AMAZE SUBMISSION

Submission to Productivity Commission’s NDIS Costs Position Paper

July 2017
## Contents

Recommendations ................................................................................................................ 3
Introduction ........................................................................................................................... 4
1) The Victorian Parliament’s Final Report from its Inquiry into Services for people with Autism Spectrum Disorder .................................................................................................... 4
2) The participant experience and quality, consistency and transparency in NDIS planning. 5
3) NDIA roll out timetable and investment in the NDIA, ILCs and the service provision workforce. ............................................................................................................................. 7
4) Early Childhood Early Intervention eligibility – List D ..................................................... 8
5) DSO support for participants post planning .................................................................. 10
6) Building specialist knowledge ....................................................................................... 11
7) Meaning of ‘reasonable and necessary’ and clarifying the boundaries of NDIS funding 12
Conclusion .......................................................................................................................... 13
Recommendations

I. The Productivity Commission have strong regard to recommendations of the Victorian Parliament’s Family and Community Development committee outlined in its Inquiry into Services for people with Autism Spectrum Disorder Final Report.

II. Development and distribution of clear and accessible information on the NDIS, tailored to the needs of different audiences, including autistic people and disaggregated into the different life stages. The development of “autism friendly” resources should occur through co-design with people on the autism spectrum.

III. Further investment in peer networks and pre-planning support, drawing on successful experiences funded through the DSO program.

IV. Review the potential short and long term social and economic impacts, together with the inequalities that may be further embedded by prioritising participants with more urgent and complex needs, delaying the transition in some areas or an across-the-board slowdown.

V. Cost benefit analysis of whether the scheme’s social and economic objectives could be met within the current rollout to full scheme timetable if resources were increased in the short term to develop internal planning related capacity and expertise.

VI. Development of guidelines for NDIA, LAC and ECEI staff regarding the appropriate timing and facilitation of accessing an autism diagnosis for ECEI participants.

VII. If PEDI-CAT is to be preferred by the NDIA, it utilise PEDI-CAT ASD to measure the adaptive behaviours and functional needs of all young children, particularly those aged 0 – 7.

VIII. Removal of the KPI for ECEI providers that only 50% of entrants to the ECEI will be progressed to the NDIA to become a participant.

IX. Build understanding and knowledge among planners and LAC’s of how they can best support a participant to engage in the planning process, with greater understanding of how a person’s disability, such as autism, may impact their capacity to plan, attend and participate in a planning meeting, comprehend information and/or express goals and support needs.

X. Establish specialised planners and planning teams for autistic participants and engage specialist autism disability organisations in the pre-planning process.

XI. NDIA build the capacity of planners to communicate the “reasonable and necessary” criteria and its application to participants.

XII. Review 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.

XIII. Improved transparency, monitoring and evaluation of planning decisions to ensure that individualised assessments of reasonable and necessary support needs are being undertaken.
Introduction

Amaze welcomes the findings and draft recommendations outlined in the Productivity Commission’s *NDIS Costs Position Paper* (‘Position Paper’). We agree that if adopted, these reforms could vastly improve the NDIS planning process and outcomes for participants and their families/carers. These reforms would also maximise the scheme’s sustainability and capacity to meet the expectations of participants, their families/carers and the broader community.

We are pleased that many of the recommendations outlined in our submission to the Productivity Commission’s *NDIS Costs Issues Paper* have been incorporated into the Position Paper. Central to our submission was the direct lived experience of autistic people, their families and carers which we were able to share following our survey of the Victorian autism community in May of this year. We appreciate the voices of the 150 respondents to our survey (who identified the issues they are facing in regards to the NDIS and how they would like them to be addressed) were heard and able to inform the Productivity Commission’s findings and draft recommendations.

This submission to the Productivity Commission’s Position Paper highlights our general support for the findings and draft recommendations contained therein. It also aims to highlights the importance of the NDIA and Commonwealth Government recognising the unique challenges and strengths of autistic people and the importance of involving autistic people, their families, carers and their representative organisations in all aspects of NDIS development and operations that impact on them.

1) The Victorian Parliament’s Final Report from its Inquiry into Services for people with Autism Spectrum Disorder

We are pleased to highlight that on 22 June 2017, shortly after the release of the Productivity Commission’s Position Paper, the Victorian Parliament’s Family and Community Development committee released its Final Report from its *Inquiry into services for people with Autism Spectrum Disorder* (‘Final Report’).¹

This Final Report followed an 18 month consultation with the committee receiving over 150 submissions, conducting 11 hearings with over 120 witnesses (including many autistic people and their families), a number of site visit and an overseas study tour. Amongst its 101 recommendations, the report includes a number of specific and detailed recommendations on how the NDIS may be improved and the importance of clarity, transparency, ongoing review and reporting with respect to the NDIS and state government boundaries and obligations.

We trust that the Productivity Commission will take these recommendations into account before drafting its final report, particularly with respect to the urgent need for:

- Clear and comprehensive or easy to understand information for participants and people with disability about the planning process and evidence based therapies;
- Comprehensive training program and ongoing professional development for planners;
- A more effective ECEI gateway for young autistic children;

• Effective service integration between the NDIS and state based service systems, such as education and health;
• Continuity of services being phased out by state governments or under Commonwealth programs (such Helping Children With Autism).
• Ensuring that NDIS supports are made available to participants while in prison or youth detention, particularly in relation to their transition to the community on release.

The first and most welcome recommendation in the Victorian Parliament’s Final Report was that autistic people, their families and advocates always be included in the development of any and all policies, programs, services and supports that impact them.

Amaze has been disappointed to learn that that NDIA has not engaged with autism organisations such as Amaze and similar organisations following the NDIA’s public statement on the 6 July to improve the NDIS experience and planning processes. With one third of scheme participants on the autism spectrum\(^2\), and no engagement with the autism sector who represent and understand the specific issues autistic people are experiencing day-to-day with their interactions with the NDIS – it is difficult for the intent of this statement to be viewed as sincere.

We urge the Commonwealth government, Productivity Commission and NDIA to have strong regard to the recommendations in the Victorian Parliament’s Final Report given the inquiry’s level of engagement with autistic people and their families, carers and advocates. We are hopeful the NDIA will be encouraged to better consult and work in partnership with autistic people and their families/carers into the future.

Recommendation:

I. The Productivity Commission have strong regard to recommendations of the Victorian Parliament’s Family and Community Development committee outlined in its Inquiry into Services for people with Autism Spectrum Disorder Final Report.

2) The participant experience and quality, consistency and transparency in NDIS planning.

We welcome the Productivity Commission’s Draft Finding 9.5 that the NDIA needs to find a better balance between participant intake, the quality of plans, participant outcomes and financial stability.

The quality of the planning process and participant plans is key to achieving positive outcomes for autistic participants. By investing in a quality planning process now and ensuring autistic people receive cost-effective supports, their lifetime outcomes will be significantly improved, together with the financial stability of the scheme. The social and economic costs of autism will also be reduced, and unlock greater economic return through improved workforce participation and greater independent living.

We therefore welcome the NDIA’s recent public statement to review and improve the planning process. We also welcome the Productivity Commission’s Draft Recommendation 4.1 to improve access to clear, comprehensive and up to date information about the planning

process, and participant’s rights and options, as well as the recommendation that the NDIA review phone planning protocols.

As outlined in our previous submission to the Productivity Commission’s NDIS Costs Issues Paper, we agree that clear, comprehensive and up-to-date information about how the planning process operates, what to expect during the planning process and participant’s rights and options is crucial and urgently needed. However it is vital that these information resources also be tailored to the needs of different audiences, including autistic people and disaggregated into the different life stages.

Given autism is the single largest diagnostic group of participants within the NDIS, autism specific or “autism friendly” information provision, which recognises the unique challenges and strengths that autistic people can bring to the planning process, is urgently required. A trusted, independent and experienced organisation could 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 and co-delivering with people on the autism spectrum to ensure the utility of the developed products. Ongoing investment in information that is accessible to culturally and linguistically diverse groups and Aboriginal and Torres Strait Islander people, taking into account cultural perceptions and understanding of autism, will also be essential to ensure that these groups are fully informed about the planning process and are fully supported to engage in the planning process and express their goals and supports needs. As recognised by the Victorian Government in its Final report on autism services, clear information is also required on evidence based therapies, particularly in the ECEI pathway.

Participants must be provided an informed choice about how they engage in the planning process (whether by phone or face to face) with regards to sufficient pre-planning time. Planning meetings should never occur during cold calls. If a participant chooses to engage in the planning process by phone, they should first 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 and understand the matters they need to consider for the planning meeting. This will ensure a participant is ready to meaningfully engage with the planner – reducing planning time and creating a higher quality plan – both which will have a positive impact of scheme sustainability.

We would also encourage the Productivity Commission to recognise the ongoing need for Disability Support Organisations (DSO) to provide pre-planning support, including specialised support for autistic people. Through Amaze’s work as a DSO over the last 24 months, we have observed the significant benefits our facilitated pre-planning sessions provide to autistic people and their families. The overwhelming feedback from workshop participants is that our workshops have been vital in enabling them to meaningfully participate in their planning meeting and drive their plan. Having support from peers through these workshops, including those who were further along in the planning process, was also considered extremely valuable.

It follows that information resources are crucial but will not be enough alone, many people for reason of their disability or other individual or cultural reasons, will be best supported through face to face pre planning workshops where they can engage in active conversations and be guided by peers and experts. These workshops are particularly important to enable

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people to obtain advice that is relevant to their specific individual circumstances. The peer-to-peer relationships developed through these sessions also have ongoing impact to participants providing moral, emotional and wellbeing support through their NDIS journey and contribute to reducing social isolation which many autistic people and their families experience.

We therefore encourage the Productivity Commission to recommend investment in ongoing capacity building by DSO’s and peer networks capable of supporting participants in the planning process.

Finally, we agree the quality of, and consistency in the planning process and participant plans will be improved by greater transparency, monitoring and accountability. We therefore welcome the Productivity Commission’s Draft Recommendations 9.3 and 9.4 to ensure greater transparency and accountability, including by requiring the NDIA to report on reviews (including frequency, timeframes and outcomes) and to monitor and report on its performance against the scheme objectives.

Recommendations:

II. Development and distribution of clear and accessible information on the NDIS, tailored to the needs of different audiences, including autistic people and disaggregated into the different life stages. The development of “autism friendly” resources should occur through co-design with people on the autism spectrum.

III. Further investment in peer networks and pre-planning support, drawing on successful experiences funded through the DSO program.

3) NDIA roll out timetable and investment in the NDIA, ILCs and the service provision workforce.

A high quality planning process will be paramount to a successful and sustainable NDIS. We agree with the Productivity Commission and the NDIA that the scale and pace of the NDIS rollout to full scheme cannot be permitted to compromise participant outcomes or the scheme’s sustainability.

In response to the Productivity Commission’s Information Request 9.1, if an operationalised slowing down of the current roll out timetable is considered necessary, we would encourage the government to carefully review the potential social and economic impacts, together with the inequalities that may be further embedded by prioritising participants with more urgent and complex needs, delaying the transition in some areas or an across-the-board slowdown. The effectiveness of any slowdown will then be contingent on firm agreement being reached across the states, the Commonwealth and the NDIA on who should be prioritised and how this should be implemented. It is essential that people with disability are not left worse off by state based services ceasing before NDIS supports are available.

We would also encourage a review of whether the scheme’s social and economic objectives could be met within the current rollout to full scheme timetable if resources were increased in the short term to develop internal planning related capacity and expertise. Cost-benefit analysis may find that increased investment in staff/capacity now would yield greater outcomes socially and economically in the short, medium and/or longer term. It would also be a more equitable approach to supporting people with disability, regardless of their location or support needs. We strongly support the Productivity Commission’s
recommendation that the Australian Government reconsider the existing staffing cap on the NDIA.

We support the Productivity Commission’s Draft Recommendation 5.1 that funding for ILC activities be increased during transition, to be equivalent to full scheme, to allow for an accelerated national rollout of ILC activities. We agree that this will be critical to capacity building across mainstream services and ensuring people with disability are connected to the most appropriate services within and outside of the NDIS.

As recognised by the Productivity Commission, current gaps and shortages in the disability services workforce also pose significant risks to participants receiving the support they need and the sustainability of the scheme. We therefore support Draft Recommendations 7.1 to 7.3 to build the workforce and ensure that the roles and responsibilities of the NDIA and the Australia, State and Territory Governments are clear and transparent. We also welcome the recommendation in the Victorian Parliament’s Final Report on autism services, to fund more places in Victorian universities for students to study speech pathology, to examine the option of a scholarship program for speech pathologists to work in rural and regional Victoria and to fund the development of a post-graduate diploma in behavioural therapies.4

**Recommendations:**

IV. Review the potential short and long term social and economic impacts, together with the inequalities that may be further embedded by prioritising participants with more urgent and complex needs, delaying the transition in some areas or an across-the-board slowdown.

V. Cost benefit analysis of whether the scheme’s social and economic objectives could be met within the current rollout to full scheme timetable if resources were increased in the short term to develop internal planning related capacity and expertise.

4) Early Childhood Early Intervention eligibility – List D.

We welcome the Productivity Commission’s Information Request 3.1 on the advantages and disadvantages of maintaining ‘List D — Permanent Impairment/Early Intervention, Under 7 years — No Further Assessment Required’ in the NDIA’s operational guidelines on access.

We support the maintenance of List D on the basis that it does reduce the burden of assessments for families and recognises the individual and community wide benefits of early intervention for children experiencing the 130 identified conditions, including autism and global developmental delay. List D ensures that children are able to enter the scheme as soon as possible and receive supports immediately from an ECEI Partner. However, the success of this approach will be highly dependent on the knowledge and approach taken by ECEI Access Partners.

Given the high number of children in the 0-7 age cohort with an autism diagnosis (average of 50% of participants in the South Australian and Nepean Blue Mountains 0-7 aged based trial sites), 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 will have a diagnosis of autism, precursory autism-like traits or autism-like traits without a formal diagnosis.

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Therefore it is vital that ECEI Access Partners have a significant level of autism specific experience relating to identification of early autism signs, diagnosis of autism, all evidence based clinical and therapeutic autism specific interventions and have the capacity to support families before and after diagnosis. Once the signs of autism are apparent to skilled and trained ECEI staff, there should be no delay in a diagnosis being facilitated with assistance from their ECEI partner and specific interventions and supports being accessed to maximise the child’s developmental trajectory.

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.  

We therefore encourage the Productivity Commission to recommend that the 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. As emphasised by the Victorian Parliament in its Final Report on ASD, the NDIA must also 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.

Valid, reliable, accurate and efficient assessment tools must be used to measure the adaptive behaviours and functional needs of very young participants. As raised in our previous submission, there is evidence that the commonly used assessment tools, 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 young autistic children’s diverse support needs (particularly between the ages of 0 to 5) and indeed, may be providing a barrier to young autistic children accessing the levels and types of early intervention they require, via the ECEI pathway. As recognised by the Productivity Commission’s in its Position Paper, these tools may also be skewing the NDIA’s data and wrongly suggesting that 40% of children entering the scheme do not have substantial functional deficient relative to their peers.

If PEDI-CAT continues to be the NDIA’s recommended assessment tool, in order to mitigate against the tools flaws in functional assessment in young autistic children, research suggests that the PEDI-CAT, modified for autism spectrum disorder PEDI-CAT (ASD), would be a more efficient and sound assessment tool for this group. Amaze therefore encourages the Productivity Commission to recommend the use of the PEDI-CAT ASD for all children, particularly those aged 0 – 7.

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8 For more information, go to www.pedicat.com
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 would be set within an entitlement based scheme, and furthermore how this will affect practices of the ECEI partner.

In the case for autistic children, 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. We therefore encourage the Productivity Commission to recommend that 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.

**Recommendations:**

VI. Development of guidelines for NDIA, LAC and ECEI staff regarding the appropriate timing and facilitation of accessing an autism diagnosis for ECEI participants.

VII. If PEDI-CAT is to be preferred by the NDIA, it utilise PEDI-CAT ASD to measure the adaptive behaviours and functional needs of all young children, particularly those aged 0 – 7.

VIII. Removal of the KPI for ECEI providers that only 50% of entrants to the ECEI will be progressed to the NDIA to become a participant.

5) DSO support for participants post planning

We welcome your information request 8.2, querying whether there is scope for DSOs and private intermediaries to play a greater role in supporting participants and if so, how their role would compare to LACs and other support coordinators.

It is unclear whether this query relates to the short term roll out period (while LAC’s are engaged primarily in planning, to improve efficiencies etc.) or at full scheme (to provide long term support for participants).

We are of the view that significant benefits could flow from DSOs and private intermediaries providing ongoing support to participants, but only if they can demonstrate that they have a strong understanding of the NDIS and its scope, as well a strong awareness of appropriate services in a participant’s area. DSO’s and private intermediaries would also need to be adequately funded to do this work.

Through our Autism Adviser service, we have demonstrated our ability to provide sound, consistent and evidenced based information and support to HCWA recipients in Victoria. A DSO such as Amaze that engages with members of the autism community on a day to day basis could be well placed to provide post planning support, specifically meeting the information and support needs of autistic participants and their families. We could also facilitate valuable autism peer support groups to enable participants and their families to

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share their plan implementation experiences, including how to find and arrange supports and how to connect with inclusive community organisations.

6) Building specialist knowledge

We welcome the Productivity Commission’s Draft Recommendation 4.2 that the NDIA should ensure planners have a general understanding about different types of disability and that for types of disability that require specialist knowledge (such as psychosocial disability), there should be specialised planning teams and/or better use of industry knowledge and expertise. Amaze recommends that investment into the NDIA and its partners developing specialist knowledge be proportionate to the number of participants to whom specialist knowledge will be relevant.

As recognised in your Position Paper, Amaze’s 2017 survey found that 65% of respondents rated their planners’ knowledge and understanding of autism as ‘none’ to ‘moderate’. We have also been concerned that to date, the NDIA and LACs have failed to consult with the autism sector or utilise our disability specific knowledge and expertise to build their knowledge. If current participant trends continue to full roll out, approximately one third of people with disability seeking to enter the scheme will be autistic. It is vital that the NDIA and LAC’s start drawing on the expertise of organisations such as Amaze to build their knowledge of autism and the incredibly diverse challenges, strengths and support needs of autistic people.

As recognised by the Productivity Commission in its Position Paper, the planning process is currently not inclusive for all or sensitive to the needs of participants that can arise from their disability. Concern has been expressed to Amaze about planners and LACs lack of understanding of how a participant’s autism may impact on their engagement in the planning process, for example by limiting their capacity to comprehend long verbal advice in planning meetings, to understand the specific intent/meaning of questions asked and provide appropriate and complete answers. It is important that planners and LACs have the knowledge and skills required to ensure that participants have been provided all information and advice in a manner that they can understand, that they have been supported to communicate their goals and support needs in the manner that is most appropriate for them and that they have been empowered to participate in the planning process to the fullest extent possible.

Accordingly, we would support the establishment of specialised planners and planning teams for autistic participants. There are clearly significant benefits of having a specialised planner for autistic participants given the significant size of this group, which would, justify the cost of specialisation. At the very least, specialist disability organisations should be involved in the planning process by providing across the board training to planners and expert advice on the development of individual plans.
Recommendations:

IX. Build understanding and knowledge among planners and LAC’s of how they can best support a participant to engage in the planning process, with greater understanding of how a person’s disability, such as autism, may impact their capacity to plan, attend and participate in a planning meeting, comprehend information and/or express goals and support needs.

X. Establish specialised planners and planning teams for autistic participants and engage specialist autism disability organisations in the pre-planning process.

7) Meaning of ‘reasonable and necessary’ and clarifying the boundaries of NDIS funding

We agree that greater transparency is required for participants, planners and LACs on the meaning of the ‘reasonable and necessary’ criteria for supports, along with the term being applied to each participant’s individual circumstances when developing a plan.

We are particularly concerned about the lack of transparency to date regarding the “First Plan” process and that resulting in inconsistent meaning and application of the ‘reasonable and necessary’ criteria.

Under the “First Plan” process, planners and LACs allocate a typical support package based on participant’s reference groups (disability type, age and level of function). They should then adjust that package as appropriate, taking into account the supports that are “reasonable and necessary” in the participant’s circumstances. However, as outlined in our previous submission, we are concerned that the reference groups and packages currently applied are not sensitive enough to recognise the very diverse and individual support needs of autistic people. We remain concerned that many planners and LACs under pressure to process first plans quickly have been allocating typical support packages without adequately assessing the reasonableness and necessity of supports in participant’s individual circumstances.

We are also concerned that most participants are unaware of the First Plan approach and NDIA guidelines regarding the meaning of “reasonable and necessary”. As discussed above, clear, comprehensive and up-to-date information about the types of supports that are considered reasonable and necessary, and how this test is applied, is urgently required. It should be easily accessible, non-jargonistic and be tailored to the needs of different audiences, including autistic people and disaggregated into the different life stages.

We also agree that greater clarity, transparency and accountability is required with respect to the boundaries of the NDIS and services and supports that remain the responsibility of state and territory governments. We are particularly concerned by reported closures of state based services before NDIS funded services or NDIS funding has become available. We are also concerned by the lack of clarity about the types of services that fall within the boundaries of the NDIS and states and territories in sectors such as the education and health sectors. For example, as recognised in the Victorian Parliament’s ‘Inquiry into Services for People with Autism Spectrum Disorder’ Final Report, there is an urgent need for clarity about when NDIS funded therapy supports can be provided in classrooms (and when
these supports are appropriately considered to fall within the responsibility of state and territory governments).\textsuperscript{10}

We therefore support Draft Recommendation 5.2 to ensure that that the states and territories are continuing to provide supports and services that are not within the boundaries of the NDIS and to identify any gaps as they arise. We also support Draft Recommendation 5.3 to ensure that COAG continues to review gaps, duplications and other boundary issues and report on these as appropriate.

**Recommendations:**

\textit{XI. NDIA build the capacity of planners to communicate the “reasonable and necessary” criteria and its application to participants.}

\textit{XII. Review 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.}

\textit{XIII. Improved transparency, monitoring and evaluation of planning decisions to ensure that individualised assessments of reasonable and necessary support needs are being undertaken.}

**Conclusion**

We thank you again for the opportunity to comment on the findings, information requests and draft recommendations in your Position Statement and look forward to reviewing your final report.

If you have any questions arising out of our submission or we can provide further information, please contact Braedan Hogan, Amaze’s Policy Manager,

12 July 2017