

Speaking notes for QDN NDIS Legislation Response

About QDN

QDN has been established for over 10 years as a network of, for, and with people with disability. The network regularly brings members together to campaign on issues that affect their lives. From such gatherings, and through input from Local Area Networks, the members determine the focus of the network and activities undertaken.

This process has been used to develop QDN's submission to the Productivity Commission's inquiry into a Disability Care and Support Scheme that developed the NDIS proposal and has also been used to develop this response to the Senate Standing Committee on Community Affairs' Inquiry into the draft legislation that would begin the work of implementing the NDIS in Australia.

NDIS Legislation – overall optimism

QDN shares the optimism of its members about the NDIS, and the potential changes it will bring to people's lives. People with disabilities want to live ordinary, everyday lives in the community, in alignment with the expectations of the lives of other Australian citizens. Life as everyone knows, and experiences, is seldom nice, neat and proper. It is often full of complexity. As such, the NDIS Bill must reflect this need for flexibility to allow the scheme to achieve its goals.

Concerns

QDN does have some concerns about aspects of the legislation, in particular:

- That the Bill may entrench age discrimination by denying people with disability over the age of 65 access to the NDIS and its benefits;
- That people with disability may be required to rely on the assessments and assistance of allied health professionals who often take a risk-aversion approach and have limited understanding Community living options;
- That the Bill's requirement that an individual's support delivers "value for money" may be used to deny a person's access to expensive but essential support;
- That the Bill does not require the proposed NDIA to provide reasons for its decisions; and most significantly
- That the Bill leaves the door open to the continuing practices of block funding, forced co-tenancy and institutionalisation.

QDN's submission document includes detail about many aspects of the legislation. QDN has strong beliefs about not only what the legislation should look like, but also how it should be implemented. The submission includes real examples of what the ramifications of different parts of the legislation could be. QDN is acutely aware of the significance that this legislation will have on all QDN members and, indeed, all Australians with a disability. However, it is the Bill's openness to the bad practices of the past that warrants the most attention in this presentation.

Participants and their Plans - Chapter 3, Part 2, Division 2, Section 35

The rules of the NDIS are the most relevant section of the legislation in terms of its practical implications on the lives of people with a disability. It is crucial that the rules must not be used as a way of diluting the power of the legislation and in turn, reduce the effective entitlement of people with disabilities.

QDN is gravely concerned about this section of the legislation, particularly Sections 35(2) and 35(3). The provision of supports (both reasonable and necessary, and general supports) with criteria regarding the "manner in which the supports will be funded and by whom the supports so funded are to be provided" leaves open the possibility that funding could be attached to specific service providers (block funding). QDN believes that the only purposes where block funding is appropriate are:

- To build the capacity of people with disabilities (individually and in groups);
- To provide random, "ad hoc" services to people with disabilities who don't have packages of support, but without this support will end in crisis situations (eg homeless, incarcerated, or hospitalised);
- To fund emergency respite or support;
- To assist when a family member providing informed support is ill or absent;
- To support a person to attend one off cultural, spiritual, or ceremonial events;
- To provide training and support on an intermittent basis for the adoption and ongoing use of new technology, aids and equipment;
- To relieve a primary carer to allow the carer to lead a normal life;
- To provide support for participants to access legal support, tenancy maintenance, domestic violence issues, custody periods (child access support);
- To provide support for participants in hospital when they live in group homes that have no flexibility in their care arrangements;
- Education of the community when people with complex behaviour or mental health disability are re-entering into community life.

Page 5 of the Statement of Compatibility with Human Rights (Explanatory Memorandum) outlines some of the general principles of the NDIS. The fifth of these states that:

"People with disability should have the same right as other members of Australian society to be able to determine their own best interests, including the right to exercise informed choice and engage as equal partners in decisions that will affect their lives, to the full extent of their capacity."

Block funding of individuals' packages of support is a scary proposition for people who for too long have had their funding attached to a service provider that they have not found satisfactory. This has been a breach of their rights to "exercise informed choice" about their lives and contravenes the NDIS' focus on 'choice and control'. This must not continue in the future. People with disabilities see the NDIS as a

turning point in their lives, with the separation of their support package from an allocated service provider, being the catalyst for this optimism.

People with disabilities must not be locked into packages of support from nominated service providers as this will stifle any benefits that a competitive market can provide. The upshot of this change will be better services for people with disabilities, and better lives for people with disabilities.

Supported Accommodation (Forced Co-tenancy)

The most powerful example of the perils of having support packages linked with specific service providers (Block funding) lies in the supported accommodation sector.

People with disability need to have the same tenancy rights as other members of society. Currently, people in supported accommodation are not protected by the Residential Tenancy Agreement.

All other Australians have the choice and capacity to live with whom they wish or move. People with disability, who are reliant on their formal supports to have their personal care needs met, currently do not have this right. While technically they can leave the house it comes at a cost, a cost that all Australians would agree is an unreasonable cost – the loss of their support that allows them to eat, go to the toilet, and have a shower!

For as long as individual's personal care support funding is linked with an allocated place of accommodation, Australians with disabilities will not be afforded their basic rights - rights that are stipulated in Article 19 (a) of the CRPD of which the Australian Government is a signatory.

Article 19 of the Convention of Rights for People with a Disability (CRPD) states that

"States Parties to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

(a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;

People with disabilities will not have a real choice to move if they know this is likely to impact upon the level of support they receive and, perhaps mean they cannot eat, shower or communicate as a result.

The current system of funding arrangements for accommodation and personal care must be separated, so that people with disabilities can choose their place of residence without having to worry about if they can go to the toilet when they get there.

QDN is not opposed to group living per se. QDN acknowledges that many people with disability want to live in a shared accommodation setting for a variety of reasons. But in the same way as university students choose who they are prepared

to live with in shared accommodation, so too, should people with disabilities, have that freedom.

Article 3 of the CRPD states that non-discrimination is a general principle to all rights in CRPD. Given that only people with disability in Australia are faced with their ability to have their personal care needs met, entwined with their place of residence, the NDIS must take steps to address this indirect form of discrimination. The legislation must ensure that this part of the system is changed.

Dignity of Risk

The NDIS must be implemented with a positive vision. A perspective that accepts that people with disabilities have often never had the opportunity to manage their own lives, and as such, may need some skilling up before they can successfully manage to achieve this goal. The NDIS is obliged to not only give people the opportunity, but to also give them the best chance of succeeding to ensure that these new possibilities become new realities, not just a distant goal in a distant mirage. The dignity of risk must be afforded to people with disabilities. Participants must feel reassured that they can take a risk and think “outside the square” in their plans, without the fear that (if something doesn’t work out as they had hoped), they will suffer consequences for any mistake in all of their future interactions with the Scheme.

Generic services

Generic services, such as cleaning, ironing, household maintenance, or even a nanny to enable parents to return to work, are often determined to be outside of the scope of current funding guidelines. Yet, these services, if offered to people with disability, are far more economically efficient when compared to disability-specific services.

QDN believes that these generic services should be included as reasonable and necessary support options. QDN also holds the belief that these generic services need not be provided by registered service providers. It is crucial to the potency of the NDIS, that participants are not limited to a menu of service providers that are registered with the NDIS.

Individualised funding, Accountability and Capacity Building

Along with this choice, people with disability must be able to easily transition from one service provider to another. Funding and accountability processes need to be assigned to the person and their vision for a good life. The satisfaction of the person with disability, how they achieve their life aspirations, and how the service responds to them as individuals, must be linked to accountability processes.

QDN sees this area requiring significant capacity building for the NDIS participants. Many participants will have no experience of record keeping prior to the NDIS.

It is important that participants are able to easily and efficiently make changes to their plan. When a change of circumstance or goal change occurs, the participant should be able to make a quick call and set the process in motion for any modification to the plan. A simple process is crucial so that participants feel that things can change without it potentially being a massive overhaul of their entitlements and lives.

Privacy

Service Providers must honour this legislation by providing to their staff, only the information that is required for the services to be delivered. Often extra personal information about a person, that is not relevant to support being delivered, is passed on from service providers, to staff or others, and this is not acceptable practice.

Safeguards

An inverse relationship must exist between the capacity of the participant and the level of safeguards required to protect the individual. This capacity must be assessed to determine the level of safeguards that are required.

Participants with very high capacity do not require support workers with formal training as they are able to provide specific training and tailoring of the supports in an "on the job" fashion.

The level of safeguards required for participants must have flexibility built into it. The assessment must establish the capacity of the individual and therefore their level of vulnerability in the community. QDN believes these principles must be taken into account when writing and administering the rules for service providers:

- * Level of screening should align with the capacity of the participant (i.e. staff working with people with impaired decision making will need more screening than staff working with people with higher capacity). It could be that 20% of staff only require minimal screening, 60% might require moderate screening because of the vulnerabilities of the participant, and 20% might require high level screening with regular reviews because of the extreme vulnerability of the participant.
- * Level of training for service provider employees should align with the capacity and needs of the person with disability. Mandatory minimal training on purpose of NDIS and values based on rights of people with disability. It could be that 20% of staff will need basic training on WH&S and safe manual handling techniques, 60% will need training in more complex disability support work including communication and working with vulnerable people, 20% will need a degree, or similar qualifications, to meet support needs of people with complex disability, impaired decision making and/or challenging behaviour.
- * Cultural awareness training must be provided to all support workers working with a person with a disability who identifies as Aboriginal and Torres Strait Islander, or from a non-English speaking background, or from a Lesbian, Gay, Bisexual, Transgender, Inter-gender background.

Compensation payments - Chapter 5, Part 1, Section 104

If the CEO imposes a requirement to pursue compensation, the agency must support the participant to achieve this. This will require a litigation arm of the agency and must come at no cost to the participant.

While the action is pending, an eligible person with disability should be included in the NDIS, with the legal action being the agency's responsibility to act on the person's behalf.

Compensation payments - Chapter 5, Part 2, Section 107 (3)

The Agency should only be able to recover costs relating to the support of an individual, not for the loss of income, or for pain and suffering and other areas of compensation.

Fiscal Arrangements – funding the NDIS

QDN sees that the legislation exposes the NDIS to potential changes in the fiscal policy arrangements supporting its implementation. This could erode the potency of the NDIS.

Conclusion

QDN is appreciative of the opportunity to contribute to the inquiry. QDN is aware that the consultation on the NDIS has been exhaustive and has welcomed this approach. The NDIS is exciting for people with disabilities, particularly those have been frustrated by the current system that they are dealing with. QDN hopes that our input into this process is valued and all of our concerns are considered.