



Submission to the Senate Select Committee on Autism

July 2020

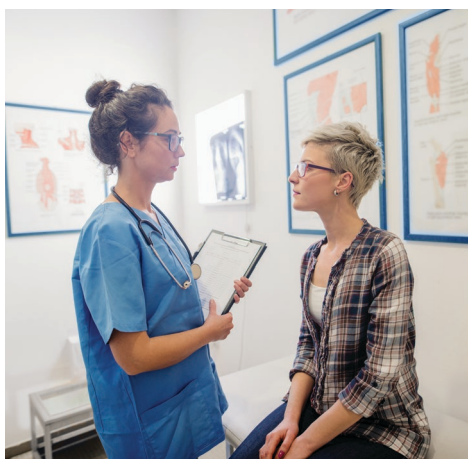


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Introduction

Autism CRC applauds the Senate for establishing the Senate Select Committee on Autism and thanks the Committee for the opportunity to make this submission.

Autism is a collective term for a group of neurodevelopmental conditions that affect social interaction, communication, behaviours and interests. Every person on the autism spectrum is unique. The developmental challenges and their presentation can vary widely in nature and severity between individuals, and in the same individual over time. Many people on the spectrum experience additional challenges with educational and vocational attainment, physical and mental health and family functioning.

Life outcomes for people on the autism spectrum and their families have been and continue to be far from optimal on many dimensions. Today, we better understand that it is often an individual's co-occurring conditions, circumstance and a non-inclusive community environment that are disabling. As a result, the significant strengths and interests of autistic individuals have often not been recognised and engaged for their and the community's benefit.

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, service 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 cooperative venture of stakeholders, Autism CRC is able to address significant areas of need identified by the community, industry and government; and, importantly, strategically invest in major research activities and the translation of outputs to effective practice and policy at a national scale. Examples are included in this submission.

Autism CRC's cooperative research centre program focuses on three main themes:

- the Early Years – delivering a national protocol for earlier, accurate assessment and diagnosis;
- 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 and participation in higher education, further training and employment, and improving the health and wellbeing of people on the autism spectrum.

FY21 is the final year that Commonwealth CRC funding is to be provided for that program. Autism CRC is presently securing a legacy operation beyond that time to address research priorities for practice and policy determined by autism community stakeholders.

A list of the current participants in the Cooperative Research Centre is given at Appendix 1. A number of these will likely be making submissions to the Senate Select Committee in their own name.

This submission addresses the following Terms of Reference:

A, B, C, D, F, G, H, I, J, K and L.

The Senate Select Committee Terms of Reference are broad-ranging, appropriate to an enquiry into autism in Australia. Similarly, with a commitment to research across the lifespan, Autism CRC's research program and related activities are broad-ranging and of relevance to many of the Committee's Terms of Reference. This submission does not attempt to describe all activities being undertaken by Autism CRC. The details of Autism CRC's program may be found through the Autism CRC website (www.autismcrc.com.au), including its Annual Reports.

We would welcome the opportunity to speak with Committee members on the matters in this submission or other matters of relevance to the Committee's Terms of Reference.

Summary of recommendations

1. Fully implement the National Guideline for Assessment and Diagnosis of Autism in Australia (National Guideline), across states and territories and service systems (particularly health, disability and education).
2. Implement the National Guideline for Assessment and Diagnosis of Autism in collaboration with representatives from clinical professions, service providers and community groups consistent with the way the Guideline was developed.
3. Develop a person-centred clinical care pathway centred on the National Guideline for Assessment and Diagnosis of Autism, integrating neurodevelopmental surveillance and a national quality framework for early intervention.
4. Revise the Medicare Benefits Schedule to align with the assessment and diagnosis process in the National Guideline for Assessment and Diagnosis of Autism, including for adolescents and adults.
5. Rationalise assessment requirements and funding mechanisms across service systems to avoid duplication.
6. Establish a national autism data register, with appropriate data linkages, to facilitate improved services, policy development and research, as well as individualised healthcare, interventions and supports.
7. Implement the National Guideline for Assessment and Diagnosis of Autism – noting the important consideration of factors of gender and gender diversity (Guideline Recommendations 61 and 62).
8. Enhance existing tools, or develop new ones, for use in the identification, assessment and diagnosis of autism to account for presentation in differing gender phenotypes.
9. Develop a National Quality Framework for Best Practice in Early Intervention for autism / neurodevelopmental conditions, maintained for currency of the most recent evidence.
10. Commit funding to quality research addressing gaps in the evidence for early intervention approaches, and mechanisms for guiding delivery of effective intervention given an individual's functional need and circumstance.
11. Integrate within the framework of national education reforms of needs-based funding models, aligned individualised learning and Nationally Consistent Collection of Data (NCCD):
 - i. information on comprehensive assessment of individuals consistent with the National Guideline for Assessment and Diagnosis of Autism; and
 - ii. inclusive education principles and practices for students provided with a multi-tiered system of support and universal design for learning in mainstream early childhood, primary and secondary education settings.
12. Incorporate inclusive education principles and practice as fundamental elements within existing professional development and systematic accountability frameworks for school leaders.
13. Commit resources to ongoing development and review of evidence for maintenance of a Quality Framework for Best Practice in Inclusive Education.
14. Ensure major national practice and policy initiatives affecting state and local government service sectors be coordinated at a national level through bodies such as the Council of Australian Government's Disability Reform Council.
15. Create National Guideline for Assessment and Diagnosis of Autism data linkages with other service systems (e.g. health, education and disability) with a view to the quality, consistency and efficiency benefits of access to permissioned data for person-centred planning and supports within these sectors.
16. Upskill national clinical workforce in autism and the presentation and clinical management of co-occurring conditions as a matter of urgency.
17. Develop and disseminate best-practice tools and resources, including risk assessment tools, to help families, clinicians and services match and address individual needs, improving health outcomes and reducing preventable deaths.
18. Integrate evidence-based transition planning resources for autistic school-leavers for use in high school-based transition planning and the Australian Curriculum: Work Studies Years 9-10; as well as the NDIS School Leaver Employment Supports program.
19. Develop work experience programs for autistic school students, with government supporting their implementation through capacity building incentives.

20. Ensure that any national autism strategy or policy framework is founded on the following principles:
 - i. individual and family-centred – goals, strengths, challenges, needs and circumstance;
 - ii. whole-of-life and whole-of-spectrum;
 - iii. co-produced – developed, implemented and reviewed with all stakeholders, with autistic individuals and families/carers at the centre of that process;
 - iv. evidence-based – guiding practice and policy; and
 - v. innovation – commitment to high quality research and continuous improvement.
 21. Commit to further funding of national, collaborative research, at scale – at least maintaining existing levels of investment over multiple years.
 22. Ensure that national priorities for research – as may be reflected in a national autism strategy – address issues across the whole-of-life and whole-of-spectrum, and are determined through a stakeholder representative body, akin to the Australian Autism Research Council.
 23. Enhance the evidence-base and understanding of supports for work readiness and employment to:
 - i. build capacity of the employment services sector and employers to provide quality support to autistic job-seekers and employees; and
 - ii. support job-seeker informed choice and control, consistent with the NDIS Participant Employment Strategy and the 2018 Disability Employment Services reforms.
 24. Support the further development and evaluation of neurodiversity employment programs for application beyond Information Technology roles.
 25. Codify and promote the evidence-based benefits of, and practices for, neurodiversity in the workplace through major employer groups, such as the Business Council of Australia and the Australian Public Service.
 26. Integrate employer-focused programs and resources for neurodiverse workplaces within human resource management training and professional development programs.
 27. Ensure full consideration of the physical and digital environments, as enablers of social and economic participation, within a national strategy or policy framework and associated research.
 28. Continue to invest in capacity building in community-led advocacy and services through Information, Linkages and Capacity Building grants and other development programs enabling autistic adults to fully contribute as peers to policy, practice and research that impact upon their lives.
- Autism CRC has commenced work towards a legacy operation beyond the term of current CRC Program funding. It is engaging with government across the range of portfolios regarding a coordinated program of activities addressing a number of areas relating to the Senate Select Committee Terms of Reference and the above recommendations – including best practice in assessment and diagnosis and targeted early intervention; improved health and health services; and greater economic participation through employment.
- Autism CRC welcomes the national, whole-of-government view adopted by the Senate Select Committee. Such a comprehensive and integrated approach to policy and practice, and to the research evidence supporting these, is necessary if outcomes for autistic Australians, their families and carers, and society are to be maximised.

Term of Reference (A):

Current approaches and barriers to consistent, timely and best practice autism diagnosis

The diagnosis of Autism Spectrum Disorder (ASD) can present a range of clinical challenges. The accurate diagnosis of ASD is not always straightforward because:

- there is no established biological marker for ASD in all individuals, meaning ‘gold standard’ diagnosis is a best estimate clinical judgement^{1,2,3,4};
- there can be extensive variability in signs and/or symptoms between individuals, and considerable overlap with other developmental conditions; and
- assessing whether an individual meets ‘behavioural criteria’ for ASD, as outlined in the Diagnostic and Statistical Manual of Mental Disorders (DSM), or the International Classification of Diseases (ICD), is a subjective task, and its accuracy relies on clinician experience and skill.

The challenge of providing accurate diagnoses, and a consistent standard of care across Australia, is further complicated by geographical variations in:

- the composition of the clinical diagnostic team – while some states have historically required the consensus of an experienced multidisciplinary assessment team, other states have had less stringent criteria;
- the quality and quantity of assessments administered;
- the ability to attract and maintain a suitably trained workforce in urban, regional or remote contexts; and
- the diagnostic interactions between the health, education and disability public services offered by each state/territory and federally.

A review of ASD diagnostic practices in Australia⁵ concluded that this geographical variability is likely to have contributed to uneven service provision and confusion among clients undergoing diagnostic assessment.

A 2016 Autism CRC report³ further confirmed that there is a lack of consistency in diagnostic practices across Australia and that some professionals may not be practising in a way that is consistent with international best practice guidelines.

For example, the report found:

- Most clinicians conduct at least two assessment sessions before making an ASD diagnosis. The length of assessment sessions is significantly longer in the public sector compared to the private sector.
- There are more multidisciplinary assessment teams in the public sector than in the private sector. While multidisciplinary teams usually conduct assessments together, sole practitioners may not necessarily collaborate with other professionals to make diagnostic decisions.
- A small number of health professionals reported having diagnosed autism when an individual does not meet criteria for the disorder, usually to ensure that the individual can access intervention or support services.
- Few clinicians provided diagnostic assessments for autism in regional, rural and remote areas of Australia. The wait for a diagnostic assessment in these regions was significantly longer than the wait list period for families in major cities.

The existence of many processes causes much confusion, time and resource wastage, frustration and entrenchment of disability.

“Adopting a minimum national standard for ASD diagnosis across Australia would improve diagnostic practices and consistency across the country, and ensure that future diagnostic assessments are in keeping with best practice Guidelines³.”

A new national standard

In response to these issues, Autism CRC developed Australia’s first National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorders in Australia⁴. The Guideline was developed in close consultation with key clinical professional Societies and Colleges, autism service providers, and the community; with funding support from the National Disability Insurance Agency (NDIA).

All 70 Guideline recommendations were subsequently endorsed by the full Council of the National Health and Medical Research Council (NHMRC), following extensive international review of both methodology and content. The Guideline was launched on 18 October 2018 by the Commonwealth Minister for Health and the Commonwealth Minister for Families and Social Services.

Term of Reference (A) continued

The Guideline defines clinical best practice for the assessment and diagnosis of ASD, and sets a new national standard. It aims to provide greater:

- **Equity** – in access to and delivery of a rigorous and comprehensive ASD assessment;
- **Transparency** – in the diagnostic and decision-making process; and
- **Confidence** – in the accuracy and reliability of diagnostic decisions.

In terms of content, the Guideline provides detailed recommendations within a process for the assessment and diagnosis of ASD, from the time of referral, including recommendations on the content of information gathered and generated, professionals involved in the process, and settings.

Critically, the pathway defined by the Guideline includes a comprehensive health and functional assessment in understanding the individual – their strengths, challenges, potential and support needs – as the first step on the diagnostic pathway. The Guideline also highlights other factors that need to be considered in order that that understanding is holistic and accurate, being:

- age;
- intellectual and/or communication capacity;
- gender;
- Aboriginal and Torres Strait Islander, and Culturally and Linguistically Diverse (CALD) backgrounds;
- regional or remote location;
- complex psychosocial factors; and
- differential diagnosis and co-occurring conditions⁴.

This comprehensive understanding of the individual, reviewed and updated over time, should then inform a pathway of services and support across health services; disability support (including through the NDIS and the Early Childhood Early Intervention Pathway); education; and other community settings, including in workplaces and the justice system – many of which relate to the Select Committee's other Terms of Reference.

Guideline implementation

More than 15,000 people have registered to access the National Guideline for the Assessment and Diagnosis of Autism since its release, including approximately 8,000 professionals such as paediatricians, psychologists, speech pathologists and occupational therapists. These professionals

are based across Australia, and urban, regional and remote settings (see Figure 1 on the following page).

While initial research indicates adoption of the National Guideline at the grass roots level by many providers across Australia, substantial benefits from the new national approach will only be realised through consistent, national implementation in practice, across the health, disability and education sectors.

Autism CRC is working with the Commonwealth Government, led by the Department of Social Services (DSS), to support greater implementation of the Guideline recommendations by diagnosticians across Australia. This work includes developing online resources to support clinicians, service providers and the community to understand the assessment process and guidance for clinicians and organisations on implementation of the National Guideline's recommendations. These resources will be made available and widely promoted in the last quarter of 2020.

Autism CRC is also supporting DSS in engaging representatives of clinical professions' colleges and societies, service providers and the community, together with representatives of other Government departments and agencies, to guide national implementation – in keeping with the approach of involving key stakeholders that saw the development of the National Guideline. It is anticipated that peak bodies will develop resources and guidance for their members in line with the Guideline recommendations.

Since 2013, significant progress has been made to increase the consistency and quality of diagnostic practices across Australia, but there is much more work to be done to support the implementation of the National Guideline's recommendations, address systemic factors, nationally, and ensure all Australians seeking assessment and autism diagnoses can access the same optimal level of service irrespective of geographic location or family income.

Integrated care pathway

The full benefits of consistent, quality assessment and diagnosis of autism are only realised if integrated in a care pathway, which includes:

- A national system of surveillance, identifying and referring individuals for assessment and, potentially, diagnosis at the earliest opportunity, particularly in early childhood. Autism CRC has successfully trialled early childhood surveillance tools developed at La Trobe University in two

Term of Reference (A) continued

- States with maternal and child healthcare nursing systems. It is presently conducting a multi-State trial of protocols for national early childhood surveillance in General Practitioner clinics.
- A national quality framework for targeted access to the right evidence-based interventions and supports, based on individual goals, strengths and needs, provided at the right place and at the right time. Such a framework should also deliver evidence-based information to providers, funding agencies and families, allowing the latter to exercise informed choice and control.
- Consistent implementation across systems, particularly health, disability and education, avoiding the significant financial and emotional cost of replicate requirements. This includes a review of the public funding mechanisms for neurodevelopmental assessments (through Medicare, the NDIS and other mechanisms), whether this is adequate to meet the assessment process described in the Guideline and, again, seeking to reduce the number and cost to individuals and government of multiple assessments across systems.

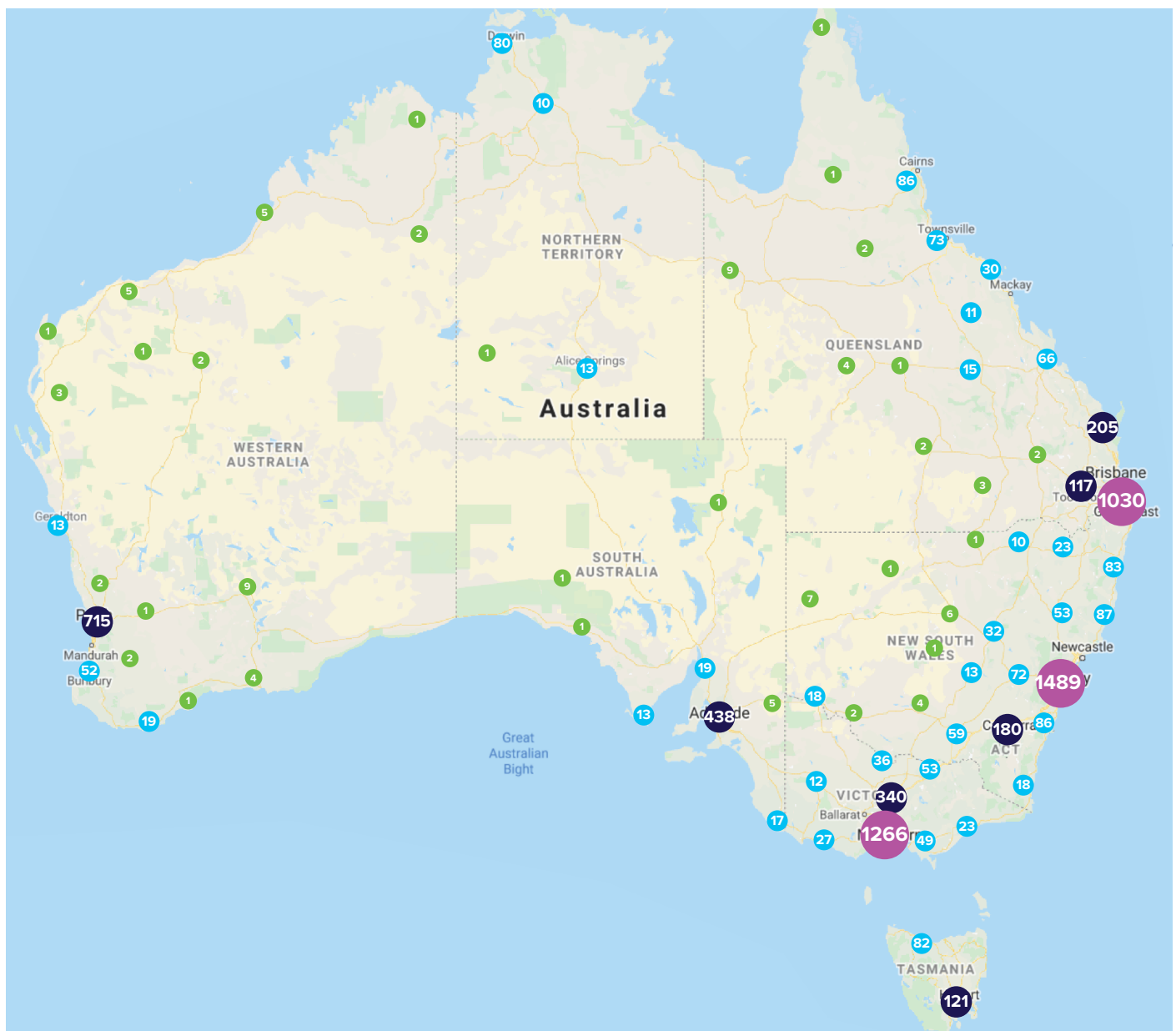


Figure 1. National Guideline registrations by professionals across Australia.

Term of Reference (A) continued

Recommendation(s):

1. Fully implement the National Guideline for Assessment and Diagnosis of Autism in Australia, across states and territories and service systems (particularly health, disability and education).
2. Implement the National Guideline for Assessment and Diagnosis of Autism in collaboration with representatives clinical professions, service providers and community groups – consistent with the way the Guideline was developed.
3. Develop a person-centred clinical care pathway centred on the National Guideline for Assessment and Diagnosis of Autism, integrating neurodevelopmental surveillance and a national quality framework for early intervention.
4. Revise the Medicare Benefits Schedule to align with the assessment and diagnosis process in the National Guideline for Assessment and Diagnosis of Autism, including for adolescents and adults.
5. Rationalise assessment requirements and funding mechanisms across service systems to avoid duplication.

Term of Reference (B):

The prevalence of autism in Australia

Autism is among the most complex, prevalent and heritable of all neurodevelopmental conditions. Prevalence rates around the world are increasing; for example, with a recent report from the US Centers for Disease Control showing an estimated 1 in 54 8-year-old children were identified with ASD in 2016⁶.

The number of Australians self-reported as having a diagnosis of autism in the ABS Survey of Disability, Ageing and Carers (SDAC) has increased by 25.1% from 2015 to 2018, to 1.3% of males and 0.4% of females⁷. These latest ABS figures put the prevalence rate of autism diagnoses for children aged 5-14 years in Australia as approximately 3.2%, up from 2.8% in the 2015 data.

Similarly, there have been a number of Australian research projects that have indicated a significant increase in prevalence over the past decade, including studies using data from the Longitudinal Study of Australian Children⁸ and the Helping Children with Autism⁵ funding package.

However, we do not have a good understanding of the prevalence of autism in Australia and trends

over time. Such an understanding is necessary for effective planning for both the provision of services and policy development.

As part of the process of implementation for the National Guideline, there is an opportunity to establish a national autism data register. Not only does this provide a direct opportunity to assess prevalence, but aligned with the data needs outlined in the Guideline, rich clinical data arising from the comprehensive assessment process (e.g. functional ability, IQ, health data, diagnosis) may be gathered. This would be of significant value to policy-makers, service providers and researchers globally, while providing important information for individuals and an integrated and person-centred clinical care pathway across service sectors.

Such a register should also be established with linkages to other related national datasets, such as those administered by the Australian Institute of Health and Welfare, the health system and the NDIS, and operate under the national data management framework of the National Data Commissioner.

Recommendation:

6. Establish a national autism data register, with appropriate data linkages, to facilitate improved services, policy development and research, as well as individualised healthcare, interventions and supports.

Term of Reference (C):

Misdiagnosis and under representation of females in autism data, and gender bias in autism assessment and support services

The National Guideline for Assessment and Diagnosis of Autism⁴ states that autism is diagnosed more commonly in males than females (often reported 4:1). The 2018 SDAC figures indicate prevalence for males is 3.5 times that for females⁷. That said, there is growing evidence this may not reflect the true gender ratio of autism, but a bias towards the identification of males in the diagnostic process. This may in part be because females are better able to ‘camouflage’ or ‘mask’ behaviours and manage difficulties, together with the current design of instruments used to assess behaviours reflecting a presentation more common in males than females.

Evidence from scholarly literature indicates:

- Females on the autism spectrum are commonly quite adept at camouflaging, which can make detection more difficult, and often causes individuals to doubt themselves⁹.
- There needs to be greater recognition of the female autism phenotype, including the increased tendency to internalise mental health issues⁹.
- Mothers of girls on the autism spectrum found that red-flags were often dismissed by health-professionals, leading to later diagnosis¹⁰.
- Mothers with daughters on the autism spectrum, often felt a sense of incompetency, encouraged by the lack of information and resources available about females on the spectrum¹⁰.
- Importantly, gender does not significantly predict the age of diagnosis¹¹.
- Parents, of girls diagnosed with autism, describe the diagnosis as being a catalyst for positive change. The increased understanding of their child’s needs led to decreased stress and positive outcomes for family harmony¹⁰.

There is also growing evidence that being transgender or gender diverse is more common in individuals on the autism spectrum than for the broader population. The National Guideline suggests that assessment teams have a good understanding of gender diversity and its potential impact on behavioural presentation and needs.

Given the importance of early diagnosis and intervention, an understanding of how autism manifests differently between genders is critical.

Early assessment and diagnosis is important for the management of co-occurring health conditions. By way of example, there is a growing body of literature indicating a link between anorexia nervosa (AN) and autism, studies showing one in four adolescent and adult females with AN meeting the clinical criteria for ASD¹².

Community feedback

In 2019, the Australian Autism Research Council (AARC) (which operates under the auspices of Autism CRC) undertook a major community consultation process on national priorities for autism research. The consultation process, which allowed the community to respond to seven draft priorities developed by the AARC, received online survey responses and submissions from over 1,100 individuals and organisations. As part of the survey, respondents were able to suggest other research priority areas. More than 600 respondents chose to suggest one or more additional priorities, and many of these indicated concern about the efficacy of existing autism diagnostic tools, particularly for women and girls¹³.

Some respondents mentioned that there needs to be more research to prevent late autism diagnoses among women and girls, as well as a need for more support for those who have received a late diagnosis.

In addition to the draft research priorities identified by the AARC, respondents were provided with a list of potential research priority areas based on the UN Convention of the Rights of People with Disabilities. “Women and Girls” was the most commonly selected additional priority area by autistic respondents (79%).

“World leading experts ... have come to understand that girls and women present differently than males and are generally much better at trying to fit in, masking and trying to pass as ‘normal’, because they are so misunderstood (to the detriment of their mental and physical health and well being) and, it seems that many in the medical profession, in education, in the government, etc. have not caught up with the latest understanding of this. Education and understanding of the latest research on autistic girls and women needs to much more widespread and accessible to those who affect the lives of autistic girls and women

Term of Reference (C) continued

and their families and carers ... It is a huge problem that I can see at the moment – from first-hand experience, as well as observations.”

AARC Community Consultation Respondent.

There has been significant research in recent years on the autistic female phenotype. It is essential that such evidence is incorporated in assessment and diagnostic instruments and professional understanding.

Recommendation(s):

7. Implement the National Guideline for Assessment and Diagnosis of Autism – noting the important consideration of factors of gender and gender diversity (Guideline Recommendations 61 and 62).
8. Enhance existing tools, or develop new ones, for use in the identification, assessment and diagnosis of autism to account for presentation in differing gender phenotypes.

Term of Reference (D):

International best practice with regards to diagnosis, support services and education, effectiveness, cost and required intensity

Diagnosis

The National Guideline for Assessment and Diagnosis of Autism was developed on the back of a series of systematic reviews of the literature and extensive consultations with professional and community groups⁴. Subsequently, following independent international methodological and content reviews, all 70 of the Guideline's recommendations were endorsed without amendment by the full Council of the NHMRC in 2018. It describes optimal clinical care for the assessment and diagnosis of autism.

Effectiveness and required intensity of interventions

Interventions for individuals on the autism spectrum share a universal goal of minimising the impact of developmental challenges on the individual's abilities and quality of life and maximising their long-term autonomy over their own life choices.

'Early intervention' is a term used to describe therapeutic (and non-pharmacological) interventions designed to improve developmental outcomes that is first applied during the early years of life. Early intervention is considered important, providing significant opportunities to support early development and reduce longer-term disability.

A wide range of early intervention approaches for autism are offered by providers. These are often divided into the following categories¹⁴:

1. Behavioural
2. Developmental
3. Naturalistic developmental behavioural interventions
4. Sensory-based interventions
5. Technology-based interventions.

As individuals on the autism spectrum vary widely in developmental abilities and needs, it is recognised that there is no 'one size fits all' approach to autism intervention; that is, there is no one therapy model or mode of delivery that improves outcomes for all children¹⁵.

Autism CRC is currently undertaking a study, commissioned by the National Disability Insurance Agency, to review the international evidence

supporting autism early intervention approaches for children up to the age of 12 years ('Early Intervention Review'). This Autism CRC study will seek to answer the following questions:

- What interventions have been examined in systematic reviews?
- What effects do these interventions have on child outcomes?
- What effects do these interventions have on parent/caregiver outcomes?
- What are the optimal delivery characteristics of these interventions?
- What child characteristics impact on intervention outcomes?

This study is due to be completed in September 2020. 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 the highest level of clinical evidence. We do not accept less for pharmacological therapeutics or other therapies used in clinical practice for other conditions – and should not in the case of autism.

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 there is use of intervention approaches for autism in Australia for which efficacy is not well supported by evidence¹⁶. 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 the health and disability systems.

It is essential that current information on the best practice in early interventions, and the evidence-base supporting these, be available to the community, service providers and researchers, as well as to government and related agencies, such as the NDIA. A national quality framework 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.

Term of Reference (D) continued

There is a need and opportunity to develop this framework upon 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 health care services and educational and care services.

A National Quality Framework would better inform and equip service providers and families (so they might make more informed choices), as well as Government, on evidence-based practice in early intervention. This will also 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.

Finally, it is critical that there is major research investment in addressing gaps in the evidence-base for early intervention. Evidence is required to guide critical decisions, e.g. intervention type for given age and need, and intensity and duration of delivery. As a result of prior investments in research and infrastructure, Australia is well placed to advance evidence-based practice in this regard. The study currently being completed by the Autism CRC (commissioned by the National Disability Insurance Agency) will provide an excellent understanding of gaps in early intervention evidence, and could be used as one mechanism through which research priorities in this area are devised.

Recommendation(s):

9. Develop a National Quality Framework for Best Practice in Early Intervention for autism / neurodevelopmental conditions, maintained for currency of the most recent evidence.
10. Commit funding to quality research addressing gaps in the evidence for early intervention approaches, and mechanisms for guiding delivery of effective intervention given an individual's functional need and circumstance.

Education

The Convention on Rights of People with a Disability (CRPD) Article 24, Comment 4 highlights rights of all children to attend their local school with their siblings and in their community¹⁷.

The 2018 Australian Survey of Disability, Ageing and Carers (SDAC) documented that intellectual disability was the most common (4.5%) disability affecting children⁷. The same survey reported that the number of Australians on the spectrum increased by 25.1% from 2015 to 2018, with autism prevalence for Australian children aged 5-14 rising to approximately 3.2%⁷.

In regards to educational provisions, the available data present an interesting picture, with nearly 31.2% of the students with disabilities in general being placed in special classes in mainstream schools or special schools; while the figure is 40.8% for students on the autism spectrum⁷.

The 2018 data also revealed that 77.7% of autistic individuals attending school or another educational institution reported social, learning and communication difficulties at their place of learning⁷. These findings reflect that greater identification and

presence of students on the spectrum in mainstream education have not been accompanied by adequate educational supports in response to their needs¹⁸.

In the last five years, there has been extensive investigation into the educational experiences of Australian students with disability, including those with developmental disabilities. There has been a review of Australia's Disability Standards for Education, major evaluations in four Australian states and territories (Queensland, New South Wales, Victoria, and Northern Territory), and a national Senate inquiry. In April 2019, a Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability was announced by the Australian government, with schools falling into its Terms of Reference. The commissioned reviews and reports have documented concerning inconsistencies in the access and implementation of inclusive practices throughout Australia. These may explain:

1. the growing number of students with disabilities in segregated settings^{18,19}; and
2. the dissatisfaction of students with disabilities and their families with their school experiences²⁰.

Term of Reference (D) continued

The number of children being home-schooled is increasing. In NSW, for example, the number registered for home-schooling has increased by 65% between 2014 and 2018²¹. In 2018, 25% of home-schooled students listed “special learning needs” as the reason for home-schooling, an increase from 20% in 2016²¹.

International evidence indicates that inclusive education is good for students with and without disability²². However, many Australian families with a child with disability are not provided with inclusive mainstream education when considering schooling needs and options for their children.

International best practice suggests that a Multi-tiered System of Support (MTSS)²³ that embeds Universal Design for Learning principles (UDL)²⁴ can be an effective framework for providing support for the needs of all students in inclusive schools, including those on the autism spectrum^{25,26}.

UDL is a set of principles to support teaching for diversity in a classroom where teachers are encouraged to teach and assess student’s learning in flexible ways. This is an ideal approach for providing a foundation of support in inclusive education. UDL requires teachers to provide multiple methods of engagement, representation, and action and expression²⁷, helping to increase interest and understanding. For students on the spectrum, this may involve building on their special interests. The framework of UDL can incorporate a range of evidence-based teaching strategies that support educators to accommodate individuals with a wide range of abilities and backgrounds²⁸. These principles have underpinned Autism CRC’s work in Program 2, “the School Years”.

Autism CRC’s School Years program built on foundational research undertaken in Australia’s first nationwide needs analysis of the educational needs of autistic students (aged 5-16 years). This study gathered inputs from almost 1,500 school administrators, teachers and specialist support staff, ancillary support staff such as teacher aides, parents and students.

Over the past six years, the School Years program has seen over 25 research projects conducted on-ground in over 300 state, catholic and independent schools across Australia, aimed at developing:

- tools and practices to enhance teaching and the learning experience (classrooms of excellence);
- evidence-based tools and programs for supporting social, emotional and behavioural needs of children and adolescents;

- a better understanding of the developmental and behavioural trajectories of Australian students on the autism spectrum; and
- the skills and confidence of teachers and support personnel.

With support through the Positive Partnerships program, this research was extended to support the effective delivery of outputs in remote, Aboriginal and Torres Strait Islander and CALD communities.

On 18 May this year, the Commonwealth Minister for Education launched *inclusionED*, an online professional learning community, co-designed with educators, for educators (www.inclusioned.edu.au). *inclusionED* provides evidence-based and research-informed teaching practices and resources for educators to employ in supporting students with diverse learning needs and styles in inclusive mainstream schools – founded in the principles of Universal Design for Learning.

The *inclusionED* platform represents the translation to practice of the research outputs from the School Years program of work in schools across Australia over 6 years, those outputs now embedded within practices and resources for use in the classroom. Presently, there are 27 practices available through the platform, with more to be added as current projects complete.

inclusionED also provides a national community of practice (currently more than 1,100 members), enabling social sharing and educator reviews on the experience of implementing specific practices. Detailed information supporting practice implementation aligned with the Australian Institute for Teaching and School Leadership’s High-Quality Professional Learning Cycle is provided – supporting educator professional development.

The *inclusionED* platform has only been made possible by investment in education research at a national scale and over a period of years allowing needs analysis, design, development, trial and translation – together with the collaborative efforts of thousands of individuals across the research community, school systems and schools, educators, parents and students. Both have been enabled by the nature of the investment in the CRC program.

In providing tools and skills development for educators to better support the diverse learning needs and styles of students, *inclusionED* is one of the most significant steps to develop inclusive classrooms and practices in Australian schools. As Article 24 of the CPRD states, inclusive education involves a process of systemic reform, where

Term of Reference (D) continued

changes and modifications are made to content, teaching methodology, approaches, structures and strategies in order to remove barriers that prevent all students from accessing an equitable, participatory learning experience¹⁷. Hence, in addition to furthering the inclusive educational practices for educators through *inclusionED*, there is much to do taking a systemic view of education across Australia if students and families are to be provided with inclusive mainstream education when considering schooling needs and options.

Recommendation(s):

11. Integrate within the framework of national education reforms of needs-based funding models, aligned individualised learning and Nationally Consistent Collection of Data (NCCD):
 - i. information on comprehensive assessment of individuals consistent with the National Guideline for Assessment and Diagnosis of Autism; and
 - ii. inclusive education principles and practices for students provided with a multi-tiered system of support and universal design for learning in mainstream early childhood, primary and secondary education settings.
12. Incorporate inclusive education principles and practice as fundamental elements within existing professional development and systematic accountability frameworks for school leaders.
13. Commit resources to ongoing development and review of evidence for maintenance of a Quality Framework for Best Practice in Inclusive Education.

Term of Reference (F):

The interaction between services provided by the Commonwealth, state and local governments, including:

(i) health and mental health, (ii) education, (iii) employment, (iv) justice, and (v) housing

General

The clinical pathway for autism typically starts during childhood and has typically seen a fragmented system of support through the health, disability, education and social services systems, at state and Commonwealth levels. This can mean that unnecessary or inadequate supports are provided, health concerns overlooked, and the doubling-up of requirements as people move from system to system, significantly increasing the financial and emotional cost of support.

From commencing operations in 2013, Autism CRC's program of work has targeted research goals with significant national application and impact. As such, work has been conducted across state and territory boundaries, with and through the more than 50 participant organisations across Australia. In that work, we have observed the differences between systems, states, and particularly between the Commonwealth and the states, who have responsibility for services delivery in most of the sectors mentioned in the terms above. As an example, a review³ of diagnostic practices in Australia highlighted the geographic variability across (and within) states, and formed part of the needs analysis that led to the development of the National Guideline. The picture is made more complex in this case by the variability in application of diagnostic practices between service sectors, e.g. health, disability and education.

Similarly, differences and disconnects have been evident between the states in relation to education and health services. In saying this, we have enjoyed significant support from the Queensland Department of Education and the Tasmanian Department of Health, both participants in the CRC, in contributing to our national program.

Consistent with Autism CRC's focus on end-user driven research, we have engaged health and allied health professionals (including colleges, societies and associations), educators and disability service providers directly in our research and research translation activities – aiming at tools and other resources suited to practical application. Similarly, dissemination of these resources for use has primarily been by direct means to practitioners.

Dissemination and use of evidence-based outputs from research in this way does effect change. However, if the maximum benefit is to be realised from major initiatives, such as consistent national adoption of the National Guideline or inclusive education practices, systemic implementation across Commonwealth, state and local government service sectors is required. It is recommended that such implementations are coordinated at a national level by bodies such as the Council of Australian Government's Disability Reform Council.

Specifically, in relation to the National Guideline, the comprehensive health and functional assessment undertaken should not only inform the diagnosis, but also a supports pathway that is person-centred and covers all relevant service sectors. In implementing the Guideline, and the data management systems associated with it, there is an opportunity for these comprehensive data to inform:

- health services, consistent with personalised healthcare principles;
- disability support, including through the NDIS with participant-centred practice and needs-based supports;
- education, supporting individualised learning plans and needs-based school funding; and

Recommendation(s):

14. Ensure a joint national practice and policy initiatives affecting state and local government service sectors be coordinated at a national level through bodies such as the Council of Australian Government's Disability Reform Council.
15. Create national Guideline for Assessment and Diagnosis of Autism data linkages with other service systems (e.g. health, education and disability) with a view to the quality, consistency and efficiency benefits of access to permissioned data for person-centred planning and supports within these sectors.

Term of Reference (F) continued

- accommodations and supports in community settings, including workplaces and the justice system.

Health and Health Services

Over 90% of individuals on the autism spectrum report having one or more co-occurring conditions¹³, with autistic individuals having significantly worse physical and mental health outcomes than experienced in the general population. A longitudinal study of young Australian school leavers (aged 15 -25 years) showed significantly higher rates of anxiety, depression and Attention deficit hyperactivity disorder (ADHD) among autistic participants than for the non-autistic participants²⁹.

A recent study of a large Australian health dataset showed that autistic individuals have a mortality rate more than twice that of the general population³⁰. Unlike the general population where the principle cause of death was cancer, the main cause of death for autistic individuals was ‘injury and poisoning’, which includes suicide, self-harm and accidents. For people on the autism spectrum with an intellectual disability, the leading cause of death was ‘nervous system and sense organ disorders’, which includes epilepsy. Suicide rates for the autistic community are seven times those for the general population³¹.

There is an urgent need to better understand the differing risk factors, causes and presentation of

co-occurring conditions, and therefore clinical intervention strategies, if the enormous gap in health outcomes is to be addressed.

Autism CRC’s Adulthood program has worked with health professionals to develop a number of tools to upskill the clinical workforce on autism and its presentation. These include:

- the Comprehensive Health Assessment Protocol for Autism (CHAP-A), a self-health assessment tool for autistic adults to share with GPs, building upon the very successful CHAP tool developed at the University of Queensland and used around the world for individuals with an intellectual disability;
- development of an autism pathway with information and linkages, embedded in the national portal HealthPathway system used by health professionals, including GPs; and
- resources and professional development modules made available to GPs across Australia (with almost 4,000 logged PD module completions to date).

Again, dissemination and use has been via direct engagement with clinicians.

Implementation will require a systemic approach through national and state health service sectors.

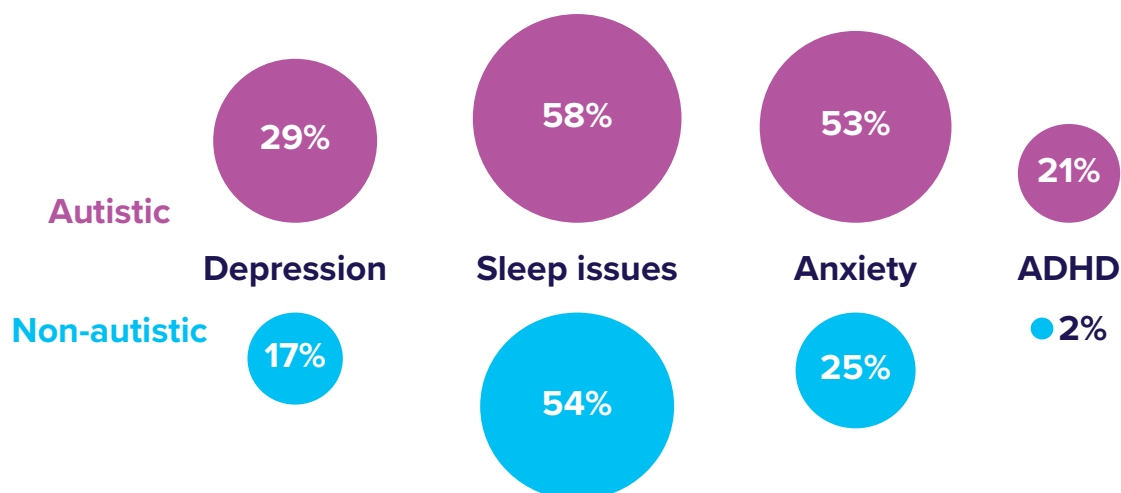


Figure 2. Rates of anxiety, depression and ADHD among young school leavers (aged 15-25 years)

Recommendation(s):

16. Upskill national clinical workforce in autism and the presentation and clinical management of co-occurring conditions as a matter of urgency.
17. Develop and disseminate best-practice tools and resources, including risk assessment tools, to help families, clinicians and services match and address individual needs, improving health outcomes and reducing preventable deaths.

Term of Reference (G):

The social and economic cost of failing to provide adequate and appropriate services, including to support key life stage transitions of autistic people

Life stage transitions can be times of significant challenge. For example, transition to school is generally regarded as a challenging time for many on the autism spectrum, families and significant others (e.g. teachers) – with transitions bringing changes to the physical environment, personal relationships, expectations, routines and processes³². The following focuses on one of the major transition challenges for individuals – that from school to further education, training and employment.

Transition from school to further education, training and employment

The most recent ABS data (2018) put unemployment rates for autistic individuals at 34.1%, more than three times the rate for people with disability (10.3%) and almost eight times the rate of people without disability (4.6%)⁷. Further, only 44% of autistic adolescents are likely to attend post-secondary education and training, significantly less than their peers with other disabilities⁷.

The economic cost of unemployment of autistic individuals is substantial. In 2011, a Synergies Economic Consulting report the cost of lost productivity at \$1.87 billion to \$3.22 billion, excluding transfer costs of social services and reduced taxation revenue^{33,34}.

There are approximately 44,000 young Australians on the autism spectrum aged 14-25 years, and two-thirds (i.e. 29,000) are unemployed or underemployed⁷. Young autistic people face unique challenges that affect their employability, such as difficulties with social communication required for the workplace; sensory seeking or avoidance behaviours; and the need for structure, routine, or predictability in work tasks and instructions³⁵. Other challenges include anxiety about life after school, difficulties imagining their life after high school, and limited opportunities to engage in real-life experiences that help them develop important skills and successfully transition to work and independent living³⁶.

Successfully transitioning from school to work and/or further study can significantly improve an individual's long-term economic future, social inclusion and

wellbeing, but individuals on the autism spectrum face major barriers to gain entry into the labour market. Having a clear and coordinated transition planning approach makes it more likely that an adolescent on the spectrum will enter the workforce or undertake further education/training after leaving school³⁷.

Providing young autistic people with early support using a tailored career planning program can set them up for future success with employment. The research literature indicates that starting career planning and goal setting early, preferably in Year 9 of high school, ensures adequate time and opportunities to identify career interests, develop life skills including independent community mobility, and participate in work experiences^{37,38}.

One of the key themes of Autism CRC's Adulthood program has been the development of programs and tools to support transition from high school to further education, training and employment. This program saw the development of the Better Outcomes and Successful Transitions for Autism (BOOST-A) and its subsequent evaluation in a nationwide randomised control trial, involving adolescents and their parents, and by education and health professionals who support them. Students reported higher levels of self-determination to achieve their goals for further study or training and employment goals, than students who used the existing generic school-based transition planning processes³⁹.

Autism CRC has since incorporated BOOST-A in a new smart web platform, *myWAY Employability*, designed specifically to help young people on the autism spectrum plan and prepare for their working life. *myWAY Employability* guides young people through a series of questions to help them identify their strengths, interests, and learning and environmental preferences; undertakes matching to relevant potential careers and employment pathways; and provides scaffolded goal-setting to track progress towards employment. It also contains a variety of information articles co-produced with the autistic community, covering topics such as Preparing for Work Experience, Getting Around, Creating a Job Application, Pathways to University, TAFE, or College, and Disclosure in the Workplace.

myWAY Employability is scheduled for launch in August 2020.

Term of Reference (G) continued

An educator's guide to using *myWAY Employability* is currently being co-designed and developed with professionals and educators to use in transition planning support services and schools. These are planned to be available (via the *inclusionED* practice platform) in early 2021.

Work experience during school years is an enabler of post-school employment, developing employability, increasing awareness of career options and employment, and increasing self-understanding and confidence. As will be discussed further in response to Term of Reference K, there are an increasing number of Australian companies that are engaging autistic employees and implementing neurodiversity employment programs – including Commonwealth and state government agencies. The relatively low level of workforce readiness of potential employees has been highlighted by employers as a barrier or additional cost to recruitment.

Such organisations provide appropriate environments for work experience or internships for autistic students, aiding transition to employment post-school. The development of work experience programs for autistic school students, their

implementation supported by government, may not only encourage these organisations to offer work experience opportunities, but may also encourage other employers to do so and consider adopting neurodiverse employment policies more generally.

Finally, poor school completion rates, as well as lower levels of further education and training attainment, are barriers to successful transition to employment. ABS data show that 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 without disability (15.4%). Similarly, 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 non-autistic individuals.

These data only highlight the need for more inclusive educational environments in mainstream schools, better supporting the social and academic success of diverse students – one of the primary objectives of Autism CRC's School Years program – and the need therefore to effect national implementation of inclusive education practices and transition supports.

Recommendation(s):

18. Integrate evidence-based transition planning resources for autistic school-leavers (such as *myWAY Employability*) for use in high school-based transition planning and the Australian Curriculum: Work Studies Years 9-10; as well as the NDIS School Leaver Employment Supports program.
19. Develop work experience programs for autistic school students, with government supporting their implementation through capacity building incentives.

Term of Reference (H):

The adequacy and efficacy of the National Disability Insurance Scheme (NDIS) for autistic people, including: (ii) the utility of the Early Childhood Early Intervention (ECEI) Pathway for autistic children

The core principle underpinning the ECEI Pathway 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, promotes longer-term, positive functional outcomes for individuals on the autism spectrum^{40,41}.

Delayed receipt of intervention does not capitalise on the highly 'plastic' elements of neurodevelopment within the early years of life. 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 years^{42,43}.

It is generally recognised that the initial implementation of the ECEI arrangements has not adequately delivered the desired benefits of early childhood intervention, including family capacity building. The Tune Review of the NDIS legislation found that more flexibility is needed in the pathway to maximise the benefits of early intervention supports for children with disability⁴⁴.

The implementation of the National Guideline is consistent with and will support the effective delivery of the ECEI Pathway, and should be integrated with the ECEI gateway. The Guideline prescribes that a comprehensive health and functional assessment take place as the first step in the diagnostic pathway, and that individuals should be referred for services based on needs identified in that process. Implemented consistently and nationally, the quality of the process and information provided in referral should lessen the overhead of resources and time in providing access to services through the Pathway.

Further, in the longer term, effective implementation of the clinical care pathway described in response to Term of Reference A – with appropriate resources and training for providers – will build the capacity of the system to deliver the objectives of the NDIS ECEI Pathway and reduce systemic bottlenecks.

- A system of universal early surveillance implemented through primary healthcare providers across the nation will support identification of children for referral for assessment at the earliest opportunity (within the first two years).
- Following assessment and referral for supports in accordance with the National Guideline, a National Quality Framework for Best Practice in Early Intervention will provide the information required by families, with the support of ECEI partner organisations, to make informed choices for supports for their child and the family. The Early Intervention Review currently being undertaken by the Autism CRC (commissioned by the National Disability Insurance Agency) will be key to informing the development of this Framework.

Recent research undertaken with Autism CRC indicates that commencing intervention at infancy (less than 18 months of age) may be particularly effective in reducing long-term disability, where early autism interventions traditionally commence at the point of diagnosis (typically older than two years of age). The research tested a developmental intervention for infants (aged 12 months of age) showing early behavioural markers for autism. It found that, while the intervention did not reduce autistic symptoms, the children receiving the intervention had better parent-reported communication and social skills compared to a control group when assessed 6 months later⁴⁵.

This promising area of research only further highlights the need for clinical pathways supportive of the earliest identification and assessment of need, and for investment in quality research that builds upon a Quality Framework for Best Practice in Early Intervention, matching that need to the appropriate evidence-based intervention.

The above consideration of the ECEI Pathway and maximising its utility only reinforces:

- Recommendations 1 and 3 in response to Term of Reference A relating to implementation of the National Guideline at the centre of clinical care pathway; and

Term of Reference (H) continued

- Recommendations 9 and 10 in response to Term of Reference D relating to implementation of a National Quality Framework for Best Practice in Early Intervention and the need for quality early intervention evidence, and therefore research funding, to guide delivery of supports.

Term of Reference (I):

The development of a National Autism Strategy and its interaction with the next phase of the National Disability Strategy

The prevalence of autism continues to grow in Australia and around the world. Autism represents the largest cohort within the NDIS participant base, with 31% having a primary diagnosis of autism⁴⁶.

Over the past decade, there has been growing recognition that an understanding of both the strengths and challenges of an individual and their family are important in determining the areas of functioning, need and potential, and therefore for service delivery. A strengths-focused approach further highlights the significant socio-economic cost, both direct and opportunity cost, of autism to individuals, families and the community, if not adequately addressed.

It is therefore appropriate that specific consideration is given to autism within the context of broader Government policy settings and strategy. Further, it is critical that an integrated national view of such be

adopted, so to avoid the significant costs of previous fragmented approaches across states and territories, and across systems, such as health, disability and education.

At the same time, it is important that any such considerations, particularly in relation to assessment of needs and the provision of supports, be centred on the individual and take place in the context of broader neurodevelopmental and behavioural conditions. An appropriately formed diagnosis of autism will be founded upon a comprehensive assessment of an individual's health, functioning, needs and potential. Further, a diagnosis is very important to an understanding of self and by others. However, the presence or absence of a diagnosis alone should not be the determinant of needs and supports⁴.

Recommendation(s):

20. Ensure any national autism strategy is founded on the following principles:

- i. individual and family-centred – goals, strengths, challenges, needs and circumstance;
- ii. whole-of-life and whole-of-spectrum;
- iii. co-produced – developed, implemented and reviewed with all stakeholders, with autistic individuals and families/carers at the centre of that process;
- iv. evidence-based – guiding practice and policy; and
- v. innovation – commitment to high quality research and continuous improvement.

Term of Reference (J):

The adequacy of funding for research into autism

There are three important elements to this question:

1. What is the quantum of funding?
2. Where is it directed?
3. How is impact realised?

Research funding

The first Australian autism research papers were published in the mid-1970s, and until the last five to ten years, research was heavily focused on early childhood and genetic studies. Despite autism being a lifelong condition, very little research was undertaken on adolescent and adult life.

An Autism CRC study conducted by Macquarie University⁴⁷ analysed the extent and nature of autism-related research funding by:

- the Australian Research Council, National Health and Medical Research Council in the period 2008 to 2012; and
- the Australian Research Council, National Health and Medical Research Council and Autism CRC in the period from 2013 to 2017 (with Autism CRC operating from July 2013).

Of note from this study:

- For 2008-2012, almost half of the total funding of \$14 million was allocated to biological research, with no identifiable funding allocated to lifespan issues, infrastructure or surveillance.
- In the following five years, 2013-2017, there was a clear shift in both the quantum and distribution of autism research funding, with a total value of

almost \$44 million and significant funding now allocated to lifespan issues, infrastructure and surveillance (including, in the case of Autism CRC, resources for longitudinal study of matters affecting autistic adolescents and adults).

- Over the period 2013-2017, there was a significant increase in funding of \$30 million (210%). Autism CRC was the largest contributor to total funding awarded for the period with \$20 million, with the NHMRC at \$19.3 million and the ARC at \$4 million.
- Over the period 2013-2017, the NHMRC awarded more than \$3 billion in research funding, with \$19.3 million directed to autism-related research.

Throughout this submission, we have identified areas of significant need for evidence-based practice and policy. Given this, increasing prevalence and the lifelong nature of autism, the level of funding allocated to related research would appear to be disproportionately low. With funding to Autism CRC under the Commonwealth CRC program coming to an end in FY21, this will be significantly lessened at a time of increasing need, without a commitment of substantial ongoing research funding to the sector.

It is noted that this analysis relates to the cash funding of research only. It does not include the value of in-kind invested in research by participant organisations, many in the end-user community, as is a feature of the Commonwealth CRC Program. Over the same period 2013-2017, in-kind participant contributions to Autism CRC funded research projects totalled approximately \$56 million.

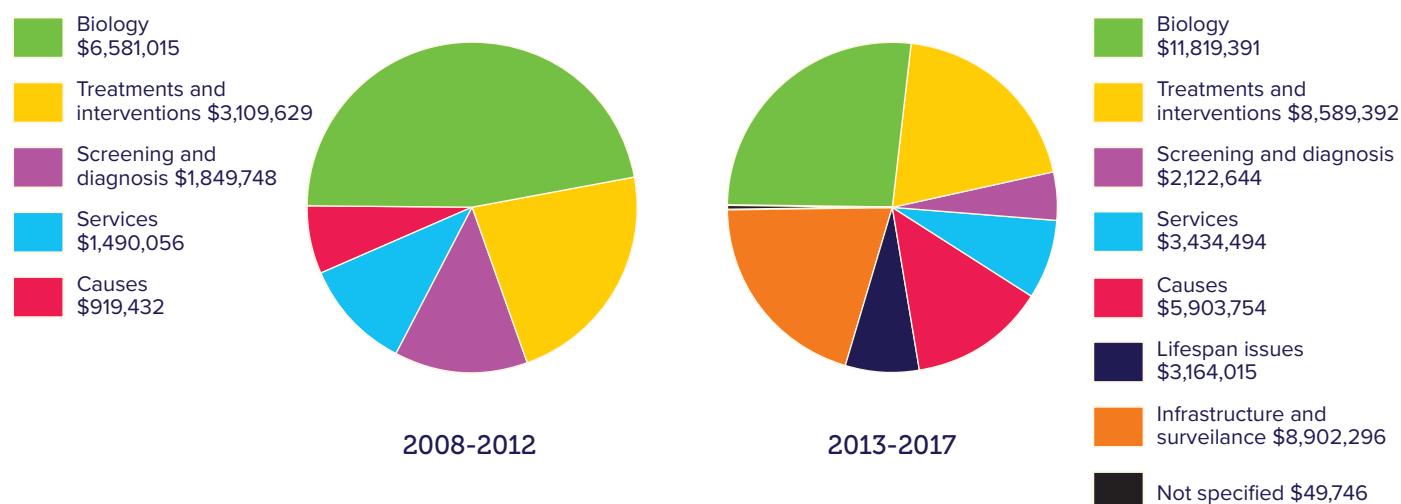


Figure 3. Distribution of Australian autism research funding in 2008-2012 (left) and 2013-2017 (right)

Term of Reference (J) continued

Research priorities

Autism CRC's current program of work, under the Commonwealth CRC Program, was developed in consultation with the end-user and research communities, to ensure that it was directed to priorities identified for research that would have impact on improved policy and practice. This resulted in the three program themes described earlier, addressing the Early Years, the School Years and Adulthood.

In 2018, Autism CRC established the Australian Autism Research Council (AARC) to review and determine national priorities for autism research and address areas of need for the autistic and broader autism communities. The Council is made up of representatives of the key stakeholder groups – autistic individuals, parents/carers, service providers, health/education professionals, government and researchers – such that priorities are agreed by and for the stakeholder community.

In June 2019, the AARC conducted a large community consultation with the aim of understanding community research priorities.

The resultant report¹³ identified 10 research priority areas identified for autism research in Australia, listed alphabetically below.

- Built environment
- Choice in living and housing
- Communication
- Education
- Employment
- Family and carer support
- Gender, diversity and inclusion
- Health and disability services delivery
- Health and wellbeing
- Justice

The AARC is currently undertaking further investigation to identify specific areas of community need associated with these research priorities, and has an ongoing charter to review and update research priorities as defined by community stakeholders.

Research impact

The experience of the Autism CRC highlights two important elements that deliver positive impacts in the lives of autistic individuals and their families.

1. Collaborative research, co-designed and co-produced by the research and user communities

Enabled by the Commonwealth CRC Program, Autism CRC has been able to bring together previously disparate research, clinical, service provider and government organisations to work collaboratively on research priorities of national importance. There are currently 56 organisations engaged as participants in the CRC, located across Australia and overseas. These organisations represent health and education professionals; major service providers across Australia and New Zealand; universities and a medical research institute; school systems; an international healthcare company and other technology companies; Commonwealth and State Government departments and agencies; and, critically, those on the spectrum and their families.

The collaboration of these organisations has the capacity to design and conduct research activities, and translate the outputs to practice and policy.

It is also noted that Autism CRC has been at the forefront of driving participatory research practice in Australia, including through the Research Co-Production program offered through the Sylvia Rodger Academy to develop the capacity of autistic adults and autism researchers to work as peers in research.

2. Research at scale – in terms of objectives, impact, timeframes and resources

With the time and resources available through the eight-year Commonwealth CRC program, Autism CRC has been able to strategically invest in quality research projects, involving multiple parties over multiple years, and bring these together to address significant national needs. Without such time and resources, the National Guideline for the Assessment and Diagnosis of Autism and the *inclusionED* education practices platform could not have been delivered, founded as they were on prior years of research on needs analysis, development and evaluation.

Term of Reference (J) continued

Recommendation(s):

- 21.** Commit to further funding national, collaborative research, at scale – at least maintaining existing levels of investment over multiple years.
- 22.** Ensure that national priorities for research – as may be reflected in a national autism strategy – address issues across the whole-of-life and whole-of-spectrum, and are determined through a stakeholder representative body, akin to the Australian Autism Research Council.

Term of Reference (K):

The social inclusion and participation of autistic people within the economy and community

Employment

The most recent ABS figures from 2018, show that autistic individuals have significantly lower rates of participation in the labour force (38.0%) than do people with disabilities more broadly (53.4%) or those without a disability (84.1%)⁷. The unemployment rates for autistic individuals (34.1%) are almost eight times that for those with no reported disability⁷.

It is also noted that the level of labour force participation for parents and other primary carers is also significantly lower than for non-carers. The 2018 ABS Survey of Disability, Ageing and Carers put these rates at 58.8% for primary carers generally and 81.5% for non-carers⁷.

As previously mentioned, successful transition to further education, training and employment requires a focus on raising the level of educational attainment, as well as planning and preparing for that transition from the middle years of secondary school. Young people on the autism spectrum are more likely to struggle with successfully transitioning from school compared to their non-autistic peers – and those who do not make a successful transition are at a significantly greater risk of long-term exclusion from the labour force as well as social isolation and physical and mental health issues³⁷.

In recent years, there has been a growing recognition of the benefits of neurodiversity in the workforce amongst a number of prominent companies and government organisations. Through the provision of employment practices and environments that enable use of autistic strengths, these benefits extend to better identifying and leveraging the talents of all employees⁴⁸.

At the same time, companies implementing neurodiversity employment programs have encountered challenges in doing so, for example, in identifying and sourcing suitable candidates, and managing employee anxiety⁴⁸ post-recruitment. These all require a change to workplace practices, which again, implemented systemically, might bring benefits to all employees and the organisation.

Importantly, the more mature employment programs have developed their practices to support sustained careers.

Autism CRC is working to increase awareness of these successful programs through the Autism@Work employer forum initiated with DXC Technology,

through which resources from existing program providers and their experiences are shared with other employers.

Autism CRC has also developed tools to assist employers develop an inclusive workplace and management practices that support the sustained employment of neurodiverse employees – including the Integrated Employment Success Tool, soon to be released following a successful trial with over 100 Australian employers.

While there has been an increasing number of companies and government organisations implementing autism employment programs – such as ANZ Bank, SunPork Farms and the Department of Defence – the number of organisations and the number of individuals employed through these programs are low. There remains limited understanding amongst employers generally of the benefits of neurodiversity in the workplace⁴⁹ and the pathway to implementing appropriate programs.

There needs to be a significant scaling of understanding and practice in order to provide greater opportunity for employment to the 62% of the 94,600 autistic individuals of working age (at last measure⁷) not participating in the labour force, and their families.

- There needs to be greater connection between supply and demand. Employer and employment service provider information on work experience and employment opportunities should form an input to transition planning programs for school-leavers post-education job seekers (per Recommendations 18 and 19).
- The accessibility of and quality of information on employment services for autistic job-seekers, and their capacity to support sustainable employment both need to be enhanced.
- The existing successful programs need to be adapted, evaluated and applied to other industry sectors. Many of the successful autism employment programs have had a focus on Information Technology related skills and roles. One exception is the Autism & Agriculture program implemented by SunPork Farms with support from Autism CRC and Specialisterne Australia, which sees 12 autistic employees engaged in on-farm operations at two SunPork sites – those individuals having been employed now for over 2.5 years.

Term of Reference (K) continued

- The benefits of neurodiversity in employment need to be viewed as an important and beneficial component of workforce diversity like other dimensions of diversity, e.g. gender, culture. A North American study showed that, while nine out of ten companies claim to prioritise diversity, only 4% have specific programs that are disability inclusive⁵⁰. This may indicate a ‘public good’ view of such programs. It is therefore important that the business benefit of workforce neurodiversity is evidenced.

Recommendation(s):

- 23.** Enhance the evidence-base and understanding of supports for work readiness and employment to:
 - i. build capacity of the employment services sector and employers to provide quality support to autistic job-seekers and employees; and
 - ii. support job-seeker informed choice and control, consistent with the NDIS Participant Employment Strategy and the 2018 Disability Employment Services reforms.
- 24.** Support the further development and evaluation of neurodiversity employment programs for application beyond Information Technology roles.
- 25.** Codify and promote the evidence-based benefits of, and practices for, neurodiversity in the workplace through major employer groups, such as the Business Council of Australia and the Australian Public Service.
- 26.** Integrate employer-focused programs and resources for neurodiverse workplaces within human resource management training and professional development programs.

Accessible environments and technology

Many autistic individuals have co-occurring medical conditions, which also have physical or neurological accessibility requirements. Improving built environments can have tangible outcomes for everyone – unlocking options for independent living, education, employment and health – with potentially even greater impact for those with higher access requirements. One study assessing factors that contribute to learning progression reported up to a 16% contribution of built environment factors⁵¹.

Inclusive technology is also key to supporting people with disabilities generally, and can have particular relevance to autistic individuals to support communication and social inclusion.

The United Nations has emphasised the importance of affordable assistive technologies and removing barriers to access⁵², particularly for the 20% to 30% of autistic people who do not have spoken communication.

Accessible transportation is also a key enabler to greater participation in the economy and communities. Autism CRC has already undertaken research and trialled programs to facilitate greater access to public and private modes of transport. Work is needed to scale these solutions with major transport service providers.

A national strategy for promoting greater social and economic participation should include consideration of evidence-based practice and tools that support inclusion in physical and digital spaces.

Recommendation(s):

- 27.** Ensure full consideration of the physical and digital environments, as enablers of social and economic participation, within any national strategy or policy framework and associated research.

Term of Reference (L):

The capacity and sustainability of advocacy, self-advocacy and self-determination supports for autistic people, including mechanisms to self-represent to government as enshrined in the United Nations Convention on the Rights of Persons with Disabilities

In the research sphere, the benefits of co-production include increased research quality through better designed studies, more trustworthy conclusions and the potential to generate more relevant and appropriate research that is responsive to the needs of people on the spectrum. Co-production supports research implementation and translation as research findings and interventions are more likely to be accessible, useful and sustainable, and more widely disseminated. In addition, end-user involvement in research co-production can increase empowerment, personal development and self-esteem for individuals and autistic communities^{53,54,55,56,57,58}.

Similar benefits may be gained through the participation of individuals with disabilities in the direction, development and delivery of policies and services.

In the autism community, both internationally and in Australia, there has been a significant increase in the strength of autistic participation and leadership in both advocacy and in delivery of services; for example, with the Autistic Self-Advocacy Network (Australian and New Zealand) and the ICAN Network. Both organisations are participants in the CRC.

More generally, the autistic community is increasingly represented in the governance and management of organisations supporting the community. For example:

- a number of autism service providers have appointed autistic individuals to Board and management roles;
- the Australian Autism Alliance has a number of autistic members and has two co-chair positions, one at least to be filled by an autistic member;

- similarly, the Australian Autism Research Council has a number of autistic members and has two co-chair positions, one at least to be filled by an autistic member; and
- two of the five members of the Autism Advisory Group to the NDIA are autistic.

To support the aspirations and attainment of autistic adults in this regard, the Sylvia Rodger Academy (SRA), established under the auspices of Autism CRC, delivers nationwide programs in research co-production; leadership and advocacy; and organisational governance. The Academy's mission is to provide programs, pathways and networks that create communities where autistic people fully contribute and influence policy, practice and culture in partnership with their peers. Currently, 14 autistic adults are completing the Governance Program and 45 autistic adults have participated in the Future Leaders programs since 2018. Autistic people have been involved in SRA since inception, and at all levels of its work. This includes program development, content delivery, mentoring and strategic direction.

In our experience, when given the opportunity to learn and contribute, autistic individuals have diverse and vital skills and attributes which would be beneficial to Boards and other positions of influence. Examples include superior attention to detail, unique approaches to problem-solving and a strong sense of justice – providing opportunities for individuals to develop and apply their skills, and for emerging organisations to develop good governance, assisting the autistic community to make a greater contribution to the autism community and society.

Recommendation(s):

- 28.** Continue to invest in capacity building in community-led advocacy and services through Information, Linkages and Capacity Building grants and other development programs enabling autistic adults to fully contribute as peers to policy, practice and research that impacts upon their lives.

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Appendix 1 – Our Participants

Participant name	Type	Organisation type	ABN
AEIOU Foundation	Essential	Industry / Private Sector / End-user	19 135 897 255
Autism Queensland Ltd	Essential	Industry / Private Sector / End-user	79 253 351 418
Autism Spectrum Australia (Aspect)	Essential	Industry / Private Sector / End-user	12 000 637 267
Autism New Zealand	Essential	Industry / Private Sector / End-user/ International	
Curtin University	Essential	University	99 143 842 569
Griffith University	Essential	University	78 106 094 461
F. Hoffmann-La Roche Ltd	Essential	Industry / Private Sector / End-user/ International	
La Trobe University	Essential	University	64 804 735 113
Mater Research Ltd	Essential	Industry / Private Sector / End-user	28 109 834 719
Queensland Department of Education and Training	Essential	State Government / End-user	76 337 613 647
Queensland University of Technology	Essential	University	83 791 724 622
University of New South Wales	Essential	University	57 195 873 179
University of Queensland	Essential	University	63 942 912 684
University of Western Australia	Essential	University	37 882 817 280
Affymetrix Inc	Other	Industry / Private Sector / End-user / International	
Amaze	Other	Industry/Private Sector/ End-user	15 600 724 949
Asperger Services Australia	Other	Industry / Private Sector / End-user	14 389 908 238
AssistiveWare	Other	Industry / Private Sector/ International	
Australian Advisory Board for Autism	Other	Other / End-user	53 085 018 408
Australian College of Rural and Remote Medicine	Other	Other / End-user	12 078 081 848
Autism Association of South Australia Inc	Other	Industry / Private Sector/ End-user	41 905 977 886
Autism Association of Western Australia Inc	Other	Industry / Private Sector/ End-user	54 354 917 843
Autism Awareness	Other	Industry / Private Sector/ End-user	42 130 217 962
Autism Specific Early Learning and Care Centre - Anglicare SA	Other	Industry / End-user	69 187 578 153
Autism Specific Early Learning and Care Centre - KU Children's Services	Other	Industry / End-user	89 000 006 137
Autism Specific Early Learning and Care Centre - La Trobe University Community Children's Centre	Other	Industry / End-user	64 804 735 113
Autism Specific Early Learning and Care Centre - Nathan QLD (AEIOU)	Other	Industry / End-user	19 135 897 255
Autism Specific Early Learning and Care Centre – St Giles	Other	Industry / End-user	79 067 523 335
Autism Specific Early Learning and Care Centre - WA (AAWA)	Other	Industry / End-user	54 354 917 843
Autistic Self Advocacy Network of Australia and New Zealand (ASAN AUNZ)	Other	End-user	12 266 839 266
Autism Tasmania	Other	Industry / End-user	90 215 494 454
Autism West	Other	Industry / End-user	38 262 080 944
Brisbane Catholic Education	Other	Private sector / End-user	49 991 006 857
Catholic Education Commission of Victoria	Other	Private Sector / End-user	92 119 459 853
Catholic Education Office of WA	Other	Private Sector / End-user	97 244 688 522

Participant name	Type	Organisation type	ABN
Children's Health Queensland Hospital and Health Service	Other	State Government / End-user	62 254 746 464
Department of Health and Human Services Tasmania	Other	State Government	11 255 872 006
Department of Communities (Disability Services Commission), WA	Other	State Government / End-user	36 922 715 369
Hear and Learn	Other	Industry / Private Sector	26 125 822 479
I CAN Network	Other	End-user	63 608 173 100
iiNet Ltd (Acquired by TPG Internet Pty Ltd in August 2015)	Other	Industry / Private Sector	48 068 628 937
Joseph Piven	Other	Individual / International	
Macquarie University	Other	University	90 952 801 237
Minds and Hearts	Other	Industry / Private Sector/ End-user	51 128 736 103
National Rural Health Alliance	Other	Other / End-user	68 480 848 412
Pathwest Laboratory Medicine WA	Other	State Government	13 993 250 709
Renaissance Beaumont Enterprises Pty Ltd	Other	Industry	50 129 179 675
South Australian Group Enterprises (SAGE)	Other	Private Sector/ End-user	40 005 498 775
The Aspergers Syndrome Clinic	Other	Industry / Private Sector / End-user	39 090 503 601
The Association of Independent Schools Queensland	Other	Industry / Private Sector/ End-user	88 662 995 577
The Royal Children's Hospital	Other	State Government / End-user	35 655 720 546
The Sydney Children's Hospital Network	Other	State Government / End-user	53 188 579 090
University of Sydney	Other	University	15 211 513 464
University of Wollongong	Other	University	61 060 567 686
Wenn Lawson	Other	Individual	13 004 434 638
Western Australian Autism Diagnosticians Forum Inc	Other	Other / End-user	51 286 721 089

Other major partners

Aspect as manager of the Positive Partnerships program, funded by the Commonwealth Department of Education and Training – contract research services

Commonwealth Department of Social Service – contract research services

DXC Technology – Autism@Work employment initiative

National Disability Insurance Agency – contract research services

Salesforce – turnkeyCRC CRM and project management system (commercialised by Autism CRC)

Specialisterne Australia – autism employment collaboration

Telstra Foundation – *myWay Employability* development program

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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