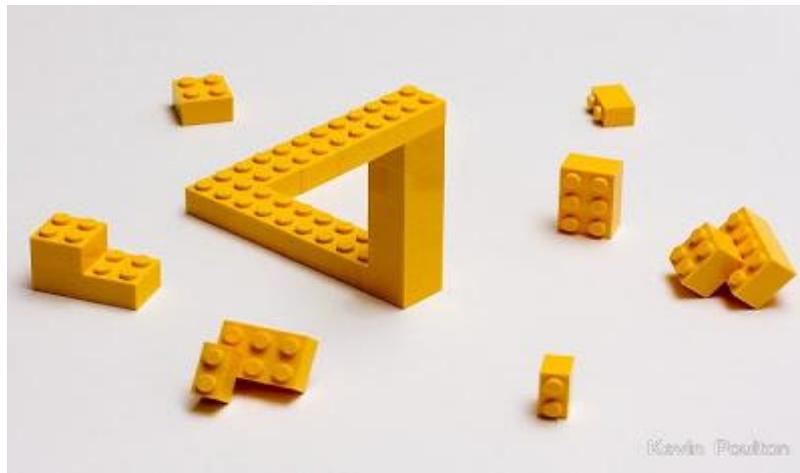


A short discussion paper -

# Insufficient Housing Options for People with Intellectual Disability

‘Trying to fit the pieces together’



Justin Nix



equitable access solutions

SDA | accessible housing | project management

abn 56 781 082 715

Justin Nix  
0417 358 549

[justin@equitableaccess.com.au](mailto:justin@equitableaccess.com.au)

# Contents

1.	Introduction .....	3
2.	Intellectual Disability in Australia .....	3
3.	National Disability Insurance Scheme .....	4
4.	Specialist Disability Accommodation .....	4
5.	Housing Options for 'Non-SDA Participants' .....	5
6.	Housing Discrimination & Human Rights.....	6
7.	The Impact.....	7
8.	Fitting the Pieces Together.....	8

## 1. Introduction

This short discussion paper is not intended to be a comprehensive analysis, and is not intended to offer solutions to a complex issue.

The objective of this brief document is to highlight and raise greater public awareness regarding the issue of a severe lack of appropriate housing and accommodation options for people with intellectual disability, and the consequential impact of ageing parents who continue to provide care for their sons and daughters living with an intellectual disability.

The need for accessible housing for people with Intellectual disability has never been greater, and ironically this large cohort of people now face increased discrimination due to a housing initiative known as the Specialist Disability Accommodation (SDA), designed to increase the supply of accessible housing throughout Australia.

One of the numerous support groups throughout Australia for carers who support their family members with Intellectual disability is Community Lifestyle Accommodation Ltd (CLA). CLA is an outcome driven, not-for-profit organisation of passionate volunteers who seek to work in partnership with Federal, State and Local Governments, non-government providers and the wider community, to deliver increased accommodation options for people with Intellectual Disability (ID).

Rather than write this document on behalf of groups such as CLA, the commitment to write this document comes from my own personal experience as an accessible housing consultant with 28 years' experience working in the public and private housing and disability sector. The views, observations and opinions expressed in this document are from my perspective (unless otherwise quoted sources) as a consultant, working with people with disabilities and their families. I also work with Community Housing Providers, Housing Associations, Support Providers, Compensable 'Disability' Insurance Agencies, Developers, Architects and Builders.

## 2. Intellectual Disability in Australia

### ***Australian Bureau of Statistics -***

Intellectual disability is a term used to describe a reduced ability to understand new or complex information and to learn and apply new skills. The Survey of Disability, Ageing and Carers (SDAC) defines intellectual disability as "difficulty learning or understanding things."

In 2012 there were around 668,100 Australians (2.9%) with intellectual disability, which represents a statistically significant increase from the estimated 565,000 people (2.6%) with intellectual disability in 2009.

Parents are the main providers of care to people with an intellectual disability who need assistance with everyday activities, according to a report released from the Australian Bureau of Statistics (ABS).

Two-thirds of the 660,000 Australians living with an intellectual disability need assistance with everyday activities such as preparing meals, using transport or communicating. Three-quarters of these people are getting help from family, friends and neighbours, with parents the most common source of help.

People with disability are twice as likely to be in the bottom 20% of gross household incomes, and 45% of people with disability live on or below the poverty line.

The recent introduction of the National Disability Insurance Scheme (NDIS) will provide assistance to some people with Intellectual disability who are eligible for the NDIS, however the necessary supports to deliver suitable housing options for people with Intellectual disability are extremely limited.

### 3. National Disability Insurance Scheme

An overarching principle of the National Disability Insurance Scheme (NDIS) is that the scheme will provide Australians under the age of 65 who have a permanent and significant disability with the reasonable and necessary supports they need to enjoy an ordinary life, and to achieve their goals. This may include greater independence, community involvement, employment and improved wellbeing.

As an insurance scheme (not a welfare scheme), the NDIS takes a lifetime approach, investing in people with disability early to improve their outcomes later in life. When the scheme reaches full implementation by 2019, the NDIS will support approximately 460,000 Australians with a disability.

The NDIS recognises that people with disability have the same right as other Australians to determine their best interests and to have choice and control over their lives.

### 4. Specialist Disability Accommodation

Specialist Disability Accommodation (SDA) refers to accommodation for 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.

SDA does not refer to the support services, but the homes in which these are delivered. SDA may include special designs for people with very high needs or may have a location or features that make it feasible to provide complex or costly supports for independent living.

SDA refers only to specialist solutions and is not intended to encompass the housing needs of all people with disability. Historically, SDA has been delivered or sponsored primarily by State and Territory governments. From 1<sup>st</sup> July 2016, the responsibility for funding SDA transitioned to the National Disability Insurance Scheme (NDIS).

However, the issue with SDA is that choice and control around suitable housing options and outcomes are limited to approximately 28,000 of the 460,000 cohort of NDIS eligible participants. Only 6% of NDIS participants will be eligible for Specialist Disability Accommodation (SDA).

#### ***SDA Eligibility for People with Intellectual Disability***

Part 3 of The National Disability Insurance Scheme (Specialist Disability Accommodation) **Rules 2016** outlines the Eligibility for SDA.

The SDA assessment criteria is extremely complex, however broadly speaking, in accordance with the SDA Rules a participant is eligible for SDA if –

- (a) the participant has **extreme functional impairment** and requires an SDA response; or
- (b) the participant has very high support needs most appropriately met by an SDA response.

Part 3.5 of the SDA Rules defines extreme functional impairment if –

- (a) the impairment results in an extremely reduced functional capacity of the participant to undertake one or more of the activities of mobility, self-care or self-management; and
- (b) the participant has a very high need for person to person supports in undertaking the activity even with assistive technology, equipment or home modifications.

Furthermore, when the Disability Reform Council released the ***SDA Pricing and Payments Framework***, the paper described ***Participants who require a specialist built-form*** as follows (acknowledging that the paper does cover broader aspects of policy in respect of SDA) –

- 65. The accommodation needs for some participants are not currently met by the housing market because the functional impairment and impact of their disability requires accommodation with

specific design features or amenity which is not readily supplied through mainstream housing and which involves a significant cost beyond what would be funded as home modifications.

66. These participants need accommodation in properties which are either physically accessible (for example, have ramps and rails) or are designed to minimise the effects of the features of their disability (for example, have a floor plan which facilitates a greater level of independence or building materials and features which minimise sensory stimulation).
67. Participants meeting these criteria are those with high and/or complex needs, including:
  - Those with significant physical limitations; and/or
  - Those who have significant sensory, psychosocial or cognitive impairments.
68. This will include participants with the diagnoses of:
  - Spinal cord injury (SCI)
  - Cerebral Palsy
  - Multiple Sclerosis
  - Stroke
  - **Intellectual disability (ID) with limited mobility**
  - Global developmental delay
  - Acquired Brain Injury (ABI) with limited mobility
  - Autism Spectrum Disorders (ASD)
  - Psychosocial conditions which may have physical sequelae due to long term medication use, such as schizophrenia

A large percentage of people with intellectual disability have extreme functional impairment, however early antidotal evidence has indicated that many people with intellectual disability are not eligible for SDA in their individual plans.

## 5. Housing Options for 'Non-SDA Participants'

Similarly, for all Australians, access to suitable and secure housing in Australia remains largely an issue of affordability. However, people with a disability face a magnified issue of affordable and suitably designed housing.

### **Social Housing**

For people with intellectual disability who are not eligible for SDA, housing options are extremely limited, and fall back to the already stressed Social and Affordable housing system, with huge waiting lists. Much of the social and affordable housing stock is not suitably designed or located in the community to offer reasonable housing options for people with disabilities.

Social housing is expected to support a significant percentage of people with a disability who are not eligible for SDA.

### **NDIA Funded Supports**

Although the NDIA is not responsible for social or affordable housing, the NDIA will fund 'reasonable and necessary' supports, support coordination and capacity building to assist people to live as independently as possible. Ironically, there is no question that ongoing long-term support costs are absolutely intrinsically linked to suitable housing and associated shared support models of care.

Therefore, people with intellectual disability who do not have access to suitable housing will impact long term actuarial scheme costs.

### **Home Modifications**

Alternatively, the NDIA will also fund 'reasonable and necessary' home modifications, although this is of no use to people with intellectual disability who cannot access the private or rental housing market, or to ageing parents who provide large amounts of gratuitous care.

Most people with intellectual disability do not have a home of their own to modify.

### **Institutional Care**

Unfortunately, a 'last resort' housing option for people with Intellectual disability is an institutional type outcome in a Group Home or Residential Aged Care (RAC) / Nursing Home. Currently there are approximately 6,200 young people living in RAC in Australia, and each year in Australia, nearly 300 people under 50 years are admitted to nursing homes. Sadly, 53% of these young people will receive a visit from a friend less than once per year.

Often, Residential Aged Care is a likely eventual pathway for people with Intellectual Disability who live with ageing parents.

## **6. Housing Discrimination & Human Rights**

### **Human Rights**

We often need to remind ourselves of the human rights aspect. Human rights should be equitably applied to every person. Recognising that people with disability are often overlooked in human rights discussions, in 2006 the United Nations adopted the Convention on the Rights of People with Disabilities (the UN Disability Convention). Also, in 2008 Australia committed to protect and respect the rights in the Convention. The UN Disability Convention sets out how human rights and freedoms apply to people with disability. Articles 9 and 28 include the right to:

*"People With Disabilities (PWD) have a human right to live independently and we must remove all barriers that prevent access to suitable housing"*

*"PWD have a human right to an adequate standard of living"*

*"PWD have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement"*

In addition, the International Covenant on Economic, Social and Cultural Rights (ICESCR) Article 11, states *"that every person has the right to an adequate standard of living, which includes the right to adequate housing."*

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.

## SDA Discrimination Issues

Broadly speaking, in my opinion we continue to discriminate against people with disabilities in Australia by not legislating a minimum access provision for all new residential housing. Some great advocacy work is currently being carried out by the Australian Network of Universal Housing Design (ANUHD) to change this.

The introduction of SDA has been a wonderful initiative to provide housing choice and control for people with a disability who are SDA eligible (6% of NDIA participants). One of the unintended consequences of SDA is the extreme focus of 'SDA compliant' accessible housing and SDA potential income. Most housing projects for people with a disability currently being funded or developed by both the for-profit and not-for-profit sectors are aimed towards attracting SDA eligible participants. This focus is effectively dividing the disability community into people who are SDA eligible and people who are not SDA eligible.

In addition, SDA compliance consists of Livable Housing Australia (LHA) Silver or Platinum compliance, with additional 'Plus' requirements applicable to the relevant SDA design category. LHA Silver and Platinum compliance is largely focused on access for wheelchairs users. Therefore, much of the current 'New Build' stock of accessible housing is largely focused on people with high physical support needs, or the 'High Physical Support' SDA category which attracts a higher SDA return for the provider.

People with intellectual disability who require access to accessible housing may be discriminated against by not being offered a tenancy when another potential tenant is SDA eligible and will provide the building owner with a far greater financial return.

It should be acknowledged that there are also some SDA providers who are delivering housing models that utilise SDA income to re-invest and offer other non-SDA eligible participants an affordable tenancy solution.

## 7. The Impact

The impact on people with intellectual disabilities and their ageing parents is a huge social issue. A constant re-occurring theme and very emotional message from many ageing parents is -

*"I'm so worried about what's going to happen to my adult son/daughter when I pass away. Where will they live?"*

The impact of this stress is the deterioration of mental and physical wellbeing of ageing parents who have adult sons/daughters with an intellectual disability. This impact cannot be underestimated, and many of these parents have already provided a lifetime of gratuitous care to their children with high support needs. I have often heard many ageing parents say "I'm at breaking point".

Ageing parents of people with Intellectual Disability deserve the right to retire and enjoy the later stages of their lives knowing that their adult child has the necessary supports that they require to live a life as independently as possible. This includes secure tenancy within suitable long-term housing, not the fear of institutionalised care facilities or residential aged care. Independent living certainly starts with a place to call home.

The other impact of a lack of suitable housing and efficient housing models that integrate (or give consideration to) housing and support is higher long term actuarial costs associated with increased paid care by support workers.

## 8. Fitting the Pieces Together

Suitable responses to address the housing issues for people with intellectual disability are certainly complex, and need to be more openly discussed and debated. There is certainly no 'one size fits all' response, or no single particular housing model that will suit the needs of everyone. Some of the issues and pieces that need to be considered are –

- Expanding the SDA eligible cohort beyond 28,000 people with disability will certainly assist NDIA participants who 'almost' fit the eligibility criteria, however this won't assist the majority of people with intellectual disability who require a long-term housing response.
- A Government or NDIA funded 'Housing Assistance Package' will provide people with Intellectual Disability and their families much needed financial assistance to deliver a suitable outcome. When compared with the SDA framework, a reasonable funding amount to assist people would be minimal in comparison, perhaps less than the 'Basic' Design Category annual amount for Existing Stock SDA. The existing Commonwealth Rental Assistance (CRA) is minimal in terms of assisting with delivering a housing outcome.

Any such Housing Assistance Package could benefit a person with intellectual disability by –

- providing an annual rental subsidy (similar to National Rental Affordability Scheme, NRAS), to encourage the supply of suitable housing (response from the housing sector)
- providing an income to service home ownership debt
- providing a pathway to shared equity home ownership
- supplementing other housing project finance sources
- covering the cost of establishment costs associated with housing projects
- covering the financial cost of ongoing maintenance and typical ongoing ownership costs of 'Owners Corp' type operating expenses associated with innovative, small cluster housing models
- A united response and assistance is also required to enable all groups of ageing parents in the same situation to gain access to tools and resources such as legal advice, housing trust structures, finance opportunities/sources, design advice and access to companies, consultants, designers, developers etc., many providers who have already developed great resources on a philanthropic or pro bono basis for this cohort of people.
- An evidence based evaluation and forecast impact analysis of long term actuarial costs associated with not providing suitable housing for people with intellectual disability, including the impact on their ageing parents.
- A united National based or peak body advocacy and voice to maximise and consolidate efforts to influence and affect policy change.
- The NDIA has committed to continue to work with other agencies and departments with housing responsibilities to stimulate accessible and affordable housing options for people with a disability. More detail and greater transparency is required as to what exactly this work is and how it will deliver increased access to housing for people with a disability who aren't eligible for SDA.

This brief paper seeks to raise a higher level of awareness of the issues associated with a lack of suitable housing options for people with an intellectual disability, as well as the impact on their ageing parents and the broader community.

We cannot pretend to fully understand the extent of the issue, or the impact on individuals and families unless we have walked in the shoes of an ageing parent with an adult child with an intellectual disability.

I hope this document at least promotes much needed discussion and debate. While an in-depth analysis of the issues are required, so to is much needed urgent action to deliver real outcomes and assistance.

A handwritten signature in blue ink, appearing to read 'Justin Nix', with a stylized, cursive script.

Justin Nix

**M:** 0417 358 549 | **E:** [justin@equitableaccess.com.au](mailto:justin@equitableaccess.com.au)