



**PEOPLE WITH DISABILITY
AUSTRALIA**

**A voice
of our
own**

Inquiry into the implementation of the NDIS and the provision of disability services in NSW

**Response to supplementary questions from NSW
Legislative Council Portfolio Committee No 2 Health
and Community Services**

**OCTOBER
2018**

About PWDA

People with Disability Australia (PWDA) is a leading disability rights, advocacy and representative organisation of and for all people with disability. We are the only national, cross-disability organisation - we represent the interests of people with all kinds of disability. We are a non-profit, non-government organisation.

PWDA's primary membership is made up of people with disability and organisations primarily constituted by people with disability. PWDA also has a large associate membership of other individuals and organisations committed to the disability rights movement.

We have a vision of a socially just, accessible and inclusive community, in which the human rights, belonging, contribution, potential and diversity of all people with disability are recognised, respected and celebrated with pride. PWDA was founded in 1981, the International Year of Disabled Persons, to provide people with disability with a voice of our own.

PWDA is a NSW and national peak organisation and founding member of Disabled People's Organisations Australia (DPO Australia) along with Women With Disabilities Australia, First Peoples Disability Network Australia, and National Ethnic Disability Alliance. Disabled Peoples Organisations (DPOs) are organisations that are led by, and constituted of, people with disability. The key purpose of DPO Australia is to promote, protect and advance the human rights and freedoms of people with disability in Australia by working collaboratively on areas of shared interests, purposes, strategic priorities and opportunities.

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Responses to supplementary questions

Question 1: Definitions of disability used by government agencies

The Committee's question:

In your evidence, you indicated that 10-20% of all people in NSW have some form of disability. For the purposes of that statistic, can you clarify your definition of a person with a disability?

In our evidence to the public hearings for the inquiry, our statistics were drawn from the Australian Bureau of Statistics (ABS). This source is referenced in our submission to the committee, *Realising the State of Inclusion: the role of the NSW Government for people with disability*.¹

Further, the definition of 'a person with a disability', from which this statistic is drawn, is not PWDA's definition, but rather the criteria used by the ABS to identify people with disability.

The ABS's definition, and its own source, is explained in their glossary to their 2015 Survey of Disability, Ageing and Carers (SDAC).² The ABS states:

Disability

In the context of health experience, the International Classification of Functioning, Disability and Health (ICFDH) defines disability as an umbrella term for impairments, activity limitations and participation restrictions. It denotes the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environment and personal factors).

In this survey, a person has a disability if they report they have a limitation, restriction or impairment, which has lasted, or is likely to last, for at least six months and restricts everyday activities. This includes:

- *loss of sight (not corrected by glasses or contact lenses)*
- *loss of hearing where communication is restricted, or an aid to assist with, or substitute for, hearing is used*
- *speech difficulties*
- *shortness of breath or breathing difficulties causing restriction*
- *chronic or recurrent pain or discomfort causing restriction*

¹ People with Disability Australia, 2018. Submission 329, Realising the State of Inclusion: The role of the NSW Government for people with disability, <https://www.parliament.nsw.gov.au/lcdocs/submissions/61696/0329%20People%20with%20Disability%20Australia.pdf>

²<http://www.abs.gov.au/ausstats/abs@.nsf/Latestproducts/4430.0.10.001Explanatory%20Notes502015?opendocument&tabname=Notes&prodno=4430.0.10.001&issue=2015&num=&view=>



- *blackouts, seizures, or loss of consciousness*
- *difficulty learning or understanding*
- *incomplete use of arms or fingers*
- *difficulty gripping or holding things*
- *incomplete use of feet or legs*
- *nervous or emotional condition causing restriction*
- *restriction in physical activities or in doing physical work*
- *disfigurement or deformity*
- *mental illness or condition requiring help or supervision*
- *memory problems or periods of confusion causing restriction*
- *social or behavioural difficulties causing restriction*
- *long-term effects of head injury, stroke or other acquired brain injury causing restriction*
- *receiving treatment or medication for any other long-term conditions or ailments and still being restricted*
- *any other long-term conditions resulting in a restriction.*³

According to the Australian Bureau of Statistics Disability, Ageing and Carers, Australia: Summary of Findings, 2015, there are 1.3724 million people with disability living in NSW.⁴

According to the NSW Government's NDIS website: "In NSW, the NDIS is expected to benefit up to 140,000 people with disability."⁵ This figure is based on the modelling the Productivity Commission undertook as part of their inquiry that led to the development of the NDIS. These figures were contained in the Productivity Commission's reports from its original inquiry into Disability Care and Support, which estimated that the NDIS would provide packages to 410,000 people across the country.⁶ 140,000 is the estimate of how many people with disability in NSW would be eligible.

The comparison between 1.3724 million people with disability living in NSW and estimates of 140,000 people with disability in NSW being eligible for the NDIS leads to a figure of 9.8% or 10% of people in NSW being eligible for funded individualised packages under the NDIS.

This is consistent with national estimates that 10%, or 475,000 people with disability of the 4.3 million people with disability in Australia, will be eligible for individualised funding packages under the NDIS.⁷

³ Ibid.

⁴ Australian Bureau of Statistics, 2015. *Disability, Ageing and Carers, Australia: Summary of Findings, 2015*, Data Cube: New South Wales
<http://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/4430.02015?OpenDocument#Data> Released 12/01/2017

⁵ NSW Government, *The NSW and Australian governments sign landmark agreement*
<https://ndis.nsw.gov.au/2018/05/landmark-agreement/> May 25, 2018

⁶ Productivity Commission, 2011. *Disability Care and Support Productivity Commission Inquiry Report Volume 1 No. 54*. <https://www.pc.gov.au/inquiries/completed/disability-support/report>

⁷ Productivity Commission, 2017. *National Disability Insurance Scheme (NDIS) Costs*, Study Report October 2017, Figure 1, p. 4, <https://www.pc.gov.au/inquiries/completed/ndis-costs/report/ndis-costs.pdf>

Question 2: Further outline and analysis of definitions of disability used by government agencies

The Committee's question:

Does your definition of 'disability' align with the NDIA's definition of 'disability'?

If not, how do the definitions differ? What implications does this present for people accessing the NDIS? How could these be addressed?

As noted above, the definition of disability used to provide estimates of NDIS numbers in our submission is not PWDA's definition. It is the definition used by the Australian Bureau of Statistics to determine the population of people with disability in Australia.

Furthermore, the legislation that governs the National Disability Insurance Scheme (NDIS), **National Disability Insurance Scheme Act 2013** outlines the criteria through which a person with disability may be able to access the NDIS.⁸

By its very design the NDIS is an insurance scheme that enables people with disability to access funding for services and supports that they choose to enable participation in everyday life and in the wider community.

Under Section 24 of the NDIS legislation, it states:

24 Disability requirements

(1) A person meets the disability requirements if:

- (a) the person has a disability that is attributable to one or more intellectual, cognitive, neurological, sensory or physical impairments or to one or more impairments attributable to a psychiatric condition; and
- (b) the impairment or impairments are, or are likely to be, permanent; and
- (c) the impairment or impairments result in substantially reduced functional capacity to undertake, or psychosocial functioning in undertaking, one or more of the following activities:
 - (i) communication;
 - (ii) social interaction;
 - (iii) learning;
 - (iv) mobility;
 - (v) self-care;
 - (vi) self-management; and
- (d) the impairment or impairments affect the person's capacity for social or economic participation; and
- (e) the person is likely to require support under the National Disability Insurance Scheme for the person's lifetime.

(2) For the purposes of subsection(1), an impairment or impairments that vary in intensity may be permanent, and the person is likely to require support under the

⁸ National Disability Insurance Scheme Act 2013: <https://www.legislation.gov.au/Details/C2016C00934>

*National Disability Insurance Scheme for the person's lifetime, despite the variation.*⁹

Section 25 of the legislation also outlines the requirements to access early intervention.

In response to the Committee's supplementary question, the NDIS has been designed as an insurance scheme that people with disability can apply to access. The role of the National Disability Insurance Agency is to assess, in accordance with the legislation, the eligibility of a person with disability to access the insurance scheme. The NDIA explains the eligibility process in this way on its website:

Disability

You may meet the disability requirements if:

- *you have an impairment or condition that is likely to be permanent (i.e. it is likely to be life long) and*
- *your impairment substantially reduces your ability to participate effectively in activities, or perform tasks or actions unless you have:*
 - *assistance from other people or*
 - *you have assistive technology or equipment (other than common items such as glasses) or*
 - *you can't participate effectively even with assistance or aides and equipment and*
- *your impairment affects your capacity for social and economic participation and*
- *you are likely to require support under the NDIS for your lifetime.*

*An impairment that varies in intensity e.g. because the impairment is of a chronic episodic nature may still be permanent, and you may require support under the NDIS for your lifetime, despite the variation.*¹⁰

PWDA fully supports the NDIS and its objects and principles stated under Part 2 of the Act.¹¹ Reworking the definitions of disability, as is implied in this question, will not solve the current challenges with the implementation of the NDIS. The ABS definition and the NDIA criteria for assessing NDIS eligibility serve different purposes.

As outlined in our submission to the Committee, the challenges that some people with disability are experiencing with their access to the NDIS may be due to a range of factors such as lack of accessible information, inadequate referral pathways, isolated and marginalised living arrangements, lack of independent advocacy support, poor understanding of disability by NDIS planners etc.

PWDA believes the implementation of the NDIS will be strengthened, not by changing or redefining the definition of disability, but rather by:

- better training for planners and assessors working within the NDIS

⁹ National Disability Insurance Scheme Act 2013 - <https://www.legislation.gov.au/Details/C2016C00934>

¹⁰ NDIA website: <https://www.ndis.gov.au/people-disability/access-requirements.html#Disability>

¹¹ National Disability Insurance Scheme Act 2013 <https://www.legislation.gov.au/Details/C2016C00934>

- enhanced access and planning pathways for those in marginalised and isolated situations
- greater transparency on the assessment of plans
- addressing, as a matter of urgency, the delays in the reviews and reassessment of plans.

We believe that the NSW Government, as a partner in the implementation of the NDIS under the bi-lateral agreements, has a strong and important role to play in advocating through the Disability Reform Council for measures to improve the implementation of the NDIS.

Question 3: Cohorts of people with disability experiencing issues with the NDIS implementation

The Committee's question:

Are you aware of any discrete cohorts of people with disability (such as those being on the autism spectrum) who are experiencing issues with the implementation of the NDIS?

As the committee will be aware, the full roll-out of the NDIS is ongoing in NSW. Based on member feedback and our experience with our individual advocacy and boarding house programs, we are aware of the following cohorts of people, including children and young people and older people with disability, who may be experiencing issues with the implementation of the NDIS:

- people with psychosocial disability
- people with health conditions and impairments who are deemed as solely needing health system supports, instead of recognising the necessary disability specific supports that facilitate daily living and community participation, for example arthritis, chronic fatigue syndrome, and Ehlers-Danlos Syndromes
- people over 65 years of age who are unable to access the disability specific supports through the NDIS or through the aged care system
- people with disability who have complex needs or may be experiencing crisis, including contact/involvement with the child protection system, juvenile justice system, the adult justice system
- people with disability who are from Aboriginal, CALD, or LGBTIQ+ communities
- people with disability, including women with disability, who may be experiencing or at risk of violence, abuse and neglect
- people with disability who are living in highly segregated and isolated settings such as in boarding houses, or who are experiencing homelessness
- children and young people from families living in disadvantaged and/or rural and remote communities.

We emphasise this list is not exhaustive. This is an area that would benefit from research. A recent example of research into the implementation of the NDIS highlights that there are numbers of children from different backgrounds and communities who are at risk of not being able to access the NDIS due to lack of awareness and lack for referrals from mainstream services.¹²

¹² Christiane Purcal, Trish Hill, Ariella Meltzer, Nirosha Boden, Karen R Fisher, 2011. Implementation of the NDIS in the early childhood intervention sector in NSW: Final Report, page 16. <http://unsworks.unsw.edu.au/fapi/datastream/unsworks:51165/bind4d5c93e-d4f7-416d-a104-ca7e8903c097?view=true>

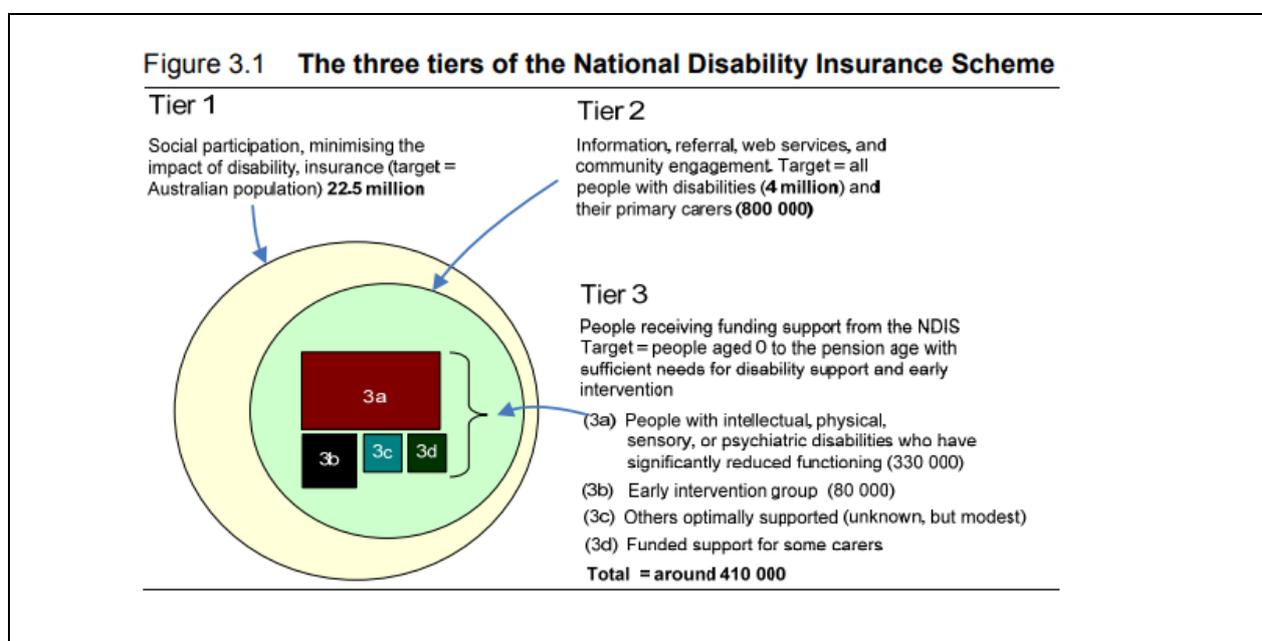
Question 4: Groups of people with disability who are not being captured by the NDIS and how they are accessing services

The Committee's question:

Are you aware of any specific groups of people with disability who are not being captured by the NDIS and thus not receiving the NDIS funding?

How are these groups accessing the support and services they need, if not by the NDIS?

In Productivity Commission's original proposals for the NDIS, the scheme was designed with three tiers of access.¹³ These are outlined in the following diagram:



Caption: Extract from Productivity Commission's Disability Care and Support Report, 2011

The Productivity Commission also noted that the majority of costs for the scheme would be directed to the Tier 3 NDIS participants, or those receiving individualised funding packages, originally estimated to be 410,000 people nationally.

Since this original proposal, the NDIS is now framed in terms of NDIS individual funding packages and NDIS Information, Linkages and Capacity Building (ILC). The NDIS was never intended to provide funding for disability supports to all people with disability, only those that met the eligibility criteria as outlined above under our response to question 2. The ILC "is designed to provide information, linkages and

¹³ Productivity Commission, op. cit, p.160.

referrals to people with disability, their families and carers, with community and mainstream supports”.¹⁴

ILC is aimed to reduce reliance on NDIS-funded support by ensuring that people with disability, particularly those who are not eligible for NDIS funding are able to receive supports through other service systems, such as health, housing, education, transport, justice etc.

Under the NDIS, as it has been implemented, people with disability apply to the NDIA to access NDIS funding to receive disability supports so they can participate in everyday life. This application to access the NDIS includes an assessment of eligibility, development of a plan and the assessment of the plan by the NDIA.

As noted above, there are a range of people with disability who may not be NDIS eligible, or who may not be able to access the NDIS and there are a variety of reasons for this. These reasons may include:

- lack of awareness of the NDIS
- limited or no access to appropriate referrals and advocacy to apply for the NDIS
- people do not have ‘significant and permanent conditions’ that would deem them to be eligible for the NDIS, noting that the Productivity Commission only ever envisaged that the NDIS at full roll-out would cover around 410,000 people across Australia.¹⁵

People with disability who may not be eligible for the NDIS need to access services through mainstream and specialist human services such as health, mental health, education, child and family services, justice services. As we clearly outline in our submission, this means that services delivered by the NSW Government and its funded agencies must be fully accessible and inclusive of people with disability, and where necessary, must include specific, tailored disability supports for people not eligible for NDIS funded packages.

Our submission provides a number of case studies drawn from our membership and our individual advocacy work that highlights critical gaps for people in NSW who are not eligible for the NDIS:

- they may no longer receive disability specific supports due to the NSW Government withdrawing from the provision of disability services
- they are unable to receive accessible supports and services through mainstream or community service systems, including those provided by the NSW Government
- they experience gaps at the interface of the NDIS and mainstream and community supports.

¹⁴ Productivity Commission, op. cit., Study Report October 2017, p. 30.

¹⁵ Productivity Commission, op.cit, p. 160.

Our submission provides a range of recommendations that are directed at these critical gaps and that clearly highlight the critical responsibility that the NSW Government still has to people with disability in NSW.





**PEOPLE WITH DISABILITY
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For individual advocacy support contact the **Disability Rights Information Service (DRIS)** between 9:00 am and 5:00 pm (AEST) Monday to Friday on (02) 9370 3100 or Toll Free on **1800 422 015** or TTY Toll Free on **1800 422 016** or email dris@pwd.org.au

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