



Summer Foundation Senate Inquiry National Disability Strategy 2017 Submission

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INTRODUCTION

About the Summer Foundation

The Summer Foundation, established in 2006, works to change human service policies and practices related to young people (18-64 years old) living in, or at risk of, entering Residential Aged Care (RAC) facilities.

OUR VISION is that young people with disability and complex support needs will have inherent value as members of our society, with access to services and housing that supports their health and wellbeing.

OUR MISSION is to stop young people from being forced to live in aged care because there is nowhere else for them.

Young people in aged care in Australia

According to recent Senate Estimates there were 6225 young people in Residential Aged Care (RAC) (Parliament of Australia, Senate Community Affairs Committee, March 2, 2017). Young people with disability living in RAC are one of the most marginalised and isolated groups of people in our society. Fifty three per cent of young people in RAC receive a visit from a friend less than once per year and 82% seldom or never visit their friends (Winkler, Sloan, Callaway, 2007). They generally lead impoverished lives, characterised by loneliness and boredom. They are effectively excluded from society with 45% seldom or never participating in leisure activities in the community (Winkler, Sloan, Callaway, 2007). Kate shares her story in the hope that it stops other young people entering nursing homes and to advocate for better housing options for people living with disability. You can view her digital story [here](#)

Kate was studying to be a kindergarten teacher when she was first diagnosed with Multiple Sclerosis. The diagnosis came as a huge shock and initially she lived in a state of denial. Kate completed her studies and began working as a Kindergarten teacher. She realised the importance of housing options for people with disability ten years later when she became acutely unwell. After a three and a half month stay in hospital, Kate was presented with only one option – life in a nursing home. She was 31, highly educated and determined to make things work if given the opportunity, but she had no one to advocate on her behalf. She lived in the nursing home with people 50 years her senior. Many of the residents had dementia. Not surprisingly she lost confidence and started to lose hope.

“My grandparents never even went to a nursing home. There were no trees, no open space, no colour in the nursing home I then saw everything in black and white. I felt like I was being punished for being a drain on the health system. I spent 15 months there. I couldn’t have stayed much longer.”

Australia's human rights obligations

While young people are still living in Residential Aged Care, Australia will fail to meet its obligations as a signatory to the United Nations Convention on the Rights of Persons with Disabilities (CRPD). Article 19 of the United Nations CRPD says that all people with a disability have a right to live in the community. The convention stipulates that people with a disability should have the “opportunity to choose their residence and where and with whom they live on an equal basis with others, and not be obliged to live in particular living arrangements” 9, p. 13 (United Nations Convention on the Rights of Persons with Disabilities, 2007). This convention also states that people with disability should have a “range of in-home, residential and other community support services including personal assistance...to support living and inclusion in the community, and to prevent isolation or segregation from the community”.

Australia's National Disability Strategy and the current inquiry

Australia's National Disability Strategy 2010-2020 provides a ten-year national policy framework for improving life for Australians with disability, their families and carers (Parliament of Australia. Social Service Portfolio, May, 2012). It represents a commitment by all levels of government, to address the challenges faced by people with disability, and in doing so, should stop young people being forced to live in aged care. In this strategy, Australia has committed to a range of outcomes including:

- People with disability to live in accessible and well designed communities with opportunities for full inclusion in social, economic, sporting and cultural life.
- People with disability, their families and carers to have access to a range of supports to assist them to live independently and actively engage in their communities.

We understand that the current inquiry of the Senate Community Affairs References Committee is focused on barriers and solutions to build inclusive and accessible communities. Our submission will address the issue that poses the most significant contribution to forcing young people to live in nursing homes: the planning, design, and regulation of housing.

This submission brings together expertise from our Ambassador Program and Tell Your Story program. The case studies and examples outlined are real people who have had their stories deidentified, unless they were featured in our digital stories where participants have provided their consent to have their stories publicly available on YouTube.

Our Ambassador program provides us with insights that are only possible through our ambassadors' first-hand experience of living in a nursing home, or being at risk of entering RAC. Our Ambassadors work in a variety of ways to advocate for young people with disability who are at risk of entering aged care.

The Tell Your Story Program enables young people with disability who have a personal connection to the issue of young people living in nursing homes to capture their story in a way that can be shared with the broader community. These stories demonstrate the determination of young people to make a difference in the lives of others. Many of these digital stories are available [here](#) and some of these have been linked in our current submission.

THE UNMET NEED FOR AFFORDABLE AND ACCESSIBLE HOUSING IN AUSTRALIA

There is a chronic shortage of well-located, affordable housing for people with disability, particularly for those with high and complex needs, and those who need accessible and adaptable housing design. There is a critical need for new housing options that are close to shops, services and public transport, both for ease of access but also because a disproportionate number of people with disability are on low incomes. But such well-located housing is often unaffordable or not designed for people with disability and mobility impairments (Tually & Beer, 2010).

People with complex and high-level physical disabilities are forced to live in nursing homes because they have limited access to necessary support and limited suitable housing options. The introduction of the NDIS will provide the support needed to live independently and for some it will also provide funding through Specialist Disability Accommodation (SDA) payments, to meet the cost of accessible housing. However, Australia's current housing market will not come close to meeting the demand for such housing unless Governments take action to stimulate supply. At recent Senate Estimates hearings in March 2017 it was reported that hardly any SDA payments have been made and this reflects the lack of SDA housing options in the community (Parliament of Australia, Senate Community Affairs Committee, March 2, 2017).

Peter's story shows how NDIS recipients are stuck in aged care because of the lack of availability of accessible and affordable housing:

Peter who has a neurological condition, registered as a NDIS participant in late 2016. Since then he has been able to secure 50 hours of physical therapy per year, but without a home environment where he can utilise all the new skills he learns, it is unlikely the benefits can be built on in any meaningful way. The process with his planner for the NDIS has not been smooth either. In fact, he believes the planner had little training or experience, and was ill equipped to understand his complex health needs.

Having a secure home environment where he can express himself and build a life is paramount for his emotional and physical health. Life in a nursing home is making a bad situation far worse. He is ready and willing to take on the challenge of a more independent life but the longer he continues to have everything done for him in the nursing home, the quicker he will lose the vital skills he needs to pursue a quality life.

The life changing impact of access to accessible and affordable housing is demonstrated through David's story, where timely access enabled him to be diverted from entering a nursing home:

In November 2015, David acquired a brain injury that would dramatically and permanently change the direction of his life and that of his family. Devoted and persistent advocacy from his wife, combined with fortunate timing has prevented this man from falling through the cracks and ending up in a nursing home. He lived in an NDIS trial site at the time of his accident and while he was receiving inpatient rehabilitation, a rare supported housing opportunity emerged. The team supporting his

rehabilitation worked with the housing provider, support service provider and the NDIS to implement a transition plan. The advocacy required to co-ordinate his move to a new supported home was extensive, and largely driven by his wife. Such a great outcome is rare, and aside from the heavy-duty advocacy required to achieve this, a pathway to a new permanent home from hospital is exactly how it should be in an ideal system. His wife reflects, *“It’s such a relief, its such a lovely lovely outcome for all of us...I know it would have been hard for our children to come and visit David in a nursing home, that was never going to be OK.”*

The barriers to accessible and affordable housing for people with disabilities

People with disability experience multiple challenges gaining access to appropriate and affordable housing (Beer & Faulkner, 2009). The income levels for people living with disability are generally lower than community averages. People with disability often incur additional day-to-day living expenses as a result of their disability. There are also additional costs when purchasing home modifications. If the person with disability needs any significant modification it can effectively exclude them from the private rental market.

There are limited opportunities for people with disability to participate in the mainstream housing market because of their low rates of employment and therefore limited purchasing power (Beer & Faulkner, 2009). This group often lacks the capital to establish a deposit and the income to service a mortgage. Rental housing is also often inaccessible to people with disability, both because of the high cost of renting privately and the physical characteristics of the housing stock (Tually & Beer, 2010). Central to including people with disability in the mainstream of society is providing a stable living environment (both housing and support) and moving away from a crisis response to addressing housing, services, and support needs (Tually & Beer, 2010).

The Productivity Commission’s report on Disability Care and Support (Productivity Commission, 2011) identified an overall lack of housing options for people with disability. This shortage is particularly severe for those with profound disability and complex needs who require supported and accessible housing. For this group, there are limited models and significant shortfalls in supply, with options for those requiring near 24-hour support and/or monitoring usually limited to nursing homes, living with parents, or living in group homes (also called “shared supported accommodation”). This predominant group living model limits choice in where people live, with whom they live, and how they live.

For the past 20 years, the group home has been the dominant disability housing model for people with more complex support needs. In this model people live with four or more people with limited privacy. While group homes may work for some people with disability, they do not work for everyone. Research and consultation with young people in nursing homes (or at risk of entry to nursing homes) have strongly indicated the desire for a wider range of living options than those which have traditionally been available.

A VISION FOR ACCESSIBLE AND AFFORDABLE HOUSING

More contemporary models of housing and support are needed that support an individual's ability to have greater choice and control over how they live. Most existing models of housing and support for people with significant disability do not work well for people with families and most are not well integrated within mainstream housing. People with disabilities want to decide where and with whom they live as do all other members of our society.

A coordinated response is needed across sectors

Many people with high and complex support needs who require access to 24-hour support and/or monitoring are not on public housing waiting lists because of the multitude of sectors that need to work together to meet their complex housing and support needs (Winkler, Reynolds, Klein, & McLeod, 2015). Improved planning and co-ordination across government services is an essential part of the process to align available and suitable housing with individualised disability support funding, funding for equipment and ongoing rehabilitation.

Accessibility must be embedded into Australia's national housing strategy

Provision of housing for people with disability should be viewed as a mainstream housing issue. The housing needs of people with disability should be an integrated part of national and state urban and housing planning strategies. These strategies need to recognise that many people with significant disabilities are on low incomes and need access to secure affordable rental housing. However, there are also likely to be some people with disability who have access to some financial resources that would enable them to pursue partial or full ownership options.

The NDIS is a huge and exciting reform that has the potential to transform the lives of people with disability in Australia. However, the impact of the NDIS on the social inclusion of people with disability in Australia will be limited by the dearth of accessible and affordable housing. Unless the whole community begins to act now, we may find that when the scheme is fully implemented, young people in nursing homes and tens of thousands of other people with disability will have funding for support – but no new housing options.

We need a range of options including models that enable people to live with their partner and/or children. Many (46%) young people in RAC are in partner relationships and 27% are parents of school-aged children (Winkler, Sloan & Callaway, 2007). Tanya is a mother of 3 and her story illustrates that Australia desperately needs to create more housing that is both accessible, affordable and family friendly. Rather than continuing to build segregated specialist housing, the housing needs of people with disability and their families need to be incorporated into mainstream housing strategy. With such a strategy, families can stay together when one member acquires or happens to be born with a disability.

Tania's family is her world. Tania and her husband Leonard became friends when they were three years old and have been married for over 25 years. Tania, Leonard and their daughter Faith were enjoying life, and had taken time away from their normal routine for

a camping trip around Australia when their lives changed forever. During the trip Tania had a stroke that left her with complex disabilities, including loss of her mobility.

Tania is a proud member of the Awabakal People. In the early days following her lengthy stay in hospital, support provided by her mob helped to keep her out of a nursing home. Eventually however, Leonard had no choice but to re-admit Tania to hospital and from there she was discharged to a nursing home.

Once funding became available, Leonard started the long process of looking for a rental home for the family. Leonard says he looked at around 38 houses. They finally settled on a home, but it was inaccessible. When they moved in Tania was fearful of using her wheelchair in the rental property. If the chair damaged the property they could be evicted, and to her this would mean returning to a nursing home. Tania chose to have her bed in the dining room. She said, *“I still wanted to be together and have that closeness. Everyone sort of gravitates toward the fridge so I can still have a yarn with them, and keep in touch.”*

When Tania found out about a new model of housing for people with high care needs, she put in an application and was successful. After a long housing journey, Tania has now moved into an accessible apartment with her family. Tania says she feels, *“Relief really, because now I know that I never have to go back to a nursing home. It is a feeling of being safe.”*

Essential elements of housing for young people in nursing homes

Stable, quality housing is essential to bringing young people in nursing homes back into mainstream society. The following aspects are considered essential to future housing and support options for young people with disabilities (Taleporos, Craig, Brown, McNamara & Forbes, 2013)

Location: proximity to shops, transport and other services is critical to enabling people with disability to easily get out of their home and have a meaningful life. Being located near family and friends and living in a familiar neighbourhood is also essential for maintaining relationships and community inclusion.

Range of housing options: young people in nursing homes are a diverse group; they need a range of options to meet their needs, preferences and family circumstances.

Physical design: accessible design that is adaptable to the diverse needs of this group is essential in order to maximise independence and community inclusion, and reduce life-time care costs.

Technology: advances in technology provide the potential for increasing independence and autonomy, and decreasing reliance on paid supports. Mainstream smart-home and communications technology can provide cost effective solutions that enhance independence,

allow people with disability to alert others when they need assistance, and remotely monitor a person's safety and wellbeing, if required.

Individualised and flexible supports: supports should assist people to develop as much independence as possible, build people's capability to live more independently, and encourage and facilitate building a life that is meaningful and satisfying. Support approaches need to be tailored to the individual's needs and be flexible enough to respond to changing needs, abilities and preferences. Many people with disability, and their families, have learned to live with very low expectations. Support providers often need to focus on building capacity and enabling people to have bigger dreams and a meaningful life.

Community belonging: housing and support options should maximise opportunities to build and maintain relationships with spouse, family, friends and acquaintances and build new connections.

Choice of housemates and the option to live on your own or with family/friends: Another key factor in relation to appropriate housing for people with disabilities relates to having choice over who you live with. This is something which the predominant model of disability housing does not currently provide. This is illustrated in Molly's story:

When a routine surgery did not go to plan, Molly suffered a stroke. She was confined to a hospital bed for 5 months. Upon discharge from hospital Molly was not in a position to return to her flat and the only option for her was to move into a nursing home that offered some rehabilitation. During her time in the nursing home she was constantly looking for other housing options. Molly felt really unsure about her future and this uncertainty filled her with fear. She says the information provided to her regarding her accommodation options was infrequent and inconsistent.

Molly knew she needed to get out of the nursing home. She was faced with the difficult choice of moving to supported accommodation close to her family, or supported accommodation a great distance from her family but close to a train station that would enable her to continue her studies. Molly chose the latter and now finds herself living with a housemate whose illness leaves her highly emotional and disruptive. The conditions are not conducive to Molly's study, and friends and family find it difficult to visit. Though Molly is grateful to be out of the nursing home, she still doesn't have real choice about where she lives, and who she lives with.

The Summer Foundation housing demonstration projects: A new Australian Standard for accessible housing is needed

The Summer Foundation is taking action by developing new innovative housing and support models to demonstrate new living options for people with high-level physical disabilities to begin addressing the unmet need and to demonstrate design features that can be replicated and improved upon. These projects deliver new models where accessible and adaptable design in conjunction with innovative approaches to support, and the use of assistive technology support people with significant disabilities to live with greater independence. The need to develop new

models emerged from the mismatch between existing design standards and the high and complex needs of our target group.

Michael and Emma's stories highlight the difference that our housing solutions are making to young people who had been living in residential aged care.

Michael was married with four young children when at the age of 38 he had a series of strokes that would change his life forever. Michael's marriage broke down at this time and he spent the following years living with his parents, with his devoted Mum as his full-time carer. Sadly, Michael's father passed away and it was no longer realistic for his ageing mother to care for him by herself. There was no other option available to him but to move into a nursing home at the age of 44. Michael has never felt at home in the nursing home. He has lost his independence, and the ability to make basic decisions and choices for himself. Visiting her son in a nursing home has been heartbreaking and stressful for his elderly mother.

After 6 years in the nursing home, Michael found out about a new model of housing for people with high care needs. With support from his Mum and an advocate Michael applied to be a tenant and was successful. Michael will move in to his own apartment shortly and his Mum is thrilled that this housing option was available for her son. *"If this sort of thing had been available to Michael 6 years ago when they decreed he was high care and couldn't be looked after by me it would have been wonderful, he wouldn't have had to come into an institution,"* she says. Michael is looking forward to moving into the accessible apartment, making his own choices and having his children visit him again.

Emma was diagnosed with Muscular Dystrophy at the age of five. She was living at home with the support of her mother and younger brother, but after her mother's passing, Emma's living situation broke down. She was forced to move into a nursing home in her late thirties where she shared a four-bed room with numerous residents – many of whom had dementia. Emma lived in a nursing home for eight years. Emma lost her privacy and independence, and missed doing everyday things such as cooking, laundry and paying bills. Emma said, *"Independence is important; when you are in a wheelchair you don't have much to start with. When I was at home I did more stuff myself."* Despite her challenging living arrangements, Emma worked tirelessly to complete her HSC in the nursing home. A reminder of what she could achieve with the right tools and access. Several months after successfully completing her HSC, Emma moved into a Summer Foundation Housing Demonstration Project. When asked what independent living will mean to her Emma said, *"Now I have a chance to see what I am capable of."*

From our work developing housing solutions for people with high and complex needs, we have found that while LHA Gold standard will enable more people with disabilities to find accessible and affordable homes and allow all of us to age in place, it is not sufficient to meet the needs of people with complex physical disabilities. In fact, while LHA Platinum level comes closer to meet complex physical support needs, it still is not sufficient.

Development of an appropriate design framework is critical for people with high and complex needs as the design of their home, along with appropriate supports, has a major impact on their ability to live as independently as possible. The ability to access all areas of an individual's home environment such as the garden or the balcony, not just their bedroom, bathroom and the front door is critical to the wellbeing of the occupant.

We recommend the development an appropriate design framework to assist the housing sector in delivering suitable housing for people with high levels of physical disabilities (Nix, 2016). This is particularly important to support people to be able to exercise choices for more independent living made possible through the NDIS. We recommend the development of a carefully developed and articulated Australian Standard specifically for 'Accessible Housing' to fill this gap and provide industry with greater guidance (Nix, 2016).

Above all, an appropriate design framework that delivers well-designed accessible home-like environments integrated into communities has significant potential to reduce long-term care costs and improve people's wellbeing. The potential savings associated with long term care costs need to be taken into consideration when evaluating any initial increases in the construction cost associated with more accessible and adaptable design. A design framework that is appropriate for people with significant disability living more independently in their home will also support 'ageing in place'.

The integration of assistive technology or home automation is another critical design element not referenced in any existing design guideline. Assistive technology can greatly enhance independence and safety. There are also people with a significant disability who are not able to live independently without the use of assistive technology, no matter how accessible the home environment is. There is growing recognition (including by the NDIA) about how assistive technology, including home automation, can change life opportunities for people with significant disabilities. In the development of any new design framework, guidance should be included about key considerations for future cost effective installation of home automation and other technologies.

It is proposed that an appropriate design framework for people with significant disabilities addresses all of the following:

- Incorporation of Universal Design Principles
- Compliance to Platinum level of Liveable Housing Design Guidelines (however this is not enough as a singular compliance standard)
- Creation of home like, rather than institutional environment
- Flexibility and adaptability to suit the different needs of various individual tenants of a property across time

- Provision for integration of assistive technology, where it will assist the occupant's independence
- Durability and low maintenance
- Ability to sell property as an attractive asset on the open market

All of the above components need to be articulated in a carefully considered design brief in order to achieve the desired design objectives (Nix, 2016). A successful design brief is more likely to result when created in collaboration with an access consultant, clinical therapists, an architect and project manager with experience in innovative housing models and takes into account feedback from tenants about what features support them to live with greater independence.

Furthermore, development of such a standard would require significant input and review by people with disabilities who are dependent on effective accessible and adaptable design in order to live with as much independence as they can. This is a particularly important and relevant issue considering the current implementation of the NDIS, commentary regarding proposed review and changes to AS 4299, and the further development of the AS 1428 series of standards relating to access (Nix, 2016).

The potential of an effective SDA market

The NDIS Specialist Disability Accommodation (SDA) framework has enormous potential to provide the necessary housing to enable young people to move out of aged care and into the community. The SDA pricing and payments framework sets a strong foundation for the development of a diverse and robust SDA market. What is also needed is an effective, coherent and outcomes focused national approach to quality and safeguarding. An inconsistent and disjointed approach to quality and safeguarding will hamper the market and reduce client choice and control. We believe an effective quality and safeguarding framework:

- Builds on mainstream regulation and safeguards – People with disability should be adequately protected like all Australians through the Building Code of Australia and state tenancy laws.
- Enables independent community living - Quality and safeguards should outline the minimum design requirements for accessibility based on the goal of maximising independence and enabling social inclusion.
- Maximises the role of technology - The latest technological advances should be maximised to safeguard participants and maximise the independence.
- Fosters innovation and investment - Regulation should be reasonable and necessary for safety while maximising investment in new innovative housing in the community.

- Meets diverse functional and cognitive abilities - quality and safeguards should recognise the diversity of the cohort that will be accessing SDA payments so that housing solutions can be individualised and fit for purpose.
- Clearly defines roles and responsibilities – there will be a range of players responsible for the implementation of SDA including housing providers, support providers, tenancy managers, support coordinators and investors. The obligations and responsibilities with respect to compliance with rules and regulations need to be clearly and appropriately defined and assigned.

STRATEGIES TO INCREASE ACCESS TO MAINSTREAM HOUSING

The need for minimum accessibility standards for new housing

Australia's failure to regulate accessibility in new housing developments has been a major factor in the lack of accessible and affordable housing. In order to create an accessible and inclusive Australian community, it is essential that all new housing is required to have a minimum level of accessibility. We believe that the submission to the current enquiry by the Australian Network for Universal Housing Design (ANUHD) puts forward a strong case for regulation with respect to the accessibility of new housing. The submission shows that the current voluntary approach is resulting in a dismal failure to meet the target set by the National Dialogue in 2011.

We therefore strongly support the recommendations of the Australian Network for Universal Housing Design (ANUHD) for regulatory intervention involving an amendment of the National Construction Code (NCC) to include access features as specified in LHA's Gold level in all new and extensively modified housing. These changes to the NCC will require education and training of the housing sector and the broader community. Initial steps towards the establishment of minimum accessibility standards for new housing occurred at the Building Ministers Forum in April when Ministers agreed to propose to COAG that a national Regulatory Impact Assessment (RIA) be undertaken as soon as possible to consider applying a minimum accessibility standard for private dwellings in Australia.

The Summer Foundation Social Finance Think Tank (Winkler, Reynolds, Klein, & McLeod, 2015) provided an opportunity for people from a range of disciplines to have grounded conversation about increasing the supply of quality and affordable housing for people who are as disadvantaged as young people in nursing homes. The Think Tank grappled with the challenges and identified a number of potential strategies and solutions. Some of these solutions have become government policy following the introduction of SDA payments. Below are some of the other strategies that are yet to be implemented.

Leveraging accessible accommodation through government planning requirements

In exchange for the use of public land, developers of urban renewal sites could be required to provide 5% of apartments for people with disability at cost. These dwellings would be purchased through social finance and managed by a community housing provider.

If it is possible to obtain apartments at cost, this could be a significant saving. The size of the potential savings margin would depend on market conditions in the particular location. Recognising that there is a developer profit margin built into the price of newly constructed units, it may be possible to have this effectively passed on to investors in accessible housing through a lower acquisition cost as a government requirement for certain unit developments. This would result in a higher investment return being available to social investors.

Scope may exist for some sharing of developer profit, in aid of the cause. Many national apartment developers will target returns on their equity of 15-20% per annum. This higher return is required to encourage developers to take on the risk of project delivery, planning approvals, and selling of the units. This target return typically implies a 5-15% pre-tax profit margin on

apartments sold (thus targeting between \$25,000 and \$75,000 profit for every \$500,000 apartment sold) depending on specifics of development timeframe, sources of funding, specific developer hurdles/thresholds, and market conditions.

Tenant or family equity in housing

Some people with disability have assets available and they, like other Australians, wish to be able to have some ownership of their home. Other families are willing and able to put significant funds towards building housing for their family member. More commonly, a family may be able to provide, for instance, \$100,000, and would be keen to do so if it meant more choice and/or better housing. A scheme that caters to these needs will also have the important effect of facilitating the addition of private capital to assist in bridging the gap between the unmet need for accessible housing and the resources available from government.

Current Australian examples of mixed equity

A recent report from the Australian Housing and Urban Research Institute (AHURI) finds that shared home ownership schemes for people with disability bring potential benefits but also expose people to debt risks. The report investigated the most appropriate and beneficial shared home ownership models for people with disability.

Housing Choices Australia (2015) provides an example of a mixed equity program that enables families and people with disability to finance and secure equity in their long-term housing. It is targeted at people with disability who have sufficient assets to be disqualified from government subsidised housing, yet they have difficulty using their own funds because of the challenges of the responsibilities that go with home ownership.

In this case, a house is purchased with funds from the applicant, the Office of Housing, and Housing Choices Australia. Housing Choices Australia retains title and the applicant has secure tenure under a lease, pays rent at Office of Housing rates, and signs a Mixed Equity Partnership Agreement securing their financial interest in the property.

The applicant's investment in the property is in accordance with their initial project contribution. If an applicant wishes to end the agreement in the future and has contributed 30% to the cost of purchase, they will receive 30% of the sale price of the property, less selling costs.

In Western Australia, the Keystart Housing Loan Scheme provides home ownership opportunities for people on low to moderate incomes through loan schemes ("Disability Home Loan, 2015"). The Disability (or Access) Loan product is a shared equity scheme where the state holds up to 40 per cent equity. Between 2009-10 and 2011-12, there were 162 Disability Loans to people with disability, their families or partners. The income limit for a family is \$80,000 per family (Gilchrist & Vanopoulos, 2014).

The New South Wales Government also provides assistance (Government of New South Wales, 2015) for social housing tenants who wish to buy a home. The assistance is not in the form of mixed equity, but enables people in certain circumstances to buy their home from the government with exemption from transfer duty, and in some cases with the assistance of a government rebate.

Special Disability Trusts

Special Disability Trusts (SDT) (Department of Social services, 2015) were established in 2006 as a legal form, as a mechanism for making it more attractive for families to make provision for a family member with a severe disability. The typical scenario whereby a special disability trust adds value is when parents of the person with disability have assets which can be applied for care and accommodation, and where the parents can qualify for a pension by utilising the Centrelink exemption which applies to special disability trusts.

While the concept of the SDT has merit, in practice the strict eligibility criteria and other limitations are such that they have not been widely used. This is the case despite a Senate Inquiry (Senate Community Affairs Committee, 2008) in 2008 and the relaxation of some of the restrictions progressively between 2008 and 2011. There are still significant limitations, potential disadvantages and complexities associated with using SDTs, including that the person with disability cannot invest their own funds and cannot decide who should act as trustee, plus a raft of other matters such as stamp duty, Centrelink gifting rules, and first home owners grants, adding to the perception that the SDT was a good, but ultimately flawed, idea. As at 2012, some 320 SDTs were in existence with total assets around \$30m. Anecdotally, most of these are established via the execution of a will rather than during the parents' lifetime.

The very low take-up can be attributed to the complexity and the limitations imposed by the laws of governing SDT's. People with disability and their families should not have to navigate through a minefield of practical and legal issues; nor should they be prejudiced by the inordinate complexity and disadvantageous application of Centrelink and other rules. The SDT program should be reviewed to reduce red tape. Furthermore, a combination of "off-the-shelf" legal options and subsidised access to practical and legal advice to access and set up a SDT.

Land banks owned by government or not-for-profit organisations

There is a significant amount of land owned by government and churches that is currently under-utilised. Obtaining land free of charge or at a reduced cost would make a significant impact on the model of social finance. For example, where there is currently old public housing stock in good locations, the entire site could be redeveloped with a higher yield and a mix of private and social housing. The sale of the private apartments would effectively fund the social housing, including accessible units for people with disability.

Community Land Trusts

In the USA and UK, land trusts have been established to both benefit disadvantaged groups and to revitalise certain locations. For example, in the USA a not-for-profit organisation owns the land and leases the buildings (usually for 99 years) and places restrictions on how and what price the lease can be transferred. At present in Australia, there is no simple way to separate the ownership of the home from the underlying land without new legislation (Gilchrist & Vanopoulis, 2014 ; Crabtree, 2013).

CONCLUSION

Being forced into aged care is a terrible outcome for young people, their families and friends and for our country. These young people's emotional, physical and mental health all decline while they live in aged care. We need to take action to ensure that the promise of the National Disability Strategy is fulfilled so that people with disabilities can live in accessible and inclusive communities with a home of their own.

Australia desperately needs a long-term strategy to create more housing that is both accessible and affordable. Rather than continuing to build segregated group housing, the housing needs of people with disability need to be incorporated into mainstream housing strategy. For an inclusive Australia, all new private housing should be designed so that people with disabilities can visit friends and family and buy or rent in the mainstream housing market. This will ensure that all new housing is accessible and adaptable to meet the needs of people with disabilities and our ageing population.

Accessible design in all new housing will allow all of us to remain in our own homes for longer as we get older. Giving all people with disability greater access to mainstream housing will enable many people with severe disabilities to move to more independent living and to be included in the community.

We need a national housing strategy that is responsible for increasing the funding, planning, designing and building of accessible private, social and public housing. We also need a range of strategies that bridge the gap between what people with disability can afford to pay for housing and the cost of good quality housing that is well located and designed to maximise independence.

We need to improve accessibility in the mainstream housing market and develop Specialist Disability Accommodation (SDA) that leads to positive outcomes associated with an active and full life in the community. The SDA pricing and payments framework is an excellent policy initiative but we also need an effective national approach to quality and safeguards to provide clarity with respect to the roles and responsibilities of SDA providers.

RECOMMENDATIONS

Recommendation 1: Amend the National Construction Code to require all new housing to be built according to LHA Gold standard

Regulation is essential for the future growth of accessible housing as voluntary standards have failed to create supply of accessible housing. Gold standard in all new dwellings will allow more Australians to age in place and more easily modify their house for greater accessibility should this be required.

Recommendation 2: Develop an appropriate design framework to meet the specific housing needs of people with high levels of physical disability.

The current LHA guidelines and Australian Standards do not meet the needs of people with high physical support needs. Therefore, a new design framework would include what is needed to appropriately inform the housing sector and SDA providers about how to build suitable housing for people with high levels of physical disabilities. This new standard will draw on the learnings from the Summer Foundation housing demonstration projects.

The development of a new Australian Standard for accessible housing would streamline the design process and result in improved outcomes and housing options for people with significant disabilities. The objective of such a standard would be to provide a mixture of design compliance and design guidance leading to highly accessible home environments, which are also adaptable in terms of meeting the changing needs of various occupants with significant disability.

Recommendation 3: Increase investment in accessible and affordable housing and implement policy that will enable more people with disabilities to access housing.

Most people with disabilities and their families are seeking community-based mainstream solutions to their housing needs. Increased investment in accessible and affordable housing is essential and will reduce demand for Specialist Disability Accommodation which is only intended to meet the housing needs of 6% of NDIS participants. Changes to government policy are needed to maximise housing opportunities by:

- Increasing investment in social housing and ensuring that all social housing is built to a minimum gold standard (LHA guidelines)
- Requiring accessible housing to be included in all new housing developments
- Enabling home ownership by people with disabilities through mixed equity
- Removing the red tape governing Special Disability Trusts
- Freeing up government and nonprofit owned land for accessible and affordable housing
- Establish community land trusts to both benefit disadvantaged groups and to achieve urban renewal

Recommendation 4: Support SDA market readiness

In order to encourage the development of the SDA market we recommend that:

- The NDIA prioritise including the Specialist Disability Accommodation payment in the packages of young people in aged care in existing NDIS sites.
- The NDIA, housing providers and financiers should work closely to examine the level of confidence that investors have in developing housing through the NDIS payments framework. Where there is high investment risk (especially in regional and remote areas) governments should develop alternative strategies to reduce risk and encourage investment.
- The government develops an effective national approach to quality and safeguards to provide clarity with respect to the roles and responsibilities of SDA providers.

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