



Down Syndrome
Queensland

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Submission to Queensland Productivity Commission on its draft report into the National Disability Insurance Scheme (NDIS) market in Queensland

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Patrons: The Governor of Queensland, Paul de Jersey, AC, QC, and Mr Wayne Grady



About Down Syndrome Queensland

Down Syndrome Queensland was established in 1946 and is the peak body for people with Down syndrome in Queensland. Our mission is to build community awareness and to support, advocate for and empower people with Down syndrome to take their rightful place as valuable and contributing members of their communities. We work collaboratively with the Down Syndrome Australia, and other State and Territory associations to achieve our mission.

Our vision is an Australia where people living with Down syndrome are valued, reach their potential and enjoy social and economic inclusion.

Down syndrome is a genetic condition in which the person has an extra copy of some or all of chromosome 21. This additional chromosome results in a number of physical and developmental characteristics and some level of intellectual disability. There are approximately 3,000 people in Queensland who have Down syndrome and approximately 1 in every 1,100 babies in Queensland are born with Down syndrome.¹

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¹ Down Syndrome Australia (2020). Down Syndrome Population Statistics. Retrieved from <https://www.downsyndrome.org.au/about-down-syndrome/statistics/>

Submission to Queensland Productivity Commission on its draft report into the National Disability Insurance Scheme (NDIS) market in Queensland

Down Syndrome Queensland (DSQ) welcomes the opportunity to provide a submission to the Queensland Productivity Commission on its draft report into the National Disability Insurance Scheme (NDIS) market in Queensland. Our response focuses on issues relating to the experience of people with Down syndrome and their families.

Overall perspective on the NDIS and people with Down syndrome

Our 2018 survey on the experiences of people with Down syndrome and their families with the NDIS highlighted the following:

- NDIS has been a positive change for most people with Down syndrome, with most people getting access to more support than they have had before. It has had positive impacts on independence, wellness, employment and education.
- There are some significant challenges and barriers for how people interact with the NDIA. This includes the access process, knowledge of planners, issues around implementing plans and understanding of the NDIA.
- People want more information on how to get ready to enter NDIS including understanding what relevant goals might look like, what evidence is required and what they should expect.
- People want more support and better IT systems to support self-management of plans.
- Families value having access to peer support and getting advice from other families who have already gone through the planning process.
- Participants want greater consistency, staff who understand Down syndrome, and a more appropriate process for access to the scheme.

More detailed responses from the survey identified the following in specific areas which the Commission may find useful in response to a number of the recommendations and findings in the draft report:

Access:

- 52% had to get specialist reports to get access to the NDIS. 24% already had the necessary reports, and 21% had automatic eligibility.
- Many people had to pay for specialist reports with costs ranging from \$100-\$1500.
- Only four people reported that they were denied access to NDIS but these decisions were overturned on review.

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- People noted having to access specialists that they had not previously seen (e.g. psychologists) due to the proof required for access.

Planning meeting experience:

- NDIA representative's understanding of Down syndrome - 49% said poor/fair, 23% said very good/excellent
- NDIA representative's communication with you and the person with Down syndrome - 31% said poor/fair, 23% said very good/excellent
- The discussion of goals with you and the person with Down syndrome - 38% said poor/fair, 38% said very good/excellent
- The overall experience of the planning meeting - 36% said poor/fair, 38% said very good/excellent

Plan and use of funds

- Satisfaction with plan received - 48% of NDIA managed were satisfied, 61% of self-managed were satisfied
- Are you having any difficulty with this way of managing your funding? - 41% of NDIA Managed said Yes, 22% of self-Managed said yes
- Have you been able to get the supports you need to implement the plan? - 66% of NDIA Managed said Yes, 77% of Self-Managed said Yes

Barriers to getting supports

The principal barriers to getting supports were:

- Difficulty finding the right support workers (38%)
- lack of services available (37%)
- difficulty finding the right provider (35%)
- time involved in providing support to attend therapies (30%)
- insufficient funding (27%)
- transport to services (23%)
- needing more time to adjust to changes to routine/new therapies (23%)
- Understanding of NDIS, (33% of families reporting their understanding of NDIS was poor or fair)



Impact of the NDIS:

- Developing friendships with people outside of the home - 43% said it had been somewhat, very or extremely helpful
- Supporting education and learning - 51% said it had been somewhat, very or extremely helpful
- Helping to get involved in community groups - 31% said it had been somewhat, very or extremely helpful
- Employment - 16% said it had been somewhat, very or extremely helpful
- Independence - 55% said it had been somewhat, very or extremely helpful
- Wellbeing - 56% said it had been somewhat, very or extremely helpful

Down Syndrome Queensland's Response to the Draft Report

Below are DSQ's specific responses to some of the key Draft Findings, Draft Recommendations and Information Requests as they relate to people with Down Syndrome and their families and carers.

Participant Outcomes

Recommendation 1

Independent monitoring and evaluation of independent assessments

The view of DSQ is that the Queensland Government should go further than just proposing the independent monitoring and evaluation of Independent Assessments, and should in fact question the rationale for the implementation of Independent Assessments.

These changes will fundamentally undermine the individualised and personalised nature of the NDIS. In their place will be an automated process which we are concerned will not adequately consider individual need and circumstance. These assessments and the new process for determining participant plans and budgets may actually exacerbate existing problems or create new unintended ones.

The introduction of mandatory assessments is the biggest change to the NDIS since it began. Despite the scale of the changes, they have not been rigorously tested or undergone an independent evaluation, consultation has been rushed and the substantial concerns of people with disability, their families and the organisations that support and represent them have not been addressed.

Based on the information released by the NDIA, we are concerned that a desire to cut costs is the main motivation for the hurried introduction of these reforms.

We want the NDIS to succeed. But we cannot support legislative or operational changes which we believe undermine the intent of the scheme. And may leave people with disability without the support they need.

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We would be happy to provide more information on our concerns with the introduction of Independent Assessments

Review of National Advocacy and Decision making supports

Unfortunately, people with intellectual disability are not always made aware of their rights or supported to stand up for their rights. It has been noted repeatedly that the *Disability Discrimination Act 1992 (Cth)* (**DDA**) has provided limited protection to people with intellectual disability from discrimination. The majority of high-profile cases have related to sensory or physical disability². For example, data from the Australian Human Rights Commission found that from 2017-2018 only 3% of complaints relating to the Disability Discrimination Act related to a person with an intellectual disability.³ This is despite the evidence suggesting that 1 in 5 people with an intellectual disability experiencing discrimination⁴ and 23% of participants in the NDIS report having an intellectual disability as their primary disability⁵.

Peak organisations play an essential role in protecting the rights of people with intellectual disability through their advocacy work. In particular, peak organisations are responsible for not only providing crucial information to people with intellectual disability regarding their rights but also in raising awareness regarding the rights of people with intellectual disability in a range of different settings including employment, education, the health care system and in the broader community.

Importantly, these peak organisations give a voice to people with intellectual disability and act as a conduit between people with disability and governments and communities. For instance, DSQ established the Queensland Down Syndrome Advisory Network (DSAN), a network of people with Down syndrome across Queensland. This group helps to ensure the work of DSQ reflects input from people with Down syndrome and it provides a forum for people with Down syndrome to get involved in self-advocacy and to develop leadership skills. DSQ supports people with Down syndrome to give input to NDIS, provide input into submissions we develop (such as this one), and provide an opportunity to have their say on what is happening in Government agencies. For example, peak disability organisations played an important role in raising key issues around the COVID-19 Response with Government.⁶

Therefore we support a review of National Advocacy and decision making supports but with a focus on ensuring the above issues are addressed.

² <https://humanrights.gov.au/about/news/speeches/human-rights-people-intellectual-disabilities-australia-where-here>

³ https://humanrights.gov.au/sites/default/files/AHRC_Complaints_AR_Stats_Tables_2017-18.pdf

⁴ <https://www.abs.gov.au/AUSSTATS/abs@.nsf/Previousproducts/4430.0Main%20Features972015?opendocument&tabname=Summary&prodno=4430.0&issue=2015&num=&view=>

⁵ NDIA Quarterly Report 31 March 2020

⁶ Children and Young People with Disability Australia (2020). An Open Letter to the National Cabinet: Immediate actions required for Australians with disability in response to Coronavirus (COVID-19). Retrieved from

https://mcusercontent.com/c75d12b0ea3d513c036636c7d/files/dcff274-d57b-4f60-89de-6382b7fbb293/An_Open_Letter_to_The_National_Cabinet_Final_small.pdf



Recommendation 3

Facilitate re-allocation of budget to support co-ordination where it improves plan utilisation and participant outcomes

DSQ supports the ability to re-allocate budget to support co-ordination. We have heard many stories recently of a blanket approach of not providing support co-ordination without due consideration of the benefits that support co-ordination may have to the ability of the participant to make effective use of their plan in order to achieve their goals.

The extent to which participants are being supported in developing and pursuing learning and employment goals

Data from the National Disability Insurance Agency shows that the vast majority of NDIS participants who have an intellectual disability and are employed are working within segregated employment. 70% of participants aged 25 and over with an intellectual disability who are employed- are employed within an ADE (segregated employment) after being in the scheme for 3 years.⁷

About half of the adults with Down syndrome who do not have a job have listed a work goal in their NDIS plan. This confirms that many people with Down syndrome wish to work but find it difficult getting a job.

DSQ argues that there is a need for a new approach to supporting people with an intellectual disability to participate in employment. We know from international examples, that it is possible to move away from segregated employment models and have good outcomes for people with intellectual disabilities.

DSQ makes the following specific recommendations on employment for people with Down syndrome:

- **An 'open employment first' approach to providing services and supports.** The NDIS should focus on building skills to support people with an intellectual disability being supported in open employment.
- **Better support for transition from school into open employment.** Often schools use ADEs as 'work placements' for students with an intellectual disability. This limits their ability to develop workplace skills and to fully explore their options. Work experience should be provided within open employment for all students. Opportunities to access work experience should begin early (year 10) where possible.
- **Improvements in post-school educational pathways for people with intellectual disability.** There are a few examples in Australia of programs that provide further educational pathways to work. However these options are limited. Often inaccessible curriculum design and assessment processes mean that people with Down syndrome are effectively shut out of vocational courses run by TAFE's.
The NDIS Price guide is also prohibitive in terms of providing continued learning experiences as there are no line items relating to the engagement of someone with a teaching qualification and

⁷ NDIA (2019) People with an intellectual disability in the NDIS. <https://data.ndis.gov.au/media/2126/download>



as such, any such programs are very difficult to run other than at a loss (as only “support worker” type rates can be charged). This can be contrasted to capacity building activities that include an Allied Health Professional such as Occupational Therapist, where the Price Guide supports prices of over \$200 per hour.

Impact on health and wellbeing of carers in Queensland and how easy to get respite support

In our view the NDIS needs to better consider the burden that the system puts on the health and wellbeing of carers in Queensland. Carers Queensland 2019 Quality of Life Audit found that, of survey respondents: 57% indicated that their mental health and physical health had worsened as a result of their caring responsibilities 50% had experienced an illness that had lasted at least 6 months, and of this group, 79% indicated that their caring responsibilities had impacted their recovery⁸. The challenges of navigating the NDIS, with all of its complexities and inconsistencies is a significant part of this burden that should not be underestimated.

In particular, in relation to people with Down syndrome we all too often see examples of parents being told that their son or daughter with Down syndrome will not be receiving supports as the activity is within “normal parental responsibilities”. This assessment is a justified one, however should be applied appropriately and with consideration not only of other informal supports available, the age of the child, but also of the caring burden of the child with Down syndrome.

Improving market coordination and supply

Does the Information, Linkages and Capacity Building (ILC) program serve Queensland well?

Community attitudes are one of the barriers faced by people with disabilities in several different domains including health, education, employment and community participation. Stigma about intellectual disabilities tends to be even greater than other types of disabilities. People with Down syndrome are often subject to harmful and inaccurate portrayals, resulting in some community members adopting negative attitudes towards them.^{9,10}

A recent survey of community attitudes in Victoria highlights the exclusion and discrimination faced by people with intellectual disability.¹¹ It found that:

- 75% of respondents indicated that they were likely or very likely to ‘pity’ a person with intellectual disability
- 56% of respondents indicated that they were likely or very likely to avoid a person with an intellectual disability.

⁸ Carers Qld Quality of Life Audit 2019 [Quality-of-Life-Audit-2019.pdf \(carersqld.com.au\)](#)

⁹ Gilmore, L., Campbell, J., & Cuskelly, M. (2003). Developmental Expectations, Personality Stereotypes, and Attitudes Towards Inclusive Education: community and teacher views of Down syndrome. *International Journal of Disability, Development and Education*, 50(1), 65-76.

¹⁰ Gilmore, L. (2006). Perceptions of Down Syndrome in the Australian Community. *Journal of Developmental Disabilities*, 12(1), 1-13

¹¹ Victorian Government. Department of Health and Human Services. Survey of Community Attitudes Towards people with a disability. https://www.statedisabilityplan.vic.gov.au/application/files/5415/7526/0530/University_of_Melbourne_Community_Attitudes_Final_Report_19.06.19_-_PDF.PDF



- One in five responded that children with disability should only be educated in special schools, and that employers should be allowed to refuse to hire people with disability.

Negative attitudes and a lack of awareness also extend in some cases to the health profession. A 2011 study conducted with 1,500 physicians found that nearly a quarter of physicians (24.3%) felt that including students with Down syndrome in classes with typically developing students is distracting. In addition, almost 10% of physicians indicated that they did not feel comfortable providing medical care to people with Down syndrome.

Given these findings, DSQ is suggesting an increased focus from the ILC funding on the Capacity Building of Communities to change their attitudes which would then result in more opportunities for inclusion in the Community. It is essential that tailored approaches are taken to addressing community attitudes as often public awareness type campaigns might focus on physical disabilities but do little to address stigma associated with intellectual disabilities. It is essential that any strategy to tackle community attitudes recognises the diversity of disability types and the experiences of people with a disability.

The implementation of the ILC must take into account the multiple ways that changes in community attitudes can be achieved. For example, here is an important interaction between negative community attitudes about intellectual disability and the practice of segregation of people with intellectual disabilities. Exposure to children with intellectual disabilities has been shown repeatedly to have a positive impact on awareness and attitudes about intellectual disability¹².

As outlined by the Social Policy Research Centre in 2011¹³, there are several principles that need to be considered in order to successfully address attitudes about disabilities. These include:

- Adequately resourcing the approach
- Supporting people with disability (and disability representative organisations) in the development and implementation of any awareness initiatives
- Addressing multiple levels of intervention
 - Personal- changing the attitude of individuals through information, education, training, positive portrayal and supported opportunities for contact
 - Organisational- focusing on changing attitudes within a particular sector (inclusion Ambassadors within a school, or disability action plans within a major company)
 - Structural- Changing policy/legislation to improve inclusion and promote positive attitudes
- Recognising the diversity of disability types and circumstances of people with disability
- Implementing the strategy over a prolonged period to reinforce positive attitudes and replace negative attitudes.

¹² Cairns, Bernadette & McClatchey, Kirstie. (2013). Comparing children's attitudes towards disability. *British Journal of Special Education*. 40. 10.1111/1467-8578.12033.

¹³

https://www.dss.gov.au/sites/default/files/documents/05_2012/39_community_attitudes_to_disability_accessible.pdf



These principles should be included as part of the framework for the ILC.

Participant employment outcomes

Are NDIS employment supports helping participants find and maintain employment

As outlined above, data from the National Disability Insurance Agency shows that the vast majority of NDIS participants who have an intellectual disability and are employed are working within segregated employment. 70% of participants aged 25 and over with an intellectual disability who are employed- are employed within an ADE (segregated employment) after being in the scheme for 3 years.¹⁴

DSQ argues that there is a need for a new approach to supporting people with an intellectual disability to participate in employment. Segregated employment should not be considered as the first choice of appropriate employment for someone with an intellectual disability, and the NDIS should adopt the approach proposed previously in this submission of 'employment first'.

Summary

Whilst the NDIS has provided significant opportunities for many people with Down syndrome, there is still a long way to go to have a scheme that fully supports choice and control of the participants and funds their supports appropriately for this to be achieved. DSQ welcomes the opportunity to provide this submission to the Queensland Productivity Commission and would be more than happy to provide any further input or information that would assist the Commission.

¹⁴ NDIA (2019) People with an intellectual disability in the NDIS. <https://data.ndis.gov.au/media/2126/download>