



**RIGHTS &  
INCLUSION  
AUSTRALIA**

**Submission to the Review of  
the National Disability  
Insurance Scheme (NDIS)  
August 2023**

**FINAL**

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# 1. Introduction to Rights & Inclusion Australia.

Rights & Inclusion Australia (R&IA) is a national Disability Representative Organisation (DRO) promoting the rights and inclusion of people with disability. Founding members of the organisation were involved in the development of the United Nations Convention on the Rights of Persons with Disabilities, and R&IA has remained associated with the international movement of people with disability through our acceptance into the Pacific Disability Forum in 2020. Our main areas of focus in Australia are the built environment, accessible housing and achieving equity of inclusion for First Nations people with disability.

R&IA is a member of the Australian Network on Housing Design (ANUHD) and has had significant engagement about housing with Government and the community. Since late 2019 this engagement has been consolidated in the ACT, when an ACT Government grant enabled the establishment of the *Accessible Housing Innovation Project*. The project aimed to provide information and resources to people with disability and their families who were looking for housing and support solutions in the ACT, and to broker new opportunities that may arise from bringing together stakeholders from the housing disability support, community, peak and Government sectors. The project was extended to the end of 2020, after which R&IA was successful in obtaining funding to extend the project within the ACT, and nationally, through an Information Linkages and Capacity Building (ILC) grant through the Australian Department of Social Services. Our partners in the “Opening the Door” project are National Shelter, and their state and territory affiliates, and Enliven Community. These partnerships have helped us to influence much more strongly the advocacy for housing reform in general to include housing for people with disability (beyond SDA). **In addition we are working closely with the Community Housing Disability Network, an initiative of Community Housing Industry Association, which is looking at the solutions necessary to make community housing, and other housing types and tenures, more suitable and more available to people with disability. We believe these types of collaboration represent the correct strategy to address solutions for a truly inclusive housing system that caters for all Australians, including people with disability.**

## 2. The NDIS Review – Overview of R&IA response

Rights & Inclusion Australia (R&IA) welcomes the review of the NDIS after 10 years of operation, and provides this submission aiming to promote possible solutions, rather than dwelling on problems and issues. **Its principal focus will be on housing**, although other elements of the operation of the NDIS and the National Disability Insurance Agency (NDIA) will be commented on. This will be in part to address concerns with current operational process, and in part to identify areas of proposed change that will need to be in place to

facilitate the implementation of the solutions we believe are required are necessary in housing and living options areas.

Some more details of problems and issues may be required when it comes to articulating what particular solutions are meant to be addressed. Wherever possible this additional information about “problems” will be delivered through examples and the real stories of people with disability. It has been our intention to reflect the words of people with lived experience of disability where possible, and originally we planned to include three “interviews” with people in full to provide context for our comments and our proposed solutions. In the interests of time and also readability only two of these interviews have been replicated (at Appendices A and B), and the interactions with others have been directly alluded and referenced where relevant.

The submission also references a number of other submissions that have been and continue to be made about housing under the NDIS. The ACT Housing Solutions Innovation Group (HSIG) is making its own submission, and as R&IA is the current secretariat for the HSIG, we include the agreed submission as Appendix C at the end of this document. We reference in the body of our submission the work of other people, including that of Cheryl Crilly and José Robertson, and we include the latter’s submission to the NDIS Review at Appendix D, to avoid excessive summarisation of material already under consideration by the NDIS Review.

Finally, the submission endeavours to follow, as far as possible, the format and logic of the *What we have heard* report from the NDIS Review team. We do not follow the order of its findings, in order to firstly present our thoughts about the administration of the NDIS and its placement within Government, which requires us to lead off with the topic of “A complete and joined up ecosystem of support”.

### **3. List of Recommendations**

The following recommendations are made throughout the submission:

**Recommendation a): Responsibility for outcomes for people with disability, framed by Australia’s obligations under CRPD, needs to be consolidated under one Ministry for Disability.**

**Recommendation b)(i): A new Office for Disability should be set up within the Australian Government, run predominantly by people with lived experience of disability, with responsibility for the implementation of CRPD and direct accountability to the Minister for Disability, together with a coordination role across the Departments of Health, Social Services, Prime Minister and Cabinet and Attorney General; or**

**Recommendation b)(ii): The National Disability Insurance Agency (NDIA) should combine its limited funding function with the safeguarding**

**functions of the Quality and Safeguarding Commission under the umbrella of a new Executive branch, run predominantly by people with lived experience of disability, with responsibility for the implementation of CRPD and direct accountability to the Minister for Disability, together with a coordination role across the Departments of Health, Social Services, Prime Minister and Cabinet and Attorney General.**

**Recommendation c): The Executive of the NDIA, outlined in Recommendation b)(ii) or the new Office for Disability, outlined in Recommendation b)(i) must be given a budget and powers to allocate resources to stimulate or fully fund initiatives that occur within the community that can facilitate community development and assist in overcoming identified barriers.**

**Recommendation d): The Executive of the NDIS, outlined in Rec b)(ii) or the new Office for Disability, outlined in Rec b)(i) should be given carriage of the Information Linkages and Capacity Building (ILC) funding, to identify and fund projects in the community which will provide lasting opportunities for capacity building amongst people with disability in Australia.**

**Recommendation e): The Executive of the NDIA should fund existing community organisations, including Disability Representative Organisations (DROs) and others led by people with disability, to build community capacity as well as be the principal generators of individual capacity building initiatives.**

**Recommendation f): The Executive of the NDIA should work with the Australian Government to:**

- a) Investigate and implement measures to be undertaken with the residential property sector (e.g., property developers, real estate industry, property managers) to address the housing needs of people with disability.**
- b) Increase investment in social and affordable housing to address current and projected shortfalls;**
- c) Investigate and implement financial measures to assist people with disability to purchase their own housing; and**
- d) Investigate and implement financial measures, including through tax concessions, to assist people with disability to rent suitable housing.**

**Recommendation g): The Executive of the NDIA should support the development of housing-disability forums in each jurisdiction – co-designed and led by people with disability – to ensure comprehensive information sharing and systemic advocacy to address housing issues.**

**Recommendation h):** The Executive of the NDIS should work with state and territory governments to ensure their social housing operational policies allow households with disability to access social and affordable housing:

- a) Paying full or part market rent;
- b) As tenants in Specialist Disability Accommodation (SDA), provided by state/territory public housing authority (such as Housing ACT) as an SDA Provider

**Recommendation i):** The Executive of the NDIA should work to ensure that state/territory-owned land development agencies (e.g. Suburban Land Agency in the Australian Capital Territory) have operational policies that support eligible households with disability to:

- a) Obtain residential dwelling lots outside of residential estate ballot processes; and
- b) Purchase accessible affordable dwellings with the waiving of income eligibility thresholds

**Recommendation j):** The role of Local Area Coordination needs to be redesigned and an alternative approach taken to the important task of “community development” that will address systemic barriers in the community, provide easier access to people with disability to everyday goods and services, and ultimately reduce reliance upon individualised funding to assist NDIS participants overcome these barriers. Ideally this community development will take place via the network of existing, and potential future, Advocacy services and Disability Representative Organisations.

**Recommendation k):** The role of Local Area Coordinators in assisting individuals needs to be redesigned to take on board many of the roles currently undertaken successfully by Coordinators of Support, and be funded outside of and separate to the NDIS.

**Recommendation l):** The process for applying for individualised resources from the NDIA must be supported by administrative practices undertaken by Planners/Delegates which are geared toward the acceptance of individuality, in both personal characteristics and social and environmental circumstances, and which encourages and accepts a strengths-based presentation of each applicant’s aspiration – in accordance with the requirements of the NDIS Act 2013.

**Recommendation m):** The NDIA must subvert its current approach to assessing the eligibility and funding levels of individual participants to one which seeks to get to “yes” rather than “no”, and which uses indicative costing as guidelines for funding levels rather than treating them as hard funding categories.

**Recommendation n):** The Executive of the NDIA should develop a short, medium, and long-term vision to define what NDIS home and living supports will look like over the next 15 years, with a clear pathway to achieve it.

**Recommendation o):** The Executive of the NDIA should develop and undertake a regular survey to establish the housing needs of people with disability.

**Recommendation p):** The Executive of the NDIA should develop and undertake an ongoing audit of national housing stock suitable for people with disability to quantify current availability and inform supply.

**Recommendation q):** The Executive of the NDIA should in future move to use the resources available to it for housing to directly engage the Community Housing sector to develop and manage housing that needs to be built to the specific requirements set out currently in the SDA program.

**Recommendation r):** The NDIA should incrementally wind back the current SDA program and target individual participants and their housing needs specifically, rather than attempt to address the chronic shortage of suitably designed housing through a broad approach of incentives for private developers.

**Recommendation s):** R&IA has a strong preference for the establishment of a national home modifications program, similar in design to England's Disabled Facilities Grant, which through a housing appropriation provides the bulk of funding to individuals based on their mobility requirements relative to the home in which they dwell, and is not tied wholly to their eligibility to social care programs such as the NDIS or My Aged Care, or any other qualifying care/support based program.

**Recommendation t):** The Executive of the NDIA should provide funds to Home Modifications Australia (MOD.A) to oversight quality in the home modifications sector, deliver and/or accredit training to builders, project managers and occupational therapists, and assist participants with resources to inform their understanding of how to be effectively involved in a home modifications process.

**Recommendation u):** The Executive of the NDIA should consider the introduction of means/assets testing for home owners who require modifications, and require a co-contribution from those who are deemed to have access to assets and income that enables them to contribute and for whom the home modification will substantially increase the value of their property. This will bring it further into line with the way that home modifications are delivered in the Australian aged care system.

**Recommendation v):** The NDIA, if it is to continue to administer home modifications to eligible NDIS participants, needs to outsource participant applications for home modifications to a suitably qualified and expert assessment team, similar to the system in New Zealand which contracts out to Enable NZ, which can undertake thorough investigations and provide detailed solutions in consultation with the participant.

**Recommendation w):** The NDIA, if it is to continue to administer home modifications to eligible NDIS participants, must mandate the use of project managers for modifications which are complex, and to fund and mandate follow-up inspections of completed modifications to ensure they are done in accordance with plans, and are fit for purpose.

**Recommendation x):** The Executive of the NDIA should take steps to monitor the quality of the home modifications that have been funded to date by the NDIS and introduce measures that demonstrate genuine “stewardship” over the strength and viability of a specialised home modifications industry. Data should also be collected about the availability of quality home modifications in rural and remote areas, and also to particular populations of the community, and to those in rental properties.

**Recommendation y):** The Executive of the NDIA needs to develop a short, medium, and long-term vision to define what NDIS home and living supports will look like over the next 15 years, with a clear pathway to achieve that vision.

**Recommendation z):** The NDIS must adjust its eligibility and funds allocation settings to take adequate account of each individual’s income, current living situation and previous opportunity or its lack when determining funding and resource allocations that are made to assist the participants achieve their stated goals.

**Recommendation aa):** The NDIS should consider providing an element of rental relief to participants who are experiencing extreme housing stress due to the rising private rental prices, to enable them to remain living in their homes and reduce the risk of homelessness.

#### **4. A complete and joined up ecosystem of support**

**Recommendation a):** Responsibility for outcomes for people with disability, framed by Australia’s obligations under CRPD, needs to be consolidated under one Ministry for Disability.

The *What we have heard* report highlights the issue of the failure of the NDIS to stimulate an ecosystem of disability supports which, as well as delivering funding to individual participants promotes opportunities and creates awareness of issues impacting on people with disability. Such an ecosystem



should provide information about and referrals to “relevant community and mainstream services” that will step up to assist people with disability who may not be eligible for NDIS individualised funding.

R&IA shares the concern of the Review team in identifying the lack of any real progress within the broader community to make it more welcoming and able to accommodate a greater diversity of need within the regular suite of services that its members use such as health, education, transport and housing, as well as those services set up to provide more specific assistance such as drug and alcohol and domestic violence protection services. This issue, however, goes well beyond the provision of “services”. The social model of disability<sup>1</sup> identifies the policies and infrastructure which frame the lives of people in the community, and which have traditionally been designed and implemented without due consideration for diversity, including disability. The NDIS’s aspiration of universality clearly has to consider how it will in future work to alter the policy frameworks which still drive governments at all levels in Australia to provide for the “mainstream” and consider people with disability as a “special” category. Under the leadership of the NDIA it does not appear to have attempted to do this over the course of the last 10 years.

In order to provide solutions for this, R&IA is focusing on Australia’s obligations as a signatory to the Optional Protocol of the Convention on the Rights of Persons with Disabilities (CRPD), and the way in which Australia’s complex system of government serves to effectively disaggregate the responsibility for meeting these obligations. The submission draws on our experience of how responsibility for outcomes for people with disability is dissipated across ministerial portfolios within the Australia Government, exacerbated by the difficulties of negotiating across state/territory jurisdictions, which in turn have responsibilities for people disability spread across portfolios and departments. Our proposals for solutions point to the need for leadership at the federal level, both political leadership through the consolidation of disability portfolios and coordination across ministerial responsibilities; and departmental leadership by modelling how administrations can and must design and implement policy that caters for the diversity of our communities.

Arguably the most influential Ministry with relevance to people with disability in the current Australian Government is the Minister for the NDIS. Significant responsibility, however, resides with the Minister for Social Services, whose portfolio includes responsibility for disability employment and Advocacy services, as well as oversight of Australia’s Disability Strategy and responsibility via the Disability Services Act. The portfolio, however, has

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<sup>1</sup> For a description of the Social Model see *Australia’s Disability Strategy 2021-2031*, Available [online]: <https://www.disabilitygateway.gov.au/document/3106>, p7.

responsibility for a much wider range of social and community issues within Australia, beyond disability. The diversity of the Social Security portfolio makes it impossible to champion only disability issues and to oversee the practical application of CRPD and Australia's obligations after signing the Optional Protocol. It is R&IA's proposal that overall responsibility for disability be taken by the Current Minister for the NDIS in an expanded portfolio.

**Recommendation b)(i): A new Office for Disability should be set up within the Australian Government, run predominantly by people with lived experience of disability, with responsibility for the implementation of CRPD and direct accountability to the Minister for Disability, together with a coordination role across the Departments of Health, Social Services, Prime Minister and Cabinet and Attorney General; or**

**Recommendation b)(ii): The National Disability Insurance Agency (NDIA) should combine its limited funding function with the safeguarding functions of the Quality and Safeguarding Commission under the umbrella of a new Executive branch, run predominantly by people with lived experience of disability, with responsibility for the implementation of CRPD and direct accountability to the Minister for Disability, together with a coordination role across the Departments of Health, Social Services, Prime Minister and Cabinet and Attorney General.**

There is need for a new bureaucracy to administer a scheme as innovative as the NDIS. The scheme demands an administration which is capable of outreach to individuals and delivering customised responses in a manner which assures their trustworthiness first and foremost, and which addresses their strengths-based goals. This was a challenge from the beginning of the scheme that was never met. The NDIA has worked hard to deliver outcomes for many people on the NDIS, for whom this is perhaps the first occasion on which their actual needs have been addressed and who are receiving for the first time the support they require, or close to it, to achieve the ambitions they have for inclusion in the community.

That said the innovation that the NDIS has introduced to Australia has not been matched by innovation in the way the NDIA has administered the scheme. In fact, this is an area which appears to avoid scrutiny and needs to be addressed. It is hard within the scope of a submission round to propose the kind of innovation needed to achieve this new form of administration, and its recommendations just seek to establish the framework in which the innovation might occur.

The current NDIA appears to be restricted to funding only individuals, given its focus on the delivery of funds which can be controlled by individual participants to get the goods and services that will meet their goals. This in fact places a good deal of pressure upon individual participants to address the systemic barriers on an individual basis, and leaves the NDIA unable to

effectively apply resources to address these barriers more collectively. For example, the SDA program is one which is attempting to stimulate the building of suitably accessible housing that is not currently available within Australian housing markets. Yet it does so through a highly complex funding mechanism which has to pre-allocate funding amounts to as yet unknown participants in order to provide the incentives for developers to build this housing. This has fostered uncertainty and hesitation within the building industry and also has tended to “box” participants into specific categories rather than treating them in a truly unique and individualised way.

Should there be no political appetite for the consolidation and, arguably, elevation of disability matters into a single, larger ministerial portfolio, or the development of a new Office for Disability to support it, a new Executive branch of the NDIA should be formed to bring together the functions of funding individuals (which has become the sole focus of the current NDIA, with “policy” areas formed to resolve problems of its own creation) and the safeguarding mechanisms provided by the NDIS Quality and Safeguards Commission. This Executive branch will be under the leadership of a CEO with lived experience of disability, and all division heads within it will be people with lived experience of disability. The resources and policy expertise required by this Executive branch to implement the CRPD will be drawn from the existing NDIA structure, whose function will be reduced and structure flattened to focus on the important job of supporting Planners/Delegates to interact in a positive and meaningful way with participants who need NDIS funding to meet their aspirations and needs.

**Recommendation c): The Executive of the NDIA, outlined in Recommendation b)(ii) or the new Office for Disability, outlined in Recommendation b)(i) must be given a budget and powers to allocate resources to stimulate or fully fund initiatives that occur within the community that can facilitate community development and assist in overcoming identified barriers.**

The extent of the powers and the limit of the resources will be determined by whether a separate Office is formed or an Executive function added to the existing NDIA. The important principle must be established, however, that to address systemic issues it is appropriate for the NDIS Executive (which is how it will be referred to in the remainder of this submission) needs the ability to engage with and provide resources to external agencies and organisations to put into effect programs and initiatives that will effect systemic change. Elsewhere this submission will address this in relation to housing, and here it will focus on the issue of community development, which has been raised by us as a criticism of the current LAC program.

**Recommendation d): The Executive of the NDIA, outlined in Rec b)(ii) or the new Office for Disability, outlined in Rec b)(i) should be given**

**carriage of the Information, Linkages and Capacity Building (ILC) funding, to identify and fund projects in the community which will provide lasting opportunities for capacity building amongst people with disability in Australia.**

**Recommendation e): The Executive of the NDIA should fund existing community organisations, including Disability Representative Organisations (DROs) and others led by people with disability, to build community capacity as well as be the principal generators of individual capacity building initiatives.**

Funding for ILC initiatives has been significant and has delivered some excellent pilots. A frustration for many who run these projects is the lack of any capacity to maintain initiatives which might deliver ongoing capacity building support on the ground beyond a project's timeframe. The introduction of the NDIS in a form limited to funding individual participants without the requisite community development strategies, has resulted, arguably, in a shrinkage of community capacity over the past decade. The lack of ability for the NDIA in its current form to actively resource community capacity has led to a shortfall in capability at a time when the opposite is needed. Professor Alan Fels authored the report of the Steering Committee of the Stronger Community Organisations Project which back in 2007 saw the future of community organisations as one which they:

...act as agents for addressing a full range of social concerns and priorities, advancing long-term community interests and objectives by:

- Contributing to civil society and creating platforms for citizen voice;
- Providing opportunities for participation and inclusion; and
- Developing and delivering important services to the [Victorian] community.<sup>2</sup>

The systemic barriers that challenge the inclusion of people with disability cannot be overcome by single government agency policy making and need instead to be addressed in community by community organisations. The Opening the Door project, for example, which has focused on providing capacity-building to individuals who wish to have better housing options, is significantly impeded by the current housing crisis in Australia, and is focused on alleviating that crisis through systemic intervention, as well as continuing to deliver information support to people who need it. This project builds on the previous initiative of the ACT Housing Solutions Innovation project, which in turn led to a continuing forum focused on housing and support in the ACT, run by R&IA, and known as the Housing Solutions Innovation Group (HSIG). The HSIG meets regularly (every 6 weeks) and brings together people with lived

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<sup>2</sup> Stronger Community Organisations Project (2007), *Report of the Steering Committee*, p.11

experience and family members to discuss housing issues with housing providers, government departments and service providers, as well as funding agencies, and other Advocacy and peak groups. There is benefit to an established capability such as the HSI, to adapt and renew its efforts to meet challenges as they arise, and to innovate when opportunities arise, such as within the private rental sector. Grassroots initiatives like this need to be resourced if the community development that the NDIS requires is to be achieved.

There is a direct correlation between the perceived and actual lack of housing supply, and the enthusiasm for knowledge about how to access more independent living options, which currently is low because of a belief that it is beyond the reach of most people. This points to a more stable and long-term solution, in the form of an advisory service (or multiple advisory services, ideally placed around the country), to which people with disability can come for information, and which can also serve the purpose of being involved in discussions and negotiations, and innovations, at the local level to stimulate the availability of housing under better terms for people with disability. The Australian Disability Dialogue in its *Blueprint on housing*<sup>3</sup> has recommended that disability-led organisations take the lead in providing a specialist information and advisory service capability to assist people with disability “navigate the rental housing and support ecosystem, both for those who use the NDIS and those outside.” R&IA has made specific recommendations to the ACT Government for a similar service to be established, which could be replicated across the country.

**Recommendation f): The Executive of the NDIA should work with the Australian Government to:**

- e) Investigate and implement measures to be undertaken with the residential property sector (e.g., property developers, real estate industry, property managers) to address the housing needs of people with disability.**
- f) Increase investment in social and affordable housing to address current and projected shortfalls;**
- g) Investigate and implement financial measures to assist people with disability to purchase their own housing; and**
- h) Investigate and implement financial measures, including through tax concessions, to assist people with disability to rent suitable housing.**

**Recommendation g): The Executive of the NDIA should support the development of housing-disability forums in each jurisdiction – co-**

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<sup>3</sup> Obtained from website [www.australiandisabilitydialogue.com.au](http://www.australiandisabilitydialogue.com.au)

**designed and led by people with disability – to ensure comprehensive information sharing and systemic advocacy to address housing issues.**

The submission of the ACT Housing Solutions Innovation Group (HSIG) at Appendix B provides detail regarding initiatives that would allow greater choice across markets, if there was targeted investment made at the federal level, as well as the introduction of incentives to encourage the private market to make itself more available to people with disability. The NDIA Executive has to be more proactive in seeking from the Australian Government as a whole, and across individual portfolios and departments, these and other innovations which may provide better access to the already limited housing supply, and to improve the quality of that supply so that it is more available to people with disability. Currently the responsibility for addressing these issues to Government sits with the largely unfunded community sector.

Whilst there is a strong role for governments to work collectively to address problems which fall across a range of ministerial portfolios, there is also a role to play for community organisations, adequately resourced to be assisting in this. Again, the HSIG has already commenced some discussion within the community, government and commercial entities which meet regularly about how the private housing sector (rental and purchase) can better identify housing that is accessible, and to embark on a campaign of education to owners and landlords about the benefits of upgrading properties to meet the new standards in the National Construction Code (NCC), both those mandated and voluntary. This work is no doubt occurring across the country, but the lack of any resourcing for community groups to shoulder this responsibility leads to a lack of coordination and ultimately to the loss of momentum. The NDIA needs to recognise the benefit of investing in community organisations to do work which cannot be done with any success from within the policy bunker of a national government bureaucracy.

**Recommendation h): The Executive of the NDIS should work with state and territory governments to ensure their social housing operational policies allow households with disability to access social and affordable housing:**

- c) Paying full or part market rent;**
- d) As tenants in Specialist Disability Accommodation (SDA), provided by state/territory public housing authority (such as Housing ACT) as an SDA Provider**

**Recommendation i): The Executive of the NDIA should work to ensure that state/territory-owned land development agencies (e.g. Suburban Land Agency in the Australian Capital Territory) have operational policies that support eligible households with disability to:**

- c) Obtain residential dwelling lots outside of residential estate ballot processes; and**
- d) Purchase accessible affordable dwellings with the waiving of income eligibility thresholds**

The experience of R&IA, in terms of working directly with state or territory administrations has been predominantly with the ACT. The Housing Solutions Innovation Group (HSIG), which was an initiative of R&IA and National Disability Services in the ACT, has enabled an ongoing dialogue across people with disability and their supporters, housing providers, support providers and government departments. The HSIG's submission to the NDIS Review has drawn on its experiences in the ACT and identified the need for practical solutions to be worked out between states/territories and the Commonwealth, due to land title and the responsibility for building and tenancy regulation sitting predominantly at the state/territory levels. The submission of Cheryl Crilly and José Robertson at Appendix D addresses in some detail the specific policy areas within states and territories which need to be addressed, and the need for greater interaction between the state and territory bodies with the NDIA and other Commonwealth agencies.

Housing policies in states and territories tends to restrict eligibility based on income, and this hard line provides a further blockage to people with disability who may not qualify on income grounds, but for whom there is no other option in the private housing markets. This points to a need for greater flexibility in housing policy to enable states and territories to put into effect the provisions they claim to make for people for whom social housing is the only available option. Whilst all states and territories administer and regulate their housing markets differently to each other, there is an opportunity for greater harmonisation across the country when faced with such a crisis of supply and growing concerns about rental stress and discrimination. There is a role for the Executive of the NDIA to be more proactive in brokering the types of relationships and deals that are necessary with states and territories to alter policy and work on the supply of suitable dwellings.

## **5. Applying and getting a plan**

**Recommendation j): The role of Local Area Coordination needs to be redesigned and an alternative approach taken to the important task of “community development” that will address systemic barriers in the community, provide easier access to people with disability to everyday goods and services, and ultimately reduce reliance upon individualised funding to assist NDIS participants overcome these barriers. Ideally this community development will take place via the network of existing, and potential future, Advocacy services and Disability Representative Organisations.**

**Recommendation k): The role of Local Area Coordinators in assisting individuals needs to be redesigned to take on board many of the roles currently undertaken successfully by Coordinators of Support, and be funded outside of and separate to the NDIS.**

The *What we have heard* report highlights problems with the performance to date of Local Area Coordinators (LACs), in their role of providing “support to people with disability outside the NDIS” and their ability to “deliver community capacity building and link people to services or community activities as intended”. Outside of the report there has been criticism throughout most of the ten years of the NDIS’ operation about the sub-contracting of LACs to undertake tasks that should have been assigned to Planners/Delegates, effectively shuttering the latter behind an administrative wall and denying the NDIA the public interface that many of its participants expect.

This stems from a fundamental misstep by the architects of the NDIS, who chose to adopt and scale up the government-funded and administered model that operated with great success in regional parts of Western Australia since the late 1990s. In the context of individualised funding, but prior to the conception of the NDIS the WA LAC model had been talked about as part of the discussion about how individuals could be supported, in a partisan way, to conceptualise, build and administer their individualised plans (ie at pre-application, application, Plan development and ongoing administration and evaluation stages). The LAC model was very effective in coordinating community-based supports for individuals in regional WA because of the authority it brought (as a Government agency) to negotiations with other government and community agencies which might provide resources, such as housing, to individuals with disability who needed it.<sup>4</sup> The effectiveness was enhanced by the ability of LACs to call upon individualised funds from within the WA Disability Services Commission (DSC), when local resources were not available or adequate to meet an individual’s needs.

The NDIS’ LAC program was set up with none of the (government) advantages of its progenitor, and also confused the individualised role of WA LAC’s with a broader community development role. This community development role is crucial to the success of the NDIS, but is not well served by the LAC model. The LAC model itself, R&IA believes, is not the ideal way in which to assist people with disability to either apply for and manage their Plans, nor to assist individuals to navigate amenities and services in the community should they not require individualised funds to purchase goods or services.

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<sup>4</sup> See Bleasdale, M. (2007) *Supporting the housing of people with complex needs*, AHURI Final Report No. 104, Australian Housing and Urban Research Institute Limited, Melbourne, <https://www.ahuri.edu.au/research/final-reports/104>, p15.



Submissions to the Productivity Commission’s inquiry into Disability Care and Support (2010-2011) identified a role of “brokerage” which had been devised specifically to support people who were moving from traditional block-funded services into an individualised funding arrangement. The Submission by In Control Australia described how this role can serve to assist an individual, in a partisan way, to identify what they require and to assist them with achieving that:

The role of the broker in assisting people with disability to access the supports they require, in ways that suit them and those around them, has been in development since the devolution of the Woodlands institution in British Columbia back in the 1970s<sup>5</sup>

Submissions made to the Productivity Commission in 2010 identified the need for a robust and independent service structure to support the capacity of individuals who were to use the new NDIA to be able to be informed and empowered consumers. This structure was described as “Independent information, advice and representation” and was to be resourced by Disability Resource Centres, Independent planning supports (as per the description of “brokers” above), and Advocacy agencies – with the preference for the latter to be specifically resourced for Advocacy to people applying for and on the NDIS, in addition to the funding and provision of general Disability Advocacy<sup>6</sup>. None of these were implemented: the functions described for the Disability Resource Centres were sheeted to the ILC Grant program under the control of government; the independent planning supports given over to both LACs (as part of the government-led assessment process) and to Support Coordinators, who could only be purchased once a participant was accepted to the NDIS, and then with limitations; and Advocacy services were not provided with separate or additional funds to deal with NDIS matters, or assist people who were being denied, apart from specific allocations for, for example, AAT appeals when it became obvious that there were significant problems with the way in which the NDIA was administering the NDIS.

At the time of making these submissions in 2010, the argument was made in response about the confusion of roles that may emerge due to these new functions (e.g. brokers), and for the simplification of roles. R&IA would argue that there is now significant confusion of roles, mainly due to the “paywall” of the NDIS, such that some crucial supports for individual (such as Coordinators of Support) are only available through individualised packages. It is evident to us that when this function is done well it includes elements of good Advocacy practice, and works better when it is working partisan to the participant, both

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<sup>5</sup> In Control Australia 2010, Submission to the Productivity Commission inquiry into disability care and support, available [online]: <https://www.pc.gov.au/inquiries/completed/disability-support/submissions> (sub0570), p 23-24

<sup>6</sup> PWD 2010, Submission to the Productivity Commission inquiry into disability care and support, available [online]: <https://www.pc.gov.au/inquiries/completed/disability-support/submissions> (sub 524), p.21

when engaging with external parties (as was the expectation of LACs) and with the NDIA itself. For this reason, we are of the view that its functions are critical and need to be included in the redesigned role we envisage for the LACs, which sits external to the funding provided by the NDIA for eligible participants, and needs to be resourced instead by an Executive of the NDIA which has concern for the implementation of CRPD.

It is the view of R&IA that these functions need to be named something other than LACs. The original LAC model as it was conceived and implemented in WA, should perhaps be considered as a means by which to link people in regional remote and very remote areas of Australia to the NDIS.

**Recommendation l): The process for applying for individualised resources from the NDIA must be supported by administrative practices undertaken by Planners/Delegates which are geared toward the acceptance of individuality, in both personal characteristics and social and environmental circumstances, and which encourages and accepts a strengths-based presentation of each applicant’s aspiration – in accordance with the requirements of the NDIS Act 2013.**

**Recommendation m): The NDIA must subvert its current approach to assessing the eligibility and funding levels of individual participants to one which seeks to get to “yes” rather than “no”, and which uses indicative costing as guidelines for funding levels rather than treating them as hard funding categories.**

This submission has already identified the need for structural reform of the NDIA, to flatten the current structure to one which supports the ability of Planners/Delegates to interact on an individual basis (rather than through a set of pre-ordained funding categories) with existing and potential NDIS participants. The current structure of the NDIA encourages the elevation of decisions seen as above the capacity of Planners/Delegates to specialist teams at significant arm’s length from participants, in exactly the same way as these issues were dealt with under the state-based administrations which were responsible for the circumstances which were described in detail in the seminal publication *The Shut Out Report*<sup>7</sup>. Once abolished in the new structure of the NDIA, the resources can instead be deployed to determining how the CRPD can be implemented, and what needs to be done both within and external to the NDIS to achieve its aims.

In terms of supporting individuals who apply for or are within the NDIS the aims of the NDIS Act 2013 clearly point toward people with disability identifying and articulating their aspirations and goals. The experience of

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<sup>7</sup> Available at <https://www.dss.gov.au/our-responsibilities/disability-and-carers/publications-articles/policy-research/shut-out-the-experience-of-people-with-disabilities-and-their-families-in-australia>

people applying has been one of an administration that takes the position of blocking people rather than accepting them; and of requiring them to demonstrate their weaknesses and vulnerabilities, rather than promote their strengths and potential, which NDIS funding is meant to encourage and progress.

Appendix A illustrates the very painful journey of one participant onto the NDIS. Thankfully the person has been accepted onto the NDIS, but the candid detail in the interview, much of which is derived from the participant's blog, demonstrates how the NDIA requires a person to lay bare their desperation in order to be deemed eligible for funding. Importantly it also illustrates how the NDIA does not understand nor accept the concept of disability as defined by the World Health Organization (WHO) (multi-dimensional and inclusive of social and environmental factors), which has been articulated by the participant JH, nor the possibility that disability can be temporary and then permanent in the way that Multiple Sclerosis, for example can be intermittent and recurring. This inability to adapt to the reality of participants' experience demonstrates that the NDIA has been set up according to somewhat outdated bureaucratic principles which appear incapable of accommodating individual and nuanced requirements, and points to the abandonment of the much-celebrated actuarial approach to its delivery.

The recently released report by Dr Simon Duffy and Dr Mark Brown<sup>8</sup> has highlighted, amongst other things, the need for a “fundamental shift” in the thinking that currently underpins the administration of the NDIS. One element of this shift is to honour the rhetoric which was prevalent around the time of the scheme's launch, that people with disability were “experts” in their own lives and their requirement for support, emphasising choice and control. But this is not the experience of those applying to get into the scheme and on it, where there is a strong sense of mistrust of participants and a requirement to constantly justify receiving funds and resources to pay for goods and services. One of their principles for reform is:

1. Disabled people and those with chronic illnesses are fundamentally **trusted** and have principal roles in the oversight, governance, and administration of support systems (p.59, emphasis added)

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<sup>8</sup> Duffy, S and Brown, M (2023), *Redesigning the NDIS: An international perspective on an Australian disability support system*, Citizen Network Research, [www.citizen-network.org](http://www.citizen-network.org). Available [online]: <https://www.dana.org.au/online-dana-discussion-redesigning-the-ndis-report/>

The participant journey outlined in detail in Appendix A clearly identifies the entrenched and institutionalised mistrust that pervades the NDIA and is one reason why it needs to be radically overhauled and a new approach adopted that encourages a positive response to the requests for support to meet individual participant goals and address their daily needs.

## **6. Support and Service Marketplace**

### **6.1 Supported Disability Accommodation (SDA)**

R&IA's main involvement with the NDIA has been in relation to housing and support initiatives such as the Home and Living policy framework and Supported Disability Accommodation (SDA) program, and this section will focus in the main on our knowledge of the NDIS' performance in relation to providing Australians with disability with the housing of their choice. Our Opening the Door project has benefitted from the input of engaged NDIA officers who have been able to communicate the intent and the detail of the Independent Living Options and other initiatives which are hoped to be scaled up through the implementation of Home and Living, to enable people to have housing and support choices beyond the congregate ones which currently tend to predominate.

The co-designed initiatives of Home and Living are limited, however, by the approach of the NDIA generally to housing, and what many in the housing sector believe to be a less than successful overall approach to addressing the chronic undersupply of housing that is suitable for many participants, and non-participants, to live in. The problem facing the NDIS, and thus the NDIA, is a historic and wilful policy failure of design for diversity in the supply of housing across all markets, which is only now beginning to be addressed through the adoption of the Livable Housing Design Standard (LHDS) at the Silver level in the National Construction Code (NCC). In addition to the NDIA's lacklustre performance addressing systemic issues there have been numerous accounts of its inability to meet the very specific and relatively straightforward needs of participants who only need suitably accessible housing, and have the means to pay market rates, in order for them to lead full, active, participating lives as home makers, parents and workers.

The NDIA, in our view, does not have the relevant housing expertise to adequately address this entrenched problem, and should in future seek through its Executive function to work in collaboration with the housing sector, in particular the Community Housing industry, which has both the social charter and commercial and development expertise to rapidly plug the gaps in housing currently, and to model best practice in tenancy management and engagement. That said, it does have a responsibility to identify and articulate the housing needs of people with disability, and could take a more proactive role in gathering data and planning for these needs to be met.

**Recommendation n): The Executive of the NDIA should develop a short, medium, and long-term vision to define what NDIS home and living supports will look like over the next 15 years, with a clear pathway to achieve it.**

**Recommendation o): The Executive of the NDIA should develop and undertake a regular survey to establish the housing needs of people with disability.**

**Recommendation p): The Executive of the NDIA should develop and undertake an ongoing audit of national housing stock suitable for people with disability to quantify current availability and inform supply.**

**Recommendation q): The Executive of the NDIA should in future move to use the resources available to it for housing to directly engage the Community Housing sector to develop and manage housing that needs to be built to the specific requirements set out currently in the SDA program.**

**Recommendation r): The NDIA should incrementally wind back the current SDA program and target individual participants and their housing needs specifically, rather than attempt to address the chronic shortage of suitably designed housing through a broad approach of incentives for private developers.**

There is a good deal of interest in and criticism of the Specialist Disability Accommodation (SDA) program. R&IA is aware of some excellent apartment developments and also innovation in approaches that enable tenants to exercise choice and control over support providers in situations where the cost imperatives require a single provider to be allocated. But there remains significant concern about the SDA program incentivising the building of new congregate care facilities because of the profit margins achievable in that model. The submission made by Joseph Connellan<sup>9</sup> to the SDA Pricing Review in June 2023 has highlighted the recent deeming of currently allowable configuration or location as being considered “appropriate” contradicts the Contemporary Four-bedroom Group Home proposed in the NDIA Home and Living Consultation Paper. This illustrates our concern about the potential tokenism of the co-designed Home and Living Policy, if in fact it has no impact on the actual housing options that the NDIA makes available to participants. The submission identifies the significant cost blowout that SDA on its current trajectory will yield to the NDIS budget, estimated at \$35bn of NDIS funds over 20 years. By way of summary when the submission answers

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<sup>9</sup> Connellan, J. (2023) *SDA Pricing Review: Comments by Joseph Connellan MC Two Pty Ltd* June 2023 <https://www.mctwo.com.au/post/sda-price-review-june-2023-comments-by-joseph-connellan-mc-two-pty-ltd>

the question “Is the SDA pricing methodology fit for purpose?” it responds “No”.

In many respects we have gone backwards in the past ten years, both in the rights of people living in group home accommodation, and their options to choose alternatives, and in the separation of property management and support management. “Stewardship” as defined by the NDIA in this regard has little or no concern over these rights issues. The inability of the SDA program to provide housing for many participants who are eligible also demonstrates that the NDIA is not a successful player in the housing development market.

The submission made to the review by the Community Housing Industry Association (CHIA) points to the expertise of that industry in housing people with disability and managing tenancies, and argues “that engaging with registered Community Housing Organisations (CHOs) can effectively and efficiently deliver better housing for NDIS participants”.<sup>10</sup> This is an argument for a more direct partnership with this industry by the NDIA, rather than the NDIA attempting to operate in the difficult world of private property development – at least when it comes to scale building. The lack of willingness or ability for the NDIA to engage with wider housing issues, such as the issue of accessibility in the NCC, and in future opportunities such as the National Housing and Homelessness Agreement (NHHA) and the Housing Futures Fund (HFF) disadvantages all people with disability in Australia who require housing. It points to the need for the NDIA to admit its limitations and seek to progress housing matters systemically via the expertise of national groups like National Shelter, CHIA and the National Association of Tenants Associations.

Where the NDIA, at both its Executive and operational levels, can continue to innovate is by the development of bespoke housing for eligible participants, where other options are simply not available. The submission of Cheryl Crilly and José Robertson (Appendix D) provides a detailed set of solutions about how SDA could more effectively meet the stated aims of the NDIS to improve the quality of life of participants through housing and support. While some details of Cheryl’s journey are mentioned as part of the description of the solutions put forward, many punches have been pulled, and it does not fully articulate the horrendous damage done to Cheryl and her family as a result of the NDIA’s inability to address her fairly straightforward request through the rubric of their increasingly failing SDA policy framework. An intention of this submission is to give air to Cheryl’s situation, to illustrate more clearly how the NDIA has not provided a housing solution for a family to remain living together in housing that is accessible and functionally capable of enabling Cheryl to

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<sup>10</sup> Community Housing Industry Association 2023. *A Submission to the NDIS Review* <https://www.communityhousing.com.au/wp-content/uploads/2023/07/Good-Foundations-CHDN-Community-Housing-NDIS-Review-Home-and-Living-submission-FINAL.pdf> , p.1.

lead her own life and to take on the roles of being a positive contributor to the workforce, a mother, and a partner. Cheryl and José's submission speaks for itself. Its proposals are endorsed by R&IA and deserves special attention by the NDIS Review Panel.

## **6.2 Home Modifications**

The home modifications program of the NDIS has delivered significant amounts of funding to provide modifications to participant homes. Data is not available to scrutinise either the quality and effectiveness of those modifications, nor on what housing type and tenure they have been provided.

R&IA's Opening the Door project has identified significant problems for people with disability living in private rental accommodation having access to the modifications they require. The majority of renters with disability rent their homes in the private rental market. The NDIA's claim of "market stewardship" rings hollow in this regard and points again to a need for much greater advocacy by its Executive to housing and related initiatives, and the development of strategies which are increasingly acted on by organisations with genuine housing expertise.

**Recommendation s): R&IA has a strong preference for the establishment of a national home modifications program, similar in design to England's Disabled Facilities Grant, which through a housing appropriation provides the bulk of funding to individuals based on their mobility requirements relative to the home in which they dwell, and is not tied wholly to their eligibility to social care programs such as the NDIS or My Aged Care, or any other qualifying care/support based program.**

R&IA in its work, and through the associated interests and work endeavours of its staff and Board Directors, has good insights into the operations of home modifications nationally in Australia, and internationally by comparison. It is our observation that Australia has expectations both from its consumers and its governments that home modifications will be funded for those eligible, when compared for example with the USA and Canada where the bulk of funding for home modifications comes from private householders. That said, we do not have a comprehensive home modifications system, such as the Disabled Facilities Grant (DFG) in England, which is available to all people who experience mobility impairment regardless of age, and which in recent years has seen its budget allocation almost double due to the effectiveness of its results and the cost offsets seen in, for example, the Health budget due to reduced admissions to Accident and Emergency departments in hospital, and reduced and/or shorter admissions to residential nursing homes.

The UK Government announced an increase early this year<sup>11</sup> to the DFG, bringing it up to £675 million per annum from central government, topped up as required by the local authorities who are required to fund and provide modifications on demand. Even allowing for the larger population this represent a significantly greater investment in home modifications than is provided in Australia, despite it being means-tested and capped at £30,000 per applicant and the cost of modifications (trades and materials) being significantly less than in Australia. The approach in the UK is based on an understanding that homes have not been designed and built to accommodate diverse needs and levels of mobility impairment, and that a national approach is needed to address a systemic problem. Added to this are the results that have been evident in offsetting other costs associated with accidents and housing disruption due to poor design, which lead to a conclusion of a need for investment in **housing** which will benefit those living within it.

The NDIA has been set up in its current form with a therapeutic approach, and not one which understands or has the ability to deal with the systemic issues which need a broader policy approach rather than an individual therapeutic one. What is needed is a program which acknowledges the existence of a housing supply problem and funds the remediation of the housing barriers created by decades of poor planning and poor housing design standards in Australia.

**Recommendation t): The Executive of the NDIA should provide funds to Home Modifications Australia (MOD.A) to oversight quality in the home modifications sector, deliver and/or accredit training to builders, project managers and occupational therapists, and assist participants with resources to inform their understanding of how to be effectively involved in a home modifications process.**

The Australian experience is of devising systems which are broadly similar to each other, but which deliver to differently defined population groups, and thus provide different experiences with different costs attached. It is grossly unfair and inequitable, and a prime example of departments and ministerial portfolios operating in silos. Alongside the review of the NDIS the aged care system is undergoing its most significant reform in 30 years following the shocking allegations of abuse and neglect made explicit in the report of the Royal Commission in Aged Care Quality and Safety<sup>12</sup>. There is currently no information available about how home modifications will be delivered under the new In-Home support system, but it is likely that a grant system for eligible older people (eligible for care and support) will be established, with very limited caps on funding. Currently virtually all recipients of home modifications

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<sup>11</sup> See: <https://wwwFOUNDATIONS.UK.COM/102m-of-additional-dfg-funding-announced/>

<sup>12</sup> See: <https://agedcare.royalcommission.gov.au/publications/final-report>



under the Commonwealth Home Support Programme (CHSP) are required to pay a substantial contribution (usually around 40% of total cost), and the amount of total subsidy available is \$10,000. Those who rely on Home Care Packages have a varied experience based on their ability and the willingness of their package providers to keep funds aside for spending on home modifications. Technically this can be on a full cost-recovery basis, but will at times require client contribution as the amounts in the package are not adequate to cover the cost of the modification. Arrangements are different again for those who experience catastrophic injuries in car accidents, mostly full cost-recovery and evidence of significant whole-of-premises adaptations; and different again for Veterans.

This disjointed and siloed administration of home modifications cannot be described as a “system”, and when significant reforms such as those in aged care take place, or reviews of large schemes such as the NDIS are conducted, it is incumbent on those leading such initiatives to consider the potential benefits of consolidating a program into one which will may be strengthened by having a single method of assessment and delivery. The benefits that R&IA can see from a single scheme similar to the DFG relate to the ability for participants and clients and all who need modifications to understand the process; and the identification of a cohort of the building sector with specific expertise in home modifications construction and project management, and the ability to improve quality through active monitoring and certification of finished work, and through targeted training and other quality assurance toward that cohort.

Foundations UK has been successful in providing support to the industry which deliver home adaptations in England, and is funded by the UK Government to do this, as well deriving some income from training and other events it provides. This stands in contrast to the current arrangements in place for the Australian equivalent, Home Modifications Australia (MOD.A), which quickly adapted to the national approach of both the NDIS and aged care system by transforming in 2015 from a NSW-based association (the NSW Home Modifications and Maintenance Service State Council) to a national organisation with members nationwide and a Board which represented a diversity of involvement in home modifications as well as being from across the country. Whereas previously the NSW HMMS was funded by the NSW Department of Ageing Disability and Home Care to deliver a range of training and quality to the sector in NSW, once the NDIS had emerged this funding ceased and MOD.A was never able to obtain funding from any Commonwealth body, and ceased to provide support to its members in September 2017. This has left the industry with a diluted voice (MOD.A still represents the industry on a voluntary basis through its Board), and no capacity to deliver the quality training and oversight which is arguably needed now more than ever. The

level of funding provided to Foundations UK<sup>13</sup> by the UK Government, and the expectations of that funding, serve as a useful model to consider for funding MOD.A.

The lack of any funding to support quality in the home modifications sector has led to a paucity of data which can be directly related to client and other outcomes. The experience of NS (Appendix B) demonstrates how the lack of availability of a building contractor with relevant expertise in home modifications led to unacceptable delays in the delivery of the contracted work, and an extensive list of faults and defects with the execution of the work under contract. The “registration” of suppliers of home modifications providers in the NDIS serves in no way as a mark of quality, expertise or experience. Such a quality mark has to come from a viable and active industry association.

**Recommendation u): The Executive of the NDIA should consider the introduction of means/assets testing for home owners who require modifications, and require a co-contribution from those who are deemed to have access to assets and income that enables them to contribute and for whom the home modification will substantially increase the value of their property. This will bring it further into line with the way that home modifications are delivered in the Australian aged care system.**

R&IA is acutely aware of the additional cost impositions of housing to people with disability, due to the legacy of non-inclusive design that pervades all housing markets. The current practice of the NDIS, and the compensation schemes, to fully fund home modifications is laudable and in the vast majority of instances justifiable when other considerations are taken into accounts, such as assets and access to income. It is also justifiable as a broad policy when considering building new homes, when the cost of building something to an accessible standard (Gold or above) requires additional cost beyond the regular cost of construction. It is, however, not equitable when compared to the requirement for older people in the aged care system to have to make contributions for all modifications, unless hardship is evidenced, nor is it equitable if the relative wealth of NDIS participants is taken into account, particularly their assets and access to income. The payment for home modifications, similar to many payments made by the NDIS are based on principles of equality and not equity, so that the relative benefit to those who have more to begin with tends to be greater than to those who are modifying a fairly modest home.

Home modifications across all programs have been unsuccessful in making inroads into private rental properties, and this is going to increasingly impact

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<sup>13</sup> See <https://wwwFOUNDATIONS.UK.COM/> for details of how Foundations UK operates to support home adaptations in England.

on those people (we would argue the majority) who rely on private and other rental arrangements to make their homes. Whilst there is no direct connection between client contribution and the provision of modifications in rental properties, the relative disadvantage of participants living in those two different situations is exacerbated by what is available and what is not. In a more mature and resourced home modifications system in Australia it is possible that the principle of contribution could be inverted to focus on the government contribution to private landlords to incentivise them to improve their properties and make many more homes available to people with disability and older people in the short- and medium-terms across all markets.

**Recommendation v): The NDIA, if it is to continue to administer home modifications to eligible NDIS participants, needs to outsource participant applications for home modifications to a suitably qualified and expert assessment team, similar to the system in New Zealand which contracts out to Enable NZ, which can undertake thorough investigations and provide detailed solutions in consultation with the participant.**

During the trial phase of the NDIA, Home Modifications Australia (MOD.A) was tasked with visiting Enable NZ to understand how that organisation handled the assessment process for the NZ Accident Compensation Corporation (ACC) and made recommendations to the ACC for funding modifications, which were generally accepted. This was the recommended model proposed by MOD.A, albeit with some alterations to account for Australia's federated system, its larger population and the logistical challenges posed by its geography. There are benefits from this approach, in that it also offers a level of project management, not dissimilar to that offered within the English Housing Improvement Agencies when undertaking home adaptations through the Disabled Facilities Grant. Models exist in Australia to, notably icare's home modifications scheme in NSW, where project management is undertaken from within the agency, and builders and tradespeople are contracted on a preferred provider basis. Australia has the ability to implement a system similar to that which has worked effectively in New Zealand, through existing units such as that at icare, and also through specialist project managers in the community and private sectors throughout the country.

There have been many improvements in home modifications policy since the NDIS' initial focus solely on prescription on funding. The NDIA's current senior management team that oversees home modifications has a good understanding of the complex system of building and allied health in which home modifications are delivered. The structure of the NDIA, however, is such that it is R&IA's opinion that Planners/Delegates will never be able to have the level of understanding necessary to readily approve a home modification, and that the mechanisms set up within the NDIA do not allow for timely, fair, equitable or effective decisions about home modifications, nor have the capacity to innovate when circumstances such as those described by NS

(Appendix B) pertain. There was a deal of complexity to NS' application for home modifications, in that he was technically homeless (having sold his previous modified unit and needing to finance another), but his circumstances while 'between' homes is hardly exceptional or unique. There appeared, however, to be no way for the NDIA to provide in-principle approval for home modifications, which potentially could have led to an ongoing situation of homelessness for NS, unable to commit to purchase a unit which he may not be able to access. In NS' case the intervention of the State Minister for Disability's office was critical in forcing the hand of the NDIA to act.

Its inability to handle the complexities of ordinary life and dealing with the realities of the housing sector and the building industry leads us to conclude that, on balance, home modifications are better outsourced from the NDIA.

**Recommendation w): The NDIA, if it is to continue to administer home modifications to eligible NDIS participants, must mandate the use of project managers for modifications which are complex, and to fund and mandate follow-up inspections of completed modifications to ensure they are done in accordance with plans, and are fit for purpose.**

There is currently no mechanism available to test the effectiveness of the funds that the NDIS has spent on home modifications, on whether those modifications are effectively meeting the goals of the participants who have them, nor whether many of them are offsetting the cost of personal supports which may otherwise be required to assist people with the tasks of daily living in inaccessible homes. There are enough examples of the opposite, namely of Plans where significant funds are expended on supporting people to function in homes which cannot be made accessible because they are in the private rental market. Research has been conducted on the relative benefit of rendering homes accessible due to the offset of support costs<sup>14</sup>. And modifying a home to maximise the functional independence, and reducing reliance on paid supports, fits well within the insurance principles of the NDIS.

The interview with NS (Appendix B) indicates problems with quality of registered providers, which will be addressed below. It also highlights the difficulties that anyone can expect to have when effectively given carriage of managing their own very complex build. Home modifications, whilst individual options and choices are clearly central to the effectiveness and utility of the finished product, do include a range of building and construction activities which are delivered to standards which require specific expertise, and which are often beyond the ken of most consumers. This is why a suitably qualified

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<sup>14</sup> See Phillippa Carnemolla and Catherine Bridge (2011) Home Modifications and their impact on waged care substitution 1st ed. Sydney: Home Modification Information Clearinghouse, University of New South Wales. (July) [online]. Available from: <https://www.homemods.info/resources/hminfo-research-publications/occasional/home-modifications-and-their-impact-on-waged-care-substitution>

project manager is essential, not just having the knowledge about whether various tasks have been conducted correctly according to Plan and according to the National Construction Code and related standards, but also having the ability to negotiate with tradespeople and builders and have mistakes remediated quickly. Essential also within a home modification arrangement is the communication with the occupational therapist (OT) and the participant. In NS' case, project management was included in his package, but not visible in his Plan other than on the portal. Consequently the benefits of project management were not explained. In retrospect NS would have utilised these funds and it is likely the modification would have been done quicker, correctly and without the need for costly and time-consuming complaints, which are still to be resolved.

**Recommendation x): The Executive of the NDIA should take steps to monitor the quality of the home modifications that have been funded to date by the NDIS and introduce measures that demonstrate genuine “stewardship” over the strength and viability of a specialised home modifications industry. Data should also be collected about the availability of quality home modifications in rural and remote areas, and also to particular populations of the community, and to those in rental properties.**

A lack of data on the quality of home modifications limits this submission to anecdotal evidence only. The interview with NS has identified serious problems with the way in which the engaged builder, registered with the NDIS but not specifically expert in the delivery of home modifications, delivered a poor product which will end up costing the participant funds from their own pocket. There is further anecdotal evidence of price gouging by builders who know they are working for a NDIS participant, with one participant telling us that a bathroom renovation undertaken at the same time as her sister's (not an NDIS participant) cost her 25% more, for very similar work – and done in the same apartment complex! And, from the industry perspective there are stories about assessment work being undertaken over significant periods of time (up to 3 years in one case, due to participant input to options), costed and quoted, with the quote then being taken to a builder without home modifications experience and undercutting the quoted price. From the perspective of those who have been involved in home modifications for many years it would appear that the NDIA has taken on the role of market disruptor rather than market steward, and there is perhaps little incentive on its part to undertake an audit of both the quality of the product and the process.

There is a growing need for the collection of data relating to home modifications in Australia, which relate to quality, as discussed above, and also the availability of home modifications in rural and remote areas, and the extent to which people in particular housing types and tenures have access to home modifications. This should be an area prioritised by the NDIA Executive, and

ideally work should be funded and provided to a rejuvenated Home Modifications Australia to take carriage of.

The Opening the Door project has regularly come across the issue of people in private rental being refused home modifications, or being reluctant to ask for them in case this threatens their tenancies, in a market where rental is barely affordable. R&IA works with National Shelter and The National Association of Tenants Organisations to address legislation that protects renters' rights across the country to try and achieve greater harmonisation of regulations which will require landlords to provide justification as to why they will not allow modifications to be provided. R&IA continues to work with these national organisations which have expertise in housing matters, and which increasingly through our counsel and that of others are putting advocacy for disability housing on the mainstream housing agenda. This example should be noted by the NDIA which in contrast has shrunk from any engagement with crucial housing campaigns, including having the Livable Housing Design Standard mandated within the National Construction Code 2022. It points to the need to increasingly contract out and/or build capacity amongst agencies and associations already engaged in these matters and much better qualified and experienced than is the NDIA to handle them.

### **6.3 Plans for housing**

**Recommendation y): The Executive of the NDIA needs to develop a short, medium, and long-term vision to define what NDIS home and living supports will look like over the next 15 years, with a clear pathway to achieve that vision.**

This submission has identified that the NDIA in its current form is not well credentialed to address the shortage in housing supply and availability to people with disability. The submission has, however, identified a role for an enhanced NDIA Executive, or Office of Disability, to address housing matters across government, Australian and state/territory, and to facilitate solutions.

These recommendations are derived from Appendix C, which in turn draws on evidence from the ACT, but which point to a need for the collection of data, which will serve the needs of people with disability who require housing or who are in housing stress, and not the needs of government in need of data which serves to “manage” people with disability and track their “journeys”.

There has never been an audit of the housing stock in Australia, so, while there is a casual acceptance of the social model assertion that housing has been designed and built to a standard which excludes access as we understand it, there is no data to underpin that assertion. It would make sense for the NDIS to understand what the potential demand is regarding housing, both in terms of housing on the market and that in need of modification, before it determines its long-term approach to addressing the issue. This

points to some work being done that provides this data ahead of future determinations of funding applied to address this issue.

## 7. Reasonable and Necessary

The principle of “reasonable and necessary” appears to many participants and to those looking to the NDIS to redress the systemic disadvantage experienced by people with disability over centuries to be the guiding principle the NDIA’s funding decisions, one which prevails over “choice and control”. The NDIS has adopted a narrow framework for understanding disability, considerably narrower than that provided by the World Health Organisation, and which describes disability as a dynamic interaction between health conditions and environmental and personal factors.<sup>15</sup> Focusing on functionality tends toward a medical approach to disability, one at odds with the social model foundations of the CRPD, Australia’s Disability Strategy, and the NDIS itself.

The submission has already addressed the problems caused to people with disability who are denied access to the scheme, or experience significant difficulty in getting access, because of the raft of reports they are required to provide in order to “prove” they have disability and are thus eligible. This is linked to the problem of “reasonable and necessary”, in that one thing that needs to be satisfied is that the prospective participant is not able to obtain the support or resources they need from another source (e.g., hospital or other health facility), or that what is requested does not fall into the category of being reasonably expected to be a cost expense borne by the person in the course of ordinary daily living. This latter requirement demonstrates how the NDIS aims for equality of output to participants rather than equity of opportunity, as some systemic factors such as lack of education and poor housing significantly disadvantage some people with disability over others. Poverty and lack of access to any financial relief is a major dividing factor, and the NDIS appears to ignore this issue.

**Recommendation z): The NDIS must adjust its eligibility and funds allocation settings to take adequate account of each individual’s income, current living situation and previous opportunity or its lack when determining funding and resource allocations that are made to assist the participants achieve their stated goals.**

R&IA was fortunate to have the opportunity to meet with people living in an assisted boarding house, and speak to them about their experiences of the NDIS. Overwhelmingly this was positive, and it was pleasing to see how the individualised packages were making a positive impact on the lives of people who are and have been extremely marginalised within Australian society.

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<sup>15</sup> See <https://www.aihw.gov.au/reports/disability/icf-disability-health/summary>

Supports were largely in the form of social and community participation, which were widely appreciated. There was some issue however, about the ability of the NDIS to fund devices which would connect residents to the outside, such as iPads, iPhones and computers, and maintaining utility connections for these. Arguably such devices, generic though they may be, could be vital for people who experience entrenched poverty, as increasingly they are becoming essential for people to be able to participate in the way that the NDIS expects them to, and improve their lives such that in future they may be less reliant upon supports and funding. This is an example of a “one-size-fits-all” approach that is applied to everyone regardless of their financial circumstances – and it perpetuates inequities for many people with disability who experience poverty.

**Recommendation aa): The NDIS should consider providing an element of rental relief to participants who are experiencing extreme housing stress due to the rising private rental prices, to enable them to remain living in their homes and reduce the risk of homelessness.**

In addition to the historical housing barriers caused by poor design and planning, participants and other people with disability are currently facing a major crisis on the back of that experienced by all Australians. This is resulting in much greater housing stress and the real threat of eviction as landlords force up prices. There is an argument for the NDIS to intervene in the short term to provide financial relief to participants facing housing stress and possible eviction, until such time as systemic solutions have been put in place to provide this relief.



## Appendix A: Interview schedule – JH

### Q: Why did you apply for funding under the NDIS?

A: I saw a psychologist and began a relationship with a specialist that needs me to be introspective. It's been a rough, raw month. Childhood memories, trauma events, mistakes, reflections, and many conversations with my wife and younger brother about the 'meaning of life.'

We have concluded that life is messy and at times, unfair. Trauma is real, it impacts people differently, and is no less impactful or real to others. Trust me it's a lousy exercise to measure who the most fucked up one is.

I hate when people ask me why I have a neurological/brain disorder or why my legs wobble. I'm not too fond of it when people make assumptions or decide on my behalf what's going on for me. I have to accept many unknowns, and that's ok. While I do that, hopefully, I will get the opportunity to learn to move forward and enjoy things I have traditionally closed off; as an example, enjoy Christmas again. Whatever acceptance means to me about my disability, I know to embrace this.

I am in hospital again:

- Is this because I am in pain? Yes.
- Is this because I can't walk? Yes.
- Is this because I am unsafe at home? Yes.
- Does having a head full of family stressors contribute? Yes.

However, this is who I am for now. In the coming months, I am hoping for balance. Support at home from the NDIS would have kicked in, and equipment prescriptions underway will hopefully reduce the frequency of Hospital visits and maintain some level of independence.

- Although the NDIS does not want to talk about money, the amount I paid specialists, allied health and hospitals was not sustainable. The cost of 'maintenance', i.e. staying in the current state I am in now (unable to walk more than 200m independently with a walker, constant tremors, unable to do basic house chores, cleaning, cooking, basic personal care, and a permanent risk of significant falls). Over the last 12 months, I have not been able to attend anywhere independently and have been fearful of leaving my house. It costs \$1000 per week to 'maintain' my disability.
- I needed to keep the limited function that I had to be there for my family.
- I needed & wanted to continue to give back to the community and society, be a tax-paying individual and continue working.
- I needed to reduce repeated hospitalisations significantly impacted me and my family, whose dad was in the hospital every 8-12 weeks, and

they could see me physically declined and knew it was time for another hospital stay.

- I was informed by the social worker at the rehabilitation hospital that there were services that I could access to assist with keeping out of the hospital and longer-term recovery.
- My Family could not continue with the personal care and support needs required to keep me safe.
- I was a risk to myself, the community, and my family.
- I wanted to be Dad and Husband, I couldn't be this while stuck in a hospital or crippled with pain, tremors, and a repeated cycle that we were all fatigued and out of options.

**Q: What goals was funding from the NDIS meant to help you to achieve, and how did you believe the funding would work to achieve those goals?**

A: See below:

- The main goal was to keep me at home with my family.
- To be a true family, not one that was only in constant panic and fear of injury or extended hospitalisation.
- To assist with the financial burden, it cost tens of thousands of dollars to treat and support my disabilities, and this was not working and still resulted in repeat hospitalisation.
- We have a daughter with a disability, I was the main caregiver for her. I couldn't do this anymore without support.
- We had exhausted our savings and gone backwards, and at risk of losing everything.
- We have exhausted all treatment options for me, and I finally needed to accept that my disability was permanent and that I needed full-time care and support.
- Continue to be an active member of the community. Since the decline in disability, he has needed to stop attending church, social events, and family functions.
- Improve fatigue levels.
- I could continue the therapy that was required for my disability.
- I could obtain equipment that was required for my disability (bed, wheelchair, chair, and others).

**Q: What response did you receive from the NDIA to your application for funding?**

A: First application

- These are my words; all you get is a letter explaining what is not met and which part of the act, not an explanation. My information was from my telephone conversation with the NDIS review team.

The NDIS stated that my functional neurological disorder & chronic pain (my disability) is not fully treated.

Reasons -

- That I have not completed CBT (cognitive therapy) and other behavioural therapy therapies (complex mental health treatments).
- I have not completed a fall prevention course.
- NDIS did not believe that my crutches were medically prescribed.
- I needed a letter from my pain specialist – regarding my chronic pain to prove it was fully treated.
- I needed a letter proving that I do not have mental health (i.e., my trigger of FND is pain, not mental health).

This is what the NDIS wanted -

A Letter from my pain specialist outlining chronic pain – possibly try and link to FND (however, I have not been treated by my pain specialist re FND)

- A letter from my Neurologist stated that my FND is fully treated and triggered by pain.
- Completing a fall course (I don't even know what this is), however, have completed assessments as part of rehabilitation stays, and their assessments mention fall prevention.
- Confirmation that my crutches are medically prescribed.
- See a psychologist to confirm I do not have any mental health condition and would not benefit from CBT therapy.

I was unsure of what to do now and the next steps. Do I appeal with no additional evidence, or do I try and get a letter from my neurologist & pain specialist (however, this might take longer than 100 days).

Second attempt (appeal)

The example in the NDIS instructions and guidelines states that a commonly used item is like prescription reading glasses. This is a considerable stretch similar to a walking aide that still, for the most part, traps me in my home, car or workplace, unable to do things with my family and often misses out because of my inability to mobilise.

In short, the rejection was solely because I can use cheap, regularly available mobility equipment to enable me to walk and mobilise (even though this is done with great effort, prone to falls & need supervision and support when in crowded areas. I needed a prescription that you can't buy from a chemist. Or need to be 'more disabled' (paraphrasing here)

I am back to square one, encouraged by the NDIS to use my GP management plan and private health insurance to receive the support I require.

I applied for the NDIS to ensure I maintained my current mobility.

It ensured I could continue to work, pay taxes, and have a somewhat 'normal' life.

**The system is backward. It is set up to look for ways to reject someone's application. The scheme is not looking for ways to help the vulnerable and those who genuinely require the service.**

- I want to work.
- I want to have an opportunity to participate in civic and social activities.
- I need to be able to support and be available for my family.
- Without the NDIS support, I won't be able to continue the above long-term.
- I would need long-term repeated hospital treatment.

Information from the NDIS review is condensed below.

To meet the disability requirements the NDIA must be satisfied that all of the five criteria in paragraph 24(1) have been met.

**Criteria (a) on impairments** – a disability attributable to one or more intellectual, cognitive, neurological, sensory or physical impairments or an impairment attributable to a psychiatric condition.

**'I am satisfied that this criterion has been met for your neurological impairment resulting from Functional Neurological Disorder and your physical impairment resulting from Chronic Pain'.**

**Criteria (b) on permanence** – the impairments are, or are likely to be, permanent.

I am not satisfied that this criterion has been met for your neurological impairment resulting from Functional Neurological Disorder and your physical impairment resulting from Chronic Pain.

I understand you require and benefit from equipment such as Canadian Crutches. Reliance on such items is not considered substantially reduced functional capacity as the items required are considered to be 'commonly used items' rather than specialist equipment or technology that is specifically designed to increase the functional capacity and participation of people with disability. Section 5.8 of Becoming a Participant excludes commonly used items. If a person can mobilise with a commonly used item, then it will not satisfy the requirements of Section 5.8.

Also, as the evidence does not conclude that your diagnosis of Chronic Lower Back Pain (that triggers your neurological impairment of FND) is fully treated, stabilised, and permanent, further specialist information to determine the permanency of this diagnosis would be required before a determination can be made regarding your overarching functional impacts that are as a result from your neurological impairment.

Importantly, this criterion is not questioning the legitimacy or permanency of any diagnosis. Still, it is assessing the permanency of the impairment and functional impacts (for example, your reduced capacity for mobility, self-care etc.) that result from these diagnoses.

My National Disability Insurance Scheme (NDIS) journey has stalled again, with at least another 9-week delay. I will likely be in the hospital before this next meeting, still waiting for the NDIS to accept me into the Scheme. Not being able to satisfy the questions they asked my clinical team (More on this later).

I don't remember a time in my adult life I wasn't in pain. I have learnt to mask, tricks to take the edge off, faking it purely keep running anyways. I had a workplace injury when I was 20.

I am currently going through the Administrative Appeals Tribunal (more information here, [AAT](#) ) in short, an independent body that reviews decisions made by a commonwealth body (for me, the NDIS)

I have just concluded my second case conference. There was a simple instruction at the first case conference. For a medical professional, to answer some prepared (from the NDIS Lawyer and disputes team) questions. These questions were to focus on the following:

*“Section 24(1)(c) requires that the Applicant satisfy the Respondent that his Impairments result in a substantially reduced functional capacity to undertake one or more specific functional activities, being communication, social interaction, learning, mobility, self-care and self-management.”*

I got emotive in the hearing, explaining all the work I had done over the 12 months prior, the reports, the specialists consults, the thousands upon thousands of dollars spent on reports, working with a specialist OT going line by line over the NDIS access guidelines.

We still aren't being heard.

Although I had chronic pain and FND before 2020, I, for the most part, could independently manage all his care needs. I have been continuously employed as a senior manager in the disability sector.

Although I am educated, articulate, and driven to be the best in my chosen area of employment, this definitely has been an obstacle in interviews and reviews with the NDIS. Because I can't fit neatly in a box, its easier to say no and decline my claim.

The NDIS Guidelines state that an urgent decision can be made within 5 days (concerning accessing the NDIS Scheme) if:

- **The immediate risk to self, others, community or agency where appropriate Disability or informal supports are not in place.**
- **Unexpected, significant deterioration of disability-related functional capacity where appropriate Disability or informal supports are not in place.**

I would argue that this has been me since July 2022, and things are only getting worse. I don't fit easily into the NDIS's two categories, which articulate if you are likely either likely to meet the requirement or likely to result in having a permanent impairment.

My frustration is I have had my GP, Pain Specialist, Neurologist, Physio/s, Occupational Therapist, Rehabilitation Specialist, and Specialist/s Doctor of Occupational Therapy provide research-based reports/evidence on the permanency of my FND and chronic pain, all have written at-length stating I have a lifelong disability, with impairments that impact me every day.

My specialists have all stated that I will likely permanently require assistance from the NDIS to effectively manage the impacts of my functional neurological disorder.

All these specialists have strongly recommended I access the NDIS Scheme. We have provided significant evidence through specialist reports articulating my function concerning good days (baseline) and bad days (flair-ups).

Over the past 12 months, when I have been trying to access the NDIS scheme, these severe exacerbations can last up to 4 months. It is evidenced that approximately every 4 months (i.e. once rehabilitation supports as either inpatient or outpatient) I will return to the hospital (for 3-4 weeks of intensive rehabilitation, 7 days per week).

**Q: What do you understand to be specific grounds on which the NDIA first rejected your application and then continued to deny it?**

A: Three main issues were raised.

1. NDIS had still not considered that I have substantially reduced functional capacity as the items required are considered to be 'commonly used items' rather than specialist equipment.
2. They do not believe that my disability is not fully treated – in relation to chronic pain, I need evidence that I do not need further operations or procedures.
3. My disability is not permanent, and with concerns about the impairment and functional impacts, NDIS was not convinced that my disability impacted me enough.

**Q: What enabled you to eventually get your eligibility approved and a funded Plan put in place?**

A: A few factors:

- Pressure – I placed pressure on the AAT & NDIS with the volume of the evidence,
- I also spent time outlining my personal impact statement.
- I wrote lots of letters to NSW & Federal Governments.
- I formally complained to AAT & NDIS disputes and AAT departments.
- I worked with a disability organisation that donated their time to help me package my thoughts and needs into tangible goals.
- I kept telling my story and brought it back to my functional capacity and impairment.
- I understood the National Disability Insurance Scheme Act 2013 (NDIS Act), and when I did not understand, I asked questions, researched, and found the answer.
- I never gave up.

**Q: How long did the process take, from the point of preparing to make your first application for funding to the successful delivery of a Plan with funds attached?**

A: 18 months if you include gathering reports, speaking to doctors etc., from the application process. 8 months from submission to funds in the bank so to speak.

**Q: Did you incur personal expenses in the process of proving your eligibility for the NDIS?**

A: We have spent well over \$10,000 gathering reports over the past 2-3 years that assisted with my application. This does not include the top-tier health insurance that I have that has also assisted in the application process and hospital stays that were not afforded to me previously as a public patient; this cost a further. \$5000, plus the excess (\$500-\$1000 per year)

**Q: Based on your experience, what things could be improved within the NDIA's process for assessing eligibility for the NDIS?**

A: A number of things:

- NDIS assessment centres are set up where people can get proper advice, low-cost assessments, and help gather evidence.
- Advocates that understand how to navigate the NDIS and understand the NDIS ACT.
- Need funded pre-planners (like the coordinator of supports but before approval) to help build up evidence and talk through the process and requirements; the LACs are not helpful and will often palm you off if you are too complex or do not fit into the automatic approval categories.
- Too much time between rejections, review and AAT, this process should be quicker and NDIS / AAT should be there to help the client be approved, not with lawyers trying to find loopholes to reject.
- Fund initial 3-6 months NDIS funding pending full review or evidence, try to get early intervention working much better, not helpful for adults or complex cases.
- Remove red tape and make it easier for people to navigate the NDIS application process.
- NDIS should help when an error or missing information is found in the application, not just decline access requests.
- When the access request is declined, provide a written report, and explain in detail why, how to remedy, and some pointers on who to talk to.
- It takes too long for the application to plan enacted; it needs to get quicker and supports need to be in place once approved, not wait up to a further 5-8 weeks for the NDIS system to catch up and money is available to purchase services.

Provision of early Childhood Supports:

- There is real pressure on families to plug the gaps of under or no funding with NDIS, really labouring on informal supports to 'look after; and provide support for children, in turn reducing or gapping NDIS supports.
- Early intervention, families are confused about how the funding work and how to find a provider, scared to ask NDIS or LCA, and some are foregoing funding due to not having the skills themselves to navigate the systems and how support can crossover and or work with preschools & schools.
- NSW Government Schools and the NDIS do not work in partnership to the detriment of the child. Working through flexible timetables, therapists at school and working together for the best of the child was too hard.
- We pulled our daughter out of school halfway through year 11 due to a breakdown of her relationship with the school and therapist and a



balance between using NDIS supports and NSW education educators and supports. Although we had meeting after meeting my daughter's voice was not heard, and she was not put at the centre of the conversations. Her education and personal needs needed to fit in a neat tick box; because they didn't, she became a problem.

- When asking for a change of circumstances for my daughter, who was struggling with school attendance due to her disabilities, we were told that the only plausible solution was for my wife to stop working to care for my daughter, and the NDIS and School were not to overlap. Education was for between 9-3 pm, and NDIS was for outside these times. Because my daughter's needs didn't fit (she could only attend school 2 hours per day), the NDIS could not find a workable solution until I needed to apply pressure and explain the cost of my wife leaving. This took talking the problem to mediation and needing to involve NDIS lawyers etc. until a common-sense solution was sorted. If I did not argue, she would not have support, and our family would not have a home. They increased our support by \$90,000. (An increase of over \$87k). It took a suicide attempt, letters from specialists, and a month in adolescence mental treatment facility until someone listened.

## **Appendix B – Interview with NS re home modifications**

**Q: Briefly describe the circumstance that led to you requiring a home modification funded through the NDIS.**

NS: I previously owned a unit, which I bought before I was an NDIS participant, and it was modified by Disability SA. Due to the structural condition of the block of units, it became necessary to sell the whole block, including my unit. From the proceeds of the prospective sale I was in a position to buy another unit, and consequently bought a 3br freestanding unit in a housing estate. I tried to negotiate with the new owner of my previous unit to stay living there in the time between selling my unit and buying a new one, but due to the sale being complex, this was not an option. I then needed to go in crisis accommodation while I looked for a suitable new home that fit with the NDIS requirements for a suitable home to modify according to their guidelines – which, I might add, are quite murky as there is no formal process or guideline saying what is and is not acceptable. I was in Medium Term Accommodation (MTA) for over 12 months due to the process of buying a new home and waiting for the complex home mods completion.

**Q: What were the difficulties you encountered when applying for a home modification in a unit that you hoped to purchase?**

NS: The sale of my old house, without the ability to secure Medium Term Accommodation (MTA), meant that I was forced to use Short Term Accommodation (STA) funds to secure myself a place to live as there was not enough time to review my plan to accommodate the changing circumstances. I was not able to access MTA due to the lag between selling my old house and buying a new, suitable one, and it only would become available once I had bought my house – the guideline being that MTA is only available while one is waiting for modifications to be done. NDIS was also unclear regarding their requirements that would deem if the house I purchased was suitable for modification. I was unable to get an in-principle guarantee that home modifications were reasonable and necessary, and likely to be funded in any new purchased property – the justification being that I already had a modified property and had ‘chosen’ to sell, which was not accurate. This caused delays for me in buying somewhere to live, because I was hesitant to purchase a property only to be possibly told that the house was not suitable for modification. Market pressures at the time (mid-2022) contributed to delays in doing so, as houses were selling rapidly, often within hours, and so in-person viewing often was not possible to arrange.

I also sought answers, in cooperation with my Occupational Therapist, about whether I could remove and reuse any of my significant high-cost assistive technology from my previous unit, i.e. a bench lifter and a Neff Hide ‘n’ Slide oven, and a door automation mechanism (a removal cost of only \$4000), therefore providing value for money for any future modifications, as these

items alone were worth \$20,000 if purchased new. I met with high-level delegates in the NDIS home mods/assistive tech space who said that the NDIS does not fund removal of items as they are trying to keep accessible houses available on the market – however, in my case, the new owner changed the units to remove accessibility features. I was not provided with information about alternative ways to manage this situation. Again, due to no extension of a lease after the sale and no clear direction from NDIS, I had no choice but to pay for the removal of these items out of my own pocket, which I later had to negotiate with NDIS for reimbursement.

**Q: How did you manage to overcome these problems?**

NS: I had my State Disability Minister's office involved at two points: 1. To get a senior planner involved to get CHM funding though and; 2. When the SDA provider was not willing to accept my MTA funding and a new solution was needed. Although, senior planner 'pushed through' the complex home mods funding due to already being in crisis accommodation. This did not give adequate planning time to get a good outcome for home mods that are now completed.

**Q: You are now in your newly modified home. When did you move in and how long did the whole process take?**

NS: Modifications are now complete in my home, and I moved in in late July 2023. My house sale settled in September of 2022, after which I was able to action the request for home modifications. While this was ongoing, I was living in UCity Apartments (April 2022 – 16 Jan 2023) and then forced to move to Quest on Franklin (Jan – July 2023) when UCity would no longer accept my MTA in favour of a person with SDA funding.

**Q: What issues have you had with the process of modifying your home, once this was approved in your Plan?**

The modifications funding was rushed through as of Sept 2022 and I was then faced with a lack of availability of complex home modification providers. The earliest start date for a builder was January 2023. A builder was chosen, but negotiations were difficult due to lack of communications from the builder and lack of action from my then-Support Coordinator. Discussions were attempted in January of 2023, at which time I was in emergency negotiations to find new accommodation when UCity refused to extend my contract with them. This has meant that the modifications were done incorrectly and to poor standard, with multiple instances of the wrong plans being followed (the builder drew up plans that were vastly different from the complex home mods form completed by the Occupational Therapist), poor materials being used, poor workmanship, or some aspects of the modifications being completely missed all together -- all needing to be rectified. With my new support coordinator, we employed a building auditor to inspect the property, who pointed out numerous issues with

the work done by the construction company. The process of rectification is still ongoing and new tradespeople need to be sought.

There was also nothing written in my plan document (but apparently was on the portal somehow) about being funded for a building project manager – a fact that I was only notified of later by a new support coordinator, but by then it was too late to employ this person. This, I believe, is an administrative error that had far-reaching consequences. I am surprised that there appears to be no mechanism by which the NDIS oversees that the funding in such a high-cost area is being used fully and correctly, and ensuring value-for-money is being achieved.

There was also pressure from NDIS regarding the several rounds of MTA for which I was funded, and restrictions on how many times I could be funded, regardless of the state of the home modifications. This caused extreme stress to me every 3 months, as I was at risk of insecure accommodation. Ultimately I lived in a Quest hotel for 'extra' 6 months as this is all that was available to me while I was waiting for the builder to correct their errors.

**Q: With the benefit of hindsight what would you have done differently to manage the installation of your home modifications better and to your satisfaction?**

NS: Having access to a good and skilled Coordinator of Supports from the beginning of the process would have helped this process greatly. I had not engaged a support coordinator before this process, so I was unaware that the service being provided at that time was an unacceptable standard. As I mentioned previously, I could not see in my plan that was funded for a project manager and was not guided on how to correctly use this to better manage the modifications. I believe this was a large factor in not getting the correct oversight on the building process.

Also, if I had my time again, I would choose a building provider that was able to work collaboratively with me as a client to get the best outcome for me, rather than taking the approach of limiting my options to what they felt comfortable with. I would be more insistent on the element of choice and control, to ensure that the process always remained person-centred.

**Q: Finally, the NDIS Review wants to hear how the NDIS can improve. What suggestions do you have for how the NDIS can better provide home modifications, and avoid the problems that you have had to deal with?**

NS: My first suggestion would be to make more stringent the process for registration of complex home mods providers. There must be better ways of ensuring that the provision of these works is seen as a specialised area, requiring increased knowledge, and isn't just the realm of any builder who chooses to 'have a go' and can simply pay for registration and provide the correct audit documents.

Also, a specific problem in my case was that the registered provider outsourced ALL of their trades work to tradesmen who were not registered or trained in home modification, and therefore accessibility standards were not known, much less followed. I don't believe that this model should be accepted as a registered provider because it compromises the work, and therefore the value for money achieved by the NDIS funding.

There needs to be stronger ability for the NDIS to give in-principle approval in writing to a participant who is aiming to buy their own property, as otherwise this could prevent participants from entering into the housing market. There also needs to be more defined guidelines on what makes a property acceptable for modification in broad circumstances such as mobility disabilities, vision disabilities, etc. Otherwise, this creates a barrier by which the participant may then resort to other ongoing funding streams such as SIL, SDA, or other arrangements, increasing their funding requirements from NDIS, as they would be unwilling to make a purchase commitment; or, conversely, creates financial insecurity for the participant as they may risk purchasing a property with no guarantee that the property will be approved for modification.

I would like to see that, on completion of the works, a period of 'grace' is applied where the participant is able to use the modifications and ensure they are completed properly, before the provider is paid. I would also like to see that a participant is provided with funding for a building auditor or other suitable delegate to inspect the works and report back to NDIS regarding the standard and quality of the works. This would then allow the NDIS oversight to ensure that appropriate outcomes are achieved, and would highlight providers who carry out substandard works. Surely the NDIA is interested in ensuring that funds used for complex home modification are done to a high and acceptable standard and meet building standards. My overall experience does not reflect this.

# Appendix C: Submission to NDIS Review – ACT Housing Solutions Innovation Group

Date of issue: 31 August 2023

## About the ACT Housing Solutions Innovation Group

This submission has been prepared by the *ACT Housing Solutions Innovation Group* (HSIG), based in Canberra, ACT.

The HSIG's mission is to promote the housing rights of people with disability of all ages in the ACT, through both direct action and advocacy. It works across all parts of the housing continuum, from homeowners to renters, as well as service providers including specialist homelessness services, social housing providers, and specialist disability housing providers. Central to its efforts is the need to support people with disability to exercise choice and control in their housing choices, and for the housing system to broadly support and respond to the needs of people with disability. The HSIG draws together a broad range of stakeholders, including those with lived experience of disability, to meet these societal objectives.

## List of proposed solutions

The solutions listed below will ensure that the housing needs of people with disability are better addressed. Further details of each of these solutions are provided on the following pages.

- 1. Develop a short, medium, and long-term vision to define what NDIS home and living supports will look like over the next 15 years, with a clear pathway to achieve it.**
- 2. Develop and undertake a regular survey to establish the housing needs of people with disability.**
- 3. Develop and undertake an ongoing audit of national housing stock suitable for people with disability to quantify current availability and inform supply.**
- 4. Increase investment in social and affordable housing to address current and projected shortfalls.**
- 5. Investigate and implement measures to be undertaken jointly with the residential property sector (e.g., property developers, real estate industry, property managers.) to address the housing needs of people with disability.**
- 6. Investigate and implement financial measures to assist people with disability to purchase their own housing.**
- 7. Investigate and implement financial measures, including tax concessions, to assist people with disability to rent suitable housing.**
- 8. Fund a housing advisory service for people with disability, their families, and others, as a one stop shop for all housing options in a jurisdiction.**

9. **Support the development of housing-disability forums in each jurisdiction - co-designed & led by people with disability - to ensure comprehensive information sharing and systemic advocacy to address housing issues.**
10. **Ensure governments' social housing operational policies allow households with disability to access social and affordable housing:**
  - (i) **paying full or part market rent.**
  - (ii) **as tenants in Specialist Disability Accommodation (SDA), provided by state/territory public housing authority (e.g., *Housing ACT*) as an SDA Provider.**
11. **Ensure government-owned land development agencies (e.g., *Suburban Land Agency* in the ACT) have operational policies that support eligible households with disability to:**
  - (i) **obtain residential dwelling lots outside of residential estate ballot processes.**
  - (ii) **purchase accessible affordable dwellings with the waiving of income eligibility thresholds.**
12. **Invest in better outcomes for people with disability through public housing capital works, and repairs & maintenance programs.**

### **Overview of proposed solutions**

This submission to the NDIS Review is focused on housing-related outcomes, with reference to the NDIS Review Panel's *What we have Heard* report ('report'), published 30 June 2023. While reflecting considerations here in the ACT, we expect that there will be universal application of these solutions to a broad range of people with disability, across jurisdictions.

The HSIG recognises there are currently problems in the way that the National Disability Insurance Agency (NDIA) administers the NDIS, in particular housing. The HSIG welcomes the opportunity provided by the Review to identify solutions that will address these problems and identify ways in which the NDIA can more effectively deal with systemic housing issues.

The HSIG believes the concept of 'stewardship' should incorporate not just financially incentivising the market to deliver solutions but also leadership, safeguarding and regulation in the housing system. In particular, where there are clearly identified barriers that exclude people with disability from the opportunities that others enjoy.

The HSIG proposes solutions that encourage the NDIA to operate outside its current limited remit, while still working to deliver the outcomes laid out in the NDIS Act 2013. These solutions are associated with Part B, Sections 9 and 2 of the report's priority areas for improvement: '9. Supported living and housing' and '2. A complete and joined up ecosystem of support'.

### **Housing and People with Disability**

Housing is a critical determinant of quality of life for all in the community. For many people with disability, there are added challenges with a housing system that fails to provide appropriate, affordable, and accessible housing, with which they can easily engage. This is

the case across all income quintiles, with lack of housing supply, unaffordability for people on disability support pensions and age pensions, and unsecure tenancy forming barriers to living in suitable dwellings. The fulfilment of basic housing needs of people with disability - whether permanent or short-term disability – has a cascading effect on their life outcomes, particularly those who have intersecting issues such as poverty.

Since its founding in early 2020, the HSIg has considered a broad sweep of issues, ranging from detailed consideration of the ‘concierge’-type service approach with NDIS Specialist Disability Accommodation (SDA), through to opportunities for increased accessible housing provision through the ACT’s planning system. These issues have consistently signalled the need for a joined-up response by the NDIA, Federal, and state and territory governments, including through legislative reform in some instances.

As a consequence, the HSIg believes that there must be active stewardship by the NDIS, the Disability Reform Ministerial Council, and Housing Ministers to ensure the housing system aligns with Australia’s Disability Strategy and a properly inclusive society.

With direct reference to the NDIS, enduring themes expressed by non-government participants at HSIg meetings are:

- (i) The NDIA needs to do more of the heavy lifting on policy relating to housing and homelessness; for example, by pushing for the Australia-wide regulation of housing accessibility, which would clearly benefit the NDIS’s sustainability.
- (ii) The NDIA’s processes and ethos are a key obstruction to NDIS participants achieving their desired housing outcomes; they discourage people from obtaining what they want to achieve. We envisage a greater commitment to and development of participant-led, person-centred innovation, an intention flagged by the *Open Pathway* initiative led by the NDIA’s Home & Living Innovation Branch.
- (iii) The NDIS must provide equity of access to housing solutions for all people with disability.

The HSIg is keen to work with government and others to support this work. We note that some of the HSIg’s participants will also be making their own submissions to the NDIS Review.

## **Proposed solutions in detail**

- 1. Develop a short, medium, and long-term vision to define what NDIS home and living supports will look like over the next 15 years, with a clear pathway to achieve it.**
- 2. Develop and undertake a regular survey to establish the housing needs of people with disability.**

The HSIg believes the current supply and delivery of housing results in many people with disability of all ages falling through cracks in the housing system.

There is a clear case for a regular survey of people with disability in Australia, or a representative sample of them and their representative bodies, to establish unmet



housing needs across geographical statistical areas. This will support the meeting of a range of housing commitments by the NDIA, Federal, and state and territory governments, and would be done ahead of but in conjunction with the ongoing audit of national housing stock proposed to Solution 3 below.

Currently, neither the Australian Bureau of Statistics (ABS) through household surveys such as the *Survey of Disability, Ageing and Carers*, nor the Australian Institute of Health and Welfare (AIHW) collects sufficient data to suitably inform housing system-wide responses.

**3. Develop and undertake an ongoing audit of national housing stock suitable for people with disability to quantify current availability and inform supply.**

There is a critical need for the NDIS, and Commonwealth and state and territory governments to collaborate and jointly play a greater stewardship role to ensure that the housing system meets the needs of people with disability.

This audit, with data collected for geographical statistical areas, would be undertaken on a regular basis to support this stewardship role, informing capital works investment and other operational responses by government and others.

This would include, but not be limited to data collection through:

- (i) The ABS, which as part of the Census, collects data on the accessibility of homes, with such data to inform benchmarks for national accessibility of housing stock.
- (ii) Accessibility audits of social housing stock (e.g., *Housing ACT* in the Australian Capital Territory, and also that of community housing providers) to ascertain current and projected accessibility provisions.
- (iii) In relation to specialist homelessness services:
  - Data collection of the disability-related needs of people seeking accommodation assistance from specialist homelessness services, including barriers to NDIS engagement. This could be allied to the Australian Institute of Health and Welfare (AIHW)'s Specialist Homelessness Services (SHS) collection.
  - Accessibility audit of existing specialist homelessness service accommodation, and emergency/ crisis accommodation facilities to ascertain provisions for people with disability.

Further to this audit, there may be scope to identify prospective tenants and home purchasers with disability, for inclusion on a registry or similar mechanism so that social housing providers and others can interact with them to provide appropriate housing. This would also lessen the speculative nature of the residential development sector.

**4. Increase investment in social and affordable housing to address current and projected shortfalls.**

The current housing crisis, with the undersupply of affordable housing, does not require further reference here. However, there is a need to consider the additional challenges faced by many people with disability and those assisting them – and for national

measures (e.g., the National Housing Accord; the National Housing and Homelessness Plan) to synchronise with Australia's Disability Strategy, and similar state and territory disability strategies.

The proposed increased investment is ideally informed by Solutions 2 and 3, so as to best capture people at the margins of the housing system; for example, people with disability seeking discharge from hospital, and people with psychosocial disability needing a flexible housing response.

As part of this response, there is a need for the NDIS to:

- (i) Be a more effective market steward to ensure that appropriate affordable, accessible housing stock is coming into the market.
- (ii) Provide flexibility in planning that supports people into their own preferred housing options, with their preferred household members.

This includes supporting people with disability to move out of 'group home'/congregate settings and achieve greater autonomy, including with both their Supported Independent Living (SIL) funding but also with housing options. We note that in a natural environment, people would not typically choose to live with people based on their ability to access SIL funding from the NDIS. Yet the NDIS imposes this on people and providers through its funding models.

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There needs to be a commitment for all new, government-funded housing to be built at a level that complies with minimum accessibility standards with additional provision for identified people with disability. This would be at the National Construction Code's *Liveable Housing Design Standard's* 'Gold Level' or higher to ensure **habitability** by a significant proportion of people with physical disability. This will also increase the quantity of accessible dwellings over time, to allow people with disability to move house, like the broader population. The HSiG also recognises the need for broader consideration of housing design standards, to extend beyond physical disability, especially given increases in medium and high-density residential developments.

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Currently, private property landlords make up a large proportion of landlords for households with disability throughout Australia - with insufficient stock available for people with accessibility needs, and who may require longer security of tenure to receive funding for NDIS home modifications. Institution-financed, 'build-to-rent' developments - with the longer-term security of tenure that they provide - have a critical role to play in addressing the undersupply of appropriate, accessible housing for households with disability.

**5. Investigate and implement measures to be undertaken jointly with the residential property sector (e.g., property developers, real estate industry, property managers) to address the housing needs of people with disability.**

There is an identified need for the residential property sector to respond to the housing needs of people with disability - including through the diversity of housing product that it provides, its marketing, and in its engagement with people with disability as clients.

Market failure to deliver adequate housing stock to people with disability must be treated the same as other thin markets within the social and community care marketplace.

Consistent with Solution 3, a national registry or similar mechanism could assist prospective tenants and home purchasers with disability to identify their housing needs to the residential property sector. This could be maintained through a housing advisory service, as proposed to Solution 8 below. Married with this, there is a clear need for:

- (i) Training programs, in particular for property managers and landlords, about disability and housing.
- (ii) A universally applicable, mandatory identifier be developed for any sale/ rental listings of dwellings developed to meet accessibility provisions.

As we note in Solution 4, private property landlords make up a large proportion of landlords for households with disability throughout Australia. There is insufficient stock available for people with accessibility needs who may require longer security of tenure to receive funding for NDIS home modifications. We envisage an incentive scheme(s) to encourage private landlords to create more long-term tenancies to meet these needs.

**6. Investigate and implement financial measures to assist people with disability to purchase their own housing.**

Measures would include tax concessions and home equity purchase schemes, and also consideration of NDIS funding areas.

As part of any measures, barriers to self-funded SDA provision need to be addressed to afford households with disability the same opportunities to invest in owner-occupied housing as other Australians.

Similarly, for participants with a SIL package, the allocation of a small portion of a core funds or other funds towards capital - say \$15-20,000 of their plan per annum - could expedite their equity and ownership of a house. This would remove the burden on family, the insecurity of private rental, and costs to the NDIS in the longer term.

**7. Investigate and implement financial measures, including tax concessions, to assist people with disability to rent suitable housing.**

Private property landlords make up a large proportion of landlords for households with disability throughout Australia. There needs to be a range of incentive measures

introduced to support these landlords to make housing both accessible and affordable to people with disability – this includes through residential tenancy regulations.

**8. Fund a Housing Advisory Service for people with disability, their families, and others, as a one stop shop for all housing options in a jurisdiction.**

‘Everyone is struggling though the housing maze – would be good to help develop some clear pathways and understand who’s doing what.’

A Housing Advisory Service should receive recurrent funding, with the service to provide advice to participants and non-participants in the NDIS, their representatives, and others. Such a service would have both a physical address and online presence. We envisage that this is best provided by a non-government organisation(s), not affiliated with any other disability service or housing provider.

Importantly, this will ensure greater equity in addressing people’s housing needs, working across the broad range of barriers faced by people.

**9. Support the development of housing-disability forums in each jurisdiction - co-designed & led by people with disability - to ensure comprehensive information sharing and systemic advocacy to address housing issues.**

Similar to the ACT’s HSI, we expect that the secretariat and coordination role for these forums is best provided by a non-government organisation(s). Importantly, a breadth of stakeholders - including senior government agency representatives with decision-making responsibilities – needs to participate in these forums to ensure timely responses to existing and emerging issues. Findings from each forum, with common metrics, could be collected to support whole-of-system responses.

The forums could also have a role in supporting a housing advisory service, as part of a housing ecosystem (Solution 8 above).

**10. Ensure governments’ social housing operational policies allow households with disability to access social and affordable housing:**

- (i) paying full or part market rent.**
- (ii) as tenants in Specialist Disability Accommodation (SDA), provided by state/territory public housing authority (e.g., *Housing ACT*) as an SDA Provider.**

This solution would ensure that people’s basic housing needs are met where there is market failure, regardless of their income level.

**11. Ensure government-owned land development agencies (e.g., *Suburban Land Agency* in the ACT) have operational policies that support eligible households with disability to:**

- (i) obtain residential dwelling lots outside of residential estate ballot processes.**
- (ii) purchase accessible affordable dwellings with the waiving of income eligibility thresholds.**

- 12. Invest in better outcomes for people with disability through public housing capital works, and repairs & maintenance programs.**

# Appendix D - Submission from Cheryl Crilly and José Robertson

## ACCESSIBILITY SOLUTIONS

For submission to NDIS Review Panel

27 August 2023

The National Disability Insurance Agency (NDIA) website states:

- The National Disability Insurance Scheme (NDIS) provides funding to eligible people with disability to gain more time with family and friends, greater independence, access to new skills, jobs, or volunteering in their community, and an improved quality of life.<sup>i</sup>

Disability Ministers have asked for a review the NDIS aimed at improving the experience of participants and ensuring the NDIS is sustainable.

The Co-Chairs of the Independent Review of the National Disability Insurance Scheme have stated:

- *We are looking for solutions.*<sup>ii</sup>

The following solutions should be implemented in line with the NDIS principle of Choice and Control, and Value for Money.

- 1. Ensure the NDIA enables SDA Participants to use SDA payments flexibly.**
- 2. Ensure the NDIA enables SDA Participants to be assisted to become homeowners.**
- 3. Ensure Australian Government housing programs are accessible to SDA Participants.**
- 4. Ensure the NDIA reforms Medium Term Accommodation processes.**
- 5. Ensure State/Territory governments deliver on land supply for SDA Participants.**
- 6. Ensure the NDIA allows SDA Participants to utilise flexible design solutions.**
- 7. Ensure the NDIA provides formal SDA payment statements on request.**
- 8. Ensure State/Territory government housing eligibility guidelines address accessibility.**
- 9. Ensure Australian Government rent assistance guidelines address accessibility.**
- 10. Ensure the NDIA enables NDIS Participants to flexibly utilise their plans.**
- 11. Ensure the NDIA enables NDIS Participants to access legacy payments, e.g. Mobility Allowance.**
- 12. Implement an 'Australian Motability Scheme' to assist NDIS Participants to lease or buy personal transport, to increase their independence.**



## **ACCESSIBILITY SOLUTIONS**

### **Expanded**

#### **HOME OWNERSHIP SOLUTIONS**

##### **1. Ensure the NDIA enables SDA Participants to use SDA payments flexibly.**

The NDIA must:

- 1.1 Recognising the impediments that can prevent SDA Participants moving into SDA, enable them to 'bank' SDA payments from the time they are found eligible for SDA until the time they move into SDA – with the aim of enabling a smoother transition into SDA.

##### **2. Ensure the NDIA enables SDA Participants to be assisted to become homeowners.**

The NDIA must:

- 2.1 Reform the SDA Provider regime, to make it easy for eligible people to utilise SDA payments toward providing themselves with a home.
  - a. Participants who are SDA self-providers should not be subject to the same administration regime as other SDA providers.
  - b. While it makes sense for regulation to exist for SDA providers who are providing services to others, the additional burden of regulation should not be placed around the neck of SDA self-providers.
- 2.2 Examine innovative ways to assist people to become homeowners, e.g. by encouraging mechanisms such as 'community trusts', where friends and family of an SDA Participant without the necessary savings for a home loan deposit can contribute collectively to assist them – receiving appropriate rates of interest on their capital investment, while ensuring home ownership transfers to the SDA participant over time.

##### **3. Ensure Australian Government housing programs are accessible to SDA Participants.**

The Australian Government must ensure:

- 3.1 All Australian Government housing programs aimed at alleviating homelessness for low-income households through encouraging home ownership must be accessible to SDA Participants.
- 3.2 Any Australian Government shared equity scheme must be able to be accessed by SDA Participants, to maximise their ability to enter into home ownership.
  - a. If housing is viewed as a utility, rather than as a commodity, this Action Item could be implemented off-budget, on the understanding that initial outgoings would be returned over time.

##### **4. Ensure the NDIA reforms Medium Term Accommodation processes.**



The NDIA should:

- a. Reform the Medium Term Accommodation guidelines to remove references preventing people with approved SDA funding from accessing funding.
- b. Reform the Medium Term Accommodation guidelines to ensure the funding is made available until appropriate SDA accommodation is available.
- c. Provide people who have been found eligible for SDA with the equivalent of the current **\$137.15** daily rate of Medium Term Accommodation until they are able to move into appropriate SDA accommodation.

## **5. Ensure State/Territory governments deliver on land supply for SDA Participants.**

The Australian Government must:

- 5.1 Do all it can to ensure SDA Participants have access to land on which to build.
- 5.2 Not provide any housing-related funding to State and Territory governments unless they undertake to assist SDA Participants to easily obtain land on which to build.
- 5.3 Not forgive State and Territory housing debts unless those jurisdictions undertake watertight agreements to assist SDA Participants to easily obtain land on which to build.

## **6. Ensure the NDIA allows SDA Participants to utilise flexible design solutions.**

The NDIA should ensure:

- 6.1 In line with the principles of Choice and Control, where an SDA participant is planning a new build the SDA Standards should not focus on prescribed technical solutions; they should enable SDA Participants to determine the best way to achieve their desired outcomes.

## **7. Ensure the NDIA provides formal SDA payment statements on request.**

The NDIA should:

- 7.1 On request, provide an NDIS participant eligible for an SDA payment with a formal statement outlining the annual payment the participant is eligible for, the number of years they are eligible to receive that amount and how that amount will increase in line with CPI.
  - a. This statement must be in a form acceptable to major financial institutions.

## **HOME RENTAL SOLUTIONS**

### **8. Ensure State/Territory government housing eligibility guidelines address accessibility.**

The Australian Government should use all mechanisms available to it to influence State/Territory government policies, to ensure:

- 8.1 People with a long-term and permanent disability that significantly impacts their level of function, who qualify for an individual funding package as an NDIS Participant, are allowed to become State/Territory tenants.
- 8.2 People with a long-term and permanent disability that significantly impacts their level of function, are allowed to be tenants of a State/Territory housing system, rather than tenants of a particular home, and to be allowed to transfer between properties as their circumstances changed.

### **9. Ensure Australian Government rent assistance guidelines address accessibility.**

The Australian Government must ensure:

- 9.1 To align Rent Assistance criteria with the NDIS approach, given the extra costs people with mobility issues faces in obtaining accessible private sector rental accommodation, an additional eligibility criterion should be added, stating:

‘You can get Rent Assistance if you pay rent and you have a long-term and permanent disability that significantly impacts your level of function, and you qualify for an individual funding package as an NDIS participant.’

## **OTHER SOLUTIONS**

### **10. Ensure the NDIA enables NDIS Participants to flexibly utilise their plans.**

The NDIA should:

- 10.1 Take a more reasonable and reasoned approach to funding supports for people with disabilities.

### **11. Ensure the NDIA enables NDIS Participants to access legacy payments, e.g. Mobility Allowance.**

The NDIA should ensure:

- 11.1 To enable people to effectively and independently participate in the workforce, their NDIS plan contains provision for the annual payment of Level 3 Transport Support (**\$3,456**), if they are their own transport provider (noting this amount is less than the relevant DSS Mobility Allowance).

### **12. Implement an ‘Australian Motability Scheme’ to assist NDIS Participants to lease or buy personal transport, to increase their independence.**

The NDIA should implement a scheme based on the UK’s Motability Scheme<sup>iii</sup> to:

- 12.1 Enable people who are willing and able to be their own transport provider to have access to new, safe, modified vehicles to promote their independence and integration into the Australian community.
- 12.2 Recognising that by doing so the NDIS will achieve significant Value for Money in contrast with funding others to provide transport.

## ACCESSIBILITY SOLUTIONS

### Detailed

#### HOME OWNERSHIP SOLUTIONS

##### 1. Ensure the NDIA enables SDA Participants to use SDA payments flexibly.

The NDIA, in a media release titled *Housing and human rights – NDIS to deliver for people with disability*, has stated:

- The NDIS will transform access to affordable, stable and accessible housing by giving people with disability real Choice and Control around where they live and who they live with – a basic human right for all.

The United Nations Convention on the Rights of Persons with a Disability recognises, ‘the equal right of all persons with disabilities to live in the community, with choices equal to others.’

The NDIS exists to support people with disability to live an ordinary life, providing them with Choice and Control over the supports they need.

Affordable, stable and accessible housing is integral to that.

The current system of accommodation support is failing people with disability in Australia.

Australians with disability who are forced to live in unsuitable housing because there are no alternatives.<sup>iv</sup>

According to the 2016 Census:

- Family households made up **71%** of Australian households.
- Couple families with dependent children made up **36.8%** of Australian households.<sup>v</sup>

Having determined the level of SDA support it is willing to provide a Participant the NDIA should have no say with regard to the Building Type in which a participant chooses to live, resulting in the following key outcomes in regard to SDA policy are achieved:

- Enabling housing that fosters independence and autonomy.
- Creating more diverse accommodation options for NDIS Participants.
- Increasing participants’ Choice and Control in their SDA living arrangements.
- Ensuring a participant can commission a home that suits their individual needs.
- Giving participants more flexibility to live where they want and with whom they want.
- Enabling housing that maximises opportunities for social and economic participation.
- Helping to enable people with disability to live in high quality, accessible housing integrated in communities across Australia.

The importance of allowing an SDA Participant to utilise their SDA payments towards paying home ownership costs is demonstrated by the Final Report of the 2019 *Specialist Disability Accommodation Limited Cost Assumptions Review*<sup>vi</sup> statement that the build cost for a Standard 4-bedroom house at that time was **\$574,790**, whereas the build cost for a Fully Accessible 4-bedroom house was **\$963,634**.

The difference between these costs represents an additional impost of **\$388,844** a person in need of a Fully Accessible house must pay in order to live with their family at anything like an equitable level of amenity with 'ordinary Australians'.

Therefore, a person in need of a Fully Accessible 4-bedroom house must pay **67%** more than an 'ordinary' Australian to live an ordinary life at home.

Borrowing at the NDIA's assumed average mortgage rate of **5.2%**, to service a 25-year mortgage, means the total price premium a person with a severe disability must pay to live equitably with their family is **\$698,605** more than someone who can live in a non-accessible house (calculated using moneysmart.gov.au).<sup>vii</sup>

The NDIA's *Operational Guidelines* state:

- The NDIS takes a lifetime approach (i.e. seeks to minimise support costs over a participant's lifetime) by investing in people early to build their capacity to help them pursue their goals and aspirations resulting in greater outcomes later in life.<sup>viii</sup>

The NDIA's 2016 *Specialist Disability Accommodation Position Paper on Pricing and Payments* stated:

- Nothing in this Framework prevents the Agency from making other payments in respect of housing or accommodation arrangements.<sup>ix</sup>

The 2018 *Review of The SDA Pricing and Payments Framework* stated<sup>x</sup>:

#### *Recommendation 16*

- Remove unnecessary prescription from the SDA Framework that is inhibiting a varied or innovative response in the market.
  - This includes:
    - Assumptions around the 'rental model' and rental contributions preventing responses that integrate broader ownership and non-tenancy arrangements.

#### *Recommendation 18*

- Actively engage participants in decision making about different combinations of SDA and other support funding that will best help them meet their long-term goals.

## 2. Ensure the NDIA enables SDA Participants to be assisted to become homeowners.

### *Home Ownership is an Economic Right.*

In 2014 David Bowen, then CEO of the NDIA, wrote to Graeme Innes, then Disability Discrimination Commissioner, stating the following:

- The NDIA recognises there is a shortage of appropriate, accessible housing that meets the needs of people with disability and that without access to affordable housing that meets their needs some participants will not be able to achieve their goals and aspirations.

The 2016 Joint Standing Committee on the National Disability Insurance Scheme, *Accommodation for people with disabilities and the NDIS* reports states:

- Access to suitable housing is inextricably a part of exercising Choice and Control in any person's life, as recognised by the *Convention on the Rights of Persons with Disabilities*.<sup>xi</sup>

The NDIA stated in the 2021 *Consultation Paper: An Ordinary Life at Home*:

- An ordinary life at home means a sense of belonging, safety and security.
- You have the same rights as other Australians for physical, social, emotional, intellectual and economic development.<sup>xii</sup>

In 2011, the Productivity Commission estimated that around **28,000** people would require SDA:

- It estimated there was enough existing SDA- accommodation for 17,500 people, implying the need for new housing for an additional 10,500 people.
- In 2016 the NDIA projected the SDA program would house more than **23,000** people by 2021.
- By June 2021, there were **16,350** active participants with SDA supports.
- Although the SDA program has an expected budget of **\$700m**, by September 2021 only **\$214m** had been allocated.
- SDA funding methodology flaws remain central to its failure to deliver.<sup>xiii</sup>

In his National Press Club address of 28 April 2021 Minister Shorten stated:

- *The NDIA should be a market steward and leader.*
- *It should not delegate responsibility to the market.*

Minister Shorten has made statements such as:

- *NDIS Participants should be enabled and encouraged to become homeowners.*
- *Why should the 'big end of town' profit from the NDIS?*
- *There is a lack of policy imagination in the NDIA.*
- *If I become the Minister in a new government I will instruct the CEO to address this issue.*

The NDIA has:

- By making an assumption that people eligible for SDA payments are not capable of becoming homeowners disadvantaged the most disadvantaged Australians.
- Made an assumption that people eligible for SDA payments will not be in families, will not have partners and will not have dependent children.
- Overseen a clear case of market failure through not enabling and encouraging the construction of an appropriate number of accessible homes.
- Failed to properly provide market stewardship, by not flexibly working with participants to enable them to achieve their goals and aspirations.
- Created a convoluted set of rules that have resulted in a massive policy and program underperformance.
- Created an SDA Service Provider process that significantly disadvantages participants who want to become homeowners, by mandating compliance with a registration criteria, an auditing methodology and design guidelines that no other Australian homeowners have to comply with.
- Failed to achieve Value for Money, by overseeing a situation where Providers are building SDA accommodation speculatively, that sits empty, rather than working with participants to enable them to build home that suit them.
- Created a situation where it is actively encouraging the destruction of Australian families.
- By focussing on SDA as a rental solution, imposed a huge and unnecessary financial burden on the partners of SDA Participants.
- For a partner to live with an SDA Participant they must be prepared to accept they have no option to engage in the sharing of home ownership, as every other 'ordinary' Australian couple can.
- Effectively decreed the partner of an SDA Participant is a 2nd-class citizen, with no right to share in home ownership.
- Imposed intergenerational inequity on any children of the couple, who are decreed to have no right to inherit property on the basis of their parent/s disability.

In its 2016 *Specialist Disability Accommodation Position Paper on Pricing and Payments* the NDIA listed a number of principles, including:

- **Inclusion:** Participants to have the same housing opportunities as the broader community.
- **Independence:** Maximise independence and social and economic participation.
- **Choice and Control:** Allow participants their choice of providers of housing.<sup>xiv</sup>

The 2018 *Review of The SDA Pricing and Payments Framework* stated<sup>xv</sup>:

*Recommendation 16*

Remove unnecessary prescription from the SDA Framework that is inhibiting a varied or innovative response in the market.



- This includes assumptions around the ‘rental model’ and rental contributions preventing responses that integrate broader ownership and non-tenancy arrangements.

The NDIA must stop inventing ways to stop individuals from utilising SDA payments to build homes and let participants use their payments flexibly to become homeowners.

Encouraging SDA Participants to become homeowners would have the following positive effects:

- Positive longterm outcomes for the Federal Budget with no short-term deleterious effects:
  - SDA payments to participants would not be higher than payments to Providers.
    - SDA payments to participants would not continue once a mortgage is discharged.
    - SDA payments to Providers continue *ad infinitum*.
- Better overall health outcomes:
  - SDA Participants would feel more connected to ‘home’, and therefore be happier and healthier.

To quote Lisa Paul, Co-Chair of the Independent Review of the National Disability Insurance Scheme:

- *The scheme’s markets produce insufficient options – there are many places in which participants cannot exercise choice and control ... it’s not properly differentiated and incentives aren’t the right incentives.*

### **3. Ensure Australian Government housing programs are accessible to SDA Participants.**

Eligibility criteria based on income can assist the targeting of government programs, however income cannot be considered a determinant of a person's ability to obtain appropriate accessible accommodation if they have a long-term and permanent disability that significantly affects them.

The Australian Bureau of Statistics considers a person to be homeless if their current living arrangement is in a dwelling that is inadequate.<sup>xvi</sup>

As ACT Government Minister Rachel Stephen-Smith (then Minister for Disability) stated on 16 November 2018, at the *Having a Home Forum on Housing Options for People with Disability*:

- *Private accessible housing is a virtual impossibility.*

This Action Item accords with Recommendation 6 of the Joint Standing Committee on the National Disability Insurance Scheme's 2016 *Accommodation for people with disabilities and the NDIS* report<sup>xvii</sup>, which states:

- The committee recommends the Commonwealth government explore capital sharing, securitisation, and joint ownership options to expand the provision of appropriate accommodation for people with disability.<sup>xviii</sup>

The Australian Government once owned all housing in the ACT.

In the 1970s it enacted a policy of selling public housing properties to tenants who wished to own the properties.

Recognising public housing tenants were not necessarily in a position to save a deposit and obtain a mortgage from a financial institution, the government established and held fixed-rate mortgages, which people paying down over time, until titles passed in full from one party to the other.

If such an enlightened policy was able to be in place 50 years ago, the question arises, why could a similar scheme not work now, to enable people with a disability to become homeowners?

The Australian Government recently announced some significant and open-minded reforms the Home Guarantee Scheme.<sup>xix</sup>

This scheme and the Help to Buy Scheme should be fine-tuned to accommodate the financial needs of NDIS participants with SDA funding who are seeking to become homeowners.

These are mechanisms the Australian Government could easily use to ensure a level playing field for people in need of Fully Accessible homes.

The Minister for Housing & Homelessness issued a press release on 30 May 2023 stating:

- *All parents want to provide a stable home for their kids.*
- *That's why I've been working with the Prime Minister to make it easier for people to find somewhere safe and affordable to call home.*
- *Home Guarantee Scheme changes will help more families find safe places to call home, and work alongside our other housing plans.*

- *I'm proud to be part of a government working to deliver more security for Australians who need it most, including our nation's incredible mothers.*

#### **4. Ensure the NDIA reforms Medium Term Accommodation processes.**

The NDIA states:

- We fund medium-term accommodation so you have somewhere to live if you can't move into your long-term home because your disability supports aren't ready.
- To be eligible, you must have a home you'll move into and you need somewhere else to live in the medium-term.<sup>xx</sup>

It also states:

- We generally fund medium term accommodation for up to 90 days.
  - However, this can be extended in limited circumstances.
- We don't fund long-term rent.
- Other government and community services are responsible for:
  - providing housing and accommodation for people who need it
    - this includes making sure all Australians, including people with disability, have access to accessible, affordable and appropriate housing
  - emergency housing if you're homeless or at risk of becoming homeless.<sup>xxi</sup>

The reality is the ACT Government does not provide accessible, affordable, appropriate or emergency accommodation to people with a disability who need it if they have a job.

The NDIA has an obligation to fund medium-term accommodation until a person with a disability who has been found eligible for SDA payments is able to move into appropriate accommodation, with no caveats attached.

This obligation should extend to people in need of housing in other jurisdictions.

## 5. Ensure State/Territory governments deliver on land supply for SDA Participants.

The Australian Government should implement measures to ensure State and Territory governments deliver on their side of the Council of Australian Governments NDIA agreement with regard to land supply.

These measures should include, but not be limited to, ensuring NDIS Participants found eligible for SDA payments can choose from any available residential land on which to build an accessible residence.

At the National Press Club on 28 April 2021, when addressing *The future of the National Disability Insurance Scheme* Minister Shorten stated:

- *All levels of government should pull in the same direction.*

However, currently an ACT resident who has been found eligible for SDA payments must enter into a ballot to attempt to obtain land on which to build.

The 2019 *Specialist Disability Accommodation Pricing and Payments Framework*<sup>xxii</sup> states:

- Land that is owned by State Governments and leased/occupied by non-government providers could include lease arrangements (including 99-year leases) that are for nil cost, below market value (including peppercorn rent arrangements) or full market rental value.
- Where the cost of leasing/occupying land by a non-government provider is on a basis that is below market cost, then the cost is being met by a State or Territory government.
- The land component may form part of that government's in-kind contribution to the NDIS.

Underpinning this Action Item is the Council of Australian Governments *Principles to Determine the Responsibilities of the NDIS and Other Service Systems* states:

- All governments agree our vision is for an inclusive Australian society that enables people with disability to fulfil their potential as equal citizens.
- To achieve this vision, all Australian governments have a role to play.<sup>xxiii</sup>

Furthermore, Australia's *Disability Strategy 2021–2031* states:

- The Strategy speaks to our national aspirations to enshrine and elevate the ideals of respect, inclusivity, and equality.
- This is why all governments are committed to delivering on its principles.
- In line with Australia's commitments under the *United Nations Convention on the Rights of Persons with Disabilities* (UN CRPD), this Strategy will play an important role in protecting, promoting and realising the human rights of people with disability.
- This Strategy is based on the social model of disability.
- It recognises attitudes, practices and structures can be disabling and act as barriers preventing people from exercising their rights as equal members of the community.

- The Strategy focuses on removing barriers so people with disability can fully and effectively participate in and contribute to society.
- Accessible and well-designed housing supports independence and social and economic participation.
- Governments are committed to working together alongside people with disability, to implement this Strategy and realise its vision in a coordinated and targeted way.

To quote Bruce Bonyhady, Co-Chair of the Independent Review of the National Disability Insurance Scheme:

- *The current challenges with the NDIS will only be fixed if Commonwealth, state and territory governments work together.*

## **6. Ensure the NDIA allows SDA Participants to utilise flexible design solutions.**

The SDA Design Standards set out detailed design requirements that a new built SDA home must comply with.

Compliance with the Design Standards is mandatory, and is demonstrated by the submission of certification from an accredited SDA assessor attached to a dwelling enrolment application.

Compliance with the Design Standards is reasonable in cases where an SDA Provider is speculatively building a property, however it is not reasonable to enforce the Standards where an SDA Participant is planning a new build to suit their particular needs.

Specific clauses in the Standards would only have to be modified slightly to take into account the need for Choice and Control.

Of primary concern are some stipulations to do with heating and cooling which have the potential to create negative effects on the respiratory systems of participants, and some design clauses that are completely unnecessary.

## **7. Ensure the NDIA provides formal SDA payment statements on request.**

SDA Participants often experience great difficulty interacting with financial institutions, as they people with disabilities tend to have lower than average incomes, while experiencing higher than average living costs.

## HOME RENTAL SOLUTIONS

### 8. Ensure State/Territory government housing eligibility guidelines address accessibility.

Assistance from the NDIS is not means tested.<sup>xxiv</sup>

NDIS Participants who have significant disabilities should be exempt from State and Territory Government public and social housing eligibility guidelines that would otherwise exclude them from eligibility, e.g. criteria related to income.

For example, the ACT *Housing Assistance Act 2007* states:

- a. The main objects of this Act are –

*to maximise the opportunities for everyone in the ACT to have access to housing that is affordable, secure and appropriate to their needs; and*

*to facilitate the provision of housing assistance for those most in need.*<sup>xxv</sup>

Principle 1 of the Council of Australian Governments *High-level Principles for a National Disability Insurance Scheme* states:

- A National Disability Insurance Scheme should recognise existing best practice and build on this through foundation reforms to ‘support access to mainstream services such as housing’.<sup>xxvi</sup>

The Council of Australian Governments *Principles to Determine the Responsibilities of the NDIS and Other Service Systems* states:

- The interactions of people with disability with the NDIS and other service systems should be as seamless as possible ... supported by a no wrong door approach.<sup>xxvii</sup>

However, current policy settings result in people with disabilities who are employed being punished for seeking to be productive taxpayers.

Such people are made functionally homeless.

The Australian Government could consider extending the *Specialist Disability Accommodation Pricing and Payments Framework* statement that ‘Governments may directly provide accommodation services, and this may form part of their in-kind contribution to the NDIS’<sup>xxviii</sup> so the definition of ‘accommodation services’ extends to services provided to people with a long-term and permanent disability that significantly impacts their level of function, who qualify for an individual funding package as an NDIS Participant.

Underpinning this Action Item is the Council of Australian Governments *Principles to Determine the Responsibilities of the NDIS and Other Service Systems* states:

- The interactions of the NDIS with other service systems will reinforce the obligations of other service delivery systems to improve the lives of people with disability, in line with the National Disability Strategy.



- The interactions of people with disability with the NDIS and other service systems should be as seamless as possible ... supported by a no wrong door approach.
- Social housing providers will be responsible for providing accessible accommodation for people in need of housing assistance ... including appropriate and accessible housing for people with disability.<sup>xxix</sup>

In practice, what results in many cases is an ‘every door is wrong’ approach, for instance *Applied Principles – Housing and Community Infrastructure* states:

2. Housing and homelessness services will continue to be responsible for homelessness-specific services, including through homelessness prevention, outreach and access to temporary and long-term housing for people who are homeless, or at risk of homelessness.

and

7. The NDIS and the housing system will work closely together at the local level to plan and coordinate streamlined services for individuals requiring housing.

Implementation of this Action Item would assist the bottom line of State/Territory governments through an increase in cross subsidisation of other tenants and the displacement of construction costs, while increasing a government’s asset base.

Women should not have to choose between motherhood and accessibility.

There are no provisions for a salary earning tenant (paying market rent but staying for the access) to be transferred to a larger home.

This situation exposes the NDIA to potentially having to live in hotel accommodation – an absurd waste of taxpayer’s money for a substandard outcome.

## **9. Ensure Australian Government rent assistance guidelines address accessibility.**

NDIS Participants who have significant disabilities that preclude their ability to become homeowners but who are not eligible for SDA payments should be eligible for rent assistance if they choose to seek accommodation in the private sector.

The Services Australia website states:

You can get Rent Assistance if you pay rent and you're getting:

- [Age Pension](#), [Carer Payment](#) or [Disability Support Pension](#)
- [ABSTUDY Living Allowance](#), [Austudy](#) or [Youth Allowance](#)
- [Special Benefit](#)
- [Family Tax Benefit](#) – Part A at more than the base rate
- [Parenting Payment](#) partnered and single
- [JobSeeker Payment](#) or [Farm Household Allowance](#).<sup>xxx</sup>

Implementation of this policy will decrease functional homelessness at a minimal cost to the Australian Government, as people with disabilities will therefore be able to obtain larger rental properties, which often are more accessible as an unintended consequence of their construction and dimensions.

## **OTHER SOLUTIONS**

### **10. Ensure the NDIA enables NDIS Participants to flexibly utilise their plans.**

According to the *Reasonable and necessary supports guidelines*<sup>xxxii</sup>:

- An ordinary life is a life where you have the same opportunities as people without a disability.
- An ordinary life is one that is typical or usual for everyone in modern day Australia.
- It's a life where you can pursue your potential and participate in society on an equal basis with others.

NDIS Participants are constantly battling the NDIA with regard to 2 primary points of disputation related to how they can reasonably pursue something like the equivalent of 'an ordinary life'.

2. The amount of time and effort it takes to gain approval for expenditure on items that, to a disinterested observer, would appear to be indisputably related to a person's disability, e.g. the provision of a wheelchair, or a ramp into their house.
3. Whether or not an aid that could assist them to lead 'an ordinary life' is one that an 'ordinary' person could purchase on a whim, which therefore disqualifies it from being supplied as a reasonable support to a person with a disability whose life would be profoundly assisted by having access to the aid.
  - a. For instance:
    - i. An iPad, while a great entertainment device that someone without a disability could purchase as a discretionary spend, can be a vital communication tool that a person with a disability should be able to purchase through their NDIS plan.
    - ii. Instead of spending thousands of dollars on 'custom-made' shoes and billing the NDIA for them, a person with a disability should be able to buy appropriate shoes from a mainstream supplier at a significantly lower cost and have their cost reimbursed as part of their NDIS plan.
    - iii. While a person without a disability can upgrade a motor vehicle with 'luxury' options (e.g. automatic transmissions, adaptive cruise control, rain-sensing wipers, automatic headlights, or parking assistance aids), such technologies are able to greatly assist road safety for the participant and other road users, when the participant drives a vehicle with hand controls.

With the increasing mainstreaming of technologies the NDIA should reform its attitude towards what it does and does not fund, taking into account a participant's views.

## **11. Ensure the NDIA enables NDIS Participants to access legacy payments, e.g. Mobility Allowance.**

According to the DSS website<sup>xxxii</sup>:

- Mobility Allowance is paid to people with a disability who cannot use public transport without substantial assistance and are required to travel to and from their home to undertake work.
- Under the NDIS, participants have more Choice and Control over the types of transports covered.

According to the *Principle of 'no disadvantage' and the NDIS factsheet*<sup>xxxiii</sup>:

- Governments made a commitment – through the Intergovernmental Agreement for the NDIS Launch – that if you were receiving supports before becoming a participant in the NDIS you should not be disadvantaged by your transition to the NDIS.
- The commitment is that people who become participants in the NDIS should be able to achieve at least the same outcomes under the NDIS.

According to the NDIA webpage titled *Reasonable and necessary supports*<sup>xxxiv</sup>:

- Supports will help participants to:
  - pursue their goals, objectives and aspirations
  - increase their independence
  - increase community and workplace participation.

Participants should not be denied the equivalent of Mobility Allowance on the grounds that 'they drive their own [hand-controlled] car', disregarding the principles of Choice and Control and Value for Money.

In Value for Money terms, it would be far more beneficial for me to pay a simple annual payment equivalent to the Mobility Allowance, than to pay a provider to transport participants.

## 12. Implement an ‘Australian Motability Scheme’ to assist NDIS Participants to lease or buy personal transport, to increase their independence.

The NDIA should implement a scheme based on the UK’s Motability Scheme to:

- Enable people who are willing and able to be their own transport provider to have access to new, safe, modified vehicles to promote their independence and integration into the Australian community.
- Recognising that by doing so the NDIS will achieve significant Value for Money in contrast with funding others to provide transport.

Currently the NDIS utilises a convoluted and overly bureaucratic approach to assisting people with disabilities to provide transport for themselves, e.g. by paying for the fitting of hand-control devices to a car.

In order to qualify for assistance with regard to the fitting of the hand-control devices a participant must have already acquired at their own expense a car less than 5 years old, despite the fact that all other Australians are able to purchase any motor vehicle that suits them, regardless of its age, provided it is roadworthy.

Under the provisions of the UK’s Motability Scheme, in contrast, someone who has been found eligible for a Personal Independence Payment (PIP) is able to utilise it to pay for the cost of acquiring a car with appropriate adaptations fitted to it.

The PIP exists to help with the extra costs of living with a long-term health condition or disability.

*It is not means-tested, or affected by earnings or savings.*

If you’re awarded the PIP higher mobility rate you’re eligible to apply for the Motability Scheme.

Currently the PIP higher mobility rate is equivalent to **\$138** per week (**\$7,176** per annum).

If a person qualifying for the higher mobility rate lived in Canberra **7.5** kilometres from their workplace, and only worked **200** of the **260** work days of a year, they would incur **\$10,200** of taxi fares per annum if they caught a cab to and from work each day.<sup>xxxv</sup>

Moreover, the NDIS currently would be prepared to spend double that amount per annum, by having a service provider undertake this service.

This calculation does not take into account all the other reasons a person may want to drive themselves where they want to go when they want to go there, e.g. to pick up their child from school, attend a doctor’s appointment etc.

The UK’s Motability Scheme pays for the lease of a car through allocating the PIP higher mobility rate to a provider on a weekly basis – that’s it – the person with a disability incurs no other costs, except for what is known as an ‘Advance Payment’.

For example, a person with a disability wanting to drive a top-of-the-line 1.0 litre Ford Puma utilising hand controls:

- If a UK Mobility Scheme participant they must:
  - pay the equivalent of an ‘Advance Payment’ of **\$5,620**

- then, all lease/running costs are covered by the PIP.
- In contrast, an Australian NDIS participant must:
  - purchase the vehicle outright at a cost of **\$39,914**
  - fight for payment of the fitting of appropriate hand controls
  - face being told they do not qualify for Mobility Allowance as they 'drive their own car', and have to pay all running costs themselves.

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