



Supporting young children and their families early, to reach their full potential

Submission in response to National Disability
Insurance Agency Consultation Paper

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Australian Government
Department of Industry, Science,
Energy and Resources

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

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., Srasuebkul, 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

This leads to lost opportunity, entrenched disability and excessive 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. This does not account for the cost of supports to other systems, such as the health, education, employment and justice systems, and the broader socio-economic costs of lesser participation 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
- 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:

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

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- the National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorders in Australia⁵ (**AxDx Guideline**); and
 - the report, “*Interventions for children on the autism spectrum: A synthesis of research evidence*”⁶ (**ECI Evidence Report**).

In responding to the Agency’s consultation papers, Autism CRC has focused on the platform and guidance given in these two seminal pieces of work – consistent with the NDIA’s commitment to evidence-based best practice. Autism CRC stands ready to work with the NDIA in developing, implementing and evaluating outcomes from its considerations.

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2. Consultation Response

2.1. Holistic Context

The NDIA consultation paper, “*Supporting young children and their families early, to reach their full potential*”, and the related detailed paper, “*Early Childhood Early Intervention (ECEI) Implementation Reset*”, form elements of a broad set of policy and operational initiatives being considered and undertaken by the NDIA. Other related considerations include:

- the consultation paper on “*Access and Eligibility Policy with independent assessments*”;
- the consultation paper on “*Planning Policy for Personalised Budgets and Plan Flexibility*”; and
- the foreshadowed consultation paper on guidance for reasonable and necessary supports determination for children on the autism spectrum.

These considerations are all interconnected. As a general comment, it is critical that the overarching context and connections between these initiatives is made clear for individuals, families and those who support them – both for their fuller understanding and, perhaps, lesser anxiety through the process. This holistic picture does not seem sufficiently clear.

⁵ Whitehouse, A., Evans, K., Eapen, V. & Wray, J. (2020). Interventions for children on the autism spectrum: A synthesis of research evidence. Autism CRC, Brisbane, Australia

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. (2018). A national guideline for the assessment and diagnosis of autism spectrum disorders in Australia. Autism CRC, Brisbane, Australia

2.2. Early Childhood Early Intervention Reset

The core principle underpinning the ECEI approach in respect of autism is well-founded in evidence.

Provision of swift, 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, including those on the autism spectrum^{7,8}.

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 significant likelihood that an infant might subsequently be diagnosed as being on the autism spectrum. Providing intervention to these young children once the behavioural markers have been identified is highly likely to deliver better outcomes in reducing long-term disability compared to waiting until diagnostic behaviours emerge in later years⁹.

As a result of a number of reviews, including the Tune Review¹⁰, the proposed ECEI reset aims to more effectively deliver the benefits of early childhood intervention, including family capacity building. Many of the recommendations proposed for the ECEI approach, the operational guidelines and practices seem sensible and should deliver positive impacts. For example, the recommendation to change the age limit from 'under 7' to 'under 9' years of age should disconnect transition from the ECEI pathway to the Scheme or mainstream supports from the timing of another major period of transition – and anxiety for many – to primary school; thus allowing support to continue through that period and to education supports.

As is always the case, the effective implementation of many of the recommendations will be where the challenges lies. Autism CRC firmly believes that there are two evidence-based foundations that should be used to ensure the effective implementation and sector acceptance of initiatives undertaken to reset the ECEI Approach:

- a national Guideline for Early Intervention (**EI Guideline**), to inform and guide consumers, providers and government, as well as safe-guarding best-practice early childhood intervention; and
- the National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorders in Australia (**AxDx Guideline**), particularly its application to any tailored assessments for access to early intervention supports under the ECEI Approach.

⁷ Chasson, G. S., Harris, G. E., & Neely, W. J. (2007). Cost Comparison of Early Intensive Behavioral Intervention and Special Education for Children with Autism. *Journal of Child and Family Studies*, 16(3), 401-413. doi: 10.1007/s10826-006-9094-1.

⁸ Peters-Scheffer, N., Didden, R., Korzilius, H., & Matson, J. (2012). Cost comparison of early intensive behavioral intervention and treatment as usual for children with autism spectrum disorder in the Netherlands. *Research in Developmental Disabilities*, 33(6), 1763-1772

⁹ 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.

¹⁰ Tune Review (2019), Review Of The National Disability Insurance Scheme Act 2013, David Tune AO PSM, December 2019

2.3. National Quality Guidance for Early Intervention

Given the importance of early intervention, with its impact upon neurodevelopmental pathways, it is critical that the efficacy, optimal characteristics of the individual child and the mode of delivery, and safety of intervention approaches are supported by quality evidence.

We know that there will be variability in the degree of evidence supporting each of these elements across the range of early interventions. Further, research has shown that the efficacy of some intervention approaches being used for autism in Australia is not well supported by evidence¹¹. Early intervention recommendations are made that are not well-matched to the goals and functional needs of a child, with both families and professionals being poorly informed as to evidence-based best practice. This results in lost opportunity, suboptimal outcomes and significant additional costs to families and government services and supports.

It is essential that current information on best practice in early interventions, and the evidence-base supporting these, 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 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 also serves an important role in supporting caregivers to make informed decisions regarding the interventions 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, the Report does not give guidance in itself. It is a comprehensive description of the evidence-base. In order that a practice and policy guideline might be developed, it must be operationalised into a clinical/practitioner context by incorporating practice wisdom and 'lived voice' via comprehensive consultation.

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-

¹¹ Paynter JM, Ferguson S, Fordyce K, Joosten A, Paku S, Stephens M, ... Keen, D. Utilisation of evidence-based practices by ASD early intervention service providers. *Autism* 2017; 21(2), 167–180.

practice. It is only in going through a similar formal guideline process that the separation of the evidence from evidence-based practice and policy is spanned – a bridge that does not exist presently.

It is noted that Recommendation 3 in the Consultation Paper points to developing and publishing new Early Childhood-specific Operating Guidelines, so that NDIA decision-making processes and best practice evidence are transparent and implemented consistently by partners and NDIS planners. The proposed EI Guideline would be, perhaps, more comprehensive than this recommendation anticipates, informing all stakeholders across service sectors more broadly, while meeting the needs espoused in Recommendation 3.

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, and relatively quick (~12 months), for the development of the broadly-endorsed AxDx 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.
- Assist early intervention planning and provider capacity-building.

Many of the ECEI reset recommendations point 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 AxDx 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.

As such, the Guideline would be agnostic as to its application to early intervention supports through the NDIS (s.24 or s.25) or through other mainstream and community services. This will ensure that childcare, education, health, 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, overseen as they may be by the NDIS Commission for supports administered through the Scheme.

- Guide research priorities and investment relating to early intervention.
- Be developed independent of service providers and funding agencies, including the NDIA, ideally by an organisation with a national remit. The evidence upon which the Guideline is based should also be maintained for currency, and the Guideline regularly evaluated and updated.

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

2.4. Nationally Consistent Approach to Assessment

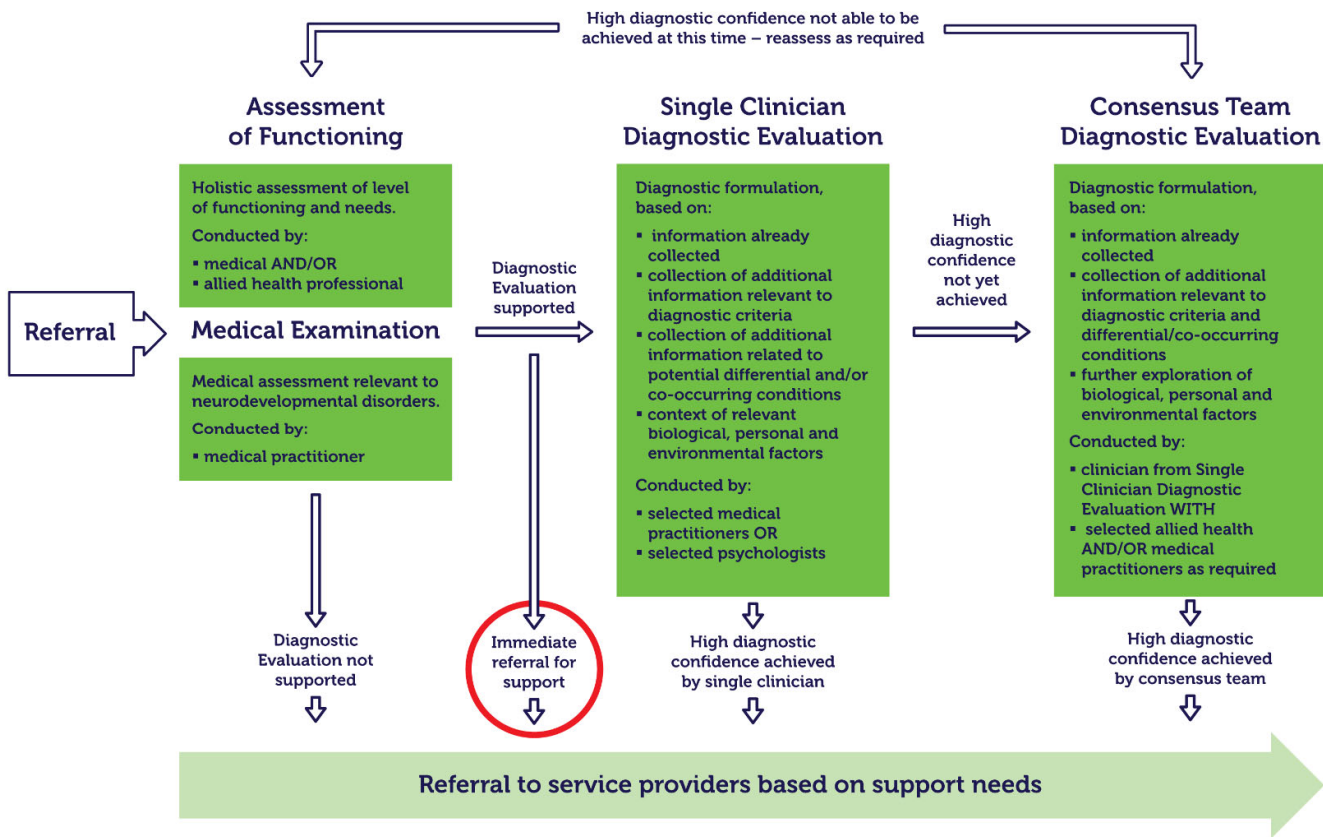
Recommendation 9 of the Consultation Paper proposes that a tailored Independent Assessments (IAs) approach for young children be implemented to support consistent access and planning decisions. This approach would engage Early Childhood partners to administer Independent Assessments for young children rather than use a separate IA Assessor workforce, as is proposed for the Scheme more generally.

The use of Early Childhood partners for an IA role, rather than an IA Assessor, might seem appropriate given they have a relationship with the child and family and undertake assessments.

Autism CRC's concerns in regard to this recommendation mirror the concerns outlined in its response to the Consultation Paper on Access and Eligibility Policy with independent assessments.

- **Assessments for early intervention purposes should be conducted consistent with the practice guidance given in the Ax Dx Guideline.** The response to the Access and Eligibility Paper describes the dimensions that need to be taken into consideration in this regard.

The Ax Dx Guideline prescribes that a comprehensive health and functional assessment take place as the first step in the assessment and diagnostic pathway (see below), and that individuals should be referred for services based on needs identified in that process – wholly consistent with international best practice and the core principle underpinning the ECEI Approach.



- **Assessments conducted in accordance with the Ax Dx Guideline should be sufficient for access and eligibility determinations in regard to the ECEI Approach, whether conducted under an IA by an EC Partner or otherwise by professionals qualified per the Ax Dx Guideline.**

As mentioned in the response to the Access and Eligibility Paper, Autism CRC is working with the Department of Social Services, the various professional bodies involved in the assessment and diagnostic process, as well as consumer and service provider representatives, to drive national implementation of the Ax Dx Guideline. This process will take account of the information requirements specified by the Agency for functional assessments, again, in seeking to develop a national approach that spans systems and avoid unnecessary duplication of costs and time. This is particularly the case here given the existence of Medicare rebates relating to the assessment and diagnosis of autism for children under 13 years of age.



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Our values



Inclusion

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



Innovation

New solutions for long term challenges



Independence

Guided by evidence based research, integrity and peer review



Cooperation

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



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