

AMAZE SUBMISSION

Productivity Commission's National
Disability Insurance Scheme Cost
Inquiry

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What is autism?

"If you've only met one person with autism, you've only met one person with autism". Dr Stephen Shore

Autism Spectrum Disorder (or ASD) is a neurodevelopmental condition with symptoms that may appear early in life. Amaze uses the terms "the autism spectrum" and "autism" to refer to this group of conditions. The term "spectrum" is used to describe the range of characteristics and abilities found in people with autism, as well as developmental changes, such as improvement in language ability, which might occur over time in a person with autism.

Autism is not a disease. People are born on the autism spectrum. It is a lifelong condition and there is no cure, but the way it affects people may change over time as a person grows and matures. Approximately 1% of the population is on the autism spectrum. Currently, four times as many males are diagnosed than females, but the number of females on the autism spectrum is increasing.

Every individual on the autism spectrum is different, but these features are present in some form: challenges in communication and interaction; sharing interests and emotions; using and understanding non-verbal communication; making friends and adjusting behaviour to different social situation; repetitive speech and behaviour; interests that are very intense or narrow in focus; and a need for predictability and routine.

Autism may be present with other conditions and it is important to understand the implications of this for each person. For example people on the autism spectrum may also be diagnosed with an intellectual disability, language delay, epilepsy, Attention Deficit Hyperactivity Disorder, anxiety and/or depression. Furthermore, no two people on the autism spectrum are alike. In practical terms this translates into each person having diverse needs for support in different areas of daily life to enable them to participate and contribute meaningfully to their community.

Currently autism represents 28.3% of NDIS participants, the largest single diagnostic group within the Scheme. Whilst autism impacts everyone differently, recent ABS data shows that 64.8% of autistic people have sever or profound disability that requires support¹.

¹ ABS (2017). Autism in Australia, 2015. Available at: <http://www.abs.gov.au/ausstats/abs@.nsf/Latestproducts/4430.0Main%20Features752015?opendocument&tabname=Summary&prodno=4430.0&issue=2015&num=&view=>

Introduction

Amaze welcomes the opportunity to provide a submission to the Productivity Commission's National Disability Insurance Scheme (NDIS) Cost Inquiry. As the peak body for people on the autism spectrum and their families in Victorian, this Inquiry presents an important opportunity to highlight the current issues facing autistic Victorians as the transition to the NDIS occurs. As the largest social reform in Australia since Medicare, the NDIS represents an outstanding opportunity to address the failures in the current disability care and support systems, with a fundamental paradigm shift from a rationed based system to one of entitlement. However, any reform of this size is subject to teething issues through implementation and the maturity of the scheme.

The large gap in outcomes for people on the autism spectrum and those without disability in Australia is stark. The gap exists across the lifespan and supported by current available data – be it in education, employment, health, wellbeing, community participation. Recent international research indicates a gap in average lifespan of 16 years. Whilst the NDIS will not address of these issues, it provides the framework and core facilitation to improve these measures over time.

Amaze's submission aims to provide an insight into the current issues of concern, or those which require greater attention, from an autism specific focus. Our submission is guided by our community's experience of the NDIS to date, and Amaze has proactively sought feedback from existing NDIS participants to inform this submission.

Autism, at its very core, impacts every autistic person differently. The NDIS as a system designed on the basis of an individualised funding approach should benefit autistic Australians. However, as autism currently accounts for almost 1 in 3 NDIS participants, there is merit in the Scheme having an 'autism specific' response to provide efficiencies in how the scheme works for autistic individuals and provide for their specific needs. Amaze is concerned that despite autism accounting for such a significant percentage of NDIS participants, it has become apparent that the NDIS requires a greater level of engagement with autistic people and their representative groups.

Our submission provides a number of recommendations in response to the questions and issues that were published within the Productivity Commission's Issues Paper.



Summary of Recommendations

- Recommendation:** The NDIA access and examine the existing Helping Children with Autism program data from the Department of Social Services to inform future modelling and planning.
- Recommendation:** The NDIS ensures participants packages of supports are developed in line with the current evidence base.
- Recommendation:** ECEI Access Partners have autism specific expertise relating to identification of early autism signs, diagnosis of autism, all evidence based clinical and therapeutic autism specific interventions and supporting families before and after diagnosis.
- Recommendation:** NDIA develop guidelines for NDIA, LAC and ECEI staff regarding the appropriate timing and facilitation of accessing an autism diagnosis for participants or ECEI participants.
- Recommendation:** The NDIA remove the KPI for ECEI providers that only 50% of entrants to the ECEI will be progressed to the NDIA to become a participant.
- Recommendation:** NDIA to work with all Governments to define the interface between the NDIS and other service systems (health, mental health, early childhood, school education, higher education and vocational education and training, employment, housing, transport, justice and aged care), recognising that not all people on the autism spectrum will be participating in the NDIS.
- Recommendation:** The NDIA ensures that ILC activities build autism capacity for mainstream services to ensure that these services are more inclusive of autistic Australians.
- Recommendation:** Development and distribution of accurate, detailed and accessible information on the NDIS, specifically in relation to autism. These resources should be developed for a number of different audiences including people on the autism spectrum, families and carers and disaggregated into the different life stages. The development of such resources should occur through co-design with people on the autism spectrum.
- Recommendation:** Invest further in pre-planning activities drawing on successful experiences funded through the DSO program.
- Recommendation:** Investment by the NDIA to build the capacity of planners in autism to provide consistent advice and support to participants throughout the planning process.
- Recommendation:** Improved guidelines for planners to:
- Ensure participants are given an informed choice about how they engage in the planning process (whether by phone or face to face);
 - Provide information in advance to potential participants, support people, families and carers as how to prepare for the planning meeting about the planning process, including the types of questions that will be asked and the matters they should consider prior to the meeting. Participants should also always be given the option of a telephone or face to face meeting after the planning meeting (i.e. planning meetings should not occur during cold calls); and
 - Ensure participants are given consistent and clear advice about criteria for support, categories of support, the supports for which funding may be used under each category and other post-planning issues
- Recommendation:** Regular evaluation of planner performance, through measuring the quality of plans/review outcomes and planners interactions with participants (through audit plans and ongoing NDIS evaluation frameworks)
- Recommendation:** Ongoing refinement of assessment tools to reflect new evidence (and concerns regarding their application in planning meetings), with a focus on developing of an assessment tool more sensitive to characteristics and highly varied levels of functioning people on the autism spectrum experience



Recommendation: Build capacity of participants to respond reliably to questions in assessment tools by giving them the opportunity to read the questions in the assessment tool prior to, or at the very least during the planning meeting. The NDIA should also pre-populate the assessment tool to the extent possible, based on expert evidence of functioning provided.

Recommendation: The NDIA further support participants to lead the development of their plan through clear and accessible information on criteria for supports and when further evidence will be required (including information tailored to people on the autism spectrum).

Recommendation: The NDIA build the capacity of planners to communicate the criteria and its application to participants.

Recommendation: Ensure that children with an autism diagnosis or demonstrating autism-like traits presenting to the ECEI are able to access early intervention in line with evidence based best practice guidelines for children on the autism spectrum as soon as possible.

Recommendation: Guidance from the NDIA to ensure that planners are consistently demonstrating the necessary level of flexibility in the application of reference packages, necessary to ensure cost-effective supports suited to individual participants are delivered (including giving appropriate weight to expert reports provided by participants).

Recommendation: Guidance from the NDIA to planners to ensure consistent advice on when further evidence from experts may be required, i.e. for home modifications, equipment.

Recommendation: A review of reference groups and packages currently being utilised, with a view to packages being developed that more accurately reflect the support needs of participants on the autism spectrum.

Recommendation: The NDIA review guidelines to ensure that participants be adequately and consistently informed of their review rights, through the provision of clear and accessible information (during planning meeting and on receipt of a plan) regarding the review process.

Recommendation: The NDIA, via a third party, support participants to lodge a review in the manner they are most comfortable.

Recommendation: The NDIA review compliance with Act to require notification of plans within 7 days, accompanied by information on review rights.

Recommendation: The urgent need for the development of a demand side development strategy to build the capacity of participants to exercise greater choice and control and are informed to a greater degree. This strategy needs to be developed with a view to measuring outcomes over the long term and funded accordingly.

Recommendation: The NDIA investigate alternate funding methods, such as an element of block funding for services in regional areas, to mitigate potential market failure in regional and remote locations – with focus on higher skilled workforce to deliver early intervention.

Recommendation: The NDIA further investigate the potential of innovative service delivery methods such as utilising telehealth models.

Recommendation: The development and open accessibility of autism specific training and capacity building is available to registered providers of supports.

Recommendation: The NDIA invest in a pro-active communications and engagement strategy to transition existing providers of specialist and allied health providers in to the NDIS as Registered Providers of Supports.

Recommendation: The requirement of all staff delivering disability services to be required to undergo pre-employment checks.

Recommendation: All staff delivering disability services be required to undergo initial and ongoing training relating to the prevention of abuse, neglect and violence towards people with disability.



About Amaze

Amaze is the peak body in Victoria for people on the autism spectrum and their supporters. Amaze is a member-based not-for-profit organisation established in 1967 that represents around 55,000 Victorians living on the autism spectrum.

In 2015 Amaze launched its Strategic Directions to 2040 – a 25 year plan to achieve social impact where society respects every person on the autism spectrum and they have real opportunities to participate and contribute. To achieve this, our three main goals are to:

- Increase community awareness and understanding of autism;
- Improve attitudes and behaviours towards people on the autism spectrum;
- Create more opportunities for people on the autism spectrum to participate and contribute to society in meaningful ways.

Amaze operates under a number of principles that guide our work and underpin our decision making. They are:

1. **Person-centered** – We ensure that the voices of people on the autism spectrum, and those that support them, are central to our decision making processes.
2. **Evidence based** – We seek data and evidence to underpin decision making and we measure the outcomes of our work wherever possible.
3. **Courage** – We do not condone, commit or remain silent about discrimination, stigmatising language or policies used to disadvantage or invalidate the life experience of people on the autism spectrum and we actively work to improve or change negative attitudes and behaviours.
4. **Collaboration** - We recognise that we cannot do this work alone so we actively seek people and organisations with whom we collaborate and partner.
5. **Acknowledging and celebrating uniqueness and achievement** – We actively seek ways to celebrate and recognise the unique contribution and participation of all people on the autism spectrum.
6. **Excellence and Professionalism** – We are committed to delivering superior performance through the highest possible standards of skill, professionalism and integrity and a culture of disciplined people, thought and action. We recognise that organisational sustainability is essential to achieve our purpose.
7. **Independence** – We are committed to representing the needs of people on the autism spectrum and their families/supporters in an unbiased, non-aligned manner.

Consultation

Amaze enjoys the benefits of an actively engaged Victorian autism community (individuals, families, careers, service providers and researchers) which we directly communicate with more than 15,000 people fortnightly. The direct lived experience of people on the autism spectrum, their families and carers is central to this submission. Amaze undertook a consultation process to capture the direct experience of the Victorian autism community and hear directly about the issues they are facing in regards to the NDIS and how they would like them to be addressed.

Amaze developed a survey asking existing NDIS participants a number of questions relating to their experience to date with the NDIS. Given the limited time available for consultation we received a strong response to the survey with just over 150 responses, coming from a mix of people on the autism



spectrum, family members of a person/s on the autism spectrum and carers of a person/s on the autism spectrum. A mix of qualitative and quantitative data was obtained through the survey which is documented through the submission.

Amaze is proud to have once again successfully engaged the Victorian autism community in the development of this submission, as giving voice to the views, opinions and experience of people on the autism spectrum and their supporters is central to our purpose.

Autism and the NDIS

Autism and sustainability of the scheme

We appreciate the cost pressures faced by the NDIA, with a projection that by 2019-20 the NDIS will cost about \$22 billion each year. However, if participants on the autism spectrum do not receive appropriate funding for cost-effective supports, their life outcomes will be severely impacted resulting in the ineffective use of NDIS funds and a higher long term costs to the NDIS. The social and economic costs of autism will also continue to rise.

By investing appropriately in autistic participants now, and as early as possible in their life time, the long term support costs for the NDIS (and via other government supports) will be significantly decreased. Outcomes and long term cost savings can will only be maximised if the most appropriate supports are funded (supports that are in line with evidence based best practice guidelines for children on the autism spectrum and emerging evidence for young people and adults). Systematic reviews of the evidence clearly demonstrate that provision of the appropriate types and intensity of early intervention support for children on the autism spectrum is key to increasing a child's developmental trajectory over their lifetime, allowing them to be as independent as possible and participate to their full potential in education, employment and their community. ² Scarce resources must not be wasted on supports that will not produce optimal outcomes.

In 2011, the annual economic costs of autism in Australia was estimated between \$8.1 billion and \$11.2 billion, with the most significant costs arising from reduced employment and the cost of informal care for adults with autism. ³ In Australia, the data on autistic participation in education and employment is well below the rate for both the rest of the population with disability and people with no disability:

- 34.7% of people on the autism spectrum do not go beyond Year 10 in school;
- 61% of people with autism who do finish school do not complete a post-school qualification: and
- 40% of people on the autism spectrum are currently in the labour force.⁴

This is clearly unsustainable from a social welfare and economic perspective and it is vital that the criteria for supports under the NDIS are applied in the manner necessary to support participation to the fullest potential across a participant's lifetime.

Furthermore, a study recently conducted in WA (2014) found the median family cost of autism was estimated to be AUD \$34,900 per annum with almost 90% of the sum (\$29,200) due to loss of income from employment. For each additional symptom reported, approximately \$1,400 cost for the family per annum was added. While there was little direct influence on costs associated with a delay in the diagnosis, the delay was associated with a modest increase in the number of ASD symptoms, indirectly impacting the cost of ASD. A delay in diagnosis was associated with an indirect increased financial burden to families.⁵ Accordingly, in the case of autism, a diagnosis and appropriate support is required as early as possible to not only maximise outcomes for individuals but also to reduce financial burden on families.

² 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.

³ Synergies Economic Consulting, Economic Costs of Autism Spectrum Disorder in Australia, Updated Study, April 2011, Synergies Economic Consulting Pty Ltd.

⁴ Ibid

⁵ Horlin C, Falkmer M, Parsons R, Albrecht MA, Falkmer T (2014) The Cost of Autism Spectrum Disorders. PLoS ONE 9(9): e106552. doi:10.1371/journal.pone.0106552



Access and eligibility

Autism in the National Disability Insurance Scheme

Autism is the largest single diagnostic group of NDIS participants (28.3%⁶), with this being significantly skewed towards the younger cohort as shown from data in South Australia (47%⁷) and Nepean Blue Mountains (49%⁸).

There has been significant public discussion over the past 18 months led by certain media outlets, about the higher than expected number of participants with autism entering the scheme, especially in the younger age cohort. The quantum of participants into the scheme on the autism spectrum has not been of surprise to Amaze, especially in the 0-7 age cohort for a number of factors; global trends in autism prevalence rates have been increasing over the past decade and Australia is aligned with these increases and our experience in delivering the Autism Adviser's service for the Helping Children with Autism (HCWA) program has seen similar numbers access this program since 2008.

It has become apparent that the data collected from the HCWA program by the Commonwealth Department of Social Services has not been analysed and incorporated to forecast anticipated participant's numbers for the NDIS. This data, collected since 2008, provides a significant opportunity to develop baseline data of children diagnosed with autism under 7 across Australia and for the scheme to plan appropriately, for both the purpose of scheme transition to ascertain the current level of 'stock', along with identifying the level of newly diagnosed children who will enter the scheme, or 'flow'. This will provide greater insights for the NDIA to establish anticipated costs associated with autism.

Recommendation: The NDIA access and examine the existing Helping Children with Autism program data from the Department of Social Services to inform future modelling and planning.

Amaze is satisfied that the early intervention entry requirements within the *NDIS Act 2013* are adequate to ensure eligibility for those children, either with a formal diagnosis of autism or showing the initial signs of autism. As a scheme based on functional impairment it is appropriate for a measure of functionality to be measured in assessing eligibility for the scheme, however there is still a role for seeking a diagnosis of autism. The value in seeking a diagnosis of autism, either prior to, or after, entry into the Scheme, is to ensure that an autism specific package of supports is put in place to support the participant.

Furthermore, in the early years it is vital that the NDIA provides early intervention packages that are evidence based, independent from preconceived ideas about certain therapies, informed by families, and families being able to fully support their implementation. Amaze is concerned that in order to curb total package size, certain intensive, yet evidence based therapies are not being considered for inclusion in participant's plans. We acknowledge that every child on the autism spectrum has varied needs and requires an individualised package of supports – but this should not rule out certain evidence based interventions given their sizable cost. Furthermore, this practice is contrary to the foundational insurance principles that underpin the scheme of investing early to increase a participants economic, social and community participation along with increasing long term scheme costs.

⁶ NDIA 2nd Quarterly Report to COAG 2016-17 Q2, <https://www.ndis.gov.au/about-us/information-publications-and-reports/quarterly-reports>

⁷ NDIA 12th Quarterly Report to COAG 2015-16 Q4, <https://www.ndis.gov.au/about-us/information-publications-and-reports/quarterly-reports>

⁸ Ibid



A subsequent issue that this submission will address is the current constraints on implementing plans due to lack of supply of specialist allied health services, which is more acute in regional and remote areas of Victoria.

Recommendation: The NDIS ensures participants packages of supports are developed in line with the current evidence base.

Early Childhood Early Intervention Approach

Amaze supports the development of the Early Childhood Early Intervention (ECEI) approach but have a number of concerns about the approach which are dependent on the approach taken by the party delivering the service.

Given the high number of children in the 0-7 age cohort with an autism diagnosis, along with Amaze's access to the HCWA data for Victoria, it is reasonable to anticipate that a significant percentage of children entering the ECEI may have a diagnosis of autism, precursory autism-like traits or autism-like traits without a formal diagnosis. Therefore it is vital that the ECEI Access Partners have a significant level of autism specific experience and capacity to appropriately manage this significant proportion of children accessing their services.

Recommendation: ECEI Access Partners have autism specific expertise relating to identification of early autism signs, diagnosis of autism, all evidence based clinical and therapeutic autism specific interventions and supporting families before and after diagnosis.

The role of diagnosis raised previously in this submission is relevant to the role of the ECEI. A fully functioning ECEI gateway should see children enter at a young age, through mature referral networks from Maternal and Children Health Nurses, GP's, family service, other mainstream social services, early childhood education facilities and not-for-profit organisations such as Amaze. These children would not have a formal diagnosis, and the family would receive supports immediately from the ECEI Partner – however once signs of autism are apparent to skilled and trained ECEI staff, children should not have any delay in a diagnosis being facilitated with assistance from the ECEI partner.

Recommendation: NDIA develop guidelines for NDIA, LAC and ECEI staff regarding the appropriate timing and facilitation of accessing an autism diagnosis for participants or ECEI participants.

Also of concern to Amaze regarding the ECEI approach is the potential for delaying entry into the NDIS for children who require a higher level of support than can be provided by the ECEI. This concern was identified in the ECEI tender documents, which outlined a number of KPI's that ECEI partners must report against. The KPI's included a monthly target that 50% of children would have an NDIS plan approved – it is concerning that a target like this is stated within an entitlement based scheme, and furthermore how this will affect practices of the ECEI partner.

In the case for children on the autism spectrum, as outlined above, delay in accessing a full suite of evidence based interventions specific for that child can severely limit their developmental trajectory – and therefore increase lifetime costs for the NDIS.



Recommendation: The NDIA remove the KPI for ECEI providers that only 50% of entrants to the ECEI will be progressed to the NDIA to become a participant.

The Interaction with Mainstream Services

The NDIS will not achieve its objective of increasing the economic, social and community participation of people with disability on its own. This is evident through the development of the *Information, Linkages and Capacity Build* policy and subsequent ILC framework along with the guiding vision of the *National Disability Strategy 2010 – 2020*.

With the focus of efforts on the NDIS since 2011, the National Disability Strategy (NDS) has taken a backseat in driving reform in mainstream services to ensure that they are equipped to deliver services, and accessible to people with disability. This is concerning as the role that mainstream services systems play in supporting people with disability, in providing an adequate education or facilitating them to enter and maintain employment, is vital to maximising the investment that NDIS is making in increasing the capacity of Scheme participants.

It is difficult to ascertain the current level of tension between mainstream service systems and the NDIA where potential cost shifting may occur, especially where in-kind contributions still exist in mainstream systems such as Education in Victoria still providing personal care. Amaze is concerned that the apparent lack of a whole-of-government approach to this issue by State Governments will lead to ongoing 'skirmishes' between the NDIA and mainstream service systems over in-scope/outside-scope services that are funded.

It is our view that a greater level of coordination and leadership is required to ensure the smooth interaction of services between systems, both Federal and State/Territory, will increase participants' outcomes along with their experience of navigating services systems. The outcome of a seamless and integrated service system will be aggregated cost savings for governments, not just that of NDIA. The greatest risk if this doesn't occur is that participants will 'fall through the cracks' where defined roles are not clear.

Recommendation: NDIA to work with all Governments to define the interface between the NDIS and other service systems (health, mental health, early childhood, school education, higher education and vocational education and training, employment, housing, transport, justice and aged care), recognising that not all people on the autism spectrum will be participating in the NDIS.

Building autism literacy in mainstream services

Amaze acknowledges that whilst the NDIS will provide packages of support to a substantial number of the estimated over 1 in 100 Australians on the autism spectrum, there will be a number of autistic Australians who will not be NDIS Participants. Amaze does not have an estimate of the size of this cohort, however these people will have needs that the ILC Framework should meet. It should also be noted that given the high levels of concurrence of autism with other disabilities, health conditions and mental health issues, a significant number may require support from the NDIS in an episodic manner.

Currently many autistic people, NDIS participants and non-participants, experience difficulties in accessing mainstream supports, delivered through the education, employment, health and transport systems. Ensuring that these service systems are inclusive of, and accessible to autistic people is key to increasing their economic, social and community participation. In building the capacity of these



mainstream services systems to better respond to the needs of autistic Australians, there will be measurable savings to the ongoing costs of the NDIS.

Recommendation: The NDIA ensures that ILC activities build autism capacity for mainstream services to ensure that these services are more inclusive of autistic Australians.

Planning Process

Amaze agrees with the Productivity Commission's assertion that a valid, cost-effective, reliable, clear and accessible planning process is essential to the sustainability of the NDIS. We also appreciate that a significant amount of learning is still occurring and that the planning process will continue to evolve based upon experiences in the trial sites and under the "First Plan" approach as the scheme rolls out.

Through our provision of the Autism Advisor service since 2008, and as a funded NDIS Disability Support Organisation (DSO), Amaze's day to day engagement with 13,000 members of the Victorian autism community has revealed the community remains unclear on the basic details of the NDIS, including eligibility, the planning process and the supports the Scheme will cover.

To be cost effective, valid and achieve positive outcomes for participants, the planning process must be fully accessible to participants and facilitated by competent and comprehensively trained planners. To achieve this, investment in capacity building is urgently needed for:

- a) Participants to fully participate in the planning process: through improved access to information, pre-planning support and support to participant in planning meetings; and
- b) Planners to provide consistent advice and support to participants throughout the planning process: through ongoing training to support participants in planning meetings, understand their disability and its potential impact on engagement in the planning process and ensure a consistent approach to the advice and information given during the planning process.

Capacity building is also required in relation to planners' use of assessment tools, the "First Plan" approach, criteria for supports and the review process. These concerns are discussed in detail below.

Feedback to Amaze's 2017 survey included:

"We have had a positive experience with the NDIS for all three plans we have in our home. A lot of this was due to our very helpful LAC and also a lot of pre-planning".

"Prior to my meeting it was very unclear how to prepare".

Building participant capacity to participate in the planning process

A core value of the NDIS is that it promotes self – determination by supporting participants to plan for their own lives. Without being the drivers of their own plan, it simply becomes a plan developed by the NDIA and imposed upon them.

Investment in information and resources

For autistic people, there is a lack of clear and accessible information about the planning process, including how to prepare for it, the questions that will be asked, the criteria for supports and plan implementation. Very little information is provided directly to participants prior to planning meetings and



the level of information provided during planning meetings can be inconsistent and/or difficult to for people on the autism spectrum to process quickly in that environment. Similarly, for people from non-English speaking backgrounds there is a lack of culturally or language appropriate information.

While a well-resourced participant and/or their carer may be able to seek out information on-line, this information tends not to be presented in an “autism-friendly” way. It is very general and does not provide clear and specific advice about what to expect during a planning meeting or how the NDIA will determine whether a support requested will be considered “reasonable and necessary”. Common experiences reported to Amaze are: the use of bureaucratic or jargonistic language and the need to search through large amounts of information.

Given autism is the single largest diagnostic group of participants within the NDIS, autism specific information, delivered in an “autism friendly” way is urgently required. A trusted, independent and experienced organisation should be commissioned to develop these resources for the autism community – in partnership with government and the NDIA to ensure accuracy of information, and also utilising a methodology of co-design with people on the autism spectrum to ensure the utility of the end products. Ongoing investment in information that is accessible to culturally and linguistically diverse groups will also be essential.

Preferably, this information should be provided prior to planning meetings to enable participants to read it, process it and be prepared to ask questions. Not only would this maximise the validity and reliability of information given during a planning meeting, and the plan subsequently developed, it would also increase the efficiency of a meeting, enabling participants to focus on their individual needs rather than being overwhelmed by new information.

Recommendation: Development and distribution of accurate, detailed and accessible information on the NDIS, specifically in relation to autism. These resources should be developed for a number of different audiences including people on the autism spectrum, families and carers and disaggregated into the different life stages. The development of such resources should occur through co-design with people on the autism spectrum.

Investment in pre-planning support

The process of identifying and articulating one’s goals and aspirations, together with the supports required, in preparation for a planning meeting can be very challenging for people on the autism spectrum.

Through Amaze’s work as a DSO, we have gained significant experience in working with autism peer support groups and building their capacity and understanding of the NDIS. We have learnt that having access, through facilitated pre-planning sessions, to independent, credible information was vital for participants to meaningfully participate in their planning meeting and drive their plan. Having support from peers, particularly those who had been through the NDIS process, is considered extremely valuable.

We are confident that pre-planning leads to more valid and efficient planning meetings, with more reliable and accurate information given, and in turn more valid, reliable and accurate plans. We have also found that while information provided in workshops has been necessary to assist participants with their initial planning meeting, ongoing support is also required to assist participants with the planning process, both initially and subsequent plans, and in particular, the implementation of their plan.

Accordingly, a sustainable NDIS will therefore require adequate investment in ongoing capacity building and peer networks capable of supporting participants not only in the pre-planning stage, but throughout the entire planning process. It will also require ongoing investment pre-planning that is capable of supporting people from culturally and linguistically diverse backgrounds.



Recommendation: Invest further in pre-planning activities drawing on successful experiences funded through the DSO program.

Building planner capacity

Investment in training to support participants to participate in planning meetings.

The NDIA must ensure that planners are fully equipped to support participants to participate in planning meetings and convey their goals, aspirations and support needs to the fullest extent possible.

Amaze is concerned by feedback from participants that their ability to engage in the planning process, and provide complete, accurate and reliable information, has been suboptimal because their planning meeting being held over the telephone, and often with little or no notice. We are also concerned that a number of participants have reported feeling rushed in their planning meeting, whether over the phone or face to face. A number of participants have also described feeling “forced” or “bullied” into a phone interview and/or denied a face to face meeting when requested.

Amaze’s 2017 survey found that almost a quarter of all respondents had their planning meeting over the phone, with the remainder attending face to face interviews.

Feedback to Amaze’s 2017 survey included:

“I was rung for an interview about my capacity with no warning and at an inconvenient time - not ideal for someone on the spectrum! I wasn’t given an option of having my planning meeting in person and, given the mistakes about my personal circumstances on the plan I eventually received, I don’t believe that the planner was listening properly or understanding my needs accurately. There was no provision for further consultation about the plan - just one phone meeting and it became The Plan with no further input from me.”

“I asked for a face to face meeting from the beginning and NDIA told me I would have to prove why I would need one. Too tired to fight it”.

While we appreciate the challenges faced by the NDIA in seeking to transition such high numbers of people with disability into the scheme, we are concerned that the quality of information provided by participants who often will struggle to provide accurate and considered information to inform plan development, and in turn, their plan and long term outcomes are being compromised.

If the NDIA intends to continue conducting planning meetings by telephone, the quality of these meetings could be improved by policy or guidelines requiring pre – planning calls to participants to discuss the planning process, should include preparatory information about the types of questions they will be asked and matters they need to consider for the planning meeting. As discussed above, culturally appropriate information about the planning process should also be provided. A participant should also always be given the option of a telephone or face to face meeting within three weeks.

We are also concerned that participants appear to be receiving very inconsistent and at times, misleading advice, from planners and NDIA staff. The NDIA must support planners with clear policy and guidelines to provide consistent advice to participants about the planning process, criteria for supports and how plans may be implemented.



Feedback to Amaze's 2017 survey included:

"The inconsistency in advice is very frustrating".

"Our planner gave us a lot of misleading and incorrect reasons for why we were ineligible for community access and equipment funding".

Many participants are reporting that they do not understand their plan, the categories of supports and the supports for which funding may be under each category. There appears to be a lack of consistent advice given by planners and participants are often unsure where to turn for reliable information – with participants often being told different things by the NDIA and providers.

Feedback to Amaze's 2017 survey included

"The way they've written in the plan is confusing".

"I was told my NDIS plan allowed my son to do 22 hours of therapy for the 12 month period that the plan is in place. I can only go by what I've been told because I asked if there was a breakdown of the plan so I knew what I could use for therapy and what other things the money was for however I was told a number of times no there is no breakdown you just get a lump sum to use."

Amaze's 2017 survey found:

- 49% of respondents reported that their planner did not explain the three areas of funding (Core, Capital, Capacity Building) to them (with 19% unsure of whether it was explained and only 31% reporting that it was explained to them).
- 47% of respondents stated that their planner did not explain the post plan implementation to them (with 18% unsure of whether they did and only 35% stating that it was explained to them).
- 35% of respondents reported that they were not confident that they would be able to implement their NDIS plan in the 12 month period (with 8% unsure, 35% confident and 23% very confident).

If planners are to facilitate cost-effective outcomes for participants, stronger guidance is required from the NDIA about the information and advice to be given in planning meetings and the supports that funding can be allocated to under each category. We are concerned that in the absence of clarity about permitted supports, participants who are self-managing may be spending their funding on non-approved therapies and supports and be required to pay that money back to the NDIA. This could obviously have significant financial and emotional implications for participants and their families. It could also mean that participants have not received supports better suited to achieving their goals throughout the year, with consequences not only for individuals but for the costs of the scheme now and in the long term.

Investing in ongoing autism awareness training.

We have received feedback from participants that their planner's understanding of autism, including how being on the autism spectrum may have impacted their engagement in the planning process, appeared to be minimal. This impacts upon participants' experience and confidence in the NDIS, as well as the adequacy of their plans.



Feedback to Amaze's 2017 survey included:

"I feel like they are talking from a script and can't answer anything outside of the script. I also feel that they don't really understand what a child with ASD is like or the support they need"

"We appealed our funds following our son's autism diagnosis and the person who we met for our appeal meeting had minimal understanding of the appeal process and autism"

Amaze's 2017 survey found:

- 65% of respondents rated their planner's knowledge and understanding of autism as none to moderate a level (with the remainder rating the planner's knowledge as high).

We understand that planners are intended to bring a range of backgrounds and experiences to the NDIS. However, given 30% of participants identify autism as their primary diagnosis, a high level of ongoing training in autism will be a necessity to developing and maintaining their capacity to reliably develop plans.

Planners (particularly those from non-disability backgrounds) must also be adequately trained on interacting with people with disabilities, including the unique aspects of autism that may limit a person on the autism spectrum's capacity to answer questions and provide information in a planning meeting.

Investment in training by experts in autism and the diverse needs of people on the autism spectrum should be a priority to avoid the costs of plans that don't meet participant's needs.

Recommendation: Investment by the NDIA to build the capacity of planners in autism to provide consistent advice and support to participants throughout the planning process.

Recommendation: Improved guidelines for planners to:

- Ensure participants are given an informed choice about how they engage in the planning process (whether by phone or face to face);
- Provide information in advance to potential participants, support people, families and carers as how to prepare for the planning meeting about the planning process, including the types of questions that will be asked and the matters they should consider prior to the meeting. Participants should also always be given the option of a telephone or face to face meeting after the planning meeting (i.e. planning meetings should not occur as cold calls); and
- Ensure participants are given consistent and clear advice about criteria for support, categories of support, the supports for which funding may be used under each category and other post-planning issues



Monitoring and evaluation of planners

Feedback to Amaze's 2017 survey included:

"We have had only good experiences with our 3 plans, and have found the NDIS to be very supportive. I think that a lot of this is up to the actual planner (we have had 3 different ones) as I know people personally who have had not so great experiences".

"Better training [in autism] is required for planners. All meetings should be documented and minuted to avoid confusion"

A planner's performance should be measured by the quality of their plans and the quality of their interactions with participants. The quality of plans and interactions may be regularly monitored by the NDIA through regular plan audits. Participant satisfaction with their plans, and their interaction with planners should also be monitored and evaluated through the ongoing NDIS evaluation framework.

The quality of the plans developed by individual planners may also be monitored and evaluated through identification of the number of their plans that are reviewed quarterly or bi-annually, whether changes were required to the plan and whether the planner ought reasonably have made a different decision, taking into account training received and the evidence before him or her. Feedback received through the complaints mechanism could also feed into this process.

All planning meetings should be carefully minuted to ensure that all evidence provided by participants, their carers or support persons are appropriately recorded. Samples of these minutes could be reviewed by senior staff as part of any monitoring and evaluation process.

Recommendation: Regular evaluation of planner performance, through measuring the quality of plans/review outcomes and planners interactions with participants (through audit plans and ongoing NDIS evaluation frameworks)

Assessment tools

We appreciate the importance of valid, reliable, accurate and efficient assessment tools to measure the level of functioning of participants in a consistent manner. We understand that the tools used by the NDIA were selected based on expert advice from professionals with specialist disability knowledge and that the tools are evaluated periodically to ensure a process of continuous improvement.

However, we remain concerned that the standardised assessment tools most commonly used by the NDIA for participants on the autism spectrum, such as the Paediatric Evaluation of Disability Inventory - Computer Adaptive Test (PEDI-CAT) and World Health Organization Disability Assessment Schedule 2.0 (WHODAS), may not be providing a valid, reliable or accurate measure of the nature, frequency and intensity of this group's diverse support needs. This may adversely impact on the sustainability of the scheme if it leads to inappropriate supports being provided to participants. The standardised assessment tools used in planning meetings are also largely deficits based, meaning that they are unlikely to identify a participant's strengths and how those strengths may be harnessed when developing a plan.

Assessment tool design

We are concerned that the standardised tests may not be suited to measuring the highly varied levels of functioning people on the autism spectrum experience, including in relation to social communication and executive functioning. For example, they may risk understating the support needs of people on the autism spectrum that have an IQ in the typical range, but require significant support with social



interaction, rigid and inflexible behaviours and executive functioning if they are to participate successfully in school and employment. To accurately measure the impact on functioning people on the autism spectrum may face, an assessment tool sensitive to the unique and highly varied characteristics of autism is required. An assessment tool more sensitive to ASD should also recognise that functional needs change across the lifespan, particularly at times of transition.

Australia's Cooperative Research Centre for Living with Autism (Autism CRC) is currently developing Australia's first national diagnostic guidelines for autism. Commissioned under a collaboration between the Autism CRC and the NDIA, this guideline is aimed at ensuring consistency and best practice in autism diagnosis, that is feasible to deliver and acceptable to those on the autism spectrum.⁹ We are pleased that Autism CRC will be working closely with the NDIA to ensure that the guidelines align with processes for entry to the NDIS and hope that it can inform the development and use of an assessment tool capable of highlighting the specific and diverse strengths, difficulties and support needs of people on the autism spectrum across their life span.

Assessment tool application and evaluation

The questions contained in the standardised assessment tools commonly used in planning meeting can lead to very subjective responses, influenced by: a person's understanding of the questions; guidance provided by a planner and their assessment of a response; a participant's and/or their support person's understanding of their disability and its impacts; differences in interpretation of when the response options (i.e. the meaning of mild, moderate, severe); and a range of other personal, cultural or language influences. A person on the autism spectrum may have particular difficulty processing the meaning or intent of these questions in a planning meeting and providing a fully informed and accurate response.

We are also concerned that the standardised tools can undermine the core intent of the NDIS, that it be participant led. The standardised tool tends to determine which functional challenges are prioritised for supports in a participant's plan, rather than the participant identifying the functional challenges they want to prioritise and the supports that would be most cost effective in their circumstances. For example, while a high score on the "Understanding and Communication" section of the WHODAS may result in a plan that provides funding for speech therapy, a parent of an older child in a special school environment may not be looking to prioritise speech therapy, but rather social communication through time conversing with a known support worker who has proved effective in the past for building the communication and social skills of that child. Similarly, the WHODAS is unlikely to highlight many of the executive functioning or sensory barriers to social engagement or employment that a participant on the autism spectrum may require support to manage.

In addition, while the NDIA's *Operational Guideline - Planning and Assessment - Assessment of Participants' Needs* state that any supporting evidence provided by a participant should be used to populate the assessment prior to the planning meeting, and then guide the use of the assessment tool in the planning meeting, our understanding from participants is that this very rarely, if ever occurs. Participants have reported that expert evidence regarding levels of functioning provided at or prior to the planning meeting, is most often ignored. Therefore the plan is often only based on the outcome of the assessment tool and the responses given to the questions in the planning meeting.

The reliability and efficient application of assessment tools could be significantly enhanced by 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.

The utility of assessment tools should be continually evaluated across the vast range of disability types, age groups and level of function that participants present. Participant's experiences in answering the

⁹ Autism CRC. Australia's First National Guideline for Autism Diagnosis. 6 October 2016. Accessed at www.autismcrc.com.au

questions provided in assessment tools could also be evaluated as part of future NDIS evaluation frameworks.

Recommendation: Ongoing refinement of assessment tools to reflect new evidence (and concerns regarding their application in planning meetings), with a focus on developing of an assessment tool more sensitive to characteristics and highly varied levels of functioning people on the autism spectrum experience

Recommendation: Build capacity of participants to respond reliably to questions in assessment tools by giving them the opportunity to read the questions in the assessment tool prior to, or at the very least during the planning meeting. The NDIA should also pre-populate the assessment tool to the extent possible, based on expert evidence of functioning provided.

Creating a support package

Our key concern is to ensure that the NDIA invests in clear, specific, non-jargonistic and accessible information for people on the autism spectrum regarding the planning process and the criteria for supports. Transparent, clear and accessible information is also required on the role that reference packages now play in the determination of reasonable and necessary supports and how flexibility in the application of these packages may be granted to planners. See further discussion regarding reference packages below.

There is also a lack of transparency and procedural fairness being accorded to participants, with respect to when further evidence will be required to meet criteria for certain supports, such as home modifications and equipment. We are aware of a number of participants whose request for these supports has been simply denied, without them being informed that they may have been considered if supporting evidence was provided.

Ongoing training for planners regarding the criteria and how it should be applied, as well as training on how to convey the criteria to participants, advise of when expert evidence is required and provide reasons for decisions when supports are denied.

Recommendation: The NDIA further support participants to lead the development of their plan through clear and accessible information on criteria for supports and when further evidence will be required (including information tailored to people on the autism spectrum).

Recommendation: The NDIA build the capacity of planners to communicate the criteria and its application to participants.

Adequacy of packages of supports

We appreciate the challenges faced by the NDIA in seeking to transition 430,000 people into the NDIS over the next three years. We agree that it should be a priority to ensure that people can enter the scheme quickly and understand the need for a budget based approach, including the Early Childhood Early Intervention (ECEI) approach, and reference package and first plan process. We are concerned, however, that the application of these approaches may be undermining some of the core values of the NDIS (e.g. that it be participant led, individual focussed, promote choice and control) and compromising the quality of many first plans, with significant costs to the scheme now and in the longer term if participant's support needs are not met.



Early Childhood Early Intervention (ECEI) approach

As outlined above, the ECEI approach is intended to provide a 'gateway' for children aged 0 – 6 to the NDIS, so that only children that meet the NDIS eligibility criteria eventually become participants of the scheme.

We agree there is a clear benefit for children who are showing signs of developmental delay entering the ECEI and receiving services that previously weren't available to them. However, it remains unclear what steps will be taken when a child with developmental delay, also or later presents with the characteristics of autism. If the scheme is to be sustainable, and minimise the long term costs of autism, children that do to enter via ECEI with the characteristics of autism must be diagnosed as early as possible.

Early diagnosis is essential to ensure that the benefits of early intervention for supports for autism are maximised. It is also vital to ensure that a participant accesses the most appropriate types of therapies, as well as the appropriate frequency/intensity of therapies (20 hours per week), in line with evidence based best practice guidelines for children on the autism spectrum. This includes:

- 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; and
- National Guidelines, Best Practice in Early Childhood Intervention, Early Childhood Intervention Australia. April 2016.

Adherence to these guidelines is also essential to ensuring that the quality of services provided meet the necessary standards for services delivering early intervention. We also want to ensure that those providing early intervention to children on the autism spectrum have autism specific experience.

Recommendation: Ensure that children with an autism diagnosis or demonstrating autism-like traits presenting to the ECEI are able to access early intervention in line with evidence based best practice guidelines for children on the autism spectrum as soon as possible.

Reference package and first plan process.

Amaze understands that in their first plan, a participant is allocated a typical support package based on their reference group (disability type, age and level of function) and that participants are asked a series of guided questions to further develop the plan and adjust the typical support package as appropriate, taking into account their individual circumstances and goals.

We appreciate that reference packages can provide consistency and are an efficient way to determine a baseline of support needs, however we are concerned that this "ground up" approach may be compromising the core values of the NDIS: that the development of goals and supports be participant led; that participants be adequately supported to maximise their participation in the process; and that they be supported to exercise choice and control in their supports.

The application of reference packages, often inflexibly by planners under pressure to process first plans quickly, can lead to a failure to take into account the individual needs of participants and recognise the specific types and combinations of supports sought.

We have recently been contacted by many members of the autism community that are frustrated by receiving plans that do not reflect their true goals and support needs, sometimes provide supports they were not seeking and then fail to provide the specific types or quantity of supports that were sought. We are concerned that this may be a result of reference packages being applied inflexibly, with inadequate weight being given to participants advice regarding their individual support needs.



Feedback we received to our NDIS participation included:

"We are a family with two PTSD parents, two autistic children and autistic parent. And one parent with a chronic serious disease. None of this was considered- we receive no respite and not enough funding to cover the basic OT and speech. No funding for psych or social groups, no funding for continence support or to get ready for school support."

"NDIS have decided my 7yo son doesn't need the basic supports such as OT and group social skills groups."

"Services we were very keen on receiving were not funded. They were very, very dismissive of ABA and aquatic therapy etc. I was told swimming lessons for children who can't cope in a mainstream pool and class were "novelty"

"I am trying to take away as much as I (can) from his OT sessions so we can work on things at home but an hour a fortnight doesn't give you much time to chat about his progress over the past couple of weeks discuss things that can assist him in the home to help with his therapy like using a trampoline using a trolley to lay on and do a puzzle plus have the OT work with him. There is an awful lot that needs to go into that 1 hour session."

"The plans are too inflexible. They don't give enough empowerment to the parents/carers who are at the front-line and trying to get the best outcome for the participant. For example when we need to buy continence products (nappies), to get reimbursed we have to buy through a registered continence provider at \$17.20 per packet. The exact same nappies are available at Woolworths for \$11.00. So we are forced to waste \$6.20 of the participant's plan if we want to be reimbursed. Ridiculous."

"Feel very stressed about attempting to implement plan, pressure to spend all allocated funds within the 12 months so that we don't end up with less next year. Some things that we currently do were not accounted for eg regular psych appointments"

"Speech Pathology. I have \$10k for therapy however the Speech Pathologist is not permitted to come to my Son's SD School so I don't know if I will use all this funding. I was unaware that School visits were not permitted when I applied for the Therapy funding. I am not prepared to drag him to the Speech Pathologist each week - he has just started School and needs some down time. I now want to spend some of this money on communication devices (he is non-verbal) but I don't know if this is permitted on the NDIS."

Amaze's 2017 survey found that:

- 56% of respondents felt that their planner took into account advice they provided in the planning meeting about their goals and support needs either not at all, to a small extent or somewhat (with the remainder satisfied that their advice was taken into account to a large extent).
- 61% of respondents felt that their final plan would meet none to only some of their support needs (with only 25% satisfied it would meet all of their needs and 14% responding that they didn't know); and
- 25% of respondents were satisfied that the NDIS had enabled them to increase their choice and control over the supports they receive to a great extent (with 30% responding that it had increased their choice and control somewhat, 21% to a small extent and 26% not at all).

Many participants have also expressed frustration that they have been unsure of when further evidence of support needs should be submitted or indeed, is required. They have also been frustrated that when evidence has been provided (i.e. from therapists, medical practitioners etc.) that it has not been given little to no weight, contrary to the obligations of planners to have regard to such assessments under *NDIS Act 2013* , s.33(5)(b).



Feedback to the Amaze 2017 survey included:

"I feel that all the reports I provide and a very in depth letter from the OT outlining what he needs help with has not been taken into account."

"My concern is that all the documents I have provided have not been taken into account and that my son won't get the help and support he needs to help him get ready for school next year and help and support for other day to day things that people can take for granted."

Amaze's 2017 survey found that:

- 64% of respondents felt that advice provided by others, eg therapists, medical practitioners etc., was taken into account not at all, to small extent or only somewhat (with only 36% of respondents feeling that it was taken into account to a large extent.)

We are also concerned that reference packages currently applied are not sophisticated and sensitive enough to meet the very diverse and individual needs of people on the autism spectrum. While two same aged participants on the autism spectrum may be assessed through standardised assessment tool as having similar levels of function, the challenges impacting their daily functioning and support needs (and therefore their support priorities) may be vastly different. It is vital that the type, quantity and combination of supports allocated in their plans reflect their true support needs.

If a reference package approach is to be continued, a number of improvements will be required to ensure that it does not impact the sustainability of the NDIS (by failing to provide the most cost-effective supports for individuals and funding supports that were not sought/appropriate). These include:

- A review of the reference groups and packages currently being utilised, with a view to further breaking down the characteristics used to identify reference groups (particularly in functioning), with more varied types of reference packages being developed that are capable of reflecting the true functioning and support needs of participants, particularly those on the autism spectrum.
- More flexible application of reference packages which gives appropriate weight to information provided by participants regarding the type and combination of supports that will enable them to meet their goals. Stronger weight must also be given to expert reports provided by participant's therapists, medical practitioners etc. to ensure their individual needs are met.
- Greater transparency to ensure that applicants understand the use of reference packages, their impact on plan development and what they will need to show to access greater flexibility in their support package.
- Greater transparency regarding when expert evidence/reports will be required, for example when seeking home modifications, equipment etc.

Recommendation: Guidance from the NDIA to ensure that planners are consistently demonstrating the necessary level of flexibility in the application of reference packages, necessary to ensure cost-effective supports suited to individual participants are delivered (including giving appropriate weight to expert reports provided by participants).

Recommendation: Guidance from the NDIA to planners to ensure consistent advice on when further evidence from experts may be required, i.e. for home modifications, equipment.

Recommendation: A review of reference groups and packages currently being utilised, with a view to packages being developed that more accurately reflect the support needs of participants on the autism spectrum.

Resolving conflicts with plans

At this stage, we are satisfied that the avenues for resolving disagreements (via the complaints process and/or the internal and external review options) provide appropriate pathways for participants that are concerned about any aspect of their planning journey or are not satisfied with their final plan.

However, the NDIA must ensure that participants are being adequately informed of their rights to make a complaint and/or seek review. It must also ensure applicants are being notified when their plan has been finalised (with consequences for review time frames).

We are also concerned that participants are being adequately supported to lodge a complaint or review in the manner they prefer (i.e. over the phone, in writing and/or in person).

Feedback received to the Amaze 2017 survey included:

"I have submitted three reviews for my sons plan and only after the last review do I feel that some of his needs have been met".

"Considered lodging a complaint... but just couldn't face their complaints form - too complicated for someone feeling fairly fragile due to the very system I wanted to complain about! I just wanted to talk to someone who could sort it out simply and quickly but there isn't that option; just a really long form which requires significant organisational skills to complete. Beyond me at the moment so I'm continuing to wait for the plan revision to come through."

"I was not given the chance to view a draft of plan to amend mistakes before it went to approval. The planner basically told me he had a quota on a list that he had to get through no time to do the 'toing and froing' When I asked to have mistakes amended I was told I would have to have a full plan review and would certainly not get the \$\$\$ we got again. Basically bullied to sit tight let the 12 months go by and tweak it at the next review."

The complaints process must be publicised and be made fully accessible to participants. Amaze survey – 57% of respondents reported that the complaints process was not explained to them or (with 18% reporting that they were unsure whether it was explained and only 26% reporting that it was explained to them).

We are particularly concerned that participants are being given consistent advice (during planning meetings and subsequently) about their rights to lodge a complaint or review application.

In response to Amaze's 2017 survey:

- 45% of respondents reported that their planner did not explain what options were available if they were not satisfied with the plan (plan review etc), with 12% unsure and only 43% reporting that their options were explained.



While information regarding the complaints and review processes are available on-line participants may not even be aware of their complaint/review rights if not fully informed during the planning process or on receipt on their plan. In these circumstances they are unlikely to go to the website to find the relevant information. For those who do go to the website, the information provided is jargonistic and not clear and accessible for a person on the autism spectrum

Furthermore, while the *NDIS Act 2013* (ss. 38 and 100) requires that a copy of the participants plan be given to the participant within 7 days of the plan coming into effect, and that as a reviewable decision, the written notice of the plan be accompanied by a statement that they may request a review, we have been advised by numerous participants that they have never received any written notice of their plan or information regarding their review rights. While this may be a result of computer errors, roll out issues etc, we are concerned that at a systemic level, participants are receiving inconsistent information about their review rights during and/or after the planning process. Furthermore, the failure to provide participants with written notice of their plans has consequences for review timelines (given review applications must be submitted within 30 days of notification of a plan).

We have been advised by a number of participants that they have attempted to lodge a complaint over the telephone but after being put on hold for lengthy periods of time have simply given up. Many of these participants won't feel confident or capable going into an office to complain or filling out the form so simply give up.

To ensure that participants are adequately informed, the NDIA should ensure that a consistent approach to informing participants of their complaint and review rights is taken during the planning process and that consistent, accessible and easy to understand information is given to participants when they receive notification of their plans.

We are also concerned to ensure that participants are being adequately supported to lodge a complaint or review in the manner they are most comfortable (i.e. over the phone, in writing and/or in person).

Recommendation: The NDIA review guidelines to ensure that participants be adequately and consistently informed of their review rights, through the provision of clear and accessible information (during planning meeting and on receipt of a plan) regarding the review process.

Recommendation: The NDIA, via a third party, support participants to lodge a review in the manner they are most comfortable.

Recommendation: The NDIA review compliance with Act to require notification of plans within 7 days, accompanied by information on review rights.

Market Readiness

Demand side development

Significant investment has been made on the development of the supply side of the NDIS market, without much focus, attention or investment in the demand side of the market. Basic economics says that if only supply is emphasised, consumers are weak, and there is little to no friction between market forces then it will not provide quality, innovation and progress.

Without innovation of new models for living in the world, a massive expansion of specialist services could emerge that will be expensive and which, perversely, will work against people with disabilities participating socially and economically. This has the potential to undermine the sustainability of the NDIS. Whereas, an NDIS that supports people to become more independent, demand quality, exercise their choice and control and become more included in the community contributes to the sustainability of the scheme.



An example of where demand side development is working well is the DSO project that is outlined above. The impact of appropriate pre-planning activities to inform participants, their families and carers has been dramatic in the quality of plans developed along with the capacity for them to actively put their plan in place once it has been agreed. This is just one example of a simple and cost effective program that has ongoing impact and creates an informed consumer.

Recommendation: The urgent need for the development of a demand side development strategy to build the capacity of participants to exercise greater choice and control and are informed to a greater degree. This strategy needs to be developed with a view to measuring outcomes over the long term and funded accordingly.

Supply side development

The requirement for growth in the disability service sector to meet anticipated demand of services is necessary for the fundamental NDIS principle of choice and control of services by people with disability to be achieved. Given the rapid intake of NDIA participants over the next few years as full roll out is achieved, there is a need for a concentrated effort by Government to stimulate growth in the skilled disability workforce.

Accessing services in regional and remote locations for people on the autism spectrum 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. This issue will be exacerbated within the NDIS in a purely market based model, especially for highly skilled staff such as early intervention practitioners in regional locations, with the clear potential for market failure leaving people on the autism spectrum without services. This is a major issue and Amaze recommends that the Victorian Government and the NDIA investigate alternative methods, such as an element of block funding for services in regional areas, to mitigate potential market failure in the short term.

Emerging research supports the efficacy of delivery of therapeutic services to remote locations via videoconferencing facilities that can be accessed within people's homes. Amaze recommends the further investigate the potential of these innovative service delivery methods such as utilising telehealth models.

There is also the need to ensure a level of quality in staff that will provide services to people on the autism spectrum through the NDIS. The provision of a wide range of support to people on the autism spectrum requires a skilled workforce that has specific understanding of autism. This extends beyond those providing higher skilled roles such as allied health professionals, through to all staff working with people on the autism spectrum in residential housing, day centres and staff providing other personal care and support. Not only will this ensure that the quality of services that people on the autism spectrum are receive, but within a market based system of disability supports, it provides a competitive advantage to disability service organisations. Amaze recommends that autism specific training and capacity building is available to register providers of supports.

Recommendation: The NDIA investigate alternate funding methods, such as an element of block funding for services in regional areas, to mitigate potential market failure in regional and remote locations – with focus on higher skilled workforce to deliver early intervention.

Recommendation: The NDIA further investigate the potential of innovative service delivery methods such as utilising telehealth models.

Recommendation: The development and open accessibility of autism specific training and capacity building is available to registered providers of supports.



A specific issue of concern to Amaze is that current approved providers of the HCWA program have not transitioned to become registered providers of support under the NDIS. Whilst the NDIA and DSS has worked to pre-approve these providers, and the transition process is simple however very few have transitioned. This lack of transition of providers is becoming of great concern as many families access their services through the HCWA program are being NDIS participants and cannot use these same providers to access services – and continuity of intervention is lost. Having spoken to a number of providers, they are unswear having not seen any of the few communications advising them of the pre-approval process to transition over to the NDIS. This issue would be simple to address with a more pro-active and engaging communications strategy going beyond DSS/NDIA sending an email. The overall impact will increase specialist services within the already limited NDIA marketplace, along with proving continually of interventions.

Recommendation: The NDIA invest in a pro-active communications and engagement strategy to transition existing providers of specialist and allied health providers in to the NDIS as Registered Providers of Supports.

Safeguards and Quality

Given the vulnerable nature of people on the autism spectrum, protecting them and safeguarding them from potential abuse is paramount, especially within a rapidly growing workforce. Amaze strongly supports the need for a highly skilled autism workforce, and that a requirement that all disability support staff undertake relevant and required pre-employment checks and receive training and ongoing professional development in regard to the prevention of abuse, neglect and violence towards people with disability. Amaze supports a zero tolerance culture being instilled across the workforce.

Recommendation: The requirement of all staff delivering disability services to be required to undergo pre-employment checks.

Recommendation: All staff delivering disability services be required to undergo initial and ongoing training relating to the prevention of abuse, neglect and violence towards people with disability.

