

10 September 2019

Amaze

Submission to the

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

NDIS Planning



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Autistic people and the NDIS: an introduction

- With autistic people constituting almost one third of all National Disability Insurance Scheme (NDIS) participants (30%)¹, a high-level understanding of autism is required across the National Disability Insurance Agency (NDIA) and its partner agencies.
- The NDIS must have an 'autism specific' approach (ideally through the development of a dedicated Autism and Neurodevelopmental stream) to provide efficiencies in how the scheme works for autistic individuals and provide for their specific needs.
- Autistic people, their families/carers and the autism sector must also be engaged by the Commonwealth Government and NDIA on all aspects of the NDIS's ongoing development and implementation.
- Autistic people accessing the NDIS should be empowered to set their own goals, be involved in every step of the NDIS planning process, and exercise self-determination through choice and control over their support services.
- Autistic people must be given an informed choice about how they engage in the planning process and given adequate opportunities to provide information to planners.
- Autism specific training should be prioritised for all individuals and services that interface with the NDIS.

Executive Summary

Recommendation 1

Establish clear and consistent eligibility criteria for autistic people, including the creation of robust and evidence-based tools to ensure assessments are autism appropriate and consistent.

- The **current method** of using the Diagnostic and Statistical Manual of Mental Disorders (Fifth Edition) (DSM-5) Levels 2 and 3 **to determine eligibility for NDIS is deeply flawed** – the DSM-5 itself clearly states that the severity levels should not be used to determine service eligibility.
- **No single functional assessment tool captures the range of difficulties** that young autistic children can present with. Caution should be taken in using any assessment tool to measure functional needs.

Recommendation 2

Create an Autism and Neurodevelopmental stream to build autism expertise within the NDIS, and offer better planning outcomes and simplify the NDIS process for autistic people and their families.

- A **specialist stream** would build autism expertise among NDIA staff, Local Area Coordinators (LACs) and Early Childhood Early Intervention (ECEI) staff including:
 - The **functional impacts of autism**.
 - How to **support autistic people to engage in the planning process**.
 - The **evidence-based supports** to derive the best short and long-term outcomes in autistic people.
- NDIS participants are often not getting the right plan due to little or no understanding of autism by planners – 65% of autistic NDIS participants (or their carers) rated their **planner's knowledge and understanding** of autism as **none to moderate**.

Recommendation 3

Increase the professional development, training, guidance and capacity building for NDIS staff, LACs and ECEI staff over the lifetime of their employment.

- Develop, implement and provide improved **guidelines for planners to support a consistent approach to the advice and information** given throughout the pre-planning and planning process to autistic people and their families/carers.
- **Increase the professional development, training, guidance and capacity building** for planners over the lifetime of their employment.

Recommendation 4

Ensure all autistic people gain access and have an approved plan within six weeks, with priority given to ECEI participants due to the implications for their development trajectory.

- The NDIA should **adhere to the set guideline of prioritising plan development to within six weeks for children under six with a developmental delay**.
- **Ensure autism specific evidence-based interventions and supports can be accessed as soon as possible by autistic people.**
 - This includes ensuring there is no delay in a diagnosis of autism being facilitated with the assistance of an ECEI partner in the case of children showing precursory autism-like traits or autism-like traits.
- The NDIA utilise **available data and** apply the **learnings and research in the ongoing development and implementation** of the NDIS ECEI approach.

Recommendation 5

Improve support, enhance transparency and provide greater flexibility for all autistic people, and their families/carers during the **pre-planning, planning and review process**.

- **Continue to fund the Amaze Autism Advisor Service** which supports autistic people and their families/carers to prepare for the access, planning and implementation phases of the NDIS.

- Continued funding to Disability Support Organisation to **facilitate pre-planning and peer supported workshops** to planners and autistic participants and their and their families/carers.
- **Ensure planners support autistic participants during the pre-planning process**, including for autistic people with **complex support needs** including through **informed choice in how they engage** in the planning process.
- **Improve the transparency, quality of, and consistency** in the planning process and participant plans, including through **enhanced monitoring and accountability by the NDIA** during planning process.

Recommendation 6

The complaints process must be **accessible to all participants (and their families, carers and the broader community)**.

- This is particularly relevant to enable complaints to be made and appropriate action taken against providers and workers that engage in unacceptable behaviours.

Recommendation 7

Stimulate targeted growth in autism services, including **early intervention services** and particularly for **participants who are women, with complex needs, in thin markets** and/or in **regional and remote areas**.

- Government **should stimulate growth in the skilled disability workforce** through the use of alternative methods, such as an **element of block funding** for services in regional areas.
- **Workforce development and investment** to ensure a level of quality in staff that will provide services to autistic people through the NDIS.
 - This should extend to those providing higher skilled roles such as allied health professionals and staff working with autistic people.

About Amaze



Amaze is the peak body for autistic people and their supporters in Victoria. Established in 1967, today Amaze represents a community of more than 55,000 autistic Victorians in shaping a better future for autism.

Amaze seeks to achieve three key outcomes:

- Community understanding of autism in Victoria increases over time.
- Attitudes and behaviours towards autistic people by the Victorian community (government, private and social sectors) improve over time.
- Opportunities for meaningful participation and valued contribution increase for autistic people.

Amaze works to ensure that the voices of autistic people, their families and carers are at the centre of all our work.

The priorities in the submission have been developed in partnership with autistic people and their families and carers. The experiences of autistic people are provided throughout the document.

What is autism?

Autism is a neurodevelopmental disability that affects the brain's growth and development. It is lifelong, with traits that appear in early childhood.

Autism facts:

- In 2015, the ABS reported there were 164,000 Australians with an autism diagnosis and a prevalence rate of 2.8% for those aged between 5-14 years (81,000 Australian children). However, the true prevalence of autism in Australia is likely to be much higher given the large numbers of autistic adults who remain undiagnosed.²
- 85% of Australians have personal contact with an autistic person.³
- Only 29% of Australians feel they have a good understanding of how to support an autistic person, with only 4% of autistic people and their families agreeing that people in the community know how to support them.⁴
- Autism is the largest National Disability Insurance Scheme (NDIS) diagnostic group – representing 30% of all participants receiving an individual funding package.⁵

Every autistic individual is different and will experience autism in different ways, however the below features are always present in some form:

Challenges in communicating and interacting with other people

- Sharing interests and emotions - this can range from a lack of interaction to wanting to interact, but not knowing how to do it in an appropriate way.
- Using and understanding non-verbal communication, such as body language, eye contact or facial expressions.
- Making friends, maintaining friendships and adjusting behaviour to different social situations.

Sensory processing difficulties

- Being either over- or under-sensitive to sensory stimuli, including sounds, smells, tastes, textures or visual stimuli. Often the same person will be over-sensitive to some things and under-sensitive to others.

Repetitive routines in behaviour interests or activities

- Repetitive speech, movements or use of objects.
- Routines, rituals or resistance to change.
- Interests that are very intense or narrow in focus.

Section 1 - Clear eligibility criteria with a focus on functional assessment

Recommendation 1

Establish clear and consistent eligibility criteria for autistic people, including the creation of robust and evidence-based tools to ensure assessments are autism appropriate and consistent.

- The **current method** of using the DSM-5 Levels 2 and 3 **to determine eligibility for NDIS is deeply flawed** – the DSM-5 itself clearly states that the severity levels should not be used to determine service eligibility.⁶
- **No single functional assessment tool captures the range of difficulties** that young autistic children can present with. Caution should be taken in using any assessment tool to measure functional needs.
- **Clear, accurate and consistent communication** is also needed **regarding diagnostic requirements** for autistic people to enter the scheme as participants

A **robust and reliable tool to ascertain eligibility** for autistic people – that doesn't rely on DSM-5 ratings – with an autism-appropriate functional assessment, is urgently needed. Clear, accurate and consistent communication is also needed regarding diagnostic requirements for autistic people to enter the scheme as participants, combined with a robust strategy for implementation of the new national diagnostic guidelines for autism.

The NDIS currently 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. The issue with utilising the DSM-5 autism diagnostic levels is that it is a subjective professional assessment that can change between assessors. **DSM-5 clearly states that the severity levels should not be used to determine eligibility for services.**

There is also an ongoing systemic failure to identify and diagnose autistic girls and women. This is due to:

- A lack of recognition and understanding across sectors of the differences in how autism presents in girls and women compared to boys and men.
- Historic gender biases in autism screening and diagnostic tools.

Commonly used autism screening and diagnostic tools – such as the Autism Diagnostic Observation Schedule [ADOS] and the Autism Diagnostic Interview–Revised [ADI-R] reflect a presentation more commonly found in boys and men than women and girls. The tool may lack the sensitivity and specificity required to identify autistic characteristics in women and girls. ⁷

Section 2 - Build autism expertise and competency in planners

Recommendation 2

Create an Autism and Neurodevelopmental stream to build autism expertise within the NDIS, and offer better planning outcomes and simplify the NDIS process for autistic people and their families.

- A **specialist stream** would build autism expertise among NDIA staff, LACs and ECEI staff including:
 - The **functional impacts of autism**;
 - How to **support autistic people to engage in the planning process**;
 - The **evidence-based supports** to derive the best short and long-term outcomes in autistic people.

Urgent investment is needed for a specialist Autism and Neurodevelopmental stream, **building on** the approach of the recently adopted **Psychosocial Disability** stream.

A dedicated Autism and Neurodevelopmental stream would lead to **better planning outcomes, greater efficiencies, and help simplify the NDIS process** for autistic people and their families. Training would also be given to all NDIS staff, LACs and ECEI staff about autism and evidence on effective supports, so that they are appropriately skilled to support autistic people and their families/carers to achieve their goals.

Recommendation 3

Increase the professional development, training, guidance and capacity building for NDIA staff, LACs and ECEI staff over the lifetime of their employment.

- Develop, implement and provide improved **guidelines for NDIA staff, LACs and ECEI staff to support a consistent approach to the advice and information** given throughout the pre-planning and planning process to autistic people and their families/carers.

- **Increase the professional development, training, guidance and capacity building** for NDIA staff, LACs and ECEI staff over the lifetime of their employment.
- Ensuring a level of quality in staff that will provide services to autistic people through the NDIS, extending beyond those providing **higher skilled roles** such as allied health professionals, through **to all staff working with autistic people in residential housing, day centres and staff providing other personal care and support**.
- **NDIA staff, LACs and ECEI staff should always consider the functional impacts** of autism on an individual as an indicator of capacity.

Build the education, understanding, knowledge and capacity of NDIA staff, LACs and ECEI staff of how autistic people may best engage with; and be impacted by the planning process including knowledge of the wide range of supports autistic people may need.

- **Understand the impact of autism on daily life and the need to delve deeper into daily living tasks.**
- **Understand the spectrum of autism.** Autism occurs on a broad continuum; whereby autistic people can have broad range of support needs. Every presentation of autism is unique – if a family has a number of autistic children autism will affect each child differently. For families with more than one autistic child, ideally one planner should be allocated for all children of the family.
- **Understand the need to use specific rather than general communication.** Autistic people often take language literally and need clear and specific language that is clear, unambiguous and specific.
- **Be across the evidence base for autism interventions and the types of services that can provide effective support** so people can make informed choices about service provision.

NDIA staff, LACs and ECEI staff should also have an understanding of:

- The role of allied health professionals in supporting autistic people.
- The role that staff, carers and families provide through personal care and support.
- Complex support needs for some autistic people, including the importance of providing a plan that addresses the individuals' needs and responds to environmental factors relevant to the autistic person.

- Developing a plan that appropriately and comprehensively addresses the complex support needs for some autistic people across multiple domains (i.e. health, mental health, justice etc.); and/or addresses the high levels of need in one or more areas.

Developing, implement and provide improved guidelines for NDIA staff, LACs and ECEI staff to support a consistent approach to the advice and information given throughout the planning process to autistic people. This includes guidance for NDIA staff, LACs and ECEI staff to:

- Ensure informed choice for how autistic people engage in the planning process (whether by phone or face to face).
- Provide appropriate information in advance to support participants and their families/carers in planning meetings.
- Give autistic people consistent and clear advice about criteria for support, the supports for which funding may be used and other post-planning issues.
- Demonstrate necessary levels of flexibility in the application of reference packages and provide consistent advice on when further evidence from experts may be required.
- Ensure that if assessment tools are to be used, ongoing refinement of those tools occurs to ensure they are sensitive to the characteristics and highly varied levels of functioning autistic people experience.

Lack of knowledge and understanding of autism by NDIA staff, LACs and ECEI staff

- NDIS participants are often not getting the right plan due to little or no understanding of autism by NDIA staff, LACs and ECEI staff.
- 65% of autistic NDIS participants (or their carers) rated their **planner's knowledge and understanding** of autism as **none to moderate**.⁸

Some autistic people who have more than one diagnosis are using alternative diagnostic conditions when applying for the NDIS because they believe that it will make the planning process easier **and required supports more accessible**.

For example, some autistic people might **rely on their psychosocial disability as the primary disability** since they believe the NDIA staff or LAC will have a better understanding of the challenges that accompany **bipolar disorder** rather than explaining **the supports they need relating to their autism**.

There is a lack of understanding by NDIA staff, LACs and ECEI staff of the high occurrence of mental health concerns and autism. Parents have reported to Amaze that planning staff assume that anxiety and depression are “just part of autism”, and **mental health issues aren’t addressed adequately with funding**. Poor mental health is a common feature in the autistic population with between **50-70% of autistic people having co-existing mental health conditions**⁹, though there are indications the prevalence may be higher. The latest data for NDIS participants reported that **36% of participants who have Autism as a primary disability, have at least one secondary disability**, with the **second most common co-occurring disability being a psychosocial disability (11%)**.¹⁰

In the last 6 months, people calling the Amaze Autism Advisor Service have described frustration and other difficulties with being understood by the NDIS planner.

Case study: Tim

Like many autistic people, 4-year-old Tim has sensory sensitivities and rigid thinking. His mother instructed the ECEI coordinator who visited her at home not to touch him. Despite this, the ECEI coordinator tickled Tim, presumably in an attempt to build rapport. The coordinator was asked again not to touch Tim, and even Tim was able to loudly advocate for himself, saying ‘Please don’t touch me, I don’t like it’. The Coordinator then demonstrated her complete lack of understanding of autism by picking Tim up.

Tim became very distressed and the meeting was derailed. Tim’s parents have lost faith in the NDIS process and in staff to understand and respond appropriately to information provided about their child’s needs.

Lack of understanding of the functional impacts

In the last 6 months autistic callers to the Amaze Autism Advisor Service have described examples where **NDIA staff and LACs have made incorrect assumptions about their abilities and life circumstances**.

For example, some LACs and NDIA staff have assumed because an autistic adult has passed a university or TAFE course or attended mainstream school, they would be able to hold down a job.

Case study: John

John is a 19 year old autistic university student. He sought transport support from the NDIS as the sensory and social environment of public transport is overwhelming, plus support to assist with his organisation, planning and time management due to challenges with executive functioning. The

Local Area Co-ordinator told John that, as a university student, he would not be eligible for the NDIS.

John withdrew from university, impacting his self- esteem, his dependency on his family and his future economic and community participation.

Section 3 - Ensure early access for participants and improve the entire planning and review process

Recommendation 4

Ensure all autistic people gain access and have an approved plan within six weeks, with priority given to ECEI participants due to the implications for their development trajectory.

- The NDIA should **adhere to the set guideline of prioritising plan development to within six weeks for children under six with a developmental delay**, where there is evidence that delay in early intervention supports would reduce the effectiveness of those supports or lead to a worsening in the impairment of the child.
- **Ensure autism specific evidence-based interventions and supports can be accessed as soon as possible by autistic people**
 - This includes ensuring there is no delay in a diagnosis of autism being facilitated with the assistance of an ECEI partner in the case of children showing precursory autism-like traits or autism-like traits.
- Any delay in accessing services could have a **significant detrimental impact on the short and long-term outcomes of autistic children**.
- The NDIA utilise **available data and** apply the **learnings and research in the ongoing development and implementation** of the NDIS ECEI approach

Evidence and experiences with the planning process

- **Waiting times** for diagnosis in the public system can be **between 12 months to two years**, with longer waits occurring in regional, rural and remote Australia. There are significant costs with accessing private assessment and diagnosis, with a mean cost of \$580 but ranging up to \$2,750.¹¹
- **Early intervention** for autistic children is estimated to **produce a net benefit of \$365 million**, however under the NDIS, children are currently facing up to 12 months delay in accessing early intervention services¹².

Prevalence of timeliness complaints

Timeliness is the most common subject of complaints to the NDIA, amounting to **one third of all complaints by participants**.¹³ Although timeliness is a key issue across the NDIS, it is a critical issue for the Early Childhood Early Intervention pathway.

Case study: Charlie

Charlie is four, with the social skills of a 9 month old. NDIS confirmed his eligibility and access in March 2018. Despite paediatrician's advice, five diagnostic reports and individual research supporting his need for intensive support, Charlie's family were told his request was not justified, forcing them to use their life savings to fund his therapies.

With the support of an advocate, his plan was finally approved 9 months later.

The need for early intervention

Systematic reviews of the evidence clearly demonstrate that intensive early intervention support for autistic children, **accessed as early as possible, is key to increasing their developmental trajectory over their lifetime**, allowing them to be as independent as possible and participate to their full potential including education, employment and their community.¹⁴

Providing early intervention to autistic children (at its most conservative estimate) has been shown to produce **a net benefit of \$365.7 million and a benefit-cost ratio of 4:1**.¹⁵

Children must be supported to access **high quality, multidisciplinary, family centred therapies**, to each child's (and family's) unique needs in line with evidence based best practice for guidelines for autistic children¹⁶. **Intensive early intervention support for autistic children is key**, with 20 hours of early intervention per week shown to be an effective number, but the types of services need to vary depending on the child and the family.¹⁷

The Commonwealth Department of Social Services has also been funding **Autism Specific Early Learning Centres** around Australia since 2010. These centres have undertaken significant research and recorded and analysed a substantial amount of data on the outcomes of children attending these centres.

Recommendation 5

Improve support, enhance transparency and provide greater flexibility for all autistic people, and their families/carers during the **pre-planning, planning and review process**.

- **Continue to fund the Autism Advisor Service** which supports autistic people and their families/carers to prepare for the access, planning and implementation phases of the NDIS.
- **Ensure planners support autistic participants during the pre-planning process**, including for autistic people with **complex support needs**. This includes:
 - Providing **ongoing funding for Disability Support Organisations (DSO)** to continue providing pre-planning workshops and peer support, including specialised support for autistic people.
 - Further **invest in additional peer networks and pre-planning support**, drawing on successful experiences funded through the DSO program.
- **Improve the transparency, quality of, and consistency** in the planning process and participant plans, including through **enhanced monitoring and accountability by the NDIA** during planning process.
- **Provide transparent, clear, comprehensive and up-to-date information**, to both participants and planners, including on:
 - How the planning process operates, what to expect during the planning process and participants' rights and options.
 - The role that reference packages now play in the determination of reasonable and necessary supports.
 - How flexibility in the application of these packages may be managed by planners
 - These resources should be tailored to the needs of different audiences, including autistic people and disaggregated into the different life and transition stages.
- **Support and facilitate informed choice for participants** in how they engage in the planning process (whether by phone or face to face). This includes ensuring autism participants:
 - Receive pre-planning supports to ensure they are fully informed about the planning process.
 - Are provided with preparatory information about the types of questions they will be asked.

- Understand the matters they need to consider for the planning meeting.
 - Are offered the option of have several shorter planning meetings rather than one long planning meeting.
- **More effective plans**, including improvements to ensure the plan **addresses the needs of autistic people to engage with daily life, including:**
 - Sections and commentary on **‘Plan reviews’** and **‘Participant apprehension’** and **‘Participant wording of goals’** in each plan.
 - For functional assessment processes, **providing participants with an opportunity to first read the questions prior to, or at least during the planning meeting.**
 - **Planners should also populate the assessment tool to the extent possible prior to, or during the planning meeting** with any expert evidence provided by the participant, e.g. evidence/reports provided by participant’s therapists, teachers and medical practitioners.
 - Include a **‘cooling off period’** for autistic participants once their plan has been approved.
 - This period could last a month and any issues that they encounter while implementing their plan could be discussed before the cooling off period ends and the plan becomes finalised.
 - Provide autistic participants **the option to see a draft version of their plan before it goes to the NDIA**, including for autistic participants with complex support needs.
 - In line with the United Nations Convention on the Rights of Persons with Disabilities the contents of **NDIS plans should be expressed in plain English.**
 - For autistic participants with complex support needs, the entire planning process should be **broken down into multiple stages with sufficient time to support multiple reviews and editing by participants.**
 - Support coordinators or case managers should be part of this process, including to support sharing relevant information as part of the planning process.
 - The NDIA **conduct research** by and with autistic people, **to further develop existing guidelines and recommendations.**
 - In the last 6 months a common issue from callers to Amaze **was NDIS access relating to ‘proving’ functional incapacity due to autism alone.** While multiple conditions seem to be considered for children’s plans, autistic adults who attend

their planning meetings seem to be disadvantaged if they present on a 'good day' with effective coping strategies in place, rather than on their 'worst day'.

- In the last 6 months, **a number of callers sought advice about obtaining evidence** for NDIS planning meetings, **several displayed distress in the preparation process, including** crying during their phone call; feeling overwhelmed; and being unable to process information and what next steps they need to take in the planning process
- Communication difficulties are a common trait among autistic people¹⁸, and **conveying their particular circumstances can be problematic, especially to multiple planners**

Providing a pre-planning phase and peer support workshops

Amaze has been working as a Disability Support Organisation for over 4 years and has observed the **significant benefits of facilitated pre-planning and peer supported workshops**. An early evaluation of DSO workshops found they have a positive impact, specifically around the areas of **disseminating NDIS information and building NDIS readiness**, creating positive social and community inclusion and cohesion, and improving self-advocacy and autonomy.

The overwhelming feedback from participants is that the workshops have been key to enabling **meaningful participation in their planning meeting. Having support from peers through these workshops**, including those who were further along in the planning process, was also considered extremely valuable.

Lack of support with developing goals during planning meetings

Some participants experienced LAC or NDIA delegates had re-written their goals without their consent **or that the plans do not match their expressed goals**. This has resulted in some autistic adults to request a plan review so that the wording of their goals can be changed to the wording which they had agreed at the meeting.

Some autistic adults expressed dissatisfaction when the planning meeting did not **consider their NDIS goals**. Many noted that discussions regarding **goals are limited and focus on maintaining activities** rather than new ways to improve or extend their skills and abilities.

For example, an activity goal might be to continue going out with a social group to the movies instead of having a goal of attending workshops aimed at improving social

skills in anticipation of finding suitable employment or developing independent living skills.

The Amaze Autism Advisor Service **regularly receives enquiries about how autistic people can volunteer, gain work, or maintain education activities.** Specific enquiries on these topics were noted in the last 6 months.

Reference packages

Reference packages often fail to **take into account individual needs** of participants and to **recognise the unique types and combinations of supports sought** and/or **take adequate regard to reports submitted by participants**, i.e. from psychologists or speech pathologists.

One caller to the Amaze Autism Advisor service is currently querying his plan regarding the need for funding for allied health support which was urgently needed. They had received **\$55,000 in core supports that he was not using** but was unable to get additional funding or approval to use this existing funding for allied health support.

Feedback received by Amaze has been that participants also often **don't know when further evidence should be sought or is required**, such as for home modifications and equipment.

Adapting the planning process

A significant proportion of autistic adults prefer communications that are not face to face. Evaluation of Amaze's information service consistently shows that **autistic people utilise the webchat facility at three times the rate of their use of the live phone option.**

A significant proportion of autistic people experience cognitive processing delays and heightened anxiety, it may be **more effective to run a series of shorter planning meetings, rather than one, long session.**

Some autistic participants are **finishing their planning meetings quickly due to their difficulties with social communication** which they encounter while interacting with an NDIA planner or LAC. In the last 6 months, a number of **callers described being too anxious to continue the planning process.**

Some autistic adults have explained that they are having to retell their entire life story to a different person each time they conduct a planning meeting. This burden is

confronting for many autistic adults as they have to **build rapport with a new person, retell their entire story from the start, and then hope that the new person understands the important elements in the story.**

Limited support obtaining documentation

Some autistic adults are finding the task of obtaining the necessary documentation for their planning meeting **logistically and emotionally difficult.** This burden of collecting evidence is also **disrupting to their lives, including going to work.**

Lack of support and concerns with plan reviews

Some autistic adults are reporting that their **concerns for a request for a plan review are not being taken seriously.** They are often having to wait **a long time for a review** to occur and this wait is **impacting on their ability to use their NDIS plan.**

In the last 6 months, a number of autistic adults contacted Amaze seeking advice regarding what to do **while waiting for delayed plan reviews.** Intolerance of uncertainty and higher rates of anxiety are recognised autistic traits, leading to poorer outcomes for NDIS participants who have concerns about their plan.

Some autistic adults have contacted the NDIA to initiate a plan review because the **funding in their plan does not reflect the needs their psychologist or health professional** has recommended in the evidence reports provided to the LAC.

Some autistic adults are **apprehensive to initiate a plan** review because they have **been told that their funding could be reduced.**

Complex Support Needs

- Many NDIS participants have multiple conditions which affect their functional capacity. It is estimated that **15-25% of autistic people have complex support needs.** Additionally, about 5% of participants had ASD as a secondary disability, with two-thirds of these having a primary intellectual disability.¹⁹

Autistic people with complex support needs may also have complex communication needs. For adults with severe to profound disability, in particular, communication can vary from unintentional behaviours to limited symbolic skills

- The Office of the Public Advocate has described the difficulties for people with complex and challenging support needs to obtain adequate supports under the NDIS.^{20 21}

- While this report does not focus on autistic people, a majority of the OPA's case studies that explain barriers involve people diagnosed with autism. The key barriers are:
 - *NDIS worker capability* - For people with complex and challenging support needs, it is essential that planners take sufficient time to engage with the person and accept advice from people who have worked with them to understand their unique and complex support needs.
 - *Lack of case management*: Many people with complex needs have large, multidisciplinary care teams and multiple service providers. However, the NDIA does not fund case management and does not always provide funding for care team communication, information sharing and training.
 - *Lack of skilled/motivated service providers*: The thin market problem is exacerbated for people with complex needs with challenging behaviour and/or in crisis. Despite the high levels of funding on offer through their NDIS plans, many service providers are unwilling to assist people with complex needs because of the complexity, challenges and risks involved in meeting their needs. These NDIS market issues are compounded by the absence of any designated service provider/s of last resort.
 - *Accommodation*: In addition to the challenges of engaging and retaining suitable service providers, many people with complex support needs are failing to realise the transformational benefits that should be possible through their NDIS plans because of accommodation issues. Without suitable and stable accommodation, many of the other necessary supports cannot be implemented or will be ineffective. Accommodation is discussed further below, in the section titled 'Accommodation'.

Section 4 - Improve the autism accessibility of the complaints process

Recommendation 6

The complaints process must be **accessible to all participants (and their families, carers and the broader community)**

- The NDIS Quality and Safeguards Commission (the Commission) to work with a **trusted, independent and experienced organisation** that works in close collaboration with autistic people, **to ensure that the complaints process is fully accessible to autistic people.**
- The Commission should support providers to **develop autism accessible complaints methods and procedures.**
 - The process should ensure complaints can be made and **appropriate action taken against providers and workers** that engage in unacceptable behaviours.
 - **A variety of methods for lodging complaints** with providers and the Commission must be available (i.e. in person, by telephone, online etc.) to ensure all participants can comfortably, reliably and comprehensively complain about any potential breach of the Code.
- The Commission should also be required to ensure that participants, their families, providers, workers and the broader community are **aware of the complaints process and how they can lodge a complaint.**
- The right to lodge a complaint under the Code should be **clearly explained during the planning and post planning stages** and **widely promoted across a range of communication mediums.**
- All **service providers**, or at the very least registered providers, should also be **obliged to inform participants and their families about their rights** to complain and **how to lodge** a complaint under the Code.

Autistic participants have varying levels of comfort and confidence with different types of communication. The **complaints process may need to be tailored to support the individual** to ensure they are enabled to enact their right to make a complaint.

Some participants may **not feel confident or able to complain in person** or may **have difficulty comprehending long verbal instructions** over the telephone. Others may **not feel confident or able to express their complaint** over the telephone or in person and/or may have difficulty understanding or filling out complex forms.

Section 5 - Stimulate targeted growth in the disability services sector and investment in the disability workforce

Recommendation 7

Stimulate targeted growth in the autism services, including **early intervention services** and particularly for **participants who are women, with complex needs**, in **thin markets** and or in **regional and remote areas**.

- Government **should stimulate growth in the skilled disability workforce** through the use of alternative methods, such as an **element of block funding** for services in regional areas.
- **Workforce development and investment** to ensure a level of quality in staff that will provide services to autistic people through the NDIS.
 - This should extend to those providing higher skilled roles such as allied health professionals and staff working with autistic people.

Emerging research also supports the efficacy of **delivering therapeutic services to remote locations via videoconferencing facilities**.

Autism **specific training and capacity building** should be available to all registered providers of supports.

Current approved providers of the Helping Children with Autism (HCWA) program must also be adequately supported and **encouraged by the NDIA to transition to becoming Registered Providers of support under the NDIS**.

The lack of market development is **impacting on the options of autistic** adults in accessing services. It is also **causing them anxiety as they fear that the funding in their plan might be reduced** during the next plan period **because they have not utilised their funds**.

In the last 6 months, 41 autistic adults contacted the Amaze Autism Advisor service seeking assistance with finding suitable service providers who had autism expertise.

Case Study: Alex

Alex is an autistic adult with high support needs who is cared for by his father Margus, a 65 year old single dad.

Alex is not having his needs addressed for short term accommodation in his plan, putting incredible strain on Alex and Margus – who has his own health concerns, having recently undergone a complete hip replacement.

Alex's short term accommodation was previously block funded by the Queensland Department of Disability Services, Alex's contribution to the cost of four overnights during the week was \$235 which was affordable and paid from his Disability Support Pension. The balance of costs was covered by the block grant. When the NDIS took effect from 1 July 2018, Alex (and many other participants) did not receive sufficient funding to cover the cost of his stays, at around \$2,700 each. This is a prohibitive expense – however, with no short-term accommodation options now viable for Alex and Margus, they are struggling to maintain their relationship and individual wellbeing.

With no respite from his caring role, Margus is suffering from chronic sleep deprivation, which is debilitating and quickly breaks down his resilience and general well-being. He is exhausted and is often so fatigued that he feels like a 'dysfunctional zombie'. This environment is causing incredible strain for Alex and Margus, and without a clear path forward the situation will only deteriorate.

Accessing services in regional and remote locations for autistic people is currently very difficult, with people often reporting to Amaze having to travel many hours to access specialist services, often only if they have the means to pay for them privately.

Lack of recognition that autism presents differently in women and there is a lack of gender-specific support services for autistic women. In contrast, autistic men appear to have a **wider** range of services that they can access.

While at least 58 women rang the service seeking assistance with finding a psychologist to gain an autism diagnosis, **only 6 women in the past 6 months contacted Amaze pursuing NDIS access for themselves.** This suggests that many women may be autistic but do not access supports, potentially compromising their ability to **participate to their full potential, including education, employment and their community.**

References

- ¹ NDIS. (2019) *2nd Quarterly Report to COAG 2018-19 Q4*, 30 June 2019
<https://www.ndis.gov.au/about-us/information-publications-and-reports/quarterly-reports>.
- ² ABS. (2017) *4430.0 - Disability, Ageing and Carers, Australia: Summary of Findings*, 2015.
<http://www.abs.gov.au/ausstats/abs@.nsf/Latestproducts/4430.0Main%20Features752015>.
- ³ Amaze, (2018) *Strategic Directions to 2040 and Strategic Plan 2018-2021*.
- ⁴ Jones S et al. 2017, *Experiences of Autistic People and their Families*, Centre for Health and Social Research, Australian Catholic University.
- ⁵ NDIS National Dashboard as at 30 June 2019. <https://www.ndis.gov.au/about-us/publications/quarterly-reports>
- ⁶ American Psychiatric Association: *Diagnostic and Statistical Manual of Mental Disorders*, Fifth Edition. Arlington, VA, American Psychiatric Association, 2013.
- ⁷ Lai, M., et al 2015. Sex/gender differences and autism: Setting the scene for future research. *Journal of the American Academy of Child and Adolescent Psychiatry*, vol. 54, no. 1, pp. 11-24, available at <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4284309/>; Rynkiewicz, A., et al 2016. *An investigation of the 'girls/women camouflage effect' in autism using a computerized ADOS-2 and a test of sex/gender differences*. *Molecular Autism*, vol. 7, no. 1, pp. 1-8, available at <https://molecularautism.biomedcentral.com/articles/10.1186/s13229-016-0073-0>.
- ⁸ Productivity Commission. (2017) *NDIS Costs – Productivity Commission Study Report*. October 2017. pp29.
- ⁹ Australian Advisory Board on Autism Spectrum Disorders 2012, *The Interface between Autism Spectrum Disorders and Mental Health: The Ways Forward*. Discussion paper, December 2012
- ¹⁰ NDIS. (2019) *COAG Disability Reform Council Quarterly Report 4th quarterly report* July 2019.
<https://www.ndis.gov.au/about-us/publications/quarterly-reports>.
- ¹¹ Parliament of Victoria, Family and Community Development Committee. (2017) *Inquiry into Services for People with Autism Spectrum Disorder - Final Report*.
https://www.parliament.vic.gov.au/file_uploads/FCDC_Report_into_Services_for_people_with_Autism_Spectrum_Disorder_Z5KhPNcW.pdf.
- ¹² Synergies Economic Consulting (2013), *Cost-Benefit Analysis of Providing Early Intervention to Children with Autism* (August 2013).
https://www.pc.gov.au/_data/assets/pdf_file/0004/215266/sub0032-ndis-costs-attachmenta.pdf
- ¹³ NDIS. (2018) *COAG Disability Reform Council Quarterly Report*. 30 September 2018.
<https://www.ndis.gov.au/about-us/publications/quarterly-reports/archived-quarterly-reports-2018-19>
- ¹⁴ Prior M, Roberts J, Roger S, Williams, K & Sutherland R 2011. A review of the research to identify the most effective models of practice in early intervention of children with autism spectrum disorders. Australian Government Department of Families, Housing, Community Services and Indigenous Affairs, Australia; Roberts J, Williams K 2016. *Autism Spectrum Disorder: Evidence-based/evidence-informed good practice for supports provided to preschool children, their families and carers*. Commissioned and funded by the NDIA. February 2016.
- ¹⁵ Synergies Economic Consulting (2013), *Cost-Benefit Analysis of Providing Early Intervention to Children with Autism* (August 2013).
- ¹⁶ Nationwide Children's Hospital. 'Centre for Autism Spectrum Disorders'. Available from <https://www.nationwidechildrens.org/specialties/center-for-autism-spectrum-disorders>.
- ¹⁷ Provision of services under the NDIS Early Childhood Early Intervention Approach. Joint Standing Committee on the National Disability Insurance Scheme, December 2017
https://www.aph.gov.au/Parliamentary_Business/Committees/Joint/National_Disability_Insurance_Scheme/EarlyChildhood/Report

¹⁸ Australian Institute of Health and Welfare. (2017) *Autism in Australia*.

<https://www.aihw.gov.au/reports/disability/autism-in-australia>.

¹⁹ NDIS, Outcomes for participants with Autism Spectrum Disorder (ASD), 30 June 2018.

<https://www.ndis.gov.au/about-us/data-and-insights/reports-and-analyses/outcomes-participants-autism-spectrum-disorder>

²⁰Office of the Public Advocate. (2018) *The Illusion of Choice and Control*. Available from:

<https://www.publicadvocate.vic.gov.au/our-services/publications-forms/519-the-illusion-of-choice-and-control?path=research-reports/ndis>

²¹ Iacono, T., Bould, E., Beadle-Brown, J. & Bigby, C. (2017) 'An exploration of communication within active support for adults with high and low support needs', *Journal of Applied Research in Intellectual Disabilities*.