



Members of the Autism Family Support Association (AFSA) committee attended a meeting with the National Disability Insurance Agency (NDIA) Autism Advisory Group on June 17th 2021 (held electronically).

Below is a copy of the AFSA Discussion Points presented at this meeting, followed by a copy of the NDIA response received by AFSA on 29th July 2021.

AFSA welcomes any comment, experiences or concerns from Victorian parents and carers in relation to our discussion points and the NDIA responses. These can be emailed to secretary@afsconnect.org.au.

This is the link to the NDIA Autism Advisory Group

<https://www.ndis.gov.au/about-us/reference-group-updates/autism-advisory-group>

They have issued three communiques since their inception in 2018. These can be accessed from this weblink – the June 2021 communique referenced AFSA's meeting with the group.

AFSA DISCUSSION POINTS

AFSA is a collective voice for autistic people with complex and high support needs and their parents, carers and families. AFSA is managed by a voluntary committee. We represent lived experience and speak on behalf of our autistic family members and their loved ones.

AFSA asserts that there is a lack of suitable services and appropriately trained practitioners and support staff for autistic people with complex needs.

A "Provider of last resort" is non-existent under NDIS. This is failing our family members

Current Accommodation models including SDA are often not suited to the needs of individuals with challenging behaviours and high support needs

AFSA believes that the NDIS is effectively paying for students who have been fully or partially excluded from school to stay at home

Current avenues of discussion and appeal are intimidating and unfair to parents/families trying to obtain the necessary supports – legal, cultural and language challenges are overwhelming to most families. Some families report attending the AAT unsupported while facing paid legal representatives.

1. Autism (ASD) is a complex disorder with very individualised presentations. In 2016 Amaze estimated that around 25% of those diagnosed with an ASD have high support needs due to a combination of communication, behaviour and sensory challenges, and in many instances other co morbidities. Those supporting and caring for this cohort of autistic individuals are the voice of their 'lived experience'. We contend that this cohort is increasingly the 'forgotten group' within the larger group of individuals diagnosed with an ASD.

What is the NDIA doing to better support participants with complex needs?

2. Care and support of this high needs cohort requires an individualised, multi-disciplinary team approach – both short term and long term – and is provided by families, medical and allied health practitioners, disability support providers and members of the community.

What autism expertise currently exists with the NDIA and what plans exist to expand that expertise?

3. The Autism Family Support Association has over 230 Victorian member families, the majority of whom are supporting family members in this high support needs cohort. Families are invariably the 'drivers' ensuring that necessary and adequate supports are made available. The NDIS has provided both real – and missed – opportunities for autistic individuals and many challenges for their families/carers.

Will the NDIA ensure that the use of Independent Assessments will not replace the input from families, carers and autism experts.

AFSA has previously prepared and circulated the following relevant statements – which are available on our website:

- [AFSA Agenda of NDIS Issues 2019-20](#)
- [AFSA Statement on Independent Assessments 2020](#)
- [AFSA Statement on COVID19 and Related Health Emergencies 2020](#)

We have identified the following specific issues pertaining to the operation of the NDIS that present our identified cohort of autistic individuals and their families with challenges that diminish and undermine opportunities and impact negatively on the quality of life of families and their family member/s with autism. We will present a number of examples of real life experiences to illustrate our concerns.

◆CCN/CSN – Complex Communication Needs – Complex Support Needs

- **Functional Communication** – this term has been used to identify the communication challenges experienced by autistic people, but it also references a range of systems of positive communication supports such as technology, signing, symbols and behaviour analysis.
- There is a significant short supply of NDIA accredited allied health practitioners with the appropriate qualifications and expertise to prepare Communication and Behaviour Support plans.
- There is limited training and consequently a poor understanding across support coordinators and disability support providers and their staff of the importance of preparing and implementing individualised, dynamic and achievable Communication and Behaviour Support Plans.
- The NDIS model does not support the provision of a collaborative team approach as a standard support. Such an approach is rarely achieved within a plan, and then only when those representing the participant are knowledgeable and persistent and have a similarly knowledgeable planner.

The NDIA needs to work more closely with service providers, universities and relevant health and allied health professionals to ensure they develop and deliver relevant accredited training courses.

- Identical twins – different presentations, different needs but the same NDIS plan – why?
- 45yo non-verbal woman has for the first time communicated using a digital device – only achieved by NDIS funding for a speech and language assessment by a practitioner who had the appropriate expertise – more good luck than good management. We know of others not given this opportunity.
- Many families report that their planner does not include a behaviour or communication plan in their NDIS plan, even when this is specifically requested – why?

◆Impact of poor liaison between state Education sectors and the NDIS

- Reported instances Australia wide of students with ASD being denied appropriate, full time education placements. Parents/carers required to take on the education burden and provision of at home support.

- Home schooling
- Part time school attendance and double dipping – schools get funding (state and NDIS) to support a student with ASD, parents/carers also use NDIS funding to secure supports for when their child is at home – but should be at school.

◆ Special Disability Accommodation challenges

- This is an area of great concern to families, especially older families, due to the complex transition arrangements for permanent accommodation between the states and the NDIA. There is no longer a clear pathway to obtaining permanent, quality accommodation and care for family members who can no longer be cared for by their family.

There is an urgent need for the NDIA to develop a clear and accessible pathway to obtaining suitable permanent accommodation for participants with complex needs.

- Inconsistent carry-over of 1:1 funding from ISP to NDIS plans.
- Disconnect between group funding and individualised funding.
- Difficulty obtaining the specific assessments by specially trained practitioners required to determine eligibility for SDA.

IN CONCLUSION

AFSA welcomes this opportunity today to raise our issues of greatest concern with this Advisory Group and requests your continued consultation with groups like AFSA who, as NDIS users, can best present issues from the ‘lived experience’ of those with autism and complex needs.

NDIA response to Autism Family Support Association’s (AFSA) key discussion points

1) A “provider of last resort” is non-existent under NDIS. What is the NDIA doing to better support participants with complex support needs?

The Complex Support Needs (CSN) Pathway operates nationally, with planners located in every state and territory. At 31 March 2021, there were 104 planners supporting 5,060 participants with complex support needs, and 79 planners supporting 5,054 participants living in residential aged care facilities.

The expansion of the CSN Pathway also includes 23 Health Liaison Officers and 16 Justice Liaison Officers (as at 31 March 2021). The liaison officers provide a key role in connecting the NDIA to mainstream service systems, and supporting people to access the NDIS.

As part of the Participant Service Improvement Plan, the NDIA is reviewing the CSN Pathway. This review is looking to optimise the CSN Pathway model to improve its operational efficiency and capability, and outcomes for participants. The NDIA expects the review to be completed in the first quarter of FY22.

In addition, the NDIA implemented the Exceptionally Complex Support Needs Program (ECSNP) in late 2019 to improve outcomes and experiences for participants with exceptionally complex support needs. This was established through a grant round. Cohealth delivers this service in Victoria

ECSNP providers work closely with providers and services to improve their practice working with people with exceptionally complex support needs. This is done through planned proactive capacity building activities with services and systems.

The ECSNP also includes a crisis referral service for NDIS participants aged 18 and over who present to key emergency services because of a breakdown in their disability supports. The role of the ECSNP Provider is to

work with the participant in crisis to utilise their plan for short-term supports to respond to the disability related crisis, and to refer to the NDIA the following business day for appropriate action.

While the ECSNP contracts are due to conclude across all state and territories at the end of the current grant arrangements from September 2021, the NDIA and states and territories will continue to closely monitor the service systems, options available to address any emerging issues, and whether responses should be NDIA, state/territory, or sector-led. In addition, the NDIA is currently investigating options for a continued crisis referral service.

2) Current accommodation models including SDA are often not suited to the needs of individuals with challenging behaviours and high support needs.

More than 1,000 participants in the Complex Support Needs pathway are receiving Specialist Disability (SDA) Accommodation. The Robust SDA category is suitable for most participants, however there are some participants with very complex behaviour needs where the Robust SDA category has not proved suitable.

The NDIS is continuing to consider how the needs of this group may be more appropriately met, including discussions with state and territory governments who have the overall responsibility for providing housing. The SDA review in 2023 (Pricing and SDA Design Standard) will provide an opportunity for consideration of how different designs (including specifically for sensory needs) may be incorporated into the Robust category/pricing.

3) AFSA believes that the NDIS is effectively paying for students who have been fully or partially excluded from school to stay at home

There is an expectation that NDIS participants of a school age will have the opportunity to engage in education through an inclusive and supportive learning environment. Schools have a responsibility to make reasonable adjustments for students with disability in line with the Disability Standards for Education 2005.

The Commonwealth is continuing discussions with state and territory governments to ensure collaboration between NDIS funded supports and the school system. The NDIA is happy to raise individual cases with state and territory education departments.

The NDIS funds personal care in schools, as an in-kind support. If you are at a government school, your state or territory government pays for the support and it is delivered by your school. Personal care in schools supports help with personal care only; it does not cover help with schoolwork. More information is available [here](#).

4) Current avenues of discussion and appeal are intimidating and unfair to parents/families trying to obtain the necessary supports – legal, cultural and language challenges are overwhelming to most families. Some families report attending the AAT unsupported while facing paid legal representatives.

As part of our Service Improvement Plan, the NDIA is progressing improvements to the delivery of the Scheme. The plan reflects feedback we have received from participants and their families. We are making concerted efforts to improve Agency communications. This includes:

- Clearer public guidelines and procedures so there is consistency in how we make decisions;
- Guidelines in plain English descriptions and more examples; and documents with consistent terms and definitions with less jargon; and
- Clearer information on what reasonable and necessary supports mean, with case studies and examples.

In addition, the Participant Service Guarantee sets out clear timeframes for key NDIS processes. The NDIA must make decisions about access, plan approvals, plan reviews and nominee changes within these timeframes. This gives participants, families and carers greater certainty about how long processes will take.

The Agency applies an early resolution model for AAT matters that helps participants by working with them and their representatives to resolve their matter as early as possible in the AAT process.

DSS provides funding for advocacy services, which can be accessed by applicants for AAT matters. The Commonwealth Government is providing \$10.8 million in 2020-21 to support appeals through this program, with 42 advocacy organisations and 8 Legal Aid Commissions funded.

The NDIA informs applications about the availability of advocacy and legal services and encourages applicants to seek that support, while supporting applicants through the review process.

5) What autism expertise currently exists with the NDIA and what plans exist to expand that expertise?

The NDIA has an Early Childhood and Autism Strategic Adviser, who provides strategic advice on the development of NDIA policy and processes impacting autistic participants. In addition, the Agency has over the years collaborated with Autism CRC to develop important research and guidelines, including:

- Australia's first national guideline to improve autism diagnosis; and
- A comprehensive review of the current evidence about non-pharmacologic interventions for children on the Autism Spectrum.

The NDIA policy team is currently undertaking a key piece of work on interventions for children on the autism spectrum. This year, the Agency released a consultation paper (available on the NDIS website) outlining a policy framework to support evidence-based practice.

The NDIA employs a number of autistic people with lived experience and provides awareness training and information to NDIA staff and partners about autism. In addition, the NDIA Early Childhood Branch and Partners have skilled allied health professionals and educators with specific autism expertise and experience.

6) Will the NDIA ensure that the use of Independent Assessments will not replace the input from families, carers and autism experts.

On 9 July 2021, the Minister for the NDIS, Linda Reynolds CSC, met with state and territory disability ministers. The Ministers agreed Independent Assessments would not proceed, and that they would work in partnership with those with lived experience of disability through the Independent Advisory Council and disability representatives, on the co-design of a new person-centred model that delivers consistency and equity in access and planning outcomes, consistent with the legislative requirements for assessments as set out under the National Disability Insurance Scheme 2013 Act.

The Agency supports this decision, and will undertake deep engagement with people with disability, the sector and state and territory governments to develop a new person-centred model for assessments.