

OUR CONCERNS

- ❖ **LACK OF SUITABLE HOUSING** - AFSA wants suitable housing options to be available for all Australians with autism (ASD), complex presentations and high support needs. Our vision is for options that provide a home that represents an optimal outcome for each individual with autism in this cohort.
- ❖ **LACK OF URGENCY** - AFSA asserts that there is a lack of urgency, will and collaboration by state and federal governments and their agencies around the proper provision of housing options targeting this cohort.
- ❖ **LACK OF ACTION** - Governments need to get the “settings” right – stimulate supply, ensure value for money in construction and development and enter into partnerships with the private sector to provide incentives to investors such as the Build to Rent models.
 - The Commonwealth Budget in October 2022 talked about up to one million new dwellings being provided over five years. How many will be geared or available for people with disabilities, especially the cohort we represent?
 - The re-elected Victorian Government offered a five-year plan to increase social housing. In Victoria substantial waiting lists for social housing for all Victorians in need, including those with disabilities, have ballooned to extremely high levels.

HOUSING NEEDS FOR THOSE WITH AUTISM SPECTRUM DISORDER

A number of reports, conferences and meetings in recent years have discussed and highlighted some of the stresses on the system of providing suitable housing for those in need (refer to the list at the end of this statement). This AFSA statement picks up some of the issues identified in these well-articulated reports that apply specifically to the cohort we represent.

Our statement will highlight that people with autism, complex presentations and high support needs are being forgotten in the planning and delivery of suitable housing. Demand for housing services for these people who currently reside with family caregivers, many of whom are aging, will increase significantly. This issue is particularly critical for those who have not been able to access Specialist Disability Accommodation (SDA).

Our statement also highlights the challenges faced by families and carers to establish and maintain the necessary care and supports required to ensure optimal housing outcomes for the cohort we represent.

AFSA is calling for new and innovative housing solutions to be developed that include:

- A collaborative approach to developing a sustainable supply pipeline of housing stock suitable for the Australians we are the voice for. To be achieved by investment by state and federal governments in partnership with the NDIS, the property industry, superannuation funds and investors.
- A proactive, individualised and accessible planning and implementation process that enables a successful and sustainable move into appropriate supported housing and ongoing care for the family members we represent.

ROLE OF THE NDIA

The future – no certainty, planning is a nightmare

“My autistic son is approaching middle age and I am approaching old age. He resides with me in the family home that is set up to meet his social, sensory, special interest and care needs. He is happy and settled and assisted by carers funded by his NDIS plan. But I fear for his future welfare and well being. What happens if I need aged care? What will happen to my son even if he can stay in the family home? Or worse, if he is required to move elsewhere? No one can satisfactorily answer these and my many other questions. As a family we have no reassurance of ‘a system’ ready to step in. His NDIS plan has no mention of his future needs. What will he qualify for?”

The NDIA/NDIS needs a more pro-active approach to ensure that questions about a participant’s housing – current and future – are properly addressed in the NDIS planning process. The NDIS currently has limited remit regarding planning and funding of participant housing. The NDIA as a lead agency should be collecting and analysing data at a macro level about options and initiatives that support participants’ housing needs at different stages in their lives. Planning, in consultation with other stakeholders including relevant government departments and provider agencies - at state and federal levels – should focus on coordination, supply and management of suitable housing options.

The current situation

Specialist Disability Housing (SDA) is a design feature of the NDIS. SDA is intended to be a housing option for a portion of NDIS participants with complex disability and support needs. The artificial caps or limits on provision of SDA should be discarded and this option must be available for those who need it.

Eligibility criteria for SDA are “onerous” requiring that a NDIS participant has an extreme functional impairment and has high support needs. Extreme functional impairment is described as an extremely reduced functional capacity to undertake one or more of the activities of mobility, self-care and self-management. The participant has a very high need for person to person supports in undertaking daily life even with assistive technology, equipment or home modifications.

The current 'assessment' criteria for SDA eligibility do not satisfactorily capture the impairments specific to autism – communication, social, sensory, executive functioning and need for routine and predictability.

There are five SDA design categories:

- Basic – housing without specialist design features but with a location or other features that cater for the needs of people with disability and assist with the delivery of support services.
- Improved liveability – housing that has been designed to improve “liveability” by incorporating a reasonable level of physical access and enhanced provision for people with sensory, intellectual or cognitive impairment.
- Fully accessible – housing designed to incorporate a high level of physical access provision for people with significant physical impairment.
- Robust – housing designed with a high level of physical access provision and to be very resilient, reducing the likelihood of reactive maintenance and reducing the risk to the participant and the community.
- High physical support – housing designed to incorporate a high level of physical access provision and to be very resilient.

Our Journey – why is it so hard to get the best outcome?

We are working toward achieving a suitable forever home for our autistic son. Initially we obtained quotes and a report from a specialist OT to be submitted to the SDA panel for approval. Success - SDA was approved but put on hold and not included in his NDIS plan because of negotiations about some plan issues and a pending AAT appeal. Mid 2022 and the procedure changes – we will have to go through a reassessment (more costly reports?) by the new Home and Living Options panel. We are still waiting (January 2023) to find out if he qualifies for SDA.

Currently the process for a participant to seek SDA, usually through their nominee (family), is time consuming, costly and can often result in not being offered anything suitable in a location that meets participant needs.

The process needs to be streamlined and wait times reduced.

The SDA pricing mechanism needs to be more responsive to the market. Greater certainty needs to be provided to investors.

The situation in Victoria

Following the “privatisation” of “Group” homes in 2019 the Victorian State Government does not have a direct stake in the provision of disability housing. It does however have a role in regulation and oversight. In reality this role is convoluted and families are experiencing many ‘dead ends’ when seeking support to rectify unacceptable services and decisions.

The state government has a role to support disadvantaged citizens in accessing accommodation and permanent housing through the provision of social housing.

However, limited options currently exist for help and support in finding suitable housing – housing advocacy needs to be expanded. The Victorian Council of Social Services (VCOSS) advocates for better housing for disadvantaged Victorians including those with disabilities and government must continue to support those with disabilities.

End to End model of support including housing

Housing options should be properly integrated with Supported Independent Living (SIL). Housing on its own not enough – properly integrated support services need to be put in place. Service providers need to work together collaboratively to ensure a seamless provision of housing, support and care. Families have a role to play and should be listened to and respected. There should not be an expectation that families take a lead role in management and decision making especially if conflict arises between service providers.

A number of organisations have developed innovative models.

- Ability Dignity Access Management (Les Cope) supports a small number of people with disabilities in a range of housing models.
- Gippsland 's Freedom Housing offers another model of disability care.

OTHER HOUSING OPTIONS BESIDES SDA.

The widely used group home options are not for everyone and are especially unsuited to people with autism and complex presentations. But what are the options?

Shared Ownership options (See AHURI Report)

Shared ownership is an umbrella term for a range of housing models where ownership of a dwelling is divided between a person who lives in the house and a 'non-person' equity partner. Shared ownership models enable consumers to access and sustain home ownership, even though they have lower income and savings than those that are typically required to afford a loan deposit and repayments.

Shared ownership—including shared equity and mixed equity models—is considered to be one of several housing policy options that can help address unmet need in affordable housing and barriers in entry to home ownership for people with disability. More work needs to be commissioned on the potential for expansion of shared ownership in Australia, and the particular models that would be most appropriate and beneficial for people with disability.

However, many people with a disability experience circumstances that could affect their capacity to enter, sustain and benefit from shared ownership, including low incomes, family circumstances and restricted access to SDA. In the case of the cohort we represent, the high support levels required would likely make this option unsuitable. The location of a home also needs to provide safe and convenient access to services, community amenities, family and transport.

Different Approaches and Options

Leaving aside SDA, other models, pilot schemes and ideas need to be considered. For example

- Hybrid models of living and funding housing – family co-location and family investment where chosen resources and NDIS monies are more flexibly available.
- Tax breaks to support entering the housing market eg superannuation early release for families or participants who have superannuation; downsizing concessions for families seeking to support a family member with a disability entering housing.
- “Try before you buy”. People with disabilities should not necessarily be “shoehorned” into a decision that does not leave room for change or adjustment. So, opportunities need to exist for “try before you buy”.
- Long term secure leases of a housing property may be a better option for some rather than committing to an “equity” contribution.
- Village style options for multiple NDIS participants including rural and regional options.

Housing Design For Those With Autism

A report called “Advancing Full Spectrum Housing” set out in excellent detail design features that should be present in new (or re-purposed) housing for people with ASD, especially those with complex needs.

This report highlighted some of the features that should be present in housing for people with ASD to maximise their wellbeing. These features include

- appropriate floor plan strategy, with well-designed living/community rooms, safe and secure kitchen, bedroom, bathrooms and laundry.
- Well-designed lighting and acoustics to take account of sensory issues.
- Best use of technology.
- Outdoor spaces that provide opportunities for recreation, gardening and “downtime”.

Many adults with ASD have health problems like seizures, sleep disorders and other ailments. The core characteristics of many with ASD – routinised behaviour patterns, challenges in social skills and communication can contribute to anxiety. People with ASD need an environment that reduces stress. Well-designed housing can contribute to greater wellbeing.

Re-purposing and re-designing some existing buildings to be more “autism friendly” should also be part of the solution.

Respite Housing is also needed to prepare adults with disabilities for change and to support families and carers.

WHAT NEEDS TO HAPPEN

- ❖ **Understanding the requirements of individuals with autism and complex needs**
- ❖ **Forward thinking, pro-active planning pathways**

- ❖ **Availability of more responsive housing and funding options**
- ❖ **Supports to assist families, carers and nominees in making decisions**
- ❖ **Improved liaison between all stakeholders**

What are we trying to say? This family's experience in 2023, even after 20 years, is an alarming snapshot of failure.

This is my full-time job!

My adult son has very high support needs and has been residing in out of home care for nearly 20 years. It has been a tough journey with many swings and roundabouts to navigate on his behalf. I could write a book – but for now this is what I am currently coordinating on his behalf:

- *Official - acting as Administrator (financial), NDIS Nominee, Medicare Nominee, Centrelink Nominee*
- *NDIS – liaison between his Plan Manager, Support Coordinator, SIL service provider, Community Access service provider*
- *Health - coordinating his medical, dental and specialist health appointments*
- *Financial – monitoring his rent, house savings card (personal expenses), health insurance, residents trust fund, Centrelink reporting, transport costs and banking*
- *Housing – following the break down of several group home placements, after more than two years we are still waiting for his purpose-built unit to be completed and NDIS plans to be finalised so he can finally move into his own space and with his own preferred staffing supports*
- *Emotional – ensuring his welfare and well being in light of staff and service changes, behaviour and medical crises. Poorly trained staff and unacceptable practices by service providers are a constant source of anxiety and behaviour challenges for my son and extreme stress for me.*

In almost all instances his many different services and agencies do not communicate with each other – guess who has to be the conduit? On any one day I might have to balance six or more phone calls and emails to ensure adequate coordination and communication to maintain my son's care and safety.

WHO IS AFSA

The Autism Family Support Association is the collective voice for autistic people with complex and high support needs and their parents, carers and families. We provide fellowship, peer support and information. AFSA actively raises our community's concerns with state and federal government policy makers to achieve better services and outcomes for autistic people and their families. Via our website, social media and meetings AFSA provides links to contemporary evidence-based information and resources, networks and support services. AFSA is managed by a voluntary committee. We represent lived experience and speak on behalf of our autistic family members and their loved ones. We partner with like organisations to share our experiences and information.

Reports used for reference in this statement include:

Housing & Home: National Disability House & Living Conference sponsored by Disability Services Consulting, December 2021

Advancing Full Spectrum Housing - Designing for Adults with ASD, Araluen. Researched by Arizona State University, May 2020

Get Building SDA, March 2019

Shared home ownership by people with disability, Australian Housing and Urban Research Institute (AHURI), 2017



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