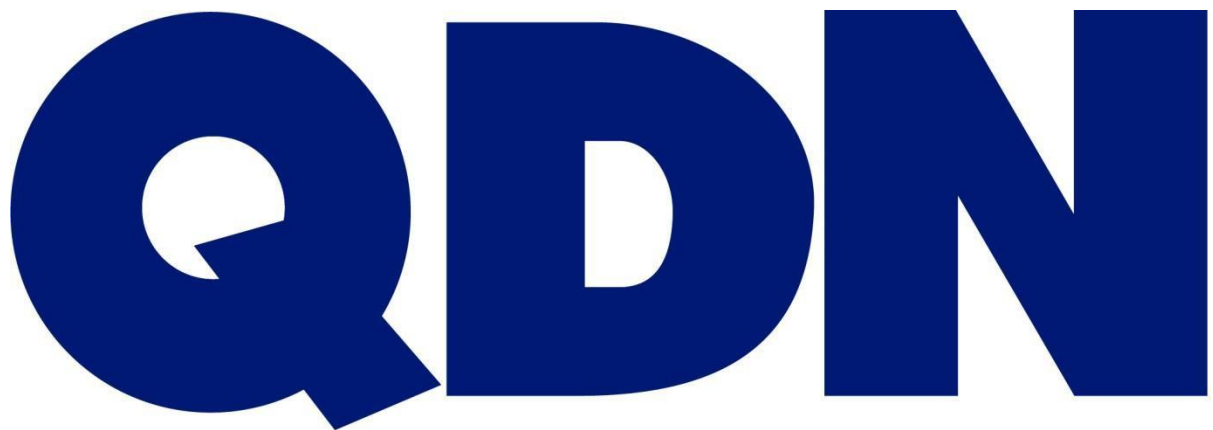


Submission –
National Disability Insurance Agency
Home and Living Consultation – An
Ordinary Life at Home



QUEENSLANDERS WITH DISABILITY NETWORK
NOTHING ABOUT US WITHOUT US

“Everybody no matter who they are wants a place of their own to live. That means different things to different people.” Gary, QDN member

Queenslanders with Disability Network

Nothing About Us Without Us

24 September 2021

About Queenslanders with Disability Network (QDN)

Queenslanders with Disability Network (QDN) is an organisation of, for, and with people with disability. The organisation's motto is "nothing about us without us". QDN operates a state-wide network of over 2,000 members and supporters who provide information, feedback, and views from a consumer perspective to inform systemic disability policy and disability advocacy. This submission is informed by the lived experience of our members and supporters.

QDN Values Statement

QDN believes that:

- All people with disability have a right to a place in the community and have contributions to make to community. This is as empowered, free citizens who are valued, present, participating and welcomed as members of any dynamic and diverse society.
- The place of people with disability in the community is not just about people with disability having a house in the community. Core to this is that they are welcomed in the community as ordinary citizens where they have genuine opportunities to contribute and actively participate. People with disability need to be in communities where their individuality, their talents, and their lived experiences of disability are recognised and acknowledged.
- Culturally and historically, people with disability are not afforded the same value, opportunities, or access to community life.
- Any inclusion in community for people with disability is conditional and vulnerable to withdrawal.
- Many people with disability in Queensland are excluded from the most basic experiences of ordinary lives.
- Current exclusionary practices are unacceptable and must be challenged.
- These issues affect not only people with disability but the whole community.

Introduction

QDN welcomes the opportunity to make a submission to the National Disability Insurance Agency Home and Living consultation – An Ordinary Life at Home.

QDN's work around home and living for people with disability is underpinned by the housing principles designed by our members. This has supported us to work with government, business, and community on a shared approach to these complex issues. Our housing principles are detailed below.

Housing is a fundamental need and human right and key to enabling people with disability to be included in community and family life, and to participate fully as citizens within Australian society.

QDN acknowledges Article 12 and article 19 of the *Convention on the Rights of Persons with Disabilities* (CRPD) which seeks to promote and protect the equal rights of all persons with disability to live independently and be included in the community. The articles state that people with disability must "have the opportunity to live independently in the community and to make choices and to control their

everyday lives, on an equal basis with others”.¹ Being included in the community facilitates the “social networks and naturally occurring community support (including friends, family and schools)” that is critical for supported decision-making.²

In the context of living arrangements, the choice of where to live and who to live with is often not the individual choice of people with disability but more often that of family members, guardians, NDIS nominees, NDIS planners, service providers, and policy makers.³

For people with disability to be able to make meaningful choices in their lives, including where and with whom to live, and for the free development of the person, Australia needs to meet its obligations under article 12 and replace substitute decision-making with supported decision-making that respects the rights, will and preferences of people with disability⁴.

“When you live in a group home you don’t get any choice about who you live with and [the service] moves people around to different houses and sometimes you live with people you don’t know” – QDN member

QDN notes that under National Disability Insurance Scheme (NDIS) Supported Independent Living, group homes remain a principal form of supported accommodation, despite calls for more innovative housing and support models for people with disability. QDN welcomes the national reform agenda under the NDIS that emphasises choice and control including choice of service providers. QDN notes that most of the current NDIS Specialist Disability Accommodation (SDA) residents live in premises that were previously State Government funded group homes and receive Supported Independent Living (SIL) funded NDIS supports, as part of legacy arrangements.

QDN acknowledges that 17,000 people with disability live in group homes in Australia and while there is no doubt that people with disability have benefited from the move from large institutional settings, the experiences for many people living in group homes include social isolation, denial of basic human rights, and the experience of violence, abuse, neglect, and exploitation.⁵

¹ Committee on the Rights of Persons with Disabilities, *General comment No. 1 (2014) Article 12: Equal recognition before the law*, op. cit., para 44.

² Ibid, para 45.

³ See for example, French, P, *Accommodating Human Rights: A human rights perspective on housing, and housing and support, for persons with disability*, People with Disability Australia, 2009, p. 52. Available at: <https://pwd.org.au/resources/library/reports/>; Joint Standing Committee on the National Disability Insurance Scheme, *Report into Supported Independent Living*, (May 2020) Commonwealth of Australia, p. xviii. Available at: https://www.aph.gov.au/Parliamentary_Business/Committees/Joint/National_Disability_Insurance_Scheme/independentliving/Report

⁴ Disability Royal Commission: WWDA’s Response to Group Homes Issues Paper, July 2020. p 19,

⁵ Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (2019). Group homes: issues paper.

QDN supports the NDIA's intention in the development of the Home and Living policy to "create a clear and personalised approach to helping you live ordinary lives, in ordinary homes, in ordinary communities".

"We want to have a family home" – QDN member

Queenslanders, including 830,000 people with disability in this state, are currently experiencing an affordable housing crisis. Additionally, Queenslanders with disability face extra barriers in securing a home. Extra barriers include a likelihood to have lower incomes than the general population, and as a result, an increase in housing stress; a lack of accessible private and public housing; the failure of the building industry to take up universal housing design; the inability to afford modified housing; assumptions about the need for institutional and congregate care, and difficulty negotiating and advocating within the housing system, particularly for those with complex needs, including people intellectual and cognitive disabilities.

QDN acknowledges that affordable, accessible, safe housing and a place for people with disability to call home is impacted by a range of local, state and commonwealth government policy, legislative, and funding arrangements. However, it is critical that this is taken into consideration and that the NDIA take a broader view of this with regards to the Home and Living policy. It is also important that integrated planning across systems is undertaken, with effective levers, funding, and investment across the National Housing Agreement, National Disability Agreement and National Disability Strategy. A clear goal to deliver a program of investment in accessible, affordable housing infrastructure and communities will enable everyone, including people with disability and mobility issues, to have an ordinary life in an ordinary home in an ordinary community.

We need to raise expectations for real housing alternatives in both the private and social housing markets. Only when fundamental housing needs are met is it possible for people with disability to be fully included as active, valued citizens in the social and economic life of the community.

The current environment offers a unique opportunity for government, industry, business, and the community sector to show strong leadership and work collaboratively with people with disability and families/carers to drive reforms that deliver improved housing for Queenslanders and, more broadly, Australians with disability.

QDN's Housing Principles

QDN's housing principles have been informed and developed by and for people with disability and guide QDN's work. The key principles are documented in QDN's housing policy platform "Going for Gold: Accessible, affordable housing now" and include⁶:

Rights

People with disability have the same rights to housing assistance as other people and should be supported to exercise those rights.

This means:

- Housing is designed to enable family and friends with disability to visit.

Choice

People with disability choose where, how and with whom they live.

This means:

- People can afford to live in housing suitable to their needs
- People can make informed decisions about their housing choices.

Inclusion

Housing enhances the independence and social and economic participation of people in family and community life.

This means:

- Housing is non-congregate and encourages a mix of occupants with and without disability in housing developments
- Housing is located within communities close to amenities and services
- Housing is designed to meet the principles of universal housing design as developed in the Liveable Housing Design Guidelines and incorporates assistive technology as needed
- Queenslanders are educated and aware of benefits of universal housing design and the need to include people with disability in local communities.

Control

The provision and management of housing is separate from the provision and management of paid support.

This means:

- Housing is primarily a person's home, not someone else's workplace
- A person can change their housing without affecting their support arrangements.

⁶ Queenslanders with Disability Network: Going for Gold- Affordable, accessible housing now, QDN Position paper on housing for people with disability, March 2017. <https://qdn.org.au/wp-content/uploads/2018/06/QDN-Going-for-gold-position-paper.pdf>

QDN's response to the NDIS Home and Living Issues Paper

Changing the conversation

QDN supports the intention to 'change the conversation' and sees that QDN's four housing principles – rights, choice, inclusion, and control - are a useful and practical framework to shift practice and change the conversation. A principled, rights-based approach that is co-designed by people with disability is essential for effective policy implementation that can influence attitudes and practice to deliver positive impacts for individuals with disability and the broader community.

Part of changing the conversation is ensuring people do actually have choice and control in their lives, particularly in relation to their living arrangements. Under the NDIS, Specialist Disability Accommodation (SDA) provides the funding for eligible participants to choose their housing option and Supported Independent Living (SIL) provides funding for eligible participants to choose essential daily support providers. QDN sees that it is imperative that housing and supports are separated to prevent people with disability being compelled to live in particular living arrangements in order to receive essential support, negating their choice and control and human rights.

QDN acknowledges the shift to replace the focus of planning conversations with the four Home and Living discussion themes - where I live, who I live with, who supports me and the things I use. However, there are a range of things that need to be determined to identify if this is a new planning approach across the board for all NDIS participants, or only for those who have identified Home and Living as a goal. QDN sees that it is critical that this is an option, approach, and framework for all NDIS participants to explore their home and living options. Additionally, QDN sees that it is important that this does not become an automated process to generate plans based upon 'personas' and remains individualised, person-centred, and responsive to the person with disability.

QDN members strongly recommend that NDIA does not only offer Home and Living conversations to people at particular life stages or transition points, or in particular cohorts, but to all participants at every planning conversation. The opportunity to be funded for exploration and design of home and living options should not be confined to those exploring ILO.

The consultation paper highlights training for LAC and NDIA planners around changing the conversation. QDN sees this as an essential part of a planner's training, supervision, and demonstration of change in practice. Furthermore, QDN members urge the NDIA to include people with disability as part of the workforce to deliver staff training. It is important that training is co-designed and co-delivered with people with disability. They are the experts and should be treated as such and looked to for their expertise.

QDN supports the idea of the Home and Living 'campaign' suggested in the consultation paper and suggests that the approach be one of potential futures: stories of what people's future could look like, and full explanations of more innovative and contemporary options, including challenges and solutions.

QDN also urges the NDIA to ensure that there is no exploitation of people with disability and their families in such a campaign. People should be paid properly (award wages where appropriate) for any contribution to such a campaign.

It is also critical that the communication needs of diverse cultural groups be considered and responded to well in general communication and in specific campaigns. The experience of diverse communities during the pandemic – where poor attention to their communication needs has impacted negatively on individuals and people have died. We need to ensure that government agencies deliver targeted strategies that address the needs of diverse communities in all critical communications in the future. QDN sees that it is critical that the NDIA promote accessibility and transparency by providing more comprehensive information about the range of multiple living options, including ILO, Supported Independent Living (SIL), and SDA on the NDIS website, including Easy Read material, professional translations, and descriptive information.

To deliver on this policy and reform it is critical that the conversation is broader around affordable, accessible, and safe housing. The disadvantage people with disability experience in finding and keeping suitable housing cannot be dismissed as analogous to the experience of all other Australians. This is not true. The NDIA has an important role to play to influence the bigger picture of the housing crisis, which profoundly impacts people with disability as a group more than most.

It is important that the NDIA ensures that Specialist Disability Accommodation (SDA) is more easily accessible for those who need it and does not require separation from their partners and children. Feedback from members consistently states that approval for home modifications funded by the NDIA is a torturous process and must be simplified and streamlined so that people can act quickly in a volatile market and have their needs met. Innovative approaches to supporting people into home ownership must be co-designed with people with disability and championed by the NDIA, as must other solutions such as an increase in social housing stock.

In addition, changing the conversation extends to community, to raise awareness and drive change around community attitudes and investment in accessible, liveable, flourishing communities. As identified previously, this policy context is within national agreements and strategies across housing and disability including the National Disability Strategy, the Information Linkages and Capacity (ILC) Building program, and State/Territory and Local Government disability plans.

The NDIA has an important leadership role to deliver for NDIS participants and the broader disability community, including through its significant cache of data to highlight evidence and need, speaking with a strong voice about what is needed, to influence a changed conversation and strategic investment. It could also directly invest through both individual plans and ILC funding for peer support to build individual and collective capacity through locally led conversations around housing and homes. These place-based conversations and solutions would aim to influence collective change, in addition to individual exploration and design conversations. QDN has been pioneering work in this area (My Housing Matters workshops) and encourages the NDIA to explore this and similar work that has already been done in local communities.

The NDIA has the opportunity to play a leadership role in working collaboratively across systems and mainstream services. This can contribute to activities and investment via individual plans and ILC that can impact upon the ability of people with disability to live ordinary lives, changes in housing availability and accessibility, and more welcoming, inclusive communities that contribute to positive outcomes for Scheme participants.

“We want a backyard for a pet and grandkids to run around in” QDN member

Supporting you to be an informed and empowered consumer

QDN has strongly advocated in both the design and implementation of the scheme for the critical need for people with disability and their families to be supported to be informed and empowered consumers within the NDIS system. For systems to operate effectively, informed, and empowered consumers who can navigate, activate, and implement their NDIS plans effectively deliver benefits and outcomes for all stakeholders.

Expanding exploration and design funding to more participants is important for a significant proportion of NDIS participants, not just people eligible for ILO, and needs to be included and considered.

Making education and information available on Home and Living and the opportunities this presents must include attention to the communication needs of diverse cultural groups and cohorts with complex communication needs through co-design and by offering Easy Read resources, translations into multiple languages, and stories that reflect different individual and cultural experiences, expectations, approaches, and values.

Training for participants’ informal and paid supporters to learn communication and decision-making support is essential for people who have high and complex communication support needs. Funding for this training must be routinely included in people’s plans, as must support coordination funding to support people with these needs to understand and implement their plans. Effective supports coordination is key to delivering on this. Feedback from QDN members continues to highlight the discrepancies of inadequate supports coordination that does not deliver what individuals need, in a way that empowers them, and is person-centred. In addition, the NDIA must meet participants’ right to fully understand their plans by ensuring Easy Read and accessible versions are available to those who require them.

Automated systems and technology as a strategy for identification of participants who may need a new home and living situation can only be used to complement the individual planning process and need for skilled communication and relational, person-centred approaches to planning, and may encourage the assumption-making mentioned above – where planners make assumptions rather than asking good questions and listening to the answers.

Feedback from QDN members details varied experiences with planners not working well with the participant to help them understand and fully explore what they need in relation to their SIL supports. Member feedback reinforces that some SIL providers are directly providing information to NDIA planners to be input into a participant’s

plan without actively including the participant in pre-planning discussions or giving the participant and/or their family information in a 'user-friendly' way about what is in the quote, what is not in the quote and what this will mean for the person's day-to-day supports. As discussed above, it is often difficult to disaggregate 'shared' versus 'individualised' and flexible supports under SIL, leaving participants without adequate individualised social and community participation supports and/or without options to have a holiday, as the extra support hours were not built into the SILS quote provided by the service provider to the NDIA. This is likely to lead to the isolation of the participants from their families, social networks, and community. Key to being an informed and empowered customer is having timely, accessible information that enables you to make decisions and understand what is happening.

Additionally, the suggested provision of key information and communication to peer networks needs to be strengthened. Peer networks can be key to the success of efforts to support people to be informed, empowered consumers. The development of peer networks and mentoring relationships over the years since the NDIS began has led to them being an invaluable resource, and QDN urges the NDIA to treat these networks as key partners in the design and implementation of the Home and Living policy. Lived experience offers a perspective that cannot be matched by training. Continued investment in peer support will increase the already existing capacity for mentoring and guidance and enable people with disability to provide excellent peer support and exploration, and design services to other people with disability free of provider bias. Likewise, circles of support and micro boards are models which should attract investment in capacity development to ensure an ecosystem of supports that has diversity and is not dominated by paid supports and service providers.

[Expanding support for decision making](#)

As noted above, peer support networks are an invaluable resource for the NDIA and NDIS participants. The proposal to "promote growth of peer support networks in providing support for decision making" needs to have clear aims, outcomes, and deliverables. A commitment to funding and championing peer networks as key potential supports for decision-making is needed and needs to be identified as a priority investment strategy of ILC.

Likewise, the proposal to "work with the NDIS Quality and Safeguards Commission to be clear about when it is not appropriate for providers of support coordination or SIL to be the provider of other funded supports in a participant's plan" also needs to have clear aims, outcomes and deliverables that are measurable. The default should be mandated as the starting point to separate providers for provision of these supports, with rare exceptions. This conflict-of-interest issue is having significant impacts upon individuals who are forced into home and living situations that are not their choice and actively disempower them.

Good support for decision-making needs to occur in a variety of ways, with independent advocacy and support, and is impacted when people are in closed settings and legacy housing models. This includes young people in nursing homes and whilst previous targets and investment have been made for this particular cohort, a comprehensive plan is still needed to incentivise innovative housing options

for people with disability that deliver on the four housing principles, with clear targets and timelines and clear action plans to achieve them.

QDN has also made a submission to the Supports for Decision-Making consultation which addresses this topic in more detail.

Reforming the funding model

QDN supports the proposed increased flexibility in use of funding in ILO arrangements, and questions how the proposed safety measures for participants to ensure they are always able to afford the supports they need from their budget fits with this flexibility. More detail around what this means in practice, particularly for plan and self-managed participants, is needed. Part of the ILO model relies on the participant to provide 'supplement' supports that are unpaid or informal supports for a specific amount of total support times, which would negate this being an option for many people with disability who do not have this in their life.

QDN supports the proposal to target participants in traditional housing models (large group homes, aged care, and closed setting SIL homes) to explore and design other options, where that is their choice (though target is an unfortunate term to use in this case – perhaps focus would be better). A long-term plan to transition to more individualised options reflective of what happens around where and with whom people live in the broader community will provide the impetus needed to bring about change in this area. Participants and providers will be highly motivated to explore and design new options if there is a clear plan and opportunity to transition to new options.

Improving choice and control through flexible budgets

QDN supports the proposed measures in this section with one caveat – the suggestion that the Agency makes skilled supports available to help participants design a budget and approach that fits within their funding level and this needs to be in a person-centred way that upholds choice and control, whilst maintaining quality and consistent delivery of this type of support.

Assisting implementation and maintenance

QDN supports the proposed measures in this section and urges the NDIA to invest in training and education that is co-designed and co-delivered by people with disability. QDN also recommends that providers should be included in the list of cohorts in need of education and training mentioned, as they will be critical to the success of a new approach.

Engaging the market and driving innovation

QDN has a strong history of advocacy and work around housing for people with disability. Our work includes the development of our Housing Principles (adopted by the Queensland Department of Housing and Public Works to guide them in working to develop housing solutions for people with disability), My Housing Matters workshops in local communities and Going for Gold, a housing policy platform that addresses the critical issues around housing, including the infrastructure supply

crisis, and offers several innovative solutions to these issues. It is critical, if the conversation, choices, and outcomes are really to change for people, that the NDIA ensures that policy responses can impact at the individual, service provider and systems level. Key to this is a foundation of investment in people with disability, in changing community attitudes, and in advocating for key improvements and increases in infrastructure in the broader housing market.

QDN supports the proposed measures in this section and again urges the NDIA to ensure a key role for peer support and peer networks in co-designing, demonstrating, and communicating innovative solutions.

Conclusion

QDN welcomes a new approach to Home and Living and changes that will deliver improved rights, choice, inclusion, and control for people with disability. This policy exists within a broader environment of a national housing affordability crisis, and the flow on impacts of this to ensuring there are a range of options for affordable, accessible, safe housing for people with disability.

QDN recommends that QDN's guiding housing principles - rights, choice, inclusion, and control - are reflected in the practice and principles of NDIS Home and Living. QDN also recommends that work needs to be done to enhance partnerships and information sharing and a range of broader strategies that will increase accessible housing supply, improve access to affordable private rental, social housing, and innovative solutions to lead to greater home ownership, planning and infrastructure for more inclusive neighbourhoods, housing advocacy services and strategies to address the needs of rural and remote Australians, including people from Aboriginal and Torres Strait Islander backgrounds.