



AutismCRC

Interventions for children on the autism spectrum

Submission in response to National Disability
Insurance Agency Consultation Paper

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Australian Government
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AusIndustry
Cooperative Research
Centres Program

autismcrc.com.au

1. Introduction

1.1. Autism in Australia

Autism is a collective term for a group of neurodevelopmental conditions that affect social interaction, communication, behaviours and interests. It is a lifelong condition.

Every person on the autism spectrum is unique. The challenges and their presentation can vary widely in nature and severity between individuals, and in the same individual over time, as can their needs and nature of engagement with service sectors. Many people on the spectrum experience additional challenges with educational and vocational attainment, physical and mental health and family functioning.

Despite growing awareness and understanding of autism and neurodevelopmental conditions over the past decade, the need for relevant evidence-based policy and practice to address the significant disadvantages for individuals and families – seeking to pursue their goals and interests and meet societal challenges – has arguably never been greater.

- Autism prevalence rates continue to grow rapidly, 25.1% from 2015 to 2018, with more than 200,000 Australians having a diagnosis of autism¹.
- Approximately 3.2% of Australian school-aged children are on the autism spectrum, and these will grow up to be autistic adults¹.
- The proportion of autistic individuals whose highest level of educational attainment is Year 10 or below is 32.4%, more than double that of those with no disability (15.4%)¹.
- The proportion of students proceeding to complete post-school certificate III/IV, diploma, advanced diploma or degree qualifications is 26% for autistic individuals compared with 59.3% for those with no disability¹.
- The 2018 labour force participation rate is 38.0% for autistic people of working age compared with 84.1% of those without disability, with an unemployment rate for autistic individuals almost eight times that for those without disability¹.
- Autistic individuals have a mortality rate more than twice that of the general population².
- Suicide rates for the autistic community are seven times those for the general population³.

For the growing number of Australians on the autism spectrum and with other neurodevelopmental conditions, life outcomes in education, vocation and health and family functioning continue to be far from optimal. The capacity of service sectors and communities to support autistic participation, health

¹ Australian Bureau of Statistics (2018). Autism in Australia. Survey of Disability, Ageing and Carers (2018). Available at: <https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release#autism-in-australia>.

² Hwang, Y. I., Srasuebku, P., Foley, K.-R., Arnold, S., & Trollor, J. N. (2019). Mortality and cause of death of Australians on the autism spectrum. *Autism Research*, 12(5), 806-815. doi:10.1002/aur.2086

³ Hirvikoski, T., Mittendorfer-Rutz, E., Boman, M., Larsson, H., Lichtenstein, P., & Bölte, S. (2016). Premature mortality in autism spectrum disorder. *Br. J. Psychiatry* (2016). 208(3):232-238. doi:10.1192/bjp.bp.114.160192

and wellbeing remains inconsistent and inadequately supported by evidence-based practice and understanding.

This leads to lost opportunity, entrenched disability and greater support costs over a lifetime.

For the NDIS, at 30 June 2020, 31% of participants had a primary diagnosis of autism – being 122,830 individuals – with package support costs totalling \$4.9B per annum⁴. The December 2020 NDIS Quarterly Report to disability ministers shows the percentage of Scheme participants with a primary diagnosis of autism had risen to 32% or 141,635 participants⁵. This does not account for the cost of services to other systems, such as the health, education, employment and justice systems, and the broader socio-economic costs of lesser participation than is desired by autistic individuals and their families and carers.

1.2. Autism CRC

The Cooperative Research Centre for Living with Autism was established in 2013 under the Commonwealth Government's Cooperative Research Centres (CRC) Program and the management of Autism CRC Ltd. It is the world's first national collaboration between researchers, services providers, clinicians, education professionals, government and the end-user community – autistic individuals and their families and carers – working to develop and implement evidence-based and research-informed practice, products and policy that deliver whole-of-life outcomes for people on the autism spectrum (see www.autismcrc.com.au).

Autism CRC's vision is to see

autistic people empowered to use their diverse strengths and interests,

through its mission to

motivate, facilitate and translate collaborative autism research, across the life-span and the spectrum, underpinned by inclusive practices.

As a national collaboration of stakeholders, Autism CRC is able to invest in significant areas of need identified by the community, industry and government; and, importantly, co-produce and translate outputs to effective practice and policy at a national scale with its stakeholder network.

Autism CRC's cooperative research centre program takes a whole-of-life approach through its three core programs

- the Early Years – delivering a national protocol for earlier, accurate assessment and diagnosis, and defining pathways to effective early intervention;
- the School Years – developing educational environments and programs, and equipping teachers, to better support students' social, behavioural and academic development and success; and

⁴ National Disability Insurance Agency, *Submission to the Senate Select Committee on Autism* (July 2020)

⁵ National Disability Insurance Agency, *NDIS Quarterly Report to disability ministers* (31 December 2020)

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- Adulthood – enhancing opportunities for successful transition to post-school life, participation in higher education, further training and employment, and improving the health and wellbeing of people on the autism spectrum.

Autism CRC has worked closely with the NDIA on a number of projects that are of direct relevance to the Agency’s current consultative activities and subsequent considerations. These provide evidence-based guidance to formulating and implementing best practice, in particular:

- the report, *“Interventions for children on the autism spectrum: A synthesis of research evidence”*⁶ (**ECI Evidence Report**), commissioned by the NDIA; and
- the National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorders in Australia⁷ (**AxDx Guideline**).

In responding to the Agency’s consultation paper, Autism CRC has focused on the platform and guidance given in these two pieces of work – consistent with a commitment to evidence-based best practice.

Please direct any questions relating to this response to:

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⁶ Whitehouse A., Varcin, K., Waddington, H., Sulek, R., Bent, C., Ashburner, J., Eapen, V, Goodall, E., Hudry, K., Roberts, J., Silove, N. & Trembath, D. (2020). Interventions for children on the autism spectrum: A synthesis of research evidence. Autism CRC, Brisbane, Australia

⁷ Whitehouse, A., Evans, K., Eapen, V. & Wray, J. (2018). A national guideline for the assessment and diagnosis of autism spectrum disorders in Australia. Autism CRC, Brisbane, Australia

2. Consultation Response

2.1. National Quality Guidance for Early Intervention

A core principle of early intervention for children on the autism spectrum is that supports are well-founded in evidence.

Provision of appropriate early intervention following the earliest clinical indications of developmental delay, whether or not a diagnosis has yet been attained, is key to promoting longer-term, positive functional outcomes for individuals. Delayed receipt of intervention means the highly 'plastic' elements of neurodevelopment within the early years of life are not capitalised upon. There is now a wealth of scientific evidence for a range of 'behavioural markers' identifiable during the first two years of life that indicate a higher likelihood that an infant might subsequently be diagnosed as being on the autism spectrum. Providing support to these young children once the behavioural markers have been identified is highly likely to support better outcomes in the long-term compared to waiting until diagnostic behaviours emerge in later years⁸.

Given the impact of early intervention upon neurodevelopmental pathways⁸, it is critical that the efficacy, mode of delivery, and safety of intervention approaches are supported by quality evidence.

Comprehensive, up-to-date information on best practice in early interventions, and the evidence-base supporting these, needs to be available to consumers, service providers and researchers, as well as to government and related agencies, such as the NDIA.

The ECI Evidence Report, commissioned by the NDIA and produced by Autism CRC, represents the most comprehensive review of current international evidence on autism-related early interventions. It provides the highest quality foundation for the development of a national Early Intervention (EI) Guideline.

In addition to defining the core principles critical to early intervention – holistic assessment; individual and family-centred; lifespan perspective and evidence-based – the Report contains:

- A Narrative Review that describes the various types of early intervention and the key principles underpinning each of these, together with the professional qualifications and training pathways typically required to deliver these interventions in Australia.
- An Umbrella Review that summarises data from systematic reviews of intervention research for children on the autism spectrum. The report clearly showed the patchwork of current high-quality evidence for early intervention types and their effect on desired child and family outcomes, as well as shortcomings. It represents the best available evidence of the effects of a range of interventions for children on the autism spectrum.

This information can help to inform clinical and policy decision-making regarding the most appropriate clinical supports for children on the autism spectrum and their families. The information can also serve an important role in supporting caregivers to make informed decisions regarding the interventions

⁸ Zwaigenbaum, L., Bauman, M. L., Choueiri, R., Kasari, C., Carter, A., Granpeesheh, D., . . . Natowicz, M. R. (2015b). Early intervention for children with autism spectrum disorder under 3 years of age: Recommendations for practice and research. *Pediatrics*, 136(Supplement 1), S60-S81.

they access, as well as early intervention providers, to support their child(ren)'s learning and participation in all aspects and activities of their lives.

However, it is important to note that the ECI Evidence Report does not give practice or policy guidance in itself. It is simply a description of the evidence-base.

In order for a practice and policy guideline to be developed, the evidence must be operationalised into a clinical/practitioner context by incorporating the wisdom of both practitioners and the 'lived voice', via comprehensive consultation and collaboration, designed to achieve consensus amongst all stakeholders.

The development of national guidance in this way is critically important given the nature of the currently available evidence. There is an immediate need for guidance and it is only through a transparent, collaborative stakeholder process that trusted, consensus-based guidance might be developed.

This same process led to the development of the Ax Dx Guideline, with all its practice recommendations subsequently approved by the NHMRC and recognised internationally as best-practice. It is only in going through a similar formal guideline process, independently led, that the separation of the evidence from evidence-based practice and policy is spanned – a bridge that does not exist presently.

A comprehensive national EI Guideline would:

- Assist to 'operationalise' the best evidence into best practice guidance, by incorporating clinical and consumer feedback through an iterative consensus-building process. This process was highly effective for the development of the broadly-endorsed Ax Dx Guideline.
- Guide consumers in navigating the landscape of early intervention types and providers to make informed choices as to the type of intervention and the provider that might deliver the desired child and family outcomes, and an understanding of the evidence underpinning these. This is paramount to the tenant of consumer 'choice and control' that sits at the core of the NDIS.
- Assist early intervention planning and provider capacity-building.

Many of the recommendations in the previous ECEI reset consultation paper pointed to the need to inform and build capacity in the supports network around the child and their Early Childhood partners and providers.

- Guide planning and the determination of reasonable and necessary supports under the NDIS, as well as other agencies funding mainstream and community supports.
- Provide guidance regarding goal-setting, and the appropriate timelines for reviewing the efficacy of any given intervention according to those defined goals.
- Provide detail on the evidence and practice recommendations on individual factors to be considered in informing intervention choice, goal setting, delivery and review.

Individual factors to be considered in an assessment – such as age, co-occurring conditions, gender, family supports, CALD backgrounds, and regional and remote locations – are a key

and well-regarded feature of the Ax Dx Guideline. An EI Guideline would provide similar detail on the consideration of individual factors.

- Be consistent with existing National Quality Frameworks, including the NDIS Quality and Safeguards Commission – Behaviour Support Competency Framework 2018 and the Early Years Learning Framework and Quality Standards, which guide practice and policy within early childhood healthcare services and educational and care services.

This will ensure that childcare, education, health, disability and other child services professionals have a unifying set of language and standards that would ease communication and program delivery across sectors. It will minimise both gaps between service sectors and service duplication.

It would also provide a basis for determining early intervention regulations, standards and quality safeguards.

- Guide research priorities and investment relating to early intervention.

A national quality guideline for early intervention in autism / neurodevelopmental conditions – a living framework that is maintained for currency of evidence – should be developed in full consultation with all stakeholders as a matter of priority.

2.2. Quality and adequacy of existing evidence base

As mentioned, the ECI Evidence Report represents the most comprehensive review of current international evidence on autism-related early interventions. However, one of the report's most important findings was the lack of quality evidence for many early intervention approaches, due to insufficient investment in high quality research in this area to date.

Importantly, the report found there is almost no evidence about the effects of intervention practices on quality of life outcomes. Similarly, only 8 of the 58 systematic reviews included any information on potential adverse effects of interventions. **Both of these areas should be considered urgent priorities for future research.**

There was also insufficient or inconsistent evidence to determine whether particular delivery characteristics (e.g., individual or group delivery; clinic, home or school setting; amount of intervention) may maximise the effects of intervention and, if so, for which children.

While the review was able to report findings at a broad level (i.e., which interventions have a positive effect on which outcomes), there was insufficient research evidence to understand the effect of interventions at the individual level (i.e., which interventions have a positive effect on which outcomes, for which children).

In summary, the review identifies clear gaps in knowledge that can guide future research investment. Future research priorities include an understanding of:

- How child characteristics (e.g., age, core autism characteristics, and communication skills) may influence the effects of interventions.
- How the way an intervention is delivered may influence the effects of interventions, and how this differs between children and families.

- The amount of intervention that may maximise the effects of interventions on outcomes, and how this differs between children and families.
- The costs and benefits of interventions including unintended consequences, negative impacts, and opportunity costs that can occur when time and money is spent on less effective interventions.
- How interventions may improve or otherwise impact **broader areas of child and family wellbeing, such as quality of life.**

2.3. Early intervention principles

The principles described in sections 6.1 and 6.2 of the Consultation Paper should be generally well supported. However, further clarity is needed for the community – individuals, families and practitioners – about how these principles will be implemented, including how they will be used in planning decisions.

For example:

- Section 6.1(5) states that, “Research evidence shows the intervention can work for people on the autism spectrum”. There needs to be clear guidance on the quality of evidence that will be accepted as meeting this threshold – not all scientific evidence is of equal quality, as the ECI Evidence Report states. How this will be assessed and by whom also needs to be made clear. Further, as mentioned earlier, there needs to be clear consideration given to the effect of approaches for desired child and family outcomes – there is no singular approach. These are not simple questions, and again point to the importance of agreed national guidance, founded on combination of evidence and experience, which can provide a framework for such considerations.
- Section 6.2 talks to a number of standards for delivery of early intervention, which appear broadly appropriate. There needs to be transparency as to how such standards will be implemented and regulated. Again, we would argue that such matters should be defined and agreed through a consultative process with the autistic community, families and carers, and practitioners, in developing an early intervention guideline. Such standards should then be integrated and applied more generally for intervention provided across the breadth of settings, not just for services supported by the NDIS.

2.4. Reasonable and necessary supports

We have a number of concerns about the proposed approach to determining reasonable and necessary supports described in section 7 of the consultation paper.

- In developing a funding framework, the report refers to ‘operationalising’ scientific evidence, including that available from the ECI Evidence Report, by “further incorporating the voices of consumers and experienced clinicians / professionals” to support evidence informed practice. Autism CRC has consistently recommended a community consensus-based guideline be developed on the back of the evidence-base, in prior submissions and in this response, so that

the science might be truly operationalised for practice. Research evidence without community context does not represent best practice. Far greater community engagement would be required in developing guidance for early intervention, including funding frameworks, if national guidance is to be developed to a standard consistent with that used and approved for the Ax Dx Guideline.

- The data, evidence and methods used to determine the proposed funding framework are not defined and therefore not apparent to those considering this framework. The ECI Evidence Report did not consider matters of funding for early intervention or funding models. There needs to be clarity as to how any data, research or practice evidence (including community input) is interpreted and used to support a funding model.
- The funding model with its simply proposed levels seems fundamentally flawed in its apparent assumption that reasonable and necessary supports may be determined on a singular dimension, in this case the amount or intensity of intervention. Such a model implies that there is a one-size-fits-all approach to intervention that is only varied by amount. This is clearly not the case.

Many variables are to be considered in determining how much support a child/family may need to help them thrive – for example, relating to the goals, challenges and circumstance of the child and family. ‘Functional need’, used in the levels of the proposed model, is but one such variable. Its use alone may well lead to outcomes that do not effectively or efficiently meet the child’s and family’s needs. It is very possible that a child with high needs in one ‘area’ only (currently in Level One in the proposed model) will not thrive unless intensive support is provided. Conversely, it is very possible that a child with ‘three high areas of need’ (currently, Level Four) may require a lesser level of support than is implied by the singular dimensional approach in the proposed model.

Adopting a singular-dimension ‘cookie-cutter’ approach, as appears inherent in the proposed funding level model, not only poses risks to the definition of effective and efficient supports and the long-term benefits of these, it does not appear aligned with the participant-centred and ‘reasonable and necessary’ principles of the NDIS.

The variability in practices relating to the assessment and diagnosis of autism across our states and territories was recognised by stakeholder communities as a major impediment to the effective and efficient delivery of supports to individuals and families. Founded on a comprehensive picture of the international evidence, all stakeholders worked together, with financial support from the NDIA, to deliver high-quality consensus guidance in the Ax Dx Guideline – its national implementation now being guided jointly by government, clinician and consumer organisations.

All stakeholder communities have an interest in the effective and sustainable delivery of early intervention supports to individuals and families through the NDIS, as well as through other mainstream systems. Autism CRC, again, strongly recommends a similar comprehensive approach to the development of a quality national guideline for early intervention be adopted, bringing all stakeholders to consensus on meeting that shared goal.

Our values



Inclusion

Working together with those with the lived experience of autism in all we do



Innovation

New solutions for long term challenges



Evidence

Guided by evidence-based research and peer review



Independence

Maintaining autonomy and integrity



Cooperation

Bringing benefits to our partners; capturing opportunities they cannot capture alone



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