

QDN's Response to Productivity Commission Draft Report into a Disability Care and Support Scheme

Introduction

Queenslanders with Disability Network Inc (QDN) is a Network of, for and with people with disability, with over 850 members across Queensland. In the past weeks, QDN has met with members across Queensland and held conversations on the Productivity Commission's Draft Report into a Disability Care and Support Scheme. The overall feeling of these conversations was a positive reaction. However, QDN's members expressed a strong sense of apprehension as to how a National Disability Insurance Scheme (NDIS) would be funded, if it would remain impervious to lessening by future Governments and how it will be implemented. Taking this into consideration, QDN and its members strongly support the establishment a NDIS and a NDIA that would meet the support needs of people with disability throughout their lives.

Over View

QDN acknowledges and supports the Productivity Commission's view that the current system is not well funded and does not meet the needs of people with disability in Australia. The Draft Report's recommended changes will move towards developing a system of support for people with disability that is based on entitlement, acknowledges people's citizenship and right to participate in society, and supports economic participation through meaningful employment.

In such a system, there is also a need for generic services, such as housing, education, transport and health care. People with disability should be able to access the services that other Australian's expect as a right. In the current system, people with disability are expected to be grateful for being treated in a segregated manner reminiscent of an apartheid system. The proposals outlined in the Draft Report provide a "road map" that could transform the current system so that it meets the needs of ALL people with disability.

Tier 1

Overall need for change

QDN agrees that part of the overarching role of the National Disability Insurance Scheme will be to educate and inform the broader community on the needs of people with disability. This will be important in raising awareness to the fact that the real needs of people with disability are not currently being met.

Any new system of Disability Care and Support must reflect and enact the United Nation's Convention on the Rights of Persons with Disability. The Convention is very clear on what people with disability should be able to expect in countries, such as Australia, that have signed the optional protocols. The Productivity Commission would be very aware, from the recent consultations across Australia, that the current system does not meet the needs of a large number of people with disability currently receiving services let alone those not receiving any.

Apart from providing direct support, a key feature of the Draft Report's proposed Scheme that will change the lives of many people with disability is increased social participation. This will need to be targeted towards:

- Changing community attitudes to be more welcoming of people with disability. This will increase community responsiveness to assist people with disability with opening doors, paying transport fares; and access to the built environment.
- Modifying the built environment to be more accessible to people with disability.
- Engaging society in the process of change through engaging in an intellectual change movement to alter perceptions of people with disability.

Tier 2

Disability support organisations

QDN agrees with the Draft Report's plan to establish a number of **disability support organisations**. Such organisations might fulfil roles similar to QDN's information and referral work, but would also support people with disability in envisaging what a life in the community could look like. This facilitates in sourcing and connecting the different pieces of a flexible and responsive system of supports.

Individuals and families/supporters seeking assessment

An individually tailored, taxpayer funded system of support, based upon entitlement determined by a monitored and rigorous, user-friendly assessment is supported. QDN supports the Productivity Commission's view that many people currently receiving support would be (re)assessed and either receive the same level of support, or more support.

Un-met and under-met need

The one caution that QDN highlights is the current lack of information regarding *un-met* or *under-met* need. QDN flags with the Productivity Commission that implementing a fairer system will also bring many people with disability into the application and assessment processes. This is because people with disability, and/or families/supporters, have often tried unsuccessfully to get support and given up on the system. A fairer intake system and more information on what is possible will attract many disengaged people with disability and their families.

National and Portability

QDN supports a national scheme that will enable people with disability to live anywhere in Australia and move according to their life choices and/or circumstances. A national scheme will also eliminate the current state variances that occur across disability types/diagnoses.

Principles of an entitlement based support system

QDN support the NDIS providing it remains true to the following principles and goals, so that people with disability have access to and choice of:

1. Equitable access to supports and services across Australia;
2. Responses to identified need that recognise local and cultural differences, including rural and remote communities;
3. A system that focuses on building on people's abilities and maximises participation;
4. Self-directed supports and/or funding to be used to support their lives and participation in work, leisure, creativity and spiritual development; and
5. A system that makes timely investments in people with disabilities and their families to maximise personal development, inclusion and skills, negates the effects of impairment or handicap, and supports existing natural networks of support.

Equipment

Access to funding for aids and equipment is vital for many people with disability who use assistive technology (AT), to access community, work, communicate, recreate and function. As informed by the International Classification of Function (ICF) and consumer input, AT users' priorities this requirement can be defined as:

- The best combination of equipment, personal care and environmental design to meet their needs in every area of life
- Access to sufficient funding to pay for good quality and long lasting equipment
- Having needs looked at holistically, so that each piece of equipment works well and does not interfere with other equipment or supports
- Accessing support through the whole process of getting equipment, including equipment trial, training and maintenance
- Having personal preferences and identity considered when identifying equipment to suit lifestyle and participation.

(de Jonge, Layton, Vicary: 2010)¹

Equipment should not be limited to pre-set list of approved equipment. Assessors need to be more responsive to the person's views on what is best for individual situations. Equipment provision should provide choice to person and move beyond mobility/continence aids to include devices used for communication, learning and social participation or interaction.

¹ de Jonge, Layton and Vicary, 2010 "The AT System in Review" (in progress)

Transport

Transport should be included in a NDIS so that people with disability have access to affordable transport options that are delivered in a uniform manner across Australia. This should include:

- Serious progression of DDA Accessible Public Transport standards and their implementation timeframes of December, 31 2007 25%; December 31, 2012 50%; December 31, 2018 90%; and December 31, 2022 100%. There is currently only patchy compliance with many companies having exemptions to compliance timelines;
- Nationalisation and indexation of the Taxi Subsidy Scheme to provide an affordable transport option for the most vulnerable; and
- Vehicle modifications are another area on which QDN's concurs with the Productivity Commission around the need for funding, and supports one-off funding for vehicle modifications to make vehicle ownership affordable for people with disability. Many people with disability or families could afford the cost of a \$28,000 small to medium sized car. They cannot afford \$60,000 to \$100,000 for a modified vehicle.

QDN supports the Productivity Commission's recommendations that the current diversely different State-based taxi subsidy schemes be amalgamated into a National Taxi Subsidy Scheme. This would need to be equitable; QDN suggests 75% subsidisation, indexed with inflation and the distance/length-of-journey not capped until travelling outside city limits. Such a move would significantly reduce social isolation by enabling people with disability to travel.

In addressing the transport needs of people with disability, all states and territories should undertake to make all public transport accessible and safe. In cities or regions where there is no public transport additional taxi subsidisation should be provided.

Employment

QDN supports the incorporation of the current system of Disability Employment Services into a national framework. Key features of such a system will need to be:

- User choice in terms of which service people with disability use; and
- A genuine attempt to place people in meaningful employment which matches their skills' set. Currently, people with disability with technical or tertiary qualifications find that many Disability Employment Service staff are intimidated by their qualifications and cannot meet their needs.

For these reasons, people with disability are often amongst the most educated by un/under-employed group. The following example is a frequent scenario:

A woman with disability who has a Bachelors and Master's degree used a disability specific employment agency for 4 years without success.

She then approached Centrelink and asked to be referred to a large generic Job Network. After 6 months with this Job Network, she successfully found employment and received professional workplace modifications that fully met her needs.

This is not an isolated scenario and has been relayed to QDN by numerous members who have experienced similar inefficiencies in relation to Disability Employment Services.

Support to include: activities of daily living, communication, community access and participation in education, learning and employment

QDN strongly agrees with the Productivity Commission's recommendations that the current range of supports be funded. This should include assisting people with disability with activities of daily living and communication.

QDN requests suggests that the Productivity Commission is cautious around determining what supports are required. In particular, QDN has a concern about the phrase 'reasonable and necessary' with regard to what supports would be funded by the National Disability Insurance Scheme.

It is QDN's position that if a person with a disability requires support to be part of the community; this should be funded by the National Disability Insurance Scheme. Such support might include assistance with the activities of daily living (as informed by the International Classification of Function {ICF}), assistance with communication, accessing services and/or activities in the community, participating in education or further learning and employment.

Housing

With regard to housing and accommodation options, QDN agrees that people with disability require assistance and this will need to be covered by the NDIS.

A multifaceted response is required and QDN recommends that it incorporate the following elements:

- Social housing being made accessible by reflecting universal design principles;
- People with disability on the Disability Support Pensions and people with disability on low incomes having access to finance/grants to purchase appropriate housing;
- Funding for home modifications to make privately purchased dwellings accessible;

*For example, one person purchased their first home and had to privately fund access and bathroom modifications to the cost of \$45,000. This seriously impacted upon, and delayed, other renovations required to improve an affordable inner-city house. It also meant that the person's non-disabled partner became fully acquainted with the **real** cost of disability, where many people incur costs that other Australians would not and could not afford.*

- Encouraging the private rental market to identify the economic benefits of making rental properties access and compliant with Universal Design Guidelines; and

- The Australian Government to build and maintain a stock of accessible public housing for people with disability, who cannot afford, secure or access any other form of housing.

On a broader level, QDN points out that housing needs to be located close to community hubs, such as shopping centres and entertainment venues.

As one person says, by living in an inner city suburb of Brisbane I have great access to public transport, a good supply of support workers, nice shops, coffee shops and local shops. Also entertainment venues are close by in the city and it's usually only \$12 to \$15 for a taxi home late at night.

QDN believes that all people with disability should have access to similar housing choices that reflect their lifestyle preferences.

NDIS and aged care

QDN notes that, once people with disability have support from an NDIS, they will not willingly transfer to a nursing home run by the health system. Of particular importance is the case in Queensland where people with disability who receive equipment from the Medical Aids Subsidy Scheme lose all entitlement to equipment if they enter aged-care.

To solve this equipment should be provided by both systems. If considering transferring to an alternative system, people will need to be with provided information on such equipment eligibility so they can make informed decisions and not be worse off for opting to transfer into aged care.

Health and allied or alternative therapeutic interventions

Mainstream Health System

Without significant reform, the health system will continue to not meet the needs of people with disability and will be a serious drain on NDIS resources. This is because many people with disability are forced to use extra support for regular health check-ups or hospitalisations.

A recurring theme among QDN members is that staff in hospitals cannot and *do not* assist with personal care, such as showering, eating or positioning in the bed. Patients with disability are sometimes left unable to access the basic essential of hospital care, such as the call button to signal for assistance. This causes many people with disability to use extra support *in case* they need to signal that they have pain or are in distress.

Alternative therapeutic interventions

There is much anecdotal evidence supporting the use of alternative therapies to ease the impact of the long-term effects of disability on the body. QDN's position on "what should be funded" is in line with private health insurance guidelines. Therefore, if it is recognised as a refundable intervention under the private health insurance

industry, it should be covered by NDIS. This would include things such as massage, acupuncture, podiatry, naturopath, and counselling.

In addition, it could be beneficial for people with disability to get regular exercise as it has been shown to be beneficial in assisting people with disability to maintain function or regain function after an injury or incident relating to their disability. It has also been found that people with disability who exercise regularly to maintain strength, balance and flexibility, require less intensive support, in terms of personal care and/or lifting equipment as they age.

For these reasons, investing in supporting people with disability to exercise, and maintain physical health and strength, will have a positive impact on the overall cost of funding the NDIS.

In addition to therapies, consideration should be given to funding natural-based supplements that are proven to reduce the impact of particular disabilities.

Independent advocacy critical

QDN identifies that the Productivity Commission draft report into a Disability Care and Support Scheme makes only passing mention of the role of systemic and independent advocacy in the current system.

The Institute for Family Advocacy and Leadership Development in Australia defines advocacy as:

... the process of standing alongside an individual who is disadvantaged and speaking out on their behalf in a way that represents the best interests of that person.

Advocacy often involves:

- Representing and working with a person or group of people who may need support and encouragement to exercise their rights, in order to ensure that their rights are upheld
- May involve speaking, acting or writing on behalf of another person or group
- Differs from mediation or negotiation because these processes aim to reach a mutually acceptable outcome between parties;
- Has no prescribed or clearly determined method. What constitutes advocacy will differ in different circumstances and according to the skills and needs of the individual or group:
- May involve working against established or entrenched values, structures and customs, and therefore needs to be independent of service providers and authorities
- Advocates are not impartial because they work entirely from the perspective and interests of the older person. Their role is to assist people by representing their wishes.

(Rights of Older People, <http://www.agedrights.asn.au/rights/whatis.html>, date accessed 20 April 2011)

Advocacy is currently funded by a combination of State and Federal Governments funding to non-government organisations who undertake advocacy on behalf of

some of the most vulnerable people with disability in the community. This is a vital service which must be continued. To truly stand beside or for people with disability, advocacy must remain separate from, and independent of, service delivery and service providers. For these reasons, the Productivity Commission should include some clear recommendations around advocacy provision and funding.

Eligibility

QDN generally supports the eligibility criteria set out in the draft report, as long as people with disability, who require occasional support to be part of inclusive Australian communities, would have access to that support when and where they require it.

QDN is in agreement with the recommendation that Australian residents with a permanent disability who have:

- i) Significant difficulties with mobility, self-care and/or communication;
- ii) An intellectual disability; or
- iii) A diagnosis suitable for which early-intervention, at diagnosis, change in disability, or point at which a different intervention becomes available would be beneficial in reducing the impact of that disability.

QDN agrees that the impact of the person's disability should be 'significant' and that this would be an appropriate threshold in terms of assessment and support.

People with disability, family or supports must be able, as outlined in the draft report, to request follow-up assessments as their needs or circumstances change. This should be driven by the person with disability or those who know them well. It should not be limited to major life transition points.

People with intellectual disabilities should get flexible support on an as-need basis and in line with assessments that focus on establishing and maintaining independence in the communities of their choice. This will need to include assistance with some personal care, but might focus on supporting function in relation to the systemic complexities of the societies in which Australians now live. For example, just having the power and/or telephone connected can be a confusing and complex interaction beyond the skill of some people with intellectual disability.

Support needs to be responsive and as required, because stress can exacerbate many of the impacts of disability. Therefore, early intervention is vital.

In some cases, early intervention would take the form of community orientation for visual impairments, where the person acquires an impairment or when they change place of residence or employment and must navigate a different build environment.

Assessment

QDN supports the use of the International Classification of Function as a benchmark from which to commence the development of a full assessment toolkit.

Such a toolkit would be based around a conversation or series of conversations with the person and, if they choose to have or require support, their support person. Care must be taken to avoid hasty decisions that could lock the person into an unworkable arrangement.

People with disability and parents, in Queensland, are currently only offered minimal, unworkable, support or forced co-tenancy. This means being forced to share supports and housing with up to 7 other people with disability.

These arrangements are institutions in any language.

On-going research and development of conversation-based assessment tools is supported by QDN. Also supported is the moderating and review of all assessments conducted, so that standards are established and can be bench-marked against. QDN strongly encourages the use of independent assessors and for a pool of accredited and monitored assessors to be trained, maintained and reviewed across the nation.

Self-directed funding and services: A Choice

QDN strongly supports the principles of establishing a simple to use system where people with disability can choose to self-direct their funding to source the supports they require. This would be done using established budgets and agreed upon plans that could be monitored by local case-managers. The trust, power and decision-making must be placed with the person with disability.

Underpinning self-directed funding would be a system of:

- Easy to use forms for the acquitting of funding;
- Simplified processes for changes to funding use, such as to hire/purchase equipment to make support more productive;
- Options and processes that allow people with disability to cash-out a portion of funding for approved items;
- Reasonably priced, fully-funded by support budgets and easy to navigate access to police checks to reduce risk of abuse and neglect; and
- Reasonably priced and fully-funded by support budgets, workers compensation insurance.

Where people with disability or their supporters believe self-directed funding might be too difficult to coordinate or manage, QDN agrees that there should be a choice of options whereby people with disability can access support from 1 or more direct service providers. Such a choice would be based around the type of service delivered and value for money.

Innovative arrangements

Where people with disability have a choice and service providers are driven by delivering services that meet identified needs and are fully funded, there will be an increase in the innovation and flexibility of services offered.

In also arrangements between people with disability and service providers, the NDIA should establish a set of guidelines around the percentage of administration fee that service providers can charge. This would eliminate the current situation where some people have their support funding charged administration fees of between 6% and 45%. This creates huge variances in the level of support which people with disability, receiving the same funding, can purchase.

Workforce issues – Case managers

QDN is supportive of the use of local case managers or community navigators. However, it must be remembered that these people will require a broad skills-base and vision for people with disability to be part of the communities in which they live. Case managers will require intense training in understanding the social model of disability and ways to assist people with disability to navigate the new system.

QDN also suggests that people with disability have the option of easily changing case managers where they feel that will best meet their needs.

Like with assessment, the results achieved by case managers and the level of satisfaction experienced by people with disability will need to be regularly reviewed and moderated so that high standards of case management, remaining true to the intent of the NDIS, are maintained.

Complaints mechanism – what would this look like?

QDN recommends that establishment of a separate statutory body to review complaints. This is similar to Victoria's Disability Services Commissioner, who works with people with disability, to resolve complaints about disability service providers, and, with disability service providers, to improve outcomes for people with a disability.

The Commission and Commissioner encourages and assists the resolution of complaints in a variety of ways including informal discussions, conciliation processes, or under certain circumstances, formal investigation.

In Victoria, the Commission is established under the Disability Act 2006 which brings in major reforms aimed at improving services for people with a disability in Victoria. The legislation commenced on 1 July 2007.

The Commissioner is independent of government, the Department of Human Services and disability service providers, and reports through the Minister for Community Services to Parliament each year.

QDN would like to see this, Victorian, model adopted nationally.

Separate scheme for catastrophic injury

QDN supports the establishment of a NIS or no-fault scheme for injuries from motor vehicle, medical, criminal and general accidents.

For example, a young station hand sustained an acquired brain injury whilst mustering in the Gulf of Carpentaria. He had his medical bills covered and broken bones set but has to rely on family and friends for personal care and legal support. The family rang QDN seeking assistance. We referred them to advocacy but know that there is no scheme that will meet his or his family's needs.

Under the NIIS, any permanent injuries, resulting in eligibility for the NDIS should be covered. QDN agrees that such a scheme should be funded by funds from WorkCover schemes and Compulsory Third Party insurance funds. Any monetary pay-outs received by people should be taken into account compensation, but this not be a barrier to eligibility.

QDN suggests that people with disability, who have acquired their disability prior to the introduction of the NIIS will need to be eligible for the full range of supports available under the NDIS.

Implementation

QDN is concerned with the tight timeframes for implementation but thinks these should be maintained as they are reflective of the urgency of the situation. Therefore, a staged commencement from 2014, moving towards being fully-operational by 2018 is supported.

QDN does flag with the Productivity Commission, the very real potential of desperate people with disability and family, who are not currently receiving support, choosing to relocate to 'trial' areas in an attempt to gain a better life for themselves and their families.

It is essential that the NDIA and NDIS actively recruit people with disability to be both on the governing body and on the operational staff. In this way, real connection to issues at the heart of what is be aimed for a more likely to stay in sharp focus.

Conclusion

QDN is supportive of most of the proposed structure. Concerns arise in relation to the lack of adequate data upon which to base costings and the need for the system to allow for fine finessing of the solution to ensure that the need of all are met. There should not be too heavy a reliance on 'informal' supports as this has been a downfall of the current system. In a workable system people with disability must be entitled to the support required to perform the tasks of daily living with respect and dignity.

In summary, a Disability Care and Support Scheme should facilitate people with disability designing and directing their service/s, so that they receive the right amount of service with the right equipment, by the right people, in the right way, and at the right time.