



**Submission to the National Disability Insurance
Agency's *Home & Living* consultation**

10 September 2021

ABOUT CARERS AUSTRALIA

Carers Australia is the national peak body representing the diversity of Australians who provide unpaid care and support to family members and friends with a:

- disability
- chronic condition
- mental illness or disorder
- drug or alcohol problem
- terminal illness
- or who are frail aged

Our vision is an Australia that values and supports the contribution that carers make both to the people they care for and to the community as a whole.

We believe all carers, regardless of their cultural and linguistic differences, age, disability, religion, socioeconomic status, gender identification and geographical location should have the same rights, choices and opportunities as other Australians. They should be able to enjoy optimum health, social and economic wellbeing and participate in family, social and community life, employment and education.

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Carers Australia acknowledges Aboriginal and Torres Strait Islander peoples and communities as the traditional custodians of the land. Carers Australia is based on Ngunnawal and Ngambri country, and pays respect to and celebrates elders past, present, and emerging. As an inclusive organisation, Carers Australia also celebrates people of all backgrounds, genders, sexualities, cultures, bodies, and abilities.

Introduction

This submission is made in response to the consultation paper [Home and Living consultation – An ordinary life at home](#). The submission has been informed by the network of state and territory Carer organisations.

Carers Australia welcomes the opportunity to engage with and provide comments on these papers, and wants to work with the National Disability Insurance Agency (NDIA), other relevant area of government, people with disability, disability representative organisations (DROs), disabled peoples organisations (DPOs), and advocates to improve the National Disability Insurance Scheme (NDIS) for participants, carers, families and the community.

Carers Australia notes these consultation papers have been developed by the NDIA following the 2019 Independent Review of the NDIS Act 2013 (the “Tune Review”). The Department of Social Services (DSS) describes the current suite of reforms activities as seeking to “improve the NDIS” and “make the NDIS fairer, with better information for decision making, at less cost for participants and those applying to become participants.”¹

At the time of writing this submission, in response to widespread messages of concern from participants, carers, advocates, and peak bodies across the sector, Minister for the NDIS, Senator the Hon Linda Reynolds CSC announced independent assessments will not proceed.² The advice and recommendations provided in this submission may need to be revisited once the new person-centred model is developed and implemented.

Home & living policy considerations

Carers Australia affirms the importance of rooting all frameworks and policy about decision-making and choice in the [United Nations Convention on the Rights of Persons with Disability](#) (CRPD). Carers Australia believes people with disability have the right to make decisions, including where they live and who they live with.

In the consultation paper, the NDIA has outlined a range of challenges and problems currently experienced by participants, carers, families and advocates relating to home and living. The NDIA is congratulated for the progressive and future-focused thinking which underpins the home and living policy development process. However, Carers Australia is concerned the ambitions in this area will be undermined if the new policy is not implemented alongside a major ideological shift to full inclusion across all NDIA policy and NDIS operations,

Carers Australia supports the principles underpinning the draft home and living policy. This submission provides a range of recommendations to further nuance the proposed home & living policy to better meet the needs of participants, carers, and the community.

Making decisions about home and living

Carers Australia has also provided a response to the NDIA’s *Support for Decision Making* consultation paper. Please see this submission, provided through the ‘Have your say’ platform, as it outlines the key issues in current decision making processes, and offers solutions which will benefit participants, carers and the community. The NDIA must ensure it has developed and implemented an evidence-based, community-approved supported decision making process as it will underpin the new home and living policy.

¹ Department of Social Services (2020). *NDIS Reforms – Information Paper*. Accessed 19 August 2021 <<https://www.dss.gov.au/disability-and-carers-programs-services-for-people-with-disability-national-disability-insurance-scheme-2019-review-of-the-ndis-act-and-the-new-ndis-participant-service-guarantee/ndis-reforms-information-paper>>.

² National Disability Insurance Scheme (2021). *Independent assessments proposal*. Accessed 19 August 2021 <<https://www.ndis.gov.au/about-us/history-ndis/independent-assessments-proposal>>.

Safeguarding 'choice and control' for participants

In both 'home and living' and supported decision-making policy, the NDIA must include tangible safeguards to ensuring providers are not unduly influencing participants to only choose a home and living option provided by their organisation.

Recommendation: *The NDIA should provide a clear and simple pathway to report suspected undue influence must be easily accessible to participants, carers, family, friends or other supports.*

Improving home and living options for participants with a range of diverse identities

Empowering Aboriginal and Torres Strait Islander participants, carers and other supports

The NDIA, NDIS frontline staff, and NDIS providers must be responsive to the different needs of Aboriginal and Torres Strait Islander participants, carers, families and communities. Due to the actions of colonists and the systems of federation, many Indigenous participants have personal or familial trauma relating to segregation enforced through stolen generations policies. Participants may distrust services due to this history of abuse, exploitation, and discrimination from medical and social professionals towards Aboriginal and Torres Strait Islander communities.

Many of the home and living options currently available to participants replicate segregation and institutionalisation, particularly group homes. The NDIA must work with Aboriginal and Torres Strait Islander peak bodies, advocates, participants and carers to create future housing support options which are tailored and culturally appropriate so as to deliver culturally safe services to meet the participants' needs and choices. To create these culturally safe options, the NDIA must be guided by Indigenous leaders and will require whole-of-government collaboration and funding.

Recommendation: *The NDIA should work with Aboriginal and Torres Strait Islander participants, carers and community leaders to improve the breadth of culturally safe home and living options.*

The NDIA should also play a role in better capturing information about the experiences of Aboriginal and Torres Strait Islander people with disability. Both the Australian Bureau of Statistics and the Australian Institute of Health and Welfare have significant limitations in the data currently captured to inform policy and funding decisions relating to this cohort.³

Empowering culturally diverse participants, carers and other supports

The NDIA, NDIS frontline staff, and NDIS providers must recognise, respect, and respond to the varying cultural norms and expectations regarding home and living situations. Participants, carers and families from a culturally and/or linguistically diverse background may present with different approaches to and opinions about home and living options.

Similar to supported decision making, some participants and carers may feel shame or guilt about requiring support, or asking for help to change away from their current home

³ Australian Housing and Urban Research Institute (2017). *Housing and Indigenous disability: lived experiences of housing and community infrastructure*. Accessed 19 August 2021
<https://www.ahuri.edu.au/__data/assets/pdf_file/0028/13699/AHURI-Final-Report-283-Housing-and-Indigenous-disability-lived-experiences-of-housing-and-community-infrastructure.pdf>.

and living options. There may also be situations where a participant declines an option due to cultural reasons, and this decision must be respected by NDIS frontline staff and NDIS providers.

Recommendation: *The NDIA should work with multicultural participants, carers and community leaders to ensure participants have access to culturally appropriate home and living options.*

Empowering LGBTIQ+ participants, carers and other supports

The NDIA, NDIS frontline staff, and NDIS providers must be responsive to the different needs of participants, carers and families who belong to the LGBTIQ+ community. Due to a long social history of queerphobic abuse and rhetoric, many LGBTIQ+ participants may not be comfortable disclosing their gender identity, sexual preferences and other parts of their identity. Many older LGBTIQ+ people with disability will have experienced abuse due to their sexuality or gender, and will need trauma-informed options for home and living. LGBTIQ+ participants, carers and families who have previously been institutionalised may also have experienced trauma (from invalidation to abuse), especially in faith-based accommodation settings.

Where home and living options are not expressly safe spaces for this community, participants and carers will not be able to work towards the goal of full inclusion in an ordinary life. In supported accommodation settings, including group homes, there are a range of factors which need to be considered when evaluating whether a home and living option is LGBTIQ+ inclusive. These include:

- where underpinning policies are inclusive, ensuring the delivery of services and support in the home are also LGBTIQ+ inclusive,
- providing options for training other participants, carers and families connected to LGBTIQ+ participants in group accommodation settings to minimise participant-to-participant discrimination or abuse,
- providing training to staff about using inclusive language (for example, asking about a male participant’s “partner” rather than assuming he has a “girlfriend”),
- where residential staff are communicating with residents around sex education, ensuring messaging is LGBTIQ+ inclusive by partnering with organisations and community leaders who represent LGBTIQ+ people with disability, and
- introducing a “no tolerance” position on homophobia, queerphobia, transphobia and other discriminatory behavior in settings which currently have “no tolerance” positions on bullying. This will require both wrap around support for the affected participant, carer and family, alongside pathways for perpetrators to be engage in education and opportunities to practice inclusive behaviours.

Recommendation: *The NDIA should work with LGBTIQ+ participants, carers and community leaders to ensure participants have access to inclusive and safe home and living options.*

Implementation considerations

In moving beyond policy design and into the implementation phase, there are several core issues which the NDIA must consider and address. These include:

- aligning the home and living policy with the forthcoming *Australia’s Disability Strategy 2021 - 2031* and its Targeted Action Plans for implantation,
- working in collaboration with other government departments and agencies to ensure any reforms to construction regulation enables a greater supply of private and public housing which is accessible to and suitable for people with a range of disabilities,
- allowing participants to use their NDIS funding to subsidise their private or public rental,

- removing current systemic incentives for SDA providers which lock participants in to group home situations.

To ensure quality and timely progress reporting against targets, the NDIA must:

- work with the sector to collaborate on a reporting framework which clearly articulates accountability and responsibility for outputs and outcomes,
- develop time-bound targets and the actions required to meet them, and
- include participants and carers in the regular reporting processes.

Additional actions for Appendix D

In addition to the actions proposed in Appendix D of the consultation paper, the NDIA should consider the following to best enable carers to support a participant to make decisions about their home and living arrangements.

Changing the conversation

The proposed action “start a home and living ‘campaign’” must be properly co-designed with participants, carers, families and the community. A focus should be twofold; empowering participants to choose their home, and educating carers, families and communities on how best to support a participant to make these decisions. This will be a key driver of changing old attitudes and dispelling myths in the broader community about how people with disability should live.

Upskilling and providing tailored, up-to-date resources for carers and families about the whole range of home and living options available in their state will create range of benefits. Where a carer can support a participant to make an informed choice about their preferred living arrangements, this is both live true to the intent of ‘choice and control’ as well as reassure carers that the person they care for has been able to consider all available options.

Given the large number of children currently participating in the scheme, the NDIA needs to work with parents, carers, families and guardians to design resources which help people in caring roles to begin conversations with participants about living arrangements well before decisions need to be made. These materials should affirm a participant’s ‘choice and control’ while being realistic about the current market and its significant limitations. Parents, carers and guardians may also benefit from peer-to-peer support mechanisms, similarly to how parents, carers and guardians are supported by others within school communities when children begin new academic phases.

Updating the Operational Guidelines alongside providing mandatory training for LACs and NDIA Planners which is tailored to their geographical area will be a critical element of changing the conversation.

Reforming the funding model

Carers Australia affirms the importance of working with participants currently residing in “traditional housing models” (and their carers and families) to explore and design other options. This could provide participants with genuine choice and control in a way they have previously been locked out of in their decision-making.

While the NDIA will consider the market impacts of these changes, it is imperative that any changes to current models are at the request of participants, carers, families, advocates, and peak bodies, not service providers as they have an inherently vested interest in the current funding model.

Conclusion

Establishing evidence-based, community-approved processes which enable participants to make decisions about their home and living arrangements is critical to uphold the

human rights of people with disability, and to provide the 'choice and control' promised to participants by the NDIS. The NDIA currently has a unique opportunity to drive widespread reform to home and living options for people with disability and their carers, based on the progressive and future-focused policy ideas set out in this consultation paper. To further progress internal work underpinning the home and living policy, the NDIA must work closely with participants, carers, and families to ensure the policy and any associated operational guidelines both align best practice, and are practically applicable and tailorable to real life.