



Access and Eligibility Policy with independent assessments

Submission in response to National Disability
Insurance Agency Consultation Paper

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Australian Government
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Business
Cooperative Research
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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

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 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.

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

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

Autism CRC also undertook a study commissioned by the NDIA evaluating the “*Reliability, Validity and Usability of Assessment of Functioning Tools for Autism Spectrum Disorder and Neurodevelopmental Conditions in the Australian Context*”, which included consideration of the PEDI-CAT (ASD) and the Vineland Adaptive Behavior Scales, Third Edition.

In responding to the Agency’s consultation papers, Autism CRC has focused on the platform and guidance given in these 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, “*Access and Eligibility Policy with independent assessments*” 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 “*Supporting young children and their families early, to reach their full potential*”, and the related detailed paper, “*Early Childhood Early Intervention (ECEI) Implementation Reset*”;
- the consultation paper on “*Planning Policy for Personalised Budgets and Plan Flexibility*”; and

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

- 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.

2.2. Independent Assessment

Autism CRC's comments relating to the proposed use of Independent Assessments for determining access and eligibility relate to:

- The need for consistency the National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorders in Australia (**National Guideline**).
- Consideration given by the NDIA to like assessments, made in accordance with the Guideline and their application to access and eligibility decisions.
- Ensuring currency in practice in Independent Assessment consistent with the best available evidence.

2.3. National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorders in Australia

The National Guideline was developed by Autism CRC, with financial support from the NDIA, and launched by the Commonwealth Minister for Health and Minister for Social Services in October 2018. All 70 practice recommendations contained in the Guideline were approved by the full Council of the NHMRC after rigorous international methodological and content review. As such, the Guideline defines optimal clinical care in the assessment and diagnosis of autism, recognised internationally as best practice.

The National Guideline defines a range of practices relating the assessment and diagnosis of autism, including a comprehensive assessment of an individual's health and functioning after referral for signs of autism or developmental delay as the first step in the process, prior to proceeding to a diagnostic evaluation and possible receipt of an autism diagnosis.

Section 7 of the National Guideline deals specifically with guidance on comprehensive assessment of functioning. **It is essential that the implementation, including assurance of standards, of the Independent Assessment approach be wholly consistent with the National Guideline**, both in terms of its guiding principles and the specific guidance on assessment of functioning. This includes application of the Guideline to the tailored approach using Early Childhood Partners proposed for assessments within the ECEI Approach.

The Guiding Principles define the clinical context in which an assessment of autism concerns should take place.

- **Evidence Based** – Clinical decision-making is to be based on a review of the best available research evidence. This implies a process of continuous improvement, evaluating and updating practices and tools based on the best available evidence.

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- **Individual and Family Centred** – Assessment professionals collaborate with individuals and their families to identify the unique needs, strengths and contexts of the person undergoing assessment and their broader family unit.
 - **Holistic Framework** – An individual is to be evaluated within their personal, activity and environmental contexts (as outlined, for example, by the World Health Organisation’s International Classification of Functioning, Disability and Health), and that referrals for further supports are based on an individual’s functioning and needs, rather than their clinical diagnosis.
 - **Strengths Focused** – Assessments should take a strengths-focused approach, identifying the strengths, skills, interests, resources and support systems of the individual and their caregiver(s) and/or support people, which are recognised as important as identifying limitations.
 - **Equity** – The assessment process should be accessible and rigorous for all Australians regardless of age, gender, cultural background, socioeconomic status or geographical location.
 - **Lifespan Perspective** – Consideration is given to the individual’s present *and future* challenges and opportunities.

It is noted that the principles outlined by the NDIA in the Consultation Paper mirror a number of these, particularly in relation to individual and family-centred practice; a holistic evaluation framework; and a strength-based approach. In particular, it is noted that assessment is consistently referred to as occurring within the context of an individual’s circumstances and environment. There is a concern amongst the sector that there will be an over-reliance on functional assessment tools in conducting assessments.

The challenge for the NDIA in overseeing Independent Assessments and Assessors will be to ensure adherence to these principles.

In relation to the National Guideline’s recommendations specifically relating to assessment of functioning, we highlight the following.

- **Professionals’ Involvement**

Recommendation 21:

An assessment of functioning be conducted by a clinician or clinicians meeting one of the following eligibility criteria:

- *medical practitioner who holds general or specialist registration with the Medical Board of Australia;*
- *nurse practitioner who holds general registration with the Nursing and Midwifery Board of Australia and is endorsed as a nurse practitioner or as a registered nurse with relevant experience as a clinical nurse specialist/consultant and is practising under appropriate medical supervision;*
- *occupational therapist who holds registration with the Occupational Therapy Board of Australia;*

- *psychologist who holds general registration, with or without a practice endorsement, with the Psychology Board of Australia;*
- *social worker who is eligible to be a member of the Australian Association of Social Workers; or*
- *speech pathologist who is eligible to be a Certified Practising Member of Speech Pathology Australia.*

AND

Recommendation 22:

An Assessment of Functioning be conducted by a clinician who, in addition to the relevant training and expertise required by all members of the Assessment Team, has relevant training and expertise in:

- *the impact of the signs and/or symptoms of ASD and other neurodevelopmental disorders on daily functioning and participation in age-appropriate activities;*
- *the evaluation of the abilities, challenges, strengths, environmental context and support needs of individuals with ASD and other neurodevelopmental disorders (along with those of their caregivers and support people).*

The need for relevant training and expertise specific to autism and other neurodevelopmental conditions has been highlighted as a concern with the proposed implementation of IA by a number of autism advocacy groups.

• **Information Collected**

Recommendation 23:

Information be collected during an Assessment of Functioning on the following topics:

- *medical and health history, including any existing diagnoses;*
- *family history and family functioning;*
- *language/s used at home and level of written/spoken proficiency in English and any other home language;*
- *developmental and educational history;*
- *ASD-specific signs and/or symptoms;*
- *other relevant signs and/or symptoms;*
- *developmental and functioning abilities/impairments across a broad range of domains (e.g. cognitive, language, social-emotional, motor and adaptive behaviour);*
- *activity-related and character strengths;*
- *environmental facilitators and barriers; and*
- *observed and expressed support needs.*

Recommendation 24:

Information be collected during an Assessment of Functioning through a variety of means, including:

- *file review of existing assessment reports;*
- *interview with the client;*
- *observation of the individual undergoing assessment;*
- *administration of standardised and non-standardised assessments as required; and*
- *communication with other professional(s) as required.*

Recommendation 25:

It is recommended that the use of standardised assessments that cover a broad range of developmental domains (e.g. cognitive, language, social-emotional, motor and adaptive behaviour) be strongly considered for the Comprehensive Needs Assessment.

The NDIA proposed toolbox approach to evidence-based assessments tools is a sensible one, as there is no one tool that might be used for all individuals. It is also true that the use of a suite (toolbox) of evidence-based tools should be tailored to the individual being assessed, not simply applied without such considerations across all individuals. This again points to the importance of the relevant training and expertise highlighted in the recommendations relating to Professionals' Involvement.

- **Settings**

Recommendation 26:

It is recommended that the Assessment of Functioning take place in a setting where the client feels comfortable and confident to discuss their level of functioning and support needs. This may be in a clinic, community or telehealth setting. Information is to be collected about the individual's level of functioning in all relevant community settings, though it is not essential for the clinician to make direct observations at these locations.

The critical element of concern is that the client (and their supporters) are to feel comfortable and confident to discuss functioning and support needs. This goes to the setting, supporters and comfort with the assessor. This has been identified as a major area of concern for the community, not just the autism community. For someone on the spectrum, heightened anxiety associated with an uncomfortable setting poses a risk to both the individual and the NDIS with the quality of the resulting assessment.

- **Decision-making and Outcome**

Recommendation 27:

The Assessment of Functioning involve the following steps:

- *the identification and prioritisation of observed and expressed support needs*
- *connection to appropriate services based on the client's support needs where impaired functioning is identified, without the requirement for a clinical diagnosis of ASD.*

Recommendation 28:

It is suggested that when providing information to clients regarding services that may meet their support needs, clinician(s):

- *disclose to the client any financial or other conflicts of interest in service recommendations; and*
- *provide information on a range of services available, where possible.*

- **Repeated Assessment**

Recommendation 29:

The Assessment of Functioning be repeated throughout the individual's life to ensure that changes to level of functioning and support needs are identified and acted on in a timely manner. Further assessment can be conducted as required by clinicians engaging with the client at the particular time.

This is a particularly relevant recommendation to the engagement with the NDIS for an autistic individual. Autism is a lifelong condition and its impact, along with that of co-occurring conditions, upon the level of functioning and supports of that individual often vary over time. The capacity to function may lessen and the need for support may increase, for example, with periods of transition, such as starting school or leaving school. As such, where these impacts are significant, an individual may engage and disengage with the NDIS sporadically over their life.

The Ax Dx Guideline provides an evidence-based and practical process for the assessment of children and adults on the autism spectrum. Furthermore, this Guideline process was co-developed with, and endorsed by, key clinical and consumer stakeholders in the autism community. The near-unanimous endorsement across the sector on the practicality and importance of the Ax Dx Guideline, makes it an ideal platform on which to build the IA process, particularly as it pertains to individuals on the spectrum. Adherence to the Ax Dx Guideline process, which describes optimal clinical care, will help drive sector-wide adherence to best practice, which will translate to better outcomes for NDIS participants.

2.4. Nationally Consistent Approach to Assessment

Assessments conducted in accordance with the National Guideline should be sufficient for access and eligibility determinations in to the NDIS, whether conducted under a NDIA independent assessor or otherwise by professionals qualified per the Guideline.

Autism CRC is working with the Department of Social Services (**DSS**), professional bodies involved in the assessment and diagnostic process, as well as consumer and service provider representatives, to drive consistent national implementation of the National Guideline in the assessment and diagnosis of autism and other neurodevelopmental conditions.

The Expert Reference Group includes representatives of:

- the Royal Australian College of General Practitioners;
- the Royal Australian College of Psychiatrists;
- the Neurodevelopmental and Behavioural Paediatric Society of Australasia;

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- the Australian Psychological Society;
 - Occupational Therapy Australia;
 - Speech Pathology Australia;
 - the Autistic Self-Advocacy Network – Australia and New Zealand;
 - Autism Awareness Australia; and
 - the Australian Autism Alliance. 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.

It is essential that IA practices are consistent with the National Guideline as implemented. DSS will engage the NDIA in the implementation process.

As stated, a current assessment conducted by a qualified professional, consistent with the Guideline, should carry equal weight to that of a NDIA-contracted independent assessor. To do otherwise would see:

- individuals and families having to go through the emotional and likely financial mill of additional assessment processes – the bad, not-so-old days of differing systems across states and services that the Guideline was developed to address;
- additional and unnecessary costs to the public purse of additional assessments; and
- the risk of divergence in practice and cracks between the systems for assessment between the NDIA and other systems.

It is noted that the DSS-led implementation and evaluation program might also provide the vehicle for the development of quality standards and compliance mechanisms, administered consistently across the sector, including for NDIS independent assessors.

2.5. Maintaining currency in evidence-based best practice

A commitment to evidence-based practice, requires a commitment to diligently monitoring and evaluating the evidence-base for emerging guidance, tools and resources. There is significant research, for example, on the development and application of tools more comprehensively mapped to the ICF Core Sets for autism.

The NDIA will need to ensure that resources are committed to this activity.

Under NHMRC Guidelines, the National Guideline itself is to be reviewed and revised by 2023. In the meantime, the DSS-led Guideline implementation includes an independent evaluation of implementation, which will also inform its revision.



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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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