

10 September 2021

National Disability Insurance Agency
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Carers NSW welcomes the opportunity to provide a submission to the National Disability Insurance Agency (NDIA) on the Consultation Paper: An Ordinary Life at Home. This brief submission will focus on the positive aspects of the proposed home and living model as well as the policy and practice limitations of the model that reduces the choice and control of National Disability Insurance Scheme (NDIS) participants and their carers over their home and living options, and the quality and safety of these options.

Carers NSW is the peak non-government organisation for carers in New South Wales (NSW). A carer is any individual who provides care and support to a family member or friend who has a disability, mental illness, drug and/or alcohol dependency, chronic condition, terminal illness or who is frail. Carers NSW is part of the National Carer Network and a member of Carers Australia. Our vision is an Australia that values and supports all carers, and our goals are to:

- Be a leading carer organisation in which carers have confidence
- Actively promote carer recognition and support
- Actively support carers to navigate a changing service landscape that will be characterised by ongoing policy reform
- Promote connected community experiences and opportunities for carers that are inclusive of diverse carer groups
- Lead and advocate for carer-specific and carer-inclusive policy making, research and service delivery
- Continue to be a quality-driven, responsive and carer-focused organisation

Thank you for accepting our submission. For further information, please contact Melissa Docker, Senior Policy and Development Officer at melissad@carersnsw.org.au or on (02) 9280 4744.

Yours sincerely,



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CEO
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Introduction

Carers NSW thanks the NDIA for the opportunity to provide feedback on the NDIS home and living consultation on 'an ordinary life at home.' Carers NSW believes in the importance of autonomy and self-determination for people with disability and is supportive of policy and practice that facilitates their independence and meaningful participation in community life, including living in a home of their choosing.

Carers NSW recognises that not all people with disability receive informal support or would identify as having a 'carer'. However, family members and friends are important in the lives of all Australians, and the Australian Bureau of Statistics (ABS) reports that the majority of Australians with a reported disability who need assistance receive at least some of that assistance from a family member or friend; in many cases, on a daily basis.¹ Many people with disability also live with the family members and friends who provide this support.

Carers NSW commends the NDIA on recognising that home and living discussions are a fundamental part of support planning that should be embedded within the support planning process for all NDIS participants. Carers NSW also commends the NDIA for recognising the importance of including support networks such as family members or friends, where they may be present, in discussions regarding home and living options. Carers NSW has recently stressed the importance of including carers as supporters with decision making in our recent submission to the NDIA in response to the 'support for decision making' consultation, which is also running at this time.

While Carers NSW supports some of the proposed changes to the NDIS home and living approach within the consultation paper, we have concerns that a lack of appropriate, affordable accommodation options for people with disability will undermine the choice and control that NDIS participants have over their living arrangements. Additionally, challenges accessing NDIS funding for accommodation supports, inadequate support for informal carers, and concerns about the quality and safety of accommodation services are likely to further limit the effectiveness of the proposed changes.

Enabling choice and control in living arrangements

Ensuring appropriate, affordable accommodation options for people with disability

Carers NSW commends the NDIA on their acknowledgement of a need to move away from traditional models of disability accommodation such as group homes and institutions. While some people with disability may prefer to live in a communal environment for social and financial reasons, many people with disability would prefer to live independently, either living alone or with a partner, friends or relatives.

While Carers NSW supports the right for everybody to live in a home of their choosing, Carers NSW has concerns that the significant unmet demand for social housing and ongoing rise in rental costs in NSW will inhibit NDIS participants and their carers, especially where they choose to reside in the same household, from exerting choice in regards to their living arrangements. While the NDIA has noted that they intend to fund Specialist Disability Accommodation (SDA) for a small proportion of participants,² Carers NSW has concerns that many NDIS participants and their carers, with whom they choose to live, will experience significant challenges with obtaining and sustaining appropriate accommodation without support with bricks and mortar costs or greater financial support to meet the rising cost of rent.

¹ Australian Bureau of Statistics (2019) *Survey of Ageing, Disability and Carers 2018*, TableBuilder Dataset, available online at: www.abs.gov.au

² National Disability Insurance Agency (NDIA) (2019), Specialist Disability Accommodation, available online at: <https://www.ndis.gov.au/providers/housing-and-living-supports-and-services/housing/specialist-disability-accommodation>, viewed 26 February 2020.

As at 30 June 2020, there were 46,087 applicants on the NSW Housing Register, awaiting a public housing dwelling to become available.³ There were 5,308 applications for priority housing outstanding. Most allocation zones indicate an expected wait time of at least 5 years.⁴ Where people with disability require an accessible dwelling to enable them to move around their home safely, wait times can be even longer. Additionally, carers report ongoing confusion regarding responsibility for the funding of home modifications in public housing dwellings in NSW, making it even more challenging for participants and their carers to secure appropriate accommodation in public housing.

As a result of significant delays accessing public housing in NSW, many people with disability and their carers have no alternative than to enter the private rental market, however, they are often significantly limited in choice of location and dwelling due to growing rental costs and limited availability of accessible dwellings. Anglicare has recently estimated that only 0.5% of Australian rentals are affordable and suitable for a person living on the Disability Support Pension.⁵

In cases where participants require additional financial support to secure appropriate accommodation, not only are they limited in their housing options, but in many cases this support is provided by their informal carers, who often experience financial hardship themselves due to the impact of their caring role on their ability to work and additional costs associated with caring. The Carers NSW 2020 National Carer Survey⁶ (the Survey) found that of respondents caring for a person with disability, almost one in four (24.8%) contributed to the accommodation costs of the person that they care for, compared to approximately 1 in 6 (16.5%) for other carers.

The Survey⁷ also found that carers of people with disability were more likely to report contributing to the costs of home modifications for the person they care for (15.6%) when compared to other carers (11.5%). Carers NSW has heard from carers that in some cases they have had to fund urgent home modifications to enable safe access to, or movement around, a dwelling for the person they care for, as it often takes a substantial period of time to have home modifications approved and funded under the NDIS.

Furthermore, in order to be able to afford accommodation costs, many people with disability and their carers have no choice but to live in inaccessible or unsafe dwellings on the fringes of developed areas or in regional areas where accommodation is affordable. This is often further away from the services and supports which facilitate optimal outcomes for participants and may require greater practical or financial support from carers with transport. In many cases, living in these arrangements limits the independence of a participant, as well as the inclusion and participation of a participant and their carer in the community, as it is more difficult to access community infrastructure as and when they need to.

Carers NSW believes that in order to provide NDIS participants and their carers with true choice and control over their living arrangements, the NDIA must acknowledge the systemic barriers to housing options that participants and their carers face and take active steps to address them. Carers NSW recommends that the NDIA:

- Develop a broader housing strategy for NDIS participants that addresses housing issues for participants beyond the SDA market
- Expand eligibility for SDA to enable more participants to access SDA
- Invest in accessible public housing

³ NSW Department of Communities and Justice (2020), *Expected waiting times*, available online at: <https://www.facs.nsw.gov.au/housing/help/applying-assistance/expected-waiting-times>

⁴ Ibid

⁵ Anglicare (2021) *Rental Affordability Snapshot 2021*, available online at: <https://www.anglicare.asn.au/publications/rental-affordability-snapshot-2021/>

⁶ Carers NSW, (2020b). *2020 National Carer Survey, unpublished data*.

⁷ Ibid.

- Coordinate with the Australian Government to implement legislative requirements for new dwellings to comply with universal design principles
- Provide additional financial support to meet rising accommodation costs for NDIS participants and their carers

Improving access to Specialist Disability Accommodation (SDA) and Supported Independent Living (SIL)

While some people with disability choose to live in supported accommodation arrangements, for many, funding constraints have historically limited their accommodation options. The transition to the NDIS has seen the introduction of funding for Specialist Disability Accommodation (SDA) (bricks and mortar) and Supported Independent Living (SIL) (services and supports in the home that facilitate independent living).

The shift from traditional block funded accommodation models to individualised accommodation support funding has diversified accommodation options for some people living with disability. However, many carers have reported ongoing difficulty accessing SDA and SIL funding to enable the person they care for to exercise choice and control over their living arrangements.

Carers have reported to Carers NSW that gaining approval for SDA and SIL under the NDIS is complex, time consuming and places undue stress on carers who often support their care recipient with advocacy and administrative tasks. Carers have reported that delays and complications accessing NDIS funding for supported accommodation, whether in an independent or group setting, have resulted in extended hospital stays and risk of homelessness. Additionally, where approval for SDA has been provided by the NDIS, some participants have been unable to access their preferred independent living options due to SDA market shortages.

Furthermore, some carers of NDIS participants who would like to live independently have reported to Carers NSW that they have felt pressured by NDIS representatives to place their care recipient in a group home setting during NDIS planning meetings, raising concern for the future security of accommodation arrangements. Beyond accessing funding, participants and carers must also be supported to understand and explore accommodation options available to ensure that participants have optimal choice and control over where they live and who they live with.

While Carers NSW acknowledges the introduction of additional line items funded under the NDIS to support the development and facilitation of Independent Living Options (ILOs), Carers NSW believes that the NDIA must continue to address barriers and delays associated with the funding of more complex accommodation arrangements to reduce strain on carers and enable better outcomes for participants.

“When my sister was homeless, I couldn't get any accommodation providers to offer us a placement in a group home unless I had the accommodation costs factored in the NDIS plan. However, the NDIA person would not provide those costs whilst she was homeless but wanted to wait until she was placed into care and receive a quote from the group home. My sister spent 12 months living in a hospital mental health ward and missed out on 6 placement offers because we didn't have that money...”

Carers NSW 2018 Carer Survey respondent

Meeting carer needs in home and living arrangements

Carers NSW commends the NDIA on recognising the need to include support networks, including family and friend carers in discussions around home and living arrangements with participants. Carers often assist NDIS participants to express their will and preferences and can provide a significant level of care or support on a daily basis, whether they are residing together or in different households. Carers of NDIS participants who responded to the 2020 National Carer Survey⁸ estimated that they provide on average nearly 60 hours of formal, care per week.

Carers NSW believes that beyond including of carers in discussions regarding planning home and living supports, there must also be consideration of carers' own needs, including respite, during these discussions to ensure the sustainability of caring arrangements, which form the foundations of sustainable home and living arrangements for many people with disability. Carers NSW has heard from many carers that during NDIS planning discussion, there have been limited opportunities to express their own support needs in order to continue providing care. This can then limit the subsequent funding available under a participant's NDIS Plans to facilitate supports that enable carers to take breaks from their caring role and help to sustain caring arrangements.

The 2020 National Carer Survey⁹ found that just over one third (35%) of respondents caring for an NDIS participant reported that they were asked about their own needs during NDIS support planning. The survey also found that while more than half of respondents (55.2%) agreed that supports provided under an NDIS plan met the participant's needs, less than one third (28.8%) agreed that NDIS supports met their own needs. Additionally, less than half of respondents agreed that supports provided under the NDIS enabled them to take a break from the caring role.

Where a participant prefers to live with their carer, or to live independently with support from their carer, there must be adequate supports available to ensure that these caring arrangements, and in turn a participant's living arrangements, are sustainable. Carers NSW has significant concerns that where adequate supports are not available to enable carers to focus on their own health and wellbeing or participate in education or employment activities, preferred living arrangements for NDIS participants may be jeopardised, and participants may have no choice but to move into alternate living arrangements where informal caring arrangements breaks down.

Any breakdown in caring relationships resulting from inadequate support for carers is likely to not only jeopardise the housing security of NDIS participants, but will also have significant emotional impacts on participants and their carers. Carers NSW believes that in order to sustain informal caring arrangements and in turn participants preferred living arrangements, carers' needs must be considered in the planning of home and living supports.

Improving the quality and safety of accommodation services

It is essential that NDIS participants living in supported accommodation, their families and carers have the opportunity to address any issues or complaints they have in regard to the quality and safety of services, whether directly with their service provider or through advocacy support. It should be noted however, that many advocacy services offering such support have been depleted with the transition to the NDIS, following the closure of the NSW Department of Family and Community Services, Ageing, Disability and Home Care (ADHC).¹⁰ Without enough suitable advocacy support, many participants,

⁸ Carers NSW (2020).

⁹ Ibid.

¹⁰ Productivity Commission (2017) *National Disability Insurance Scheme (NDIS) Costs*, Study Report, Canberra.

their families and carers must navigate the often complicated and stressful environment of complaints mechanisms and pathways themselves.

For example, Carers NSW is supportive of enabling the NSW Civil and Administrative Tribunal (NCAT) to hear matters raised by tenants or providers, but has concerns regarding the level support people with disability, their families and carers would receive in this context, particularly if they are not familiar with relevant legislation, service agreements and policies, or are from a culturally and linguistically diverse background.

In addition, Carers NSW has heard from many carers that they, or the person they care, for who lives in supported accommodation is hesitant to raise a complaint with the service provider directly or with the appropriate complaints body, as they fear this will negatively implicate the resident or disrupt the security of their housing arrangement. Carers NSW has also heard from carers that in some cases, where they have raised concerns about the quality and safety of services received from SIL providers, the provider has made subsequent attempts to challenge guardianship orders that may be in place or apply for new guardianship orders to exclude carers from discussions regarding services.

Carers NSW has concerns that where adequate protections are not in place for participants and their carers to raise complaints, they may be reluctant to do so. This is likely to place participants under greater risk of abuse, neglect and exploitation from service providers. Additionally, where participants choose to employ the same service provider for SIL, SDA and Support Coordination, they may be at greater risk of isolation or being 'cut off' from other persons in their support network, such as their carer. Carers NSW believes that where a participant chooses to employ the same provider for these supports, there must be independent oversight through programs such as the Community Visitor Scheme (CVS) to safeguard participants from potential neglect or abuse, and ensure that they have opportunities and feel safe to report any concerns about their service provider to an external, independent body.

While Carers NSW understands that agencies like the NDIS Quality and Safeguards Commission have been established to monitor and investigate complaints regarding unsafe practices within NDIS services, including supported accommodation, Carers NSW believes that further protections are needed for participants and carers to feel confident raising complaints regarding accommodation services.

Conclusion

Carers NSW commends the NDIA's work to improve home and living options for NDIS participants, their families and carers. The 'ordinary life at home' consultation presents a valuable opportunity for significant and meaningful reform in the context of home and living options for people with disability, however Carers NSW has concerns that without broader reform to address the lack of affordable and accessible housing options, and increased support for informal carers in the funding of home and living arrangements, the proposed changes will not enable participants to overcome the entrenched systemic barriers to creating an ordinary life at home that people with disability and their carers experience.