**Submission**

Review of the National Disability Insurance Scheme Act

People With Disabilities (WA) Inc. (PWdWA) welcomes the opportunity to be involved in the Review of the National Disability Insurance Scheme Act, and provides the following comment on the key questions that the review is seeking to address.

PWdWA is the peak disability consumer organisation representing the rights, needs and equity of all Western Australians with disabilities.

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.

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1. Do the Objects and Principles of the NDIS Act provide a sufficient basis for giving effect to Australia’s obligations under the Convention on the Rights of Persons with Disabilities?

As this is the basis for all of the reform; the NDIS is about more than giving effect to specific articles of the convention, but rather is an important component to giving effect to the whole convention.

While the objects and principles outlined in Chapter 1 (Pt 2) of the NDIS Act generally provide sufficient basis for giving effect to Australia’s obligations under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), other sections of the NDIS Act do not comply with the UNCRPD and so it is impossible for government to give effect to the objects and principles in practice.

Section 3(1)(a) of the Act specifically states that one of the objects of the Act is to give effect to Australia’s obligations under the UNCRPD. Section 4 of the NDIS lists all the rights and supports people with disability and their families and carers should have and to which they are entitled.

However, other sections of the NDIS Act, such as s.22(1), do not comply with the UNCRPD and therefore do not enable government to give effect to the objects and principles. The UNCRPD makes no qualification or restriction relating to age being a factor in the application of this right as the NDIS Act has sought to do.

Section 22(1) contravenes the UNCRPD by restricting access to the NDIS to those people who are aged under 65. The UNCRPD does not discriminate against people on the basis of age and therefore, the NDIS Act directly contravenes the UNCRPD.

In addition, the NDIS Act was exempted from the Age Discrimination Act 2004. This action deliberately discriminates against people with a disability aged 65 and over and is contrary to the UNCRPD.

One of the key principals of the NDIS ACT is that “People with disability and their families and carers should have certainty that people with disability will receive the care and support they need over their lifetime.”

The principles are there to engender a culture of choice and control for people with disability, and an expectation that people with disability will participate in the broader community. However the aspect of duty of care often stops this from happening. Including reference to the dignity of risk in the principles would assist that cultural shift.

2. Does the design of the legislative framework (i.e. high level primary legislation supported by detailed NDIS Rules) enable government to further the objects and principles of the NDIS Act?

The design of the legislative framework appears sound.

3. Question 3: How well do the access criteria enable government to further the objects and principles of the NDIS Act?

With particular reference to the following principles:

People with disability have the same right as other members of Australian society to realise their potential for physical, social, emotional and intellectual development People with disability should be supported to participate in and contribute to social and economic life to the extent of their ability People with disability and their families and carers should have certainty that people with disability will receive the care and support they need over their lifetime.

We have concerns that the access criteria do not enable government to further the objects and principles of the NDIS Act.

The access criteria, as set out in Chapter 3 (Pt.1) of the NDIS Act, expressly exclude a group of people with disability. That is, as stated above, s.22(1) states that a person meets the access criteria if:

1. The person was aged under 65 when the access request in relation to the person was made.

With particular reference to the three principles listed above, the access criteria prohibits people over the age of 65 at the point upon which their disability causes significant functional impact on their independence from accessing supports and services under the NDIS.

Therefore, the access criteria are in breach of the UNCRPD and do not enable government to further the objects and principles of the NDIS Act.

It was the intention of Government to refer people over the age of 65 with disability to the aged care system. The aged care system is inadequate and ill-equipped to deal with disability. There are a number of issues that this raises. Currently, the amount of funding and support that is able to be accessed in the aged care system is simply not adequate, where somebody acquires a significant disability that is not age-related such as quadriplegia. There are also a number of disabilities, particularly sensory disabilities which increase with age. This is much more likely to be delivered under the NDIS.

4. How clearly defined are the access criteria?

The access criteria need to clarify and recognise slow, progressive diseases and conditions that lead to disability. There is a need for recognition of when disability occurred otherwise people with impairment will be excluded simply by manipulation of dates.

Access to the NDIS relates to the definition of disability. With many diseases and conditions that affect people, it is common to be diagnosed with a disease that will result in impairment in years to come but not immediately. Therefore, someone can be diagnosed with a condition that will lead to disability but if the disability does not manifest itself until after the arbitrary cut-off date of 65 years old, a person will not be covered by the NDIS.

Not allowing people to be covered for an early diagnosis also contravenes the principle in the NDIS Act of a commitment to early intervention.

For example, There is concern that the requirement using the term developmental delay may not include children who are designated 'at risk' before a formal diagnosis of autism is delivered. Children who are 'at risk' benefit greatly from early intervention, particularly in the areas of communication.

5. What amendments could be made to the legislative framework (if any) to:

a. Enhance the clarity of the access criteria?

b. Improve the effectiveness and/or efficiency of the access request process?

The clarity and effectiveness of the access criteria and the access request process would be enhanced by amending the legislative framework, to:

1. Remove the age restriction – include people with disability over the age of 65

2. Include a register of early diagnoses – capture those people with an early diagnosis of a disease (before age 65) that will lead to disability in the future (after the age of 65).

3. Make an exception to the ‘Disability requirements’ – section 24 of the NDIS Act outlines the disability requirements of the access criteria. Section 24(1) (c) refers to a ‘substantially reduced functional capacity’. However, people with an early diagnosis will not necessarily have a substantially reduced functional capacity immediately upon diagnosis but will have in years to come. If they reach the age of 65 before their functional capacity is substantially reduced, they will not be covered by the NDIS despite being diagnosed before age 65. An exception needs to be made to this section of the NDIS Act to ensure people who are diagnosed with slow, progressive diseases are not excluded from the NDIS after the age of 65. This is subject to an individual in this situation being covered by the early intervention provisions as outlined in s.25 of the NDIS Act.

6. How well does the legislative framework’s definition of what constitutes ‘reasonable and necessary supports’ support the independence and social and economic participation of people with disability?

The legislative framework’s definition of what constitutes ‘reasonable and necessary supports’ does not support the independence and social and economic participation of people with disability.

There can be no expectation that family or friends have the capacity or interest in providing informal supports which arguably should be provided to facilitate independence of activity and decision making. People with disability need to be as independent as possible with the appropriate equipment and support.

7. What amendments could be made to the legislative framework (if any) to:

a. Improve the effectiveness and/or efficiency of the participant planning and assessment process (including review)?

b. Ensure the NDIA has the required capacity to control costs in relation to participant plans?

The legislative framework needs to be amended to allow individuals to pre-complete a plan in accordance with the requirements. This allows the individual to consider carefully and in their own time their needs without the pressure of an interview.

Assessment process.

There is currently no provision within the legislative framework that specifies the timeframe for the planning process. A balance is needed between a plan being finalised in a timely manner and a plan being finalised in the time frame that suits the individual. The legislative framework needs to include reference to a reasonable time frame for the finalisation of an individual’s plan with the ultimate choice and control of the timing to reside with the individual.

Such amendments would significantly improve the effectiveness and efficiency of the participant planning and assessment process and result in participant plans that are much more specific to an individual’s needs.

More emphasis needs to be given to the notion that the person with a disability owns the information about themselves and has the right to give permission for its use.

There are concerns when it comes to privacy. an external agency should not be compelled to provide information without permission from the person.

8. How well does the legislative framework (including, but not limited to, the provider registration requirements) enable government to promote innovation, quality, continuous improvement, contemporary best practice and effectiveness in the provision of supports to people with disability?

The legislative framework, including the provider registration requirements, will have (or is having) an adverse effect on research and innovation in the disability sector. Traditionally, for instance, the established service providers in the blindness sector have carried out substantial research and innovation, resulting in continuous improvement and contemporary best practice. These established service providers acquire a substantial amount of their funding through philanthropy.

However, some are reporting that the introduction of the NDIS is resulting in a reduction in philanthropy as donors are directing their donations away from the disability sector due to the misunderstanding that all disability services are now covered by the NDIS. This means less money for not-for-profit service providers and less ability to engage in research and development.

In addition, it is imperative to ensure innovation is in cooperation with the sector in general.

9. Do the registration requirements strike the right balance between supporting principles of choice and control, including in relation to taking reasonable risks and the rights of people with a disability to freedom from abuse, neglect and exploitation?

There is concern that some registered providers of supports may not have the required specialist knowledge necessary to be providing people with disabilities with equipment and advice. While a balance is needed between choice and control (and the dignity of taking risks) and freedom from exploitation, there is concern participants may spend their money on incorrect supports due to non-specialist assessments.

This risk can be mitigated by ensuring all people under the NDIS have timely access to specialist assessments.

10. How clearly defined is the NDIA’s role in the registration of providers?

NDIA’s role in the registration of providers appears to be very minimal and is not clearly defined. The registered providers are not required to report regularly and there is no requirement for continuous improvement such as ongoing skills development, accreditation, allied health accreditation or compliance with standards.

11. What amendments could be made to the legislative framework (if any) to enhance the effectiveness and/or efficiency of the provider registration process?

As outlined in question 10, there is a concern NDIA’s role in the registration of providers is minimal and not clearly defined. There is a concern the process for becoming a registered provider may not be rigorous enough and could possibly result in the exploitation and abuse of vulnerable consumers.

Recommend a full review of the requirements and standards that apply to registered providers. As a minimum, would be recommending all registered providers comply with the National Standards for Disability Services that apply to disability service providers.

12. How well do the nominee provisions provide choice and control to, and protect the rights and wishes of, people with disability?

In relation to nominees Article 12 of the UN Convention on the rights of people with disability should be referenced and as reflected in the objects and principles, the process followed should be one of supporting decision-making by the person with the disability rather than substitute decision-making.

The nominee provisions do not include a choice for people with disability to have a nominee either with specialist skills, or the opportunity to gain specialist information or knowledge in order to promote the best plan for the individual, if that is what the individual’s preference is.

13. What amendments could be made to the nominee provisions (if any) to:

a. Enhance effectiveness/and or efficiency

b. Ensure the legislative framework interacts appropriately with State and Territory legislation?

The nominee provisions need to be amended to ensure individuals have a choice of access to a nominee with specialist knowledge and skills should they choose to do so. In addition, the nominee provisions also need to be amended to ensure any nominee is provided sufficient support and knowledge to help the individual with a disability under these provisions.

Amendments need to be made to the legislative framework to specify that all information is provided to participants in appropriate accessible formats.

14. What amendments could be made to the legislative framework (if any) to enhance the effectiveness and/or efficiency of the merit review process?

The principles and objectives of the legislation should include a principal of any person with a disability being able to access the support of independent advocacy. A definition of independent advocacy should then be included in the section with definitions. Including the right to access advocacy should not be confused with the need to fund advocacy, which should be done through current systems as recommended by the productivity commission to keep it independent. The importance of advocacy being independent means that an advocate can represent and advocate with the person with a disability with no other conflict of interest. There is such a large diversity of people with disability with many who are vulnerable because of their disability and others who are vulnerable because of their personal circumstances, that access to independent advocacy must be a given. (Note: in the disability sector advocates are not legal counsel, but rather a person who can speak on your behalf).

Also, any information about the merit review process needs to be readily available in an appropriate alternative format, if needed. Therefore, amendments need to be made to the legislative framework to specify that all information is provided to participants in appropriate accessible formats.

15. What amendments could be made to the legislative framework (if any) to

a. Enhance the effectiveness and/or efficiency of the compensation and/or debt recovery processes?

b. Ensure the NDIA has the required capacity to control costs in relation to the compensation and/or debt recovery processes?

If the agency believes that they should be eligible for compensation. There is a cost, both emotional and financial which comes with undertaking legal cases for compensation. Unless the agency is prepared to support and assist the person to try and get compensation (where it is not evident that compensation can be easily obtained), then no-one should be forced to try and get compensation.

16. How well do the governance arrangements enable government to further the objects and principles of the NDIS Act?

Both the Board and the Advisory Council of the agency must have people with disability. It is not ok to assume that you will get board members with disability. There are people with those skills but if the legislation does not specify that there are people with lived experience of disability on the Board then it may not happen.

The governance arrangements need to ensure there is sufficient (50%) representation of people with lived experience. In addition, those who represent lived experience may also require support to gain further knowledge in relation to the governance arrangements. These representatives need to be supported to acquire this knowledge.

While representatives with actuarial skills and expertise ensure the scheme is sustainable, too many may result in restricting the principles and objectives of the NDIS Act. There is a need for a balance between responsibility and care.

17. What amendments could be made to the legislative framework (if any) to enhance the effectiveness and/or efficiency of the NDIS’s administration?

The legislative framework must be amended to allow for an audit and risk group in an advisory role to the NDIS Board to monitor and report how the NDIS is running financially in order to enhance the effectiveness and efficiency of the NDIS’s administration.

18. Are there any other aspects of the NDIS legislative framework that you believe are impacting on:

a. Government’s ability to further the objects and principles of the NDIS Act?

b. The efficiency of the NDIS’s administration?

c. The capacity of the NDIA to control costs?

d. Other legislation, including State and Territory legislation?

The National disability strategy is a government policy which aims to give effect to all other areas of the convention, there are a number of sections in the NDIS legislation which talk about people with disability getting support from other areas which would not be covered by the NDIS. There is a general understanding that the reason behind this is so other systems like education, health and employment will still provide the necessary support required for people with disability to access those systems. Building the capacity of mainstream community and general support systems such as health and education require the National disability strategy to be taken seriously and to be working in conjunction with the NDIS.

There is a concern that aspects of State and Territory legislation as well as the new bilateral agreements between the Federal Government and the States relating to the roll-out of the NDIS may result in changes to funding that will create a gap for disability services.

In particular, there is a concerned that State and Territory governments will withdraw their funding of disability services because they are making a contribution to the NDIS. However, many people with disability will not necessarily be eligible for funding under the NDIS (i.e. those who acquire a disability at the age of 65 or over) and therefore will still need to rely on government-funded services in their States and Territories.

It is currently not known if those aged 65 or over will be supported under the Information Linkages and Capacity Building Policy (ILC). Even if that is the case, they would still not be considered NDIS participants based on the NDIS Act.

In addition, NDIS should consider individual funded packages to be the gold standard of support and there should not be discrimination based on age. It would be unfair and inequitable if a person aged over 65 with the same level of severe functional impairment as a person aged under 65 receives a lower level of support.

Recommend that the legislative framework for the NDIS Act should have sufficient interface with all other relevant legislation, including legislation that underpins the aged care system.

It is unclear in this legislation that funds going directly to a participant or a nominee for the purpose of funding the participants plan are not considered income for tax purposes or in relation to income support.