



Brotherhood
of St Laurence

Working for an Australia free of poverty

Interventions for children on the autism spectrum

Response to NDIA Consultation

Brotherhood of St. Laurence

May 2021

The Brotherhood of St. Laurence and the National Disability Insurance Scheme

The Brotherhood of St. Laurence (BSL) is a social justice organisation working to prevent and alleviate poverty across Australia. Our mission is to pursue lasting change, to create a more compassionate and just society where everyone can thrive. Our approach is informed directly by the people experiencing disadvantage and uses evidence drawn from our research, together with insights from our programs and services, to develop practical solutions that work.

BSL has a strategic focus on building evidence-informed policies and practices that promote community inclusion and participation of all people, especially those experiencing exclusion or disadvantage. This commitment underpins our role as a LAC and ECEI provider for the NDIS in the North Eastern Metropolitan, Hume Moreland, Western Melbourne, Brimbank, Melton and Bayside Peninsula areas in Victoria. We have been delivering LAC since July 2016 as part of the first phase of NDIS implementation. We commenced as an ECEI provider in November 2016, and now work with around 40,000 people with a disability in LAC and ECEI. Our engagement in this planning and community capacity building is driven by the recognition that people with disability are among the most socially and economically excluded Australians, while also making an enormous contribution to our community.

Through our Research and Policy Centre and in partnership with the Melbourne Disability Institute of the University of Melbourne, we undertake research and evaluation activities with the aim of driving transformational disability policy and informing the successful implementation of the Scheme to support people with disability to live a good life.

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Summary

The Brotherhood of St. Laurence (BSL) welcomes the opportunity to respond to the NDIS consultation on Interventions for Children on the Autism Spectrum.

BSL welcomes the stated intention of the proposed changes – i.e. to streamline and create certainty and consistency for participants and their families and carers through a ‘focus on what should constitute reasonable and necessary early intervention supports for children on the autism spectrum’.

While we generally support the identified principles and standards and suggest the standards could be usefully elevated to guidelines, we ask the Agency to identify how the standards will be implemented and monitored.

BSL does, however, hold concerns about the model of budget allocation, the rationale for it and the process undertaken to implement the changes. In addition, we are concerned that this model implies that children with autism require a separate model of service provision, and believe that is inequitable and against the Principles of the NDIS Act.

BSL recommends that NDIA:

- 1. Clarify how Independent Assessments (IA) will translate into the levels identified for children with autism, and how the IA and planning process will be undertaken.**
- 2. Pilot the proposed IA and planning process for children on the autism spectrum to ascertain its effectiveness and impacts.**
- 3. Remove the association of funding levels with a specific diagnosis.**
- 4. Halt work on the proposed interventions model and funding for children on the autism spectrum, in line with the IA process, to allow time:**
 - to incorporate changes and any developments to the process resulting from the IA trial and Minister’s consultations; and**
 - to undertake a trial of the proposed model for children on the autism spectrum.**
- 5. Clarify the basis for the proposed funding model, including age-based categorisation, and provide data on dual diagnosis and plan budget utilisation as an evidence base for funding levels.**
- 6. Undertake a more comprehensive consultation with families and carers, and with providers, to develop a model that best meets the needs and goals of children on the autism spectrum, in line with Scheme principles and intent, and with ECEI reset recommendations.**
- 7. Develop tools and resources, in collaboration with families and carers, and providers, to support families’ and carers’ decision making and understanding of the autism interventions and supports.**

1 Introduction

The Brotherhood of St. Laurence (BSL) welcomes the opportunity to respond to the NDIS consultation on Interventions for Children on the Autism Spectrum.

Our response is underpinned by our commitment to ensuring the NDIS lives up to its transformative potential for people with a disability, their families and carers, and the wider Australian community. We provide feedback designed to ensure the aims of the proposed reforms are achieved, based on a deep understanding of the strengths and risks of proposed actions, informed by the experiences of people with disability and their families, and BSL staff. BSL welcomes the stated intention of the proposed changes – i.e. to streamline and create certainty and consistency for participants and their families and carers through a ‘focus on what should constitute reasonable and necessary early intervention supports for children on the autism spectrum’.

However, we hold concerns about the model, its rationale, the budget allocation and the process undertaken to implement the changes. In addition, we are concerned that this model implies that children with autism require a separate model of service provision.

BSL sees this Autism model as a further demonstration of the broader ambition for change of the NDIS currently being stepped out pre-consultation, by the NDIA. We believe that these changes essentially change the intent and vision of the NDIS and its principles of choice, control, independence, participation and person-centred support.

Without a trial of the proposed Autism model, it is difficult to ascertain its effectiveness, impacts and outcomes. BSL recommends that NDIA halt the implementation of the model for interventions for children on the autism spectrum, to allow time to test and review the model.

Our submission draws on consultations with BSL staff delivering Local Area Coordination and Early Childhood Early Intervention services, and participants in the Scheme, and previous submissions made to the recent consultations on the introduction of Independent Assessments (IA) for access and planning (Brotherhood of St. Laurence 2021a), and the Early Childhood Early Intervention (ECEI) reset (Brotherhood of St. Laurence 2021b).

Regarding the proposed model for Reasonable and Necessary Interventions for Children on the Autism Spectrum, we are responding to questions under two of the key consultation areas identified in the paper:

- Consultation Area 2: Reasonable and Necessary
- Consultation Area 3: Supporting Parents and Carers to Exercise Choice and Control

Additional comments are provided on issues identified through our consultation process.

A note on terminology: The BSL consultations identified differences in preferences for the terms ‘*person/child with autism*’ and ‘*autistic person/child*’. In this submission, we’ve used the term ‘child on the autism spectrum’ in line with the consultation paper.

2 BSL responses to the consultation paper

Consultation Area 2: Reasonable and Necessary

Questions 4–5: Principles and standards

BSL generally endorses the key Principles and Standards identified in the consultation paper as a guide to the provision of support and intervention for children on the autism spectrum. We suggest that the Standards may be useful as a baseline for service delivery and could be elevated and developed into guidelines.

However, several issues in relation to the Principles and Standards and their utilisation were identified through our consultations. We raise the following for consideration:

- There is insufficient focus on a **strengths-based approach** in the principles and standards. While the consultation paper acknowledges the core principle of Holistic Assessment which recognises the importance of an individual's strengths, challenges, goals and preferences to developing intervention targets that are meaningful to the child and family, this is not reflected in the proposed model and process for supporting children on the autism spectrum and their families and carers. Families and carers, and ECEI and LAC staff were concerned that the proposed changes were based on a deficit model of autism and provision of support—for example, by implying that behaviours and characteristics need to be 'fixed'. This is a criticism that family members have suggested could be directed at much of the approach of the proposed reforms.
- There is little discussion of **family-centred practice**. Although it is included in the core principles identified as important to interventions for children on the autism spectrum, this importance is not reflected in the Standards and Principles.
- The **principles and standards are open to interpretation and are subjective**. For example, Principle 1, which refers to 'a good understanding of autism'. This principle may need additional description and qualification in line with the current evidence base. Similarly, principles 5 and 6 refer to interventions that 'work'. People queried what this means in practice, and that what works for one person may not work for another.

BSL also suggests that these principles and standards should apply to service provision and support for any child with disability. We are concerned that the model separates out children with autism from the rest of children with disability and creates a separate pathway and model of funding, as we discuss below. In our submission to the Early Childhood reset, BSL suggested the concept of 'a plan for all' using NDIS Early Childhood Services (Brotherhood of St. Laurence, 2021b). Such a plan would support a better experience for participants and families, as it could be used differently as needs change. A plan might include funded supports and could minimise the concept of transition as it would apply before, during and after the provision of NDIS EC services. We believe this concept should apply to children on the autism spectrum as for all children, and potentially all people, with disability.

We also hold concerns about how the Standards would be implemented and monitored, and suggest this be clarified. BSL supports the development of an auditing, or similar process that would ensure compliance with the standards through checks and balances.

Questions 6–7: Explanation of ‘reasonable and necessary’

BSL staff and family members we consulted noted that the examples of reasonable and necessary supports are not particularly useful. They found the language used was problematic, reflecting a deficit model approach to provision of interventions and support.

BSL suggests that rather than the proposed examples, case studies could be co-designed with parents and providers and reflect a range of scenarios where a clear decision is made and explained.

Questions 8–10: Indicative levels of funded support for children on the autism spectrum

The consultation paper outlines the feedback the Agency received from participants about the ECEI reset, and highlights people’s concerns about the lack of clarity on how decisions are made on what are reasonable and necessary early intervention supports. We acknowledge the Agency’s intent to address these concerns, and that documenting the levels of functional impact, and the budget range to be applied to those levels, may provide some certainty and clarity for families as they enter the planning process.

However, BSL is concerned that the model raises several questions that remain unanswered.

The following areas require clarification and further information to support the rationale and development of the model:

- The issue of independent assessments has created concern for many families. As outlined in our submission on the ECEI reset, we support a comprehensive assessment including observation, use of standardised tools and consideration of family capability and circumstances. We have some concerns about use of the results of the independent assessments to inform access and planning decisions.
- There is a lack of clarity about what will be included under Capacity Building and which current Core Supports will be rolled into the proposed budgets.
- The model in effect ‘puts autism in a box’, suggesting that autism is a stand-alone area of need. There is little recognition of dual diagnosis, in the model and the paper, and the impact of this is underestimated in the development of the model. We suggest that clarification is required on how co-occurring conditions will be supported and/or addressed, in conjunction with supports under the proposed model. Provision of data on the incidence of dual diagnosis, to provide a more complete description of the actual situation for children on the autism spectrum would also be useful.
- Similarly, this model appears to associate funding levels with a specific, named diagnosis. This is discriminatory, and in contradiction of NDIS principles and Act.
- The budget ranges identified are unlikely to meet the requirements of all families and children on the autism spectrum. In particular, there is a lack of focus on parent capacity building and training, and there is no certainty this support will be funded under the new model, or that it will be feasible within the budget levels.
While some families may receive increased levels of funding, others are at risk of having significant reductions in their budgets.
- The strong expectation in the paper and model that need for supports will reduce over time, and that attendance at school will reduce the need for NDIS funded supports appears unrealistic. This neglects the impact of other co-occurring conditions and changing needs and issues at key transition points.

BSL recommends that NDIA:

1. **Clarify how Independent Assessments (IA) will translate into the levels identified for children with autism, and how the IA and planning process will be undertaken.**
2. **Pilot the proposed IA and planning process for children on the autism spectrum to ascertain its effectiveness and impacts.**
3. **Remove the association of funding levels with a specific diagnosis.**
4. **Halt work on the proposed interventions model and funding for children on the autism spectrum, in line with the IA process, to allow time:**
 - **to incorporate changes and any developments to the process resulting from the IA trial and Minister's consultations; and**
 - **to undertake a trial of the proposed model for children on the autism spectrum.**

Consultation Area 3: Supporting Parents and Carers to Exercise Choice and Control

Questions 11–12: Support to implement plans

While the questions identified in the paper provide a useful frame for families and carers, BSL staff and other stakeholders are concerned that families and carers may not be able to effectively use the information given to them by providers, without additional tools and resources, especially in the early years after diagnosis. The consultation paper indicates that a decision-making tool is being developed and this may be a useful resource, particularly if it is developed in consultation with families and carers.

Additional supports and capacity building could enable parents to make well-informed, right choices and understand the evidence and best supports for their children. Programs such as Monash University's Act-Now training, delivered in conjunction with Regional Autism Co-ordination Groups (ReACT), have been shown to be effective in building the capacity and understanding of parents and families about autism and interventions. It may be beneficial for NDIA to use the learnings from this and similar programs and implement programs of support.

Other feedback

1. Lack of consultation with families and carers and providers

BSL staff and family members we consulted expressed considerable concern that this consultation process is not seeking input on the model but is primarily about refining the implementation of this pre-determined model. Nowhere does the paper suggest the consultation is about collaborating with families, carers and providers to develop the best model for children on the autism spectrum.

This approach is at odds with the 'nothing about us without us' ambition of the NDIS. This should not be considered a 'nice to have' approach; rather it is essential for effective and efficient model design, implementation and impact.

BSL contrasts this consultation process with the recent ECEI reset process, which saw considerable engagement with participants, families and carers, advocacy organisations and providers, resulting in well-supported recommendations.

2. Concerns about fundamental changes to the Scheme

BSL appreciates that the recent proposed NDIS access and planning policies seek to make the Scheme more equitable, consistent and sustainable.

In our recent submission on the introduction of IAs, the BSL has supported:

- the Agency's objectives to improve consistency of decision-making and equity
- the revision of Access processes to focus on the impact of disability on a person's life rather than a specific diagnosis, particularly when determining access to the Scheme
- the provision of fully funded assessments for all participants
- focusing the role of Local Area Coordinators, and ECEI, on helping a person to navigate the Scheme and make the most of community and mainstream supports
- increasing flexibility for plan budget usage.

However, we received strong feedback from people with disability, families and carers expressing concern that 'Independent Assessments' (as proposed) will take the Scheme backwards rather than forwards, as it impacts on the underpinning principles of choice and control, and individualised goal-based and person-centred planning.

We welcomed Minister Reynolds' recent decision to pause the implementation of Independent Assessments, pending the outcomes of the current trial and further consultation with participants, families and carers and providers.

In our response to the NDIS Consultation on Access and Planning Policy the BSL identified that:

The proposed planning process flips the current approach to planning, with a budget being prepared and sent to a participant prior to consideration of their goals and aspirations. A familiar event, the planning meeting, has been given a new meaning, and 'reasonable and necessary' is now used to describe funding assigned after considering IA results, rather than supports. Terms used in the recommendations of the Tune review such as draft plans and joint planning meetings have been included in the process, but the terms are used to describe a different activity.
(Brotherhood of St. Laurence 2021a, p. 20)

We believe these concerns are borne out in the proposed model for funding interventions for children on the autism spectrum.

Further, BSL is concerned that the proposed model marks a reintroduction of a capped support system based on diagnosis, and in doing so creates a different and inequitable pathway for autistic children compared with other cohorts of participants in the Scheme.

3. Lack of alignment with recent Scheme reforms

The recent consultations on Scheme reforms focus on increasing flexibility in plans and budgets.

However, BSL is concerned that the proposed model for interventions for children on the autism spectrum goes against these scheme developments, with a predetermined budget and level of need being introduced for this cohort.

Further, the ECEI reset recommendations were largely supported and welcomed by the sector.

We suggest that the NDIA clarify how the proposed model for interventions for children on the autism spectrum aligns with these recommendations.

4. Impacts on choice and control and person-centred planning

BSL considers the proposed model turns on its head the original intent of the Scheme to ensure participants have choice and control in the supports they use. Rather than plans being developed based on participant goals and preferences, and then budgets being developed to support these goals, this model allocates funding based on diagnosis and assessment with goals and preferences then identified within the parameters of the budget.

Families and staff see this as a loss of focus on individualisation of planning and supports, and that this is contrary to NDIS principles and the Act.

5. Concerns about evidence base and rationale for the model

We appreciate the use of the CRC research to inform the approach to be taken to support autistic children and their families, and the commitment of NDIA to evidence-informed practice and interventions. While the discussion of the research and the intent to apply an evidence-based approach gives the impression of a rationale for the proposed model, there are concerns that the evidence has been used selectively and does not align with the model developed.

Although there was no discussion about funding in the CRC report and they determined there was 'no consistent evidence as to whether the amount of intervention influenced child and family outcomes', the NDIA have referred to the CRC report as the basis for the development of the model.

Family members and BSL staff also raised concerns that when the evidence is inconclusive, as identified by the CRC's research, how is best practice being determined and by whom; and furthermore, who is determining what is reasonable and necessary?

Our consultations also noted:

- Evidence-based interventions for children on the autism spectrum are difficult to determine as the evidence is still emerging. Family members and staff identified the need to ensure there is capacity for trialling innovative therapies and using individualised interventions.
- BSL staff expressed concern that the model cut-off is at age 13, when the child is transitioning to secondary school. They saw this as a key developmental point when additional supports may be required and suggested that the age range be extended to include the early secondary school year or years.

BSL suggests that more detail is required about the evidence and data that informed the development of the proposed model.

6. Lack of process for appeals and requests for review

BSL is concerned that there is no discussion in the paper of appeals and review processes for decisions on levels and budgets.

While the funding is identified as indicative, the paper also suggests that very few individuals would be likely to receive the upper budget amounts. This does not provide assurance about scope to seek additional funding outside the determined range.

The impact on existing participants and their plans and budgets is also unclear, as discussed below.

7. Impacts on participants and families and carers

BSL staff expressed concern about the impact on families and children who are currently on NDIS plans, noting there is no certainty that current participants will be assessed as being at the level that matches current funding.

They also suggested that many families are likely to be financially impacted, with the low levels of funding under the proposed model resulting in families having to partially or fully fund interventions and support outside the scope of the budget.

BSL suggests that NDIA needs to develop effective communication to families to support their decision-making and develop resources on evidence and supports to enable them to navigate the plethora of information that is provided by providers.

BSL recommends that NDIA

- 5. Clarify the basis for the proposed funding model, including age-based categorisation, and provide data on dual diagnosis and plan budget utilisation as an evidence base for funding levels.**
- 6. Undertake a more comprehensive consultation with families and carers, and with providers, to develop a model that best meets the needs and goals of children on the autism spectrum, which is in line with Scheme principles and intent, and with ECEI reset recommendations,**
- 7. Develop tools and resources, in collaboration with families and carers, and providers, to support families' and carers' decision making and understanding of the autism interventions and supports.**

3 Conclusion

The Brotherhood of St. Laurence welcomes the opportunity to contribute to this consultation on Interventions for Children on the Autism Spectrum.

We look forward to working with the NDIA on the refinement of this model to achieve the best outcomes for children with autism and their families and carers.

References

Brotherhood of St. Laurence 2021a, *Independent assessments, access and eligibility policy, and planning policy: response to NDIS consultation papers*, BSL, Fitzroy, Vic.,

http://library.bsl.org.au/jspui/bitstream/1/12520/1/BSL_response_NDIS_reforms_to_access_and_planning_policies_Feb2021.pdf

Brotherhood of St. Laurence 2021b, *Response to NDIS consultation paper Supporting young children and their families early to reach their full potential*, BSL, Fitzroy, Vic.,

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