

Submission to the Joint Standing Committee on the National Disability Insurance Scheme Inquiry into the Capability and Culture of the National Disability Insurance Agency

16 December 2022

1.0 INTRODUCTION

1.1 About the Australian Autism Alliance

www.australianautismalliance.org.au

The Australian Autism Alliance (Alliance) aims to provide ‘A United Voice for Autism’. The Alliance was established in 2016 and aims to improve the life chances of autistic people and facilitate collaboration within the autism community. Operating as a cohesive network of 12 organisations with a diverse focus on autism, we have a national reach that brings together key autism organisations representing and led by autistic people, advocacy groups, peak bodies, service providers, educators, and researchers. We reach well over half a million people through our communication channels and providing support to people with autism across the lifespan. Most importantly, our work is informed by autistic people and their families and carers.



1.2 Overview

The Alliance welcomes this Joint Committee Inquiry. There is no doubt that that the National Disability Insurance Scheme (NDIS) has enormous value and has been life changing for people with disability in Australia. There is, however, much room for improvement. The rapid rollout has resulted in significant implementation changes and many bolt on solutions to shape it.

This brief submission covers the following scope of the Terms of Reference:

- a. the capability and culture of the National Disability Insurance Agency (NDIA), with reference to operational processes and procedures, and nature of staff employment
- b. the impacts of NDIA capability and culture on the experiences of people with disability and NDIS participants trying to access information, support, and services from the Agency; and
- c. other relevant matters – informal supports.



With autistic people constituting almost one third of all NDIS participants, our submission is directly informed by the lived experience of the autistic people and their families and guardians who contributed to the largest consultation survey of the autism community conducted in Australia with over 3800 responses collated in July 2020 by Australian Catholic University Engagement on behalf of the Alliance, as well as reinforced by the thousands of autistic people and their families who interact with Alliance members on a daily basis.

2.0 THE CAPABILITY AND CULTURE OF THE NATIONAL DISABILITY INSURANCE AGENCY (NDIA), WITH REFERENCE TO OPERATIONAL PROCESSES AND PROCEDURES, AND NATURE OF STAFF EMPLOYMENT

2.1 Significant barriers remain to entering the scheme

Repeated themes from our survey and engagement include:

- There is a **lack of information and support** for autistic people and their families/carers to apply for the NDIS.
- Concern that **NDIA assessment tools are not fit for purpose** and unfairly screen out autistic people.¹

2.2 Lack of support for autistic people not admitted to the scheme

Over 80% of our survey respondents with unsuccessful NDIS applications reported not being given information about other supports.

2.3 Lack of understanding of autism among NDIA planners and partners

Just 18.1% of autistic adults and 31.8% of parents/carers reported that their planner had a good understanding of autism in our recent survey. There was also a theme that the lack of continuity of staff disrupt the continuity of information and relationships.

2.4 Lack of Support to engage with the NDIS Planning Process

The overwhelming majority of respondents reported needing more support to engage with the planning process and the NDIA.

- Just 31.6% of autistic adults and 35.8% of parents/carers felt they had enough information in advance to understand the planning process.
- Just 28.4% of autistic adults and 33.8% of parents/carers indicated that NDIA planning process was easy to understand.
- 38.1% and 46.9% that the language used by NDIA was accessible and easy to understand.
- Well over half of these respondents (64.5% of autistic adults and 60.1% of parents/carers) reported that they needed more support to engage with the NDIA and understand what they would need to do in their planning meeting.

¹ The NDIS utilises DSM-5 Levels 2 and 3 as conditions by which children and adult autistic people are likely to meet access requirements to the NDIS. DSM-5 clearly states that the severity levels should not be used to determine eligibility for services given the levels can change over time and with different assessors.



These challenges are further compounded by the market model that the NDIS is predicated upon, which requires participants and their carers to broker directly with service providers in an environment often marked by poor information regarding the types and appropriateness of services that are on offer. Within the NDIS market, where some providers remain unregistered, participants are left to themselves distinguish between evidence-based supports and other marketed offerings.

2.5 There are significant barriers to accessing the Complex Needs Pathway

The Complex Needs Pathway within the NDIS recognises that participants with personal circumstances may require specialised planners to ensure that their needs are appropriately supported. However, there remains a lack of transparency around the pathway, and specifically, how participants are identified for referral into the Pathway. Only eight autistic adults and 59 parents/carer respondents to our survey indicated that they were accessing the Complex Support Needs Pathway – yet 414 reported having a Level 3 autism diagnosis, which is indicative of complex needs. Low awareness of the pathway was reflected by the 61.1% of autistic adults and 69.2% of parents/carers with a current or pending NDIS plan reported that they don't know about the NDIS Complex Support Needs Pathway.

2.6 Lack of a provider of last resort under the NDIS model remains a live issue for participants with multiple complexities who may be unattractive to providers.

The Australian Parliament's Joint Standing Committee on the NDIS recommended (and the Government in its response to the Inquiry agreed)² that the NDIA urgently release its policy on provider of last resort arrangements. Despite this, a lack of clarity and information remains. While the NDIA has developed the Maintaining Critical Supports approach, and within that, the Exceptionally Complex Support Needs Program, it's unclear whether these measures will be sufficient to ensure all participants are able to be connected with providers willing to support them.

2.7 The current iteration of ECEI is not a good fit for autistic children

There is significant concern that participation in ECEI can delay access to diagnosis. Further, the light touch and short-term approach of an Early Intervention plan can postpone autistic children accessing the intensity of supports early enough that evidence shows makes a real difference to their trajectory. Systematic reviews clearly demonstrate that intensive and comprehensive early intervention support for autistic children, starting as young as possible, is key to improving their life outcomes, enabling them to be as independent as possible and participate to their full potential in education, employment, and their community.³ Providing early intervention to children with autism has (at its most conservative estimate) been shown to deliver a Benefit-Cost Ratio of 4.1.⁴

² Government response to Joint Standing Committee Inquiry into NDIS Market Readiness, March 2020. Available at: https://www.aph.gov.au/Parliamentary_Business/Committees/Joint/National_Disability_Insurance_Scheme/MarketReadiness/Government_Response

³ Prior, M et al., 2011. A review of the research to identify the most effective models of practice in early intervention of children with autism spectrum disorders. Available at: https://www.dss.gov.au/sites/default/files/documents/10_2014/review_of_the_research_report_2011_0.pdf; Roberts J, Williams K., 2016. Autism Spectrum Disorder: Evidence-based/evidence-informed good practice for supports provided to preschool children, their families and carers. Available at:

<https://webcache.googleusercontent.com/search?q=cache:kVtO3NLKyYJ:https://www.aph.gov.au/DocumentStore.ashx%3Fid%3Db203535f-060d-48f5-bcf6-276ce828aa19%26subId%3D670195+%&cd=3&hl=en&ct=clnk&gl=au>

⁴ Synergies Economic Consulting, 2013. Cost-Benefit Analysis of Providing Early Intervention to Children with Autism. Available at: <https://www.synergies.com.au/reports/cost-benefit-analysis-of-providing-early-intervention-to-children-withautism/>

2.8 The Role of the NDIA

The role of the NDIA is unclear. Feedback received by participants indicates they feel that NDIS representatives (planners and/or NDIS Partners) opinions on services, including “substitutes” appears to hold more weight than a participant’s needs, and/or the recommendation of a practitioner report. The role, scope, authority, and evidence of the NDIA representative needs to be clear.

2.9 Contribution to unnecessary costs by the NDIA’s behaviour

The sustainability of the scheme has been emphasised. It has been observed that the NDIA itself contributes to several ways to increasing costs unfavourably, albeit it driven by good intent. Some examples include:

- NDIA representatives relaying messages that encourage participants to spend their funding regardless. Messages such as “if you haven’t spent your funding it demonstrates you don’t need it the following year so your plan will be cut” or “this is your first year, so we have provided you with “x” funds. Do not expect to be funded to the same level next time”. The evidence in this instance that is valued is demonstrating a zero variance between expenditure and funding budget. There are many valid reasons why expenditure has not occurred, including simply that there are instances it is best to undertake services sequentially and not in parallel. As participants in the majority, act with integrity as they value the life impact of the scheme, this create a moral dilemma between doing what is best for the participant to be able to fund their ongoing goals and what sits comfortably with their values.
- Budget lines and amounts included in plans that individual participants have strenuously indicated will not be of value due to need, prior experience, and evidence provided by practitioners. Examples include sleep program packages, fit programs, and community access with support workers.
- A participant having to validate multiple times for a plan funding request that has previously been supported by the AAT, but NDIA wish to challenge again.
- A focus on meeting demand such as Positive Behaviour Practitioners has encouraged the emergence of unregulated practitioners. There are observations of ineffective behaviour plans causing participant trauma and inappropriate behaviours, resulting then in the need for more funded supports.

There are many more examples that the constraint of a brief submission does not make allowance for.

3.0 THE IMPACTS OF NDIA CAPABILITY AND CULTURE ON THE EXPERIENCES OF PEOPLE WITH DISABILITY AND NDIS PARTICIPANTS TRYING TO ACCESS INFORMATION, SUPPORT AND SERVICES FROM THE AGENCY

3.1 The Scheme is deficit focussed.

Autistic people and parents of autistic children are often required to repeatedly justify why their support needs should be met by the NDIA. This process can be demeaning and hurtful to the self-respect and identity of the autistic person. This does not provide a conducive environment to result in optimal outcomes with a focus on justifying deficits, rather than strength based.

“..... I cannot believe we were made to take a child to a planning meeting, and then spend 2 hours sitting there pointing out every flaw and behavioural issue she has in front of her. It’s disgusting....The only way to get help is to totally downgrade a person into a diagnosis and not be



human about it and the recovery time that it took for my daughter after I spoke about her, like that, to someone we don't even know. I think she will never forget it. And it was over 18 months ago."

3.2 Individual funding is often inadequate, and difficulty accessing services.

Just over one-third of respondents with a current or pending NDIS plan reported that their NDIS funding is adequate. Often then there is difficulty in accessing services as participants are not aware how to give effect to their plans exacerbated in situations by:

- a. not having funded or adequately funded support coordination; and/or trying to engage with multiple services and agencies; and/or
- b. LACs who do not have adequate knowledge and refer to unfunded Peak bodies.

3.3 Reinforcement of the negative message that the scheme will fail due to autism.

Autistic people and their families report of feeling responsible and less worthy to access the scheme due to the continual message of cost blow outs and lack of sustainability. Reference to cost blowouts does not consider the contribution of autistic people to the economy and society more broadly. There is also significant concern what the recent reference to "profoundly disabled" means.

"The NDIS system is terribly flawed for autistic people, especially 'high functioning' ones. The reason most adults and children have a level 1 label is because of copious amounts of therapy and work. Just because someone is better at masking their disability and fitting in with a neurotypical world does not mean they do not deserve support for doing so."

3.4 Other Key Themes

- Administration errors
- LAC poor performance / non-existent supports
- Poor understanding of best practice supports
- Challenging and lengthy wait and process
- More guidance and support in writing a plan required
- Little or no communication from NDIS
- Experiencing perceived threats during plan renewal process that if don't accept the plan being offered it is likely a delegate review will result in a reduction
- Actual plan cutting
- Constantly demonstrating eligibility to the scheme
- Inability to apply for funding without professional assistance
- Overwhelming, appalling, and difficult process
- Lack of transparency, and respectfulness
- Difficulty managing and processing for autistic people applying for themselves
- People questioning the worth of going through the complex and lengthy process of applying and fearing rejection
- Need for review when already been tested in a review or AAT outcome

After battling with the NDIS for the last few years, talking with many families in similar situations. I find the entire process disgraceful. The lengths you must go through to even obtain funding let alone an appropriate amount is exhausting, over complicated and stressful. Once you have jumped through all the hoops there is still no guarantee that the random person who decides the plan who has never actually met your child, or who has any real knowledge of the disability and what daily life is really like makes decisions that determine how much support you can access. It's disheartening and stressful and a process I dread every year.

The culture experienced wears participants down. Participants are more likely to agree with bad decisions or ineffective plans just for the process to be over.

4.0 OTHER – INFORMAL SUPPORTS

As reported in the [Senate Committee Inquiry on Autism](#) report⁵ despite the wellbeing of parents and carers being critical to the success of autistic people, there is overwhelming evidence that support for parents and carers is currently inadequate. There are concerns in relation to the support available under the NDIS. The indirect economic costs of caring are well known and were one of the factors that led to the establishment of the National Disability Insurance Scheme (NDIS).⁶

The NDIS was also seen as a particular source of anxiety and stress for parents.⁷ A small investment in making the complex simple and providing some capacity building has significant positive multiplier effects that requires a submission off its own.

5.0 RECOMMENDED SOLUTIONS

Key recommendations are outlined below.

5.1 Information dedicated to autistic participants

A straightforward way to improve the accessibility of the NDIS to autistic people is to publish information on the Scheme specifically tailored to their needs. Development of such resources needs to occur through co-design with the autistic and the autism community.

5.2 Dedicated Autism and Neurodevelopmental Stream

Limited understanding of the needs of autistic people, and inconsistencies in funding processes were both common themes in our survey responses regarding the NDIS. The NDIA has developed specialist streams for people with psychosocial disability and hearing loss, enabling NDIA and Partners in Community staff in those areas to build specialised skills and expertise. A similar approach is urgently needed for autistic participants. A specialist stream would build autism expertise, including a better understanding about the diversity of autism including co-occurring conditions⁸, among NDIA staff, LACs and ECEI staff, including the functional impacts of autism, how to support autistic people to engage in the planning process and the evidence-based supports to derive the best short and long-term outcomes in autistic people. While we recognise current efforts, including the Autism Staffing & Recruitment Strategy, there is a long way to go to make the scheme autism proficient.

5.3 Pre-planning support and peer networks

Pre-planning support and peer networks are needed, drawing on successful experiences of the previous NDIS Disability Support Organisations (DSO) program.

⁵ Senate Select Committee report on Autism, March 2022. Services Support and Life Outcomes for autistic Australians, Chapter 4

⁶ The Productivity Commission estimated that about \$1.5 billion per annum of economic benefits would occur from carers re-entering the workforce.

⁷ Senate Select Committee report on Autism, March 2022. Services Support and Life Outcomes for autistic Australians, Chapter 4 4.23, pg 41

⁸ Note, according to the Raising Children website, 75 per cent of autistic children have a co-occurring condition. Raising Children: the Australian parenting website, Conditions that can occur with autism, www.raisingchildren.net.au/autism/learning-about-autism/about-autism/conditions-that-occurwith-asd (accessed 10 December 2021).

Program evaluations (unpublished) highlighted the benefit of pre-planning and the efficiencies they delivered in the planning process by improving participants understanding of how to prepare for their meeting. Likewise, peer support plays an important role in strengthening participant capabilities to exercise their choice and control.

5.4 Overhaul ECEI

The ECEI Reset process needs to deliver a strengthened ECEI offering. Autistic children need to be admitted as scheme participants and provided with a robust individually funded disability plan (rather than a short-term EI Plan) at the earliest opportunity. This will provide the best return on investment for the NDIS in the long run.

The Tune Review also made important recommendations that if implemented will improve supports available to families accessing ECEI.⁹ When working well, ECEI enables access to comprehensive supports, strengthens family capacity including within natural settings, uses family centred practice and a key worker model (subject to worker caseloads), and importantly as a functional pathway into the NDIS.

5.5 NDIS Role and Focus

NDIA to date appear to be focussed on controlling inputs, including advising and in some instances directing services and supports to give effect to their definition of “reasonable and necessary”. A greater focus on governance and outcomes would be beneficial:

- a. Economic modelling on the Social Return on Investment from a total lifespan perspective including the opportunity cost (from not investing), return to society and whole of government cost impact. This will drive several critical elements:
 - i. encourage government and community to focus on the long-term individual and collective benefits of the NDIS, rather than the short-term costs. Current reference to costs does not take into consideration the contribution of people to the economy and society.
 - ii. change the narrative for a different culture to evolve and enable vertical integration, including behaviours.
 - iii. use of effective outcome framework, with accountability measures and continuous improvement cycles. Continuous improvement could include independent audits like Quality and Safeguards, undertaking its own internal audits to test if what is being operationalised is translating accurately at the front line and recording staff interactions with participants for learning purposes.
 - iv. better information to inform operational guidelines when assessing what is reasonable and necessary in the context of the implications and short-term vs long term trade-offs. This would provide planners to have a better understanding. Currently operational guidelines exist but the scope for situational interpretation is only effective if you have specific domain knowledge and/or competency to apply it to individual situations. Guidelines could include decision trees and risk matrices to bring the science and art together.
- b. Working to improve Tier 2 and intersectionality with other government agencies including improved accountability with each other. Often failures in other systems creates the need for

⁹ Tune AO PSM, D., 2019. Review of the National Disability Insurance Scheme. Removing Red Tape and Implementing the NDIS Participant Service Guarantee. Available at: https://www.dss.gov.au/sites/default/files/documents/01_2020/ndisact-review-final-accessibility-and-prepared-publishing1.pdf



greater reliance on the NDIS. For example, being unsuccessful in the school environment creates significant downstream impacts on other aspects of life – mental health, employment, social inclusion etc.

- c. Stronger regulation and care standards to ensure quality supports and to protect participants safety. This includes:
 - i. addressing the issue of autistic people with complex needs not being provided services, unregulated services and supports.
 - ii. the NDIS addressing their tendency to undertake short notice changes such as price guides, rules, and submissions.
- d. More deliberate market stewardship to ensure better access to services across Australia.
- e. Core competency of planners and NDIS Partners – re-examination of what are the core competencies required.

5.6 Co-design and Partnering

Multiple stakeholders are (or should be invested) in an enduring NDIS from individuals, their families, their supports, and the remainder who make up the eco-system. This extends to State and Territory governments.

Since the inception of the NDIS there has been tension regarding potential conflict of interest with stakeholders resulting in less engagement and sharing of information. There is real value in planning and delivery with the autistic and autism community and the broader disability community. We recognise that autistic Australians make up a significant number of the participants in the NDIS. Not addressing this head on leads to continued poorer outcomes and increased support needs in the future.

There has been more co-design occurring recently but there is still more we can all do to enhance this. By truly working together we can develop a common understanding of the baseline, identify drivers of the real problems to solve, understand each other's true respective constraints, develop impactful solutions, identify appropriate evidence "what good looks like" to measure outcomes and importantly hold each other accountable.

A further valuable investment would be in innovation as the current environment does not effectively support this. Many partnership models exist in other sectors demonstrating government agencies working successfully with sector stakeholders despite perceived conflicts of interest. Examples include social bonds and alliance models sharing risk and reward. Such partnerships would ensure neurodiverse people and human rights are at the centre.

In this vein it is critical that representatives from the autistic and autism community are involved in important discussions. We recognise and very much value the significant increased channels for inclusion that we have seen more recently, including by the NDIS Minister and NDIS itself, and the impact that the Autism Advisory Group has had. An important consideration, however, to working in a more integrated model is to have autistic and autism representation to existing and (future) advisory groups, such as the Independent Advisory Council.

5.7 Building a sustainable care economy.

There is a need to build a sustainable care economy, including interaction with NDIS and capacity building as this is an important element of a successful ecosystem. Modelling¹⁰ suggests ... that informal carers of people with intellectual disability and/or ASD in Australia had aggregated lost income of AU\$310 million, lost taxation of AU\$100 million and increased welfare payments of AU\$204 million in 2015. These are projected to increase to AU\$432 million, AU\$129 million and AU\$254 million for income, taxation, and welfare respectively by 2030.

In summary, positive adjustments to the NDIS, through the adoption of these recommendations, will dramatically improve the social and economic participation of autistic people and their families and help deliver significant flow-on multiplier benefits to the broader economy.

We present the above submission for the Joint Committee's consideration and stand committed to working closely to ensure our recommendations are understood. Upon completion of this Inquiry, we are committed and look forward to working closely with the NDIA and all relevant stakeholders, including State and Territory Governments to implement impactful positive reforms.

We thank you for the opportunity to respond.

Contact:

Jenny Karavolos (she/her)

Co-chair, Australian Autism Alliance

M: 0401 988 186 | E: chair@australianautismalliance.org.au | jenkaravolos@outlook.com

¹⁰ Deborah Schofield, D., Zeppel M.J.B., et. al. (2019) *Intellectual disability and autism: socioeconomic impacts of informal caring, projected to 2030*, BJP 215, 654–660. doi: 10.1192/bjp.2019.204.