



Autism Family Support Association Inc (AFSA)

Submission to

**Joint Standing Committee on the National
Disability Insurance Scheme**

NDIS PLANNING

September 2019

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ABOUT THE AUTISM FAMILY SUPPORT ASSOCIATION AND AUTISM SPECTRUM DISORDER

The purpose of the Autism Family Support Association (AFSA) is to assist and support individuals with an Autism Spectrum Disorder (ASD) by providing emotional and practical support for parents, carers and families. AFSA is an incorporated, state wide voluntary parent based support group in Victoria. Through parent-to-parent support our aim is to improve the outcomes and quality of life for individuals with ASD and their families and carers. By supporting carers better, we can help those with ASD live more fulfilling lives.

It is estimated that about 55,000 people in Victoria live with ASD. We recognise that there are some positive things happening within Victoria as the NDIS rolls out but there are also considerable issues for participants with ASD and their NDIS Plans – and the families who provide their care and support.

We would welcome the opportunity to appear before the Committee so that we can explain in more detail the issues of concern for families of those with ASD.

An appearance before the Committee would also be an opportunity for us to share with you some of the experiences of our members and their interactions with the NDIS and the Agency.

People with ASD have the same rights to social inclusion and benefits as all other citizens, but, unfortunately, they remain some of the most vulnerable in our community. As adults, they have the right to live independent and full lives of their own choosing, with the appropriate supports.

AFSA's submission seeks to represent the voice of parents, carers and families, on behalf of or together with, their loved one with ASD, and highlight some key issues about the NDIS and planning.

AFSA represents the lived experience of those who love and care for those with ASD. AFSA would like to see a comprehensive effective, appropriate and sufficient system of support and services for those with ASD. Such a system would be tailored to the different needs and abilities of people within the ASD population.

Evidence indicates that people with ASD are over-represented within the disability support system as relinquished due to lack of support and families being overwhelmed and unable to continue to cope in their caring role.

While it might seem unnecessarily emotive, it needs to be remembered that there are regular and often tragic reports of individuals with ASD, dying through misadventure such as drownings after 'absconding', and subject to restraint and violence. This is often despite heroic efforts and struggles by parents/carers, support workers and emergency service workers to keep individuals with ASD, particularly those with complex needs, safe.

THE COMPLEXITIES OF ASD AND THE CHALLENGE OF THE NDIS

The Australian Advisory Board on Autism Spectrum Disorders (AABASD) in its 2013 submission on the NDIS stated that Autism Spectrum Disorder (ASD) is a complex, lifelong condition that includes severe social communication impairment and restricted interests and repetitive behaviours that substantially interfere with every-day functioning. People with ASD typically face challenges in all aspects of their life, including early childhood centres, school, tertiary education settings, work, and community contexts. They therefore require ongoing support in order to be successfully included in these mainstream settings.

As pointed out by the AABASD it is critical that the unique and complex characteristics of ASD be considered within all elements of the operation of the NDIS to ensure that families and individuals experience a service response that improves life outcomes. In particular, the Board identified the following focus areas:

- The functional assessment of people with an ASD must reflect the unique nature of the disability and ensure access to services that is appropriate to these specific needs.
- Families and individuals with an ASD need specific support and resources to navigate the service system.
- All people and organisations delivering services to the autism spectrum community must be skilled, competent and trained in the unique supports and interventions required to ensure the best possible outcomes.
- The NDIS must support a mechanism for the continued capacity building of autism expertise across Australia.
- All people with an ASD in regional and remote locations must receive a level of service that is of commensurate in quantity and quality to that received in metropolitan locations.

The AABASD maintained that reasonable and necessary supports for people with ASD must include close and ongoing collaboration between disability support services and mainstream services. It is AFSA's belief that the NDIA has not shown sufficient leadership in improving linkages between disability services and mainstream services, or taken a lead role in the coordination of these services.

No two individuals with ASD are the same. The presentation of ASD varies considerably depending on factors such as cognitive ability (IQ), personality and age. Some people with ASD have learning, sensory, and communication difficulties. Some people with ASD may have an average or above average IQ, and acquire spoken language at the same age as typically developing children. People with ASD often find understanding and relating to other people challenging and anxiety provoking.

Individuals with ASD vary in their communication skills. Some may never develop language. Others might acquire simple language, whilst others will develop fluent and effective language. Some have sophisticated vocabulary and/or the ability to speak with great technical complexity on certain topics, but may still have difficulty understanding or expressing complex or abstract concepts, especially in social situations. Sometimes their conversations may be very one-sided, and they struggle with the back-and-forth nature of conversations.

Some individuals with ASD have comprehension problems, often more so than suggested by their expressive language. Even the most able individuals with ASD report auditory comprehension difficulties at times at some level. Many rely heavily on visual skills to compensate for auditory comprehension problems. Some individuals with ASD may not develop speech but will be able to communicate through alternative assisted communication methods such as signing, picture exchange systems and AAC systems.

CHANGE IS NEEDED IN THE MARKET – PLANS WITHOUT AVAILABLE SERVICES ARE USELESS!

AFSA asserts that there should be substantial government involvement (Commonwealth and State) including alternative commissioning models and market deepening to improve support for people with autism. AFSA asserts that governments both Commonwealth and State should use the full ambit of their legal frameworks, their roles as funders of various service providers and their community and “moral” leadership roles to increase the supply of services to people with autism (especially those with complex and high support needs). There is no point in having even a well-funded plan if there are no or inadequate services and supports.

There is a thin market (at least in Victoria) for people with autism (particularly those with complex and high support needs) as there is a clear gap between the needs of people with autism, of all ages, and the services available in the (Victorian) market.

This applies as many service providers view people with autism as ‘vulnerable clients’. There are challenges in recruiting and retaining qualified workforces as well as providing learning and professional development opportunities.

GAPS IN THE MARKET

- There are some with complex needs and funding packages providing 1:1 support that providers will not service. Why is this case? The problem appears to have gotten worse since NDIS rollout. In the past services and clients were able to get assistance from the Victorian DHHS for additional support. For example, block funding or targeted funds going direct to services to pay for home modifications or behaviour supports. Why is this not able to be done now?
- There are also those whose packages are not adequate for example in the area of allied health support around communication and behavioural support. Many do not have sufficient funding to adequately address communication concerns and for individualised behaviour support plans. Proper support and intervention takes time, the development of detailed plans with measurable outcomes and adequate training/upskilling of those providing direct support.
- Difficulty finding suitable therapists who have expertise supporting those with ASD and complex needs. In particular speech therapists with expertise in Assisted Augmentative Communication and therapists skilled in behaviour intervention and the conduct of a functional behaviour assessment to form the basis of meaningful behaviour support plans. Many families are finding that junior therapists simply lack experience.
- There is also alleged denial of funding for vital communication equipment for example an iPad when the primary purpose is to assist an individual’s functional communication.
- Query: what are the qualifications that NDIS require for therapists to be NDIA accredited to provide behavioural support so participants can compare skills and expertise and receive a quality service?
- Many therapists charge travel and add on costs for phone calls, emails etc. that decreases a participant’s available funding pool for direct service provision.

- Lack of support for carers of those with ASD by providing adequate funding for respite - now termed short term accommodation - for participants. Also, suitable short term accommodation is hard to find especially for more complex participants who require “active “overnight support.
- Lack of assistance to find suitable housing for those with ASD. Many participants may not want to go into group homes but feel pressured to do so.
- Lack of “crisis” support under NDIS system
- Lots of what appears ‘buck passing’ of participants and families between various government departments leaving families of those caring for those with ASD in crisis. For example, children not attending school full time.
- Need for more of the old style DHHS case management type approach to those with ASD and complex needs rather than support co-ordination as many support co-ordinators do not appear highly skilled and/or are not funded adequately to provide a holistic service.
- Some participants with complex needs are not granted support co-ordination in their NDIS plans placing the burden on families and carers for plan implementation as the support provided by the Local Area Co-ordinators is in reality very minimal or virtually non-existent.

FAILURE OF RESPONSIBILITY BY VICTORIAN GOVERNMENT AND LARGE PROVIDERS

AFSA notes statements made by ministers after COAG on 28 June 2019 concerning a continued commitment and shared responsibility to deliver on the NDIS’ objectives with action. We note also statements about improving the service experience of children unable to live at home because of their complex disability support needs. We are awaiting real cooperation between Commonwealth and State to ensure action occurs, responsibilities are accepted by relevant agencies and gaps do not emerge in service provision.

There is clear evidence of a growing incidence of autism in the community in recent years. Despite the rollout of the NDIS services for people with autism have failed to keep pace with the growth in demand regional Victoria and metropolitan Melbourne.

There is compelling anecdotal evidence that many of the larger providers of services to adults, in metropolitan Melbourne at least, are refusing to accept autistic adults with complex or high support needs into their ‘day’ programs. That it is ‘all too hard’ and they can’t or won’t employ trained and competent staff to support such autistic individuals. This is despite such potential clients having received ‘one on one’ funding in their NDIS package.

The Victorian Disability Act 2006 imposes various obligations on the State Government. Victorian Government responsibilities should include the effective operation of the justice system, crisis support, diagnostic services, health and mental health services, suitable housing options, disability workforce development and training, adult services especially for those with high support needs, employment options and inclusive education for all Victorians.

The Victorian Government should not walk away from its legal and moral obligations to people with disabilities because it believes it is no longer its responsibility.

OUR CONCERNS AND ISSUES WITH THE NDIA

In brief, our concerns and issues with the NDIA include the following – all of which are impacted in one way or another by the NDIS Planning process as it currently operates.

1. A lack of knowledge about ASD in NDIA staff and uncertainty about the eligibility of support for people with ASD.
2. Many of our members have experienced what they see as excessive “bureaucracy” in getting to the right person (including the requirement to only using “secure” email) and the right information. Other members have had difficulty having complaints dealt with effectively and in a timely manner. There sometimes appears to be a lack of transparency in explaining what is in a plan.
3. While many of our members have much experience navigating the disability sector, the lack of readily available personal advocacy support for families of NDIS participants, where the participant cannot ‘self-advocate’, is a problem. There also seems to be limited understanding by participants and families of the “review” process.
4. There seems to be considerable confusion as to who can receive support co-ordination, the capping of transport funding is a major concern to many of our members and some service agreements seem to be very onerous.
5. There is preliminary evidence that the “market” may not be working and that there will be a lack of suitable services especially for participants with greater support needs. On the other hand, some much needed ‘therapy’ services are apparently finding it difficult to be registered with the NDIA, potentially shrinking the available pool of providers.
6. Finally, there are worrying reports that some participants and their families are actually worse off than they were before receiving their first NDIS package, measured against their previous ISP package.

OUR CONCERNS WITH NDIS PLANNING

- 1. ASD Knowledge**
 - a. NDIS staff do not appear to have adequate knowledge of ASD.
 - b. Concern with unqualified staff making decisions about what is a reasonable and necessary support and ignoring reports and recommendations from clinicians.
 - c. Concern about unqualified staff conducting assessments such as ‘Pedi-cat’ to determine the functional impact of ASD.
- 2. NDIS access**
 - a. Concern about classification of ASD and eligibility for the NDIS.
- 3. Bureaucracy**
 - a. Participants and their families who are confused about the NDIA process even after having attended pre-planning information sessions.
 - b. Excessive difficulty or too many layers to getting the right information or the right person, often in order to rectify apparently simple issues.

- c. NDIS have appointed LAC's to meet with participants and their families but there appears to be confusion as to what is the role of the LAC's. Do they develop the plan or do they gather information and send this to the NDIA plan delegate who builds the plan? If it is the latter, then someone who has not had direct contact is developing the plan which can potentially lead to misunderstanding and poor quality plans.
- d. Participants who have had several LAC's for a variety of reasons and do not have a central point of contact or consistency.
- e. Participants who cannot get their questions answered by LAC's who are meant to be the interface with the NDIA.
- f. Participants not informed of their rights to have meetings face to face or for a review etc.
- g. Participants who are not supported once the plan is approved to actually implement the plan.

4. Complaints process

- a. Carers experiencing delay and frustration with having their concerns addressed which is causing much stress.
- b. Carers report waiting seven or more months to have concerns addressed.
- c. NDIA not responding to complaints or correspondence in a timely manner.
- d. NDIA not responding to requests for reviews of a reviewable decision or plan reviews in a timely manner and confusing the two.
- e. NDIA confusing complaints as feedback.
- f. Ombudsman report (May, 2018) with recommendations due to the increase in NDIA complaints to their office.

5. Lack of Transparency

- a. Participants who have been refused a draft of their plan before final approval.
- b. Participants not getting a copy of the detail and breakdown of the figures in their plans for each category and what they represent.
- c. Participants not receiving written reasons as to why a particular support that was requested was denied.

6. Assistive equipment and technology

- a. Procedures that make it a difficult process to secure the assistive equipment, which may include communication equipment, which is needed.

7. Communication issues

- a. There is also a communication issue many are experiencing with the NDIA regarding the practice of sending a secure email from the Department of Human Services. Many do not wish to log in and open a separate email account with the Department of Human Services to receive email correspondence from the NDIS and prefer to use their personal email accounts.

8. Advocacy

- a. Advocacy – lack of available personal advocacy support for families when there are issues that may involve some complexity or uncertainty; not necessarily advocacy from the NDIA but advocates from NGOs or other organisations who understand some of the NDIS rules and systems who can support families in navigating the system.
- b. There is also confusion about the role of the LAC and potential conflict of interest in regard to advocating and assisting the participant to request reviews.

9. Support Co-ordination

- a. Confusion as to who should receive support co-ordination and how many hours.
- b. Apparent lack of inclusion of support co-ordination funding in initial plans.
- c. No explanation provided by the NDIA as to why participants have not been funded for support co-ordination.
- d. Some that have received support co-ordination are not happy with the service they are receiving and query the expertise of providers in this area.

10. Transport funding

- a. 'Capped' at three specified levels; not sufficient for many with complex needs and/or challenging behaviours. For example, it is reported that NDIA will pay \$11,000 for students with disabilities being transported on special school buses but cap transport costs to the three levels for other participants.
- b. Participants not encouraged to request more to cover their specific needs.

11. Worse off than under the Victorian State system

- a. Carers advising they are worse off and being required to pay for previously funded supports.
- b. Some participants appear to be 'worse off' after receiving their first NDIS package. Surely 'grandfathering' must occur and someone who was previously in receipt of support by a State Government individual support package should not be getting less in quantity or quality under the NDIS.
- c. Carers concerned about the pricing of services that have appeared to have increased, with some carers now having to pay the difference to ensure receipt of necessary services.
- d. Carers concerned about the funding models for centre based day services.

12. Service Agreements

- a. Some are more onerous than the NDIS model agreements and there is a take it or leave it approach from some service providers.
- b. Lack of support and understanding in negotiating these agreements especially with no support co-ordination.
- c. The cost of many services for those with disabilities appears to have increased significantly since NDIS. (While AFSA and other disability support organisations are

strongly in favour of good wage levels for disability workers and recognise that disability service organisations need to be commercially viable the rate of cost increases needs to be scrutinised to ensure no 'gouging' and that services are affordable).

13. Lack of funding

- a. Exclusion from the NDIS of worthwhile 'therapy' services. (While AFSA recognises the need to ensure 'charlatans' or unqualified people are not exploiting vulnerable people, reputable therapists must be allowed to provide necessary services and support especially for those people with disabilities who have behaviours of concern.)
- b. Undue regulation could mean that many therapists will cease to be registered with the NDIA for behaviour therapy which will shrink the pool of available providers.
- c. The NDIA, in a move to cut costs, is apparently allocating an amount for therapy assistants to work under qualified therapists. In reality therapy assistants are not available as many therapists do not have such assistants.

14. Reviews

- a. Lack of understanding of review process.
- b. Reports of funding being cut after reviews with no reasons provided.

15. Market forces

- a. Lack of services especially for participants with greater support needs resulting in many individuals with ASD sitting at home despite having money in their packages.
- b. No provider of last resort leaving some individuals with complex needs with no services.
- c. Is the 'market' working? What impact is the funding of individuals, as opposed to block funding, having on the organisations that have been providing disability services? No-one wants the unintended consequences that otherwise worthwhile service providers are 'forced out of business.
- d. Providers not willing to negotiate on fees and some providers charging vulnerable participants more than the scheduled fee.

16. Other Issues and Concerns

- a. Participants with complex needs being referred to LACs. The screening process does not appear to be working. Many cases should have been seen by planners in the first place (the actual decision makers) and not LACs.
- b. Lots of families waiting for reviews for many months. Families experiencing lots of stress and uncertainty because there is no guaranteed timeline.
- c. Participants who could not use their funding due to lack of available services/therapists having their funding slashed at review time.
- d. Long waiting lists particularly for therapists.
- e. Some complex participants put on a cycle of three months plans with constant reviews because it appears NDIA questioning the supports required.
- f. Participants' goals being altered by planners/LACs.
- g. Participants/families being discouraged from self-managing their funding

- h. Families with children out of school had no knowledge that NDIA is meant to pay for the “personal care” their child requires in school. Families did not have this recorded in their plans as an “in kind” support. There appears to be no transparency about this issue and query what is happening to the money allocated here?
- i. Too much reliance on families as informal supports (especially in regard to transport) even when participants are adults.
- j. Concerns about funding arrangements for group homes and issues around the support required (usually 1:1) for community access.
- k. Participants who do not know who the NDIA planner was because only their first name and initial is recorded in their plan.
- l. Participants being told by LACs and even planners what supports they can and can't have when this information may not be correct. For example, family with a child with professional reports recommending weekly speech sessions told by LAC that this was not possible.
- m. Inconsistent advice received from NDIA 1800 number.
- n. Some would like to go to an NDIA office and speak to someone face to face about issues but it appears this is not possible or not encouraged?
- o. Participants who need to constantly go through the 1800 number and leave a message because they are not given the planner/LACS direct number or email address.
- p. Complaints appear to be “handballed” around the agency with no time frame or central point of reference.
- q. NDIA losing paperwork. This was raised by two members who had put in for reviews and they had to chase the matters and send the paperwork in multiple times.
- r. Lots of pilot programs which are trialled and don't then appear to be rolled out. Members queried what has happened to the improved planning pathway pilot and the complex needs pilot?
- s. Families unclear why supports requested have been denied because they never received a clear explanation. Why can't a “timely” written explanation be provided?
- t. Families concerned about privacy and documents some highly sensitive (medical information and even complaints) which have been uploaded to the portal. Who uploads them and has access to these documents when participants can't access/read them?

17. Internal NDIA workings and Structures – Lack of Transparency

- a. NDIA need to better explain work of and role of its Branches including the Complex Support Needs Branch (CSNB). Is there a definition of “complex needs”? (Many people with autism have both complex needs eg around communication, behaviour and cognitive). Where does “high support”(eg need for 24/7 support because of safety, health etc) come into consideration?

SOME OTHER AFSA QUESTIONS AND ISSUES

1. Does Complex Support Needs Branch have linkages with NDIA Autism Advisory Group?
2. Does NDIA have any “in-house” autism experts or expertise? AFSA would like to have some input to them based on the “lived experience”? If not, is it planned to develop some in-house autism expertise given the very significant autism cohort who are part of NDIS?
3. If NDIA is aware of and accepts the lack of support services for people with autism with complex needs, what is NDIA doing to address? NDIA would seem to have leverage (carrots and sticks) to influence providers to do more for complex needs clients. Is NDIA considering “partnerships” with Providers, educators and State Governments to increase for example the workforce of those who can support people with autism with complex needs?
4. Is NDIA aware of some of the difficulties that residents of what were known as Community Residential Units (CRUs) recently “outsourced in Victoria to private sector have in managing their packages and ensuring no gaps in services? (AFSA can provide examples). If so, what is being done to work with State Governments and providers to overcome “bureaucratic” issues?
5. Is NDIA supportive of trying to ensure that “multi-disciplinary” teams can be catered for in “packages” of those with complex needs? [For example that psychologists, OTs, speech therapists and others can work with primary care providers and be funded/supported. And, that there is necessary “integration” of services including medical and health that are not funded directly by the NDIA?]
6. Does NDIA recognise the needs of many NDIS clients who have little or no functional communication and therefore need appropriate teaching, devices and support?
7. The current NDIA pricing guide does not include Board Certified Behaviour Analysts. Which therapists can provide behaviour support under NDIS for those with complex needs?
8. Funding for transport for those with complex needs who cannot use public transport or go unaccompanied in taxis continues to be an issue.
9. There are school-aged children with autism who are not allowed to go to school full time. Who is supporting this group?
10. Does NDIA have any particular services or support for families of NDIS clients who have complex (and/or high) support needs? If not, AFSA would be happy to be consulted on some practical things that NDIA might be able to do for families.

Submitted by the Autism Family Support Association Inc.
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