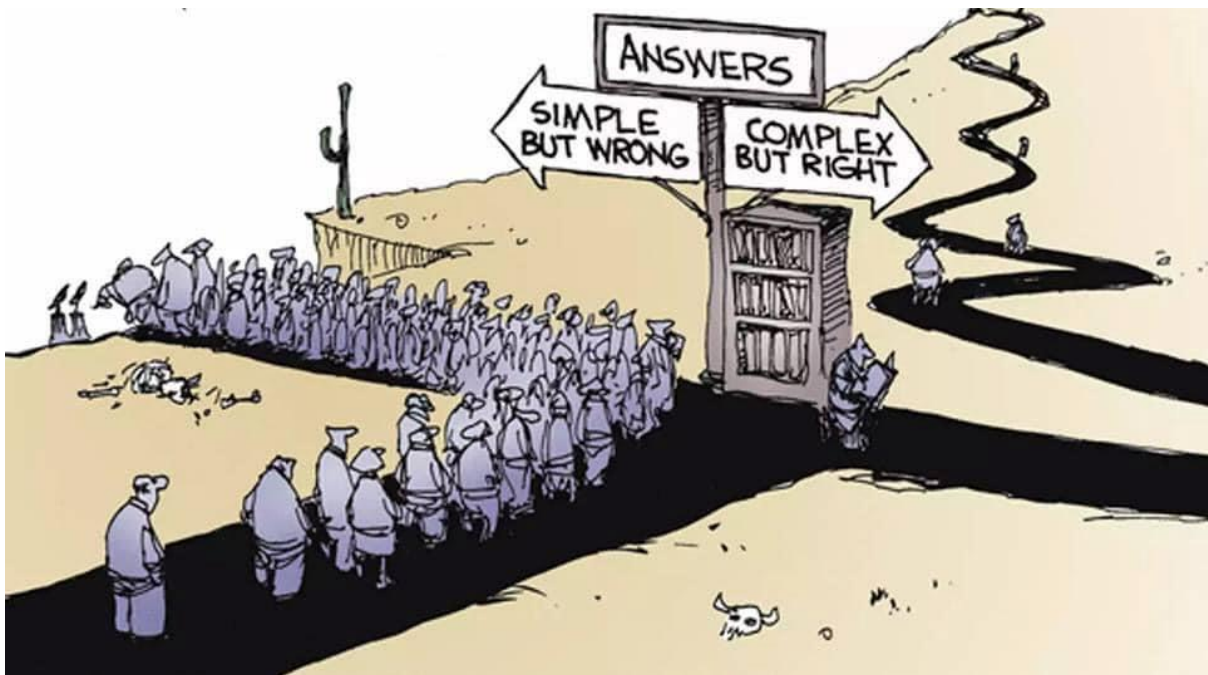




Autism Aspergers Advocacy Australia

A Submission to
the Joint Standing Committee on the National
Disability Insurance Scheme inquiry
into
the Capability and Culture of the NDIA.
from Autism Aspergers Advocacy Australia



Hanlon's Razor - "Never assume malice when incompetence will suffice as an explanation".

Fred Clarke's Law - "Sufficiently advanced incompetence is indistinguishable from malice" especially when becoming that ignorant results from malicious intent.

The following submission is for the [Joint Standing Committee on the National Disability Insurance Scheme](#) inquiry into the [Capability and Culture of the NDIA](#). A4's submission focuses on the National Disability Insurance Agency's (NDIA's) approach to supporting autistic NDIS participants.

[Autism Aspergers Advocacy Australian](#), known as A4, is:

- the autism-related Disability Representative Organisation (DRO) listed on the [Department of Social Security's \(DSS's\) DRO webpage](#);
- a member of the [Australian Federation of Disability Organisations](#) (AFDO) & the Disability Australia Consortium; and
- a member of the [Australian Autism Alliance](#).

The NDIA has a very poor culture in relation to community engagement generally. A clear and simple example of especially poor culture is how the NDIA runs its so-called Independent Advisory Council (IAC). A particular example is advice relating to the so-called Independent Assessments (IAs).

1. The advice that the IAC provided was that the IAC approved of the so-called Independent Assessments as long as the NDIS made some adjustments to their operation. This advice was contrary to the views of the disability sector – clearly, the IAC's advice was not aligned with the sector on this major issue. This is a major failing for the IAC
2. Neither the NDIA nor the IAC acknowledge this major failure. Neither of them has sought subsequently to re-build the IAC's credibility.

The so-called Independent Assessments were particularly heinous in relation to autistic NDIS participants. After ignoring our concerns, the NDIA CEO wrote to participants claiming IAs would be conducted "The [assessment] tools have been designed to assess the capability of people with disability and used all over the world for many years". A4 pointed out that this simply is not true in relation to autistic people: there are no disability assessment tools that are "used all over the world" to assess autistic people. Assessing autistic people with inappropriate assessment tools has very poor outcomes. The NDIA did not respond – apparently, their culture is to ignore sector concerns like this. The CEO's letter and A4's questions are at <https://a4.org.au/node/2247>.

Simply, the NDIA's approach to autistic NDIS participants is unacceptable. While we cannot discern reasons for the NDIA's culture and lack of capability, we can discuss its effect on the implementation, performance, governance, administration, and expenditure of the NDIS in the submission below.

From the start of the NDIS, everyone, the Productivity Commission, state/territory Disability Agencies, and the NDIA, underestimated the number of autistic NDIS participants at full NDIS roll-out ... and beyond. The autism sector warned everyone we could that their estimates of autistic NDIS participant numbers were wrong. For some reason, those involved in planning and implementing the NDIS chose to ignore the voices of the autism sector.

The practice of ignoring the autism sector is ongoing. Continued ignoring of the autism sector is damaging for Autistic Australians, the disability sector, the economy and the nation generally.

- Ignoring autistic Australians and their needs leads to poor outcomes including substantially increased support needs.

- Increased support needs are met through either Informal Supports (usually parents, partners and/or siblings) having reduced economic participation and quality of life, or formal supports that need to be funded.
- Increased provision of basic support is less progressive for the economy than more progressive disability outcomes like increased disability employment. Basic supports are sub-optimal in terms of social and economic participation outcomes for people with disability, especially autistic people.
- Community wellbeing improves through a more progressive and economically productive disability sector

Initially, the Productivity Commission, states/territory governments, and the NDIA expected 9-11% of NDIS participants would register with autism as their primary disability. And they expected numbers would be stable. Data from the Australian Bureau of Statistics, and Carer Allowance (child) data, showed:

- a. Substantially higher diagnosis rates for autism among Australian children; and
- b. Increasing numbers of autism diagnoses.

By 2018, the pattern in the NDIS was relatively clear. On 1/6/2018, the NDIA told the Senate Community Affairs Legislation Committee in a Senate Estimates hearing:

Senator WATT: Does the NDIA have concerns about the number of people with autism entering the scheme?

Mr De Luca: Does it have any concerns with it? Our focus is to make sure that those eligible for the scheme get into the scheme. At the moment, 29 per cent of our active participants have a primary disability of autism. The Productivity Commission's expectation at full scheme was around 20 per cent. So it's not materially different to what the Productivity Commission's expectations were.

Senator WATT: I would have thought 10 per cent is a pretty big—

Mr De Luca: Yes, and the slight difference is that ...

The NDIA CEO (at the time) went on to claim that estimates of the NDIS having 20% autistic participants in 2020 are “the best estimates that exist”. We dispute that they were the best estimates for autism at the time.

Anyway, the estimate/expectation that autism in the NDIS would decrease from 29% to 20% was very wrong. The numbers of autistic NDIS participants continued to increase and was 34% of NDIS participants in June 2022. Most autistic NDIS participants are under 25 years of age which is different from most other disability types¹.

The NDIA has not made its latest estimates clear, beyond telling recent NDIS Ministers that the NDIA now feels autism is a major risk to NDIS sustainability. It seems that the NDIA lacks the capacity and capability to engage with the autism sector about:

1. what is the precise nature of the risk that autism poses for the NDIS's future,
2. whether aspects of the risk can be avoided, and
3. how best to address and possibly minimise or reduce risk associated with autistic Australians.

¹ NDIS participants with Developmental Delay or Global Developmental Delay have an even more extreme age profile in the NDIS.

Clearly, the NDIA did not plan for this number of autistic NDIS participants. There are no discernible attempts to assess/measure the preparedness and skill of:

1. NDIA planners to meet the needs of this unexpected participant profile;
2. The disability services workforce to meet the needs of the greater than expected numbers of young autistic NDIS participants;
3. LAC, support coordinators and plan managers to help autistic NDIS participants and their Informal Supports to find and access the supports they need; and
4. The disability sector to ensure disability services for autistic Australians are provided at an acceptable quality and quantity.

The Government's war on autistic Australians is documented on A4's website:

- [Coalition government's ongoing war on autistic Australians](#)
- [unanswered question about the Government's war on autistic Australians](#)
- [Dear PM - the Government's war on autistic Australians](#)
- [Government agency accused of being 'at war with those it should be supporting' as appeals against NDIS cuts spike](#)
- [Home Affairs targeting autistics](#)

Add to this the NDIA:

- recently omitted evidence-based early intervention services for autistic children from its price list (subsequently corrected, remarkably, appearing now under the 'other' category).
- Acting CEO exaggerated claims that autistic participants mostly make excessive requests for support.
- Prefers to fund cheap early intervention that is usually ineffective² for autistic children.
- Excludes autism representative from its so-called [Independent Advisory Council](#) (IAC)
- The NDIA has an ineffective [Autism Advisory Group](#) (AAG)³

NDIA culture strongly opposes evidence-based early intervention for autistic children. Informed families of young autistic children seek evidence-based early intervention. Unfortunately, expert reports suggest only one approach is considered "evidence-based". The clearest description is available on the DSS website: see ???, especially the Table at ???

As mentioned in letters to the NDIA CEO and the Prime Minister (see above), NDIS officials have told families that "the NDIS does not fund ABA". Autism representatives have sought to discuss policy and programs with the NDIA but were refused.

Some families do not want evidence-based early intervention for their children, they want alternative approaches ... or they may have tried evidence-based methods and found they do not work or do not suit their child. Most of these families get much of the support they request (because it is cheaper and considered affordable).

But the NDIS is meant to be about choice and control. And evidence-based practice clearly meets s 34 of the *NDIS Act 2013*.

The only conclusion is that the NDIA has a strong cultural (and unlawful) opposition to supporting evidence-based early intervention for autistic children. One provider of evidence-

² hence *not* value for money.

³ that was meant to meet and publish a communique after each meeting – there are two communiques on the webpage: July 2018 and August 2019. The IAC doesn't even refer to the AAG.

based early intervention has observed that all their clients were given NDIS Plans with insufficient support for early intervention. Of those who took the matter to AAT review, 100% got settlements without going to hearing. The settlement fully funded early intervention, so the NDIA's practice of forcing autistic children to AAT review only delays their access to (and diminishes the effectiveness) of early intervention for autistic children.

This practice of denying or delaying access for autistic children who are NDIS participants and whose family wants evidence-based early intervention is unconscionable conduct.

A4 is very concerned that the NDIA has not taken sufficient steps to ensure sufficient workforce capability and capacity to address the growing needs of its expanding numbers of autistic NDIS participants.

A4 is also concerned that rather than recognise and appreciate "the estimated annual replacement value of all unpaid care in Australia has risen to \$77.9 billion", much of which replaces care that would otherwise need to be funded via the NDIS – see <https://www.carersaustralia.com.au/replacement-value-of-unpaid-care-in-australia-rises-to-77-9-billion-per-year/> - report <https://www.carersaustralia.com.au/wp-content/uploads/2020/07/FINAL-Value-of-Informal-Care-22-May-2020-No-CIC.pdf> Instead, the NDIA's culture is to expect Informal Supports are likely to attempt to rort the system, that they are untrustworthy. Of course, this is rarely the case, and much of the fraud come from the formal and funded service providers.

The NDIA's culture, in how it treats Informal Supports, is despicable and counter-productive.

There is a lot more A4 could say but time is limited to deliver this submission.

Annex A: AAT 2019/5857 – NDIS review example/case study

Mr Hill submitted his *Application for Review of Decision* with the Administrative Appeals Tribunal (AAT) on 18/9/2019. Most of this matter was settled under s 42D with a new NDIS Plan for the Applicant on 10/5/2021.

The remaining issue to be decided is the transport provisions to be included in the Applicant's NDIS Plan. The Respondent made three settlement offers:

- a. The 40km per day offer that appears in the Respondent's Statement(s) of Facts, Issues and Contentions 19/7/2021 at rates of \$0.68/km to \$0.72/km. In para. 21, the Respondent says "the Federal Court decision in *McGarrigle v NDIA* [2017] FCA 308, the Respondent accepts that, once the Tribunal determines the level of transport support that is a reasonable and necessary support for the Applicant, the Respondent is required to fully fund that support"⁴ but rejects the evidenced⁵ level of transport provided.
- b. The Respondent made a without prejudice offer (27/1/2021), and further clarified its offer in a letter (lawyer's ref. MEW:NDI001-00347 on 12/2/2021). The offer proposed unnecessary and unreasonable restrictive practices for the Applicant.
- c. The latest open offer (25/8/2022), replacing previous offers, is funding for 72km per day of driving at "standard vehicle" rates.

The Applicant does not accept any of these offers. The Applicant rejected the latest offer since the Respondent's calculation underestimate the average daily driving and the distances driven in the Informal Supports' cars (see below) and ignores the Applicant's need for a modified vehicle.

Following is a list of issues with the Respondent's case and conduct in this matter.

1. The NDIA obtained an expert witness report based on the *incorrect premise* that there was no reduction in driving when the Applicant's supports transitioned from centre-based to home-based day program. The record shows clear reductions in driving. Basing the expert witness report on a false premise invalidates E/Prof Einfeld's second report: the Respondent cannot rely on it as evidence.

A further problem with E/Prof Einfeld's second report is that he was shown selective partial records to review for his report. Significant "incidents" that occurred while the Applicant was in the care of NDIS-funded support workers were omitted from the material that the Respondent provided for E/Prof Einfeld to review. The selected material did not provide E/Prof Einfeld with an accurate description for his review.

2. The NDIA relies heavily on reports from Zest Care support workers that were riddled with hearsay, that is reports of things that they could not have witnessed. It was clear from the outset that a key support worker was not a credible witness. Subsequently, documents that the NDIA subpoenaed from the support worker's employer, Bunji, show that the key support worker severely defamed the Applicant's mother; consequently, her employment was terminated.

⁴ *McGarrigle v NDIA* [2017] FCA 308 at [94]

⁵ via vehicle odometer readings from independent sources.

3. The Respondent claims “there is no evidence before the Tribunal that the Applicant’s parents maintain lower levels of agitation than the support workers or that their differing approaches result in a decrease in agitation”. But there is plenty of evidence.
 - a. Both Informal Supports (parents) manage the Applicant in numerous settings on their own when support workers are not present. They do this for longer periods than support workers manage, especially over weekends and extended public holidays.
 - b. The Applicant’s Informal Supports drive him in the front seat of their cars. They rarely, if ever, use the modified vehicle (with its passenger barrier) that support workers have to use to transport the Applicant.
 - c. Lojic’s Behaviour Support Plans report that “Peter and Allison have demonstrated that they have a significant level of instructional control with Matthew, ...”. Support workers have less “instructional control” with the Applicant.
 - d. Both Informal Supports (parents) manage the Applicant in supermarket settings, especially in a chocolate isle. Similarly, in other community settings.
4. The NDIA made numerous claims that the Informal Supports (parents) made false and misleading statements to the Tribunal. The NDIA suggested that the Applicant lied about
 - a. logbooks provided by the Applicant’s Informal Supports, suggesting they were for kms driven in the Applicant’s car, not in their own cars.
 - b. not having receiving transport payments (see above).
 - c. the average km driven in the Applicant’s car by calculating the average km by dividing the kms driven by the number of days he was driven on instead of the days elapsed. The NDIA’s calculation includes days driven in other vehicles and omits distance driven in other vehicles).
5. There are numerous problems with the Respondent’s approaches to the Applicant’s driving needs.
 - a. None of the provisions in his NDIS Plans recognise the Applicant’s individual needs (which is a central element of the entire NDIS).
 - b. The Respondent’s offer in its SFIC (12/11/2019) and subsequently avoid mentioning vehicle modification (barrier installation) to the Applicant’s vehicle or recognising that the Informal Carers had to purchase a vehicle as a specific requirement of the Applicant’s home-based program.
 - c. Wording in the NDIA’s offers indicate the Agency’s belief that Matthew’s Informal Supports have not been *genuine* in how they address his behaviours and overall support needs. The evidence shows they were more than genuine and they have been effective.
 - d. The plans, and their initial offer, did not fully fund the Applicant’s driving needs, which is contrary to the *McGarrigle* decision that said partial funding is not legal.
 - e. Most notably, the NDIA’s (without prejudice) offer of 22/1/2021 (with further clarification on 12/2/2021) was conditional on numerous inappropriate and unnecessary restrictive practices. The conditions that the NDIA offered were demeaning for the Applicant and his Informal Supports. We understand that the Tribunal could not endorse such a settlement anyway. This offer shows the NDIA’s profoundly demeaning attitude to Informal Supports, apparently more so for autistic participants.
 - f. The offers refuse to recognise that the Applicant’s car is a vehicle that is modified to meet the needs of the Applicant’s disability
 - g. The Respondent’s latest without prejudice offer (25/8/2022) exaggerates the support provided by support workers which diminishes the work of Informal

Supports and the amount of driving they need to do. The Respondent claims to have driven the Applicant 6 days per week (up from 5 days per week) from 6/5/2020. In fact, support increased by up to a ½-day per fortnight from 30/1/2021, not from 6/5/2020 as claimed.

6. The Applicant's rejection of the NDIA's offer resulted in the withdrawal of support from NSW Legal Aid and the NDAP-funded advocacy service. Clearly, they were not there to support the Applicant, or to help protect his human rights. Their goals are unclear to the Applicant.
7. The Applicant mentioned that they did not receive any transport funding until 1/5/2021. The Applicant provided bank statements to support this claim. The Applicant also put into evidence records from the Respondent that also support this claim.
 - a. The reason that they did not receive payment until 1/5/2021 was because the Applicant did not provide bank details for where the transport amounts should be paid until that date.
 - b. The Respondent claimed they made regular payments. The records show they made some payments that appear to have been on some fortnights.
 - c. The records show they did not make any payments of any kind for the periods 14/2/2017 to 25/9/2017, 30/11/2017 to 27/5/2018 and 11/5/2021 to 22/9/2021.
 - d. Payments of accumulated funds were made on 1/5/2021 and 22/9/2021. Regular payments did not start until 26/9/2021, though the NDIA claimed otherwise.
 - e. The NDIA included \$3,900 in transport payments in the Applicant's NDIS Plan that started on 30/11/2017 (T22) but never paid it.
8. Since the Respondent's first SFIC they have acknowledged that transport funding they allocated in the Applicant's NDIS Plans was substantially insufficient. They have dragged the matter out for years, thereby with-holding substantial amounts of money from the Applicant over an extended period. The NDIA's latest offer of settlement, when calculated out, exceeds \$60K owed to the Applicant. We doubt the government would tolerate a NDIS participant owing it an amount like that.
9. The NDIA refused to provide basic information about payments made against the Applicant's plans. They said they could not do this while there was a matter before the AAT. This is complete rubbish.
10. The NDIA, the respondent, issued several subpoenas for all documents from a) Zest Care who provided support workers initially when the home-based program started, b) Bunji who took over when Zest Care could not provide the required service, and c) the latest OT. The Tribunal denied the Applicant's attempt to obtain basic records from the Respondent, even though the information should have been easily available, and the Respondent used the existence of the AAT review as its reason for rejecting the Applicant's requests. Clearly, the Tribunal has a serious bias in how it conducts its business.
11. The NDIA has delayed the matter as much as possible. It issued successive subpoenas, apparently to avoid hearing dates being set or to avoid paying any part of the substantial amount of money that it clearly now owes.
12. In her letter (8/7/2022) to Mr Peter Hill, Dr Studdert, Acting CEO NDIA, refers to the "without prejudice" offer made on 27/1/2021. Mr Hill detailed the requirement for restrictive practices in his letter to the CEO on 7/7/2022, quoting from the clarifying letter on 12/2/2021. Dr Studdert wrote (8/7/2022) to Mr Hill, "In making the offer, the NDIA does not require the use of restrictive practices." This is an attempt to gaslight Mr Hill.

Deloitte's report [*The value of informal care in 2020 Carers Australia*](#) (May 2020) "estimated that the total cost to replace all informal care in 2020 is \$77.9 billion" (an annual figure). This is more than double the cost of the NDIS. The above shows how government does not appreciate and respect the enormous contribution that Informal Supports make.

The review process above brought to light aspects of previous decisions (and non-decisions) that also deserve review. The Applicant submitted two more dubious NDIA decisions for AAT review.

Given the evidence and the offers already made by the NDIA, we are confident that the Tribunal will find that the transport decision under review needs to be replaced. We have no idea what the Tribunal will replace it with, though we feel it is likely to improve substantially on the NDIA's original decision. We feel that a) the average distance driven needs to be based on actual days when the Applicant is driven (which is fewer than the NDIA claims which increases the average daily kms relative to the NDIA's latest offer), and b) modifications to the Applicant's car should be recognised. We also suggest that it is not necessary to predict km: it would be better to pay the actual distances completed.

Annex B. RJTY and the AAT

RJTY was born in 2015 with Phelan McDermid Syndrome (PMS, also known as 22q13.3 deletion syndrome). She needs constant support; her Informal Supports (parents) cannot provide all the support she needs so they need lots of assistance.

The amount and complexity of support RJTY needs requires an extensive and skilled team. It takes a long time to recruit and train such a team.

The NDIA has a cruel approach to this family. The NDIA has instigated a cycle where they underfund RJTY's support. When RJTY's family ask the AAT to review the NDIS support decision, the NDIA settles the matter with a large NDIS Plan for a short period of time⁶. When the short (5 month) plan completed, they cut the funding by 57%. A cut like this destroys the supports that built up: the supporting businesses cannot sit around waiting for the reassessment/review process to play out, businesses need more certainty.

The NDIA cannot be trusted: when the 5-month plan was delivered, the NDIA said the family should not worry about the plan review process that would follow. Clearly, they should have worried as a 57% funding cut followed.

After 2 months of insufficient funding, the NDIA's internal review process increased funding a little. The cut was reduced to 42.75% which is still an enormous cut in supports.

The Informal Support, as a result of such an enormous cut to NDIS Plan funding, have to "let go" most of their trained formal support staff. While the Informal Supports, RJTY's safety net, have to make up support that is more than two full-time jobs: and further, they are left on their own trying to mount an especially complex appeal in the AAT without legal aid or a funded disability advocate.

The NDIA simply do not understand RJTY's disability. RJTY's PMS is associated with:

- Autism spectrum disorder that severely affects communication and behaviour.
- Extreme sleep disturbance
- Numerous other physical and cognitive conditions.

Bizarrely, the AAT process prevents it from recognising the pattern of failing plan review and consequent AAT matters. The matters are treated in isolation. The previous matters are hidden from the latest AAT review, even if it is exactly the same material being rehashed over again. So much for people not having the trauma and frustration of having to repeat their worst experience.

This certainly goes against the idea of just telling your story once: basically, you are expected to retell your story each time you go to the AAT. You have to describe your worst situations over and over again. The process aims to cause maximum trauma.

In RJTY's latest AAT review, it took 5 months for AAT and the NDIA to know about the existence of previous cases. NDIA representatives claimed they were not aware of previous cases ... and could not consider them until RJTY's Informal Supports "released" the "history". The Applicant is expected to resubmit all the evidence needed to justify a complex combination of support.

⁶ Most recently, the NDIS settled through an offer of a 5-month NDIS Plan. At the end of the Plan, they waited a month to review the plan. The review cut the plan annual rate by

In the meantime, RJTY's supports have fallen apart. Funding for crucial services were cut so the services stopped. Often, it is difficult to find replacement services especially for autistic children. So it is impossible to access reduced services from different providers. The Agency then expects that you don't even need the lesser funding because your NDIS Plan utilisation is down.

The NDIA told RJTY's mother that RJTY was being taken out of the complex needs team because her previous contact person was moving to another job. RJTY's mother objected and was then told RJTY was back in the complex team. But there has been minimal contact from the new complex needs person since being put back in that category.

In summary, RJTY get less the 5 months of the supports that were agreed in the NDIS Plan settled in the AAT. The rest of the time, her Informal Support struggle to support her sleep (leaving them severely sleep deprived), her therapy gains (so she quickly loses many of her skills). At the same time, they have to cope with one of the most complex NDIS reviews before the AAT without a funded advocate or legal support.

A leading disability advocate said recently that she could not understand how an autistic child could need so much support (an amount substantially less the RJTY needs). Clearly, many people in the disability sector do not as yet understand the needs of autistic people.

The AAT "culture" is not fit for the purpose of processing NDIS independent reviews.