



Queenslanders with Disability Network's Response
to NDIS Rules Consultation Paper

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This response is produced using input from Queenslanders with Disability Network (QDN) members across the state of Queensland. As a member-driven organisation, QDN focussed on consulting with people with disability to gain their input into the organisation's submissions. The information presented here also aligns with QDN's vision, mission and values which have been developed from member input over time.

About Queenslanders with Disability Network (QDN)

QDN has been established, as a network of, for, and with people with disability, for ten years. 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.

Value Statement About the Place of People with Disability

Since its inception, QDN has spent considerable energies clarifying the values that underpin its way of working and interacting with other agencies. The following statements articulate the values of QDN, in relation to the place of people with disability in an inclusive, Australian society.

QDN believes that:

- All people with disability have a right to a place in the community and contributions to make to community. This is as empowered, free citizens who are as 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. The crux of the issue is that they are welcomed in the community as ordinary citizens where they are genuinely given 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. The National Disability Insurance Scheme (NDIS) must address this inequity.
- QDN acknowledges that history has proven that inclusion in community for people with disability is conditional and vulnerable to withdrawal. This must be changed to ensure people with disability have the rights of other Australian Citizens.
- 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.
- The responsibility is shared. It lies within government (federal, state and local) and the community at large, to ensure that people with disability have a place and are resourced to belong in community.

Introduction

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 Rules must reflect this need for flexibility to allow the scheme to achieve its goals.

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

- the ability of people aged 65 to continue in the NDIS if they wish;
- the need for participants to have access to a "planner", with experience in planning for and facilitating community living options for people with disability. Such people often come from people with non-allied health backgrounds and these skills will be useful in facilitating Part A of the plan;
- the definition of "value for money" in reference to the provision of supports;
- the need to have a rule that will prevent the attachment of individual packages of support to the provision of supported housing, from the same Service Provider, for the same individual;

What is the National Disability Insurance Scheme?

QDN is concerned that the "reasonable and necessary support" that people with disability need requires a more detailed definition. QDN believes that an addition to the criteria should read,

“(i) reasonable and necessary supports for people with disability ***will align with the expectations of other Australian citizens***”.

This would provide a clearer definition of what is reasonable and necessary.

A good example of this is one that a member of QDN raised about showering. He makes the case that not only should a person with a disability be entitled to the supports required for a daily shower at the time of his choosing, but that he also would like to be able to shower a second time in a day on occasions when he is going out in the evening after work, or after visiting the gym on the way home from work. This is a clear example of where an application of the "expectations of other Australian citizens" test would clarify that, indeed, this is a reasonable request for such support. QDN believes that this will provide clarity to those writing the rules, and also the CEO, in their application of the rules.

Becoming a Participant – Age Requirements

QDN strongly supports the choice for people to stay with a NDIS package of supports after they reach the age of 65. While QDN does not believe that people who need disability support for the first time after the age of 65 should have their needs met through the aged care system, if this is this case, the age threshold

should be in alignment with the existing age cut off for the Aged Pension. As this threshold changes, so too, should the NDIS threshold.

Registered providers of support

“It is also important that the process for the registration of registered providers of supports promotes the policy objectives of the Bill to enable people with disability to exercise choice and control in the pursuit of their goals and the planning and delivery of their supports.”

This will not work if all services providing support are required to be registered. It must be that people with disability can use a portion of their ‘package of support’ on generic services ie non-disability registered providers!

Should the rule also set out the types of information the Agency will need to establish that a person meets the age requirements?

Yes. This is one area of eligibility that can be made very simple and clear and therefore should have explicit criteria in order to meet the age requirements. People with disabilities are very anxious about the entry process into a new system and this is one area that can be simple and clear, therefore removing some of the anxiety associated with the NDIS.

What factors should be taken in to account in deciding whether a person meets the residence requirements?

A participant should have resided in a launch site for six weeks with stable tenancy to be eligible to be part of the NDIS.

What types of evidence are appropriate to determine if a person meets the residence requirements?

A Lease agreement, power bill, telephone bill, and other standard criteria that are used as proof of residence would be sufficient evidence.

What boundary issues between launch and non-launch locations are likely to arise and how could these be resolved in developing the rules?

QDN believes that local government areas should be used to define launch sites. QDN acknowledges that boundary issues will almost certainly arise as people try to access better packages of support. This is a symptom of the inadequate services that have been identified in the Productivity Commission Report. The likelihood of people moving into launch sites should not be under-estimated. For many people with disabilities, they have been living in poverty for many years. Many people have few assets, no jobs and minimal informal supports. Without these, the incentive to stay in situ is low, especially when an NDIS may provide increased packages of support. In some cases a better package of support may allow someone in the family to enter the workforce. All Australians will consider changing residence if their job prospects are enhanced.

The plight of people with disabilities in the current system have left many families in desperate need of assistance. If an NDIS offers some hope for change toward a better life, it is understandable that people will move to where they think they can achieve it.

What factors should be considered in deciding whether the NDIS should provide continuity of support to someone who has been receiving assistance under other programs, but who would not otherwise be eligible for NDIS support?

The Productivity Commission Report highlights the need for “Grandfathering” where people who are currently receiving funding should not be worse off under an NDIS. Therefore, people already receiving assistance should receive the equivalent or better assistance under an NDIS.

People with disability who are at risk of being forced into other forms of care, hostels or nursing homes must be catered for by the NDIS to prevent more substantial cost in the long term. The same applies to those who are at risk of homelessness or being part of the criminal justice, child protection or mental health systems. Consideration must also be made for those who are at risk of discontinuing their education.

What criteria/factors should be taken into account in determining whether a person meets the disability requirements?

The key criteria should include the capacity of the participant to manage self-care, activities of daily living, communication, and their ability to form and maintain social and community relationships.

Should there be any guidelines on people being able to provide existing assessments to meet the disability requirements?

Yes, assessment used to access current supports should be used as a baseline. This will ease pressure on the in-take processes.

What should be considered in developing a rule on the types of persons who should conduct assessments?

This is complex and should include a combination of allied health professionals, for diagnostic based assessments, and disability sector personnel with experience in social inclusion and community living initiatives and possibilities.

What should be considered in developing a rule on the kinds of assessments that could be provided or undertaken as part of meeting the disability requirements?

A conversation-based assessment that focusses on what the person with disability needs on a daily basis. This needs to include what aids and equipment the person will need and the replacement/depreciation and services and maintenance of such equipment.

How can we make sure the rules determine disability on the basis of a functional assessment of what a person can or aspires to do, rather than on the basis of diagnosis?

Use this strengths-based conversational style to form part A of the plan.

What criteria would be useful for considering the benefits of early intervention for mitigating or preventing deterioration in a person's functional capacity to undertake activities such as mobility, self-care or self-management?

Interventions that are rebate-able through health insurance funds should be considered to have an evidence-base. Exercise programs that strengthen a person's body and increase or maintain ability, also need to be considered.

For children, programs that prepare them for kindergarten or prep or schooling, including social and communication skills development, also need to be considered within the scope of the NDIS.

How can the support provided by families and other carers be made more sustainable by early intervention?

Support family to be family. This includes occasional ironing or cleaning in the home to enable parents/primary carers to participate in skills development or work. Provide some in-home respite, such as a nanny, to enable parents of children with severe/multiple disabilities to sustain relationships.

For parents/carers in lower socio-economic groups, self-development courses might prove to be the most effective intervention, in the short and long term.

How should the rules support innovative approaches to early intervention and balance this with the need to get the best outcomes for people with disability and for the scheme to be accountable and sustainable?

Ensure that the aspirations for the person with disability align with community expectations for people of the same age, culture and societal group.

What criteria should be applied to determine 'evidence-based' assessment of the benefits of early intervention?

Interventions that are rebate-able through health insurance funds should be considered within scope of the NDIS. Exercise programs, that strengthen a person's body and increase or maintain ability, also need to be considered. These will contribute to the long-term cost effectiveness of the NDIS as many people with disability experience aging differently and earlier because they do not have access to physical exercise that could maintain flexibility and strength. The loss of flexibility and strength means some older people with disability require hoisted transfers. These and other deterioration impacts increase the length of time required for personal care assistance.

For children, programs that prepare them for kindergarten or prep or schooling, including social and communication skills development, also need to be considered within scope.

What methods or criteria should be used to determine those supports that would not be provided or funded by the NDIS, based on the criteria set out in clauses 34 and 35 of the Bill?

Things that are illegal should not be allowed. Things funded by other systems, such as education or health.

Are there any issues that are not covered by these proposed topics for determining reasonable and necessary supports that should be?

Social and community, including accessing sexual practitioners should be considered reasonable for people with disability who identify the need, are severely disabled, and have no other avenues for establishing or experiencing sexual expression.

What criteria should be used by the Agency in deciding whether there is an unreasonable risk for the participant in self-managing funding?

Fraud conviction, vulnerability to exploitation by family or friends, limited capacity or financial literacy (the latter 2 could be addressed by capacity building).

What flexibility should a person have in making changes to their support arrangements without requiring a review of the plan?

Change of service provider, change of supports, anything within budget and eligibility criteria.

What circumstances should trigger an automatic review of a person's plan?

Overspending or significant under-spending. High spends in areas of the plan that would not usually have that expensive every year, eg a new power-drive wheelchair every year.

What matters within a participant's plan must not be managed by the participant?

The funding allocation needs to be broken into particular areas of expenditure, such as, personal care, home modification, and aids and equipment. Discretion should be allowed between these or similar line items.

How can the concept of 'dignity in risk' inform the development of these rules?

Once the budget is agreed/set, people with disability should be able to expend funds on items as long as they acquit the funds. People with disability will need to be able to use funds on generic supports (domestic assistance, such as cleaning, and mowing) without the rule that "suppliers", under the NDIS, must be registered service providers.

How do we strike the right balance between making sure people don't have to repeat their story and personal information, and making sure people's' privacy is respected at all times?

People need to have an e-copy of their story, updated regularly, which they can share with services. People need to be able to say what parts are shared and what parts are not. This sections needs to support the overwhelming desire of people not to have to keep telling their story!

How can the Scheme ensure that providers don't have to go through a lot of red tape, while also ensuring that services are of a standard and quality to best support people with disability?

Allow people with disability, who are not vulnerable, to be active consumers, protected by consumer legislation.

What registration information should the agency collect from registered providers of supports that will promote the policy objectives of the NDIS Act to enable people with disability to exercise choice and control?

- Processes they use in assisting people with disability to develop or implement plans;
- Audit performance by interviewing people with disability using the service;
- Identifying (naming and shaming) services that are only paying lip service to choice and control;
- Reviewing complaints (are service users having experiences of life that align with those of other Australians);
- How are group living arrangements deconstructed or changed;
- How are rosters set (by people with disability or service);
- How are staff recruited and trained (in all services there should be at least SOME evidence of people with disability saying "I want this person to work for me" and the service meeting that need/wish).

What registration information should the agency collect from registered providers of supports that will build data for public evidence based decision making?

Use of decision-making frameworks, what works, why they change, and how they are evaluated.

What criteria would a decision-maker need to take into account to appoint someone other than a parent to act on behalf of a child or young person?

It is QDN's belief that decisions where the CEO appoints a nominee, should be made by a panel of people who have gathered information from a network of people involved in the participant's life. It is important to not just speak to the participant's General Practitioner, but also other stakeholders such as schools, existing service providers, and cultural elders (where appropriate). This will give the panel a rounded picture of the social setting and an insight into how the participant's life functions through good times and bad. The ultimate aim is to select a nominee that has the

best interests of the participant at heart and has demonstrated a deep level of care and understanding for the participant's needs.

What criteria should be considered in deciding to include a child or young person under the age of 18 from being involved in decisions about the support they receive?

If a young person wants something, that aligns with the expectations of other young people, but the parents don't support it, because they're afraid and over protecting the young person, then the wishes of the young person should be treated as paramount.

What is the best way for children and young people to be encouraged to express their views about the support that they receive?

Peer networks.

What criteria should guide the decision to appoint a nominee?

When there is no-one already closely connected to the person.

What criteria should be used to select an appropriate nominee?

The nominee will preferably know the person and their circumstances and should not stand to gain financially as a result of their appointment.

Other important issues to consider

The NDIS must be a scheme for all people with disability. There must be particular rules that relates to protecting people with disability who have high and complex support needs and are vulnerable to being 'warehoused' in group homes or congregated settings.

Too often, people with disability who have little or no communication and complex needs are turned into 'commodities' that are then exchanged between government and services or services and services. For these people with disability, the NDIS needs particular rules that prevent this 'trading' between service. Another insidious practice that the NDIS rules need to prevent is where people with disability are treated like livestock that are 'agisted' in group homes owned and operated by services. Both of these practices occur and are serious breaches of the *Conventions on the Rights of Persons with Disability* and Human Rights treaties that outlaw 'trafficking' in human beings.

Conclusion

QDN is appreciative of the opportunity to comment on the NDIS. The process would have been more real if the organisation had been able to comment on the actual rules.