



Submission on and response to the Draft National Standards for Disability Services

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The current **National Standards for Disability Services**¹ (NSDS) came into effect in 1993. These Standards govern existing disability services nationally. Experience from the existing NSDS teaches crucial lessons.

The annual reports of government departments responsible for existing services and of government-funded service providers proclaim proudly their success, efficiency and compliance with these Standards.

Independent reports based on experiences of people with a disability (PwD), and sound data, contradict reports from disability administrators and service providers: describing dismal outcomes instead. For example, the Productivity Commission report says²:

The current disability support system is under funded, unfair, fragmented, and inefficient, and gives people with a disability little choice and no certainty of access to appropriate supports. ...

and

Under funding is only part of the problem. Systemic failures include:

- the fragmented structure of the disability system, and a lack of coordination, have made it extremely difficult for service users and their families to access services.
- a lack of portability of disability supports between states.
- outdated service models which distort allocation decisions.
- a lack of person-centred planning and a general lack of consumer choice.

¹ <http://www.fahcsia.gov.au/sa/disability/standards/pages/policy-nsds1993.aspx>

² <http://www.pc.gov.au/projects/inquiry/disability-support/report>

- a lack of certainty around waiting times and the availability of supports mean that families can not plan for the future.
- more timely and forward looking service delivery could save the system money.
- the lack of essential frameworks that would allow the system to identify and solve its problems. These include a strong governance structure and data systems.

Under the CSTDA/NDA, state/territory governments provide (or administer) most disability services. *Autism Aspergers Advocacy Australia* (A4) is not aware that a single state/territory government has yet acknowledged its role in and responsibility for the current abysmal state of disability services in its jurisdiction. Despite clear evidence and numerous negative reports, state/territory governments persist with their spin and misinformation about the disability service that they provide and administer.

The NSDS are ineffectual. They fail to deliver quality disability services.

No doubt, the better disability service organisations review their compliance with the NSDS from time to time. Our observation of typical organisations is that each review is conducted in a rush. The focus of each review quickly becomes justifying the provider's existing practices in the terms of the NSDS. Even in the very best disability service organisations, the NSDS do little or nothing to improve service practices in disability service providers.

Service organisations that struggle to deliver adequate services (most of whom have good intentions) can easily claim compliance with the NSDS, so the NSDS do not make a difference when service provision is of marginal quality, or worse.

The NSDS do not address key aspects of disability services, such as waiting lists or unmet need. For example, while service providers all comply with NSDS, the Australian Bureau of Statistics (ABS) reports³ that in 2009 there were 64,600 people with autism, 74% of them (3 in 4) have severe or profound core limitations. The ABS reported "there were 15,400 people with autism needing more help with communication (understanding or being understood by others) and 22,600 needing more help with cognitive or emotional tasks (managing their emotions and/or behaviour)." CSTDA data on the AIHW website⁴ shows in 2007-8 year, just 14,547 people with autism (around 1 in 4) were able to access any disability service at all through the CSTDA.

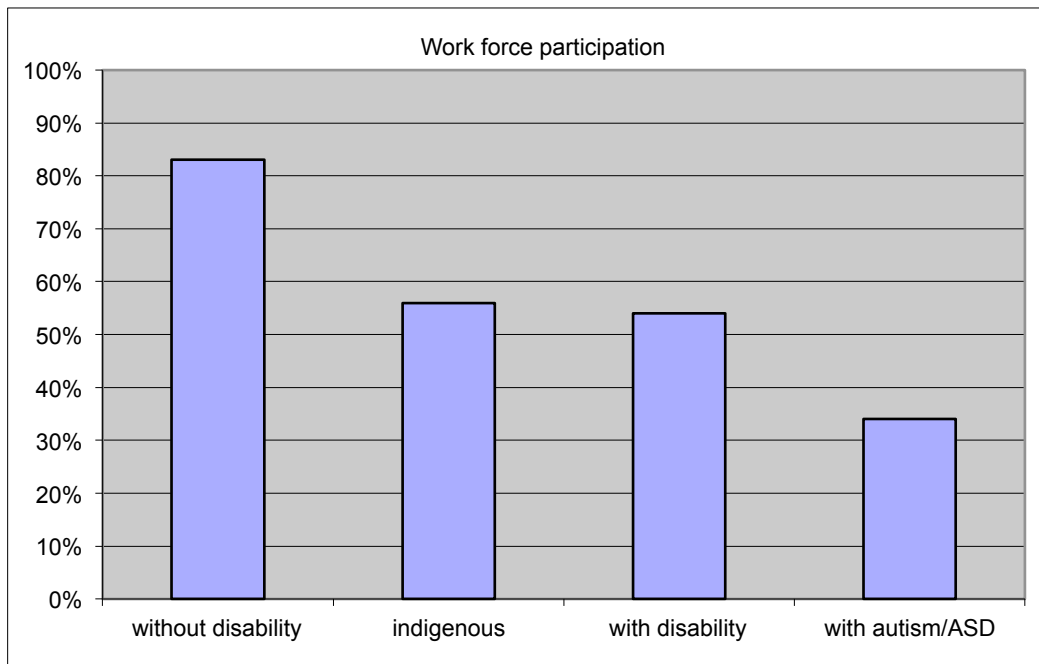
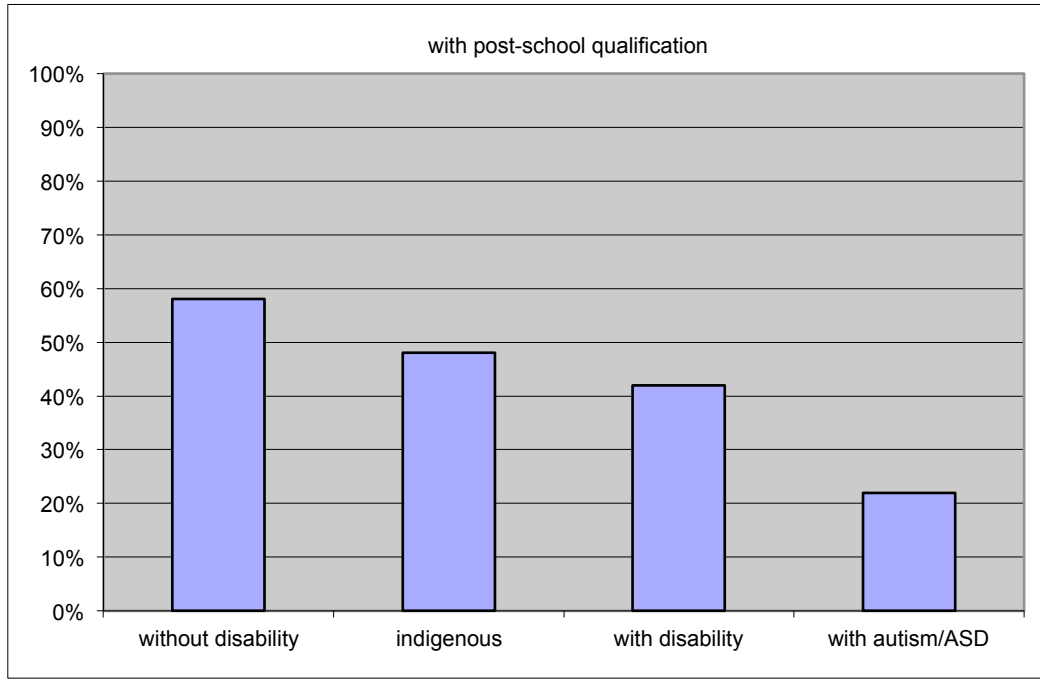
The existing level of unmet need for disability services demonstrates a major failure of the existing NSDS. Nothing in the proposed new NSDS addresses this failure.

The NSDS do not involve appropriate outcomes reporting. This is another failure not addressed in the proposed new NSDS.

³ See <http://www.abs.gov.au/ausstats/abs@.nsf/mf/4428.o>

⁴ A4 could not access 2008-9 or 2009-10 CSTDA/NDA data on the AIHW website, particularly <http://www.aihw.gov.au/data-cube/?id=10737419937>, in recent weeks because the AIHW website did not appear to be working properly.

The existing NSDS fail to deliver equity in disability services. The Australian Bureau of Statistics reports⁵ that, while people with a disability fare badly compared to people without a disability, people with autism/ASD have particularly poor outcomes; especially in education, labour force participation (employment) and receipt of disability services. The disability standards do nothing to address these gross inequities.



⁵ See <http://www.abs.gov.au/ausstats/abs@.nsf/mf/4428.o>

Increasingly, mainstream services are meant to address the needs of PwD. But the NSDS do not relate to mainstream services. For example, the Legal System⁶, of all places, should recognise and respect a person's disability. But courts condone, even promote, discrimination against PwD as shown for example in *Purvis vs NSW*. Or we find “throughout its decision the Court refers to [a student's] disability as ‘misconduct’ and ‘misbehaviour’”⁷ The ACT Coroner decided to **not** report on the unexpected deaths of Stephen Moon and Jack Sullivan, two young men with severe/profound autism; this send a clear message that the lives of PwD are unimportant. The NSDS have no (zero, zip, zilch) impact in the legal system where recognition and respect for the rights of PwD are crucial.

On 12th June, a mother asked on Facebook:

Any hints or tips? The Education Department here is giving me hell. T has been in school for about 3 weeks this year, mostly without support. I keep getting called to come and collect him. I have asked to go to a new school but the meeting today was called off.

“T” is a student with severe autism. This shows T’s access to (mainstream) education is severely limited and T’s disability severely impairs his mother’s access (and right?) to employment participation, even though the state/territory government’s disability expenditure focuses primarily on disability access (funding is for wheelchair-accessible taxis and upgrading as many bus stops as possible to meet national accessibility standards ... which are essential improvements). The NSDS do not ensure a child with a disability gets a quality service if the child receives a fragmented and chaotic service, as in this example.

The NSDS are not part of the solution that PwD need; they must be part of the problem.

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Acknowledgement

This submission owes its existence to the contributions, knowledge and experience of the people who make up the A4 Management Group.

⁶ Note: in the context of disability, the term “Justice System” is completely ironic; using the term reduces any discussion to total farce.

⁷ See <http://a4.org.au/a4/node/375>

Prompt questions for written response

Prior involvement

1. If you participated in the UNSW consultation in 2010, how do you feel the changes reflect your contributions?

People with autism have no prior involvement.

People with autism and their families/carers have not had the opportunity to contribute. ... "For many years people with disabilities found themselves shut in—hidden away in large institutions. Now many people with disabilities find themselves shut out—shut out of buildings, homes, schools, businesses, sports and community groups. They find themselves shut out of our way of life." page 6, (Shut Out- The Experience of PwD and Their Families 2009). A4 views the consultation process for the draft standards shut out the voices of people with autism, especially those who get little or no support.

Understanding and meaning

2. Do the draft standards include things that are important to people with disability? What do you think is missing?

The draft standards are incomplete, full of jargon and unclear. The content is too general. The broad statements are such that they would not facilitate any decision regarding a common law complaint or if legislation was in place to enforce these "standards". The statements have no legislative support and are therefore unenforceable. The draft has made negligible progress from the current standards. Content regarding privacy, safety, dispute resolution, and provision of services within other regulations are currently in place.

3. Do the draft standards include any concepts or ideas that you think are not relevant and could be removed?

Autism Aspergers Advocacy Australia does not see the draft as including any real standards. The draft is just generalised statements regarding what service providers should do at an individual service level. They are also confused; for example, the

management principles (page 4) say "use a process approach" and "take a systems approach" which differs from page 8 that says "inform individual service planning and delivery" and "responsiveness" to the individual. The statements are confused; they lack clarity.

4. What do you think about the language that is used? Is there anything you don't understand about the draft standards (words, sentences), or think would be difficult to explain? What words would you use instead?

The document includes terminology that is undefined and confused. For example, what are "Human Rights? Australia is one a very few, if not the only OECD country that does not have a Bill of Rights or an equivalent.

Perhaps the intention is to refer to the various treaties Australia signed but refuses to enact in law, as the treaties require. But the Government's refusal to enact in law the various treaties it signed sends a clear message that the human rights described in UN treaties are not meant to be enforced in Australia.

Even the most basic of "human rights", like a "right to life" provisions for people with a disability, are omitted from Occupational Health and Safety legislation that applies to disability services workplaces. As mentioned above, the High Court ruled in Purvis vs NSW (and more recently, the Federal Court ruled in Walker vs Vic) that children with a disability do not have a "right to education", despite Article 28 of the UN Convention on the Rights of the Child. Rather than protect people with a disability from "all forms of discrimination", Australian laws describe, even promote, a diverse range of "lawful discriminations" against people with a disability.

Not all of the policies and practices promoted through the NSDS suit everyone with a disability. Some policies and practices promoted in the NSDS deny people with severe/profound disability the freedom/opportunity to associate with friends and peers (other people with a severe/profound disability), insisting instead that some of the most vulnerable people are cast adrift (isolated) among

people with few if any shared interests and in communities that show little or no understanding. The NSDS's preference for separating/isolating people with a disability including those who need substantial support, whenever they venture into the community, maximises the cost of their services and support: since resources are limited, this results in restricting socialisation for some people with severe/profound disability. When this happens, the NSDS discriminates against some of the most vulnerable people with a disability and people with the highest needs.

Application and use

5. How easy or challenging do you think it would be for the service/s you provide or use or know best to achieve these draft standards?

The draft NSDS would give little assistance to a service provider with a deep understanding of and commitment to providing BEST PRACTICE services to PwD and their family/carers. The document contains generalised statements, and lacks clarity. The foundation of the NSDS is "rights" that simply do not exist.

The NSDS exemplify The Emperor's New Clothes ... so they are very easy to achieve if you choose to believe in them. These draft standards, like those before them, could be very convenient for service providers.

6. How easy or challenging do you think it would be for the service/s you provide or use or know best to demonstrate that they meet these draft standards?

Since the draft standards are general and untestable, it is easy to claim compliance with the draft standards. However, the vagueness of the draft standards mean it is difficult, maybe impossible, to demonstrate compliance.

7. For each draft standard, what would you look to see or experience to tell you that the service you provide or use or know best is meeting the standard?

There isn't much to see (or look for) in relation to non-existent "human rights". It is hard to see how anyone would fail to meet these draft standard, just as everyone meets the existing standards.