



Submission: Reshaping the *Disability Services Act 2006*

Recommendations based on findings from an analysis of the impact of the disability reforms on people navigating their care and support options as they age.

Produced by COTA Queensland

November 2018



COTA Queensland

Level 1/ 25 Mary Street
Brisbane 4000
Queensland
(07) 3316 2999
www.cotaqld.org.au

Authorised by:
Mark Tucker-Evans
Chief Executive
mark.tucker-evans@cotaqld.org.au

Bronwyn Bidstrup
Program Coordinator

Prepared by:
Stephanie Power
Project Officer



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Acronyms

LACs: Local Area Coordinators
MAC: My Aged Care
NDIA: National Disability Insurance Agency
NDIS: National Disability Insurance Scheme
WHO: World Health Organisation

Acknowledgement of Traditional Owners

COTA Queensland acknowledges Aboriginal and Torres Strait Islander peoples as the traditional custodians of the lands on which we walk, work and live. We pay our respects to ancestors and Elders, past, present and future.

Background

Council on the Ageing (COTA) Queensland undertook a situational analysis regarding the impacts of the National Disability Insurance Scheme (NDIS) roll out on people as they age, in particular between 50 and 65 years of age. We were particularly interested in how older people understand, access, navigate and negotiate the interface between these systems, and in capturing pressures, useful supports, and emerging issues.

For the purpose of this submission, we have extracted findings and recommendations from our analysis of the information which was collected through public forums e.g. national and statewide discussions online regarding the reforms, a literature search, and consumer interviews. We did not focus on a particular cohort, rather we sought to pull together a snapshot of how consumers who identify as older people or who provide assistance or support to older family members, navigate supports across system interfaces. The voices collated were those of highly health literate consumers, who demonstrated capacity to self-advocate and/or advocate for others across different support spaces and with multiple parties e.g. service providers, health professionals, community organisations and government. Therefore, they cannot be taken as representative of how the average Queensland consumer moves at the aged care/disability/health system interface; however, they offer valuable insight into the types of issues consumers encounter.

Recommendations

From the consumer perspective, the original recommendations were categorised according to actions: *promote and raise awareness, define and build knowledge, review, address, and acknowledge*. From the community and public forum perspective, the original recommendations were categorised according to concepts: *representation (and advocacy in all forms), choice and control, systemic processes (seeking solutions), workforce, and education, language and communication*.

We revisited these recommendations for this submission. We applied the recommendations to the five priorities outlined in the consultation report *Towards an all abilities Queensland*. Despite not directly linking to priority one *Communities for all*, we recognise our recommendations do inform priority one, in that consumer access to and maintenance of supports are dependent on welcoming inclusive and respectful

communities (qualities that COTA Queensland and Queensland Government, 2018, have identified), in which strong networks exist and where the individual can foster quality personal and community relationships (Queensland Government, 2017). If consumers feel valued, respected and supported they are more likely to have the capacity to self-advocate to access services, employment, learning and social opportunities. They would, in turn, feel better equipped to also advocate for and support others.

Lifelong learning

Queenslanders with disability have the same opportunities as everyone else to access education and learning across all stages of life.

Consumers wish to promote education and raise awareness for all (including formal and informal support people) around disability in the community and the need to work with each other. They wish to create a world that can provide appropriate spaces for consumers to learn about e.g. identity, abilities, needs, how to have voice, and be part of an inclusive world.

Employment

Queenslanders with disability have increased access to employment opportunities.

Consumers wish to promote and raise awareness around the implementation of 'radical' ideas or solutions e.g. employment of (tax free) semi-volunteers to provide support to those people who are in need but do not have adequate resources.

Everyday services

Queenslanders with disability have the same opportunities as everyone else in the community to access services, such as housing, health, transport, disability and community services, and justice and community safety are accessible and responsive to their needs.

There are numerous recommendations from consumers around access to supports and services. **Consumers** wish to review how funds are utilised and ensure that funding meets actual support needs. In addition, they wish to review the underlying culture of the new system, which is considered outdated or where consumers are made to feel like they should be grateful and not question available supports or services (even if these are unsuitable or inappropriate).

Communication systems are considered inflexible, there is an avoidance of written communication, or there are multiple modes of communication to navigate. It is hard to keep consistent communication across parties including agencies, departments and organisations. The role of discussion is very important and there is a need for more streamlined and direct feedback channels.

The delays for administrative processes act as barriers for progressing to the next step to access (promised) supports. This is not only a setback for the consumer, but also the carer who fights for consumer rights and make supports happen. There needs to be an acknowledgement of the direct and immediate impact of the staff and service provider approach to service provision – the cause and effect – on the consumer. Patience is considered key to the generation of supports.

Consumers also wish to review the NDIS eligibility, which they consider too 'black and white' and inflexible e.g. lacks nuanced support tiers for diverse capacities and/or changing needs as people age. They also wish for Ministers to have discretionary ability to waive statutory requirements. Consumers would like to address the trust issues around the new system particularly regarding the viability of system processes (and thus being able to access supports). There is a need for ongoing support once ageing family members (as informal carers) can no longer provide continuity of care for e.g. adult children, spouses. They would like streamlined service provision through one provider where possible (current and future hope for NDIS and My Aged Care services). Seamless service provision is required in particular for consumers with ongoing or changing needs e.g. access to 24/7 care. They seek assurance of coordination of vital and daily supports through services that are in place, appropriate, timely and effective.

Consumers seek a wider range of services for diverse interests, appropriate stimulus and ongoing learning and exploration e.g. social groups for women whose interests fall outside the stereotypical community interest group (e.g. knitting, crafting). They wish to know more about how to access already available services particularly when they require continual support and the hours or funding is limited (or funding is used for vital immediate supports such as nursing care). They seek more support for community involvement and building skills, including consumer education around their own health condition e.g. nutritional guidance, understanding the nature of their own disability (if this is sudden or later onset).

Consumers wish to promote and raise awareness around the importance of language as key to successful supports - quality input equates to quality outcomes. Language impacts on understanding supports and how language is used e.g. guidance around correct wording, increases likelihood of successful applications. Consumers even anticipate future guidelines around how to write applications/complete assessment. They wish to understand jargon and clarify definitions and differences between concepts such as chronic health, medical condition, and disability. There is a need to shift the focus from the medical/clinical to the individual and personal experience of disability (from the service provider/organisation and/or agency perspective). Consumers feel community members need to know what is meant by 'insurance' and 'Scheme' in the Media and how these concepts are realised in daily life.

Awareness is required around an active recruitment approach to the NDIS where people must make it work (make it work for others or make it work for themselves), and encouragement for people to use the new system/the NDIS. There is a call to action for Government departments – as well as media and leading support organisations - to take shared responsibility in promoting facts (and highlighting myths) regarding the reforms and the lived experience of disability.

Further, the staff approach to care and having appropriately qualified staff matters to consumers and can make a difference to support outcomes. Specifically, consumers require staff who can bring a personal touch (with professionalism), empathy and care, and respect the individual consumer and understanding of themselves. Skilled staff listen, take notes and engage in good face-to-face communication. They display consistent and appropriate communication skills.

Reassurance and empowerment come through knowledge. Consumers wish to build knowledge, understanding, increase health literacy, and request more facilitation of education and training in the community around redefining or clarifying the meaning of living with disability, particularly for formal support people e.g. direct support staff and planners. Some consumers feel the World Health Organisation (WHO) definition is apt. Consumers understand that disability means 1. Quality of Life is impacted upon and is outside one's control; 2. losing the usual ability to do things; and 3. there is a difference between 'impairment', 'disability' and 'handicap'; each concept holds different connotations.

In terms of assessment and eligibility for supports, there are no clear-cut categories, especially around complex or nuanced needs. More awareness is required around the reality of living with disability and the implementation safeguards only as required according to individual needs, rather than by default for all persons (e.g. too much service provision or assistance can lessen independence/create dependence).

Public education regarding the NDIS and general reforms through workshops requires adequate time to build a 'hands-on' approach to understand and use the new system. Factsheets about system changes require more clarity in wording. Linking knowledge from all sources and then making these sources available to all will help develop better support networks. Peer to peer support is especially important to overcome concerns around the reforms.

NDIS funding, particularly for those consumers new to the service system, require more clarification in addition to a clearer definition of the NDIS model. Consumers comment that the NDIS should be around fair eligibility, practical supports, accountability, adequate economic support, and continual engagement.

For the **public** and **community**, the workforce and regulation of staff qualifications are a primary focus. Similar to individual consumer perspectives, they wish for more training and education to ensure appropriately qualified staff, especially for staff who are first point or direct contact points such as pre-planners, planners, support workers, personal carers and service managers. Training topics are recommended around perceptions, nuances and stereotypes of disability and how it impacts on peoples' daily lives and access to health systems; building understanding around specific disabilities e.g. psychosocial, mental, cognitive and 'non-visible' (non-physical) disabilities; and how to provide empathy or build stronger empathy.

Further, for all parties, there needs to be more information around how to undertake assessment, and consumer advocacy rights especially during crisis situations. Communities also require enough staff numbers particularly for (at risk of or already) underserved cohorts e.g. psychosocial disabilities, and a higher percentage of the workforce to have a lived experience of disability.

There also needs to be more general awareness around the impact on the workforce of the changing system and expectations including the workload and actual capacity of

staff, particularly LACs and planners who liaise with multiple parties often simultaneously (e.g. families, consumers, health professionals and service providers). There are recommendations through the public forums for the provision of more consistent job descriptions for LACs, larger quantity of LACs in each region, and a review of the type of qualifications LACs require around disability services.

For the **public** and **community**, education, language and communication play a role in securing supports. They wish for consumer voices to play a stronger role in the media to challenge harmful or biased portrayals, which indirectly and erroneously represent societal understanding of health, chronic health and disability. Thus there is a need for wider community education and disability awareness, which addresses stigma and/or stereotypes.

Education is viewed as a protective mechanism for consumers against e.g. staff behaviours, misaligned values from the service provider, or disparate systemic processes. Building more public literacy around the NDIS and the NDIA and the use and understanding of the new language and concepts that accompany the reforms, is considered necessary.

Community members would like more public (local, state-wide, and national) discussions around the NDIS. They feel it is important to continue education and research around understanding disability and health. Experiential learning is considered one key example of opening communication processes (with the goal of becoming more consistent and accurate), which may lead to better engagement through valuing individual stories.

In addition, it is important to maintain updates and regular communication with consumers e.g. NDIS participants, who have unchanging needs (and who may require less need for regular reviews). The media has a responsibility to inform current or potential service users including NDIS participants, regarding the health reforms. The NDIA and related agencies or partner organisations have a joint responsibility to uphold open truthful and transparent communication processes between themselves and with consumers. It is also important that health professionals have access to current resources to better understand health reforms, changing health system and the details of administrative processes and assessment.

The **public** and **community** seek to resolve systemic processes and issues such as the IT system – providing more efficient information portals so people know how to access the system to obtain answers for specific queries. They wish for agencies to improve the overwhelming nature of the system in general and specifically they require clarity around the NDIS terminology, bureaucratic jargon, the quantity of paperwork and complex administration, and the unapproachable or less friendly service user options they currently use to navigate and complete required processes.

From a global perspective, community members wish to improve accessibility for people so they may live the life they wish (which is also one of the main principles underpinning the cultural shift in the aged, disability and community care systems in Australia including recent NDIS reforms), but also cementing strongly in national legislation. They recommend as a nation to follow global leaders such as Canada and learn from previous reforms, particularly through discussion and reflection they can source solutions. Obtaining feedback from staff that work directly with consumers is one way of identifying and gaining insight into primary issues. Despite the current uncertainty and the nature of the evolving reforms, the non-service user perspective recommends that consumers keep their lifestyle goals in mind while planning and negotiating supports in their preferred care and support system/s. They reassure consumers that ‘teething’ issues are to be expected and to maintain patience and flexibility as it is anticipated that the market will become more sustainable with time.

Leadership and participation

Queenslanders with disability have the same opportunities as everyone else to participate in Queensland’s society and democracy, influence decisions that affect them and take up key roles in public and private organisations.

Consumers wish to address several gaps by highlighting and creating Quality of Life supports for carers (particularly older carers). They wish to acknowledge that despite the level of health literacy/no health literacy, *all* consumers are continually adapting to an evolving system and service models, which require learning or adapting to new language, communication and administration processes. As mentioned in other areas, consumers want to encourage their peers to self-educate, become aware and take responsibility to ensure they receive tailored and appropriate supports through self-advocacy strategies such as networking and connecting to representatives e.g. local MPs.

The service providers' role is to uphold responsibilities to consumers. Consumer voices are to be heard and the individual's needs and life goals are to be respected. It takes time to get to know the individual and therefore time to conduct a quality assessment of their support needs. Government agencies and departments are also accountable for consumer wellbeing and (potential) human rights breaches must be taken into account and actioned e.g. adequate compensation to affected individuals.

For the **public** and **community**, they feel consumers require more representation (including advocacy in all forms). Consumers require self-advocacy skills including self-management/awareness/agency so they do not become disadvantaged by the reforms. People want answers from those most qualified to represent them (including NDIA and NDIS staff and higher-level professionals). They ask for stronger advocacy at national and state levels and from service/support/health organisations. There is a lack of support for unidentified or underrepresented cohorts particularly psychosocial disability (as mentioned earlier). This is also the case for ageing carers with current or future support needs, carers who wish to generate their own income, require respite, or require recognition of informal care as employment (with its own conditions and rights).

Consumers would like choice and control in all matters including consistency and choice of support staff and how consumer input is collated and used toward obtaining appropriate planning and thus better tailored supports (particularly around psychosocial disability). Examples of recommended strategies include demanding safe and locked-in legislation e.g. contingency reserves, making strategic shifts to give consumers what they need, conducting earlier reviews of mismatched or unsuitable support plans, and obtaining better understanding of how to evaluate current supports. From the non-service user perspective, it was recommended that consumers may become more proactive by e.g. asking for another planner, stating their needs directly and becoming more assertive; however, the reality of enacting such strategies are dependent on a number of factors including consumer capacity and confidence with using existing supports or navigating the system. Overall, working towards a fully inclusive society means meeting basic human rights such as housing and vital daily supports but the consumer having choice and control over these aspects such as where they live and how they live, and what type of supports, and when and how they receive the supports.

Actions

We indicate the potential relevance of COTA Queensland recommendations to certain items outlined in **Part A: New disability legislation**. Some of these items may indirectly address considerations of **Part B: Quality and Safeguards**.

Within the scope of our original investigation, we thus support the following ideas for new legislation as presented in *Reshaping the Disability Services Act 2006. An inclusive and accessible Queensland* documentation and outlined below.

Strengthening the focus on the rights of people with disability

We support Strengthening Disability Principles and introducing a Charter of Disability Rights because:

1. Consumers wish to raise awareness and promote education around creating more inclusive communities for people with disability.

Consumers wish to be in control of their choices and promote consumer autonomy through education e.g. make their peers and society in general more aware about the importance of self-advocacy and being in control (where possible), using available resources and networks (including peer support) to ensure appropriate supports. They wish for education around consumer rights in interacting with different health and care and support systems, and the need for independence (including the role of financial security).

They desire better education for health professionals and staff around individuality and nuanced needs of disability e.g. not all safeguards can be applied to each person/there is a fine line between maintaining or lessening independence.

The public seek better representation, more answers from qualified people, and stronger advocacy towards more inclusive communities. In terms of equality of opportunity and accessibility, there is a need to review how the workforce is trained and educated, particularly around building more understanding of specific cohorts and staff being equipped with lived experience of disability. Consumers feel there needs to be more awareness around staff pressures such as time limitations of delivering and planning supports, actual capacity required for certain support roles and the maintenance of consistent, appropriate and empathic communication skills.

2. Consumers wish to clarify language and processes around the health reforms and generation of supports.

Consumers want to raise awareness around the role of language in investigation, planning, negotiation and implementation of supports, including seeking advice around the correct written language for applications and assessment. There is a need to simplify jargon and clarify the wording around what the reforms entail e.g. which processes have changed and how funding works.

Increasing consistency, collaboration and accountability

We support the ideas of *Require the Queensland Government to Develop a State Plan and Strengthen Consultation, Implementation and Monitoring Requirements* because:

3. There is a need to ensure continuity of care across systems and for particular attention to be paid to those who are most at risk of ‘falling through the cracks’ as the reforms continue to roll out.

The Aged Care and Disability Reforms have created a care and support system which is continually changing and developing. This has ramifications for government, service providers, community and consumers across a range of sectors.

There needs to be an acknowledgement of government and service provider accountability including global scale concerns such as the potential to breach human rights, yet this first requires respect for the individual’s existing health literacy and capacities especially in an evolving care and support system. The public recommends overt encouragement of the use of the new systems e.g. NDIS and My Aged Care; and supporting consumers, community and service providers through awareness raising, information sharing and engagement activities which enable most appropriate use of these systems which have been designed to better meet consumers’ needs.

We support the idea of *Improve Data Collection* because:

4. The community wants to better identify, and address consumer issues, pressures and supports.

The public wishes to help inform the community around how people can best interact with services at the interface of systems and the impact of this engagement on consumer outcomes. Consumers want solutions to systemic issues such as the IT system, overcoming bureaucracy and jargon, clarifying administrative and informational processes. They also wish to engage with feedback and data from staff to assist in promoting a holistic understanding of consumer issues, pressures and supports. Consumers wish to address gaps in Quality of Life supports for carers.

Strengthening government and community partnerships

We support the ideas of Strengthening the Legal Requirements in Relation to Appointment and Membership of Committees and Establish Functions of Advisory Committees because:

5. Committees assist in bringing to light consumer issues around systemic changes including the impact of marketisation, accessibility of supports, and the changing definition of disability.

There is a need to clarify how the new system works including building public literacy around the health reforms to address stigma and stereotypes of disability. There is some distrust around privatisation or marketisation of services, new providers or the new system in general. There is confusion or distrust in the underlying culture, which some felt was outdated. There is frustration around the communication systems, which some felt were inflexible and not tailored to their particular support needs. Other big picture issues were delays in administrative processes and staff accountability for the direct and immediate impact of how service provision works/ does not work for the consumer. Consumers also recommend quite specific actions, for example Ministers to have discretionary ability to waive statutory requirements, so the person is better able to access supports when it matters most.

Finally, consumers want a more inclusive NDIS legislation in terms of eligibility for a range of disabilities and ages. There is a desire for streamlined service provision, continuity of supports (particularly when overlaid with complex family dynamics), and timely service supports. In addition to meeting a diverse range of individual needs, values and interests, there is strong support for a continued focus on capacity building for individuals and their formal and informal support systems, in enabling the person (and their carer) to live as well and independently as possible in their home and community.

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