The Australian Disability Dialogue on Housing **Discussion Paper**



About the Australian Disability Dialogue

The Australian Disability Dialogue (the Dialogue) is an initiative of Alliance 20 and Disability Action Network Australia (DANA) to drive engagement, collaboration and discission on approaches to working with people with disability and the delivery and design of services for people with disability.

The four foundational principles of the Dialogue are to:

- **be led by people with disability** and supported by providers, advocates and government, anchored by Australia's obligations under the Convention on the Rights of People with Disability
- create a space outside of government, providers or representative bodies that sets a forward vision, drives innovation and builds consensus around disability policy consistent with a rights-based framework.
- develop a new model of ground-up sector collaboration delivered by people with disability through accessible technology.
- **generate new ideas** by coming at old problems from different angles.



About this Project

The Australian Disability Dialogue on housing is the first project that has been undertaken and this discussion paper is the beginning of this process.

It has been authored by Todd Winther, an academic and NDIS consultant who lives in Supported Disability Accommodation and receives a range of supports through the NDIS.

This Discussion Paper will anchor a series of four sector consultations to be facilitated by disability advocate Elly Demarchelier.

The work is being guided by a Steering Committee comprising of the following members:

- El Gibbs (Disability Advocate Network Australia)
- Jamie Bannister (Inclusion Australia)
- Bronwyn Morkhom (Young People in Nursing Homes: YPINH)
- · Adrian Pisarski (former CEO of Shelter)
- David Swain (Endeavour Foundation)
- Terry Symonds (Yooralla)

The defining question the Dialogue will aim to interrogate emerges from the "What we have heard report" launched by the NDIS Review in June 2023, specifically the question:

"How can housing and living supply responses be encouraged to be more innovative and aligned with participant needs?"

The Design Process

The Australian Disability Dialogue on housing is designed to deliver three key outputs:

- an agreed set of foundational facts to guide the collaboration process
- · an agreed set of foundational principles to guide innovation and reform
- · an agreed set of foundational projects to develop further

To develop these outputs, we have set out the following process:

- **Discussion Paper:** laying out the starting point of the discussion, issuing a series of Design Challenges for participants in the Dialogue.
- Sector specific consults
 - · People with disability and advocates led by DANA
 - Providers led by Alliance 20
 - Allies an invite-only forum of elected representatives, academics and industry partners.
- **All sector consult:** An opportunity for all Dialogue participants to hear from each other, test assumptions and seek common ground on priorities and projects.
- Final Issues Report: A consolidation of Dialogue deliberations and agreed positions.
- Public launch: A national virtual launch event with key decision-makers and broad sector invited



About the Discussion Paper Author: Todd Winther

I currently live in a two-bedroom, two-bathroom, SDA property in Nundah, about 15 minutes north of the Brisbane CBD. My SDA property falls under the High Physical Support (HPS) design category. I live in this apartment with my wife, who has no physical disability. Summer Housing built the property, and we moved in when construction was completed in August 2020. My wife and I have been married for five years, together for eight.

My core funding enables me to access around 7 hours per day of support through my NDIS plan. However, I also access SIL funding of approximately \$140,000 per year. This SIL funding operates under what is known as the Concierge model, where a service provider is funded across the tenants of 10 high physical support apartments, who all combine their SIL funding.

The provider utilises this funding for emergency on-call response mechanisms for support that any of the tenants require outside of their core support hours. Generally, these residents have minimal contact, unless a prior friendship has been developed. For example, I know four tenants in my building, but I have no idea who the other six are, or the apartments they live in.

This was the first time I got to choose where I lived, and I had the consumer power to determine the best options for me. Consequently, my apartment is ideally suited for me, both regarding my support needs as an NDIS participant, and as a person with unique preferences.



About the Lead Facilitator: Elly Desmarchelier

I'm a 30-year-old disabled woman who lives with my partner and two rambunctious dogs. I'm a renter - always have been. Finding a rental property that is affordable and meets my disability needs is almost impossible. This makes the insecurity of renting anxiety inducing.

If my lease isn't renewed, the thought of having to find a place to live is terrifying. The lack of accessible housing means I live in a house that is inaccessible and unsafe. There are stairs I can't climb by myself and a shower I can't get into standing. It makes each day that little bit harder.

I have an NDIS plan and would like to access NDIS housing supports, but there doesn't seem to be the type of housing available that would accommodate somebody with a family. It's my dream to live in a house with my family where I can move around independently.





Context of the Australian Disability Dialogue on housing:

Disability lies within a broader Housing Ecosystem

The housing system is broken – it has turned a human right into an economic hierarchy.

The current housing system increases inequality and exclusion for all.

For those who can access the system it builds long-term economic security.

For those who are locked out, it creates economic inequality.

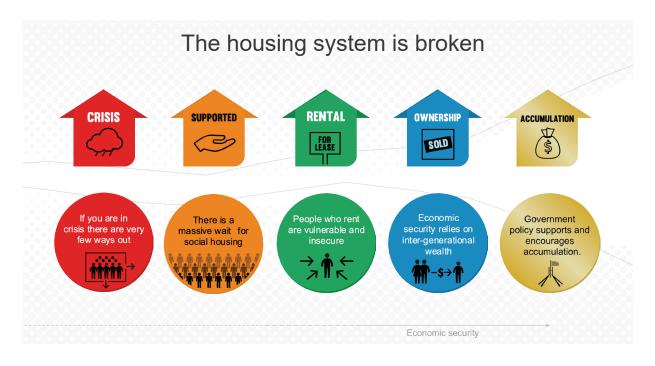
People with disability experience this most profoundly - the barriers to the community are higher than those who do not have an impairment, and the solutions are too often about separation rather than inclusion.

The experience of outsiders can help us better understand how the current system affects everyone - how it could work a whole lot better.

It starts with understanding how housing operates in Australia:

- if you are in crisis there are very few ways out
- · there is a massive wait for social housing if you can access it
- · if you have a disability, the NDIS is the 'oasis in the desert'
- people who rent are vulnerable and insecure
- · the only way to build economic security is to have access to inter-generational wealth.
- but once you are in, your wealth can grow fast
- government policy supports and encourages investment and accumulation.

For more detail on the housing ecosystem go to Appendix 1.





Experience:

Access to the NDIS defines the way people with disability live

For people with disability there are two parallel universes - those who are inside the NDIS and those who are not.

Neither is perfect - but having access to the NDIS (if you can get it) is significantly better because the supports outside are almost non-existent.

- If you don't have NDIS funding, getting the right support is almost impossible.
- Relatively few people inside the NDIS receive purpose-built accommodation or Supported Disability Accommodation (SDA). In fact, only 6% of those who use NDIS funding live in SDA.
- Others receive help to make their home accessible and to live independently. They might receive this through Supported Independent Living (SIL), Independent Living Options (ILO), and access to workers providing a range of supports defined by the person's NDIS Plan.

Within the NDIS though there are significant issues with the ongoing support of people with disability:

- How can the legacy model of group housing, which can be a modular version of institutional care, be transformed into a system that offers real choice and control?
- How can plans and programs be designed that build the agency and independence of the person with disability, and be delivered by a well-paid skilled workforce?
- How can we reconcile the individual expectations of people with disability with the commercial imperative to deliver sustainable supports?
- What does 'support within the community' really mean? Is it possible that a system designed to increase choice lead to market outcomes that leave people more isolated and alone?

For more detail on the disability home and living ecosystem go to Appendix 2.

People with disability live within this broken system Outside Inside the NDIS the NDIS 592k Purpose 1 built (SDA) Comm. Living Rent supports Disability (ILO) Home support Supports (SIL)



Key Issues:

Why is NDIS housing growing so fast?

In short, because the NDIS is meeting its intended goal - more people with disability are getting support by the government and can exercise their power to purchase the services they need. This is great news. According to the NDIA, the number of people with housing and living supports has doubled in the last four years. This has created a huge opportunity for investment in housing for people with disability, with innovative living models.

What are the theories for cost increases?

There is a time lag between people receiving their NDIS support and new homes being approved, financed and built. There is a logjam of people who should have access to housing waiting for scarce supply, which is pushing the prices up. Additionally, without thorough examination and investigation the free market approach to supports has attracted a range of new businesses creating their own levels of demand at inflated prices. What is required is effective long-term planning and considerable policy change over a generation, not just in the political cycle in the life of one Government.

Why is 'Choice and Control' so important?

This term comes from the original Productivity Commission Report in 2012, which made the original case for the NDIS. It was designed to address the lack of agency people with disability had over their lives, and remake the system entirely. People in group homes have had very little control over what happens to them. 'Choice and control' is therefore seen as a key vehicle to greater self-sufficiency and agency. It shifts the systemic focus from the rationing of scarce services to the development of bespoke services that are desired by scheme participants.

What happened to the Insurance Model?

The Insurance model was the economic justification for the Scheme, and it has largely been abandoned. The lack of investment in education, employment, transport and other government services and infrastructure has meant that many NDIS participants have received the support they might need now, but not the support to build their own autonomy. This is a particular issue for people with intellectual disability and those who have barriers to communication, where the investment in supporting decision-making can reap long term benefits for both the individual and the scheme. Rather than a transformative social insurance model, the NDIS is now seen as a very expensive welfare Scheme; the opposite of its initial intention.

What does 'Reasonable and Necessary' really mean?

Planners use the "Reasonable and Necessary" test as required in Section 34 of the *National Disability Insurance Scheme Act* 2013, but interpretation of this section's meaning can vary wildly. "Reasonable and Necessary" can determine criteria to address how resources are allocated. It does not stipulate how much of these resources are given and what or how the person with disability can use them to achieve their goals. The phrase is so broad though that it does not provide real guidance for participants about how to advocate for their own autonomy, or the limits of what constitutes "Reasonable and Necessary". How is it, therefore, possible to determine whether it is "Reasonable and Necessary for a person with a disability to request for approval where and how they wish to live?"

For more on the current challenges the NDIS faces go to Appendix 3.



Design Principles

The 4 C's

If we are going to imagine a better system of housing and support for people with disability, we need to start with an agreed set of design principles. If we agree on these principles we have a way of evaluating whether ideas are worth trialling or not.







Choice:

The NDIS is predicated on the idea of 'choice and control' consistent with the rights embedded in Article 19 of the UN Convention on the Rights of People with Disabilities (UNCRPD). This has been expressed through giving people who receive NDIS funding the right to choose how they spend their support funding and which providers can utilise it in an open marketplace. However, some people, especially those with intellectual disability, are not given the tools to exercise this choice. There are also limits to choice and control, as we all aspire to things we cannot achieve, so what are the parameters to this foundational right?



Change:

The housing and service models that currently dominate the system are part of a transition from institutional State control that did not give people choice, with providers contracted to service these untenable models.

How do we support innovation so we can test and rapidly implement new models that provide genuine choice and control? How do we support incumbent service providers to become change agents who are genuine partners with the people they exist to serve?

How do we support people with disability and families to know that different options are even possible?



Community:

A person's disability has been defined by their exclusion from the broader community. The barriers we create collectively not only make life harder for people with disability, they deprive communities of access to these natural innovators. Thinking about housing for people with disability as part of the broader housing – and living challenges – we all face, opens up new possibilities and benefits.



Cost-Benefit:

Innovations need to be created around measurable evaluation. While the NDIS has a focus of 'cost pressure', we need to build models that recognise the costs and benefits of better integrated living models for people with disability. These need to include cost transfer to other government services (health, justice, welfare and inputs (employment, development etc).



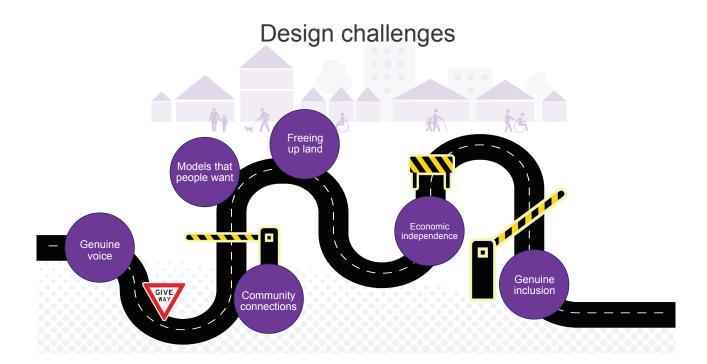
Design Challenges

Each of the specialist collaborative groups will be asked to consider two design challenges which will help us imagine a better, more inclusive housing ecosystem.

The framing of Design Challenges as 'How Might We' is a conscious call for participants to be curious and collaborative, rather than to jump to solutions.

Starting with a broad exploration of the defining problem and anchored in our agreed design principles, we fast-track the path for real inquiry and innovation.

The aim of each challenge is to present an actionable idea to pilot, test and implement over the coming 12 months.





People with Disability Consult:

How Might We better design housing solutions that reflect the life cycle of people with disability:



The brief:

The housing journey for people with disabilities - like all people - is dynamic. From school to maturity, work to partnering, to active ageing and the inevitable decline critical moments define our futures. How can we ensure that the way that people with disability live supports these stages of life, from providing the opportunity for developing skills, building companionship and supporting people, if they choose, into relationships?

What are the supports that will open enhance this journey and enhance their choice and control over their lives?

What are the barriers people currently face on embarking on their life journey?

Points of Inspiration

- What choices are available at key moments of independence such as transitioning form education to employment?
- What services and supports would help people with disability develop committed relationships?
- How can people have real choices between independent and communal living arrangements – including having the chance to experience both?





People with Disability Consult:

How Might We embed the voice of people with disability (especially people with intellectual disability) into the design of services and systems.



Q2

The brief:

What does real 'choice and control' mean for people with significant and complex support needs.

How does NDIS planning ensure people are given the space and support to make choices about how and where they want to live?

Critically, how do we support informal supporters to give people with disabilities agency in their own future?

This is not a process to deliver a pre-determined outcome, but a framework for opening up the options people have — and giving them the tools to exercise it.

Points of Inspiration

- How can people with disability provide peer support for each other about how to exercise choice and control?
- How can supported decision-making be improved and further supported in a marketplace of services?
- What role do informal supporters play in giving access to real opportunities to thrive, but also to take risks, and to fail?



Providers Consult:

How Might We find new ways of funding the right sort of housing choices for people with disability?



Q1

The brief:

The market has yet to figure out what models do and do not work because it is still in a largely experimental phase. It will then take decades to ascertain how to create the most popular and successful models at scale.

What are the models that need to be tested now, that could be rapidly scaled to meet the housing needs of people with disability?

Both providers and people with disability are just beginning to explore what support models can work for them, what the limits of these models are, and how these models can fit within and outside the NDIS. Some are creating models to build mixed facilities, where the workforce can afford to live near the people with disability they support.

Points of inspiration:

- How do we better align the supply of services with the demand for services?
- Are there alternate funding models such as social impact bonds that could underwrite new models of housing?
- What are the best service delivery models for people to choose from a range of accommodation and support options?
- How do we break the barriers between people who receive support, and people who have to capacity to provide support to others?

Case study:

MIND Australia's Haven model provides a safe and secure home for people with significant psychosocial disabilities. It features up to 16 private apartments. There is also significant indoor and outdoor shared living space for social interaction, skill building and space for on-site staff. This model aims to:

- Provide stable and affordable high-quality residences for people with significant psychosocial disability.
- · Encourage independence to manage daily activities to improve quality of life
- Increase recovery from mental ill-health
- Reduce hospitalisations and reliance on area mental health services.
- Increase social inclusion and reconnection with family.



Providers Consult:

How Might We create pathways for people with disability to get a financial stake in where they live to build their long-term economic independence.





The brief:

The 'Great Australian Dream' is living in a home of one's own, with the possibility of one day owning it.

The reality for people with disability is that people with disability are over-represented in crisis housing, public and supported housing.

Ensuring people with disability have choice and control was the introductory barrier to address a lack of participation in the marketplace.

The next step is to integrate people with disability into a capital market where they can express economic choice and control to increase personal autonomy.

Points of Inspiration:

- Could shared equity models be developed where people's accommodation supports help them purchase a stake in their property?
- Could new developments offer people with disability an equity stake at the inception of a project that could become a growing asset?
- Could development frameworks actively encourage this?



Allies Consult:

How Might We design housing and support models that drive genuine inclusion of people with disability in the broader community?



The Brief

One of the unintended consequences of the NDIS is that disability supports are delivered 'outside' the mainstream society, particularly for people with more acute needs.

The transformation of disability support into a marketplace has turned people with disability into economic units, and broken much of the social capital that existed prior to the NDIS.

A better designed marked could build new veins of social connections that deliver broader community benefit by better integrating disability housing and supports in a community setting.

This would allow us to imagine integrated community models that situate disability support in ecosystems that also provide affordable housing for key workers and social housing.

Points of Inspiration:

- What can we learn from lead tenant models where people provide supports for a housemate or neighbour with support needs?
- Can we extend integrated developments that cluster disability housing, with social and affordable properties. Achieve and Inclusive Housing Australia have secured approval to build a mixed facility in Casino, Northern NSW that will integrate disability, social and respite homes?
- What can we learn from broader community of care models such as the <u>Virtual Village Movement</u>. A virtual village for the elderly where they can design their support models across a given area, (Washington DC, Maryland and Virginia, USA) and many of the members are also volunteers?





Allies Consult:

How Might We use resources we already have to improve housing for everyone by freeing up land



Q2

The brief:

State Governments currently have large portfolios of legacy housing in the form of group homes and social housing, often salt and peppered in affluent areas, close to infrastructure, transport and jobs.

In NSW alone, it is estimated there are billions of dollars in assets held in government hands that sit on the government's balance sheet, appreciating with the property market year on year.

Critically, this housing stock is no longer fit for purpose in terms of condition and design.

Is there an opportunity to uplift and improve the stock of housing for people with disability, while at the same time opening up more social and affordable housing by redeveloping ageing assets through a standalone Government-Owned Corporation?

By providing access to this land the government would significantly ease the cost pressure on building more – and more appropriate - affordable, supported housing.

Points of Inspiration:

- What would be the broader benefits of unlocking existing land?
- What mixed model housing could be piloted to test the benefits of redeveloping existing stock?

The Housing Ecosystem



	Numbers of people	Government support (services/concessions)	
Homelessness	122,494 (ABS 2021)	National Homelessness and Housing Strategy; Increase in NHFIC funding, social housing accelerator, Housing Future fund, National Housing Accord, Home Guarantee Scheme	
Rough	47,895 (ABS 2021)	Specialist homeless services, crisis accomodation	
Couch/car	17,700 (ABS 2021)	N/A	
Crisis	As above	Specialist homeless services, crisis accomodation	
Supported			
Boarding Homes	22,137 (ABS, 2021	Largely unregulated Funded by DSP	
Disability	7,900 (AIHW, 2022)	NDIS, SDA, increase in NHFIC funding, social housing accelerator, Housing Future fund, National Housing Accord, Home Guarantee Scheme	
Social and public	790,000 people, 437,000 dwellings	Increase in NHFIC funding, social housing accelerator, Housing Future fund, National Housing Accord, Home Guarantee Scheme	
Nursing homes	407,000 (DoAC 2022)	Department of Aged Care funding packages 4,830 people with disability in aged care (AIHW June 2022)	
Rental		See below	
Market	6,510,000 (ABS 2021)	State Government Tenancy programs	
Assisted	1.5 million (ABS 2021)	Commonwealth Rental Assistance, \$5 billion in 2021-2022	
Mortgages	6 million (ABS 2021)	Home Guarantee Scheme	
Bank of mum and dad	N/A	N/A	
Work/Saving	N/A	Home Guarantee Scheme, First Home Buyers	
Ownership	22 million.	Tax incentives, 1.25 million negatively gear (ATO)	
investment	2.2 million	Tax incentives	
Accumulation	1 million	Tax incentives	

The Disability Ecosystem



	Numbers of people	Government support (services/concessions)	Key policy challenges
NDIS	The total number of Scheme participants at 31 March 2023 was 592,059. (NDIA Q3 Report 2022-23)	31,394m total Scheme expenditure (NDIA Q3 Report 2022-23)	Financial sustainability whilst ensuring people with disabilities maintain and harness choice and control
SDA	The number of active participants with SDA supports 22,680, as at 31 March 2023 (NDIA Q3 Report 2022-23)	SDA Costs NDIA \$353 million as at 31 March 2023. (NDIA Q3 Report 2022-23)	Oversupply of SDA for those with high physical support needs, undersupply of other housing types, return on investment, limited opportunities in thin markets
SIL	31,368 participants are receiving active SIL supports as at 31 March 2023. (NDIA Q3 Report 2022-23)	\$3,082m as at 31 March 2023. (NDIA Q3 Report 2022-23)	Limits choice and control. How do you supply support services in bulk while maintain uniqueness for individuals? Financial sustainability
ILO	N/A	NDIS Funding, NDIA preference this funding because it is capped. Home and Living policy out late in 2023 will state this outright.	New model; restricted funding, does it really enhance choice and control? The Higher the support needs, the less suitable it becomes, therefore it doesn't solve the SIL question as purported.
Private rental	4.2 million (AIHW)	Home Guarantee Scheme.	
Private home (eg parents)	278,000 dependants with disability live in a home that is owned by someone in their income unit (AIHW 2022)	Increase in NHFIC funding, social housing accelerator, Housing Future fund, National Housing Accord, Home Guarantee Scheme	What happens when circumstances of owners change? Enhancing choice and control essential, including through SDM. Royal Commission due in October report crucial here
Non-NDIS	3,100 people with disability need short-term or emergency accommodation .	65%, or 4800 sought specialist homelessness services (AIHW, 2022)	Numbers of people with disability, which are homeless have steadily increased in the past decade, including in length Many of these people are not eligible for NDIS
Precarious	5% of homeless are people with disability around 7,300., 2400 33% of total figure receive NDIS funding. (AIHW, 2022)	National Homelessness and Housing Strategy; Increase in NHFIC funding, social housing accelerator, Housing Future fund, National Housing Accord, Home Guarantee Scheme	Limited supply of housing for people on DSP, cost of housing nationwide escalating for all in community, those with disability hit hardest. With NRAS concluding in 2025, what's next?
DSP	(51) rentals were affordable for single people on the Disability Support Pension (DSP). The number of rentals affordable on Jobseeker was 0 percent (7) for a single person, (Anglicare Report March 2022)	As above	Limited supply of housing for people on DSP, cost of housing nationwide escalating for all in community, those with disability hit hardest. With NRAS concluding in 2025, what's next?
Social	32% of income units receiving Commonwealth Rent Assistance (CRA) (at 30 June 2020) who had at least one member receiving the Disability Support Pension (DSP) are in rental stress	Increase in NHFIC funding, social housing accelerator, Housing Future fund, National Housing Accord, Home Guarantee Scheme	Not enough policy answers for those with disabilities in social housing. Measures in policy column only recently announced

Where Are We Now? By Todd Winther



The National Disability Insurance Scheme (NDIS) was established under two bedrock principles:

- First, "choice and control" for people with disability so that they can take an active role in the services and the supports they use, away from government-controlled intervention. The intent was for "people with disabilities", or service users, to be able to design the support they required and how it is delivered.
- Secondly, the NDIS was intended to individualise services so that the power derived from this "choice
 and control" enabled the person with disability to have access to the same services and the exact
 delivery of support no matter their location in the country, their level of impairment, their economic
 status, their ability to advocate, or the level of involvement that they had in their local community.

In the decade since the NDIS was first implemented, applying these principles to the home and living framework has faced significant challenges. Most of these difficulties are systemic ones that are beyond the disability sector's control and reflect the complexities of housing and its associated infrastructure markets more generally.

Building accessible accommodation takes time to develop and includes many labour and time-intensive steps. In this regard, developing a suitable home and living policy has been challenging for the NDIA (the Agency). It is perhaps a reason why the Agency has yet to develop a written policy framework in its first decade, even though that process began in 2020 and has been extensively consulted on. The Home and Living policy was due for release in March 2023, but has not yet been made public.

While recognising the successes of the NDIS and home and living solutions it created, this paper outlines that more work needs to be done to centre people with disabilities' priorities to make more choices and control about where, and with who, they live. An innovative home and living policy should also recognise the crucial role of the providers delivering these services.

This paper does not suggest that the entire home and living framework is not working. Instead, it intends to find solutions that can be facilitated by the NDIA, offered by providers, can enact and support people with disabilities choice and control.



What is SDA?

Specialist Disability Accommodation (SDA) is purpose-built housing for NDIS people with disabilities with severe functional or physical disabilities. Participants must have defined activity limitations, need to utilise assistive technologies, require complex home modifications, and need capacity-building support. Around 6 per cent of NDIS people with disabilities are eligible for SDA funding.

There are four types of SDA housing categories that each have their own design standards.

- **Robust housing** includes physical access provisions and is designed with more structural integrity, thereby reducing the need for constant physical maintenance while minimising safety risks to people with disabilities and the community. Robust housing design is ideal for people with disabilities who require extensive behavioural support and can incorporate breakout rooms and safe spaces.
- **Improved Liveability** is best utilised to increase physical access and independence for sensory, intellectual or cognitive impairments. This design category may include extra additions to the house to ensure the participant's safety and facilitate their increased independence. For example, modifications may include increasing access to the kitchen to contribute to meal preparation.
- **Fully Accessible** incorporates design features for people with disabilities with higher-level physical support needs to increase their physical independence and reduce the need for support services. For example, design features may include significant bathroom modifications so that the participant can shower themselves independently or transfer on and off the toilet.
- High Physical Support incorporates significant access provisions for people who have severe physical disabilities and require extensive one to one support. A common feature of these properties is reinforcements placed in the ceiling to install a hoist, which allows the participant to be transferred from their bed to a wheelchair or a shower chair with the assistance of a support worker.

The number of active people with disabilities with SDA supports has increased by 18 per cent annually over the last three years, reaching 22,680 as at 31 March 2023. The average plan budgets for SDA supports have also increased by around 12 per cent per annum, leading to an increase in total SDA supports in participant plans by around 31 per cent per annum, from \$156 million as at 31 March 2020 to \$353 million as at 31 March 2023.

Total SDA payments have increased by 36 per cent annually over the last three years, from \$90 million to \$228 million. The average SDA payments per participant have also increased, by 14 per cent per annum. (Q3 Report 2023-2024, pg 98)



What is SIL?

Supported Independent Living (SIL) is a category of support that covers the supervision of activities of daily living (ADLs) in a shared living environment. The NDIA defines a shared living environment as accommodation that is shared between two and seven people. However, this strict definition is currently a recommendation, not a rule, as small groups of this number are not always a feasible option in practice.

Before the introduction of the NDIS, supported accommodation was traditionally provided in large group environments, where the majority of people with disabilities lived with others who shared similar diagnoses. Many of these residents still live in these environments while waiting for other accommodation to be built or to become available. In some cases, other residents have exercised their choice and control by stating that they wish to continue to live in a large group environment.

Residents can each use a separate SIL provider within the same living environment if they wish, although this is not common.

The National Disability Insurance Agency (NDIA) suggests that the funding for housing, particularly Specialist Disability Accommodation (SDA) and SIL funding, should be separated. As a result, not everybody that receives SIL funding will be eligible for SDA funding.

Responsibilities of SIL provision include:

- Promoting the participation of community-based activities
- Helping the residents to manage their money and household budgets.
- · Working with the accommodation provider to find prospective tenants
- Screening potential workers
- Monitoring and supervising the SIL support workers.
- Addressing support service complaints

Participants who require a higher level of support can receive additional SIL services, including:

- The active management of complex medical needs, including nursing
- Behavioural support
- Inactive overnight support



Role of NDIA

The **NDIA** is responsible for setting the prices for each activity or task that the SIL provider undertakes via the <u>SIL Price Guide</u>. All prices within that guide are based on a per person, per week basis. These prices are used to provide a quote for the individual who wishes to move into the SIL arrangement via a Roster of Care (RoC) tool. The RoC must be completed before moving into the property.

These are designed to give the NDIA an insight into the support people with disabilities will need in a typical week to determine the staffing ratios. For this reason, SIL is primarily used for people with disabilities who have highly regimented routines and require high levels of personal support. SIL funding is therefore only available to people with disabilities who require specific intensive support and can match these needs to a particular SIL arrangement.

"Total payments to people with disabilities in SIL have increased by 21 per cent annually over the last three years, from \$6.1bn to \$10.7bn. The number of people with disabilities has also increased from 22,842 at 31 March 2020 to 31,368 at 31 March 2023.

The average payment per participant for SIL supports has also increased, and comprises a large component of the total average payment for people with disabilities in SIL (noting that people with disabilities in SIL also receive other supports, such as core support for community participation, employment, and capacity building). The average payment per participant for SIL supports (core daily activities) has increased by seven per cent annually over the last three years" (Q3 Report 2023-2024, pg 97) The average payment per participant \$371,800, currently a 9% increase per annum over the past three years (Q3 Report 2023-2024, pg 96), amounting to \$10.7 billion in total payments...

There has been much discussion, particularly in the last two years, about these services' economic viability. Currently, the Minister for the NDIS, Bill Shorten, has stated that SIL funding is used by 27% of the Scheme's total people with disabilities, but is taking up more than 70% of the Scheme's entire budget. Yet, costs continue to escalate without finding more efficient ways to use this funding to allow people with disabilities to spend it as they would like. Instead, SIL funding focuses on how the supports are delivered. Consequently, SIL funding is primarily developed as a bulk product, leaving little room to customise it for people with disabilities' preferences. The concerns raised by the government are therefore valid.

The recent hearings of the Royal Commission into the Abuse, Violence, and Neglect of People with Disabilities leads to the question of how the NDIS can deliver SIL more cost-effectively, in methods that fit individual preferences, while also delivering them safely in the way that supports providers can generate the best outcomes for those who use their services?



What is ILO?

Individualised Living Options (ILO) is a more flexible type of funding offered by the NDIS to support people with disabilities inside their home. ILO is an alternative to the highly structured Supported Independent Living (SIL) funding model.

ILO is designed so that this support can be provided to people with disabilities in a way that suits their individual needs, giving them greater autonomy over how their support can be delivered. ILO funding also reduces costs over time by emphasising the acquisition of life skills. Additionally, ILO is customisable and can be designed so that people with disabilities can utilise both informal and formal support networks. These networks allow people with disabilities to share their home with family, friends, partners, or a housemate.

ILO is suitable for a participant they need is:

- Over 18
- Require more than 6 hours of support per day
- Requires short and intensive periods of support

ILO is particularly suitable for those who live in communities that the participant is familiar with, in an environment that ensures the participant's safety while maximising their independence.

There are two stages in the ILO funding process.

1. Stage one: Exploration and Design

• Facilitates the transition towards ILO funding by allowing the participant to investigate what support needs are available and how that support can enable them to achieve the goals in their NDIS plan.

2. Stage two: ILO Supports

 Monitors their progress to determine whether the foundered needs to be altered or revaluated

The ILO model is not designed for those with high support needs or medical conditions that can cause the participant severe injury.



Nursing Homes

A report released by the federal government in late 2020 identified as a problem young people who have high physical support needs who are not currently in appropriate accommodation. In response to the recommendations and findings in the Royal Commission Into Age Care Quality and Safety, the government recommended:

The Australian Government is committed to ensuring no younger person (under the age of 65) lives in residential aged care unless there are exceptional circumstances. The aged care system is designed to support the needs of older people and is not designed for younger people.

...the Australian Government announced strengthened Younger People in Residential Aged Care (YPIRAC) targets and an intention to develop a strategy to meet those targets.

The Australian Government's YPIRAC targets, apart from in exceptional circumstances, seek to ensure there are:

- no people under the age of 65 entering residential aged care by 2022;
- no people under the age of 45 living in residential aged care by 2022; and
- no people under the age of 65 living in residential aged care by 2025.

"The experiences and needs of younger people living in residential aged care, their families and carers, are central to the YPIRAC Strategy (the Strategy). The Strategy recognises and prioritises the rights of people to determine where and how they choose to live."

Unfortunately, these targets have not been met.

"The number of people in residential aged care under the age of 65 years, including those who are not people with disabilities of the Scheme, has decreased in recent quarters from 5,468 at 30 September 2019 to 2,934 at 30 June 2022 (a 46 per cent decrease).

"Also, fewer people under the age of 65 years are entering residential aged care – 386 people under the age of 65 years entered in the September 2019 quarter, compared with 99 in the June 2022 quarter (a 74 per cent decrease). (Q3 Report 2023-2024, pg 23)



Some big questions we need to ask



Why is the system growing so fast?

The Third Quarterly Report for the Financial Year 2022-23, released by the NDIA in May 2023, indicates the broader trend of cost increases throughout the home and living framework of the Scheme. SIL funding has increased by \$12.8 billion between the second and third quarters of that financial year. This figure is concerning given that it is contrary to the Albanese Government's efforts to try and limit the overall cost of the NDIS to eight per cent growth over the next four years.

Similar trends are confronting the SDA framework, with 661 people being approved for funding between the second quarter of 2022-23 and the third quarter of the Financial Year. This increase amounts to 51 people with disabilities receiving SDA funding per week, which is a dramatic increase.

In both cases, the solution for delivering SDA and SIL supports that are "economically sustainable" is not by reducing approvals or funding at a line item level but instead examining the market forces within these frameworks to try and remedy the inability to address supply and demand problems.

Both providers and people with disabilities have been lobbying the Federal Government and the NDIA to suggest possible solutions for streamlining and alleviating the financial pressures on the SDA and SIL line items. In addition, these stakeholders offer other crucial factors that affect the delivery of both frameworks.

Data concerning SDA indicating a prevalence of High Physical Support (HPS) building types is concerning. This building type is **currently oversubscribed**, often at the expense of the other building types. The most recent quarterly report indicates that the HPS building type has three times more than its counterparts (DATA).

It is a supply-side problem. Investors are encouraged to build more in the HPS building type because their return on investment is significantly larger than across the other three building types (DATA). Similar disparities occur across other SDA market factors, including design categories and location factors. Consequently, the most common SDA dwelling approved by the Agency is a one- or two-bedroom HPS apartment, in a newly built apartment block, in one of the large capital cities (DATA). This design framework, while needed by some consumers, only captures a tiny fraction of the total market of people with disabilities requiring SDA.

Consequently, the oversupply of the HPS building type has come at the expense of other SDA dwelling types, away from capital cities in rural and regional areas that utilise different building types, such as share houses, villas, or family homes (DATA). Theoretically, the SDA framework supports the principle of "choice and control" by offering a range of options that people with disability can utilise in the marketplace. Still, these supply-side issues substantially reduce the ability of consumers across the disability spectrum throughout the country who want to live in different housing types to utilise their choice and control.



To fix the SDA supply-side issues, what is needed is more substantial investment programs to encourage more diversity of options within the SDA market. Providing institutions with more significant economic incentives to invest capital, to increase supply is not a quick fix. It requires effective long-term planning and considerable policy change over a generation, not just in the political cycle in the life of one Government.

While such suggestions may provide long-term solutions, this does not address the immediate problem. Successive quarterly reports over four years have demonstrated that demand for SDA is increasing, but the supply remains static. **This trend is concerning because although SDA is only designed for roughly 6% of the Scheme's overall people with disabilities, this cohort represents the demographic of the Scheme that requires the highest level of support across all eligible people with disabilities.** Suppose this cohort is not receiving approval for SDA and suffers delays or denials of their funding because of a lack of appropriate supply. In that case, their ability to exercise their "choice and control" is severely compromised. Furthermore, by its very nature, the SDA cohort is designed to have the most "severe functional impairment", and if they cannot access basic shelter and infrastructure, how can they utilise the funding they require in other areas of the Scheme?

Similar challenges face the SIL funding framework, too. As highlighted above, the cost of SIL funding has continued to escalate over several years. Three years ago, former NDIA board member and Co-Author of the *Productivity Commission Report Into Disability Support*, the paper that established the policy argument for the NDIS, John Walsh, stated that SIL funding was only designed as a transition measure in the early stages of this Scheme. SIL was intended to support providers' transition from the pre-NDIS model of financing that relied upon "block funding", which grouped services across multiple people with disabilities, to a more individualised funding framework designed to suit the needs of a single participant.

Part of this restructuring and transition period was intended to shift the focus away from providers that funded the accommodation and towards the support the person with a disability received within that dwelling. Walsh stated that in this context, SIL funding is only designed to increase the speed of the transition to ensure that the Provision of housing and support is divided across two providers. Yet this mandatory condition has not occurred ten years after the NDIS was actualised. Therefore utilising the same provider for the accommodation and the support provided within the dwelling goes against the original intent and violates the "choice and control" principle of the Scheme. Adding to this concern is that this lack of separation of funding is maintaining a monopoly on the type of services that people with disabilities can access within the NDIS marketplace, the antithesis of why the policy was created in the first place.





What are the Theories for Cost Increases?

The justification for creating an NDIS was that historically people with disabilities had little or no say in how they chose to live their life. The broader definition of what a disability constitutes is that it is the deprivation of choice. That is why "choice and control" is more than words. The policy environment before the NDIS for people with disabilities was one where decisions were made for them, without them being present or consulted, without their involvement in assessing their options. In short, they had no self-determination whatsoever.

Societal expectations were created based on these assumptions. As a result, people with disabilities were defined by their diagnosis and treated with a focus on what they could not do rather than what they could. In other words, people with disability were defined by what is known as The Medical Model.

This did not change in policy terms until the <u>United Nations Convention on the Rights of People with Disabilities</u> was enshrined in international law in 2006. Only then did people with disabilities receive the true freedom to choose what course their lives took. Less than a generation ago, this Convention set the basic terms for how people with disabilities could play an active role in society and be part of the community.

The Convention chronicles fundamental rights for those with disabilities without asking for them. These include but are not limited to the right to make their own decisions, the right to be rescued in times of disaster, the right to have children, the right to have intimate relationships, and most importantly, for this context, the right to choose where and how they live.

It is important to remember that before this Convention was passed into international law, it was assumed and expected that people with disabilities couldn't exercise these rights. Mistaken as that may be, that assumption has severely affected how people with disabilities navigate the NDIS.

If society assumes that people with disabilities cannot make their own choices as a default stereotype, how do they practise the skills of developing self-determination? That is the ability to identify options, consider the positive and negative consequences of each decision, compare and contrast them, and then ultimately experience the implications of the choice that has been made. How do people with disabilities learn from those experiences, in a positive or negative sense, if they have never had the opportunity to participate in that process before?

Because the NDIS was created primarily based on the framework of the Convention and in response to it, part of the problem is the short lag between the creation of that document and the NDIS as a policy—just seven short years. As a result, people with disabilities did not have sufficient practice or education within their communities to imagine how to access this newfound autonomy and go through the process of self-determination before obtaining the "choice and control" taken for granted by so many other people in the community.





Unpacking 'Choice and Control'

Owing to the assumption that people with disabilities did not have these attributes before the introduction of the Convention, their ability to utilise these skills after it became socially acceptable for them to do so was severely compromised in a fully-fledged marketplace. In addition, because they have not been taught how to find new and appropriate accommodation for themselves as an individual, they have little ability to discern the right option for them. This process includes going through every step of the self-determination process that people without disabilities experience when they choose new accommodation. However, the method also requires that consumers with a disability go further by requiring them, or their supporters, to identify what barriers their impairment might create, physically and practically, but also in determining what is essential to them ideologically when picking a new home.

For example, some basic questions for a person with a physical disability may include:

- Does the suburb I want to move to have accessible footpath access around the dwelling and in nearby areas?
- Does the suburb have accessibility in all its congregate areas, such as shopping centres, public transport stops, and medical facilities?
- How does the location of the dwelling complement or hinder my ability to access the services or informal support that I need?

An understanding of these considerations will vary depending upon the person's impairment, life experience, and level of support around them. However, the initial process of self-determination and the ramifications of finally giving people with a disability access to choice and control for the first time also means exploring and brushing up against its limits. For example, preparing for their first planning conversation is often the very first time that many people with disabilities have been asked what their goals are, what they want to achieve, and where they want to head in life because it was expected before the introduction of the NDIS that those questions would be answered by someone other than themselves.

As joyous and revelatory as the process of discovery can be, discovering one's self-determination is also the experience of encountering its limits. With increased choice and control comes increased responsibility as a consumer in the marketplace. But, to test what those responsibilities are, the more significant opportunity to make mistakes comes because part of self-determination is about experiencing and experimenting. It, therefore, stands to reason that the initial phase of the Scheme, particularly in its first decade, is about exploring what "choice and control" means for individual people with disabilities. Discovering this may mean asking for less or more than required, figuring out new routines and preferences, and testing their limits, including finding the boundaries and limitations in this process. People without disabilities have been doing that for generations, and those with disabilities are now beginning to reckon with this process. However, people with disabilities have only been permitted to explore these opportunities legally and philosophically since 2006.

It is understandable, therefore, that people with disabilities will, in the short term, necessarily ask for more than they need. It is not done with malicious or nefarious intent but is part of discovering how people can live independently.





What are the limits to "Choice and Control"?

"Choice and control" is designed to open up opportunities for people with a disability who haven't had access to making choices before. When it was first implemented, the NDIS was pitched as a complete reframing of how people with disabilities saw themselves and would be treated within the community.

The economic argument for the NDIS made by the political class, and primarily the Labor Federal Government led by former Prime Ministers Kevin Rudd and Julia Gillard, saw the NDIS establish an economic market for people with disabilities. An entire business model was created that could change the social policy of Australia.

When the Productivity Commission's Report on the Provision of Disability Services recommended the formulation of an NDIS, most of the report focused on the economic benefit to the nation. There were many benefits, including for those outside the sector. The report argued that providing more disability services would lead to substantial growth in national employment, and the State Government could use previously allocated funding apportioned to disability services in other areas. While the States would still contribute to the direction of disability policy, more inclusive and accessible government services could be developed to give Scheme users more access to the community. On this basis, the Productivity Commission built strong economic foundations. These were based on three principal tiers.

Tier one was designed for all Australian citizens by providing insurance in case they developed a disability. Tier 2 would be about education and general population awareness to inform the community about disability, as well as capacity building for people with disability to act as informed consumers. Tier 2 was also intended to include services and supports for those who did not need individualised support plans. and would also offer referrals for the 80% of people with disabilities that were not eligible for the NDIS. Tier 3 is the services administered through the NDIS, where people with disabilities with the most severe impairments would gain access to the services deemed "reasonable and necessary."

The development of the Scheme has changed rapidly since the three-tier model was suggested and then disregarded. Instead of the three tiered system, there is only one, the third. That has meant that almost the entire disability sector has come under the remit of the NDIS, which was not what the Scheme was designed to do. The change in philosophy has placed more economic pressure on the Scheme. Most people with an impairment have become people with disabilities, rather than just those with the most severe impairments. Scheme costs have therefore continued to escalate beyond the control of those within the Agency, and by far more than what was already anticipated. The economic responsibility of these costs has hit the people with disabilities the hardest.

The tension and the disconnect between choice and control for people with disabilities and the overall economic responsibility of the nation has made it harder for those on the Scheme to understand their role within the NDIS. On the one hand, giving people with disabilities access to choice and control, and supplying them with this newfound power teaches them that they can use an economic market to achieve their goals. This awareness has necessarily included educating people with disabilities on how to ask for things. On the other hand, with this newfound power comes new responsibilities. As a critical player in the marketplace, people with disabilities have primarily been educated about how to engage with the benefits and drawbacks of self-determination.



A decade on, the Scheme is on an economic course that governments, no matter their political persuasion, consider heading for dangerous territory. The system that the NDIS has evolved into faces fiscal overload because of the lack of consideration given to the other services, or the importance of the three-tiered system of disability policy advocated by the Productivity Commission report. These economic concerns were communicated by and to the disability sector. Consequently, "Choice and Control" and "Economic Responsibility" seem pitted against one another, where one idea must emerge victorious.

Participants are then left with the unfair burden of determining what economic responsibility means for the nation. Whilst, indeed, it's not their responsibility alone to justify increases in financial spending for the NDIS, unfortunately, they are the ones who are the victims of economic rationalising and government policy reducing the impact of the NDIS.

In 2020, the Morrison Government attempted to introduce the policy of "independent assessments", which was essentially another way to squeeze disability policy into a medical model framework, where individuals would not receive funding based on their individual needs or what they wanted to achieve. Instead, they would be made by the determinations of expert panels, who would never meet these individuals, and instead operate on a theoretical basis to develop typical support packages based on the expectations of what individuals could do based on a diagnosis. In other words, a faceless individual would tick a series of boxes based on medical reports and different 'measurable outcomes' rather than focusing on how to support the individual to achieve their goals. Thankfully after months of campaigning by the disability sector, the Morrison Government reversed its proposal for independent assessments. Still, it provides a warning about what direction the NDIS could go if, according to governments, economic costs remain unsustainable.

So how do people with disabilities retain choice and control while governments emphasise economic responsibility? An excellent first step is revisiting the Productivity Commission report, and recommitting to the three tiers of disability service provision.

Mandating economic responsibility to the disability sector is not just about reforming the NDIS. Throughout history, people with disabilities have been educated and taught how to live in a world that is not designed for them. Part of the economic responsibility lies with people with disabilities by illustrating that there are limits to choice and control. However, there are also changes that the community has to make - to make the world more accessible and available to those with a disability. The argument that adaption is too costly for most citizens no longer has any basis. Suppose society wants people with disabilities to take economic responsibility for their choice and control in a way that benefits the community's social good. In that case, the community must meet them halfway. Equity of opportunity should be the new catchphrase of the second decade of the NDIS.

Part of this equity of opportunity also recognises that able-bodied community members have access to choice and control. Still, that choice and control is limited by various factors, including location, access to infrastructure, and the ability to navigate through self-determination.

Currently, the discourse surrounding the economic challenges of the NDIS has only been directed one way. The political class representing the wider community dictates what people with disability must do for the greater good. By doing so, they are minimising the rights, freedoms, and opportunities created by the NDIS and returning us to the vulnerable positions we were in before the introduction of the policy.





What happened to the Insurance Model?

When discussing the Insurance Model in the context of individual plans, the term "capacity building" is often used. The purpose of capacity building, as described under the NDIS, suggests that if the right supports are in place initially, the need for that support will eventually decrease. While this may be true personally, it is also true in the macro context of the Scheme. It is only a decade old in what is hoped to be a long political journey. The Scheme is only figuring out where its capacity lies on an enormous scale. Part of this process is what may be considered to be economically excessive until the foundational principles of the Scheme are embedded. This is particularly true concerning the Home and Living framework because the NDIS cohort is still figuring out what kinds of support it needs and the levels required to deliver it before it is allowed to decrease over time.

The accommodation market is especially vulnerable to escalating costs in the initial phases of the Scheme. A decade in, housing providers are just now figuring out the potential of the appropriate supply and demand levels. The market has yet to figure out what models do and do not work because it is in an experimental phase. It will then take longer to ascertain how to create the most popular and successful models at scale. This process, in its entirety, will take longer than a generation.

This is without considering how to support consumers with disabilities once they have moved in. Only through creating and building these dwellings, support providers and their consumers will know what support model work for them. Therefore, it is unsurprising that the cost of SIL is escalating rapidly. Both providers and consumers are just beginning to explore what support models can work for them, what the limits of these models are, and how these models can fit within the NDIS.

Just as people with disabilities are exploring what it means to have self-determination, providers are also discovering its opportunities in a business context. Each cost model is as unique as the service provider delivering them. This is impossible to figure out if people with disabilities don't have enough housing options to explore or even trial, to test what is best for their NDIS experience.

While the market matures, costs will continue to increase steadily. Therefore, economic forecasters should be preaching patience until the market stabilises. A single decade is not long enough to firmly decide the financial future of the NDIS, and this is especially true of any conclusion made concerning Home and Living.

