

Submission on the NDIS in the ACT

Personal and systemic perspectives relating to autistic people

to the Joint Standing Committee on the National Disability Insurance Scheme

from Bob Buckley

I attended the Committee's afternoon session at Parliament House on 12/5/2017. The session focussed on issues relating to the Australian Capital Territory.

The session was well attended but it was too short. Notably, people made brief/terse comments and limited time for the session meant few topics were discussed. The Committee Chair was only able to invite comments on a single subject. There are many other topics that people, like me, would have liked to comment on ... but it wasn't possible given the time constraint.

The following is my attempt to raise some additional issues that I, with my autistic son, and others are having with the NDIS.

Mostly, my focus is on matters relating to autistic people and people living with autism spectrum disorder (ASD). But some of my concerns relate to policy and programs for people with disability generally.

The NDIS is a new and challenging initiative. It is being rolled out quickly. I am not concerned that the NDIA is not creating *the perfect system* from the outset: I expect that the NDIS will evolve with time and experience. However, I am concerned that changes since the initial trial period have increased bureaucracy and are contrary to NDIS goals. It seems that the trial period played with a more flexible system to win over people with disability ... but the subsequent full NDIS roll-out returns to excessive bureaucracy, that is business-as-usual for a government agency.

issues relevant to people with disability generally

One of my concerns is quite general; not specifically about ASD or the NDIS.

Governments must recognise, respect and require that registered behavioural clinicians be involved in all behavioural services and supports.

Inadequate and inappropriate disability services usually result in clients using their behaviour to communicate their dissatisfaction. The clients are blamed for unwanted, problem or challenging behaviour rather than services recognising and addressing the reasonable dissatisfaction that people with disability express when services and supports are unsatisfactory.

In recent times, the media has reported on behaviour problems in schools¹, “health”², disability services³ and in juvenile justice systems⁴. Problems with the lack of recognition of behavioural clinicians goes well beyond the disability sector.

Governments in Australia refuse to ensure appropriate behavioural clinicians are involved in preventing and addressing unwanted, problem and challenging behaviour. Instead, government contracting and recruitment prefers self-aggrandisement and baseless self-promotion in selection processes, they eschew formal qualifications and training in behavioural science/methods.

The government strategy of refusing behavioural science results in inappropriate use of restraints, abuse and exclusion/denial of essential services to the most vulnerable citizens⁵.

Under international law, children and people with disability have the right to treatment Australian law does not ensure these rights. Australian law allows (even encourages) governments to ignore or refuse the most vulnerable in our community the right to professional treatment, services and supports needed for their behaviour.

NDIA issues – general

The NDIA provide poor information about the NDIS so many people are apprehensive about making the transition to the NDIS.

The first concern for most people with disability is their eligibility for the NDIS. Rather than explain their eligibility criteria, the NDIA asks that people apply and then the NDIA decides for each individual. This leaves very vulnerable people feeling extremely uncertain. There are no clear criteria that the NDIA’s decision can be tested against: the process is opaque. And clearly, some of the NDIA’s eligibility decisions are quite arbitrary.

The NDIA’s eligibility criteria particularly for ASD have been gobbledegook from the outset; expert clinicians with specialist knowledge of ASD need to guess the intent of the NDIA’s eligibility criteria for ASD ... and the NDIA refuses to even discuss the matter with key members of the ASD community.

The NDIA keeps its planning process secret ... hidden from new applicants and from the disability sector generally. The NDIA does this even though lots of people have now been through the process and services who have helped people through their initial planning are becoming familiar with the process.

¹ See [a short list of recent "isolated incidents"](#) that relate to problem behaviour in schools.

² See [Perth mental health experts call for closure of seclusion rooms, Premier intervenes after man shackled to hospital bed for two weeks, Victoria's shame: Disabled children dumped at hospital](#), etc.

³ See [Residents bearing the brunt of disability care in their street](#) or [Behavioural needs of autistic Australians must be met](#).

⁴ See [Submission to the Royal Commission into the Protection and Detention of Children in the Northern Territory](#).

⁵ See <http://a4.org.au/node/1495>

After the “trial period”, the NDIA made substantial changes to the NDIS and its processes. The ASD community is not aware of discussion or explanations of the changes since the trial. The community feels confused and disappointed.

And the NDIS is now rolling-out approaches that are largely untested since they were not trialled or adequately researched.

*Key processes/procedures, such as emergencies, exclusion from services, relinquishment, ... are unclear, possibly non-existent. There appears to be no **provider of last resort**.*

NDIS planners avoid (or refuse to address) provision for likely emergencies in peoples’ NDIS plans. And there is no systemic approach to meeting this clear need.

Already, people with disability are being excluded from essential services. Families (informal carers) are left with all the responsibility ... often much more than a family can reasonably manage without professional support (that they cannot afford).

There is no discernible service and support designed for ensure needs are met when a person with disability is excluded from essential services or when families are forced to relinquish a child whose needs the family cannot (can no longer) meet. There is no *provider of last resort*. Handling of the most difficult situations is *ad hoc*. Little or nothing happens until the story is taken to the media ... and families are forced to make their very personal lives public.

The NDIA cannot be trusted. They do not keep promises including

- *capped numbers in the ACT and SA*
- *the commitment that “No one will be worse off”*
- *its use of evidence-based practices*

The NDIA keeps saying that the NDIS is “on time and on budget” when clearly it is not.

The NDIA got started with a trial process that was much closer to the goals and purpose of the NDIS than the scheme now in place. The trial version of the NDIS resembled more of the community’s expectations.

The use of a “friendlier” trial scheme before the harsher full roll-out scheme was very deceptive. In the full roll-out scheme (for want of a better title):

- NDIS planners cut participants funding for no discernible reason
- the NDIA’s interpretation of “reasonable and necessary” has become incomprehensible
- review processes are delayed and often inaccessible
- relationships with an individual planner disappeared.

The NDIA misled the disability sector through its NDIS trials.

The NDIA stopped intake when the initial estimated numbers were reached in the trials in both ACT and SA. They were asked specifically about this happening and the NDIA assured the community that the Commonwealth would fund any excess numbers. This was untrue.

There are many examples of people who are worse off with the NDIS. Transport costs are a prime example.

The NDIA is creative/imaginative (unreliable/misguided) in its interpretation and selective in its recognition of scientific and statistical evidence.

Planners' roles and responsibilities are very unclear. It appears that too often NDIS planners are poorly trained (if they are trained at all) and do a poor job. Many vulnerable people are unable (or unwilling) to question their planner's decisions.

We cannot tell what a planner is meant to do in detail nor what processes planners use in developing individual plans: the NDIA does not describe publicly the planners' role or report on equity in planning. It is unclear what information NDIS planners need and how they turn information received about an NDIS participant into an NDIS plan for the individual. It is not clear what information belongs in a NDIS plan for an individual and what is really up to the individual or plan manager to decide.

Too often, planners with little or no relevant training or knowledge reject clear advice from clinicians and experts in relation to individuals. Far too often, planners make adverse decisions that they are not qualified to make.

Decisions by NDIS planners are unilateral.

The NDIA says that it will not review its decisions; it will only review a planner's decision if *new* information is provided.

NDIS planning outcomes are inconsistent. Different planners make different decisions based on the same information ... but the NDIS now refuses to review its demonstrably arbitrary decisions.

Clearly, the NDIA's planning process is unfair and inequitable. Inequity was a key reason for introducing the NDIS. Apparently, the NDIA has failed a key objective right from the start of the full roll-out.

The NDIA's estimates/predictions of numbers and costs are unreliable.

There are major concerns over the NDIA's estimates of costs and participant numbers.

In particular, the estimated numbers of autistic NDIS participants has been quite wrong. The NDIA and the Government apparently believe that increasing numbers of children with autism is a result of changing diagnosis. For example, the number of children born with Down Syndrome is decreasing ... apparently, the Government and the NDIA think children are now being diagnosed with autism spectrum disorder instead. I would like to see credible evidence for and an explanation of how this happens.

The NDIA's own reports show that individual plan costs are not distributed statistically as was predicted/estimated in the planning phase.

Sometimes, the NDIA denies NDIS participants “choice and control”.

The NDIA does not provide NDIS participants with choice and control in relation to NDIS planners. With the full roll-out, even consistency of planner was eliminated.

In the ACT, the NDIA appointed a single early intervention “access partner”. That does not provide “choice” or “control” to NDIS participants.

The NDIS shut down the national Autism Advisor service.

The Autism Advisor service was part of the Howard Government’s *Helping Children with Autism* (HCWA) package created in 2007. The HCWA Autism Advisor service developed into an essential source of impartial advice for newly diagnosed autistic people, especially the families of children.

The NDIA shut down this service so families no longer have access to the information that they need to make *informed* choices about improving outcomes for their autistic children.

Poor, confused and disrespectful approach to informal carers.

The NDIA shows limited respect for informal carers.

The government and the NDIA provides minimal support to informal carers; there is little or no appreciation or recognition of their contribution.

The NDIA’s attitude to *respite* is simplistic and unsatisfactory.

The NDIA does not report on and apparently has little or no respect or appreciate for reductions to the overall cost of the NDIS due to unpaid support from informal carers.

Advocacy services and supports for informal carers are hard to access.

Assistance with the process of getting adults with disability out of the family home are often non-existent.

Accommodation for people with severe or profound disability is not adequately addressed.

There is no discernible process for helping adults with severe or profound disability in moving into independent accommodation, thereby increasing their independence.

When problem behaviour arises, informal carers have to threaten relinquishment to get support and services.

There is no discernible progress for young people in nursing homes, relinquishment of children under 18 years of age, etc.

The NDIA refuses to provide information under the Freedom of Information Act.

We made several Freedom of Information requests to the NDIA. They were denied⁶.

NDIA in the ACT

The NDIA's ILC is years late in the ACT. People with disability who are not NDIS participants miss out on services.

The NDIS implementation in the ACT focuses on NDIS participants, that is those people in the NDIS who are part of an anticipated 460,000 eligible NDIS participants. Many more people have disability and need services and supports. The NDIS absorbed all the disability funding outside education and aged care in the ACT and redirected it primarily to NDIS participants. People with disability who are not NDIS participants miss out.

Originally, services and supports for the people with disability who are excluded from the NDIS Tier 3 were called Tier 1 and Tier 2 supports ... now they are called *Information, Linkage and Capacity Building (ILC)*.

The ILC will offer a very limited service. In the ACT, the previous services are gone ... and ILC services are not yet in place.

The ILC is meant to *not* provide actual services; instead it links people up with mainstream services that are meant to help them. Note that these services were not able to help them before the NDIS and there is no actual reason to expect that they will now.

The arrival of the NDIS contributed to the demise of Autism Asperger ACT.

Autism Asperger ACT was an organisation that provided a range of services and supports that many in the community considered useful. Many of those services and services and supports are no longer available.

There is no real replacement for *Autism Asperger ACT*. Supports for the growing number of people diagnosed with milder ASD and people in the process of getting a diagnosis are largely gone.

Generic disability services do not provide adequate information about ASD: they lack crucial knowledge and understanding about ASD.

⁶ For example, see [Secret NDIA business - no ABA for school students](#).

About ASD

Autism Spectrum Disorder (ASD) is a major disability type – recently at least 26% of NDIS participants.

Autism spectrum disorder (ASD) is the largest distinct primary disability among NDIS participants. The NDIA reports that

- In the NDIS trial (up to June 2016), 31% of NDIS participants were autistic
 - ‘Autism and related disorders’ is the most common primary disability across all sites (31% of participants nationally), noting that the age-specific sites are included in this figure. In South Australia, 47% of participants have Autism and related disorders listed as their primary disability due to the young cohort of participants (0-14 year olds). ...⁷
- At the 3rd quarters of the full roll-out, the NDIS reported⁸ that 26-29% of NDIS new participants are autistic.

Current estimates of ASD prevalence in Australia are based on the number of diagnoses measured or observed in various places. Here are some of the reported diagnosis rates:

Data source	Date of data collection	Diagnosis rate for children (prevalence estimate)
Australian Bureau of Statistics – Survey of Disability Ageing and Carers ⁹	2015	2.6%
Centrelink Carer Allowance (child) ¹⁰ Autistic & Asperger’s Disorders	2016	2.4%
BMJ ¹¹ school students	2010 and 2015	2.4%-3.9% (parents) 0.9%-1.7% (teachers)

The NDIA and the Department of Social Security are funding and promoting the development of national diagnosis guidelines for ASD. The project leader says that real autism prevalence is 1.1% of the population – apparently, he believes that most (>50% of) ASD diagnoses in Australia are wrong.

⁷ From <https://www.ndis.gov.au/medias/Report-to-the-COAG-Disability-Reform-Council-for-Q4-of-Y3-PDF-2.5MB-?context=bWFzdGVyfHJvb3R8MjU3NDk3M3xhcHBsaWNhdGlvb9wZGZ8aGUwL2hhMi84Nzk4MDM0NzIyODQ2LnBkZnww0ZjZkYzM0MTI5NDRjZGEzZjkyMmEyZjQyNzJhM2M1YjQyMWNiMDA0YTVhZjJjYjBjNWUzNTU1MzAxMWFjNzg0>

⁸ From <https://www.ndis.gov.au/medias/root/heb/he8/8801054359582/COAG-DRC-Report-2016-17-Q3.pdf>

⁹ from <http://a4.org.au/node/1452>

¹⁰ from <http://a4.org.au/node/1340>

¹¹ see <http://bmjopen.bmj.com/content/7/5/e015549.long>

Initial research¹² found that very few (about 2% of) clinicians would consider diagnosing ASD before they saw all the required symptoms.

Despite its clear scepticism about the validity of ASD diagnoses, the NDIA reports¹³ a 98.8% (very high) rate of “Participants as a % of total access determinations” (only Cerebral Palsy has a higher rate). This suggests there is very little misdiagnosis of ASD.

Diagnosis rates for ASD in the ACT are well below the national average.

The diagnosis rate and the level of ASD among NDIS participants in the ACT are well below the national average. This has been shown separately in both ABS data and Centrelink Carer Allowance (child) data.

There are serious concerns that the NDIA does not understand ASD and does not accept evidence about ASD.

Conclusion

The NDIS is not meeting its goals. It needs substantial improvement.

Improvement is extremely unlikely while the Government, especially the responsible Minister and agency, refuse to recognise the growing inequity in the current NDIS implementation.

People in the disability sector are deeply disappointed in politicians who try to score political points over the NDIS.

Autistic NDIS participants are over 25% of all NDIS participants ... including some of the most challenging and least satisfied participants. Yet the NDIA refuses to properly engage with the ASD community. The NDIS will not be equitable or effective for autistic Australians until the NDIA engages properly with autistic Australians.

Yours sincerely,
Bob Buckley

¹² see <http://a4.org.au/node/1213>

¹³ from <https://www.ndis.gov.au/medias/documents/hda/h8d/8800076922910/CDRC-Report-2016-17-Q2.pdf>