical accessibility) rather than paying attention to the broader social, psychological and behavioural impacts of place. Proposes an approach to supportive housing design and development based on understanding of consumer preferences and priorities and conducive to "biopsychosocial health". Advocates for consumers to be at the centre of approaches to innovative housing design, driving the process, and that consumer priorities and preferences underpin design and development, and inform market decisions about viability and value.

Yang, C. F., & Sung, T. J. (2016). Service design for social innovation through participatory action research. *International Journal of Design*, 10(1), 21-36.

Looks at the need for a more effective in-practice approach to social innovation where a diversity of stakeholders and ecological systems are involved. Challenges include: value-creation in an environment where perspectives and backgrounds diverge; sustaining involvement of stakeholders long-term; and building a mechanism to consistently prompt and support value co-creation and change. The study aims to identify activities and design tools that facilitate effective "multi-disciplinary ideation".



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