

Short of the Mark



**A Submission to Tune Review
into**

**Improving the NDIS Experience:
Establishing a Participant Service Guarantee and
removing legislative red tape**

22/10/2019

Introduction

The submission following responds to the Government's [Review of the NDIS Act and the new NDIS Participant Service Guarantee](#). The NDIS is potentially a substantive reform to benefit people with disability in Australia if it is implemented properly. *Autism Aspergers Advocacy Australia* appreciates the opportunity to express our interest and concerns.

Autism Spectrum Disorder (ASD) is a significant and distinct disability type.

The latest NDIS Quarterly Report (as of 30-JUN-2019), shows there were 85,184 or 30% of NDIS participant with "autism" as their primary disability, so autism is the most numerous primary disability type in the NDIS. The NDIS's [Outcomes for participants with Autism Spectrum Disorder \(ASD\)](#) reports a further 10,168, a further 5%, listed "autism" as a secondary disability¹ in December 2018.

Autism Aspergers Advocacy Australia, known as A4, advocates nationally for autistic people, their families, carers and other associates. A4 is a member of [Australian Federation of Disability Organisations \(AFDO\)](#) and [Disability Australia](#). A4 is listed among the *National disability representative organisations* on [the DSS website](#).

Comments on the Discussion Paper

The Discussion Paper, [Improving the NDIS Experience: Establishing a Participant Service Guarantee and removing legislative red tape](#), makes numerous bold claims about the NDIS. For example, the Discussion Paper says:

The Government is committed to providing choice and control to NDIS participants, ...

The NDIA routinely denies families of autistic children real "choice and control" for behaviour support and early intervention for ASD. Figure 2 below shows the NDIS intake pathway for young autistic children trying to access evidence-based early intervention. It shows that the typical pathway requires the slow and difficult process of asking the Administrative Appeals Tribunal (AAT) to review the NDIA's planning decisions.

Senior NDIA officials told A4 the evidence-base for good/best practice early intervention for ASD is "contested". The matter has since been tested in the AAT (see [\[2019\] AATA 1478](#) and [\[2019\] AATA 1480](#)). The AAT decided ABA or EIBI is evidence-based or best practice early intervention for ASD: the matter is resolved but A4 see no discernible change in the NDIS since the AAT's decisions. Families still have appeal adverse NDIS planning decisions denying autistic child appropriate evidence-based early intervention.

¹ Most of these NDIS participants list Intellectual Disability as their primary disability, which is unusual. Reports from the field indicate that people believe they get a more appropriate NDIS plan if they list Intellectual Disability instead of autism/ASD as their primary disability.

The NDIS is engaged in some over-zealous self-promotion. We note the Discussion Paper says:

Overall satisfaction rates of those who have NDIS plans currently stands at 90%.

The disability sector has raised concerns about this claim on numerous occasions. We understand that this claim is based on data that the NDIS collects at the end of a planning session, before people see their new NDIS plan. People feel pressured to give a positive response or they may not get as good a plan. The government's persistent use of this deeply dodgy survey technique and this ongoing reporting show that the government clearly does not respect the concerns of people with disability and disability advocates in matters of reporting.

The Discussion Paper says:

The Government is committed to providing choice and control to NDIS participants, to create opportunity in the pursuit of their goals and the planning and delivery of their supports.

The Discussion Paper talks about “support [for] participants through review processes” when it should talk about people with disability. Applicants who were rejected may also need support through various review processes.

The Discussion Paper says:

Some participants have also expressed concerns about the consistency of high quality decisions being made by the NDIA.

Few participants are concerned about “high quality decisions”; instead, they are concerned about the plethora of *inferior* decisions that the NDIA makes. They are concerned that the NDIA makes many decisions that are contrary to the Section **3 Objects of Act** in the *NDIS Act 2013*.

As in the Discussion Paper, the NDIA and the government often refer to “continue[ing] to roll out improvements to better support NDIS participants, their families and carers”. Senior NDIA officials told A4 they have hundreds of projects underway. Remarkably, none of these are to benefit autistic participants, their families and carers since the NDIA has not consulted autism advocates or representatives about these projects. This is remarkable because it suggests the NDIA is making many changes but those changes are not relevant to autistic participants ... who are the biggest primary disability type in the NDIS. And the NDIS is not addressing the plethora of issues for autistic participant.

The Discussion Paper says:

the new Participant Pathway is progressively providing a single point of contact for participants, easier-to-read plans, and is ensuring that NDIA staff have appropriate training in, and understanding of, the diverse needs of people with disability.

The NDIS will need far more staff stability to achieve anything like “a single point of contact for participants”. Perhaps there are “easier-to-read plans” ... but we are a long way from easy-to-read plans.

Most critically for the ASD community, there is no discernible evidence “that NDIA staff have appropriate training in, and understanding of, the diverse needs of [autistic] people”. Reports from the field indicate there is no change since December 2017.

The Minister’s “creation of an interim plan of \$10,000 for children whose support needs are not categorised as complex and who have experienced delays (over 50 days from having an access decision to getting a plan) with the Early Childhood Early Intervention approach” is unclear. While A4 has received reports that some autistic children have benefitted, there is as yet no discernible process for a child’s family to activate such an interim plan. From our position, this appears to be another mostly empty promise.

The Discussion Paper says:

The NDIS Act and accompanying Rules govern the way in which the NDIA makes decisions, seeks information, and delivers on the aims of the NDIS. To help the NDIA further refine its processes to be more helpful and transparent to those working with the NDIS, the Government has committed to review the NDIS Act and NDIS Rules.

A4 has been unable to access “accompanying Rules”. We are aware that the NDIS has some descriptions of its [Operational Guidelines](#) on its website. Perhaps they are what was meant.

The NDIA changes its Operational Guidelines without consulting the ASD community, despite [a previous Minister promising](#) consultations before any changes are made.

The Discussion Paper says:

The Review of the NDIS Act will not change the design and intent of the NDIS. Rather, the Review is focussed on removing red tape and making the participant experience with the NDIS better.

A4 supports the original “intent of the NDIS”; however, the design and implementation need substantial improvement. And everyone, not just participants, need better experiences of the NDIS.

The original NDIS design provided Tiers 1 & 2, since renamed the ILC, which was meant to support people with disability who were not NDIS Tier 3 participants, as well as providing supports for other sections of the disability sector.

The Discussion Paper observes that “there are many approaches across business and government to ensure people get responsive and quality service”. The approaches that are actually successful *all* respect their clients. But this approach is missing completely in the NDIS. The NDIS completely distrusts participants and their motives.

Discussion Questions from the White Paper

Possible principles for NDIA service standards

1. *Which of the above principles do you think are important for the NDIA to adhere to, and why?*

All the principles listed are very important. The problem is that the NDIS is unable to deliver on these principles. In particular, for each of the principles:

Timely: currently, the NDIS fails to achieve many decisions and processes promptly or in a reasonable time, as the law requires.

Engaged: the NDIS meets with people and their representatives but it is not *engaged*. It simply ignores their input and their needs.

Expert: NDIS staff have no discernible training in ASD or in the support needs of autistic people. Participants observe NDIS staff showing major ignorance and frequent prejudice against autistic people.

Connected: the NDIS is seriously disconnected from the ASD community.

Valued: The NDIA and its staff do not value autistic people, their families, carers and other support persons. They systematically ignore the advice of expert clinicians. They regard autistic people, their families and carers as bludgers, leaners and scammers. The NDIA does not *respect* NDIS participants or their representatives.

Decisions on merit: NDIS staff lack the training, knowledge and experience to make decision relating to autistic participants on merit.

Accessible: The NDIS persists with eligibility criteria for ASD that remain gobbledygook. The NDIS refuses to change, to improve its eligibility criteria for autistic participants. Much of their information is incomplete and confusing – for example, they do not have a clear explanation of “reasonable and necessary”, a phrase which is central to the NDIS. The description given in this part of the Discussion Paper fails to recognise communication difficulties affect accessibility and are a key issue for the most NDIS participants.

The NDIS needs to change its entire culture. The government, both politicians and bureaucrats, need to respect people with disability, their families and carers. This will only be achieved through politicians who respect and understand the disability community, and who can deliver extremely strong leadership to the bureaucratic hierarchy.

The massive cultural change that is required is beyond the scope of this review.

2. *In your experience with the NDIA, do you think they fulfilled the above principles? If not, how are they falling short?*

No.

The comments above describe how politicians and the NDIA are falling short.

3. *What other key principles are important for the NDIA to follow, that could be included in a Participant Service Guarantee?*

Respect is crucial: perhaps it should be viewed separately from “valued”.

Recognition and understanding are also crucial.

Transparency, honesty and trustworthiness are important principles: the NDIA is a spectacularly secretive organisation which leaves everyone feeling that the NDIA cannot be trusted. It keeps much of its operation and procedures secret. It has hundreds of secret projects that never see the light of day. The NDIA prefers to have secret discussions with separate autism representatives. It keeps things like its *Typical Support Package* process extremely secret.

Sustainability is an important issue: the NDIA needs to properly publicise the long-term benefits of the NDIS for the whole community rather than focusing on its immediate impact of a budget surplus.

4. *One way to measure these principles is through a set of ‘Service Standards’. Some ideas for what these Service Standards could be are listed in Attachment A. Do you think these Service Standards are fitting? Are there other standards you believe should be included?*

Service standards have not been an especially successful approach to achieving outcomes for people with disability. Service standards are a bureaucratic device for avoiding measurement or achievement of outcomes.

For example, an engagement standard might require that the agency tick off that it met various representatives ... but generally there is no requirement to accept or act on any recommendations arising from any such meetings.

Similarly, A4 prefers that outcomes, rather than any adherence to abstract principles like these, are measured. We’d prefer to see better education, employment, independent living and substantially better health & mental health outcomes for autistic people rather than a completed checklist of vague principles.

5. *Do you have any ideas on how we can measure how well NDIA has delivered on each of the principles?*

As indicated above, in our response to Question 4, A4 would prefer that outcomes for autistic people in education, employment, independent living and health & mental health were measured and reported.

A4 is not really interested on how the NDIA delivers on *principles*.

Getting started: Eligibility and application

6. What are some of the significant challenges faced by NDIS participants in the access process?

A major challenge for autistic NDIS applicants (prospective participants) in the access process is in having their clinical diagnosis accepted by the NDIA. They have to get past the initial NDIS gatekeepers.

NDIS gatekeepers control access to the NDIS application form; you cannot download a form, you have to convince an NDIS gatekeeper to send you one.

NDIS gatekeepers have told autistic applicants that “the NDIS does not support autistic children” or “Level 1 autism is not eligible for the NDIS”. These statements are incorrect but no-the-less they prevent autistic people from accessing NDIS supports.

Part of the problem is that the NDIA’s eligibility criteria for autism have always been gobbledygook, and the NDIS refuses to fix them. The NDIA promised A4 that it would review/revise the eligibility criteria for autism but is still refuses to do so.

The NDIA is so resistant to stakeholder input that it refuses to change its website to refer to the DSM-5 rather than DSM-V.

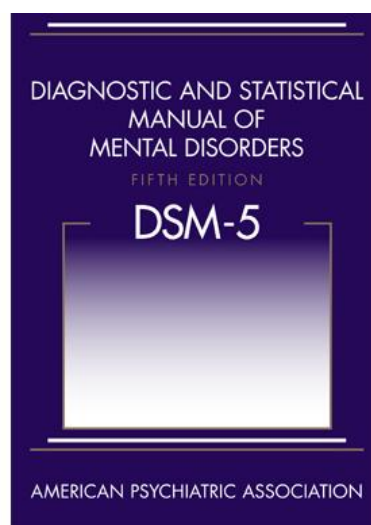
[The NDIS’s List A](#) says a person diagnosed with autism severity of Levels 2 or 3 via the “DSM-V” is “likely to meet the disability requirements in section 24 of the NDIS Act”. The NDIA has never been clear about

- What “likely” means or how it is resolved, and
- its eligibility criteria for older autistic applicants who don’t have a severity level as part of their pre-DSM-5 diagnosis.

Senior NDIS officials told A4 that their one severity rating referred to in List A is the larger of the two severity levels² that are given in a properly documented DSM-5 ASD diagnosis.

The DSM-5 states clearly that for ASD these severity ratings should *not* be used for resource allocation. Access to the NDIS is a resource allocation decision, so these severity ratings should not be used. The NDIA said it will stop using these severity ratings though there is no evidence that the NDIA has put this into practice.

The NDIA has instigated its own bureaucratic process for assessing eligibility for autistic applicants. There is no clear statement of how the NDIA decides eligibility for autistic applicants.



² The [DSM-5 diagnostic criteria for ASD](#) require separate severity ratings for Part A and part B of an ASD diagnosis, hence two severity ratings (not one, as the NDIS eligibility indicates) are required.

7. *The NDIS Act currently requires the NDIA to make a decision on an access request within 21 days from when the required evidence has been provided. How long do you think it should take for the NDIA to make an access decision?*

An NDIS applicant aged under 7 years with a valid ASD diagnosis should be accepted immediately (within 24 hours) as it should be possible to validate the diagnosis with the diagnostic service immediately. These children were all eligible for the national *Helping Children with Autism* package so they should have immediate access to the NDIS up to age 7 years under the NDIS's existing no disadvantage guarantee.

For older autistic children and adults, the NDIS should expect diagnosing clinicians to document whether the child meets the NDIS's eligibility criteria. Once this is done, the NDIS can verify the diagnosis within 24 hours and admit autistic participants immediately.

The NDIS often asks for additional reports. The resulting delay and expense are barriers to essential disability services. Autistic people and their families often cannot afford the apparently endless demand for further random reports. And the NDIS should indicate where invoices should be sent to the NDIS to pay for any additional reports that it requires.

8. *What do you think the NDIA could do to make it quicker or easier to access the NDIS?*

As indicated above, the NDIS should work with the ASD community to describe clear NDIS eligibility for autistic people. Then the NDIA should leave it to clinicians to decide eligibility in individual cases at the same time as diagnosis.

The NDIA needs to respect the clinicians and their advice/opinions.

Getting an ASD diagnosis is often a major challenge. Unless a family can afford to pay for private assessments, families first have to get a referral from a paediatrician (which can take months) then they have an 8-12 month wait for a specialist assessment from the services like those listed at <https://raisingchildren.net.au/autism/therapies-services/services/government-funded-asd-diagnosis>.

Often, families have to get a second opinion from a private service anyway.

Most of these services don't diagnose teenagers or adults.

9. *Does the NDIA provide enough information to people when they apply for access to the NDIS? If not, what else could they provide that would be helpful?*

No.

The NDIS eligibility criteria for autistic applicants are gobbledygook. People are given very little indication of what information the NDIA uses to make an eligibility decision.

And the existing NDIS gatekeepers don't know the current rules.

For children, especially under six years of age, a diagnosis should be enough information.

10. Is the NDIA being transparent and clear when they make decisions about people's access to the NDIS? What could the NDIA do to be more open and clear in their decisions?

No. And the NDIS could at least attempt to be open and honest about how it works and why its decisions are often so poor.

The NDIS need clear eligibility criteria; the gobbledygook that is currently used for autism eligibility is a major problem, not just for NDIS applicants but also for its own staff who need to interpret its "rules".

The NDIS needs to trust clinicians rather than requiring its own bureaucrats to make decisions that they are simply not qualified to make.

Planning processes 1: Creating your (first) plan

In relation to creating your (first) NDIS plan, the Discussion Paper says the participant needs to understand current supports and prepare for planning. This really relates to the transition from the previous system to the NDIS as the primary disability supports. Once the full roll-out is achieved, NDIS intake will be newly recognised participants who *do not have* "current supports" in a formal sense.

From now on, the process for an initial NDIS Plan will be about articulating goals, aspirations and expected outcomes, then agreeing on how those goals can be achieved. This all comes together in an appropriate and approved NDIS plan ... with funding.

Before the NDIS, the family of a child diagnosed with ASD was advised to contact an Autism Advisor. The advisor told them about the various support options available for their child in their area and helped them access the *Helping Children with Autism* package.

The NDIS shut down, or is shutting down, the Autism Advisor service. Young children, aged under six or seven years, may now be referred to an NDIS ECEI Partner who tries to get the child into their own service model, whether or not it is appropriate for autistic children. Other options that may be more appropriate, that may be evidence-based or best practice for autistic children, are rarely discussed; these Partners may even actively discourage the family from seeking comprehensive or impartial advice.

The current system of NDIS ECEI Partners brings massive conflicts of interest; a problem that was largely avoided with the previous Autism Advisor approach where the advisors were required to be separate from (independent of) autism service providers.

NDIS ECEI Partner often omit to mention supports like Carer Allowance (child) to families of autistic children.

10. What are some of the significant challenges faced by NDIS participants in the planning process?

The biggest challenge than an autistic NDIS participant faces in the NDIS planning process is the ignorance of and prejudice against autism among NDIS planners and their supervisors.

The NDIS continues using inappropriate tools for assessing support needs of autistic participant, e.g. planners still use PEDI-CAT assessments even when they admit the assessment results are completely wrong for the autistic participant being assessed.

An example of the significant challenges NDIS planners or LACs tell many families of autistic children that the NDIS will not fund Applied Behaviour Analysis (ABA) for their autistic child. Note that the government advises that ABA, also known as early intensive behavioural intervention (EIBI), is the *only* early intervention for ASD rated as “evidence-based” (see <https://www.dss.gov.au/our-responsibilities/disability-and-carers/program-services/for-people-with-disability/early-intervention-for-children-with-autism-spectrum-disorders-guidelines-for-good-practice-2012>) but the NDIA rejects this advice. In its recent decisions on this issue against the NDIS (see [\[2019\] AATA 1478](#) and [\[2019\] AATA 1480](#)) the AAT found:

- a) your mum needs to be an experienced lawyer to get a successful hearing in the AAT,
- b) the NDIS does not offer participants choice and control,
- c) the NDIA planners and decision reviewers largely ignore the family, and
- d) the NDIA’s preferred keyworker model of early intervention is not evidence based for autistic children.

Many families of young autistic children are extremely challenged by having to take legal action against the NDIA, a government agency, to address their child’s disability needs.

Bureaucrats are often unable to develop meaningful plans, for example they cost services in participants’ plans at the lowest item in the price guide rather than a realistic cost for the skills needed to deliver the required service.

11. Are there stages of the planning process that don’t work well? If so, how could they be better?

Often, the whole planning process fails autistic NDIS participants because NDIS planners a) do not understand autism, b) ignore advice about autism, and c) dismiss the participants goals.

Often, planners still use the PEDI-CAT to try and assess participant functioning even though the NDIS has been told repeatedly that the PEDI-CAT is very inappropriate for autism. NDIS planners often find that the PEDI-CAT rates autistic children with mild or even non-existent disability when it is very clear to everyone that the child is severely disabled.

Planning works better when planners take and respect advice from participants, clinicians and family (informal carers) in relation to the needs of

autistic NDIS participants ... and when they lose their prejudices about autistic participants.

The NDIS planning process converts goals into standard NDIS bureaucratic categories, then it describes funding for supports in its bureaucratic terms. The result is confusing for NDIS staff and participants alike.

Currently, the process encourages people to squeeze as much service from their plan dollars as possible. The NDIS's focus on dollars distracts from achieving goals and outcomes.

It would be better to have NDIS plans describe the supports that will be provided to address participant goals and meet participants' needs. For example, if a participant wants therapy to improve skills and deliver a goal outcome, then the plan should say how much of what amount and type of therapy will be provided; the plan should not be expressed in "dollars for capacity building".

The cost details are between the provider and the NDIS. Participants need to focus on goals, supports and outcomes. They should not focus on money.

Participants need access to independent advice and assistance in developing appropriate and effective goals. NDIS planning is a new process and many people do not properly understand how good goals can work for everyone's benefit.

Forward planning needs to be based on achievement of goals. Currently, there is no discernible measurement and reporting of whether a participant's individual goals are addressed or met.

Reports from NDIS participants indicate that the NDIS's *Typical Support Package* (TSP) mechanism is seriously flawed. It is very clear that it is based on gross misunderstandings of the autism spectrum and the effects of comorbid conditions.

Better NDIS outcomes need fundamental culture change. The NDIS has a culture that sees every participant is trying to rot the system. Many NDIS staff and partners do not see their role as helping. Instead, too many see themselves as gatekeepers protecting government coffers from the utterly unreasonable demands of autistic participants (who they regard as not really disabled).

12. How long do you think the planning process should take? What can the NDIA do to make this quicker, remembering that they must have all the information they need to make a good decision?

The answer is "as long as it needs".

In the above, we suggested that planning should address goals, not bureaucratically convenient funding categories. This approach would allow planning for different goals to proceed at different rates. Some goals may be easy to plan for and some may require more effort or a flexible plan. Some goals could be addressed in a plan almost immediately, but others may require better information and understanding, so they may take longer. It may involve a more relevant planner be involved.

There should be a limit of a month or so for arriving at all goals.

Note that Subsection 47(3) current imposes a universal 7-day limit.

The Government and the NDIS need to recognise that as yet we don't have all the answers for supporting autistic adults or unusual presentations of disability. In some instances, the plan will be to try different supports to see what does or might work.

13. Is the NDIA giving people enough, and the right type of information, to help them prepare for their planning meetings? If not, what else could they provide?

No. Nothing like it.

The pre-NDIS *Helping Children with Autism* package provided impartial Autism Advisors who provided comprehensive and accurate information about early intervention and, to a lesser extent, school-age supports.

Autism Advisors were not funded to help develop individualised goals but their support for autistic families was highly regarded.

This type of information is no longer available except for the dying twitches of the Government's old Autism Advisor program.

The Government, but not the NDIS, need to provide unified information, advice and advocacy services for autistic Australians and their families. Currently, the NDIS is shutting down the Autism Advisor service and DSS's National Disability Advocacy Program has no advocacy service for autistic people even though autism is the biggest primary disability type in the NDIS.

14. Is the NDIA being responsive and transparent when making decisions in participants' plans? If not, how could this be improved?

No.

NDIA planners often ignore clinical and expert advice. In relation to autism, planners often feel they know more than autistic participants, informal carers and clinicians.

Participants do not know the qualifications of their planners, or what training, knowledge and experience they have with autism. It is often clear to participants and their associates that NDIS planners have very poor understanding of ASD.

The planning process is opaque:

- the role of delegates and the operation of the planning approval process seems to vary at the whim of any NDIS staff involved, and
- the existence and operation of the TSP is shrouded in secrecy.

15. If you have been in the NDIS for more than one year, is it easier to make a plan now than when you first started? What has the NDIA improved? What still needs to improve?

Sometimes.

For most people, experience with the NDIS brings better/increasing understanding.

However, many people find the NDIS cuts subsequent plans for no real reason. Reduced plans are harder to use, and especially difficult to use effectively.

Planning processes 2: Using and reviewing plans

Data from the NDIS, see page 43 of [the NDIS outcomes report for ASD](#), shows NDIS participants have trouble using their NDIS plan; on average, people use less than 80% of their allocated support funding. This is a real problem when participant goals are already underfunded.

Participants experience difficulty for two reasons. First, because services don't exist. Second, because plan management focuses on funds instead of achieving goals and outcomes.

The NDIS culture is very conservative: it opposes and prevents innovation and creativity.

Items in plans are funded at minimum funding levels. This is unrealistic. Often, a minimum cost service cannot address or meet the needs of a participant who needs something more than the most basic service.

NDIS internal reviews are essentially pointless: mostly, they simply justify the NDIS's original decision.

16. What are some of the significant challenges faced by NDIS participants in using the supports in their plan?

The NDIS structures the funding it provides into its own categories. These categories do not relate directly to a participant's goals so participants face the challenge of re-interpreting funding categories back to the original goals. The challenge is exacerbated by concern that using funds will almost certainly lead to some form of future robo-debt.

Underfunding of goals is a "significant challenge". Participant cannot achieve their goals or use their NDIS plan effectively if their goals are under-funded. There is no meaningful advice on whether it is better to use up your funding then pay for the remainder of your support needs yourself.

NDIS plans are often hard to understand; they are written using NDIS jargon. They are not written in the language of the participant or of service providers. They are often unclear, appear inflexible and confusing.

In many cases, the services people need simply do not exist. This is particularly a problem around distressed behaviour (often called challenging or unwanted behaviour) for autistic people.

NDIS ideology often gets in the way of achieving a participant's goals.

17. Is the NDIA giving people enough, and the right type of information, to help them use their plan? If not, what other information could the NDIA provide?

No.

Participants use less than 80% of their plan (see above) because they are told what they cannot do but there is very little relevant information about what they can do.

LACs, call centre staff, support coordinators, etc. often give wrong and inconsistent advice which prevents people from getting the supports and services they need. The Facebook group, NDIS Grassroots Discussion, has over 48,700 members using the group for information because information from the NDIS itself is so unsatisfactory.

For example, information about funding for swimming lessons is inconsistent. Autistic children have a much higher risk of drowning than other children. Many autistic children simply do not learn to swim in mainstream swimming classes so it's not surprising families ask "does the NDIS cover individual or ASD-specific swimming classes?" However, the response you get from the NDIS is pretty random: sometimes "yes", sometimes "absolutely not" and sometimes "the NDIS will cover the cost difference from mainstream swimming classes". The NDIS seems to completely lack any proper process for dealing with this ... so families have to go to the AAT to get it resolved. It doesn't matter how often the NDIS has to pay the full cost of specialist swimming instruction after AAT conciliation, the arbitrary initial decisions keep coming ... and only the most determined participants progress to a more mature discussion before the AAT.

Other issues where NDIS advice is inconsistent, and often wrong, include out-of-school care, respite, behaviour supports, etc.

Generally, NDIS staff advising participants simply don't understand autism and the relevance or appropriateness of different types of support for autistic participants.

The NDIS resists having clear policy on such issues. The exiting situation is unworkable for autistic NDIS participants.

18. What other advice, resources or support could the NDIA provide to help participants to use their plan and find supports?

The NDIS could provide correct information. And it could be consistent and helpful.

As we mentioned previously, autistic participants need access to independent, comprehensive and accurate services providing advice, information and advocacy. The NDIS is shutting down the Autism Advisor service so an essential the knowledge base has largely dissipated already.

19. What are some of the significant challenges faced by NDIS participants in having their plan reviewed (by planned or unplanned review)?

The reviewers, like the planners, would do a better job if they understood disability, and the specific disabilities of the person whose plan they review.

20. What can the NDIA do to make this process easier or more effective?

Respect the advice of specialist clinicians. Recognise the limitations of bureaucrats.

The NDIA, with its current culture, cannot review plans effectively.

21. How long do you think plan reviews should take?

The NDIA cannot do the job. No matter what time they are given they cannot review plans they developed appropriately.

If this has to be part of the process, then give them a day ... a week at the absolute most. If that doesn't deliver the required plan, then the review needs to go to an external agency.

The time wasted is especially critical for autistic children who are delayed accessing essential early intervention.

Appealing a decision by the NDIA

22. What are some of the significant challenges faced by NDIS participants when they seek a review of an NDIA decision?

The most significant challenge is to find NDIS staff willing to support people with disability. The media is full of ridiculous examples of NDIA inappropriate decisions.

23. Are there other issues or challenges you have identified with the internal and external review process?

The process is to first ask for an internal review. The internal review process is about a) inflicting as much delay as possible, and then b) justifying the original decision. It is not about conducting a review.

Then people have to challenge a government agency in a full-on adversarial legal process in the AAT. Many autistic people and their families are unwilling to do this.

Often they cannot get legal aid. Autistic people and the families cannot afford to pay for legal counsel, and few of them are able to mount their own legal challenge.

24. How could the NDIA improve the decision review process?

A4 doubts “the NDIA [can] improve the decision review process”. It is up to politicians, DSS and disability advocates to improve the review processes.

People with disability need their rights protected. Australia needs laws that protect the rights of people with disability. The international community agrees (through the UN Committee on the Rights of Persons with Disability, see [Concluding Observations](#)) even if they ignore autistic Australians (see <http://a4.org.au/node/2116>).

25. How long do you think reviews of decisions should take?

The review process for young children should not take more than a month.

Similarly, urgent matters need to be addressed quickly.

No disability-related review process should take more than 3 months.

The legislative framework

26. Do you think there are parts of the NDIS Act and the Rules that are not working or make things harder for people interacting with the NDIS?

A4 has not found “the Rules” so we can’t comment. Are these the Operational Guidelines?

If there are rules, they don’t really help. NDIS decisions are quite arbitrary so if there are rules, they are not working.

27. What changes could be made to the legislation (if any) to:

- a. Improve the way participants and providers interact with the Scheme?*
- b. Improve the access request process?*
- c. Improve the participant planning and assessment process?*
- d. Better define ‘reasonable and necessary’ supports?*
- e. Improve the plan review process?*
- f. Improve the internal merit review process?*
- g. Improve the way other government services interact with the Scheme?*

We wrote about a-f above.

In relation to Q27 (f), A4 is not aware that other government services interact with the NDIS.

Plan amendments

28. What are the significant challenges faced by NDIS participants in changing their plan?

Few NDIS participants are aware that they can change aspects of their plan. Generally, they don't know that they should write their own goals, and change their goals at any time (see Section 47 of the *NDIS Act 2013*). They don't know that the NDIS is required to provide a new plan within 7 days.

29. How do you think a 'plan amendment' could improve the experience for participants? Are there ways in which this would make things harder or more complicated for people?

A4 cannot see that a "plan amendment" process would be significantly different from getting a new plan with a few changes from a previous plan. The mechanism does not seem important to participants.

30. How long should people have to provide evidence that they need the changes they are requesting in a plan amendment?

They should get as much time as they need.

Typically, the problem is that the NDIS asks for excessive amounts of "evidence" and expects the participant to fund disability-related assessments that they can't afford.

31. Are there other situations during the planning cycle where a quicker and easier way to make changes may be necessary?

Many NDIS participants have emergency and crisis situations arise. The NDIS needs a mechanism for dealing with this.

In many instances, these crises are known to be likely events, but are not addressed in the participant's plan. This is unsatisfactory.

For a young autistic child, 12 months can be a long plan, especially for an initial plan. Plans for young autistic children usually need to be particularly flexible.

32. How else could the NDIA improve the process for making changes to a plan?

NDIA officials need to respect participants, their carers and clinicians. They need to actually listen to requests, rather than listen so they can justify their previous decisions.

Responding to Terms of Reference

The terms of reference for the review say:

The review is to consider:

1. opportunities to amend the NDIS Act to:
 - a. remove process impediments and increase the efficiency of the Scheme's administration; and
 - b. implement a new NDIS Participant Service Guarantee.
2. any other matter relevant to the general operation of the NDIS Act in supporting positive participant and provider experiences.

A4 urges this review to focus on describing a new and appropriate NDIS Participant Service Guarantee and other approaches to “supporting positive participant and provider experiences”.

However, the Government needs to focus on getting the NDIS to comply with existing law. *Attachment B: Current timeframes for CEO and NDIA decisions* in the Discussion Paper lists existing time limits but A4 is not aware that the NDIS reports compliance with the existing constraints. The NDIS needs to report regularly and clearly on each of these time constraints.

The existing *NDIS Act 2013* has places where the NDIS is allowed to do things in a “reasonable” time, for example Subsection 48 (3). Currently, the NDIS regards 6-12 months for an internal review of a participant plan involving “early intervention” for a young child is “reasonable”. Only the NDIS and this Government regard such delay is accessing urgent and essential services as a “reasonably practicable” timeframe for such a review.

The NDIA is already more focused on “the efficiency of the Scheme’s administration” and on keeping the Scheme within budget. The latest NDIA Quarterly Reports has a whole section, Section 5.1, on “Delivering within budget” but does not report how well participants’ goals are met. In fact the NDIS has been so far within budget that it has taken billions of dollars that people with disability need and transfer them to the Government’s surplus.

Politicians keeps saying that NDIS funding is uncapped yet we see constant and excessive cost cutting and massive underspends. The NDIS legislation is not clear to A4 about NDIS funding.

The autism community observes a growing list of broken political and bureaucratic promises. The following list relates to the NDIS.

- The NDIS was introduced with a commitment that “no one with disability would be worse off with the NDIS” ... but many autistic Australians no longer have access to services that were available before the NDIS ...
 - the Autism Advisor service, part of HCWA, has or is being cut (it was cut in the ACT a long time ago),
 - the NDIS excludes some children who were eligible for HCWA funding leaving ineligible children with no early intervention.

- The Government's commitment to engage with the ASD community over all changes to operational guidelines didn't last a week: see <http://a4.org.au/node/1795>
- On several occasions, senior NDIS staff committed to review NDIS eligibility criteria for autistic Australians ... but so far the NDIS has made no effort to improve the gobbledygook that currently describes NDIS eligibility for ASD.
- Despite persistent advice from numerous sources the PEDI-CAT is inappropriate for assessing autistic participants, the NDIS still relies heavily PEDI-CAT ... and NDIS bureaucrats routinely overrule or ignore clinical advice,
- the NDIS's super-secret *Typical Support Package* process is not appropriate for autistic participants since it does not recognise the *spectrum* nature of ASD.
- The Government and the NDIS created an Autism Advisory Group but 18 months later there has been no discernible progress on issues raised
- The NDIS bangs on about creating a complex support needs pathway yet there is no sign of any difference.

The ASD community is extremely sceptical of any talk about an NDIS Participant Service Guarantee: a guarantee will only work if it imposes serious penalties for senior NDIS bureaucrats.

Any other matters

The concept of "reasonable and necessary" is central to the NDIS legislation. However, there is no functional definition of the term and NDIS staff impose completely arbitrary decisions on NDIS participants.

The NDIS is challenged by the lack of a good evidence base for its design and operation. Australia needs a comprehensive research scheme for its disability sector.

Attachment B of the Discussion Paper gives a list of the various timeframes in the NDIS Act 2013. The NDIS should report comprehensively and regularly on its performance against *all* of these timeframes.

Annex A. NDIS pathways for autistic Australians

An ASD diagnosis recognises that the person with the diagnosis needs support in at least two areas. Most autistic people have other support needs as well as those identified in their diagnosis.

People who do not need support in two specific areas (communication & behaviour) do not meet the diagnostic criteria for ASD; they are not autistic. ASD is not about being different: the diagnostic criteria clearly require that autistic people need supports to live their lives.

Autistic Australians can apply to the NDIS to become an NDIS participant in order to get the support they need.

There are two outcomes from an NDIS application.

- 1) The NDIS accepts the person who then gets an NDIS Plan.
- 2) The NDIS rejects the application leaving the applicant with little or no support for their ASD.

The figure below shows the pattern of support that the NDIS provides. The message is that skimping in the early years delivers higher long-term cost. The average cost for an autistic person who is an NDIS participant, to age 65 years, is \$5,974,975 in 2019 dollars. This means that it would be economic to spend about \$600,000 per child on early intervention that reduces average support costs by at least 10%. By comparison, the current average cost of NDIS plans for autistic children aged 0-6 years that include early intervention for ASD is \$17,613 p.a. ... which is clearly sub-optimal.

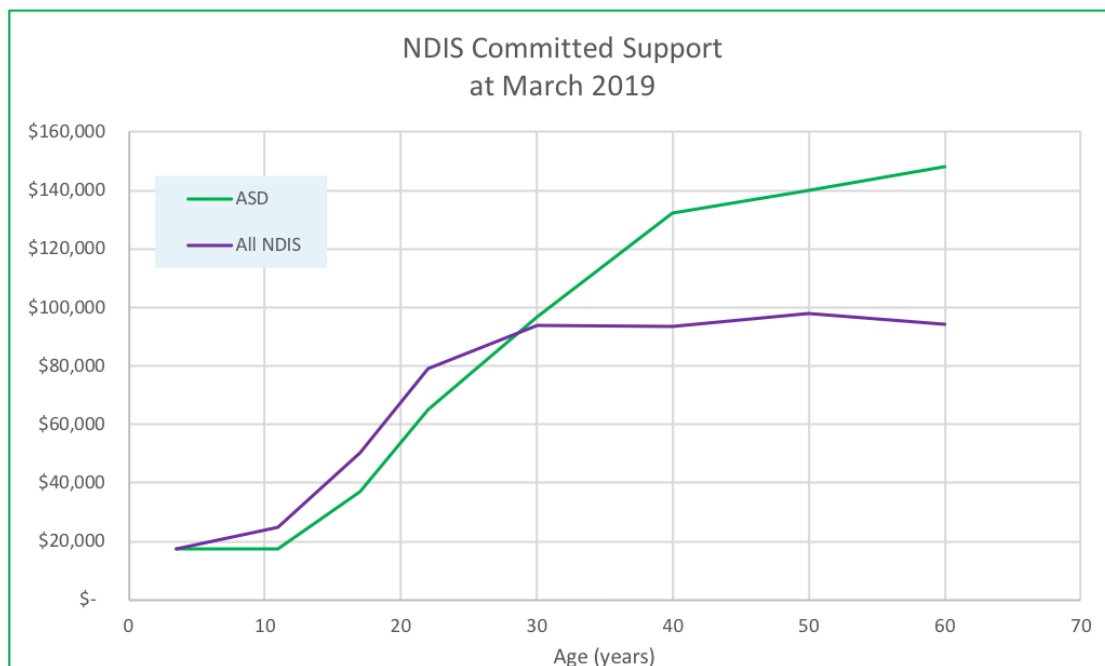


Figure 1. NDIS plans costs, autism vs other

Autistic people who are not accepted as NDIS participants are meant to get support from mainstream services. Schools, health services, employment services, etc. are supposed to accommodate people with disability. However, data the evidence shows these services fail autistic Australians.

The NDIS is meant to provide some support via its ILC program, but as yet there is very little support for autistic Australians who are not NDIS participants via the ILC or any other disability support provision.

Annex B. Early Intervention for young autistic children

The NDIS created its ECEI Approach which is inappropriate for young autistic children. The pathway for autistic children to evidence-based early intervention is complex and only via an AAT plan review. Many autistic children miss out on essential early intervention because few families will challenge a Government agency in the legal system.

The following figure shows the pathway for families who access evidence-based early intervention for an autistic child. This is not an acceptable pathway.

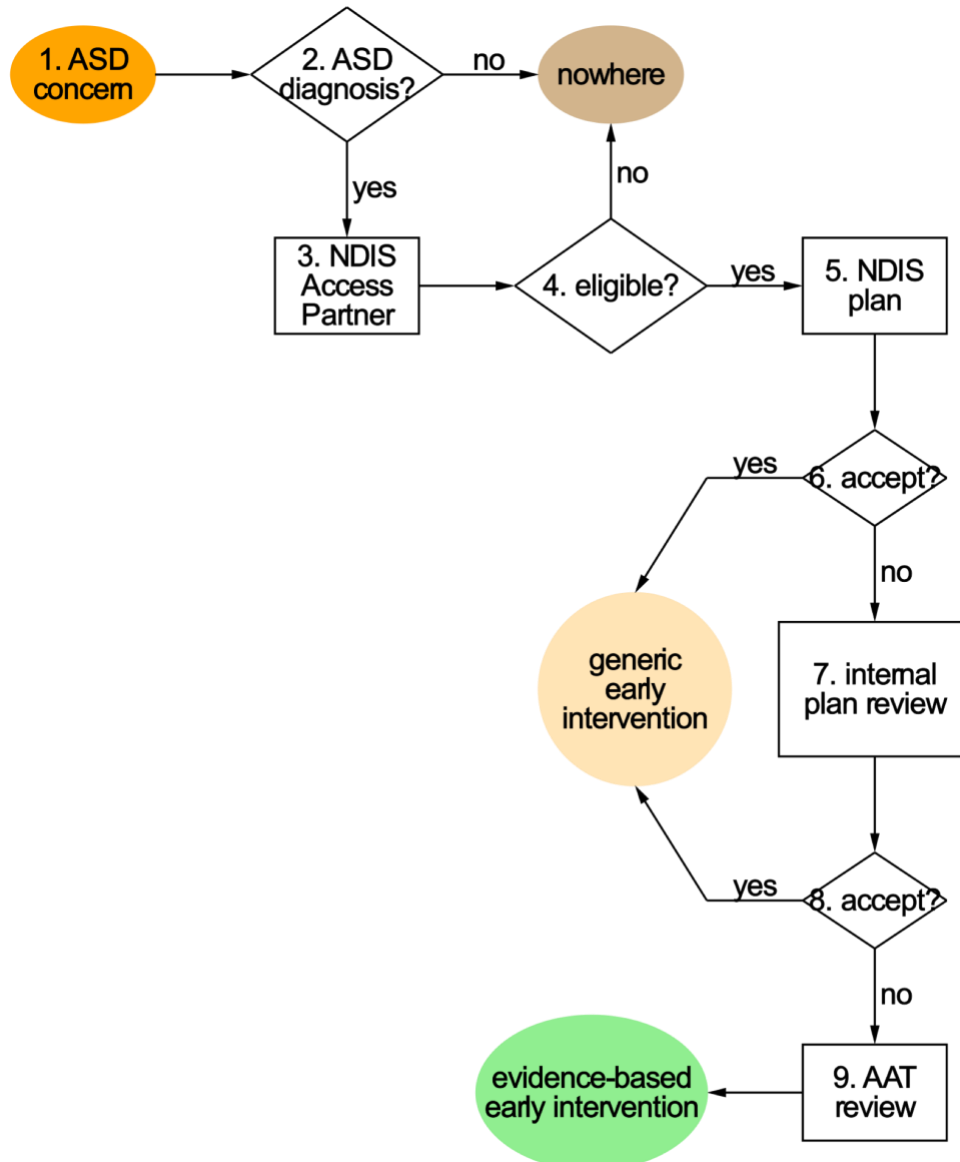


Figure 2. NDIS early intervention pathway for autistic children