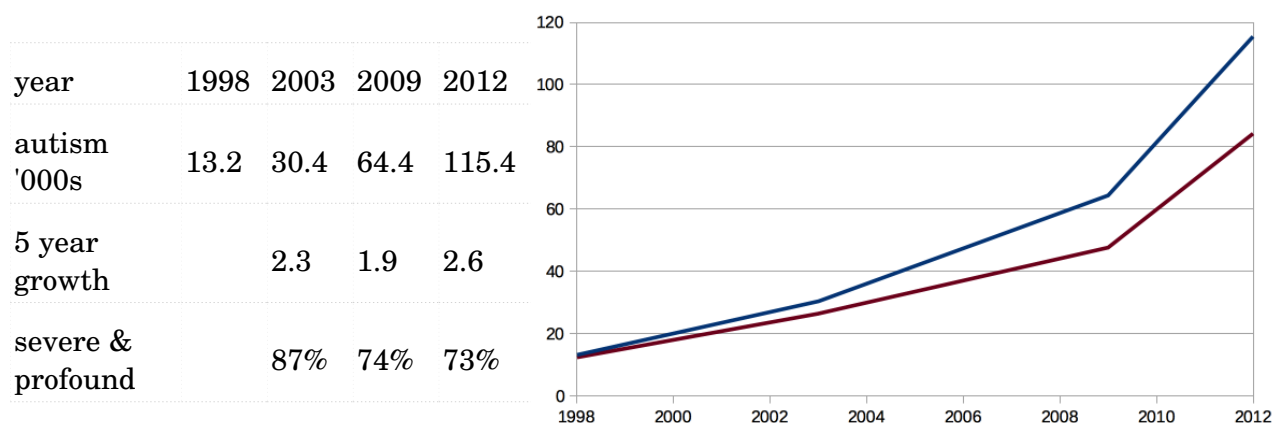


To the DSS advocacy and access team,

Subject: **Submission on National Disability Advocacy Framework**

Thank you for the opportunity to provide input to your review of the *National Disability Advocacy Framework*.

Autism Aspergers Advocacy Australia, known as A4, is a nation organisation that focuses on systemic advocacy for the growing number of people living with autism spectrum disorder (ASD) in Australia. The Australian Bureau of Statistics (ABS) estimates that the number of Australians with ASD over recent times has been ...



According to the Australian Bureau of Statistics (ABS), most people who are diagnosed with ASD have severe or profound disability.

According to reports from the National Disability Insurance Scheme (NDIS), participants with autism are the biggest distinct disability type in the NDIS.

Governments need to recognise and address the distinct needs of people with ASD in order to achieve more equitable outcomes for people with ASD. Currently, outcomes for people with ASD are abysmal.

Despite the Federal Government's long history of financial support for systemic disability advocacy and various disability peak bodies, the Commonwealth Government does not and never has supported systemic advocacy for people with ASD at a national level.

The white paper contains assertions about the Framework that we regards as dubious at best. For example:

The National Disability Advocacy Framework (the Framework) is the structure that governments work within to enable and support people with disability to protect their rights and overcome barriers.

This may be the goal ... but this goal is not realised for people with autism/ASD.

In Australia and under Australian law, people with ASD do not have and cannot access important rights. Unrecognised and inaccessible rights result in inequitable outcomes.

The available evidence shows that the current Framework delivers particularly poor outcomes for the growing numbers of people with ASD in:

- access to services
- education
- employment and labour force participation, and
- independent living.

The current Framework

The Discussion Paper says:

We want to know what you think about the current Framework to help inform development of the new Framework.

Well frankly, A4 doesn't think the current Framework is fully functional in relation to advocacy for people with ASD. So there is substantial room for improvement. We were not aware of the "current Framework"; we were not consulted. The current Framework had no discernible effect for us.

The latter part of the Discussion Paper has a section on "Key elements of the current Framework for reference". The first so-called Principle says ...

Disability advocacy operates under relevant Commonwealth, State and Territory legislation and the principles of the United Nations Convention on the Rights of Persons with Disabilities and other relevant United Nations Rights Treaties, to protect and promote the legal and human rights of people with disability

This is incorrect. While Australia signed various UN conventions/treaties, Australian Governments fail/refuse to enact the laws required by these treaties. So UN CRPD "and other United Nations Rights Treaties" simply do not protect citizens under Australian law or through the legal system in Australia. It is factually incorrect to claim/suggest that disability advocacy in Australia operates "to protect and promote the legal and human rights of people with disability" because those rights do not exist for people with autism/ASD in this country.

Specifically, children with ASD do not have the right to education since the High Court decided in [Purvis vs NSW](#) that a school (and apparently any organisation that offers a service) can choose to exclude a person and deny them service if the organisation feels there is a risk of unwanted behaviour. Under Australian law, service providers are allowed to discriminate against anyone with a disability if they are worried that behavioural issues may arise.

There is no sign that Australian law expects a service's feeling/worry about risk of unwanted behaviour to be "reasonable" or evidence-based. There is no requirement for the state, who the international treaties says is ultimately responsible, to ensure there is a "safety net" system to catch students when the "mainstreaming" education system decides that it will discriminate lawfully against children/students that they feel may be problematic.

The ACT Disability Discrimination Tribunal decided in [Woodury and Australian Capital Territory 2007 ACTDT 4](#) that "there is no evidence of discrimination as defined in the Act [[ACT DA 1991](#)]"; that is,

- the ACT Health Department did not discriminate when it provides services for people with some (mental) disorders but refuses to offer any service whatsoever for the children of the applicants for the ASD that those children were diagnosed with.
- while the ACT Education Department provided education that appears effective for students generally, it did not discriminate against these two children with autism/ASD by not offering them an effective education.

The Tribunal also said that, "122. Even if there had been discrimination, a number of "defences", in particular section 27, would have applied in favour of the [Government]".

Note that the legal system took 10 years to process these matters: there was no prospect of a positive outcome for the children with ASD.

Clearly, the growing numbers of children with ASD in Australia cannot access their rights to treatment and education described in the United Nations Convention on the Rights of the Child.

The law in Australia does not ensure the safety of people with disability while they are in the care of a disability service. OH&S law protects works. It may protect visitors. But the law does not protect the safety of clients in a disability service.

International law says people with disability should be protected from all forms of discrimination; but Disability Discrimination law in Australia delivers the concept “lawful discrimination”.

The failures of Australian law to protect people with disability appropriately makes systemic and individual advocacy far more difficult than it should be. The legal foundation for disability advocacy in Australia is weak or non-existent.

While the third principle says “Disability advocacy seeks to influence positive systemic changes in legislation”, successive Governments failed/refused to even recognise, let alone address, the need to substantial recognition in law of the rights of people with disability. Without support in law, change to “policy and service practice” is challenging, minimal and transitory.

Without legal support for improved service practice, and in a context of increasing privatisation and the absence of service quality standards that recognise the needs of people with ASD, advocates are increasingly challenged by the growing responsibility for organisations in deliver profit rather than improve disability services.

Another of the current Key Principles says:

Disability advocacy promotes leadership and capacity building by people with disability.

So the Government's current policy is to hold responsible, the completely unfunded ASD advocacy group(s), for the gross inadequacy of the education sector ... who should be responsible for these outcomes. Instead, the education sector does not measure and report on these outcomes.

The Key Principles in the Discussion Paper say:

Disability advocacy ensures that views represented meet the individual preferences, goals and needs of people with disability.

For a long time, the Government has complained that the disability sector is “too disorganised”, does not have “one voice”. The Government has a long history of complaining when disability advocacy represents the diverse “individual preferences, goals and needs of people with disability”.

The Government cut funding to the peak advocacy groups that represent “individual preferences” ... instead it chose to fund “cross-disability groups” who told the government that they'd bring a simplified consistent position on policy matters to the table. Unfortunately, the new groups have yet to express “individual preferences” across complex issues for the disability sector.

There are fundamental questions that needs to be addressed. “How much leadership should advocacy deliver? Should systemic advocacy reflect the diverse views of the community or should advocates take a leadership role? Is advocacy separate from leadership” and “How much is leadership is the community willing to fund (since good leadership cost money)?”

Disability advocacy strengthens the capacity of people with disability to speak for themselves by actively supporting and encouraging self-advocacy

First, Government should fully recognise and support that education has substantial responsibilities in “actively supporting and encouraging self-advocacy” for people with disability. In this matter, advocacy is the safety net ... not the foundation.

Government must also recognise that many people with disability are unable to be adequate self-advocates for a range of reasons including their personality type, anxiety, depression, concern over their vulnerability, etc. Some people resist individual advocacy; they insist they are only prepared to be involved in group/systemic advocacy.

Disability advocacy recognises and respects the diversity of people with disability

There are very strong and contradictory feelings in the ASD community on quite a few issue relevant to advocacy. ASD advocacy organisations need to choose whether they are going to represent a particular view held by just part of the ASD community, or try to recognise, respect and represent the community and its diverse and often contradictory views. A4 tried to be the latter type of organisation. It is crucial that we have both types of advocates ... as long as they respect each other.

Sadly, politicians and bureaucrats have complained for years that ASD (sometime disability) advocates don't know what it is that they want. This is simply untrue: all the advocates know what they want. Government would prefer that disability advocates bring them simple choices. The problem is that many issues in the disability sector are complex; there is a diversity of need that Government struggles to understand and address. Government wants it to be easy.

If Government expect advocates to bring them simple choices, then they need to pay for the community leadership and resources needed to build consensus; the Government should understand from its own attempts that consensus over issues requires considerable effort and resources. They would need to fund all that properly.

So the problem isn't with getting “disability advocacy [to] recognise and respect the diversity”, the real problem is that politicians and bureaucrats find the diversity in the disability sector is just too challenging.

The NDIS is an interesting case study. The whole disability sector agreed that people with disability need an individual plan. Agreement on this was relative easy to achieve ... and once there was agreement, it was a relative simple process to develop the required policy and start implementation. Ultimately, detailed implementation of this policy is very complex: the diverse needs are proving extremely challenging.

Disability advocacy ensures that the rights of people with disability to privacy, dignity and confidentiality are recognised and upheld.

Again, there is an enormous tension here. Government and the non-Government service providers need detailed information to a) assess eligibility, and b) deliver appropriate services for individuals ... especially when it is being done on an individual basis. Finding a good balance between “privacy, dignity and confidentiality” and convenience and bureaucratic efficiency is difficult. Probably, it has to depend on trust ... and there will always be cases where that fails.

Disability advocacy will foster effective strategic alliances to develop capacity to identify and respond to the needs of people with disability.

Of course ... but it needs appropriate funding. It also requires participation from others to form alliances.

Other Issues in the Discussion Paper

The Discussion Paper says:

The Disability Reform Council agreed that systemic advocacy and legal review and representation will be funded outside the NDIS.

We have substantial scepticism about this. The Government wants to deal with organisation that claim the represent people living with disability ... as long as those organisations espouse views that are in-line with the Government's views. Government prefers advice that is simple and matches its political agenda; it does not want to deal with advocacy organisations that reflect the complex and diverse views of people in the disability sector.

The Discussion Paper says:

The Australian Government funded National Disability Advocacy Program (NDAP), will continue to ensure people have access to advocacy support.

The Government does not, and has never before, funded systemic advocacy for autism/ASD in the NDAP or anywhere else.

Yet autism/ASD is the biggest distinct disability in the NDIS. The number of people diagnosed with ASD has grown substantially in recent years yet funding for advocacy for people with ASD has not grown. Clearly, the Government does not “ensure people [with ASD] have access to advocacy support” ... nor is there any “continue” about it.

The Discussion Paper says:

Recent public consultation on the NDIS Quality and Safeguarding Framework and the NDIS Information, Linkages and Capacity-Building Framework, has already facilitated discussion and ideas on advocacy supports in the NDIS. Feedback from these consultations will be used to inform development of the new Framework.

...

Both reviews will be conducted in line with the principles of the National Disability Agreement and the National Disability Strategy.

The “principles” of the NDA and the NDS do not recognise the needs of people with autism/ASD. In relation to ASD, these are flawed documents. Reviews that are based on flawed foundations have little prospect of real and lasting success.

Advocacy for ASD and the NDIS

The NDIS is the biggest development in the disability sector for some considerable time. It is an important change. Potentially, it can make substantial improvements for people with disability in Australia and for the nation as a whole.

If the goals of the NDIS can be realised, people with ASD will live more independently and make more of their own life choices.

It is optimistic to hope that it will help improve outcomes for people with ASD in education and employment.

The Productivity Commission and its associates, the main architects of the NDIS, showed little regard for ASD advocates. The Productivity Commission ignored advice from national ASD advocacy that they were severely underestimating the number of people with ASD and the distinct nature of ASD (see [Disability report chronically understates ASD diagnoses](#)).

By all accounts, the NDIA was unprepared for the prevalence of ASD among NDIS participant. Apparently, this has emerged as a major dispute between the Commonwealth and South Australian Governments in the current trial period (see [NDIS: autism rates blow out in SA, likely to be same nationally](#)). ASD advocates warned both sides that their estimates of the number of people with ASD were wrong, and both sides ignored advice from the ASD advocates. Now they blame each other instead of admitting their own refusal to accept advice.

Despite ASD being the biggest distinct disability group of NDIS participants, the NDIA has yet to seriously engage with ASD advocates. The only engagement with ASD advocates mentioned in the NDIA's 2015 Progress Report is it's yet-to-be-completed consultation over Early Intervention ... and academic and service provider input dominate that consultation.

The NDIA's poor engagement with ASD advocacy, the NDIS's biggest distinct group of participants, is deeply disappointing ... compared to its apparent level of engagement with disability advocacy for physical, sensory and intellectual disability that are funded by Government.

The consequence is that NDIS planning for ASD at all levels is seriously sub-optimal. The costs and other consequences from poor planning and service access are major ... though Government would be likely to reject/dispute any estimate of the cost.

Questions from the Discussion Paper

1. Do you believe the current Framework encompasses your vision of advocacy in the NDIS environment? If not, what changes are required?

No, the current Framework clearly goes no where near A4's vision of advocacy.

The section above describes briefly the poor engagement of the NDIA with ASD advocates. Clearly, the NDIA needs to engage much better with ASD-related stakeholders. It needs to recognise ASD-related issues so it can think about addressing those issues. There is such a long way to go.

2. Are the **principles** of the Framework appropriate for guiding the delivery of advocacy for people with disability in a changing disability environment, including in the context of the NDIS? If not, what changes are required?

Presumably, this refers to the current Framework ... No. The principles of the current Framework are are failing ... possibly more through inadequacy than inappropriateness.

Perhaps Government across the board could recognise advocacy, especially systemic advocacy as an essential vehicle for stakeholder engagement in policy development and service/supports planning and delivery.

And individual advocacy should be regarded as routine, even essential, in individual planning and service review.

3. Are the **outcomes** of the Framework still relevant or should different ones be included? If so, what should be included?

Government has yet to properly recognise the serious inadequacy of it disability outcomes generally, for example the level of poverty, or the outcomes for people with ASD, some of

which are reported by the ABS. These outcomes largely languish as ignored paragraphs in obscure reports.

There needs to be more positive outcomes and outcomes for people with disability need to be front and centre for Government.

The first outcome listed refers to people with disability being “accorded” rights and freedoms. For example, Judge Tracey who officiated in the [Walker vs Vic](#) matter failed/refused to recognise the applicant's disability; through his written decision, Judge Tracey described the applicant's disability as “misconduct”. And the [appeal process](#), officiated by Judges Gray, Flick and Reeves, confirms (at least fails to adjust/revise) the courts' prejudiced view of ASD. Apparently, Judges expect that an applicant's ASD will simply go away if parents simply apply sufficient discipline ... though the Judges do not explain why teachers do not get better outcomes through the discipline that's applied professionally in schools.

The first outcome, that of being accorded rights including the right to education, treatment, necessary services & supports, justice, etc., is not realised.

The available data/evidence shows that the outcomes listed are largely unachieved for people with ASD.

A crucial step towards achieving any outcome is for those responsible to recognise that outcomes are not being realised. Governments in Australia have yet to achieve this essential prerequisite in relation to ASD.

A4 feels that more of the outcomes listed would be achieved were the Government to engage with ASD-related stakeholders who advocate for the needs of people with ASD. Progress on the outcome listed last could be achieved relatively easily and could help improve the other outcomes.

4. Are the **outputs** of the Framework still relevant or should different outputs be included?

While some people with ASD can access individual advocacy, the advocacy available rarely understand the distinct issues affecting people with ASD. Advocates do not respect the goals of people with ASD when those goals do not fully embrace a *full inclusion* ideology.

Systemic advocacy for ASD is already evidence-based and transparent. Since it is unfunded, it would seem to be completely accountable.

ASD-related advocacy isn't as planned as it might be, for two reasons.

- Planning is difficult when there are few resources and no funding.
- A significant amount of systemic advocacy in Australia is highly reactive, hence unplanned, often because the Government does not engage with ASD advocates.

ASD advocacy does not have sufficient funding and resources to focus on community awareness as a major targeted output.

Advocacy for ASD can only contribute to legislation and policy when Government engages with advocates. This has yet to happen.

5. Does the Framework identify what is needed in the current and future disability environment? If not, what changes are required?

Clearly, the answer is “No”. As well as major improvements across the whole disability sector, Government, service providers and the community generally need to recognise and address the distinct needs of people affected by ASD. The Framework does little to improve recognition and understanding of the needs of people with disability.

Just for starters, politicians and the media need to stop describing people with disability as “leaners” and “rorters”. That does not help “identify what is needed”; the Framework does little to address this.

6. Do you have any other comments, thoughts or ideas about the Framework?

Yes, but A4 is interested in seeing progress in the matters that we've already raised. That's enough to be getting on with for now.

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