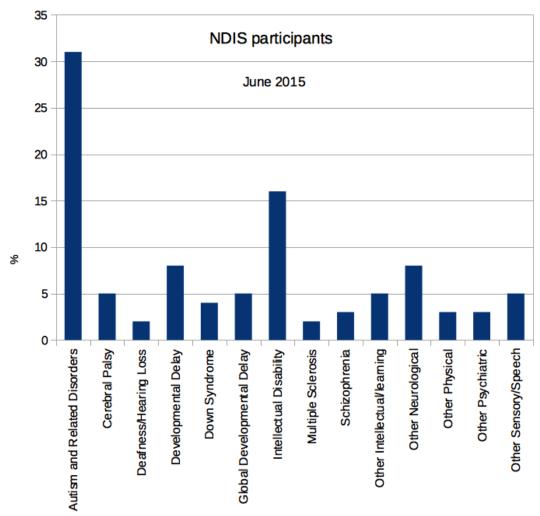
Review of NDIS Act

Response from Autism Aspergers Advocacy Australia

Thank you for the opportunity to respond to the independent review of the *NDIS Act* (see http://www.ndis.gov.au/about-us/governance/legislation/ndis-act-review).

Autism Asperger Advocacy Australia (A4) is a national grassroots organisation that advocates for people living with Autism Spectrum Disorder (ASD). Autism is currently the biggest primary disability category in the NDIS.



The following addresses the questions that are asked in the discussion paper.

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?

Not in the slightest.

The *National Disability Insurance Scheme Act 2013 (Cth)* (NDIS Act) is part of Australia's whole legal system. An article describes existing legal provisions for Australia's vulnerable (downtrodden?) whose rights may be denied saying:

There are still many in our community who are downtrodden and whose rights have been denied. The Aboriginal Australians are the most obvious group in this class. But there are others, including women, gays, the handicapped, the mentally ill, ethnic minorities, children and others whose basic rights are sometimes overlooked or denied.

From

 $\frac{\text{http://www.lawfoundation.net.au/ljf/app/\&id=/a60da51d4c6b0a51ca2571a}}{7002069a0}$

Some of the history of Australia's *Disability Discrimination Act 1992 (Cth)* (DDA) and the legal system is given in

http://www.austlii.edu.au/au/journals/MonashULawRw/1995/2.pdf. This article points out the difference between the law in the USA that provides people with disability are *entitled* to essential services and supports, where Australian law treats people with disability as *charities* ... that is, essentially without rights. Yes, that is rights described in international law.

The legal system in Australia does not protect citizens' rights, it protects the Government's budgetary decisions. The decision in <u>Woodbury and Australian</u> Capital Territory [2007] ACTDT 4 (5 April 2007) says:

91. ... it is not the purview of the [legal system] to undertake policy decisions on government budget allocation, which a determination of whether or not the requested service imposed unjustifiable hardship would, in essence, amount to.

[Note: no credible evidence that any budgetary impact would impose "unjustifiable hardship" was given as evidence in this matter; had evidence been given, it could easily have been refuted].

Australian law does not meet the requirements of the international treaties listed in *NDIS Act* Sections 1a and 1i.

In a legal contest, it is likely that a court would see the business of the NDIA as meeting the descriptions in *DDA* Sect 45(1)(b) and (c). Therefore, *every* decision that the NDIA makes is lawful (that is, not unlawful) even if it delivers inequitable outcomes of denies essential services to some people with disability. *DDA* Sect 45 protects disability services including (especially) the NDIS.

So the answer is "no", the NDIS Act does not give "effect to Australia's obligations under the Convention on the Rights of Persons with Disabilities" ... or to its obligations under the other international instruments listed in *NDIS Act Sect 1i*. Nor does the *DDA*.

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?

No. See above.

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.

In this paper, "access criteria" seems to mean eligibility for the NDIS. [Note: in the disability sector, "access" usually refers to physical and/or intellectual access a service or resource.]

People with disability in Australia don't have rights (see above). Giving people with disability "equal opportunities" does not achieve more equitable outcomes. People with disability need services and supports that other people don't need. And people with different disabilities may need different supports.

A diagnosis of ASD is a process for trained clinicians to recognise formally that a person needs support – needing support is part of the diagnostic criteria for ASD. The NDIS aims to provide that support, but in Australia the person has no legal right to support.

In relation to the NDIS, NDIA staff who often have little or no knowledge of ASD can use <u>a bunch of gobbledygook</u> to override the decisions of trained and experienced clinicians.

4. How clearly defined are the access criteria?

Assuming this means "eligibility criteria for the NDIS", our view is that NDIS eligibility criteria relating to ASD are gobbledygook (see http://a4.org.au/node/1056).

- 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 real NDIS eligibility criteria are in the implementation, not in the legislation.

The NDIA could easily talk to someone who's actually read the ASD diagnostic criteria, and understood the recent changes (see http://a4.org.au/ASDformal), to sort out eligibility criteria for people who are diagnosed with ASD.

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?

Both the terms "reasonable" and "necessary" are arbitrary, or open to interpretation, especially their legal interpretation. Any attempt to set legal boundaries will be arbitrary (lack precision).

From what we observe, the NDIA's primary goal is to stay within the initial budget allocation. The NDIS trial already has significant issues in South Australia.

Since the initial estimate of the number of eligible people, especially those with ASD, seems to have been a substantial underestimate, the NDIA has to spread the allocated funds across more "participants". The NDIA uses increasingly aggressive interpretation of "reasonable and necessary" to contain its costs.

The original commitment of *no one being worse off under the NDIS* had to be quietly dropped.

- 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 *NDIS Act* must require that every participant's plan is approved by the participant (or their guardian(s)) ... it is unacceptable that the legislation allows the NDIA to approve an individual's plan without consent/agreement from the individual. This really defeats the whole purpose and intent of the NDIS.

In our view, the role of planners in the current NDIS implementation is unreasonable and effectively impossible. To do the job properly, a planner needs to be extremely expert in assessing services and supports for all types of disability. There is no formal training for such a role ... and the role is far too complex for informal training to be adequate.

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?

It is unclear how provider registration requirements promote innovation in anything other than processes to address complex bureaucracy.

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?

Choice and control is possible as long as registrations include all or a very high proportion of providers. That is, there are registered providers for participants to choose from.

This type of legislation does not protect vulnerable people from abuse, neglect and exploitation. This is a whole different subject.

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

The NDIA controls its registration process. It sets its rules. It determines how long registration takes and how long it takes to make a registration public. The NDIA has total control.

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

The NDIA decides the process. It doesn't need legislative change.

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

As yet, we've not considered issues relating to nominees.

- 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?

As above.

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

It seems the "merit review process" isn't working as anticipated. There's not much case law being created.

We haven't yet been able to review the cases and their outcomes that went before the AAT. We have doubts that the AAT can adequately assess matters that relate to ASD. There is a problem that Government is privileged in declaring who the court should recognise as "expert" witnesses, particularly when there is relatively little real ASD expertise available to tap into.

- 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?

Compensation and ASD are rarely connected.

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

The Advisory Council seems to call itself the "Independent Advisory Council". There is a bit of "Yes Minister" about this ... dealing with difficult issues in the title/name.

While ASD and Intellectual Disability make up more than half of the NDIS's participants (according to the quarterly reports) there doesn't seem to be any

commitment to the challenge of representing these groups in the Advisory Council.

The NDIA established an Intellectual Disability Reference Group ... but we are not aware of any effort to create an ASD reference group, even though even more NDIS participants have ASD as their primary disability. And ASD is likely to continue to grow while participants with ID, as a proportion of Australia's population, is likely to remain relatively stable.

Also, the NDIA appears to have a particularly poor understanding of ASD.

There are serious concerns about political interference with the NDIA Board.

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 NDIA would perform better if it had mechanisms for participants or participant groups to formally suggest improvements to the NDIA's processes and a formal requirement that the NDIA respond to their suggestions. Currently, participants can complain about a decision affecting an individual ... but there is no way to complain directly that the NDIA's decision and operational processes and need reform.

The limited public reporting means that the community has cannot fully assess "the effectiveness and/or 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?
 - e. The effectiveness of information sharing between the NDIA, jurisdictions and providers?

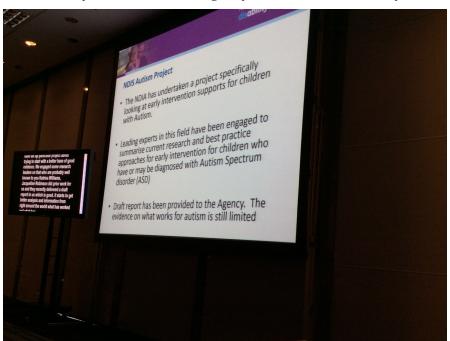
It is hard to see how the NDIS can deliver effectively on part of its Objective Sect 3(1)(c), "support ... economic participation of people with disability", without assisting in employment.

Based on the current operation of the NDIS trial, interpretation of the phrase (from Sect 3(1)(d)) "provide reasonable and necessary supports, including early intervention supports, for participants in the National Disability Insurance Scheme launch" has some mysterious meaning that is largely incomprehensible to the ASD community. The NDIA is deeply reluctant to fund evidence-base early intervention for ASD that is consistently considered "necessary".

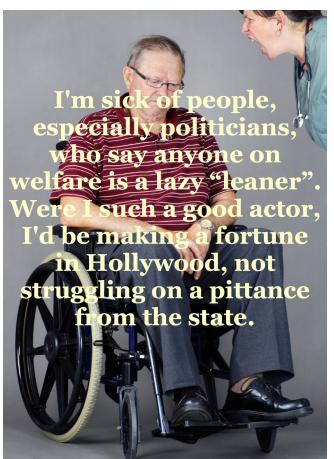
Recently, the NDIA's CEO told an audience at the Asia Pacific Autism Conference 2015 that a "draft report [on early intervention for ASD] has been provided to the Agency. The evidence on what works for autism is still limited". He omitted to mention that the draft report was provided to the NDIA to share with its secret review panel so that the report could be reviewed ... and the review panel strongly advised the agency and the authors of the report that there is clear evidence that best practice early intervention for autism is widely

regarded as effective ... that suggesting "the evidence on what works" is "limited" is not accurate.

The ASD community cannot trust an agency that behaves this way.



A Government that vilifies vulnerable people with disability, and their "informal carers", people who make massive daily efforts to achieve what they do, and calls them "leaners" or "rorters" does not help Sect 3(1)(h) that says an Objective of the *NDIS Act* is to "raise community awareness of the issues that affect the social and economic participation of people with disability, and facilitate greater community inclusion of people with disability".



In relation to 18b, we commented before on the administrative efficiency of the NDIS.

Clearly, in relation to 18c, the NDIA has the capacity to manage its costs; it can interpret "reasonable and necessary" to manage the cost of the NDIA. Rather than meeting the needs of participants, the clear goal for the NDIA is to manage the cost.

Since Commonwealth legislation dominates state and territory legislation, the NDIS lifts many aspects of disability into the federal arena. However, education for people with disability is a major area state responsibility that remains seriously problematic.

Education outcomes for people with disability are seriously disappointing, but education outcomes for autistic students are abysmal.

The need for a rash of state level inquiries (see http://a4.org.au/node/1061) demonstrates how dysfunctional education for autistic students is.

In relation to 18e, it is disappointing that consideration is not given to information sharing between the NDIA and systemic advocates and participant groups.