



## **Submission to the Inquiry on NDIS Planning**

Joint Standing Committee on the National Disability Insurance Scheme

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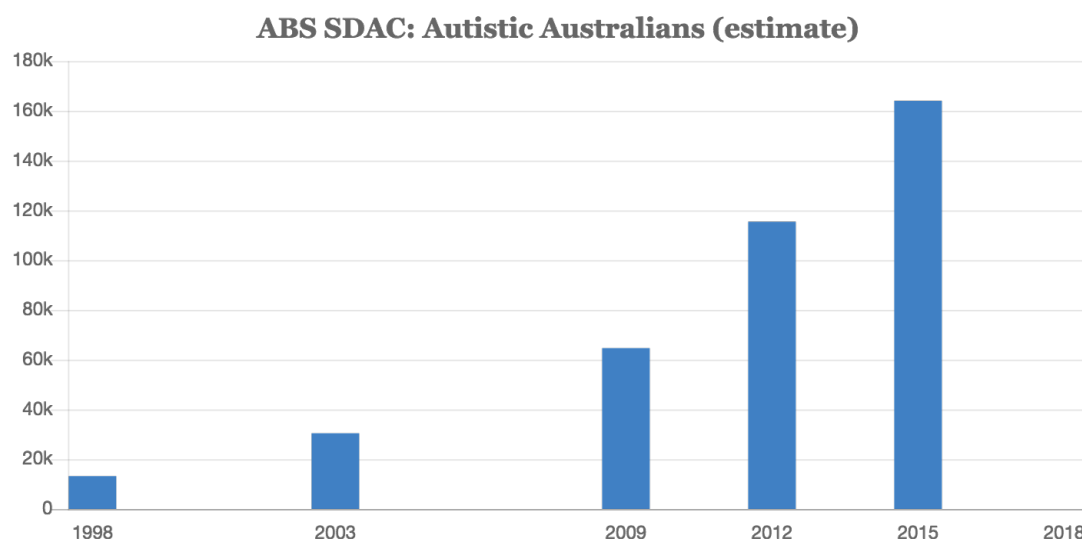
*Autism Aspergers Advocacy Australia*, known as A4, thanks [the Committee for this opportunity](#) to raise concerns about the NDIS planning process.

A4 is a national disabled people's organisation recognised on the DSS website. A4 advocates systemically for autistic Australians and for their families, carers and associates.

A4's submission following relates specifically to autistic NDIS participants.

*Autism Spectrum Disorder* (ASD) is a distinct disability. It has some distinct issues that need to be recognised and appreciated if the NDIS is going to achieve its goals in relation to autistic Australians.

The number (and proportion) of people diagnosed with ASD is increasing significantly while the levels of other types of disability in the population are stable or decreasing slowly. The Australian Bureau of Statistic (ABS) reports that the number of autistic Australians grew from an estimated 13,200 in 1998 to 164,000 in 2015; the number of autistic Australians increased 42% from 2012 to 2015.



*Figure 1. Growth in reported autism*

Some people are born with different (or neuro-divergent) brains; their atypical neurology which is likely the primary source for their ASD is life-long. Their ASD is diagnosed sometime after they are born but with appropriate treatment some of them learn life skills that mean they function independently; that is, without needing disability supports. They lose their disorder. Few autistic children in Australia are able to access best-practice or evidence-based early intervention even with the arrival of the NDIS.

Generally, disability rates increase with age but ASD is mostly diagnosed in young people. The vast majority of Australians who are known to be autistic are under 25 years of age. We see no evidence that autistic people die before they reach 30 years of age; instead, we expect this is due to massive under-diagnosis of autistic adults and while there is much better awareness of ASD for children ... which results in more diagnoses. It is not known whether actual ASD prevalence, as distinct from diagnosis rates, is increasing.

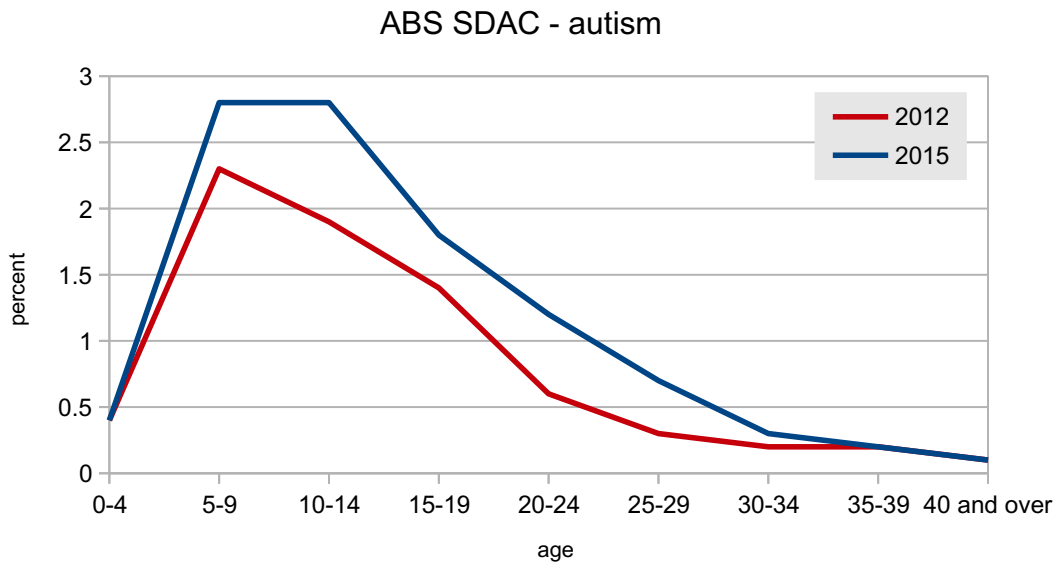


Figure 2. Autism by age in Australia

While most disability has onset later in life, ASD is usually a life-long disability. People are born with ASD or its onset is very early in their childhood. The underlying cause remains through life though some people learn or develop life skills that mean they function independently hence they can lose their ASD diagnosis.

The latest NDIS Quarterly report (Year 6, Quarter 4) shows 85,184 or 30% of NDIS participants report “autism” as their primary disability, making autism the most numerous primary disability type in the NDIS.

Autism is closely followed by intellectual disability.

There is a significant overlap between the two: over 10,000 NDIS participants with intellectual disability are also registered as being autistic and an unknown number of participants with autism as their primary disability also have intellectual disability. Some participants list intellectual disability as their primary disability because they expect to get a fairer NDIS plan; they believe NDIS planning for autistic participants is unfair.

The number of autistic NDIS participants is a substantially higher proportion of the NDIS than was expected and planned for. The NDIS expected that just 20% of NDIS participants would be autistic.

The NDIS did not plan for such an increase. The NDIS does not even recognise that the number of ASD diagnoses is likely to have increased from 2015 to 2019 – when comparing NDIS rate and 2015 ABS estimates, the NDIS made no allowance for an increase in diagnoses from 2015 to 2019<sup>1</sup>. Despite the ABS reporting a 42% increase from 2012 to 2015, NDIS officials told A4 they did not see any reason why the ABS estimate of autistic Australians would increase from 2015 to 2019.

<sup>1</sup> see [https://www.ndis.gov.au/media/1564/download\\_page\\_20](https://www.ndis.gov.au/media/1564/download_page_20).

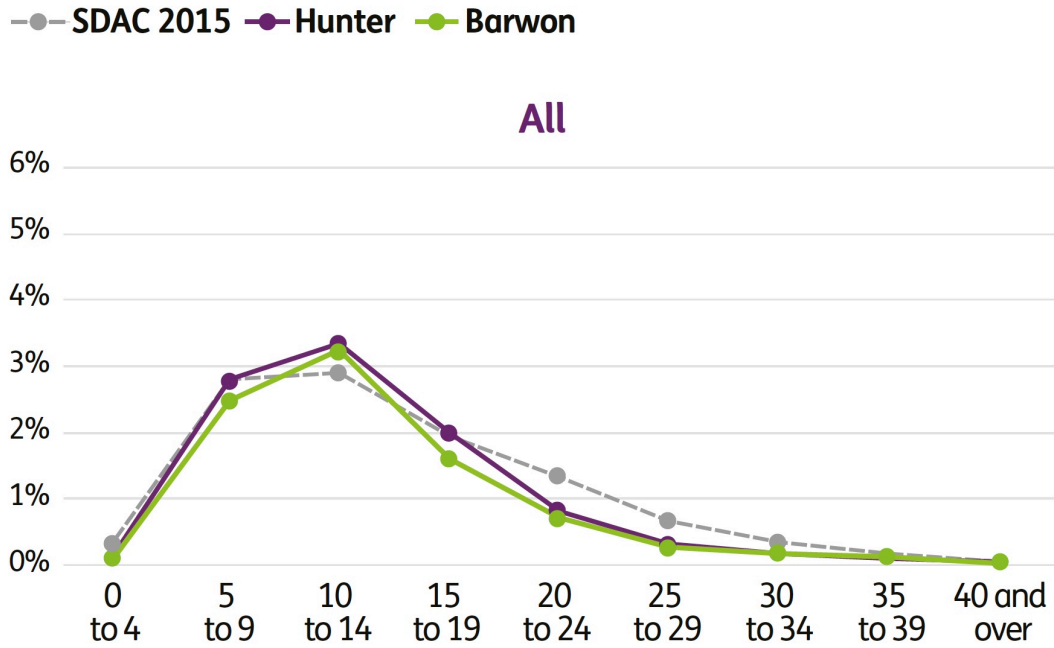


Figure 3. Autism by age from ABS SDAC 2015 and NDIS 2019 mature regions

This high rate of growth puts enormous strain on services and supports that were grossly inadequate at the start. The NDIS’s total lack of interest in developing the disability workforce to address the growing needs of increasing numbers of autistic citizens is inexcusable.

Figure 4 shows the average cost of NDIS plans for autistic participants compared to the cost of NDIS plans generally. While the shape of this chart results from historical approaches to support, the basic message is that skimping in the early years results in substantially increased cost later on. Regrettably, the NDIS is intent on maintaining this practice.

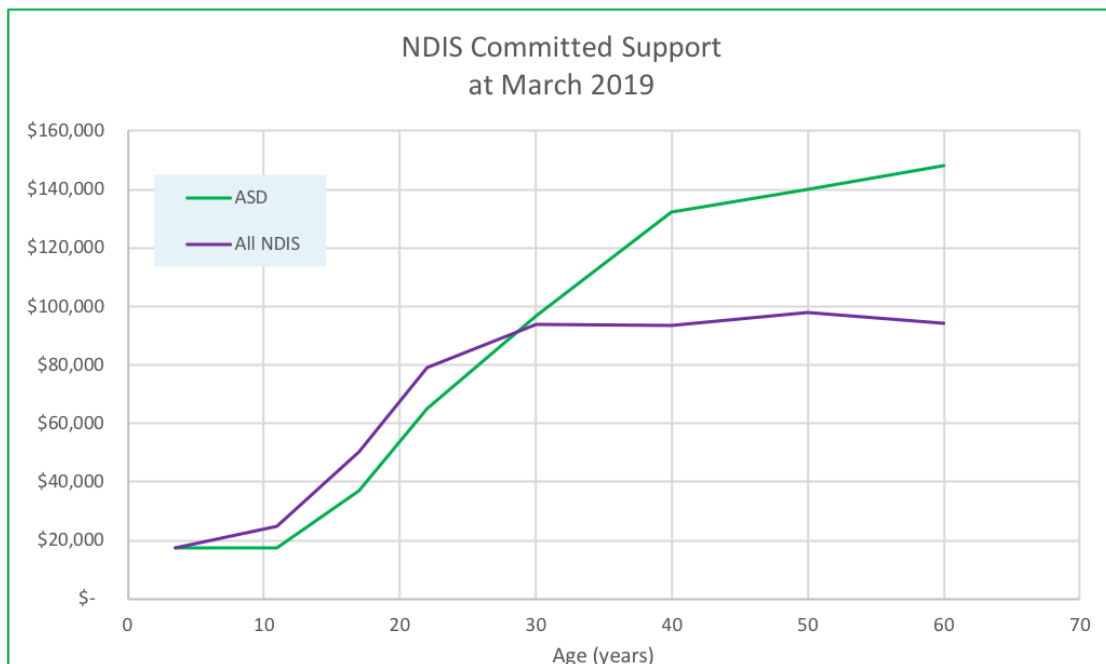


Figure 4. NDIS committed cost – autism/ASD vs disability generally

The ABS estimate of the number of autistic Australians with severe or profound disability was 106,272 (64.9% of 164,000 autistic Australians) in 2015. It is likely there has been a 20-40% increase from 2015 to 2019. The latest Quarterly report, June 2016, indicates that there are about 95,200 autistic participants, that is 85,184 (primary) + about 10,000 (secondary), so the NDIS has yet to reach some autistic Australians with severe or profound disability.

Hopefully, the ABS will soon report on its 2018 disability data.

A4 is very concerned that the NDIS made little or no discernible progress on the numerous recommendations from your Committee in its various inquiries that affect autistic participants.

Similarly, there are few if any outcomes from the NDIS Autism Advisory Group or from A4's various meetings with senior NDIS officials.

## **Items in the terms of reference**

### **a. the experience, expertise and qualifications of planners;**

Our observation is that few, if any, NDIS planners have the experience, expertise and qualifications they need to deliver appropriate NDIS plans for autistic NDIS participants.

Few people have experience providing services for autistic people. There were just 13,200 autistic Australians in 1998. Most were children. Disability services for autistic people simply did not exist so most lived at home. Consequently, disability service staff, especially more senior staff, in Australia lack knowledge and experience of autistic clients.

Most people diagnosed with autism in 1998 also had intellectual disability so many senior staff, bureaucrats and planners regard autism as a type of intellectual disability; they do not see it as distinct with very distinct support needs.

In the past, autistic people in disability environments were often provoked to various forms of distressed or challenging behaviour which lead to them either being denied services or subject to chemical restraint. This means that disability service staff rarely or never got to support autistic people properly so they have little or no real experience of autistic clients.

The people designing disability-related qualifications had little or no experience of autism so the training curricula that they design do not adequately address the needs of autistic community. Disability qualifications rarely prepare graduates to support autistic clients.

The NDIA employs few people with experience, expertise or qualifications in ASD.

Families who got advice from expert clinicians find that NDIS planners and more senior bureaucrats reject and ignore advice from clinicians with specific knowledge and experience in ASD.

Three age groups can be considered separately. There are major planning deficiencies in each of these areas.

### **1. Pre-school**

The NDIS chooses to reject advice about early intervention for autistic children that it and other government agencies commissioner and published. Senior officials in the Agency said the advice on evidence-based early intervention for autistic children is “contested”. The Agency contested this issue in the Administrative Appeals Tribunal (AAT) ... and lost the argument. More information is provided in i) about the AAT below.

As yet, A4 had not seen any response to these AAT rulings; the Agency appears to continue its resistance to providing evidence-based early intervention in autistic children’s plans.

### **2. School-age and education**

A high proportion of school-age NDIS participants are autistic. Reports indicate school-age participants are doing poorly: see [\*The National Disability Insurance Scheme is failing to improve access to education, families say. Why?\*](#) (CT, 4/9/219)

Families report that a major part of the problem is that NDIS planners expect schools to provide all the disability supports for students with disability. This makes no sense as students are in school for just 30 hours per week. The rest of the time, they are at home or in the community where many of them need significant amounts of support.

Autistic students do not succeed at school when NDIS planners do not provide the support they need for the rest of the time.

ABS reports indicate that few autistic students achieve a tertiary qualification. There is no evidence that the NDIS is changing outcome.

### **3. Adult**

Autistic adults need improved support in independent living, community access and employment.

Current, autistic adults in smaller numbers (see Figure 2 above) have substantially higher support needs through their adult life – as is shown in Figure 4 above. This is partly due to the lack of supervision by behavioural clinicians and sufficiently trained support staff.

There are major deficiencies in support training. And planners do not understand/recognise, and often resist, requests for behaviour support for autistic adults who need behavioural support.

Little relevant training and qualifications are available in Australia.

Similarly, NDIS plans for autistic adults often omit reasonable and necessary supports that are ASD-specific. Or they aim to facilitate, or even require, higher levels of socialisation than autistic NDIS participant want or request.



**b. the ability of planners to understand and address complex needs;**

A4's observation of individual plan outcomes is that few planners really understand the needs of autistic people; they do not recognise the barriers autistic people have to achieving their goals.

Autism is difficult to understand. You can't see it. It is due to different ways of seeing and interacting with the world including different perceptions of other people. Autism is poorly understood, partly because service providers have limited experience and history is supporting autistic clients ... and planners share this lack of experience and familiarity.

Autism is described as a spectrum. Autistic people have varied needs which complicates the role of planners. People say ...

*If you've met one person with autism, you've met one person with autism.*

The individual needs of autistic people vary widely. Sometimes, two autistic people have opposite support needs.

Some needs are unique and may be extremely difficult to meet. For example:

- 1) Lucy's needs have been discussed on the radio<sup>2</sup>. Her support needs are very challenging and still being developed. It is unlikely that NDIS planners currently have the required knowledge and flexibility to provide a proper plan for Lucy and others with such complex support needs.
- 2) X is a young man who has been traumatised by his encounters with police. He resists offers of paid support but his family cannot meet his needs. NDIS planners simply do not know how to start helping X.

**c. the ongoing training and professional development of planners;**

A4 has no idea what training the NDIA provides for planners. The NDIA is a very secretive organisation; it would not share its training or consult autistic people about staff training.

A4 is not aware of any ASD expertise or authority being involved in training for NDIS planners.

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<sup>2</sup> See <https://www.abc.net.au/radionational/programs/allinthemind/loving-lucy/11058990> and <https://www.abc.net.au/radio/canberra/programs/drive/being-lucys-parents/11417718>

We are aware that a “fact sheet” on autism was prepared for NDIS staff. And we believe this is quite inadequate.

A4 is concerned that the NDIA believes all its planners are able to create plans for autistic participants irrespective of their individual knowledge and experience of ASD.

Based on what we see as planning outcomes, A4 believes NDIS planners need substantially more training and professional development about autistic participants and the supports they need.

**d. the overall number of planners relative to the demand for plans;**

As above, A4 has no idea how many planners the NDIS has.

We observe extended delays in planning for autistic children. We expect excessive delays led to the Minister’s announcement that children who did not get a plan within 50 days of being found eligible would get an automatic allocation of funds: see <https://ministers.dss.gov.au/media-releases/4981> (though we have not yet seen this implemented).

Excessive delays can result from insufficient staffing ... or from overly complex processes.

Delays in autistic children accessing early intervention cost a lot of money. Currently, many autistic children experience unacceptable delays.

Senior NDIS officials told us they have hundreds of new schemes to overcome the issues. But they never ask autistic participants and their families what’s wrong or how to improve the NDIS planning process. We never see progress of outcomes reports from this myriad of “projects”.

**e. participant involvement in planning processes and the efficacy of introducing draft plans;**

The NDIS does not make participants aware that participants allow them to write and modify their own goals. Sections 33 and 47 of the NDIS Act 2013 are quite clear but few people read them ... and the NDIS officials usually misinform participants about their rights under the Act.

Many participants, and their families – especially for young children, would benefit from help and guidance to prepare for NDIS plans. The information the NDIS provides is does not help.

**f. the incidence, severity and impact of plan gaps;**

There is very little data available to A4 that might help us answer this.



Most of A4's advocacy results from poor NDIS planning for autistic children. Basically, underfunding children results in higher support needs and costs through adult life, a pattern shown in Figure 4 above.

The major plan gaps vary by age group:

- evidence-based early intervention and outcomes reporting is a frequent severe gap in the plans of pre-school-age autistic children
- ongoing therapy and behaviour support are frequent severe gaps for school-age autistic children
- transition support, that is extra support through major transitions in an autistic person's life, are usually severe gaps in individual plans

The major impact of these gaps is poor long-term outcomes and substantially increased support costs through adult life.

As for impact: A4 cannot see any data that indicates the impact of NDIS plans, so we have even less ability to describe quantitatively the impact of gaps in participants' plans.

**g. the reassessment process, including the incidence and impact of funding changes;**

Again, A4 does not have access to NDIS data.

Reassessments of participants' plans occur a) when a plan expires and a review delivers a new plan, and b) when a non-scheduled plan review occurs.

It is not surprising then that the funding changes we hear of are predominantly downwards.

A4 observes that the NDIS is strongly motivated to reduce funding from the initial funding in participant plans when participants transfer from previous state-level disability supports. The NDIS was required to ensure no one was worse off when they transitioned to the NDIS from their previous supports.

But the NDIS clearly regards many of the previous schemes as having been too generous and participants find that the NDIS cuts their second or third 12-month plan significantly. This is quite remarkable because people's previous plans were regarded as inadequate ... so it is hard to see how these funding cuts achieve the goals of the NDIS.

As we said before, the reassessment process rarely recognises the need for transition support.

A4 is extremely concerned that the NDIA's reassessment processes strongly disadvantage vulnerable participants who do not have strong individual advocacy. Autistic participants need strong family support because there are no specialist advocates for autistic people and generic disability advocates are a) already overloaded, and b) lacking in knowledge and experience of ASD.

Of course, we can't criticise the NDIS over issues like this because they have a bunch of secret projects to improve all this. Unfortunately, we'll never hear what they are or see any outcome from them. We should just trust that they are happening and that we'll forget about the issues before we can expect to see results.

#### **h. the review process and means to streamline it;**

The latest NDIS Quarterly Report indicates that the main reason for complaints<sup>3</sup> is the timeliness of the NDIS.

Reasons for reviewing NDIS plans vary.

There are regular plan reviews. There are indications that some plans may be for three years, while some participants get 3 month plans. Many participants report having their scheduled plan reviews delayed.

Currently, each of these scheduled plan reviews is a complete plan review and is done without discernible preparation for the review.

Then there are one-off reviews requested by either the Agency or the participant.

There is some indication of an informal "light touch" review process. Presumably, such a process is relatively streamlined though we don't have any information about these.

The review process might be streamlined if the parties prepare together for the review. Reviews could be streamlined by having both parties identify their issues and concerns, and share information and documents, before the parties get together for the review.

If there are no issues, then a review might be avoided.

The review can focus on the issues. It can focus on ensuring the parties understand each other.

Where differences arise, the process steps must be subject to rigorous time limits. Currently, the NDIA can (and does) delay an internal review for months or years but participants have just 28 days to decide to progress a review to the AAT. NDIS delays can leave a participant without funding which results in essential supports shutting down and pressures participants to accept unreasonable plans or they lose support while the review stagnates. A4 is helping families voluntarily whose young children are missing out on evidence-based early intervention and have never had an agreed plan in over 2.5 years.

The role of clinicians in planning needs to be clearer. Currently, bureaucrats with no discernible training or experience reject expert clinical advice.

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<sup>3</sup> See Table E.36 - <https://www.ndis.gov.au/media/1611/download>

Autistic people need access to specialist disability advocates who understand autistic clients and their distinct needs.

**i. the incidence of appeals to the AAT and possible measures to reduce the number;**

The latest Quarterly Report tells us there were 2,233 appeals to the AAT about the NDIS by end June 2019. Of these, 1,576 were resolved with just 54 going to hearing.

A4 is aware that a significant number of cases relate to young autistic clients and relate to accessing evidence-based early intervention.

Senior NDIS officials told A4 that evidence-based early intervention for autism, as described repeatedly in a series of research reviews published by the Government, is “contested”. Apparently, the NDIS decided to reject the advice it and other Government agencies received.

Families have to appeal to the AAT to access evidence-based early intervention for their autistic children. Each family has individually to present widely recognised research and relate it to their individual child.

Generally, the NDIS dragged out the AAT process for these families and in most cases the delay alone massively diminished the access of autistic children to essential early intervention. In many instances, the NDIS settles for close to the full request on the steps of an AAT hearing.

Recently, a family took the issue to hearing and won<sup>4</sup>. This didn't happen until a mother who is a lawyer herself forced the issue. Despite the AAT's decisions, there is no discernible change to NDIS policy so families still have to battle the NDIS with its bottomless resources in the AAT to get an NDIS plan to include evidence-based early intervention for an autistic child.

The AAT promised A4 that it would review these AAT processes ... but the AAT has not yet done so.

The number of appeals related to autism might reduce if:

- 1) NDIS planners understood the needs of autistic participants and respected clinicians who do know about ASD;
- 2) The funded disability advocates knew about the specific ASD-related needs of autistic people and helped communicate their needs, rather than using inappropriate generic disability approach in their advocacy.
- 3) Internal reviews considered ASD-specific evidence.

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<sup>4</sup> See <http://www8.austlii.edu.au/cgi-bin/viewdoc/au/cases/cth/AATA/2019/1478.html> and <http://www8.austlii.edu.au/cgi-bin/viewdoc/au/cases/cth/AATA/2019/1480.html>

**j. the circumstances in which plans could be automatically rolled-over;**

Previously, we suggested that before a review both the Agency and the participants identify concerns and issues with the current plan.

If a review comes around and there are no issues or concerns then the plan could be automatically rolled-over.

There may even be some well-defined and well-understood changes in circumstances where there could be automatic adjustments that allow automatic plan roll-over.

Some conditions and situations have expected change

**k. the circumstances in which longer plans could be introduced;**

The most obvious case is where both the NDIS and the participant agree that a longer plan is likely to be appropriate.

**l. the adequacy of the planning process for rural and regional participants;**

Typically, the issue of concern is that services and supports in an NDIS participant's plan are available/accessible to the participant in rural, regional or remote settings.

Services may be more difficult to access in rural settings, but specific services for autistic people are often not available in population centres. A4 sees no evidence that service availability is considered in NDIS planning processes.

**m. any other related matters.**

There are a number of other planning related matters.

- 1) The NDIS eligibility is a major problem for many autistic Australians.
  - a) the NDIS eligibility descriptions for ASD and related diagnoses remain *gobbledygook* (see [Massive row over NDIS autism eligibility gobbledygook](#)). The Agency's List A criterion for autism indicate that a diagnosis includes just one severity rating when the DSM-5 describes the need for severity ratings in two aspects of every diagnosis. ASD with levels 1 severity is not mentioned in either List A or List B.
  - b) some NDIS gatekeepers tell families that either that the NDIS does not support ASD *at all*, or that ASD Severity Level 1 isn't covered. They provide incorrect information. They prevent families from even applying by denying them an application form (which is not available of the NDIS website).

- 2) Some people have things that may or may not happen. The NDIS usually refuses to plan for the possibility so people miss out on supports that they need for likely and unexpected/unplanned events.
- 3) NDIS planning appears to be based heavily on super-secret reference packages that are unvalidated and often inappropriate. This approach deprives many autistic people of the services and supports they need to achieve their goals and aspirations.
- 4) Autistic NDIS participants often cannot access the services they need even though the NDIS committed funds to participants' plans for those supports. Many NDIS participants only manage to access 80% of the supports they need. The NDIS could collect data so service deficiencies could be identified and addressed in an evidence-based approach.
- 5) The NDIS does not report on the achievement of participants' goals. Outcomes reporting needs substantial improvement.
- 6) The NDIS planning process for autistic participants could be massively improved were the NDIA to co-design the planning process with the ASD community.
- 7) The NDIS needs planning for autistic participants with complex or greater than average support needs. The Agency talks about creating a *complex support needs pathway* but A4 has not seen evidence that this has happened ... nor any indication that it would improve planning for autistic NDIS participants.
- 8) The NDIS complaints process is there to make excuses and justify the Agency's actions. It is pointless and frustrating for participants.

A4 appreciates the opportunity to make this submission.

A4 feels that the NDIS has improved the lives of many autistic people. We acknowledge and appreciate this significant achievement, but we are concerned that the NDIS needs to meet its goals for autistic Australians. It still has a long way to go.

We wish the Committee the best of luck. From our perspective, the NDIA appears unable to implement, and often resistant to, the Committee's recommendations in previous reports. Perhaps the Agency will be more receptive this time.