

Friday, 25 January 2013

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National Disability Insurance Scheme Bill (2012)
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Dear Sir/Madam

Queenslanders with Disability Network (QDN) welcomes the opportunity to present its Submission in relation to the NDIS Bill 2012 to the Senate Standing Committee on Community Affairs Inquiry.

The feedback being provided to you in the Submission represents the views of QDN members across Queensland.

Yours sincerely

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Chief Executive Officer
Queenslanders with Disability Network

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National Disability Insurance Scheme Bill 2012 – Senate Standing Committee on Community Affairs Inquiry

Executive Summary

This response is produced using input from Queenslanders with Disability Network (QDN) members across the state of Queensland.

QDN does have some concerns about aspects of the legislation, 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 in (Section 34);
- the prospect of block funding continuing in the provision of individual support (Section 35);
- the absence of clear legislation that will prevent the attachment of individual packages of support to the provision of supported housing for the same individual;
- the absence of legislation requiring the Agency to provide reasons for a decision when a decision is made;

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 believes that the Objects and Principles (Chapter 1, Part 2) need to be strengthened to fully articulate the Australian obligations of the Convention on the Rights of People with Disabilities (CRPD).

QDN believes that the assessment process must also include some critical elements:

- An access request must be able to be self-referred;
- Independent assessment;
- An array of assessment tools must be available rather than a one-size-fits-all approach;
- People with disability and families must be able to self-identify;

- Must be available to people who are exiting the criminal justice system or child safety authorities.

QDN believes that an addition to the criteria for ‘reasonable and necessary’ should read, “(i) reasonable and necessary supports for people with disability ***will align with the expectations of other Australian citizens***”.

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.

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. Surely, if people with disabilities have the ability to seek different possibilities in their types of support, this will encourage a more flexible marketplace, with service providers encouraged by market forces to satisfy their clients.

QDN feels that the fiscal arrangements in the legislation expose the NDIS to potential changes in fiscal policy which may erode the potency of the NDIS.

QDN acknowledges that 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.

Queenslanders with Disability Network Submission

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.
- Any inclusion in community for people with disability is conditional and vulnerable to withdrawal.
An example of this is “forced co-tenancy”, where people with disability are forced to share public housing and supports with other people with disability or risk having both housing and supports withdrawn.
- 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.
- 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 Bill must reflect this need for flexibility to allow the scheme to achieve its goals.

QDN does have some concerns about aspects of the legislation, 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 in (Section 34);
- the prospect of block funding continuing in the provision of individual support (Section 35);
- the absence of clear legislation that will prevent the attachment of individual packages of support to the provision of supported housing for the same individual;
- the absence of legislation requiring the Agency to provide reasons for a decision when a decision is made;

The submission 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 every one of its 500 members and, indeed, all Australians with a disability.

Objects and Principles - Chapter 1, Part 2, Section 4 (8)

QDN believes that the Objects and Principles (Chapter 1, Part 2) need to be strengthened to fully articulate the Australian obligations of the Convention on the Rights of People with Disabilities (CRPD).

QDN sees that the idea of “own best interest” is a critical point. Feedback from our members tells us that even the most well-meaning families can unintentionally place limitations on people with disabilities, and therefore the choices that are made about their future. The ability of the person with disability to determine their own best interests is critical, and ties in closely with issues surrounding assisted decision making and the principle detailed in Chapter 1, Part 2, Section 5 (a).

Assistance for People with Disability and Others - Chapter 2 and 3 overview

QDN holds the view that these chapters require expansion to clearly articulate what people are entitled to. There is nothing in the legislation outlining what types of aids and equipment will be included in the NDIS and what types of packages of support will be available. While QDN understands that individual plans will dictate what types of supports will be required, and that the NDIS Rules will contain details, the absence of any detail regarding what types of aids and equipment will be included is concerning for many people with disability.

Assistance for people with disability and others - Chapter 2

For the NDIS to truly achieve its goal of reinvigorating the disability sector, investment must go into capacity building in people with disabilities, particularly in Tier 2 services. Disability Service Organisations must begin this capacity building now, as this process of educating and empowering will take time to be effective. Provision of extra choice and control for people with disabilities will only be effective if people have the knowledge, ability, and confidence to take the leap to use these new opportunities.

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.

Participants and their Plans - Chapter 3, Section 18 and 19

People with disabilities are very anxious about the intake and assessment process. While some may have anxiety or insecurities as part of their disability, many have had negative experiences with governments, assessors and services in the past. Some people with disability have been institutionalised, and have fears about the NDIS resulting from previous trauma. In order to reduce the stress placed on people with disability during this process, applications should be able to be completed online (as much as is possible) prior to any face-to-face contact being required. This will allow people with mobility and personal care difficulties to complete as much of their access request without the difficulties (and support requirements) associated with attending appointments. This will also give applicants a greater sense of control in the process, if on their initial face to face contact, the applicant knows they are already in the access request system.

To ensure the process is accessible for all, QDN supports also having paper-based, plain English and other formats available in which people with disability, and/or their families and supporters, can complete with assistance from a Local Area Coordinator.

QDN believes that the assessment process must also include some critical elements:

- An access request must be able to be self-referred;

- Independent assessment;
- An array of assessment tools must be available rather than a one-size-fits-all approach;
- People with disability and families must be able to self-identify;
- Must be available to people who are exiting the criminal justice system or child safety authorities.

Participants and their Plans - Chapter 3, Section 29 (1) (b)

QDN supports a participant's ability to stay in the NDIS while it meets their needs, regardless of age above 65. QDN believes that when a participant turns 65, they should have the choice between staying in the NDIS or changing to the supports provided by the Department of Health and Ageing.

Participants and their Plans - Chapter 3, Part 2, Division 1, Section 31 (e)

The "availability to the participant of informal supports" causes great concern for QDN. This may be misinterpreted and result in excessive and onerous reliance being placed on families or partners of people with disability. This will not facilitate equal participation in a relationship.

QDN believes that the legislation needs rewording to state that a participant's relationship status will not influence the packages of support that they will receive. Of course, there are practical implications of living with someone that must be taken into account like all assessments of informal supports, but the legislation as it is written appears open for misinterpretation.

Participants and their Plans - Chapter 3, Part 2, Division 1, Section 31 (f)

QDN is concerned about the principle. The plan is aimed to address the needs of the individual, which is addressed clearly in principle (h) in the same section. The statement addresses the participant's plan "support(ing) communities to respond to the individual goals and needs of participants." It is not the role of the individual plan to be supporting sections of the community to become more inclusive. The funding required for this type of support should not be coming out of an individual's support package.

Participants and their Plans - Chapter 3, Part 2, Division 2, Section 33 (1)

When the participant requires assistance to prepare their statement of goals and aspirations, this assistance should come from a "planner", not only an allied health professional. QDN members have found that allied health professionals often have limited expectations of the person with a disability, as a result of an underlying conservative (risk averse) approach to their clinical practice.

Participants and their Plans - Chapter 3, Part 2, Division 2, Section 33 (4)

QDN supports that there are timeframes legislated for a reasonable time to complete access requests and other functions of the agency, but has concerns that no

timeframe has been placed on the approval of participant supports. The legislation states “as soon as reasonably possible” but QDN believes a parameter must be placed on such a crucial period of the entire process. QDN believes that a 90 day maximum period would be a generous length of time that could account for unforeseen circumstance that we acknowledge will occur occasionally.

Participants and their Plans - Chapter 3, Part 2, Division 2, Section 34 (c)

Section 34(c) refers to the supports representing “value for money” which QDN believes may present some confusion. For some, a support may be absolutely mandatory and therefore is required at any cost, making this specific support “value for money”, but preventing the intended meaning of “value for money”. Clarification and examples of “value for money” should be provided in the rules as this is some of the specific information that is most concerning to future participants.

QDN believes the definition of “reasonable and necessary supports” require further explanation. People with disabilities are concerned about this area of the legislation as this will have the most tangible impact on their lives. QDN understands that the rules will detail these issues further, but without this sort of detail, people are left feeling uneasy about the NDIS’s effectiveness as a whole.

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.

People with disabilities from Australia or other cultures will require extra support to allow them to fully engage in the cultural and spiritual aspects of their life. In alignment with the “expectations of other Australian citizens”, it is reasonable for a person to use supports on a regular basis to access a church or spiritual group, or other gatherings that will assist them to be socially and spiritually connected.

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 concerned that there is nothing in the legislation to safeguard changes in the rules to suit the economic climate of the time. Safeguards must be put in place to ensure that any changes that may occur in the rules are subject to rigorous debate and consultation, with the same attention that the initial rules will be, and already have been afforded.

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. Surely, if people with disabilities have the ability to seek different possibilities in their types of support, this will encourage a more flexible marketplace, with service providers encouraged by market forces to satisfy their clients. 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. When people are faced with the unfortunate situation of not wanting to live with another individual, they have the resources and right to move on. Even if they are locked into a financial contract, there are still ways for citizens to move away, even if it means there will be some financial loss as a result of their decision. 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. As alarmist as this sounds, that is the current reality. When the Productivity Commission report stated that the system is “unfair”, this aspect is a prime example. Forced co-tenancy sounds like a bad idea from the outside looking in, and as one looks more closely to the centre, the picture becomes increasingly grim.

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.

Statement of Compatibility with Human Rights (Explanatory Notes)

QDN is gravely concerned about Page 9 Paragraph 2 of the Statement of Compatibility with Human Rights, that states,

“Differential treatment will not constitute discrimination if the differences in treatment are aimed at achieving a legitimate purpose and are reasonable and proportional to this purpose.”

QDN is worried that a “legitimate purpose” may be to “balance the budget” which may see discrimination allowed on the grounds that the costs of not discriminating is “(un)reasonable and (dis)proportiona(te) to this purpose.”

The issue of supported accommodation (forced co-tenancy) is often embroiled with debate around financial constraint. QDN does not want any Australians being denied their rights on this basis. QDN believes that the right to choose who you live with (or do not live with) is a non-negotiable stance for people with disabilities, that should not, and cannot, be justified on financial grounds.

Early Intervention

Every small milestone achieved by a person with disability makes a big difference for the rest of their lives. Each acquisition of a functional skill, irrespective of how minor, reduces the workload on families, carers and supports. These sometimes small gains may be the difference between families being able to cope, and not being able to manage in the long term. Activities of Daily Living such as toileting, eating, showering, are critical. The power of mobility cannot be underestimated. Early intervention that can facilitate a participant developing their skills to become independently mobile, whether by walking, self-propelling a wheelchair, or driving a power wheelchair, opens up opportunities for that person for the rest of their lives. Some participants may require specific skills training such as being able to behave appropriately in public places. Investment in all of these skills will pay great dividends both individually and for the NDIS in a fiscal sense.

Early intervention into communication will help the participant obtain the care that they want for the rest of their lives. Investment in communication strategies, training and devices is a key component in the participant's overall outcome. The ability to make a yes/no choice will empower the person with disability and make the carer's role easier and less stressful. Communication is also the cornerstone of literacy and therefore education. This will in turn have a massive impact on the participant's productivity in an economic sense in the future.

Surgery and specialist treatment is another avenue towards more sustainable care. If surgical intervention will allow a child to be able to stand, this has massive implications for carers in terms of toileting, showering and dressing. Investments in this way will make the role of caring far easier in a time sense and also in a physical sense – requiring less investment in equipment such as hoists for transfers, showering and dressing, as well as the time it takes to use such equipment. The person with disability will also have less discomfort.

Early intervention must have a strong research base as often parents of children with disabilities, in times of desperation, seek out alternative modalities with limited research supporting their efficacy. With the NDIS making a welcome shift towards early intervention, there is a risk of fraudulent operators attempting to take some of the NDIS spend on early intervention. QDN believes that private health insurance sector would be an appropriate guide in determining what treatment modalities should be included in the options for early intervention.

Early intervention to assist people with disability will have positive effects across all areas of society. With approximately 75% of people in the criminal justice system having an intellectual or psychiatric disability, early intervention is likely to have benefits for individuals, and the community at large, in the future. This strengthens the argument for the need to invest in our people with disabilities for the good of each individual, and the entire community.

It is particularly important to ensure that children who are in Child Protection have access to support in terms of early intervention. We know large numbers of children of Aboriginal and Torres Strait Islander background, who are in this particular cohort of NDIS participants, need support to connect with extended family. This could be assisted by access to identified Aboriginal Torres Strait Islander agencies to manage the foster and kinship care, and support the maintenance of contact with extended family and culture.

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 there is a need for a multi-focus approach to service delivery. Only then will people with disability be able to truly choose a service model or combination of service models that meet their needs. As such, 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.

As part of the participant's plan, the portion of the package of support that will be spent on generic services (non-registered service provider) can be determined. The capacity of the participant must be taken into account in determining the level of safeguards required for each individual when accessing services. This will safeguard the vulnerability of people with reduced capacity, while also providing flexibility that the NDIS is designed to create, by allowing people with high capacity a greater array of services at their disposal.

Individualised funding

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.

A service that has streamlined processes but applies these to restrict those for whom it is there to serve, must be seriously questioned. New accountability measures focussed on the person should avoid this.

Rural and Remote Supports

People with disability living in rural or remote areas will require specific support to cater for extra travel requirements. The use of generic supports becomes even more critical in remote areas, where the service provider options are limited.

There will also need to be special provisions in the NDIS Rules to enable people with disability in rural or remote areas to employ locals or family members if there is not service provider to meet their needs.

People with disability who are parents

Article 23 of the Convention of Rights for People with Disabilities states that:

(a) The right of all persons with disabilities who are of marriageable age to marry and to found a family on the basis of free and full consent of the intending spouses is recognized;

(b) The rights of persons with disabilities to decide freely and responsibly on the number and spacing of their children and to have access to age-appropriate information, reproductive and family planning education are recognized, and the means necessary to enable them to exercise these rights are provided;

People with disability may require support to fulfil their family responsibility as a parent. Packages of support must cater for the participant's role as a parent themselves.

Participants and their Plans - Chapter 3, Part 2, Division 2, Section 38

All plans and documentation for participants must be made fully accessible, in easy to read/plain English formats.

Participants and their Plans - Chapter 3, Part 2, Division 2, Section 40

The requirement for people with disabilities to notify the agency if the participant is leaving the country for longer than six weeks is too onerous. QDN sees this as an additional immigration exit requirement that is not required of other members of society. This notification to the agency should not have to go as high as the CEO. This should be done in a negotiation between the participant and the agency if the participant is self-managing their support. Alternatively, this negotiation should only

be required between the participant and the service provider if the participant is self-directing their support, or are using a service provider to manage their supports.

QDN believes that authorisation by the CEO should only be required if the participant will be leaving the country for a more extended period, such as 12 weeks.

Participants and their Plans - Chapter 3, Part 2, Division 3, Section 44 (2)

While QDN acknowledges the need for this part of the legislation, it does create concern for members. It is important that this section is not used to discriminate against people with specific disabilities or from a specific demographic.

Participants and their Plans - Chapter 3, Part 2, Division 3, Section 46 (2)

The need for accountability is unquestioned by QDN. 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. This may pose a challenge for some but should not be used as a reason to limit participant's ability to have more control over their packages of support. QDN believes that the record keeping practices must be standardised so that participants can become familiar with the expectations and with the assistance of staff, templates, and an interactive portal, the process can be achievable and over time, less stressful than in the learning phase.

Participants and their Plans - Chapter 3, Part 2, Division 4, Section 47

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.

Administration - Chapter 4, Part 2, Section 60

This process needs to be accessible for all people with disabilities and needs to be a free service.

Administration - Chapter 4, Part 2, Section 61

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.

Administration - Chapter 4, Part 3, Section 72

QDN believes that service providers must adhere to the rules and that these must be strongly enforced by the CEO. Penalties must be applied where the severity of the offence requires it and some service providers might become unviable because of not having clients. Too often service providers that do not deliver anywhere near a

quality service, are propped up under the guise of viability. This has to stop so that natural attrition can occur and people with disability can exit to find service providers that will meet their needs.

Administration - Chapter 4, Part 3, Section 73

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.

Administration - Chapter 4, Part 4, Section 73-77

QDN is concerned that the aspirations and goals may more closely reflect those of the parent, or nominated person who is involved in the plan, than those of the child/adult. The legislation must have some sort of test that allows the CEO to

determine if the plan is truly for the betterment of the child (future adult) with the disability or the family.

QDN members have expressed concern that their parents in the past (with the best of intentions) had been too limited in their aspirations for their child. This may be a result of a deficit-based mindset that they have been familiar with during their experiences in the medical model. Where families are not clear/ or lack a clear vision for social inclusion and community involvement, they need to be supported (forced) to access services that will assist them to fully understand the potential of their child.

A transition of responsibility must be undertaken in the planning stages of the NDIS. This transition must be made as the child shows signs of independence and the desire to become more actively engaged in their own management of supports. The process should not result in a participant turning 18 and being left with a seemingly overwhelming transition into adulthood. Rather, young adults with disability must be supported to transition from school to learning or earning and from home to independent accommodation.

Updates to plans will be more frequent during childhood. Offers to update plans should be provided in an effort to encourage parents to consider the changes that transitional stages in life take. These stages may include:

- Start of school
- Transition from primary to secondary school
- Completion of secondary school
- Entering the workforce
- Leaving home
- Retirement

Often parents of children with physical disabilities are faced with very complex and difficult decisions regarding surgery options. In many cases, the parents themselves have limited health literacy and find the decisions very stressful. There are many factors to consider, regarding outcomes and post-operative management (which is often lengthy and rigorous). Parents would benefit greatly from the option of support in the form of a **“Medical Appointment Chaperone”**. This must be someone who knows the child and living circumstances, and also comes from a medical background. The carers could discuss their options with someone during and after medical appointments to fully explore how they will handle all the issues that would arise if they follow each of their options. In this way, parents would not be left having to make a quick life-changing decision with their Specialist without being able to ask more clarifying questions that they hadn't thought of in the consultation.

Administration - Chapter 4, Part 5, Division 2, Section 86

Decisions regarding the appointment of nominees are absolutely critical in the overall outcome of the participant. 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.

Administration -Chapter 4, Part 6, Section 99

There is no section in the draft legislation that requires decision makers to provide reasons on a review of a decision. QDN believes that explanations of decisions are crucial for people to be able to fully understand the reality of their situations. Without explanations for the decision, individuals can believe that there is no hope of changing their situation; alternatively they can waste their time and public resources on an appeal that has no prospects. The provision of reasons also allows advocates assisting the individual to appeal to reasonably assess the merits of the case and provide advice.

There should also be easy access to independent advice, advocacy and representation. Community Legal Centres are not funded to levels that enable them to meet many of the presenting needs of people with disability. If legal advice is likely to be required, Community Legal Centres providing these services should be funded adequately to not only provide services to individuals, but also to contribute to systemic advocacy and review of the new NDIS structures (as outlined in section 208 of the draft bill) to ensure the system is protecting people's rights. If this is not going to be funded by the NDIA it must be funded by another Department within the Federal or State Governments. To not protect the rights of this vulnerable client group is unacceptable.

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.



National Disability Insurance Scheme Launch Transition Agency - Chapter 6, Part 3, Division 2, Section 147 (5) (b) (i)

QDN supports the Advisory Council providing advice to the Board. QDN also believes that the majority of the Advisory Council should be people with disabilities.

Chapter 6, Part 6, Section 178 and 179

QDN sees that the legislation exposes the NDIS to potential changes in fiscal policy which may 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.