

## Submission

### NDIS Review – Building a strong, effective NDIS

People with Disabilities (WA) Inc. (PWdWA) would like to thank Department of Prime Minister and Cabinet for the opportunity to provide comment for their review into National Disability Insurance Scheme (NDIS).



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## People with disabilities WA (PWdWA)

Since 1981 PWdWA has been the lead member-based disability advocacy organisation representing the rights, needs, and equity of all Western Australians with a physical, intellectual, neurological, psychosocial, or sensory disability. PWDWA do this via individual and systemic advocacy. They provide access to information, and

independent individual and systemic advocacy with a focus on those who are most vulnerable.

PWdWA is run by and for people with disabilities and, as such, strives to be the voice for all people with disabilities in Western Australia.

## **Introduction**

Systemic advocacy is an important part of PWdWA's work. PWDWA is committed to ensuring the voice of our members and people with disabilities in WA are heard and represented. PWDWA appreciate that the Minister for the National Disability Insurance Scheme, the Hon. Bill Shorten MP announced a review of the National Disability Insurance Scheme (NDIS) to look at the design, operation and sustainability of the NDIS, including ways to make the market and workforce more responsive, supportive and

sustainable. An overarching goal of the Review is to put people with disability back at the center of the NDIS. It aims to help restore trust, confidence and pride in the NDIS.

PWDWA provides individual and systemic advocacy around issues experienced by individuals, families, carers and the community concerning the National Disability Insurance Agency (NDIA) and the NDIS. Our individual advocacy services support people engaging with the NDIS processes at all levels. NDIS continues to be the most common issue PWdWA are contacted for support, especially in the areas of S100 internal reviews, the Administrative Appeals Tribunal (AAT) and insufficient funding in a participant's plan. PWdWA recognises the NDIS provides crucial support and has improved the lives of people with disability. However, PWdWA strongly believe there are some outstanding issues to be addressed with particular in depth focus on the nature and characteristics of disability, making the NDIS accessible and easier to navigate support services, and greater emphasis on participants' flexibility in choice and control. The points raised in this submission are informed by trends in our individual advocacy services, community sector consultation through an online community survey, a brief review of documented literature on the topic and the collection of related data from our members and other people with disability.

### **Survey of our members and other people with disability**

PWdWA conducted a survey to collect information from members and other people with disability via social media. Ten questions were posed which sought to establish the following: the biographical details of the respondents, level of access to the NDIS, concerns related to the NDIS and their consequences, possible remedies and commendable aspects of the NDIS.

### **The Results of the Survey**

#### **Biographical details of the respondents**

##### **Identity of the respondents:**

The total number of people who participated in the survey was 80 respondents distributed as per the table below:

<b>Category of respondents</b>	<b>Number</b>	<b>Percentage</b>
Persons living with a disability	36	45

Carers/Family members	24	30
Other disability sector workers	13	16.25
Support workers	4	5
Support coordinators	3	3.75
Total	80	100

**Noted:**

Most of the respondents were persons living with disability and their carers or family members. Their responses are significant because they frequently interact with NDIS service directly and can reliably convey their level of satisfaction with the services.

**The primary disability**

The primary disability of the person NDIS supported was reported as indicated in the table below:

Primary disability	Number	Percentage
Acquired Brain Injury	3	5.4
Blind or Vision Impaired	6	10.9
Deaf or hard of hearing	4	7.3
Developmental and/or Learning Disability	3	5.4
Intellectual Disability	6	10.9
Neurological Disability	9	16.4
Autism	9	16.4
Psychosocial Disability	6	10.9
Physical Disability	9	16.4

Total	55	100
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**Noted:**

Autism, neurological disability and physical disability were the leading primary disabilities among respondents. However, the sample respondents depicted had diverse primary disabilities represented.

**The age of the person with disability**

The age bracket of 46-55 years had 36.4% of the respondents being the majority. This was followed by 26-35 years (14.5%), 15-25 years (14.5%), 36-45 years (14.5%), 56-65 years (10.9%), 8-14 years (3.7%) , Over 66 (3.7 %) and 0-7 years (1.8%)

**Noted:**

The majority of respondents belong to the 46-55 age bracket.

**Access to NDIS**

The respondents who reported they access the NDIS were 59 (73.75% -these were active participants of the NDIS.

Of the remaining respondents (21) who reported they were not accessing NDIS, 90% reported a desire to access NDIS, but most probably were unable to access NDIS due to eligibility criteria.

**Noted:**

Access to the NDIS among those living with a disability is commendable and NDIS services are attractive even to those currently unable to access it.

**Gender-cultural diversity of our respondents**

Among the 20 respondents who responded to the question on diversity, the responses were as indicated in the table below:

Diversity group	Number	Percentage
Aboriginal	1	5
Torres Strait Islander	0	0

Aboriginal and Torres Strait Islander	1	5
Culturally and Linguistically Diverse	6	30
LGBTIQA+	6	30
Non-binary / Gender diverse	6	30
Total	20	100

**Noted:**

Culturally and Linguistically Diverse, Non-binary or Gender Diverse groups and LGBTIQA+ were equally represented among the 20 respondents who responded on the item on diversity.

**Concerns related to NDIS**

Respondents were asked to list three concerns/problems related to the NDIS. A total of 80 responses were received.

These responses were categorised into three groups: structural, operational and sustainability concerns.

Their responses are as follows:

**Structural concerns**

- These include rigidity; for instance no provision for listing deafblind combined sensory loss as primary disability; eligibility requirements and the approval process are too rigid with the effect of excluding some needy persons.
- People with complex communication disabilities do not have their own voices and choices heard
- Excludes seniors living with disability due to their age, yet MyAgeCare program disadvantage their support needs.
- Planning done inconsistently- the planners do not seem to read from the same script nor complement one another
- Limited room for individual priorities and objectives: for instance, one respondent wrote: "I want less money spent on me to join a gym or martial arts and a ride to the clubs if confidence of participation is poor."

- Mismatch between need and related funding: some needs are underfunded while others are overfunded depending on individual context
- Cumbersome bureaucracy which is not empathetic to disability needs.

### **Operational concerns**

These include:

- Encourages wastefulness by requiring absorption of money within rigid timeframes to the extent that sometimes services withdrawal or unfulfilled goals are overlooked and not achieved as outlined and stated in the plans.
- Lack of understanding and flexibility by LAC's and Planners and the capacity of Partners in the Community to deliver services.
- Ease of understanding the NDIS portal in myGov.
- Inefficiency, delays, errors, frequent changes of contact persons
- Over-priced services: some businesses providing services funded by NDIS overprice their services in their quotations. Two service providers have openly admitted they can over quote for services or use loop holes to get more money and get away with it
- Delayed payments
- Abuse and misuse of Guardianship authority to the detriment of the person with a disability under the Guardianship order
- Some planners lack adequate knowledge about the different areas of disability or understand the reality for people with disability and what is required
- Stressful plan reviews and inflexibility of plans including long time frames for plans to get approved, or plan reviews to be finalised.
- Limited options for group services which could be cost effective: Opportunity to attend groups where multiple consumers can get picked up and attend the same group
- High turnover of NDIS staff
- Double handling of invoices
- Delay in responding to queries
- AAT process is not trauma informed, it creates trauma and creates demand for advocacy and legal representation which is too complex to navigate.
- Medical safety concerns especially for individuals with intellectual disability.

### **Sustainability concerns**

These include:

- Overpriced services: Two service providers have openly admitted they can over quote for services or use loop holes to get more money and get away with it.
- Lack of synergy among the diverse stakeholders. Respondents expressed concerns about different players pulling in different directions; for instance, service providers seeking profits at all costs in a system intended for the common good. Another example is planners who do not carefully study previous plans in order to improve on what was previously done instead of appearing to start afresh.

- One of the respondents expressed concerns about sustainability by urging beneficiaries of NDIS support to be more responsible in these words: "I believe some clients of the NDIS take advantage and request funding for things that aren't actually necessary or they opt for a gold standard piece of equipment to purchase because they're not paying for it. I think there needs to be a maximum amount for certain pieces of equipment unless an OT or support co-ordinator can provide convincing evidence to support why the client needs the more expensive or top of the range equipment". Concern for the availability of even better NDIS services to future generations should be shared among all stakeholders.

### **Consequences of the concerns raised above**

- Exclusion of persons with disability who are unable to access NDIS
- Inconsistent and fragmented planning due to different perspectives and approaches of planners
- Inadequate funding in some contexts- some useful items are not funded
- Enhancement of dependence on support workers rather than promoting self-reliance
- High service provider costs
- Uncertainty and anxiety about continued funding
- Concerns about equity and accessibility of NDIS due to barriers and hurdles in the way accessing disability supports
- Impersonal treatment- the feeling you are just a statistic
- Difficulty in building relationships due to high staff rotation of workers and NDIS staff

### **The aspects of NDIS that are working well according to the respondents**

- Auslan interpreting, communication guides and allied health with expertise in deafblindness
- Time taken to respond to access requests and internal review requests
- Provision of adaptive technology and transport funding
- Access to occupational and physio therapies, counselling services and support workers
- Freedom to choose my own support workers and therapists
- Assistance to achieve my goals and participate in society
- Responsiveness to my requests and needs
- The capacity of NDIS to address diverse disability needs

## **Recommendations**

**Based on the findings of the survey, the respondents propose the following recommendations aimed at improving NDIS services**

- Work on a shared vision that is in the interest of all stakeholders



- Create awareness and support for medicine safety
- Register Deafblindness as a primary disability
- NDIA staff should clearly communicate and vividly explain why applications and approvals are rejected.
- Open the NDIS up to disabling chronic illnesses or design effective initiatives to support this cohort who also urgently need attention
- Plans should be consistent and complementary
- Roll unused funds onto the next plan instead of cutting participants plan.
- Make the review process simpler by avoiding technical legal jargon to make participants appreciate the value of their plans and the process.
- Tighten accountability and professionalism of personnel/staff in servicing participants
- Establish a base line for what the NDIS covers for particular services. If the service provider charges more, then perhaps they need to pay the difference or get quotes from other providers
- Reconsider the old LAC (WA) model where people were assisted to be connected to the community as valued participants in the life of the community. The current LAC working model is disconnected with the participants.
- Combine NDIS with MyAgedCare so that you deal with standalones unitary system that serves the nation and people with disabilities effectively by amending section 22 of the National Disability Insurance Act 2013 to remove the age limit for accessing the NDIS.
- Provide supported decision making that includes the person living with disability as the primary priority participants. Family and Carers are supplementary secondary participants.
- Research and development of disability needs and requirements considering that disability requires an integrated approach.
- Identify and extend plans that work well by providing pre-planning resources. Just one planning session is not adequate to prepare participants.
- Establish a mechanism of holding the NDIA to account
- Let funding be needs-based rather than diagnosis-based
- Thorough and competent scrutiny of reports in order to facilitate accurate resource allocation
- More training customised to the roles and needs of the different stakeholders
- Regular review and updating of eligibility criteria to enhance inclusiveness
- Lessen the paperwork for the participants and improve direct interactions.
- Let all the services be participant focused

### Review of some relevant literature

Australia's Disability Strategy 2021 – 2031<sup>1</sup> seeks to ensure that persons living with disability are appropriately supported in areas of: employment and financial security; inclusion in families and communities; safety, rights and justice; personal fulfilment; education; health and well-being.

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<sup>1</sup> <https://www.disabilitygateway.gov.au/sites/default/files/documents/2021-11/1786-australias-disability.pdf>

Furthermore, the Australian Human Rights Commission<sup>2</sup>, asserts that persons living with disability need support in meeting additional expenses when participating in employment, education and other areas of life. When such additional expenses are not catered for, the consequences are limitations in access and inclusion which in essence are infringements on the right to live as independently as possible in the community. According to Legal Foundation in updating Justice<sup>3</sup> persons living with disability have many legal and non-legal needs. They suffer multiple disadvantages that lead to diverse legal problems related to: family, government, accidents, health, employment, crime, finances, housing and personal injury.

The above needs to be considered in the review of NDIS.

## Conclusion

The purpose of NDIS is to build the capacity and autonomy of people with disability to overcome barriers so they can achieve their goals and participate fully in the socio-economic life of the community. The pathway to this goal is to facilitate supports that enable people with disability to have a voice, choice and control about what they want to achieve and how they receive supports and services.

The above responses clearly endorse the NDIS as a scheme that has achieved some remarkable transformational changes in the lives of people with disability. However, the scheme has not worked for everyone and several important themes have emerged which provides opportunity to modernise the scheme:

- Trust in the NDIS needs to be restored by making vital changes to the Scheme.
- The experience of participants throughout the NDIS needs to be prioritised.
- Meaningful choice and control must be provided for participants, and vulnerable participants need to get the support they deserve.

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<sup>2</sup>

[https://humanrights.gov.au/sites/default/files/content/letstalkaboutrights/downloads/HRA\\_disability.pdf](https://humanrights.gov.au/sites/default/files/content/letstalkaboutrights/downloads/HRA_disability.pdf)

<sup>3</sup>

[http://www.lawfoundation.net.au/ljf/site/templates/UpdatingJustice/\\$file/UJ\\_16\\_Disability\\_AUS\\_FINAL.pdf](http://www.lawfoundation.net.au/ljf/site/templates/UpdatingJustice/$file/UJ_16_Disability_AUS_FINAL.pdf)