



Submission in response to:

**National Disability Insurance Scheme Consultation Paper:
Interventions for children on the autism spectrum.**

May 2021

We would be happy to meet at any time to discuss this submission further.

Andrew Billing

Chief Executive Officer

St.Giles Society

Ph: 6343 7333

andrewbilling@St.Giles.org.au

65 Amy Road, Newstead 7250

Kathryn Fordyce

General Manager – Specialist Services

St.Giles Society

Ph: 6454 1222 or 0427 739 397

kathrynfordyce@St.Giles.org.au

Suite 5, 10 Marine Terrace, Burnie 7320

About St Giles Society

St.Giles is recognised as a national leader in the field of paediatric allied health and disability support services. Each year St.Giles teams in Hobart, Launceston, on the NW Coast and in outreach settings provide services to more than 6000 Tasmanian children; the majority of whom are aged from birth to six years.

St.Giles runs a range of services for children with autism including diagnostic assessment, early childhood early intervention, therapeutic and core supports and the Autism Specific Early Learning and Care Centre.

St.Giles Developmental Assessment Team is a multi-disciplinary diagnostic team comprised of psychologists, occupational therapists and speech pathologists who are funded by the Tasmanian Department of Communities to provide diagnostic assessment for pre-school children in the North and South of the state. Additionally the team is funded to undertake diagnostic assessments state-wide for children identified at high likelihood of autism through the use of the Social Attention Communication Surveillance tool by Child Health and Parenting Services (CHaPS) nurses.

St.Giles has operated the North West Tasmania Autism Specific Early Learning and Care Centre (ASELCC) since 2016 after the service transitioned from Burnie City Council. This service delivers autism specific early intervention embedded in a long day care environment. The ASELCC delivers services through our Burnie Hub and through programs offered in Devonport, Smithton and King Island in collaboration with mainstream early childhood education and care services. The ASELCC has been funded since 2010 by the Australian Government Department of Social Services and has delivered intensive autism specific early intervention services to more than 350 children and their families, while also focusing on building the capacity of the workforce and community and in contributing to research through local and national partnerships. The ASELCC's DSS funding is due to end in June 2021.

St.Giles is also a National Disability Insurance Scheme (NDIS) provider offering therapeutic, in-home and community support to children with autism. We have multidisciplinary teams across the state delivering a range of services using both transdisciplinary and multidisciplinary service delivery models. We have a long history of support children across a range of settings and are committed to advocating for the needs of children and families with autism so that they can thrive.



Promoting Best Practice

Q1. Which of these would you use to find information about choosing and accessing best practice interventions (or services) for children on the autism spectrum?

- NDIS website
- NDIS Operational guidelines
- Participant decision making guides (not yet developed)
- My usual NDIS or NDIS partner contact
- Autism organisations or peak bodies
- None of these

Research conducted by a consortium of St.Giles in conjunction with other ASELCCs and their research partners nationally found that early intervention providers (including allied health professionals and early childhood educators) trusted and accessed information from internal professional development, therapists and external professional development¹. The perception that a practice was evidence-based best practice was linked to the reported use of interventions and intended future use. While practitioners tended to use more empirically supported practices where they perceived a higher evidence even if the practice was not empirically supported, they were more likely to report use of, the likelihood of future use or recommendation of a practice². This highlights the need for ongoing high quality training opportunities for professionals that provide clear information about evidence based practices and alternatives to non-empirically supported practices. Other research conducted by our group found that providing training focused on debunking autism treatment myths worked but was not sustained at follow-up. This highlights the need for regular and sustained training activities that are focused on supporting practitioners to select evidence based approaches to support children with autism. Similarly, research with parents suggests they too tend to seek out, and trust, information from therapists and ASD EI providers to inform their intervention choices, and rarely ask about the evidence-base behind interventions³. As such, there is an imperative to ensure that the early intervention workforce receive high quality training and have access to high quality resources that enhance their understanding of what works for children with autism and their families.

It is our experience that families tend not to engage with the NDIS website or the NDIS operational guidelines. We do hear that parents and carers seek advice from their NDIS or NDIS partner contact, their General Practitioner, Paediatrician or other trusted health or education provider. Unfortunately it has been our experience that many of these people are not familiar with best practice approaches to early childhood intervention for children with autism, and there is a tendency towards a “medical model” of early intervention without a focus on family-centred goals and support for generalisation of skills to natural

¹ Paynter JM, Ferguson S, Fordyce K, et al. Utilisation of evidence-based practices by ASD early intervention service providers. *Autism*. 2017; 21(2):167-180. doi:[10.1177/1362361316633032](https://doi.org/10.1177/1362361316633032)

² Paynter, J., Luskin-Saxby, S., Keen, D. et al. Brief Report: Perceived Evidence and Use of Autism Intervention Strategies in Early Intervention Providers. *J Autism Dev Disord* **50**, 1088–1094 (2020). doi:[10.1007/s10803-019-04332-2](https://doi.org/10.1007/s10803-019-04332-2)

³ Deyro MC, Simon EW, Guay J. Parental Awareness of Empirically Established Treatments for Autism Spectrum Disorders. *Focus on Autism and Other Developmental Disabilities*. 2016; 31(3):184-195. doi:[10.1177/1088357614559210](https://doi.org/10.1177/1088357614559210)

settings. Further training for education and care providers and mainstream health services, as well as NDIS staff and partners in the community are necessary to enhance the understanding of best practice for families.

Where else would you like to find information about accessing best practice interventions (or services) for children on the autism spectrum?

Our staff, families and stakeholders value the training provided by the Early Days and Positive Partnerships programs and the information contained on the Raising Children’s Network and similar websites. However, there is a need to further strengthen this information to improve its usability for parents and professionals and to especially to combat autism treatment myths. It is accepted that attempts to debunk misinformation often provide sub-optimal and may even ‘backfire’ and increase the misconceptions or likelihood that a professional may recommend or a parent may choose an unsupported practice. Our research consortium trialled an “optimized-debunking” training to compare support for non-empirically supported approaches and found that this served as an effective debunking template, however the effect was not sustained⁴. This highlights the need for easily accessible information about intervention practices and approaches that utilise “debunking” principles and that remain accessible for parents and professionals to revisit regularly to refresh their knowledge of the evidence-base. Given the challenges most providers, professionals and families have with navigating the NDIS website, it would be best that this material is hosted elsewhere and with an emphasis on easy access for families.

Ongoing access to autism advisors who sit outside the NDIS and are able to provide advice and training to families and providers would be advantageous in supporting knowledge and use of the best practice interventions. It would also be positive to see the NDIS Quality and Safeguards Commission taking a more active role in oversight, investigation and targeted compliance of providers (both registered and otherwise) who are known to utilise non-evidence based practices.

Q 3. Holistic planning is a part of the proposed funding framework for early intervention for children on the autism spectrum. A description of “holistic planning” is included in Section 7.4.

St.Giles recognises the importance of holistic planning that considers the full environment of the child and family when planning intervention and support, and we commend the NDIS for recognising the need for improvements in this area. It has been our experience that the needs, challenges and barriers of families are not sufficiently considered by the NDIS and their partners in the community. There is insufficient emphasis on the impact of a child’s disability on the mental health and well-being of the parents and in turn the impact of these on the child, and on how families can be supported to better understand their child’s autism in order to effectively meet the needs of their child. Some families need more resources to achieve an effective understanding of their child’s needs, to learn how to use appropriate intervention strategies and to navigate the service system. It is unrealistic to assume that “mainstream” services are able to provide this support, and we are yet to see the Early Childhood Partners truly assume an effective capacity building role with the most vulnerable families.

⁴ Paynter, J, Luskin-Saxby, S, Keen, D et al, Evaluation of a template for countering misinformation—Real-world Autism treatment myth debunking, PLOS ONE <https://doi.org/10.1371/journal.pone.0210746>

Further, it has been our experience that very few young children are getting access to support coordination funding that would assist families in making the most of their plan, and in engaging with other mainstream health, early education and community based supports. Perhaps if there were a strengthening of Information Linkages and Capacity Building activity targeted at early childhood, and a greater emphasis on place-based initiatives that provide targeted support to engage the families of young children from vulnerable communities, there would be increased capacity in “mainstream” providers to support children with autism and their families. Considerable work is needed to ensure that there is “no wrong door” for these families. It has been our experience that the introduction of the NDIS has made navigating the service system more difficult for families and service providers. After 10 years of delivering the ASELCC where we very frequently provided services to children with autism-like characteristics prior to an autism diagnosis, we have seen a dramatic shift in our referrals with far less undiagnosed children, especially those with complex family situations, being referred directly to our service. In situations where we do receive referrals for these families, we provide considerable unfunded support to families to connect with the NDIS. While on paper the NDIS ECEI pathway should help families through this process this has not been our experience with many families falling through the “cracks”. Families from vulnerable backgrounds including parents with disability or mental health conditions, those experience family violence, those who experience generational poverty, and our Aboriginal and culturally and linguistically diverse families are not actively supported by the NDIS and their partners to engage, and trusted relationships with providers are viewed with a “conflict of interest lens” and not valued by the NDIS or their partners.

In order to address this, the NDIS and its partners needs to stop viewing all providers as “circling sharks” wanting to sell their products, but with a view that the vast majority of organisations and individual providers are invested in achieving positive life outcomes for children and families, and in making the service system make sense to the people we serve. This should be supported by both an educative and compliance functions provided by the NDIS and/or NDIS commission where providers are supported to understand and improve practice, and robust oversight, investigation and compliance is undertaken where a provider is not acting in the best interest of participants. There are opportunities to build communities of practice between the NDIS, mainstream services and providers that are mutually beneficial for these agencies and for children and families.

Reasonable and Necessary

Q4. Building from the Autism CRC research the consultation paper outlines specific principles that the NDIS considers as early intervention best practice for young children on the autism spectrum (Section 6.1.) Is there anything you would like to add?

St.Giles supports the development of principles to support high quality evidence based practice for children with autism and their families. We believe that the proposed principles are a good start but could be strengthened to explicitly recognise and value neurodiversity. As such the principles should indicate that the core purpose of early intervention is to support the achievement of child and family goals and in supporting the development of functional skills and in reducing secondary impacts of autism on the development, health and wellbeing of autism, and not on aiming to “cure” or change the underlying characteristics of autism. Having a good understanding of autism is not enough, early intervention

providers must value autism and be focused on reducing disability by creating inclusive, autism-friendly environments that allow autistic children and their families to thrive.

Further the principles need to include more emphasis on families and family-centred practice. Children on the autism spectrum live in families with families and siblings, and interventions need to focus on supporting the needs of both the child and the family.

Q5. Building from the Autism CRC research the consultation paper outlines specific standards that the NDIS considers as early intervention best practice for children on the autism spectrum (Section 6.2.) Is there anything you would like to add?

Similarly, St.Giles supports the development of standards to support the delivery of high quality evidence based early intervention for children with autism and their families. However, there is a lack of clarity about the audience for these standards and a need to adjust some of the wording and to strengthen some of the explanations.

In particular, it is important to note that in Standard 1 regarding qualified professionals that this is an overemphasis on AHPRA registered health professionals and insufficient attention to the self-regulating professions such as speech pathology, and the important role that early childhood teachers play in the delivery of early intervention services across the nation. We have found that the views, experience and reports of St.Giles' Early Childhood Teachers are not sufficiently valued by the NDIS and the partners, and that the views of allied health professionals are given preference. The expertise of Early Childhood Teachers, who are experts in early childhood development and in the provision of holistic supports, should be seen as a critical part of an early intervention team.

In relation to standard 3, there needs to be clearer reference to the benefits an intervention can have on family functioning, family quality of life and the knowledge, skills, attitudes and well-being of parents and siblings. Highly functioning families are more likely to be able to provide and remain connected to informal supports, implement interventions, and engage with mainstream services. Investment in interventions that address the whole family benefits children with autism both now and into the future, as well as enhances social and economic participation of parents.

In relation to standard 5, this should be reworded to remove reference to "significant" physical or emotional harm. The inclusion of the word "significant" implies that a little bit of harm is okay or acceptable. Any intervention that physically or emotionally harms children is not acceptable.

Q6. "Reasonable and necessary" is a term from our legislation. Appendix one of the consultation paper includes case studies which might be used to explain reasonable and necessary. Do these case studies help you to understand what we mean by "reasonable and necessary"?

It has been our experience that case studies provided by the NDIS (including the one contained in Appendix One) are usually too simplified to be meaningful to parents or providers. They often provide a 'rose-coloured' view of access to and the availability of services, a child's response to intervention, the responsiveness and capability of mainstream providers, and on a child's family circumstance. The case studies very rarely explore the complexities that occur in the majority of the families and children we

support. We rarely see case studies where parents are separated, where parents have their own physical or mental health needs or disabilities, where children are waiting on access to a diagnostic assessment or to see a paediatrician or other factors that complicate the provision of NDIS supports. It would be advantageous where case studies are used to explain concepts such as “reasonable and necessary” that multiple examples are provided and that these are co-designed with parents and providers.

Q7. Do you have any other feedback about how we explain “reasonable and necessary?”

We continue to see significant differences between the interpretation of “reasonable and necessary” with unexplainable differences between the plans of children who seem to have very similar needs. We have observed that some NDIS partners in the community tend to overgeneralise and apply their assumptions about the previous decisions of delegates to interactions with other families, rather than documenting the goals, preferences and individual circumstances of a child or family. Families have reported being told by NDIS partners that children under 7 cannot have access to particular supports such as behaviour support, support coordination or assistance from a support worker for access to community social and recreational activities or assistance with self-care activities. In many instances, these requests seem to be “reasonable and necessary” but are vetoed by the partner and as such not provided to the delegate for consideration.

Q8. Table 2 (0-6 years) and Table 3 (7-12 years) are an example of how we might explain Indicative level of funded support for children on the autism spectrum (Section 7.5.) Do these table/s clearly explain the indicative levels of funded supports?

St.Giles opposes the use of indicative levels of funded supports as the proposed funding levels seem at odds with the proposed principles which note that “the intervention is adapted to the needs of the person receiving it”. The descriptors of functional impact and the examples of how this could look in a child are confusing and inconsistent, and do not provide a realistic or helpful view of a child. The proposed funding levels do not sufficiently consider the family and other informal support around a child and as such it appears that families who would require more assistance to understand their child’s needs and to learn how to implement intervention and other support strategies may miss out on critical support. The proposed supports at each level also appear to be inconsistent with the principles and standards of proposed earlier in the consultation paper with the indicative levels providing insufficient funding to effectively embed early intervention in natural community settings such as a child’s home, childcare, school or playgroup. Further, the proposed levels do not provide adequate levels of resourcing to support collaboration between services, and between NDIS providers and mainstream services, and for the travel and additional resourcing that is required to embed services in natural settings.

Q9. Do you have any other feedback about how we explain the indicative levels of funded supports?

St.Giles is concerned that the inclusion of indicative levels of support is a reversion to the original early intervention approach that identified levels of funding of spanning from \$8,000 to \$16,000 per annum. This approach was criticised at the time as being oversimplified and for not encouraging appropriate consideration of the individual needs of children and families. Revisiting this approach without clarity in how the levels of funding would be determined and without providing assurances that there would not be

applied rigidly by NDIS partners provides unnecessary stress to parents and providers about children and families missing out on reasonable and necessary supports.

Further, we are concerned about the assumption that children with autism year on year would require less support, and as such a reduction in funding. This does not consider that a child's needs may fluctuate as the goals change, and as the demands of their life and external circumstance change. For example, many children and families require additional support as they transition to school. School can create additional pressures for the child and family, and the increased social and behavioural expectations can lead to new goals and support needs.

Additionally, St.Giles is concerned that the addition of indicative levels has been devised simply as a cost saving measure due to the significant numbers of children with autism in the NDIS, without sufficient recognition of the lifelong economic benefit that can be achieved long term by providing young children with autism with high quality early intervention⁵. Providing indicative levels of funding only for young children with autism while not providing similar for other young children with other disabilities, or for people with disabilities of other ages seems to suggest that children with autism do not have the right to access the NDIS fully.

Q10. There may be situations where families or carers need extra NDIS supports such as during first plans, or where plans reduce in value due to the impact of mainstream services. What do we need to consider in those situations?

St.Giles believes that it is essential that children suspected of having autism should have access to autism-specific supports as soon as possible. Delays to formal diagnosis should not preclude access to effective autism-specific early intervention where parents and professionals identify functional impacts that suggest autism is likely. We also are highly concerned about the suggestion that children with autism may be offered short term supports for up to 12 months with an early childhood partner prior to testing for eligibility. Our families have reported that the level of autism expertise and knowledge of best practice in autism is very limited in early childhood partners, and as such delaying access to the scheme would delay access to specialist providers the approaches and practices that are more likely to be effective in supporting functional skill development, and goal attainment. Earlier access into autism specific supports is critical in maximising outcomes, while delaying supports seems counterproductive and inconsistent with the insurance principles of the scheme.

It is pleasing to see that the NDIS is considering how the needs of families and the interface with mainstream services may impact on a child's plan, however, it is important to consider that the addition of mainstream services doesn't make the need for therapeutic and early intervention supports obsolete. In fact increased engagement with mainstream services can intensify the need for providers to build the capacity of the child, family and mainstream provider.

⁵ Synergies Economic Consulting Pty Ltd, Cost-Benefit Analysis of Providing Early Intervention to Children with Autism: Estimation of the net economic benefit of early intervention for a cohort of children with autism, 2013, <https://www.synergies.com.au/wp-content/uploads/2019/09/Productivity-Commission-Cost-Benefit-Analysis-of-Providing-Early-Intervention-to-Children-with-Autism-2013.pdf>

Supporting parents and carers to exercise choice and control

Q11. We want to support children and parents with implementing plans using the Autism CRC research and best practice. In Section 8.2 there is a suggested list of questions for parents and carers. These can be used to understand the best intervention for a child and their family and how a provider is delivering an intervention. Are these questions helpful for parents and carers when selecting providers?

The questions included in section 8.2 are a good start in supporting families to critically appraise an intervention or practice, however additional guidance is needed to strengthen this material. Positive Partnerships have previously developed material aimed at supporting families to consider the suitability of an intervention, including a range of questions to ask. We believe that it would be useful to strengthen the linkages with the principles and practices by providing guidance material on what it looks like when a principle or practice is being adhered to and when it is not, what parents might like to observe, read or discuss in order to gather information about how a service adheres to a particular principle or practice, and how they might provide feedback to a provider about their concerns about the suitability of their proposed intervention approach. This is important in thin markets (especially in regional and remote areas) where there may not be alternative providers, and negotiating with a provider to adjust their intervention approach is necessary.

Q12. What other guidance or tools do families need to feel confident to implement plans in line with the Autism CRC research and best practice?

As noted above, families would benefit from additional guidance material on the principles and practices and how they can gather information from a provider about their suitability or the appropriateness of the proposed intervention approach. This information should include advice on how to check if their provider is registered or holds membership with their professional association, and should provide explicit advice about how to make a complaint the NDIS Commission and to a providers governing/registering body. Further investment to strengthen online information about interventions to ensure that the information about non-empirically supported interventions does not inadvertently reinforce myths and implausible practices.

It seems likely that families would be more confident about the implementation of evidence based practice if there was effective and comprehensive monitoring of early childhood intervention providers. There is opportunities to learn from the experience of the Australian Children’s Education and Care Quality Authority in relation to how early intervention services are monitored and in sharing information publicly about the quality of services. In early childhood education and care, the assessment and rating results of services are publicly available, and families are encouraged to talk openly with services about the Quality standards and their Quality Improvement Plans. While such an approach for NDIS providers would need to account for sole practitioners and large multi-site providers, it would provide families with information about how each provider “measures up” and allow a starting point for open dialogue about their expectations of the service.

Conflict of Interest

Q13. This question relates to Section 8.3 of this paper: "Addressing conflicts of interest." How can we support families and carers to feel confident to make decisions about what is in the best interest of the child and family?

St.Giles recognises that families need access to unbiased information to assist them in making decisions about their child. However, we strongly reject the assumption that providers are not able to make ethical decisions that place the needs of a child and family, above a providers business needs. In an environment where most NDIS providers have massive waiting lists and where a significant proportion of NDIS participants do not fully utilise their plan, there is no need for providers to inflate the needs of a child or to continue to provide services to a child when an alternative service is better placed to address the needs of the child and family. The principles state that suitably qualified professionals should provide early intervention supports and all suitably qualified professionals are bound by professional codes of conduct or ethics that require professionals to act in the best interest of their clients, and there are defined systems for dealing with breaches of these. As such, empowering families to understand what would constitute a conflict of interest or unethical practice and how they can report this would be advantageous.

In recognising the possibility that providers could experience conflicts of interest, it is important for the NDIS to recognise the inherent conflict of interest that is held by the agency. The NDIS has an imperative to stay within its budget, local regions and states and territory data is published and compared, and there is a need to ensure the long term sustainability of the scheme. As such, the NDIS and so in turn its staff and partners in the community, have pressures to keep the cost of plans down as low as possible which may at times mean that the a lower cost plan may be built even though it is not in the best interest of the child and family.