



2020-21

Annual Report



Australian Government
Department of Industry, Science,
Energy and Resources

AusIndustry
Cooperative Research
Centres Program

Our Essential Participants



A full list of Participants in the Autism CRC is given in [Appendix 1](#).

*All Essential Participants are Members of the Company, Autism CRC Ltd, except for the Queensland Department of Education (QED).

Contents

About Autism CRC	1
Our values	1
Our strategic imperatives	2
Established assets and a strong framework for impactful delivery	2
Our current work program	3
Report from the Chair and CEO	7
1.0 Key achievements	11
1.1 Assessment and diagnosis	11
1.2 Education, transitions and employment	15
1.3 Health and wellbeing	19
1.4 Autistic and autism communities	21
1.5 Research assets	24
2.0 Our end-users	27
3.0 Our people and structure	29
3.1 Structure	29
3.2 Autism CRC Board	30
3.3 Autism CRC Management Team	30
4.0 Report on activities	31
4.1 Research and development	31
4.2 Research collaboration	47
4.3 Education and training	49
4.4 Engagement	54
4.5 Awards and honours 2020-21	58
4.6 Communication	59
4.7 Intellectual property	61
4.8 Utilisation and commercialisation	61
5.0 Governance	67
5.1 Autism CRC Board	67
5.2 Autism CRC Committees	70
6.0 Appendices	71
Appendix 1: List of Autism CRC Participants	71
Appendix 2: Annual Financial Report	73
Appendix 3: Publications 2020-21	75
Appendix 4: Resources developed 2020-21	78
Appendix 5: Conference presentations 2020-21	79
Appendix 6: Intellectual property	81
Appendix 7: Glossary	89

Statement of purpose: Together, we learn more



Vision

Autistic people empowered to use their diverse strengths and interests



Mission

Motivate, facilitate and translate collaborative autism research across the lifespan and the spectrum, underpinned by inclusive practices



Objectives

Autism CRC provides the independent, national capacity to develop and deliver evidence-based outcomes through our unique collaboration with the autism community, research organisations, education and health professionals, industry and government

About Autism CRC

Independent national source of evidence for best practice

Our programs take a whole-of-life view from very early childhood through the school years and into adult life, from assessment and diagnosis to supports and capacity building for autistic individuals, their families and those who seek to support them.

At the end of the 2020-21 reporting period, we had 56 Participant organisations, as well as other partners, based around Australia and internationally, working in collaboration. Together, we seek to build capacity and

support for neurodiverse-friendly environments in our communities, so every individual has the opportunity to reach their full potential.

Autism CRC is committed to inclusive research practices and co-production of outcomes with people on the spectrum, their families and supporters. This ensures our research provides practical and tangible outputs that benefit the community.

Our values

In undertaking our mission, Autism CRC is guided by these values:



Inclusion

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



Innovation

Delivering new solutions for long-term challenges



Evidence

Guided by evidence-based research and peer review



Independence

Maintaining autonomy and integrity



Cooperation

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

Our strategic imperatives

⋮ In order to realise our vision, Autism CRC must:

- ▶ be directed by end-user defined needs and demand-driven translation
- ▶ deliver on program objectives in an effective and timely fashion
- ▶ grow autistic leadership and promote neurodiversity policy and practice
- ▶ engage multiple stakeholders and provide a focal point for community collaboration
- ▶ focus on evidence and impact
- ▶ develop and maintain multiple sources of funding
- ▶ maintain independence and the right to communicate “good” and “not-so-good” news
- ▶ build and maintain national and international platforms and practice communities.

Established assets and a strong framework for impactful delivery

⋮ Over the course of the CRC Program, we have established an effective framework for coordinated, collaborative research and research translation with partners across Australia and beyond, as well as a range of valuable research assets and practice platforms. Together, these provide the proven capacity to deliver evidence-based change for the benefit of our end-users, nationally and internationally.



Collaborative framework

Autism CRC has been at the forefront of a renewed research focus, addressing the whole lifespan and recognising both the strengths and challenges of people on the autism spectrum. We have established the national and international stakeholder collaboration model, and the infrastructure to invest in research and its translation to practice, with the capacity to make a positive impact for future generations.



Assets

Autism CRC has developed a range of assets for national and international autism research, providing data and baselines to aid the development of future tools, practice and policy, including the Australian Autism Biobank and longitudinal studies spanning school-aged, adolescent and adult life. We have also established evidence-based platforms and resources, as well as communities of practice, supporting professionals, families and individuals across the health, disability, education and employment sectors.



Impact

Autism CRC has had a significant impact on the autism research landscape in Australia, prioritising research topics that reflect the needs and views of all key stakeholder communities – including autistic individuals and families, service providers, education and health professionals, industry and government.

Our current work program

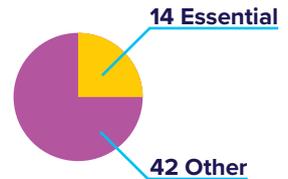
⋮ Making a positive difference to the lives of people on the autism spectrum

As we transition from our establishment phase – very much focused on the delivery of our major CRC funded program of work, while building the national collaborative framework of stakeholders and research assets to deliver this – our strategic goals shift to ones consistent with growing and sustaining an **independent, national reference body of evidence for best practice** relating to autism and other neurodevelopmental conditions across the lifespan.

3 

Research Programs addressing each life stage
Early Years, School Years, Adulthood

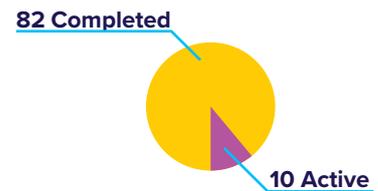
56
Participants



68%
CRC Participants are end-users

55%
CRC Participants from industry and /or private sector

92
Projects



\$126m 
Investment
in research and its translation

63 **Scholars** 
11 Active, 52 Completed
8 Early Years Program, 24 School Years Program, 31 Adulthood Program

90,000+ 
Professionals
involved in research programs or used our outputs

315+ 
Items in Knowledge Centre
and continuing to grow

131,000 
Downloads
publications, reports and resources

20,000 
eNews subscribers



Program 1 – Early Years

Our Early Years program has harnessed existing knowledge of autism to ensure earlier identification and more accurate needs assessment and diagnosis, using behavioural analysis together with breakthroughs in biological research. This identifies an individual's strengths and challenges, as well as pathways to the most effective supports and interventions.

Where have we come from?

- ▶ Parents' concerns from 12 months of age dismissed.
- ▶ GP reluctantly refers child to paediatrician at three to four years of age.
- ▶ Autism undiagnosed before four to five years of age.
- ▶ Trial and error of costly interventions, and loss of opportunity for individuals on the spectrum and their families.

Where are we now?

- ▶ **Australia's first National Guideline for the Assessment and Diagnosis of Autism**, released in 2018, was further enhanced by the development and release of an **Implementation Toolkit** for upskilling clinicians in applying the recommendations of the National Guideline. Now working with key clinical representative bodies to build the capacity of professionals engaged in comprehensive health and functional assessments, by **embedding the National Guideline's practice recommendations within the respective competency frameworks**, made possible by an Australian Government grant under the Information, Linkages and Capacity Building (ILC) program.

- ▶ **Landmark report on evidence for interventions** released in 2021, with work to begin in 2021-22 on a national practice guideline for supporting the development and participation of children on the autism spectrum and their families.
- ▶ **Recommendations for improving best practice** in the identification, diagnosis, and ongoing supports for people on the autism spectrum in New Zealand.
- ▶ **Graduate Certificate in Autism Diagnosis**, completed by 63 clinicians since the course started in 2015, with a further 24 enrolled in 2021 course.
- ▶ **Australian Autism Biobank**, increasing our knowledge of the autism spectrum and co-occurring conditions, in 2021 enhanced by the generation of **whole genome sequencing** data for more than 1,500 participants. Results from some of the **26 national and international research projects** in progress now emerging in areas of diagnosis, motor development, gastrointestinal disorders and oral health.
- ▶ **New research on very early signs, early developmental supports and childhood surveillance tools** with potential to significantly reduce age of diagnosis and improve developmental supports and life outcomes.





Program 2 – School Years

Our School Years program has supported appropriate educational environments and programs, founded on the principles of Universal Design for Learning, that work together to optimise students' social, behavioural and academic development and success, while also equipping teachers to enhance performance and support all students at school and beyond.

Where have we come from?

- ▶ Lack of trained educators.
- ▶ Social isolation and vulnerability.
- ▶ Poor school retention and completion.
- ▶ Poor academic outcomes limiting post-school opportunities.
- ▶ Absenteeism and suspension.
- ▶ Escalation of mental health issues.

Where are we now?

- ▶ **inclusionED**, the translation to practice of research outputs from more than 25 projects carried out through the School Years program. As projects have come to completion, ongoing content development on the online professional learning platform for teachers has seen the 2021 offering expand to 41 teaching practices, attracting 24,500+ visitors. Now working with key stakeholders to deepen effective, inclusive practice within and across the education and employment sectors, made possible by an Australian Government grant under the Information, Linkages and Capacity Building (ILC) program.
- ▶ **StepWrite**, iPad app launched in 2021 to help children harness their writing potential by addressing many of the challenges associated with fine motor and perceptual skills required for handwriting.
- ▶ **Resources for remote**, Aboriginal and Torres Strait Islander, and culturally and linguistically diverse (CALD) communities by working with the Commonwealth-funded Positive Partnerships program.
- ▶ **Autism Teen Wellbeing** website, a multi-layered approach for supporting the mental health of autistic teenagers with videos and resources designed for parents, teachers, schools and communities.
- ▶ **Longitudinal study of Australian students with autism** (LASA) has now collected six years of data and is one of the world's largest and longest studies following children on the spectrum. This unique project is exploring academic achievement and participation in children on the autism spectrum over time, with data collected from home, school and from some of the children/teenagers themselves.





Program 3 – Adulthood

Our Adulthood program has enhanced opportunities to successfully transition to post-school life, participate in higher education, further training and employment, and improve the health and wellbeing of people on the autism spectrum. Our program has delivered tools and national protocols giving clear guidance to autistic adults and their supporters, as well as the employers, and health and education professionals who work with them.

Where have we come from?

- ▶ Little support post-school.
- ▶ Lack of life skills and vocational options.
- ▶ Escalating isolation and mental health problems.
- ▶ Limited community participation and access.
- ▶ Very low employment rate.

Where are we now?

- ▶ **Autism HealthPathways**, web-based health information for health practitioners, including GPs, to help guide patients through the health system. Now available for adoption and adaptation in 43 health regions, caring for more than 28 million people across Australia, New Zealand and the United Kingdom.
- ▶ **myWAY Employability** smart web platform built on six years of research, trials and evaluation related to transition and career planning for young people on the autism spectrum. Attracted 10,000+ visitors in under 12 months. Secured further funding to develop an integrated person-centred, data-driven approach for transition to post-school education and vocational training and employment.

- ▶ **Adolescent/Adult Goal Setting Tool (AAGST)**, card-sort process to facilitate conversations about people's goals and aspirations being used for National Disability Insurance Scheme (NDIS) pre-planning and other decision making.
- ▶ **The Integrated Employment Success Tool (IEST)** published in 2021 to improve employer confidence, employee productivity, job retention and the overall workplace success of autistic people.
- ▶ **First large-scale, global quantitative study** into the challenges, learnings and best practices that organisations have in sustaining and scaling skilled autism employment, providing opportunities to develop evidence-based conclusions that go beyond single cases and compare different employer types and locations.
- ▶ **Health service delivery and care needs identified** for autistic young people and adults through the examination of big data and longitudinal studies. This year saw the development of mental health resources for adults and health professionals, a pioneering study defining autistic burnout, and unique research exploring quality of life for autistic adults.



In their 2020 submission to the Senate Select Committee on Autism, the Australian Autism Alliance stated:

"A coordinated national approach to autism research is critical.

The Australian Autism Alliance highly values the work of the Autism Cooperative Research Centre. Autism CRC coordinates and leads evidence-based research into autism across a wide-range of partners and supporting agencies, and translates evidence-based research into practice. It is essential to linking what could otherwise be a disconnected suite of research projects, adding value to each and ensuring that the knowledge attained through each project is understood and applied nationally."



A joint submission to the Senate Select Committee by the Commonwealth Departments of Social Services; Education, Skills and Employment; and Health noted the value for government of our collaboration, saying:

"The Autism CRC has extensive networks throughout the autism field with researchers, service providers, clinicians and people with a lived experience of autism, across Australia and internationally. Utilising these formal networks, the Autism CRC provides government with access to robust, contemporary evidence about best practice."

Report from the Chair and CEO

In reading though the 2020-21 Annual Report, you will be struck by the enormity of the work undertaken by our national and international collaboration, and its impact across the lifespan for our end-user community – autistic individuals and their families, as well as those professionals and organisations that work to support them.

The Cooperative Research Centres program has proved to be an ideal vehicle for the establishment and development of our highly impactful collaboration. It is not a simple task to bring together all key stakeholder organisations and systems with a common mission and a shared vision – particularly in a sector that has traditionally been divided along geographic and service sector lines.

As this Annual Report describes, over the past eight years, we have seen the development and effective national implementation of approaches, tools and platforms for:

- ▶ identification, assessment and diagnosis, and supports focussed on an individual's goals, strengths and challenges;
- ▶ inclusive capacity-building for educators and schools, health professionals, employers and service providers; and
- ▶ autistic individuals and their families as they pursue their own goals and interests over life's journey.

We have also seen the development of major research assets that might continue to underpin the development of new and enhanced evidence-based practice from early childhood to the school years to adolescent and adult life.

The dedicated efforts and contributions from our Members and Participants have enabled our unique collaboration to form, develop and perform, and then deliver substantial on-ground impacts, all within the relatively short time since inception.

It is imperative that we continue to capitalise on the wealth of resources, assets, infrastructure and capacity established through the CRC Program beyond its initial term which ends in June 2022. This need was affirmed in submissions to the Senate Select Committee in 2020 by the Australian Autism Alliance and the Commonwealth Departments of Social Services; Education, Skills and Employment; and Health (see side panel).

Despite significant gains in understanding, practice and policy over the past decade, for the growing number of Australians on the autism spectrum and with other neurodevelopmental conditions, life outcomes in education, vocation, health and family functioning continue to be far from optimal. This is evidenced by both the broad terms of reference of the Senate Select Committee on Autism, and in the content of the many submissions to the Committee. The capacity of service sectors and communities to support autistic participation, health and wellbeing remains inconsistent and, in too many cases, is inadequately supported by evidence-based practice and understanding. This leads to continued lost opportunity, entrenched disability and excessive costs to individuals, families and support systems over a lifetime.

The need for Autism CRC has arguably not been greater. Australia needs an independent, national reference body for evidence for best practice relating to autism and other neurodevelopmental conditions across the lifespan.

During this year, the Autism CRC Board and our Essential Participants agreed a plan for a continuing collaborative model for research and its translation beyond the end of the CRC Program agreement on 30 June 2022 – when the current company membership, as well as Essential Participant and Other Participant agreements, will also come to an end. It was agreed that Autism CRC Ltd should continue as a member-based vehicle, managing the legacy assets and operations, using the collaborative stakeholder model established for the CRC Program. We are very grateful to our Essential Participants for their valuable support.

To that end, along with the release of this Annual Report, Autism CRC is also releasing a document calling for Expressions of Interest in participating in those legacy operations. Again, using the same model as successfully delivered outcomes for end-users to now – Autism CRC will leverage the capacity and contributions of our network with funding for research on agreed sector priorities and its translation to practice.

We are seeking interest from parties wishing to be Company Members or Associates (akin to the current Essential Participants) and Affiliates (akin to Other Participants), all participating in the next phase of our national and international collaboration from 1 July 2022. Details are found in the Request for Expressions of Interest, which can be obtained by emailing a request to eoia@autismcrc.com.au.

The capacity of our stakeholder model to attract and deploy funding effectively has been demonstrated, with more than \$17 million being contributed to our activities in addition to the original CRC Program and Participants funds.

In March 2021, we secured a \$6 million grant from the Commonwealth Government's Information, Linkages and Capacity Building (ILC) program for two new major projects to help improve health services and education and employment outcomes for autistic Australians. The national capacity of our collaboration and the existence of major assets developed through our CRC Program are substantial factors in our being able to pursue the significant mainstream capacity-building objects for the two projects within a two-year timeframe.

In June 2021, Autism CRC announced that it would commission the development of a national practice guideline for supporting young children on the autism spectrum and their families. This will build upon the review of the international high-quality evidence base presented in our 2020 report, **Interventions for children on the autism spectrum: A synthesis of research evidence**. Consistent with NHMRC guidance on guideline development, this project will operationalise the scientific evidence by combining it with expertise of both clinicians and the community. This project is due to commence in October 2021 and be completed by September 2022.

Summaries of these three major new projects are given (see page 9) along with this report. They are examples of the nature and scale of projects, addressing areas of priority need, that our national, independent collaboration of all key stakeholders has the capacity to deliver – using science to test the system and evidence to improve it in practice.

Again, it is only through the efforts of our Participants that our unique collaboration is addressing such major challenges for research, practice and policy. As this eighth Annual Report details, our collaboration has now completed more than 80 projects and, by the time the CRC Program comes to a close in June 2022, that tally will approach the century mark. We have not highlighted any projects here, with each contributing to research and/or practice in some way. Rather, we'd encourage you to read through both the highlights described at the beginning of the report, as well as the detailed program, engagement and impact reports that follow. You might then get a fuller sense of the enormous depth and breadth of activities, capacity and outcomes achieved by Autism CRC, its Participants, and partners.

When we wrote our report for the 2019-20 year, we could not have anticipated the extent to which the COVID-19 challenge to professional and personal lives would morph and continue. Again, our project teams and partners have been innovative and adaptable in working to deliver outputs and outcomes for the benefit of our end-users.

On behalf of the Autism CRC Board and team, we express our sincere gratitude to all for their continued efforts and dedication. We also wish good health and good fortune to you and your families as we move forward in our COVID-impacted world.

As we complete our final year of the CRC Program over the next twelve months while transitioning to our legacy operations, we look forward to working with many of you as we continue to build Autism CRC as the independent, national reference body for evidence for best practice and realising our vision to see autistic people empowered to use their diverse strengths and interests.



A stylized, handwritten signature in black ink, appearing to read 'Robert van Barneveld'.

Robert van Barneveld
Chair



A stylized, handwritten signature in black ink, appearing to read 'Andrew Davis'.

Andrew Davis
Chief Executive Officer

Major new projects



ILC Project 1: National Best-Practice Assessment and Diagnosis

This project focuses on ensuring rapid and effective implementation of a nationally consistent, best-practice approach to assessing an individual's goals, strengths, health needs and functional challenges, in line with the Autism CRC-developed National Guideline for the Assessment and Diagnosis of Autism in Australia. The project will build on our current work with the Expert Reference Group of clinical and consumer bodies, appointed by the Federal Minister for Families and Social Services, along with government representatives, formed to drive consistent national implementation of Guideline recommendations.

The project will build the capacity of professionals engaged in comprehensive health and functional assessments, nationally, aiming to embed the Guideline's practice recommendations within the respective competency frameworks, Continuing Professional Development (CPD) programs and other relevant training programs of key clinical bodies.

The project also aims at developing protocols to integrate consistent individual assessment data across support systems, such as health, disability, education and justice, to ensure more efficient and equitable access to services.



ILC Project 2: Success in Learning; Transition to Earning

Low levels of inclusive education capacity along with inadequate planning and support for successful transition from school contribute to massive disparities in opportunity and outcomes for people on the autism spectrum. The second project will address these issues by working with key stakeholders to deepen effective, inclusive practice within and across the education and employment sectors. It will expand the content, reach and uptake of two major Autism CRC platforms:

- ▶ *inclusionED* professional learning platform for teachers (inclusioned.edu.au)
- ▶ *myWAY Employability* career planning for young people and their supporters (mywayemployability.com.au)

Most importantly, the project will connect these online platforms, and bring together other related outputs from our CRC Program, to create an individual journey passport that supports successful transitions from school to further education and training, and/or employment.



Commissioned Project: National practice guideline for supporting children on the autism spectrum and their families

This guideline will build on the Autism CRC's comprehensive and current review of the international high-quality evidence base presented in our 2020 report. The report shows there is still much research to do to develop a full picture of high-quality evidence for approaches that might support the goals of children and their families. The report also shows a significant increase in the quantity and quality of international research outputs over the past decade.

Through the development of national guideline, this science will be operationalised in practice guidance, combining the evidence-base with the expertise of both practitioners and people with lived experience as equal partners in the process. Such quality guidance is critical for ensuring the most appropriate and effective services for children and families, across all service systems.

The guideline will inform and equip families, so they might make more informed choices, and provide health, disability, education and other child services professionals with a unifying set of language and standards for consistent, effective and ethical program delivery.

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1.0 Key achievements

In this, our eighth year, we completed 24 CRC Program projects. The total number of approved CRC Program projects came to 65, of which six are still underway. Autism CRC has also undertaken a further nine discretionary projects in addition to 18 research projects with other agencies, including the Commonwealth Department of Social Services, Positive Partnerships, National Disability Insurance Agency (NDIA) and Telstra Foundation Tech4Good.

Having been successfully awarded a Department of Social Services Information, Linkages and Capacity Building (ILC) program grant, work has begun on two major projects to help improve health services and education and employment outcomes for autistic Australians.

The projects will build upon some of the major assets successfully delivered to date, allowing us to further the impact of key CRC Program outputs through mainstream capacity building in the health services, education and employment sectors.



1.1 Assessment and diagnosis



Developed practice and protocols
for consistent national outcomes

Australia's first National Guideline for Assessment and Diagnosis of Autism

24,500

Individuals
registered to access the National Guideline

16,200

Downloads of Interventions Evidence Report
to assist families and clinicians to make informed decisions when choosing interventions



Developed National Guideline Implementation Toolkit

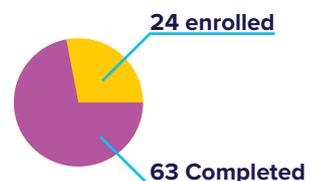
to help clinicians to upskill and deliver the recommendations of the National Guideline

640

Participants in New Zealand Autism Guideline awareness and uptake evaluation

87
Autism diagnosticians upskilled

Graduate Certificate in Autism Diagnosis



Autism CRC's work has had a significant impact on policy and practice of autism assessment and diagnosis in Australia. Our first major contribution was the development of Australia's first National Guideline for the Assessment and Diagnosis of Autism, launched in 2018. A major international research exercise was followed by extensive consultation across Australia with the clinical, allied health, service provider, autistic and autism communities to bring this to fruition.

Since then a range of research, translation and implementation projects have contributed to providing best-practice, evidence-based outputs to clinicians, the community, service providers, researchers and government and related agencies, all with the aim of providing earlier identification and more accurate needs assessment and diagnosis.

National Guideline for Assessment and Diagnosis of Autism in Australia

The National Guideline aims to provide:

- ▶ greater equity in access to a rigorous and comprehensive autism assessment
- ▶ transparency and confidence in the decision-making process
- ▶ a clearly defined pathway to support needs.

This year we focused on increased uptake and implementation of the National Guideline, which defines clinical best practice for the assessment and diagnosis of autism in Australia. The importance of the National Guideline was echoed by the community when more than a dozen organisations referenced it in submissions to the Senate Select Committee on Autism made in mid-2020. Most called for increased uptake and implementation of the National Guideline, which now has 24,500 registered users, including 17,000 professionals.

National Guideline Implementation Toolkit

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.

In December 2020 we were pleased to launch a new National Guideline Implementation Toolkit to help clinicians to upskill and deliver the recommendations of the National Guideline.

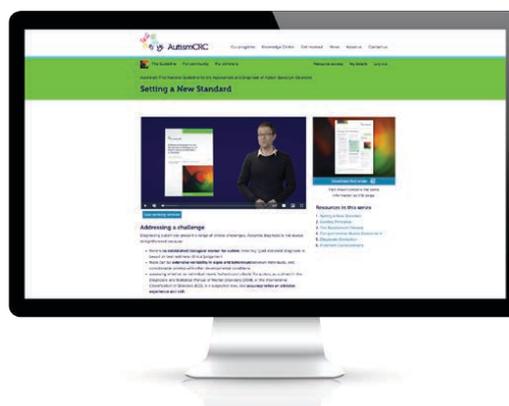
The Toolkit includes learning resources and practical tools, such as:

- ▶ videos and fact sheets – summarising key recommendations in the National Guideline
- ▶ a Baseline Evaluation and Audit Tool – to check how current practice aligns with the National Guideline and to help plan for practice revisions
- ▶ template forms – including a referral form, medical evaluation form and assessment findings report template
- ▶ training information – recommendations for obtaining and maintaining skills to deliver the National Guideline recommendations.

Community resources were also developed to explain the National Guideline and what to expect from an assessment.

This work was supported by funding from the Australian Government's Department of Social Services.

Autism CRC is also working as a specialist advisor assisting the Expert Reference Group appointed by the Commonwealth Minister for Families and Social Services, chaired by the Department and made up of representatives of clinical colleges and societies, and service provider, autistic and family advocacy organisations. The Group was formed to assist in guiding and evaluating the national implementation of the guideline recommendations. Representatives of the Commonwealth Departments of Health and Education, as well as the NDIA, also attend meetings of the Expert Reference Group.



Under the ILC Program grant, Autism CRC is working with members of the Expert Reference Group to create professional development programs, resources and competencies, as well as education and training programs, consistent with the practice recommendations for professionals involved in the assessment and diagnostic process.

Evaluation of NZ's diagnostic process

A collaborative study led to recommendations for improving best practice in identifying, diagnosing and supporting people on the autism spectrum in New Zealand.

The New Zealand Autism Spectrum Disorder Guideline (the Guideline) was first published in 2008, with a second edition released in 2016. Although good awareness of the Guideline exists in New Zealand, children are not diagnosed until six years of age on average and there is no formal diagnostic pathway for adults within the public system.

The study surveyed 640 participants, including parents/caregivers of children on the spectrum, autistic adults and clinicians in both private and public settings. The research found that:

- ▶ the autism diagnostic pathway and related timeframes varied between children and adults
- ▶ parents/caregivers and autistic adults reported that the autism diagnostic pathway is unclear and ongoing supports are lacking or uncoordinated
- ▶ most parents/caregivers and autistic adults were satisfied with the autism diagnostic process overall, but few were satisfied with post-diagnostic supports.

Clinicians indicated good awareness of the Guideline, but implementation of recommendations varied. Results show work is needed to:

- ▶ identify autism earlier and increase clarity in the autism diagnostic pathway
- ▶ support implementation of recommendations from the Guideline to ensure diagnosis is timely, consistent and accurate
- ▶ improve access to high-quality, coordinated and ongoing supports post-diagnosis.

Autism New Zealand is now working with the New Zealand Government and community towards these goals.

Interventions evidence to be followed by national practice guideline

In November 2020, we published a landmark report for families, clinicians, researchers and policy makers, which synthesises the best available high-quality evidence about interventions for children on the autism spectrum aged up to 12 years.

The report, ***Interventions for children on the autism spectrum: A synthesis of research evidence***, assists families and clinicians to make informed decisions when choosing interventions. It includes a broad overview of

intervention for children on the autism spectrum, including the principles underpinning all interventions and provides a comprehensive review of the scientific evidence for the effects of interventions for children on the spectrum, both therapeutic and otherwise.

The report, commissioned and funded by the National Disability Insurance Agency (NDIA), shows there is still much research to do to develop a full picture of high-quality evidence for therapeutic approaches that might support the goals of children on the autism spectrum and their families.

At the same time, the evidence summarised in the report also reflects a significant increase in the quantity and quality of international research outputs over the past decade. It is essential that this science is now operationalised through the development of practice guidance in the Australian context, combining the evidence-base with the expertise of both practitioners and people with lived experience as equal partners in the process – consistent with best practice guideline development.

With this in mind, in June 2021, we announced work on a national practice guideline for supporting the development and participation of children on the autism spectrum and their families.

This new guideline will build on the Evidence for Interventions Report. The guideline will inform and equip families, so they might make more informed choices, and provide health, disability, education and other child services professionals with a unifying set of language and standards for consistent, effective and ethical program delivery.

This project will be developed independently using Autism CRC funding and in-kind contributions with work set to be completed in late 2022.

Therapy for infants showing early signs of autism

A full-scale clinical trial investigated the effectiveness of a pre-emptive therapy for young infants showing early signs of autism in a real-world healthcare referral setting. The therapy aimed to support infants and caregivers through a low-intensity, non-stigmatising, home-based program, when first signs are identified, rather than waiting for children to reach an age when an autism diagnosis might be given.

Follow-up with children at two years of age found that while there were no changes in some measures, parents who received the intervention reported that their toddlers improved in understanding an average of 37 more words and spoke an average of 15 more words than the control group.

As most children were not using words at the start of the therapy period, these parent-reported language gains are an important improvement. This warranted further follow-up, beyond the immediate outcome appointment six months into the trial. Further follow-up conducted with the children at three years old indicates significant longer-term therapeutic effect. The results of these analyses were published in September 2021.

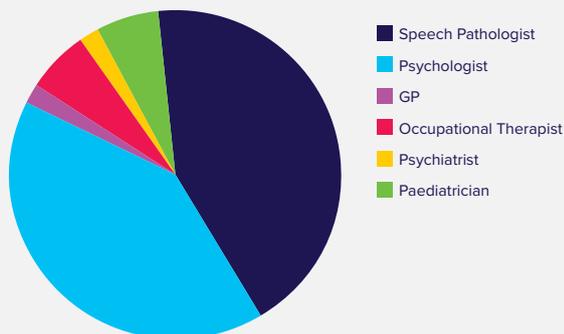
Graduate Certificate in Autism Diagnosis (GCAD)

The Graduate Certificate in Autism Diagnosis reflects international best practice standards for the assessment and diagnosis of autism, contextualised and aligned to the National Guideline.

Currently offered online through the University of Western Australia, psychologists and speech pathologists make up more than 80% of the intake, but enrollments come from all states and territories and also include occupational therapists, paediatricians, GPs and psychiatrists. Students complete a range of theoretically-driven modules, which include video-recorded lectures and practical sessions in which they apply their learning to 'real-world' cases. The GCAD culminates in two practical units in which students learn to administer, score and interpret standardised diagnostic tools for autism, and apply this new learning to clinical practice.

Students continue to provide excellent feedback on the course, stating that the content is intellectually stimulating and directly applicable to their practice.

Figure 1: GCAD completions by profession



Strengths-based approach to functioning – ICF Core Sets

The last two decades have heralded a paradigm shift in disability models and disability service provision, from a singular focus on deficits to a more holistic and strengths-based approach to functioning. The World Health Organisation (WHO) recently developed International Classification of Functioning, Disability and Health (ICF) Core Sets for autism. The ICF Core Sets provide comprehensive descriptions of functioning relevant to autism across the lifespan, but may be difficult for some autistic individuals and their families to interpret.

Subsequently, an Autism CRC project set out to co-produce user-friendly descriptions for each item of the ICF Core Sets for autism with the following objectives:

- 1 Map items on existing standardised assessments against the ICF Core Sets for autism.
- 2 Co-produce user-friendly descriptions for each item of the ICF Core Sets for autism.
- 3 Evaluate the clarity, salience and validity of these descriptions.
- 4 Share research findings with end-users.

The team has developed an assessment tool designed for health professionals in addition to proxy- and self-report versions of the assessment. The latter versions will provide more information about what autistic individuals and their parents/caregivers believe can help or hinder the functional abilities of someone on the spectrum.

This research project has taken a first and important step towards improving the assessment of functioning process in Australia, whilst confirming there is not a 'one size fits all' assessment measure to understand functioning of autistic individuals. The project utilised inclusive research methods, involving autistic individuals and their families to co-design the process and outcomes.

There is continued need for comprehensive assessment measures and processes that focus on the strengths, environmental contexts and support needs of autistic individuals when considering their functioning and quality of life. The assessment protocols and measures developed through this research project should be further co-produced with autistic individuals, embedding a neurodiversity perspective whilst facilitating the inclusion of easily understood purpose and content. This may include additional work to co-produce examples, illustrations and relatable language (including layperson definitions for ICF Core Sets for autism).

There is not a 'one size fits all' assessment measure to understand functioning of autistic individuals.



1.2 Education, transitions and employment

24,600



Unique visitors to *inclusionED*
online learning community for educators

2,760+



Educators joined the *inclusionED*
community of practice

10,060



Unique visitors to *myWAY Employability*
career planning platform for young autistic people

250+



Copies sold of *Adolescent/Adult Goal Setting Tool*
facilitating transition planning and goal setting

390



Downloads of *Integrated Employment Success Tool*
practical workplace manual for employers to improve
workplace success of autistic people

500+



Attendees at *Autism@Work* Summits

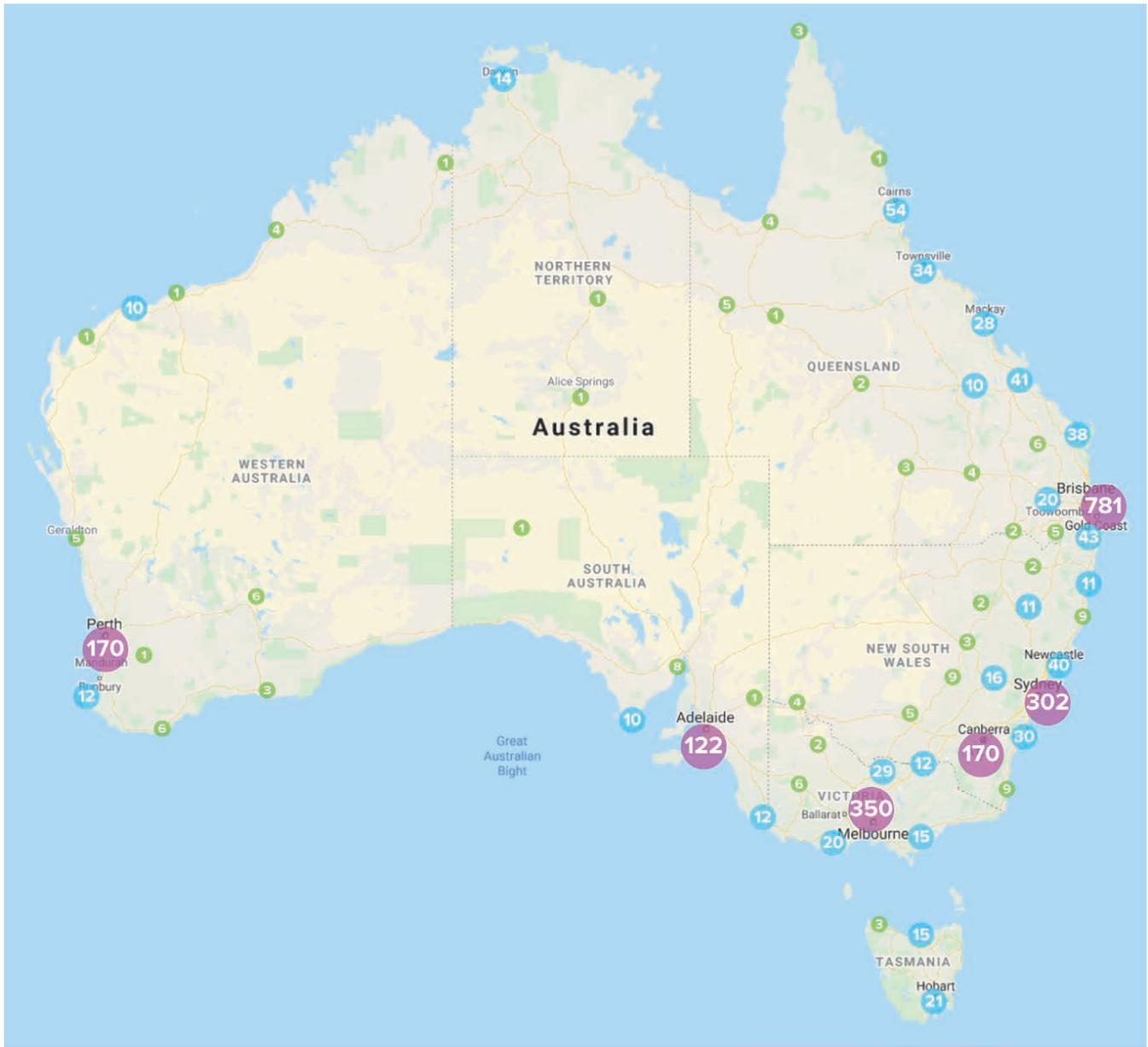
In the average Australian classroom, at least three children have a learning difficulty or neurodevelopmental disability. The support and scaffolding these children receive during school can set the trajectory for the rest of their lives, but many teachers don't feel equipped to effectively support the learning of all students in their classrooms. According to Australian Bureau of Statistics 2018 data, the labour force participation rate for autistic people is less than half that for people without a disability. Further, the unemployment rate for autistic people is almost eight times the rate for people without a disability.

inclusionED

Launched in May 2020, *inclusionED* has continued to expand its offering and now plays an important role in the national approach to addressing some of the challenges detailed above. *inclusionED* teaching practices are underpinned by the outputs of more than 25 research and development projects carried out through Autism CRC's School Years Program over the past seven years involving many researchers and organisations.

Co-designed with educators, for educators, *inclusionED* provides evidence-based and research-informed teaching practices, videos, printable templates and other

Successful transitions from school to work and/or further study can significantly improve an individual's long-term economic future, social inclusion and wellbeing. Autism CRC is focused on providing a range of evidence-based, practical and tangible tools to support teachers, schools, service providers and employers aimed at equipping young autistic people for future success in the workforce.



inclusionED National registered users

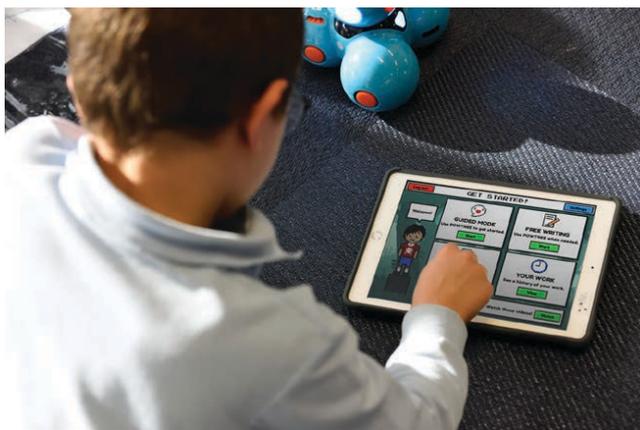
resources, designed to support diverse learners in inclusive classrooms. The *inclusionED* team continues working across several projects to develop *inclusionED* content, which now includes 41 teaching practices, 72 *inclusionED* videos and nine core research projects. Some of the new practices added focus on how to create routine and visual schedules; school belonging; and, calm space for students. The team has also focused on ensuring strong uptake, delivering professional development, training workshops and webinars to educators, education services and school outreach professionals.

The platform, which now has 2,760+ registered users, 30% of whom are from regional Australia, also facilitates a national community of practice, enabling social sharing and educator reviews on the experience of implementing specific teaching practices.

Further co-design and development of *inclusionED* is progressing under the ILC ‘Learning to Earning’ project. This will see *inclusionED* content and functionality enhanced to better support the identification and implementation of evidence-based and research-informed differentiated teaching strategies (aligned to Nationally Consistent Collection of Data on School Students with Disability - NCCD) and national professional standards.

A step in the ‘write’ direction

Autism CRC has released a new iPad app to help children, including those on the autism spectrum, harness their writing potential. The co-designed iPad app, *StepWrite*, helps children improve their writing and addresses many of the challenges associated with fine motor and perceptual skills required for handwriting. It also helps with conceptual and language skills required for written composition.



Making the transition – *myWAY Employability*

Autism CRC's new smart web platform – *myWAY Employability* – aims to support young people to take control of their future and career planning, improving the likelihood of a successful shift to work or further education.

Empowering young people to use their diverse strengths and interests, the online platform has been designed specifically to help autistic young people, ideally aged 14-30 years old.

The platform was launched in August 2020 by Jackie Coates, Head of Telstra Foundation, via an online event that attracted 920+ registrations. Uptake has exceeded initial targets with 1,110 registered users on board by the end of the reporting year.

The platform guides young people through a series of questions to help them identify their strengths, interests, learning and environmental preferences, and then matches this information to relevant potential careers and employment pathways. Unlike other career planning and information services designed for the general population, *myWAY Employability* provides a personalised profile matched to relevant career information and pathways. Scaffolded goal-setting and action planning allows users to break goals into smaller action lists to track progress.

The platform 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 further education and disclosure in the workplace.

StepWrite's motivating game-like features guide kids through a range of scaffolded tasks that improve their competency and confidence while capturing writing outcomes. Launched in May 2021, the app is most suitable for children aged 8-12 years (Grades 4-7) and can be used at home and in the classroom.

Teachers and students reported that they felt the app improved overall quality of writing outcomes and supported students to write more. Students also reported improvements in planning, setting goals, self-monitoring and evaluating. Teachers noted that student writing improved in class after they had used the app for four weeks. They were also more willing to perform writing tasks.

The app's co-design process included autistic and non-autistic children and adults, including teachers.



Autistic adult Liam Picen and Associate Professor Marina Ciccarelli, being interviewed on ABC radio Perth by Jessica Strutt about *myWAY Employability*.



In late 2020, three targeted workshops were initially scheduled with a fourth added due to demand, to upskill service providers in the use of *myWAY* with their clients. Attendees included disability employment providers, service providers, health and allied health professionals, parents and carers of autistic young people.

myWAY Employability is proudly supported by the Telstra Foundation, funded under the Tech4Good Challenge initiative.

Further development of *myWAY Employability* is underway as part of the ILC ‘Learning to Earning’ project. The work aims to deepen effective, inclusive practice within and across the education and employment sectors, working with key stakeholders to expand the content and create an individual journey passport that supports successful transitions from learning to earning.

New insights on effective autism employment practices

An Autism CRC global study investigated the challenges, learnings and best practices that organisations have in sustaining and scaling skilled autism employment.

The study involved 169 autistic employees, co-workers and supervisors of autistic employees as well as human resource directors and executives from 33 for-profit, non-profit and social enterprise organisations across 12 countries. It represents the first large-scale, global quantitative study in the area and thus an important contribution to the available research evidence. Further, it provides the opportunity to develop evidence-based conclusions that go beyond single cases and compare different employer types and locations.

The research revealed several individual (gender, disclosed/non-disclosed, level of diagnosis), as well as contextual (employment and employer type, country), factors that were related to autistic workers’ perceived helpfulness of adjustments and organisational practices, workplace satisfaction, employment-related security, and inclusion.

While the findings that emerged provide immediately useful new knowledge on effective autism employment practices, they also lay the foundation for multiple lines

of new research inquiry. In addition, channels need to be established for industry-wide dissemination of autism employment best practice and resources to improve the employment outcomes of autistic adults.

Manual helps employers create inclusive workplaces

The Integrated Employment Success Tool: An evidence-based guide for autistic adults (IEST), aims to improve employer confidence, employee productivity, job retention and the overall workplace success of autistic people. Developed specifically for employers and released in May 2021, the practical workplace manual is free to access and can be used across a variety of work environments.

Autistic adults are often subject to unemployment, under-employment and social disadvantage. Skilled employment can be difficult to find and hard to retain, despite individuals being capable and motivated. Yet, autistic employees have diverse skills, strengths and interests that enable them to be successful in a variety of roles. The IEST empowers employers with the skills and confidence to make changes in the workplace to make it inclusive, bringing benefits to all employees and companies as a whole.

The IEST provides employers with information about:

- ▶ autism and the strengths of autistic employees
- ▶ the benefits of employing autistic individuals
- ▶ the employment process and important factors for successful employment
- ▶ strategies to implement workplace modifications
- ▶ a range of resources, including editable checklists and templates.

The manual is presented according to the phases of employment starting at advertising the job, through to the interview process, job commencement, workplace modification and how to maintain ongoing support. Each phase includes information on specific workplace requirements, tips and advice, questions to consider, and checklists.



1.3 Health and wellbeing



Established pathways to improve health service delivery and wellbeing across the lifespan

2,600

Number of times GPs have accessed Autism HealthPathways

9,200

Unique visitors Autism Teen Wellbeing resources and strategies to build protective factors against anxiety and depression in young people on the spectrum

5,020

health professionals upskilled in autism-specific wellbeing through GP CHECK online training

9

Primary Health Network regions

adopted and/or localised **Autism HealthPathways**



22,000

children across the world helped by Secret Agent Society program

In the 2019 Australian Autism Research Council community consultation, which surveyed 1,100 people, more than 90% of autistic individuals reported having one or more co-occurring conditions. Research shows that autistic individuals have significantly worse physical and mental health outcomes than experienced in the general population.

Autism CRC has an unparalleled track-record of working with health systems, professionals, service providers and the community across the country to create tangible outcomes for autism-related practice, whether it is in the development of practice guidelines, clinical tools or the provision of training or evidence-based resources. By building a strong understanding of the physical and mental health challenges of autistic individuals through our research, we continue to develop outputs and policy for government, health professionals and service providers to provide better and more impactful services for autistic people and their families.

Forging new HealthPathways

Autism HealthPathways are now available for adoption and adaptation in 43 health regions, caring for more than 28 million people across Australia, New Zealand and the United Kingdom. Under a licence agreement signed in early 2021 between Autism CRC and Streamliners NZ, nine Primary Health Network regions have adopted and/or localised pathways (or are in the process of). These include:

- ▶ Mackay
- ▶ Canterbury, New Zealand
- ▶ Far North Queensland
- ▶ Sydney
- ▶ Western Australia
- ▶ Darling Downs
- ▶ West Moreton
- ▶ Wide Bay
- ▶ Western Victoria.

HealthPathways is a web-based information site that assists health practitioners, particularly General Practitioners (GPs), to guide patients through the health system. These autism-specific pathways are the first of their kind, and equip GPs with the tools to help personalise treatment and management to improve the healthcare journey of autistic people across the lifespan.

To date the team has developed autism-related content in nine HealthPathways to support the assessment and clinical care of children and adults. Developed in consultation with health experts (including GPs, paediatricians and allied health professionals), autistic individuals and caregivers, the pathways cover autism assessment and support, intellectual disability, developmental concerns, and mental health conditions, with a particular focus on post-diagnosis supports.

Since release, the Autism HealthPathways have been accessed by more than 2,600 health professionals.

Building our understanding of health and wellbeing

Our research has highlighted the very high rates of anxiety and depression in Australian autistic adults, with more than half of the people surveyed meeting clinical cut-offs for depression and for anxiety. Further, despite Australia's advanced healthcare and welfare systems, we found that that many autistic people experience significant barriers accessing healthcare. We also found higher incidence of loneliness, and overall reduced quality of life.

Mental health diagnoses (anxiety and/or depression) and Attention Deficit Hyperactivity Disorder (ADHD) are also more prevalent among autistic than non-autistic young people. Poor mental health was associated with multiple, interrelated risk factors: female gender, more autistic traits, feelings of loneliness/worry, dissatisfaction with social supports, intolerance of uncertainty, and dispositional emotion characteristics. The presence of mental health

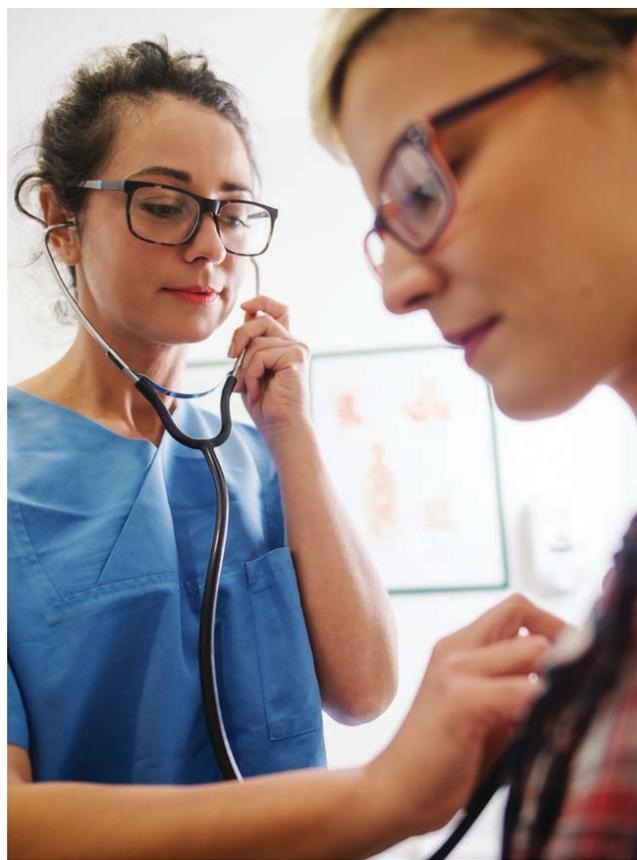
difficulties, in turn, predicted an increased risk for sleep difficulties, lower quality of life, and suicidal thoughts and behaviours.

Parents/carers of autistic young adults also reported mental and physical health challenges and a perceived lack of support. The abilities and strategies used by autistic young people and their parents/carers to deal with distress were found to relate to differences in mental health symptoms, suggesting there may be therapeutic benefit in supporting adaptive strategy use.

Revolutionary innovation for Secret Agent Society

For the last 10+ years, the Secret Agent Society (SAS) program has been evolving as it transforms children's lives worldwide. In 2020, the Social Skills Training Institute (SST), a subsidiary of Autism CRC, launched an innovative digital edition of the SAS Small Group Program.

SAS Providers now offer the evidence-based content and program through an intuitive and engaging online platform that streamlines program delivery and participation for all users in face-to-face or telehealth sessions. The digital edition offers an innovatively designed single platform, improved reporting, and greater accessibility, all whilst removing physical resources. This new digital edition of the SAS Small Group Program is by far the most revolutionary yet.





1.4 Autistic and autism communities

6

Co-production Partners



Sylvia Rodger Academy

3 Programs: Future Leaders, Research, Governance



Australian Autism Research Council (AARC)
Defining national research priorities

- ▶ 10 research priorities defined
- ▶ 1,100 responses to community consultation
- ▶ 5 research priority areas explored through focus groups
- ▶ 50 research questions identified



2021 Autism Month webinar series

- ▶ 6 webinars
- ▶ 2,735 registrations
- ▶ 78% survey respondents likely or very likely to recommend
- ▶ 94% survey respondents rated the webinars good, very good or excellent

A strengths-based approach to research, practice and policy recognises that the lack of inclusive capacity in educational institutions, workplaces and other community settings disables the application of skills and strengths for the benefit of the individual, the economy and society more broadly. Autism CRC has been a leader in facilitating initiatives consistent with this approach and community co-production, including developing Inclusive Research Practice Guides, and establishing the Australian Autism Research Council and the Sylvia Rodger Academy, both of which continue to operate under the auspices of Autism CRC.

Co-Production Partner Initiative

Evidence demonstrates that engaging autistic individuals and their families and carers as peers in research – from the definition of need to the conduct of research and its application – promotes quality, translatable research relevant to community need. To highlight those organisations who are committed to sustainable research co-production, we established our Autism CRC Research Co-production Partner initiative in 2018, which now includes:

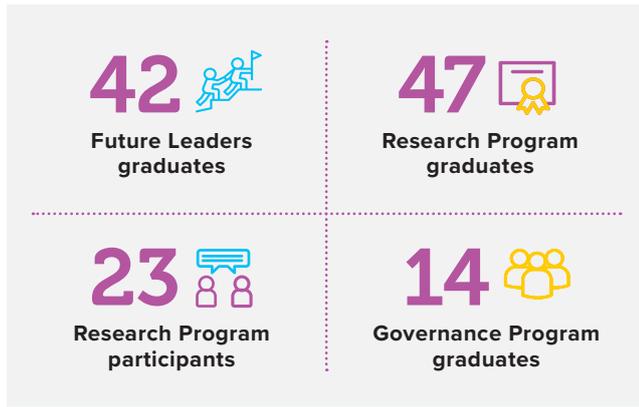
- ▶ Autism Spectrum Australia (Aspect)
- ▶ Curtin University
- ▶ Macquarie University
- ▶ University of NSW
- ▶ University of Southern Queensland
- ▶ University of Wollongong.

All Partners have demonstrated a commitment to co-production over the course of the past year. At the University of Wollongong, for example, researchers have established a community of practice to bring together like-minded autistic individuals, family members and researchers to develop research and community support that would empower autistic and neurodivergent individuals to develop and exercise self-determination in their lives. The community of practice has now become a registered association, My Life My Decisions, Inc (MLMD). Autistic individuals have been involved in all level of decision-making regarding self-determination research including determining research priorities, research methods, contributing and reviewing grant applications, and assisting with data collection.

Sylvia Rodger Academy

It was another big year for the Sylvia Rodger Academy, running each of the three established programs: Future Leaders; Research; and Governance. An initiative of Autism CRC, the Sylvia Rodger Academy delivers nationwide programs aimed at empowering autistic adults. The Academy's vision is to see autistic people thriving through discovering and using their strengths.

To date there have been 103 graduates from across Australia and overseas, with a further 23 participating in current programs, depicted below.



Australian Autism Research Council

The Australian Autism Research Council (AARC) was established to review and define national priorities for autism research and identify areas of research needed for the autistic and autism communities. It includes both autistic and non-autistic members working together and operates under the auspices of Autism CRC.

Previously, the AARC consulted with more than 1,100 members of the Australian autism community through surveys to develop community-informed priority areas. In 2020 the AARC held a series of focus groups for five Research Priority Areas (Communication, Education, Employment, Health & Wellbeing and Justice). The focus groups brought together a range of community members

(including autistic people, family members and relevant professionals) and involved a combination of online discussion groups and short surveys. The output of this process is a series of fifty research topics, ten for each of the five areas explored.

From January 2022, the AARC will be changing its name to the Australasian Autism Research Council as it expands to include members from both Australia and New Zealand.

Autism Month webinar series

Autism CRC's webinar series is held in Autism Month (April) each year to highlight the outcomes and/or progress of selected projects and initiatives. An additional webinar is dedicated to hosting autistic panellists, focusing on a topic of particular interest to an autistic audience. The webinars support the effective delivery of our current programs, projects and initiatives, focusing on translation and promoting Autism CRC as a thought leader in the national research landscape. They also serve as an important dissemination tool to our diverse end-users in the autistic and autism communities.

The 2021 Autism Month webinar series was our largest and most popular to date, with six webinars attracting 2,735 registrations. By far the most popular webinar was *Interventions for children on the autism spectrum* which sought to explain the purpose and findings of the report.

The series topics included:

- ▶ Launch of the Australian Autism Research Council 2020-21 Research Priority Update
- ▶ Writing and transitions
- ▶ Health, assessment and diagnosis
- ▶ Interventions for children on the autism spectrum
- ▶ Autism at work
- ▶ Autistic scholars panel.

Feedback from survey respondents (n=255) showed that 78% were likely or very likely to recommend the webinars to others and 94% of respondents rated the webinars good, very good or excellent.



The 2021 Autism Month webinar series was our largest and most popular to date, with six webinars attracting 2,735 registrations.

Award shines light on hidden histories

The annual **Autism CRC Awards for Achievement in Autism Spectrum Research** recognise and celebrate research and development initiatives that exemplify the Autism CRC's vision, mission and values. The awardees demonstrated high levels of engagement with autistic individuals and the autism community with projects that have the capacity to realise long-term benefits.

The co-produced project, ***The hidden histories of late-diagnosed autistic adults: An oral history study***, sought to preserve the stories of late-diagnosed adults and the lives they led before and after their diagnosis. The project team of autistic and non-autistic researchers co-designed and co-produced a study using oral history methods to investigate the life stories of 28 autistic people, aged between 45 and

72 years from diverse parts of Australia. The project was awarded the Inclusive Research Award in November 2020 in recognition of the teams' outstanding commitment to inclusive research practices.

One reviewer said, "The significance of this research is twofold: it is first worthy in and of itself in terms of representing and documenting the stories of a vastly under-represented neurominority (late-diagnosed autistic adults)...Secondly, it pioneers a participatory approach to inclusive research that lays the foundation for establishing best practice protocols to achieve authentically co-produced research to benefit the autistic community."

The project team was led by Professor Liz Pellicano from Macquarie University and Dr Wenn Lawson. The project was featured on ABC Radio National's program, All in the Mind, in 2021.

Vale Margot & Olga

... This last year saw the loss of two pioneers of autism research and philanthropy with the passing of Professor Margot Prior AO and Mrs Olga Tennison.



Professor Margot Prior AO was a true pioneer of autism research. Margot published the first Australian paper on autism in 1973, was the first female Professor of Clinical Psychology in Australia and she was heavily involved in the creation of the Australasian Society for Autism Research. The international impact of her leading research was recognised in 2018 with the International Society for Autism Research (INSAR) Lifetime Achievement Award. She passed away in August 2020.



Olga Tennison passed away in January 2021, a few months short of her 93rd birthday. Olga had a profound impact on the lives of autistic people and their families with the establishment of the Olga Tennison Autism Research Centre at La Trobe University, which would not have been possible without her significant private donations. Olga was an intelligent, impressive and inspirational woman. Olga leaves a legacy of giving and service, and long commitment to autism research.

... These inspirational women were mentors to many in our community, and both are wonderful examples of lives well-lived.



1.5 Research assets



Developed a range of valuable assets for national and international autism research

4,500

biological samples + behavioural questionnaire data stored in the Australian Autism Biobank

3,400+

Participants in longitudinal studies across the lifespan

Whole genome sequencing data generated for

1,500+ participants

Since 2013, Autism CRC has invested in and accelerated autism research in Australia, and has overseen the creation of a portfolio of research assets from a wide range of participants across Australia from early childhood through to adulthood. These assets include the Australian Autism Biobank and longitudinal studies with autistic Australian school students, school leavers and adults. These are now the most significant autism research resources in Australia. Further development of these assets, and their application in autism-related research collaborations in Australia and internationally, will continue to help guide understanding of the health and wellbeing of autistic individuals and develop new ways of making a meaningful impact in these areas.

Australian Autism Biobank

The Australian Autism Biobank contains Australia's largest collection of biological, behavioural, environmental and medical information of children on the autism spectrum and their families. Since being launched in December 2018, approved projects have requested the full range of data and samples stored within the Australian Autism Biobank.

Utilisation of the Biobank

Applications approved by the Autism CRC Access Committee, are required to return the datasets and results generated from the project to the Australian Autism Biobank for further access requests for research. Access approvals to date cover a broad range of autism research lines of enquiry, including:

- ▶ better and earlier autism diagnosis
- ▶ motor development
- ▶ sensory subtyping
- ▶ female autism phenotype
- ▶ anxiety
- ▶ gastrointestinal disorders
- ▶ sleep disorders.

Utilisation of the Australian Autism Biobank

30

Applications received

6

Requests for genomic data

26

Approved projects

6

Request for biological samples

4

Support requests for funding applications

2

Requests to recontact participants

24

Requests for phenotypic data

5

Applicant countries

Five additional datasets have been added since research projects began. The generation and return of datasets ensures that the Australian Autism Biobank will continue to grow and provide an evolving and sustainable dataset for years to come.

Whole genome sequencing

In 2020-21, Autism CRC commissioned the generation of whole genome sequencing (WGS) data for more than 1,500 participants. Initial sequencing has been carried out on DNA samples from 437 families (children on the spectrum, siblings not on the spectrum, mothers and fathers) who participated in the Australian Autism Biobank between 2014 and 2018.

The project used the expertise and innovation of Australian-based service providers party to the Commonwealth-funded National Collaborative Research Infrastructure Strategy. The bioinformatics pipeline utilised the resources of Bioplatforms Australia, with sequencing undertaken by Australian Genome Research Facility Ltd, data being securely stored at the National Computational Infrastructure and bioinformatics being carried out by the Garvan Institute of Medical Research.

To support increasing interest in the asset, and the growing number and range of datasets available for research, Autism CRC has invested in a genomic analytic platform to support access to WGS data for a range of research disciplines. The platform is due to go live later in 2021, and is supported

by an expanded web presence which includes FAQs, community information and publication outputs.

Longitudinal studies across the lifespan

The **longitudinal study of Australian students with autism (LASA)** has now collected data for six years and is one of the world's largest and longest studies following children on the spectrum over time. This unique study is exploring academic achievement and participation, having collected data from home and school as well as from some of the children/teenagers themselves.

A key area of study has been anxiety in autism, with nine research publications to date. This research has helped inform new thinking around anxiety in children on the spectrum, including identifying that:

- ▶ anxiety is impacting children on the autism spectrum as young as five years
- ▶ anxiety in autism may present more behaviourally rather than physiologically
- ▶ anxiety impacts quality of life more than autism characteristics
- ▶ almost 80% of children on the autism spectrum are impacted by anxiety at school, many of whom do not feel their anxiety is recognised by others
- ▶ difficulty with managing uncertainty may be a specific factor impacting school anxiety.



LASA data has contributed to 23 research publications to date, which have been downloaded by researchers, clinicians and others more than 2,000 times in total.

Historically, the adult years have been largely ignored in autism research, despite these years representing the greatest proportion of individuals' lives. Hence, little was known about what happens to autistic people, physically, cognitively, emotionally and socially as they pass through the lifespan. The **longitudinal study of Australian school leavers (SASLA)** focused on autistic young people in Australia, aged 15-25 years at entry, as they transitioned into adulthood, while the **Australian longitudinal study of autistic adults (ALSAA)** followed adults aged 25 years or older living in Australia over a 2.5-year period. Both have contributed substantially to international efforts to address knowledge about autism in adolescence and adulthood by bringing a focus to the experience of being an autistic adult.

Collaborations between the SASLA and ALSAA research teams have led to closely aligned study design and common data points between the two studies which has enabled rich datasets to emerge. The combination of the datasets allowed reporting of results on participants with a broad age range, from 15 to 80 years to gain a broader, whole-of-life understanding in key areas.

Data collected from these longitudinal studies were intended to support the development of approaches to improve the health and wellbeing of autistic adults. Additional specific aims were identified during data gathering which led to further research identifying changes and predictors of mental health and quality of life of autistic adults with and without intellectual disability, the description of the interval changes, and predictors of carer/support person coping strategies – all factors associated with healthy ageing for autistic adults.

The wide range of contributions arising from the ALSAA is exemplified in the numerous outputs arising or in train, including 26 peer-reviewed academic publications, more than 25 academic conference presentations and posters, and several webinars, book chapters, media outputs and policy submissions.

The SASLA survey has also yielded many important insights into the experiences of Australian young adults and their parents/carers. Autistic young people reported more bullying experiences and perceived a lack of support in education and employment settings.

The information provided by SASLA participants contributed to the critical evaluation and refinement of a range of established measures for use with autistic people.

Findings from the SASLA survey have been utilised and disseminated widely to the autism community (individuals, families, organisations, professionals) and the international research community, through 16 peer-reviewed publications with SASLA data, 55 presentations, 30 media outputs, 14 resources for end-users and six submissions to Federal and/or State Government enquiries.



2.0 Our end-users

- As a core tenet of our philosophy, Autism CRC engages with end-users at all levels to ensure that our research priorities and findings are grounded in user needs.



Our end-user environment is comprised of four major groups:



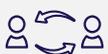
Individuals on the autism spectrum and their families and carers – the ultimate beneficiaries of our research outcomes.



Professionals who provide advice, assessment and intervention for autistic individuals (paediatricians, general practitioners, psychiatrists, community nurses, early childhood educators, teachers, psychologists, occupational therapists and speech pathologists). These professionals work across the public, not-for-profit and private sectors.



Service providers that employ professionals to provide services to individuals on the autism spectrum and their families. These include state associations and service providers; private providers; Commonwealth and state government agencies focused on education, health and disability; children's hospitals; and health service districts and practices.



Organisations providing employment and associated education and training.

During the reporting period, of the Participants engaged in our research programs, 38 were end-user organisations and 26 were Small and Medium-sized Enterprises (SMEs) – with several organisations falling under both categories. Through our engagement with these Participants, other partner organisations and our own targeted communications, our research and outputs have reached more than 90,000 professionals, family members and autistic individuals.

Over the past seven years, Autism CRC has delivered landmark national outputs and outcomes for the benefit of autistic individuals, their families and those who support them – across Australia and beyond. This has been made possible by an effective formal collaboration of all stakeholder groups needed to address the many areas of significant and unnecessary disadvantage for autistic individuals and their families with evidence-based practice and policy.

In addition to participation and co-production in our research projects, Autism CRC seeks to involve end-users in all aspects of our operations, such as governance, program advisory groups, and Autism CRC policy and program development.

To enhance the impact, utility and translation of our outputs into policy, programs and practice resources, regular communication with our end-users is maintained through eNews (almost 20,000 subscribers), targeted emails, Knowledge Centre, social media channels, our annual webinar series and regular face-to-face or virtual meetings.

Autism CRC's work with autistic individuals, parents, employment service providers, educators and hundreds of employers has produced a number of assets to support greater participation in school, post-school education, vocational training, and employment. These include:

- ▶ *The Integrated Employment Success Tool* – based on research investigating viewpoints of autistic adults and employers, developed and evaluated in a national quasi-randomised control trial with around 100 employer organisations.
- ▶ *myWAY employability* – more than 300 autistic young people, parents, allied health professionals, educators, disability service providers and employers from around Australia were involved in the co-design and development.

- ▶ Longitudinal datasets – for Australian school leavers and autistic adults, including people with higher support needs and intellectual disability.
- ▶ *inclusionED* – research and development included more than 300 schools from across Australia (public, catholic and independent), departments of education, advocacy groups, research institutions and service providers. Directly involved more than 3,000 educators, 7,000 students and 1,300 parents and carers along with allied health workers, in research co-design, user-testing and content development.

By engaging autistic individuals, parents, allied health professionals, psychologists, doctors, specialists, government, support people and service providers in development, design and testing, we have successfully produced a number of outputs that have the potential to improve the health and wellbeing outcomes of autistic people and their families. These include:

- ▶ National Guideline and Implementation Toolkit – involved Australia-wide consultation with clinicians, allied health professionals, service providers, the autistic and autism communities.
- ▶ Graduate Certificate in Autism Diagnosis – filling the training gap for diagnosticians, including psychologists, paediatricians, speech pathologists and occupational therapists.
- ▶ Autism HealthPathways – informed by extensive consultation with GPs and the autistic community.
- ▶ AAGST – development included consultation with the Australian and New Zealand Autism Self-Advocacy Network, surveys and interviews with autistic people and their family members, with the final cards' images being created by a skilled autistic illustrator.

In addition to this, Autism CRC offers capacity-building research practices through the Sylvia Rodger Academy (Research Program), upskilling autistic adults and autism researchers in research co-production. This ensures that what is being researched, and the way it is being researched is relevant to, and appropriate for, the autistic community.

3.0 Our people and structure

3.1 Structure

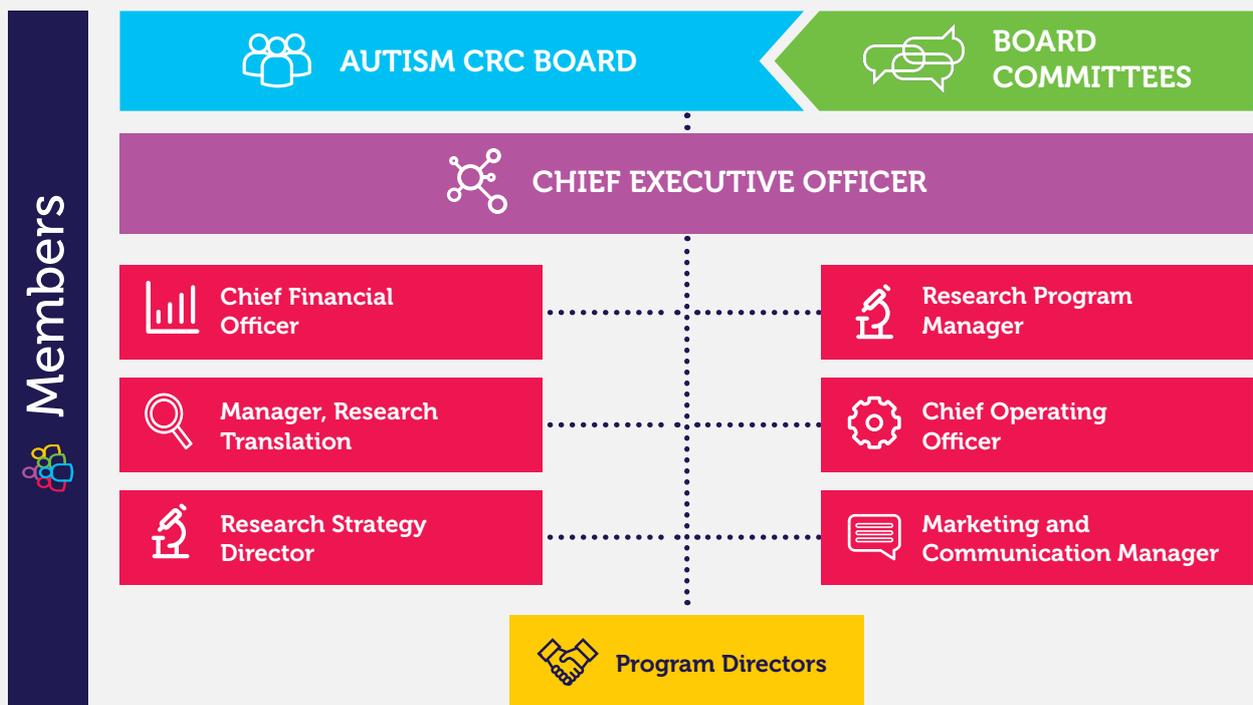
Autism CRC Ltd was established in March 2013 as a company limited by guarantee. The governance and management structure promote effective cooperation between Research and End-user Participants, ensuring translation-focused research and development.

Autism CRC ensures this by:

- ▶ involving members of the autistic community throughout the research process
- ▶ including significant industry and end-user representation on our Board and various committees, along with representatives of Research Participants
- ▶ involving end-users directly in Autism CRC research and development, enhancing project design and the applicability and uptake of outcomes
- ▶ our Program Directors engaging with end-users and in the management of Autism CRC activities.

As Autism CRC now moves towards transition from the CRC Program, the same model of collaboration and governance will be employed in its legacy operations from 1 July 2022. The member-based company, Autism CRC Ltd, will continue that successful model, working with its members and other affiliated entities, and building on the assets and platforms created through the CRC Program to deliver for the end-user community. Those interested in being a member of Autism CRC Ltd or an affiliate in its collaboration network should contact Autism CRC at eo@autismcrc.com.au.

AUTISM CRC ORGANISATIONAL CHART



3.2 Autism CRC Board



The Autism CRC Board is accountable to the Members of Autism CRC Ltd (the Company), Participants of the Cooperative Research Centre for Living with Autism, and the Australian Government for the operations and affairs of Autism CRC. The Board is responsible for decisions relating to Autism CRC strategy, our investment of funds, our research program, the translation of our research outcomes, and our overall management.

During the reporting period, the Board consisted of an Independent Chairperson, six Independent Directors, and one Nominee Director. One of the Directors has an autism diagnosis and a number of Board members are parents of children on the autism spectrum.

The Board met nine times during the reporting period, and members bring skills and experience across a range of disciplines of direct relevance to the goals and operations of Autism CRC Ltd, including:

- ▶ service provision to the autism community
- ▶ research management and disability research
- ▶ intellectual property commercialisation
- ▶ advocacy and policy development in the disability sector
- ▶ governance and management of commercial ventures, CRCs and not-for-profits.

3.3 Autism CRC Management Team

Name	Role	Organisation
Andrew Davis	Chief Executive Officer	Autism CRC
Andrew Borneman	Chief Financial Officer and Company Secretary	Autism CRC
Professor Andrew Whitehouse	Research Strategy Director	University of Western Australia
Professor Valsamma Eapen	Program 1 Director	University of New South Wales
Professor Suzanne Carrington	Program 2 Director	Queensland University of Technology
Professor Sonya Girdler	Program 3 Director	Curtin University
Cally Jackson	Marketing and Communication Manager	Autism CRC
Cheryl Mangan	Manager, Research Translation	Autism CRC
Therese Conway	Research Program Manager	Autism CRC
Wojciech Nadachowski	Chief Operating Officer	Autism CRC

4.0 Report on activities

4.1 Research and development

Our 2020-21 work program has focused largely on utilisation project activities and knowledge translation in this, our eighth year of the Commonwealth CRC funding agreement. This is evident in the number of new product, service and policy outcomes highlighted in this report.

With the ongoing commitment of our participants, the majority of our project activities have been able to progress towards completion with mild impact from the COVID-19 pandemic. However, the continuing health and economic circumstances have presented major challenges for a small number of projects, particularly where access to community settings is imperative. With support of the Commonwealth, we now enter our protracted wind-up period to June 2022, providing the opportunity to continue work towards delivery of the program objectives.

Our project work has been undertaken within the framework of Strategic, Innovation and Utilisation research projects (described below), with each investment project having at least one End-user Participant involved. We engage our end-users in the autistic and autism communities so that research is founded in end-user need and has the greatest probability for successful translation and impact for the community.

As we enter the final years of the CRC Program, the vast majority of project funds have been committed to project investments, with no new investment rounds during the reporting period. The progress of projects towards

completion, including assessment of project milestone performance, schedule, expenditure and risks, continues to be monitored by the Board, through:

- ▶ six-monthly project milestone and project cash reporting and quarterly in-kind reporting
- ▶ regular research program reporting to the Autism CRC Board on research project execution status, progress and exceptions
- ▶ ongoing engagement between Research Program Manager; Manager, Research Translation; Marketing and Communication Manager; and Program Directors.

With the major challenges created for a small number of projects by the COVID-19 pandemic and the management of the protracted wind-up period for certain CRC Program activities, the Board also closely monitored resultant variations to such projects to ensure that Commonwealth milestones might best be delivered within existing resources over the protracted term.

We are grateful for the efforts of all participants and partners in continuing to work together on our program activities in the most challenging of times.

Autism CRC invests in four types of research projects:



Commissioned projects

Commissioned by the Board of Autism CRC Ltd to meet specific Commonwealth CRC milestones, where the investment is large and feedback from the Project team occurs at Board level, rather than through the Research and Development Committee.



Innovation projects

Provide seed funding for innovation consistent with Autism CRC's overall objectives, with a maximum investment of \$50,000 and a term of one year. These projects seek creative and novel ideas that assist in meeting CRC research objectives.



Strategic projects

Relate to specific Autism CRC Milestones and must involve at least two, preferably more, CRC Participants, including end-users.



Utilisation projects

Provide funding for translation and utilisation of existing Autism CRC research outputs for impact as either products and services that may be embedded into practice, or further disseminated to inform policy and practice.



Program 1 – A better start through better diagnosis

Program 1 focuses on improving the validity, precision, timeliness and reliability associated with the diagnosis of autism and targeted pathways to early intervention.

Program goals

To use existing knowledge of the early behaviours associated with autism to:

- ▶ facilitate the accurate diagnosis of 50 per cent of children on the autism spectrum prior to their second birthday, and more than 70 per cent by their third birthday by developing tools and improving training.

To integrate biological, behavioural and clinical research and observations to:

- ▶ identify subtypes of autism
- ▶ improve understanding of the most efficient interventions that match these subtype profiles.

The Early Years Program has invested in 19 CRC projects, with 17 having been completed. The final two projects are due to be completed in late 2021.

2020-21 snapshot

- ▶ **Evaluation of New Zealand's diagnostic process** involved 640 participants and identified discrepancies between diagnostic pathway and supports between children and adults. Clinicians indicated good awareness of NZ's diagnostic guideline but implementation lacked consistency.
- ▶ **Therapy for infants showing early signs of autism** investigated the effectiveness of a pre-emptive therapy for young infants showing early signs of autism in a real-world health-care referral setting. Caregivers of toddlers who received the six months of early iBASIS-VIPP therapy reported that their child understood an average of 37 more words, and spoke an average of 15 more words, than those who received usual services.
- ▶ **Australian Autism Biobank** added whole genome sequencing (WGS) data of 1,500 participants to its repository in 2021. An expanded web presence for researchers and the community was also developed, along with a genomic analytic platform to support access to WGS data for a range of research disciplines.
- ▶ **Sensory subtypes in children on the autism spectrum** built on prior research using two large Autism CRC datasets. The project identified

homogeneous subgroups with the aim of informing early support needs to optimise life outcomes based on the sensory profile of children. It found irrespective of their overall sensory profile, all children recorded difficulties with noise (ie: "Is distracted when there is lot of noise around"). The study also found a subtype characterised predominantly by emotional regulation and attentional difficulties.

Program 1 has supported five Postdoctoral Fellows in addition to eight PhD students. The final two scholars will complete their studies in the next 12 months.

In addition to CRC-funded projects, Autism CRC has also undertaken several commissioned projects in the area of assessment and diagnosis, and early intervention. Highlights from this reporting period include:

- ▶ **Synthesis of evidence for autism early intervention**
This landmark report summarised evidence regarding the characteristics (underlying theoretical principles, key elements) and outcomes (overall efficacy, characteristics of efficacy, adverse effects) of the range of autism early intervention approaches. The report has been downloaded 16,200 times. This project was funded by the NDIA.
- ▶ **National Guideline Implementation Toolkit**
This DSS-funded project developed a suite of online resources to help clinicians implement and understand the National Guideline for the Assessment and Diagnosis of Autism. The toolkit was launched in December 2020.
- ▶ **Autism subtyping project**
This project analysed data from 760 children attending six Autism Specific Early Learning and Care Centres (ASELCCs). This project was co-funded by DSS. The study found that the children showed overall improvements in receptive language, communication skills, play, and gross motor skills.



Professor Valsamma Eapen

Program Director

MBBS, DPM, DFT, PhD, FRCPsych, FRANZCP

Output 1.1

A behavioural surveillance tool to enable correct diagnosis of at least 50 per cent of children with Autism Spectrum Disorder (ASD) before two years and at least 70 per cent by three years.

Research and development

- ▶ Evaluation of Social, Attention and Communication Scale (SACS-R)*
- ▶ Multi-state GP trial of developmental surveillance
- ▶ Development and evaluation of post-diagnosis family support package (FSP)

Outputs and outcomes

- ▶ SACS-R trial of 42,000+ children confirms need for universal surveillance of children aged 12-24 months. Roll-out in Victoria with 1,000 community health nurses trained.
- ▶ Interview data collected in GP trial of developmental surveillance has useful implications for future research and implementation of National Guideline.
- ▶ Pathways Beyond Diagnosis family support website developed and trialled. Seeking opportunities for utilisation in Australia and New Zealand.

**The Social, Attention and Communication Surveillance-Revised (SACS-R) tool is used by community-based, primary care professionals to identify children in need of further assessment for autism during their early years. The tool was developed by researchers at Olga Tennison Autism Research Centre (OTARC) at La Trobe University.*



Output 1.2

Integrated diagnostic protocol (IDPA) and ASD software analysis tool to enable better diagnosis of ASD and prediction of developing ASD.

Research and development

- ▶ Systems genomics
- ▶ Very early intervention for children pre-diagnosis with early signs of autism
- ▶ Diagnostic practices in Australia and New Zealand
- ▶ Development of national assessment and diagnostic protocol for Australia
- ▶ Establishment of Australian Autism Biobank
- ▶ Australian Autism Biobank follow-up pilot cohort study
- ▶ Defining an immune-mediated subgroup

Outputs and outcomes

- ▶ Systems genomics study finds limited evidence of direct relationships between autism and the stool microbiome. These findings are contrary to suggested causal links between autism and the gut microbiome and have widespread implications for managing nutrition in autistic people.
- ▶ Full-scale trial of targeted pre-emptive iBASIS-VIPP therapy, pre-diagnosis, for children aged under 18 months and showing early signs of autism. At two years of age, caregivers reported that their child had improved communication and language skills, compared to caregivers of infants accessing usual services. Review at three years of age being conducted. Positive implications for early diagnosis and better life outcomes for children.
- ▶ Autism NZ made recommendations to NZ Government to address identified service gaps and needs as a result of study evaluating New Zealand's diagnostic process.
- ▶ Australia's National Guideline for Assessment and Diagnosis of Autism has been downloaded 59,000 times and has 24,500 registered users. Implementation Toolkit, developed to support clinical adherence and uptake, includes fact sheets, videos, audit tool, templates and training information.
- ▶ Australian Autism Biobank established and functioning. Five additional datasets added since research project began with more in the pipeline and 26 approved projects to date.
- ▶ Using data from 240 Australian Autism Biobank participants to develop an understanding of the biological and immunological mechanisms underpinning autism with a view to providing earlier and more accurate diagnosis and supports.

Output 1.3

Identification of biological subtypes of ASD.

The ability to identify and validate accurate subtypes of autism will expedite decision-making around early intervention strategies to improve long-term outcomes for children on the autism spectrum.

Research and development

- ▶ Subtyping research with neurocognitive data from pre-school children in ASELCCs around Australia
- ▶ Integration of phenotypic and biological data to identify subtypes

Outputs and outcomes

- ▶ Detailed phenotypic and intervention data from 760 children across six ASELCCs showed overall improvements across a range of areas, confirming the benefits of early intervention. Further, parents of younger children and those who were more dysregulated tended to report more stress and poorer quality of life. This latter finding underscores the importance of parental support for children with high behavioural support needs as part of a comprehensive approach for the child and family.
- ▶ Findings from sensory subtyping project, which capitalises on use of phenotypic data and biological outputs from analysis of Australian Autism Biobank, suggests there may be sensory profiles that extend across neurodevelopmental conditions.

Output 1.4

Implementation of a Graduate Certificate for Autism Diagnosticians. Education of 12 PhDs, five postdoctoral fellows and generation of 72 scholarly publications.

Research and development

- ▶ Development and evaluation of Graduate Certificate in Autism Diagnosis
- ▶ PhD topics have covered research in developmental surveillance, therapy for infants showing early signs of autism, genomics and using the Australian Autism Biobank

Outputs and outcomes

- ▶ Online course resource and content aiding implementation of National Guideline. Scaled roll-out to other universities and education providers in negotiation.
- ▶ More than 60 autism diagnosticians graduated since the course started in 2015, and a further 24 enrolled in 2021 course.
- ▶ Eight PhD students (two active, six complete).
- ▶ Five Postdoctoral Fellows.
- ▶ Published a further 13 journal articles and posters and one book chapter. Also developed 24 resources and delivered nine conference presentations during the reporting period.

Program 1 projects

Resulting from all Investment Rounds approved by the Board.

Project	Short title	Year	Lead Participant institution	Project funds	In-kind value
Strategic:					
1.001RC*	Program 1 base resources #	2013	UWA / LTU / UNSW / MMRI	\$2,057,500	\$4,095,500
1.002RC*	Creation of Australian Autism Biobank	2013	UWA	\$1,139,527	\$2,195,257
1.004RC*	Graduate Certificate	2013	UWA	\$120,000	\$556,458
1.005RC	Developmental Surveillance SACS-R	2013	LTU	\$419,106	\$2,644,721
1.021RS*	Diagnostic practices and reliability in Australia	2014	UWA	\$47,889	\$490,600
1.022RS*	Family Support Program	2014	LTU	\$54,141	\$172,935
1.023RS	Autism subtyping	2014	UNSW	\$1,226,130	\$6,161,202
1.042RC	System genomics	2015	UQ	\$1,706,736	\$3,009,145
1.043RS*	Therapy for infants showing early signs of autism	2015	LTU	\$125,000	\$2,522,554
1.059RS*	Australian Autism Biobank pilot project	2018	UNSW	\$57,856	\$37,500
1.064RS*	A multistate trial of an early surveillance program for autism within General Practices in Australia	2019	UNSW / LTU	\$843,300	\$3,849,650
Total Program 1 Strategic				\$7,797,185	\$25,735,522
Innovation:					
1.019RI*	ASD post mortem brain	2014	UNSW	\$50,000	\$383,000
1.020RI*	BrainsTorm study	2014	MMRI	\$40,150	\$174,000
1.033RI*	Brain connectivity	2015	UQ	\$49,990	\$129,641
1.065RI*	Brain connectivity in autistic adults at clinical imaging strengths	2019	UQ	\$17,680	\$95,822
Total Program 1 Innovation				\$157,820	\$782,463
Utilisation:					
1.058RU*	Diagnostic Inconsistencies in New Zealand	2018	Autism NZ	\$58,000	\$366,000
1.073RU	Inflammation and neuromodulation in autism	2019	UNSW	\$44,214	\$234,000
1.074RU*	Sleep difficulties in children with Autism	2019	UNSW	\$49,991	\$178,500
1.075RU*	Sensory subtypes	2019	UNSW	\$50,000	\$310,600
Total Program 1 Utilisation				\$202,205	\$1,089,100
Total Program 1 projects				\$8,157,210	\$27,607,085

*Project Completed, # Base resources refers to postdoctoral fellows, research assistants in sites who are working together on projects 1.002RC & 1.005RC.



Program 2 – Enhancing learning and teaching

Research in Program 2 is enabling educators, therapists, carers, families and the general community to effectively respond to the diverse learning needs of students on the autism spectrum.

Program goals

Identifying appropriate educational environments, programs and support strategies to:

- ▶ optimise students' social, behavioural and academic development
- ▶ equip teachers to enhance performance and manage complex behaviours.

Program 2 researchers have developed and tested evidence-based teaching strategies, techniques, tools and programs in inclusive classrooms to optimise the learning and educational environments for students on the spectrum.

Program 2, School Years, has invested in 24 projects, with two due to finish later in 2021.

2020-21 snapshot

- ▶ **inclusionED** continues to expand in content and reach with the site adding a further 14 teaching practices in the last year, and registered users now exceeding 2,760.
- ▶ **StepWrite** iPad app was released in May 2021 to help children, including those on the autism spectrum, harness their writing potential. The co-designed app helps children improve their writing and addresses many of the challenges associated with fine motor and perceptual skills required for handwriting. It also helps with conceptual and language skills required for written composition.
- ▶ **Published two 'sister' books through Routledge** on evidence-based and research-informed approaches and practices to inclusive education. Each is designed to support the work of teachers and specialists in inclusive educational environments. Official book launch in July 2021.
- ▶ **Research Approaches to Supporting Students on the Autism Spectrum in Inclusive Schools**, will support researchers in the field of education disability research by outlining inclusive research approaches and their challenges, outcomes, and impact.

- ▶ **Supporting Students on the Autism Spectrum in Inclusive Schools**, will transform the capacity of teachers and specialists working with students and families to effectively support an inclusive approach to education for students on the autism spectrum.
- ▶ **Longitudinal study of Australian students with autism (LASA)** has now collected data for six years and is one of the world's largest and longest studies following children on the spectrum over time. This unique study is exploring academic achievement and participation in children on the autism spectrum over time. It includes data from home and school as well as from some of the children/teenagers themselves.
- ▶ **Scholars** - In addition to three Postdoctoral Fellows, Program 2 successfully produced six PhDs, 14 Masters and three Honours scholars. One active PhD scholar (studying part-time) is due to complete their studies by mid-2023.



Professor Suzanne Carrington

Program Director
DipTeach, BEd, MEd, PhD

Output 2.1

2.1 Evidence-based programs to optimise the learning environment ensuring successful social, behavioural and academic outcomes for students on the autism spectrum.

U2.1 Utilisation of programs and training resources by educational and health professional end-users.

Autism CRC's research and development in the education program has involved work in 300+ schools across Australia. The Classrooms of Excellence Program (CoEP), involved 36 primary schools, 10 secondary schools and a total of 350 students.

Research and development

- ▶ 20 research projects to develop and trial programs and practices in inclusive classrooms all over Australia spanning: school connectedness and collaborative partnerships in action – enacting educational change, structured teaching, assistive technology for writing, robotic pedagogy, classroom acoustics, and classroom models of practice.

Outputs and outcomes

- ▶ More than 40 teaching practices in *inclusionED*, including 72 *inclusionED* videos and nine core research projects. Site has reached 24,500+ people, with 2,760+ registering to join the Community of Practice. Almost one third of registered community members are from regional Australia.
- ▶ *StepWrite* assistive writing app has reached 135 sales. Students report improvements in planning, setting goals, self-monitoring and evaluating. Teachers noted student improvements in writing after four weeks of app use and increased willingness to perform writing tasks.
- ▶ Support under the Positive Partnerships Collaborative Agreement has seen six projects extend delivery to schools in Aboriginal and Torres Strait Islander, culturally and linguistically diverse (CALD) and remote communities.



Dr Keely Harper-Hill training teachers at Baringa State School on the use of *inclusionED*

Output 2.2

Evidence-based tools and protocols for supporting students on the autism spectrum with high impact social, emotional and behavioural needs.

Research and development under this output has been conducted via the following projects: Early Years Behavioural Support Project (EYBSP), School Connectedness Project, Autism Anxiety and School Functioning, SAS-WOC, Classroom Acoustics, Transitioning Between Tasks, Emergent Literacy, Literacy Predictors, Shared Book Reading Interventions and Transition MoP.

Research and development

- ▶ Early and Middle Years behaviour support programs
- ▶ Multi-level school connectedness program - research trial
- ▶ Secret Agent Society (SAS) social-emotional wellbeing intervention: whole-of-class evaluation

Outputs and outcomes

- ▶ Development and evaluation of a tele-classroom consultation approach to supporting students on the spectrum involving five rural and remote schools.
- ▶ Autism Teen Wellbeing website to support school connectedness has attracted 9,200+ unique visitors and 34,000 page views to date.
- ▶ Tools and protocols developed for behavioural support using tele-classroom consultation approaches.
- ▶ Secret Agent Society – whole-of-class evaluation completed. Small Group Program fully digitised as an integrated software package and launched early in 2021. SAS Program has been delivered to 22,000+ families internationally.

Output 2.3

Three training packages to increase skilled, confident teachers and support personnel capable of educating a spectrum of autistic students. An online portal associated with the Autism Connect Hub will be a repository for training materials and resources developed from Program 2 research for a wide range of end-users.

Research and development

- ▶ National survey of almost 1,500 educators, parents and students on the educational needs of students on the spectrum
- ▶ Co-design, development and evaluation of *inclusionED*, involving 200+ educators, parents and professionals and Knowledge Translation toolkit

Outputs and outcomes

- ▶ Australia's first educational needs analysis for students on the spectrum.
- ▶ *inclusionED* launched (see 2.1 for more detail).
- ▶ Worked with national education provider/s AITSL, Social Ventures Australia Evidence for Learning, and Positive Partnerships to promote *inclusionED* and where appropriate create reciprocal pathways between *inclusionED* and other educator-focused online services.
- ▶ Design and prototype validation of Relate-ABLE online platform to connect parents and speech pathology professionals for minimally verbal children.

Output 2.4

Validation of autism subtypes (Output 1.3) and their predictive value for long-term outcomes for children on the spectrum through a longitudinal study.

Through the Longitudinal Study of Australian Students with Autism (LASA), the experiences and outcomes of two cohorts of students (four to five years and nine to ten years), have been followed up annually for six years.

Research and development

- ▶ LASA involving 1,300 participants completed the following total number of surveys:
 - 1,214 parent (AVG 202 each year for six years)
 - 320 child (AVG 80 each year for four years)
 - 204 principal (AVG 68 each year for three years)
 - 529 teacher (AVG 88 each year for six years)
 - 23 early childhood (one year).

Outputs and outcomes

- ▶ To date 24 research publications using LASA data have been downloaded by researchers, clinicians and others more than 2,000 times in total.
- ▶ Areas investigated include anxiety in children, positive attributes and favourite activities, participation across home, school, and community, how teachers support their students on the autism spectrum, associations between autism characteristics and written and social communications, and early predictors of family outcomes with early intervention.

Output 2.5

Train 18 PhD students, employ six postdoctoral fellows and generate 60 scholarly publications.

Research and development

- ▶ PhD study areas have included Models of Practice, early years behavioural support, trajectory study (LASA), overcoming difficulties in written expression, and helping students stay on task.

Outputs and outcomes

- ▶ Twenty-four scholars:
 - seven PhDs (one active, six completed)
 - fourteen Masters (14 completed)
 - three Honours (three completed).
- ▶ Three Postdoctoral Fellows.
- ▶ Published a further 17 journal articles and posters, two books, 19 books chapters and delivered five conference presentations during the reporting period.

Program 2 projects

Resulting from all Investment Rounds approved by the Board.

Project	Short title	Year	Lead Participant institution	Project funds	In-kind value
Strategic:					
2.006RC*	Program 2 base resources #	2013	QUT	\$902,500	\$1,694,000
2.007RC*	Longitudinal Study of Australian Students with Autism (LASA)	2013	GU	\$1,049,040	\$5,182,411
2.008RC*	Secret Agent Society Classroom	2013	UQ	\$149,924	\$1,378,143
2.009RC*	Educational Needs Analysis	2013	QUT	\$40,000	\$295,000
2.010RC*	Overcoming difficulties in written expression	2013	AQ	\$176,684	\$1,485,866
2.011RC*	Helping students stay on task and move between tasks	2013	AQ	\$164,684	\$1,570,866
2.027RS*	Early Years Behaviour Support	2014	QUT	\$522,758	\$2,396,941
2.028RS*	Improving classroom acoustics	2014	AQ	\$273,000	\$1,319,900
2.029RS*	School connectedness	2014	QUT	\$504,384	\$2,077,500
2.037RS*	Primary school transition MoP	2015	Aspect	\$554,170	\$1,906,685
2.057RS	Middle Years Behaviour Support Program	2018	QUT	\$484,100	\$1,304,400
Total Program 2 Strategic				\$4,821,244	\$20,611,712
Innovation:					
2.024RI*	Emergent literacy	2014	GU	\$49,746	\$108,282
2.025RI*	ASD, anxiety and school functioning	2014	UWA	\$49,920	\$293,685
2.026RI*	Robotics social clubs in mainstream schools	2014	BCE	\$48,880	\$350,000
2.034RI*	Shared book reading intervention	2015	GU	\$49,900	\$194,160
2.035RI*	Literacy predictors	2015	GU	\$50,000	\$117,300
2.036RI	How was your Day?	2015	UMelb	\$49,986	\$151,804
2.060RI	Evaluating the effects of humanoid robots on narrative role-taking abilities of children	2018	QUT/QED	\$50,000	\$231,900
Total Program 2 Innovation				\$348,432	\$1,447,131
Utilisation:					
2.045RU*	Living portal	2016	QUT	\$60,000	\$451,500
2.052RU*	StoryTime	2017	GU	\$77,250	\$286,300
2.053RU*	Assistive writing program	2017	AQ	\$52,420	\$98,000
2.063RU*	Diverse Learners Hub: Education knowledge translation project Stage 2	2019	QUT	\$50,340	\$259,268
2.066RU*	Collaborative Partnerships in Action – Proactively enacting educational change	2019	QUT	\$48,400	\$217,970
2.067RU	An educator's guide to <i>myWAY Employability</i> : Enabling support with transition-planning for students on the spectrum	2019	QUT/Curtin	\$57,100	\$231,915
Total Program 2 Utilisation				\$345,510	\$1,544,953
Total Program 2 projects				\$5,515,186	\$23,603,796

*Project Completed, # Base resources refers to the Research Associate who is working across all Program 2 projects.



Program 3 – Finding a place in society

Program 3 focuses on the transition from school to further education, employment, and health and wellbeing in adult life, with the goal of assisting autistic people to find a valued place in society.

Program goals

- ▶ To directly facilitate paths towards fulfilling lives for people on the autism spectrum after school.
- ▶ To inform government policy regarding employment, education, and health.
- ▶ To gather information on profiles of Australian adolescents and adults on the autism spectrum through two longitudinal studies.
- ▶ To support employment opportunities for autistic adults.

The Adulthood Program has invested in 22 projects, with the final two projects due to finish in late 2021.

2020-21 snapshot

- ▶ **MyWAY Employability** was launched in Aug 2021 by Jackie Coates, Head of Telstra Foundation. The smart web application is based on six years of research, trials and evaluation related to transition planning for autistic young people. More than 300 autistic young people, parents, allied health professionals, educators, disability service providers and employers from around Australia were involved in the co-design and development.
- ▶ **Autism HealthPathways** are now available for adoption and adaptation in 43 health regions, caring for more than 28 million people across Australia, New Zealand and the United Kingdom. A licensing agreement with Streamliners NZ is allowing GPs and health professionals to access up-to-date information and creating the first steps towards a complete health pathway specifically for autistic people.

- ▶ **The Integrated Employment Success Tool (IEST)** was released in June 2021. Developed specifically for employers, the practical workplace manual is based on research that explored the key factors for successful employment from the viewpoints of both autistic adults and employers.
- ▶ **Quality of Life** study delivered an online Photovoice Gallery event in November 2020. This unique research output offers an insight into what affects quality of life for autistic adults, told from their own perspective, through photography and spoken word.
- ▶ **Autism@Work** research study released in March 2021. The large-scale, global quantitative study provides the opportunity to develop evidence-based conclusions that go beyond single cases and compare different employer types and locations.
- ▶ **Program 3 scholars** include six Postdoctoral Fellows and eight active PhD scholars. A further nine PhDs, one Masters and 13 Honours scholars have completed their studies.



Professor Sonya Girdler

Program Director
PhD, MSc (Occupational Therapy), BSc
(Occupational Therapy)

Output 3.1

3.1 Comprehensive and unique profile of Australian autistic adults, through two longitudinal studies, to provide them with the capacity to find a meaningful place in society.

U3.1 Utilisation of resources from Autism Connect Hub (now titled Knowledge Centre).

Longitudinal studies of students and adults on the autism spectrum aim to better understand post-school outcomes, quality of life, mental and physical health, employment, social inclusion, ageing and overall wellbeing.

Research and development

- ▶ Two large scale longitudinal studies involving autistic adults and adolescents (including those with intellectual disability), parents/carers & non-autistic participants (controls).
- ▶ ALSAA – 877 participants, 1,184 unique observations across the two time points.
- ▶ SASLA – 477 participants across two time points.
- ▶ Study using big data to better understand health and wellbeing
- ▶ Investigating autistic burnout

Outputs and outcomes

- ▶ ALSAA and SASLA studies have produced 110+ publications, conference presentations, posters and resources, along with 30 media outputs, all freely available via Knowledge Centre. A further nine publications are under review and at least 38 are in development.
- ▶ SASLA has now produced a baseline data snapshot (2018), longitudinal profile snapshot (2019), parent/carer profile snapshot (2019) and a suite of mental health resources for adults and health professionals (2021).
- ▶ Co-produced study involving autistic and non-autistic researchers, aiming to understand autistic experiences of burnout and to develop a working definition. Initial study being followed up using ALSAA data gathering to explore risk factors.

Output 3.2

3.2 Conducting empirically-based interventions for autistic adults to assist them to confidently engage in social relationships, tertiary education, employment and community activities.

U3.2 Utilisation of tools and resources by end-users.

Enhancing social relationships of autistic adults is supported through a unique package of projects.

Research and development

- ▶ Co-design, development and evaluation of Adult/Adolescent Goal Setting Tool (AAGST).
- ▶ Design, development and evaluation of Peer Mentoring and MindChip™ program for autistic university students.
- ▶ Design, development and evaluation Public Transport app and Driving program.

Outputs and outcomes

- ▶ AAGST sold 250+ copies. Licence agreement in place with Autism Queensland since 2018, with a reprint planned in 2021 and exploratory work on a digital version.
- ▶ Peer mentoring program resources and modules accessible via Autism CRC knowledge Centre.
- ▶ Fifty-six mentees and 46 mentors at Curtin University.
- ▶ MindChip™ social-emotional skills-based program developed and trialled.
- ▶ DriverReady program and OrienTrip public transport app for research purposes (400 downloads/700 sessions).

Output 3.3

3.3 Tools, strategies and techniques developed to improve health and wellbeing for autistic adults.

U3.3 Use of longitudinal data (from Output 3.1).

Research and development

- ▶ Co-design and development of Autism HealthPathways.
- ▶ Autism content added to GP independent learning program CHECK.
- ▶ Development and trial of autism specific Quality of Life (QoL) assessment tool.
- ▶ Research and development of Autism Comprehensive Health Assessment Protocol (CHAP).

Outputs and outcomes

- ▶ Autism HealthPathways for GPs and health professionals developed nine new pathways in consultation with health professionals. Nine health regions adopted or adapted (or in process of) to date. Pathways accessed 2,600 times to date.
- ▶ GP resources and professional development modules logged 5,020 completions by GPs all over Australia.
- ▶ Developed the first co-produced autistic quality of life tool, for autistic adults and clinicians to help determine if health interventions are improving quality of life. Photovoice gallery event attracted 118 registrations and the recording has been viewed 400+ times on YouTube.
- ▶ Research version of Autism CHAP developed with input from autistic adults, their caregivers and GPs.

Output 3.4

Developing tools to assist autistic adolescents/adults and their advisors in making informed choices regarding higher education and employment and ultimately creating more opportunities for autistic people to gain successful long-term employment.

Research and development

- ▶ Better Outcomes and Successful Transitions for Autism (BOOST-A) research and program evaluation.
- ▶ BOOST-A training development and evaluation involving 80+ educators, parents and professionals.
- ▶ Co-design and development of *myWAY Employability* engaging 300+ young people, parents and professionals.
- ▶ Development and evaluation of Integrated Employment Success Tool (IEST).
- ▶ Establishment of Autism@Work Australia in partnership with industry.

Outputs and outcomes

- ▶ BOOST-A quasi-randomised control trial involving 96 adolescents, parents and professionals.
- ▶ Transition and career planning training and educator resources accessible via *inclusionED*.
- ▶ *myWAY Employability* built on finding from BOOST-A research. 1,110 registered users since launch in August 2020. Three supporter training sessions attracted 160 attendees. Secured next stage funding from Telstra Foundation Tech for Good.
- ▶ IEST trialled with 100+ employers in Australia, released in 2021. More than 250 registered users.
- ▶ Autism@Work events have attracted 500+ attendees from a diverse range of industries. Organisation has begun for a virtual event for August 2021.
- ▶ Autism@Work research project involved 169 autistic employees, co-workers and supervisors of autistic employees as well as human resource directors and executives from 33 for-profit, non-profit and social enterprise organisations across 12 countries, providing new insights on effective autism employment practices.

Output 3.5

Development of the web portal 'Connect Hub'.

Research and development

- ▶ Two separate entities have been established and are in use.

Outputs and outcomes

- ▶ Connect Hub is an authenticated collaboration space and provides open thematic and closed project groups for collaboration; progress reporting by project leaders; resources and wiki-styled help articles; and a facility for project teams to upload key dissemination activity.
- ▶ Knowledge Centre is hosted on the corporate website and facilitates public access to 315+ resources, publications and reports. There have been 88,000 downloads of items from Knowledge Centre.

Output 3.6

This output will train 12 PhD students, employ six postdoctoral fellows and generate 60 scholarly and additional lay publications.

Research and development

- ▶ PhD areas of study completed in the reporting period included enhancing the social relationships of young adults, and community mobility.

Outputs and outcomes

- ▶ Thirty-one scholars have been involved in Program 3:
 - seventeen PhDs (eight active, nine complete)
 - one Masters (one complete)
 - thirteen Honours (13 complete).
- ▶ Six Postdoctoral Fellows.
- ▶ 136 published journal publications and posters (34 during the reporting period) and developed 10 resources. A further 20 conference presentations were delivered in this reporting period.

Program 3 projects

Resulting from all Investment Rounds approved by the Board.

Project	Short title	Year	Lead Participant institution	Project funds	In-kind value
Strategic:					
3.012RC*	Program 3 base resources #	2013	Curtin / LTU / UQ / UNSW	\$3,520,000	\$4,453,012
3.013RC	Australian Longitudinal Study of Autistic Adults (ALSAA)	2013	UNSW	\$370,324	\$1,835,676
3.014RC*	EVAP and IEST	2013	Curtin	\$254,765	\$3,807,035
3.015RC*	Health and wellbeing for adults	2013	UQ	\$292,096	\$1,801,051
3.016RC*	Longitudinal Study of Australian School Leavers with Autism (SASLA)	2013	LTU	\$325,836	\$2,358,764
3.017RC*	Optimisation of recruitment	2013	Aspect	\$97,023	\$332,305
3.032RS*	Enhancing social relationships of young adults	2014	Curtin	\$416,000	\$2,146,104
3.040RS*	Driving project	2015	Curtin	\$568,891	\$3,298,879
3.041RS*	Public transportation mobility	2015	Curtin	\$329,546	\$1,436,599
Total Program 3 Strategic				\$6,174,481	\$21,469,425
Innovation:					
3.030RI*	Studio G: Multimedia Program for young adults	2014	AQ	\$50,000	\$153,800
3.031RI*	Career pathway recommender system	2014	Curtin	\$48,000	\$149,212
3.038RI*	Big data, important questions, health & wellbeing	2015	UNSW	\$50,000	\$179,481
3.039RI*	Supporting staff and students with HFA in STEM programs	2015	QUT	\$50,000	\$210,239
3.046RI*	HealthPathways Autism Initiative	2016	UQ	\$50,000	\$215,640
3.047RI*	Goal-setting tool for adolescents and adults	2016	AQ	\$49,885	\$315,332
3.054RI*	Autism@Work	2017	Macquarie	\$100,000	\$279,533
3.062RI*	'Hear' to help	2018	Curtin	\$63,000	\$394,120
3.068RI	Development of an autism specific quality of life assessment for use with autistic adults	2019	Curtin	\$50,000	\$204,050
3.076RI*	Autistic burnout	2019	UNSW	\$37,880	\$78,605
Total Program 3 Innovation				\$548,765	\$2,180,012
Utilisation:					
3.048RU*	BOOST-A From research to practice	2016	Curtin	\$51,500	\$131,160
3.049RU*	Utilising Autism CRC Health Hub tools and resources	2016	UQ	\$50,000	\$96,780
3.061RU*	Development of an Assessment of Functioning Tool Based on ICF Core Sets	2018	Curtin	\$50,000	\$390,000
Total Program 3 Utilisation				\$151,500	\$617,940
Total Program 3 projects				\$6,874,746	\$24,267,377

*Project completed, # Base resources refers to postdoctoral fellows in each of four sites who are working together on projects 3.013, 3.014, 3.015, 3.016RC + Education and Vocational Assessment Protocol (EVAP) and Integrated Employment Success Tool.

4.2 Research collaboration

Collaboration between Research Participants and End-user Participants is an essential element of our work. Autism CRC requires that each project funded involves at least one End-user/Industry Participant, the only exception being base resources (personnel only) funding projects – with those personnel then engaged across a number of projects involving end-users.

Autism CRC has built on this principle to further promote and facilitate co-production practices, including the development

of Inclusive Research Practice Guides and the establishment of the Sylvia Rodger Academy.

The following table provides a breakdown of collaborations between Research Participants and End-user/Industry Participants on all Autism CRC projects between 2013-2021 (including completed projects). This includes collaborations between parties to Autism CRC Project Agreements, Memoranda of Understanding and Third Party Agreements.

All Investment Rounds to-date

Project numbers	Project name	Research Participants	End-user / Industry participants	Total
1.001RC	Program 1 base resources	4	1	5
1.002RC	Creation of Australian Autism Biobank	5	9	14
1.003RC	Genetic screening of autism (Phase 1)	3	3	6
1.004RC	Graduate Certificate	3	6	9
1.005RC	Developmental Surveillance SACS-R	4	3	7
1.019RI	Post mortem brain	2	0	2
1.020RI	BrainsTorm study	2	0	2
1.021RS	Diagnostic practices and reliability in Australia	2	6	8
1.022RS	Family Support Program	3	5	8
1.023RS	Autism subtyping	6	10	16
1.033RI	Brain connectivity	2	2	4
1.042RC	System genomics	1	0	1
1.043RS	Therapy for infants showing early signs of autism	4	1	5
1.058RU	Diagnostic inconsistencies in New Zealand	5	2	7
1.059RS	Australian Autism Biobank pilot project	1	0	1
1.064RS	A multistate trial of an early surveillance program for autism within General Practices in Australia	6	3	9
1.065RI	Brain connectivity in autistic adults at clinical imaging strengths	1	0	1
1.073RU	Inflammation and neuromodulation in autism	2	2	4
1.074RU	Sleep difficulties in children with autism	3	1	4
1.075RU	Sensory subtypes	4	2	6
2.006RC	Program 2 base resources	1	N/A	1
2.007RC	Longitudinal Study of Australian Students with Autism (LASA)	5	6	11
2.008RC	Secret Agent Society Classroom	2	14	16
2.008RC_PP	Secret Agent Society - Whole of Classroom – Positive Partnerships	2	7	9
2.009RC	Educational Needs Analysis	4	11	15
2.010RC	Overcoming difficulties in written expression	2	5	7
2.011RC	Helping students stay on task and move between tasks	3	5	8
2.011RC_PP	Helping students stay on task and move between tasks – Positive Partnerships	0	2	2
2.024RI	Emergent literacy	1	3	4
2.025RI	Anxiety and school functioning	2	1	3
2.026RI	Robotics social clubs in mainstream schools	1	1	2

Project numbers	Project name	Research participants	End-user / Industry participants	Total
2.027RS	Early Years Behaviour Support	3	8	11
2.027RS_PP	Early Years Behaviour Support – Positive Partnerships	1	3	4
2.028RS	Improving classroom acoustics	1	5	6
2.029RS	School participants	2	12	14
2.029RS_PP	School connectedness – Positive Partnerships	1	2	3
2.034RI	Shared book reading intervention	1	1	2
2.035RI	Literacy predictors	1	1	2
2.036RI	How was your day?	4	1	5
2.037RS	Primary school transition MoP	2	13	15
2.037RS_PP	Primary school transition MoP – Positive Partnerships	2	13	15
2.045RU	Living portal	2	6	8
2.051RS_PP	Aboriginal and Torres Strait Islander Community Liaison	1	0	1
2.052RU	Storytime	1	2	3
2.053RU	Assistive writing Program	1	1	2
2.057RS	Middle Years Behaviour Support	1	3	4
2.060RI	Evaluating the effects of humanoid robots on the narrative role-taking abilities of children	2	1	3
2.063RU	Diverse Learners Hub: Education knowledge translation project Stage 2	2	2	4
2.066RU	Collaborative Partnerships in Action – Proactively enacting educational change loading	2	2	4
2.067RU	An educator's guide to <i>myWAY Employability</i> : Enabling support with transition-planning for students on the spectrum	3	3	6
3.012RC	Program 3 base resources	4	N/A	4
3.013RC	Australian Longitudinal Study of Autistic Adults (ALSAA)	4	9	13
3.014RC	EVAP and IEST	6	8	14
3.015RC	Health and wellbeing for adults	4	8	12
3.016RC	Longitudinal Study of Australian School Leavers with Autism (SASLA)	5	10	15
3.017RC	Optimisation of recruitment	3	2	5
3.030RI	Studio G: Multimedia Program for young adults	1	2	3
3.031RI	Career pathway recommender system	1	1	2
3.032RS	Enhancing social relationships of young adults	2	1	3
3.038RI	Big data, important questions, health and wellbeing	2	0	2
3.039RI	Supporting staff and students in STEM programs	3	3	6
3.040RS	Driving project	1	10	11
3.041RS	Public transportation mobility	2	4	6
3.046RI	Health Pathways Initiative	2	1	3
3.047RI	Goal-setting Tool for Adolescents and Adults	1	2	3
3.048RU	BOOST-A: From research to practice	1	5	6
3.049RU	Utilising Autism CRC Health Hub tools and resources	2	3	5
3.054RI	Autism@Work	4	2	6
3.061RU	Development of an Assessment of Functioning Tool Based on ICF Core Sets	3	7	10
3.062RI	'Hear' to Help: Striving for greater participation and wellbeing through tailored chat-bot technology	2	2	4
3.068RI	Development of an autism-specific quality of life assessment for use with autistic adults	6	2	8
3.076RI	Autistic burnout	2	1	3

4.3 Education and training

Autism CRC's education and training activities seek to build capacity within both the autism research community and the services sector. Using our large collaborative network of stakeholders, we aim to facilitate opportunities and educational experiences for our PhD and Masters scholars and Postdoctoral Fellows that will enable them to contribute significantly to the autism community in Australia. With an emphasis of co-production, we envisage this next generation of professionals will be even more equipped to produce research and outputs addressing community-driven priorities.

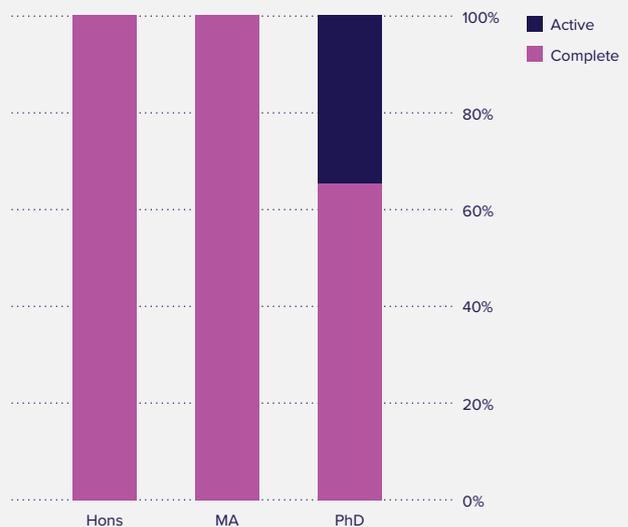
During the reporting period, a further 11 scholars completed their studies (seven PhDs, one Masters by Research, three Honours). Twenty-one PhD, 15 Masters and 16 Honours students have now completed their studies across our three programs. Of our 63 active or completed scholars:

- ▶ eight are in the Early Years Program
- ▶ twenty-four are in the School Years Program
- ▶ thirty-one are in the Adulthood Program.

Ten scholars have withdrawn over the lifetime of the Autism CRC.

Despite another year of COVID-19-related disruptions and delays, many of our scholars were still able to present their work remotely at leading conferences and symposia such as Australasian Society for Autism Research Conference (ASfAR) 2020 and International Society for Autism Research Conference (INSAR) 2021. See Appendices 3-5 for a full list of publications and presentations.

Figure 2: Percentage of active and completed scholars by qualification



Lacey Chetcuti

My PhD research was embedded within a large-scale intervention trial conducted by research teams at La Trobe University (Melbourne, Australia) and The University of Western Australia/Telethon Kids Institute (Perth, Australia), as part of the Autism CRC's Early Years Program.

The overarching aim of my PhD research was to understand how infants exhibiting signs of autism differ from one another in terms of their temperament – i.e., emotion, behaviour, attention, and regulation characteristics – and whether such differences related to social-emotional functioning outcomes and caregivers' mental health. I conceived this research with a view of enriching the existing literature, moving away from group-level contrasts (i.e., between autistic and non-autistic comparison samples) and towards the analysis of individual differences.

The findings from my PhD research highlight the diversity of the autism spectrum from a very young age, and could inform the development of support strategies that are tailored to the temperamental needs of each person. Such personalized supports have great potential to improve the lives of individuals on the spectrum.

As of July 2021, I will be returning to work with the Childhood Autism Phenotyping Team, within the Department of Psychology and Public Health at La Trobe University. I held this appointment throughout my PhD candidature, and look forward to seeing those and other projects through to completion

(but now with a PhD in tow!). As for the long-term, I hope to pursue a career in academia and further investigate temperament in autism and other neurodiverse populations – my PhD research was but a dent in this space.

Being part of Autism CRC connected me with a diverse community of talented researchers dedicated to the same goal of improving the lives of people on the autism spectrum and their families. Further to this, the Autism CRC created opportunities for me to learn about autism from an autistic perspective and helped me understand the importance and value of involving autistic people in the research process.



Yunhe Huang

My research explored the experiences of people who received their autism diagnosis in adulthood using survey and interview methods. I wanted to know how adults usually get diagnosed, how to make assessment and diagnosis more accessible, and what can be done to support these adults.

I am currently approaching the end of my PhD and focused on finalising qualitative analysis of interview data. I will also be making a summary of research findings for participants and organisations. Hopefully, my research would be useful to professionals and services that assess and/or support autistic adults.

My PhD with the Autism CRC has allowed me to develop academic skills, work with autistic adults and organisations, and present my findings to a variety of audiences. It has also given me the opportunity to connect with other students and researchers from different backgrounds. In the future, I hope to keep doing research that helps people understand themselves and each other better.



Rebecca Kuzminski

Prior to commencing my PhD, I studied occupational therapy at Curtin University. During this time, I was introduced to co-production and its benefits in research through my honours research project, which co-produced a knowledge questionnaire that was then used along with the Societal Attitudes toward Autism Scale in a survey to understand attitudes towards and knowledge about autism among the general adult population of Australia. This experience sparked a passion in me to explore topics important to the autistic community from their perspective, and with their collaboration.

My PhD has sought to understand autistic quality of life, from the perspective of autistic adults, through written and spoken communication as well as through photography. Throughout my research, I have worked collaboratively with a steering group of autistic adults to co-produce methods, resources and to identify themes. This work has informed my early development of a new autistic quality of life assessment which is currently being piloted.

While the ongoing development of a new assessment can be beneficial to clinical practice, my research has also highlighted autistic experiences of quality of life. Enabling the autistic community to drive the understanding about their experiences of quality of life has been a critical part of this project. The findings from my research highlight the importance of relationships, passions and sensory preferences as unique elements of autistic quality of life. Some examples of these experiences are shared in the Photovoice Gallery (“My Quality of Life”) that I created with participants and the steering group as part of my project. This Photovoice study and gallery have been commended for their inclusivity, with my colleagues and I receiving the Inclusive Research Award from the Autism CRC in 2020.

My PhD has provided me with opportunities to make transdisciplinary, collaborations nationally and internationally. I have shared my research on the international stage, a highlight of which was presenting my research at INSAR in 2019 in Montreal and in 2021 virtually.

Being an Autism CRC Scholar has provided me with opportunity to be part of a community with shared goals at a time where it has been challenging to otherwise connect with, and meet other researchers. The Autism CRC has provided me with the opportunity to work in a truly collaborative way with the autistic community throughout my project. Being part of an organisation with such a strong ethos around inclusive research practice has encouraged me to embed this into my practice, and I hope that future research will continue to be designed and conducted collaboratively with the community.

Autism CRC higher degree research students

Start date	Name	Degree	Uni	Project code	Research project	Term
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Program 1: Early Years

Completed students						
Feb-14	Stacey Rabba	PhD	LTU	1.005RS	Developmental Surveillance for ASD (SACS-R)	4.5 years
Mar-15	Lidan Zheng	PhD	UNSW	1.023RS	ASD subtype project	4 years
May-15	Amanda Mazzoni	PhD	UNSW	1.023RS	ASD subtype project	4 years
Feb-16	Maryam Boutrus	PhD	UWA	1.043RS	Therapy for infants showing early signs of autism	3.5 years
Jun-16	Lacey Chetcuti	PhD	LTU	1.043RS	Therapy for infants showing early signs of autism	4 years
Feb-17	Ali Morse	PhD	UTAS	1.005RS	Developmental Surveillance for ASD (SACS-R)	4 years
Active students						
Jan-18	Chloe Yap	PhD	UQ	1.042RC	Genomics	3 years
Aug-18	Alicia Montgomery	PhD	UNSW	1.059RS	Australian Autism Biobank pilot project	8 years (part-time)

Program 2: School Years

Completed students						
Jul-14	Elizabeth MacDonald	PhD	GU	2.011RC	Helping students stay on-task and move between tasks	3 years
Sep-14	Anne Ozdowska	PhD	QUT	2.010RC	Overcoming difficulties in written expression	4 years
Feb-15	Jac den Houting	PhD	GU	2.007RC	Longitudinal Study of Australian Students with Autism (LASA)	3 years
Mar-15	Danica Warner	MA	QUT	2.009/ 2.029	School connectedness	18 months
Jul-15	Rebecca Poulsen	MA	GU	2.007RC	Longitudinal Study of Australian Students with Autism (LASA)	18 months
Feb-16	Susanne Taylor	MA	GU	2.007RC	Longitudinal Study of Australian Students with Autism (LASA)	2 years
Feb-16	Christopher Edwards	PhD	QUT	2.027RS	Early Years behaviour support project	4 years
Feb-16	Annalise Eyre Taylor	PhD	GU	2.035RS	Models of Practice	4 years
Mar-16	Loretta Crawley	MA	GU	2.007RC	Longitudinal Study of Australian Students with Autism (LASA)	18 months
Oct-16	Sally Ryan	MA	GU	2.007RC	Longitudinal Study of Australian Students with Autism (LASA)	2 years
Jan-17	Kathryn Ambrose	MA	GU	2.007RC	Longitudinal Study of Australian Students with Autism (LASA)	2 years
Jan-17	Kathryn Farr	MA	UQ	2.008RC	Secret Agent Society	1 year
Feb-17	Cara Wilson	PhD	QUT	2.027RS	Early Years behaviour support project	3.5 years
Mar-17	Rachelle Wicks	Hons	GU	2.007RC	Longitudinal Study of Australian Students with Autism (LASA)	1 year

Start date	Name	Degree	Uni	Project code	Research project	Term
Mar-17	Donna-Marie Thompson	MA	GU	2.008RC	Secret Agent Society Whole of Class	2 years
Mar-17	Kate McLisky	MA	QUT	2.029RS	School connectedness	6 months
Mar-17	Monica Sweeney	MA	UQ	2.008RC	Secret Agent Society Whole of Class	2 years
Aug-17	Mellissa Hooper	MA	QUT	2.029RC	School connectedness	2 years
Aug-17	Natasha Bobir	MA	QUT	2.029RC	School connectedness	2 years
Jan-18	Madeleine Stainsby	MA	GU	2.007RC	Longitudinal Study of Australian Students with Autism (LASA)	1 year
Sept-18	Lauren Davis	MA	GU	2.007RC	Longitudinal Study of Australian Students with Autism (LASA)	3 years (part time)
Feb-19	Vedanta Swarna	Hons	GU	2.007RC	Longitudinal Study of Australian Students with Autism (LASA)	1 year
Oct-19	Sophia Clarke	Hons	ACU	2.024RI	Emergent literacy	1 year
Active students						
Feb-19	Kathryn Ambrose	PhD	GU	2.007RC	Longitudinal Study of Australian Students with Autism (LASA)	3 years

Program 3: Adulthood

Completed students						
Jun-13	Craig Thompson	PhD	CU	3.032RS	Enhancing the social relationships of young adults	6.5 years
Dec-13	Megan Hatfield	PhD	CU	3.014RC	Finding a place in the workplace and in the community	3-5 years
May-14	Melissa Scott	PhD	CU	3.014RC	Finding a place in the workplace and in the community	3 years
Jul-14	Ru Ying Cai	PhD	LTU	3.016RC	Longitudinal Study of Australian School Leavers with Autism (SASLA)	3 years
Feb-15	Melissa Black	PhD	CU	3.032RS	Enhancing the social relationships of young adults	3 years
Feb-15	Julia Tang	PhD	CU	3.032RS	Enhancing the social relationships of young adults	4.5 years
Mar-15	Ye In (Jane) Hwang	PhD	UNSW	3.013RC	Australian Longitudinal Study of Autistic Adults (ALSAA)	3 years
Feb-16	Carol Bryden	MA	LTU	3.016RC	Longitudinal Study of Australian School Leavers with Autism (SASLA)	4 years
Mar-16	Jessica Dreaver	Hons	CU	3.014RS	Finding a place in the workplace and in the community	2 years
Mar-16	Taylor Stacey	Hons	UNSW	3.013RC	Australian Longitudinal Study of Autistic Adults (ALSAA)	1 year
Jun-16	Mortaza Rezae	PhD	CU	3.041RS	Enhancing capacity to use public transport	3.5 years
Mar-17	Rachel Quinter	Hons	CU	3.032RS	Enhancing the social relationships of young adults	1 year
Mar-17	Matthew DeBroize	Hons	UQ	3.015RC	Health and wellbeing for adults	1 year
Mar-17	Premkumar Brahmhatt	Hons	UQ	3.015RC	Health and wellbeing for adults	1 year

Start date	Name	Degree	Uni	Project code	Research project	Term
Jun-17	Madeleine Harsanyi	Hons	ACU	3.013RC	Australian Longitudinal Study of Autistic Adults (ALSAA)	18 months
Jun-17	Michelle Kersten	PhD	CU	3.040RS	Community mobility in Autism Spectrum Disorder	3.5 years
Feb-17	Dawn Ee	Hons	UNSW	3.013RC	Australian Longitudinal Study of Autistic Adults (ALSAA)	1 year
Jun-17	Mariesse Sonido	Hons	UNSW	3.013RC	Australian Longitudinal Study of Autistic Adults (ALSAA)	18 months
Feb-18	Lisa Kang	Hons	UQ	3.015RC	Health and wellbeing for adults	1 year
Mar-18	Sanya Jovevska	Hons	LTU	3.016RC	Longitudinal Study of Australian School Leavers with Autism (SASLA)	1 year
Mar-18	Ensu Sahin	Hons	LTU	3.016RC	Longitudinal Study of Australian School Leavers with Autism (SASLA)	1 year
Jul-19	Nicola Coleman	Hons	ACU	3.013RC	Australian Longitudinal Study of Autistic Adults (ALSAA)	1 year
Feb-20	Samantha Lewis	Hons	LTU	3.016RC	Longitudinal Study of Australian School Leavers with Autism (SASLA)	1 year
Active students						
Mar-17	Priscilla Vindin	PhD	CU	3.040RS	Community mobility in Autism Spectrum Disorder	Upgraded from MA to PhD
Feb-18	Jia White	PhD	CU	3.014RC	Finding a place in the workplace and in the community	3 years
Mar-18	Maya Hayden Evans	PhD	CU	3.061RU	Development of an assessment for functioning tool based on the ICF Core sets for ASD	3.5 years
Mar-18	Rebecca Kuzminski	PhD	CU	3.068RI	Development of an autism-specific quality of life assessment for use with autistic adults	3 years
Mar-18	Emily D'Arcy	PhD	CU	3.061RU	Development of an assessment for functioning tool based on the ICF Core sets for ASD	3 years
Apr-18	Pia Bradshaw	PhD	UQ	3.015RC	Health and wellbeing for adults	3.5 years
Apr-18	Melanie Muniandy	PhD	LTU	3.016RC	Longitudinal Study of Australian School Leavers with Autism (SASLA)	3 years
May-18	Yunhe Huang	PhD	UNSW	3.013RC	Australian Longitudinal Study of Autistic Adults (ALSAA)	3 years



4.4 Engagement

Autism CRC has become an independent national source of evidence for best practice, bringing benefits to our partners and capturing opportunities they cannot capture alone. By focusing on research priorities of national importance, Autism CRC has successfully brought together previously disparate research, clinical, service provider and government departments. A number of end-user and government submissions to the Senate Select Committee on Autism in 2020 expressed their support of our work and the value of our role within the research and policy landscape. Our ability to attract commissioned and funded projects, and the uptake of our research and resources by government, clinicians, service providers and end-users alike is further testament to this.

There are 56 organisations engaged as participants in Autism 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; technology companies; Commonwealth and state government departments and agencies; and, critically, autistic individuals and their families.

Small and medium-sized enterprise engagement

Engaging small and medium-sized enterprises (SME) is fundamental to our work, with many of our End-user Participants falling into this category. By engaging end-user SMEs early on, we can ensure our research is not only grounded in end-user needs but that there are pathways for dissemination and utilisation of research findings. Most SMEs engaged with Autism CRC are service providers or businesses supplying equipment or technology to individuals and families, schools or service providers.

The SMEs within Autism CRC include:

- ▶ autistic advocacy and service organisations, such as Autistic Self Advocacy Network of Australia and New Zealand (ASAN AUNZ), Asperger Services Australia and The I CAN Network
- ▶ autism service providers and peak bodies such as Autism New Zealand, Autism Queensland, Amaze, Autism South Australia, Autism Awareness Australia, Spectrum Space and Autism Tasmania
- ▶ companies such as Renae Beaumont Enterprises, Social Skills Training Pty Ltd, and Assistiveware
- ▶ Autism Specific Early Learning and Care Centres (ASELCCs) across Australia
- ▶ professional groups (National Rural Health Alliance, Australian College of Rural and Remote Medicine)
- ▶ private autism clinics, which are small enterprises (Minds and Hearts; The Asperger's Syndrome Clinic).

Other industry engagement

State-based and national stakeholders include educators, clinicians, therapists and policy makers. These strategic partnerships provide in-kind support to deliver outcomes across a range of projects and industries. Autism CRC seeks industry input in the design and evaluation of projects, often through iterative testing and trials of project outcomes. A number of large entities and enterprises such as such as Aspect, Autism Association of Western Australia and F.Hoffman-La Roche Ltd are engaged as Participants.

The collaboration and engagement of health sector end-users, particularly clinicians, has been instrumental in the development and dissemination of our diagnostic and health outputs. The Autism HealthPathways are a product

To date summits have attracted a total of 500 attendees from a broader range of industries and organisations.

of the Mackay Hospital and Health Service integrated health team in partnership with the Autism CRC, Northern Queensland Primary Health Network and other partners. A growing number of health regions across Australia, NZ and the UK are now engaged with the Autism HealthPathways suite of resources thanks to a 2020 licensing agreement with Streamliners NZ. The content has been informed by extensive consultation with GPs, and health professionals have engaged with the end-product 2,600 times since its launch in July 2019.

The original research and development of the National Guideline included extensive national and international consultation with the clinical, allied health, service provider, autistic, and autism communities. Responding to industry needs, and with funding from the Commonwealth Department of Social Services, in 2020 Autism CRC released the National Guideline Implementation Toolkit to support industry uptake and implementation of the Guideline. More work is now underway to grow and expand these stakeholder relationships, particularly among professional groups, as we work toward nationally consistent uptake and delivery of the National Guideline. Autism CRC is specialist advisor to the Department of Social Services, which is leading the ministerially-appointed Expert Reference Group of clinical and consumer representatives to help National Guideline implementation, nationally. To date more than 24,500 people have registered to access the National Guideline from across Australia and overseas, including 17,000 professionals from both the private and public sectors.

turnKey CRC is a ready-to-use software solution developed by Autism CRC especially for other CRCs. Collaboration with other CRCs is critical to turnKey CRC's success, which now supports 13 clients. Clients and partners are brought together to:

- ▶ ideate and collaborate on common CRC challenges and how they can be met
- ▶ create and sustain best practice operational processes
- ▶ develop the roadmap, allowing for community prioritisation.

Our events also attract and engage other industry groups, such as potential employers looking at neurodiverse workplace programs as promoted through our Autism@Work Summits. To date, these summits have attracted a total of 500 attendees from a broader range of industries and organisations, including the Department of Defence, Australian Federal Police, small business owners, start-ups, local councils, state government departments and large corporations. In addition, these events have attracted industry partners and sponsorship from companies such as DXC Technology, NAB, ANZ, SAP and Untapped.

Autism CRC participation in the Telstra Foundation Technology and Wellbeing Roundtable alongside Google, Twitter, Telstra, and a number of youth mental health service providers and researchers, provides the opportunity to showcase our work and initiate new collaborations. Primarily an information-sharing and networking group, Autism CRC has participated for the last four years, taking advantage of the opportunity to learn from technology industry leaders.

For the past three years, Autism CRC has been represented on Education Queensland's Autism Hub Advisory Board. The advisory board meets quarterly to provide guidance on operational policies, strategies and initiatives relating to innovative and cohesive delivery of services across Queensland to improve the educational outcomes for students on the spectrum, provide support for families and build workforce capability in Education Queensland.

As with the 2019-20 program, the Future Leaders Program is again being delivered through a collaboration with Essential Participant and end-user organisation, Aspect.





Engagement with the autistic and autism communities

Autism CRC researchers are committed to engaging with autistic people and their families throughout the research process from the development of research ideas and priorities, through stages of planning, implementation, reflection, dissemination, and provision of feedback. Each of our project advisory groups includes an autistic person or family member. In addition, all project applications are reviewed by scientific and autistic reviewers. This ensures that research topics and methods are relevant and useful for people on the spectrum.

Incorporating the perspective of people with the lived experience of autism throughout the research process improves research practices and outcomes, and the opportunity to meaningfully benefit autistic individuals. As an example:

- ▶ **The hidden histories of late-diagnosed autistic adults: An oral history study:** this project sought to preserve the stories of late-diagnosed adults and the lives they

led before and after their diagnosis. The project team of autistic and non-autistic researchers co-designed and co-produced a study using oral history methods to investigate the life stories of 28 autistic people, aged between 45 and 72 years from diverse parts of Australia. Winner of the **2020 Autism CRC Awards for Achievement in Autism Spectrum Research**, one reviewer described this research as pioneering “...a participatory approach to inclusive research that lays the foundation for establishing best practice protocols to achieve authentically co-produced research to benefit the autistic community.”

- ▶ **Development of an autism-specific quality of life assessment for use with autistic adults:** this project undertook a research study where participants were asked to take photographs to represent their quality of life. A selection of 47 photographs was then developed into an online Photovoice Gallery. Careful attention was made to inclusive practices both at the initial design phase, through to data collection and analysis of findings.

Sylvia Rodger Academy

Autism CRC's Sylvia Rodger Academy provides programs, pathways and networks that create communities where autistic people fully contribute and influence policy, practice and culture in partnership with their peers. The Academy's vision is to see autistic people thriving through discovering and using their strengths. The Academy delivers programs in leadership, corporate governance and research.

During the reporting period, the Sylvia Rodger Academy had its third intake of Research Program participants. The autistic stream participants completed the first of the major components of the holistic program, comprising online learning modules and a practical component – which are features of all three Academy programs. The autism

researcher stream participants completed readings and written tasks related to co-production and the application of this to their research past and present.

The inaugural Governance Program and third Future Leaders Program was also completed during the year. Both the Governance and Future Leaders Programs were co-designed and delivered with autistic adults.



"I can be my best self and produce more and show what I can do if accommodations are put in place. If I don't have all the blocks in front of me, there's nothing stopping me. That's something I learned from Future Leaders."

Program Participant

Zoe - Future Leaders case study



Zoe participated in the 2019 Future Leaders Program.

"I don't usually take risks, but through the program I could try new things in a supported way. Participating in Future Leaders enabled me to see how much I can achieve."

Zoe is committed to promoting inclusion for people with disabilities. Through Future Leaders, she was able to hone her ideas and develop the confidence and skills she needed to bring them to fruition.

Since Future Leaders, Zoe has designed and run an inclusion day program at her local Surf Lifesaving Club, with the purpose of bringing together the community, including people with disabilities.

Her inclusion day program was the winner of the Outstanding Achievement award for the Lifesaving Victoria Awards of Excellence, and was nominated for a Bayside Council Australia Day award. The impact of the program has continued to inspire inclusion within her broader community, with one of the program's attendees deciding to make their sports programs more accessible to children with disabilities. Zoe plans to run her inclusion day program again in 2021.

4.5 Awards and honours 2020-21

Date	Personnel	Award	From	For
Jun-21	Dr Renae Beaumont	The Society of Clinical Child and Adolescent Psychology	Division 53 of the American Psychological Association	Promoting Evidence-Based Mental Health Services
Jun-21	Professor Tele Tan	Member of the Order of Australia (AM)	The Governor-General of the Commonwealth of Australia	Significant service to information and communication technology, and to people on the autism spectrum
Dec-20	Professor Liz Pellicano	Achievement in Autism Research – Inclusive research practice	Autism CRC	The hidden histories of late-diagnosed autistic adults: An oral history study
Dec-20	Rebecca Kuzminski	Highly commended – Inclusive research practice	Autism CRC	Quality of Life Photovoice Gallery
Dec-20	Sophia Clarke	Executive Dean's Commendation	Australian Catholic University	Masters Thesis: Describing the Association Between Emergent Decoding and Receptive Vocabulary in Preschool Children on the Autism Spectrum
Aug-20	Chloe Yap	3 Minute Thesis Public Choice award	University of Queensland Medicine	3 minute video on her PhD research investigating genomics in autism, including the relationship with gut microbiome



PhD scholar Chloe Yap won the 3 Minute Thesis Public Choice Award from UQ Medicine for her research investigating genomics in autism, including the relationship with gut microbiome.

4.6 Communication

The Australian autism community is large and diverse, encompassing research organisations, service providers such as healthcare professionals and educators, government and policy makers, families and carers, and most importantly autistic people themselves. The diverse needs and roles of these community members creates a range of communication challenges for the dissemination of research findings and outcomes.

Our stakeholder relations and communication strategy works to ensure effective communication both within Autism CRC and with our external stakeholders.

Communication goals

- ▶ Support the effective delivery of our current programs, projects and initiatives to the expectation of our stakeholders, with an increased focus on translation
- ▶ Capitalise on the opportunities provided by our increased reach, while continuing to take advantage of opportunities to further expand our reach
- ▶ Strengthen our internal communication efforts and ensure our broader team are acting as CRC ambassadors
- ▶ Identify and capitalise on opportunities for high impact stories through mainstream, industry and social media
- ▶ Work with the Autism CRC executive to continuously evolve our organisational narrative
- ▶ Continuously improve our marketing and communication assets (corporate website, Knowledge Centre, Connect Hub, Salesforce CRM, Marketing Cloud).



Autism CRC has now established its reputation as a trusted, independent, national source of evidence for best practice, delivering whole-of-life outcomes for autistic people and their families. Awareness and engagement from the autistic and autism communities has grown significantly, particularly in recent years with the increasing number of research outcomes and high-impact outputs being disseminated.

In line with our communication goals, Autism CRC has taken full advantage of opportunities to further expand our reach and capitalise on the opportunities provided by the dissemination of new research outcomes and outputs. This is reflected in the significant increases in event attendance, utilisation of our outputs, and in our social media following, newsletter subscriber base and website traffic. These are demonstrated by the following 2020-21 highlights.

2020-21 communication highlights

- ▶ The *myWAY Employability* platform was launched by Jackie Coates, Head of Telstra Foundation. The online event included interviews with four autistic young people who had been involved in the design and development of *myWAY Employability*, and featured a demonstration of the web platform and a live Q&A with the project team. The launch attracted 923 registrations, which resulted in 422 attendees at the live event and 270 views of the recording on YouTube. The launch event invitation was sent via direct email to Autism CRC end-user participant network, Telstra staff, individuals involved in the original research, training and/or *myWAY* development, individuals who expressed interest in *myWAY Employability* and Autism CRC's external mailing list. Launch communications included an invitation to the launch event, media release for traditional media outlets, and a share pack for education stakeholders for *myWAY Employability* promotion pre- and post-launch. The share pack included a direct link to a short promotional *myWAY Employability* animated video; *myWAY Employability* FAQs; images to support newsletter stories, articles or social media; and a sharable one-page flyer. The share pack was positively received by end-user participants, government departments and service providers, resulting in significant peer-to-peer promotion of the event and platform.
- ▶ 2021 Autism Month webinar series was our biggest and most successful to date, attracting almost 2,735 registrations across six webinars. Recordings of the webinars on YouTube have received a further 900+ viewings. This marked a second successive year where webinar registrations grew over 110% on the year before, highlighting our increasing reach to new audiences. This was particularly true for the Interventions for children on the autism spectrum webinar (1,860 registrations), which provided insights on the landmark report launched in November 2020.

- ▶ Autism CRC's Knowledge Centre provides a single online gateway to autism resources, tools and publications available on our website. It continues to grow with our ever-increasing range of resources and publications, now hosting more than 315 journal publications and other resources, freely available to the public. Taking into account our diverse stakeholder audience, final project reports are hosted on Knowledge Centre and supported by executive summaries and research snapshots. Research snapshots provide a layman's summary of project outcomes and have become a valuable communication tool.
- ▶ Capitalising on the interest and success of product launches and events, Autism CRC's newsletter subscriber base has risen sharply to 19,728, up from 12,972 last year, a 52% increase in the last year alone (Figure 3).
- ▶ Timely updates and continuous improvement to website content and user experience has seen engagement with the corporate website (autismcrc.com.au) grow significantly. The website attracted a 38% increase in unique page views (up to 341,299 from 247,730) in the reporting period; a 127% growth over the last five years (see Figure 4).
- ▶ Regular posts of engaging content have also seen Autism CRC's social media following increase across the various channels. Facebook followers are up 13% on last year at 8,741 and Twitter followers now total 2,058 (up 26%).
- ▶ Media coverage was secured across print, radio, TV and online outlets at national, state and local levels, across the country. A range of health, education and other industry publications have also reported on CRC research outcomes. Outlets discussing CRC research, outputs and/or initiatives in the 2020-21 year include Leadership ED, Child Magazine, MSN Australia, The Canberra Times, Australian Hospital and Healthcare Bulletin, WhaTech, Freedom2Live, Health Times, Scimex, Disability Support Guide and Autism Awareness Australia eUpdate.



A selection of research snapshots

Figure 3: Newsletter subscribers (eNews) July 2016 - June 2021

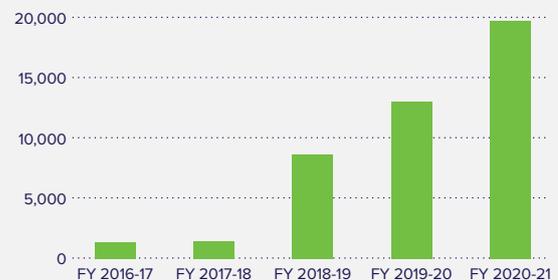


Figure 4: Autism CRC website unique pageviews July 2016 - June 2021



autismcrc.com.au



38%
increase in
page views in
the last year



127%
growth over the
last five years

4.7 Intellectual property

Autism CRC recognises the value of intellectual property (IP) and its importance in enabling utilisation and commercialisation of research outcomes. We strive to develop a culture where this is understood and respected.

A number of mechanisms are employed to identify, protect and utilise IP:

- ▶ Background IP is identified and recorded on the Autism CRC IP register, updated regularly as to the status of IP assets.
- ▶ New CRC Centre IP (CIP) – which is created through CRC programs – is identified and recorded on the Autism CRC IP register, updated regularly as to the status of IP assets.
- ▶ Publication approval processes for written and oral publications and posters and PhD theses are overseen by the Research Program Manager (on behalf of Autism CRC, the legal owner of CIP).
- ▶ All manuscripts submitted for publication and eventually published are registered in a Publications Register, along with PDF copies of the publication.
- ▶ Project Agreements and Project Plans include items on Background IP required for the conduct of the project and CIP likely to be developed/created by the project.
- ▶ IP identification, status and translation considerations are specifically required in Project Progress and Final Reports.
- ▶ Specific IP utilisation activities and milestones included in both the Commonwealth CRC Program Agreement and the Essential Participants Agreement, with projects commissioned specifically to deliver these.
- ▶ CRC staff, researchers and scholars are upskilled through relevant education and training on IP matters relevant to Autism CRC.

These practices ensure that Autism CRC complies with the National Principles of Intellectual Property Management for Publicly Funded Research. The key items of IP currently held by Autism CRC Ltd (or its subsidiary, Social Skills Training Pty Ltd) can be found in Appendix 6.



4.8 Utilisation and commercialisation

To date, more than 90,000 professionals have been involved in our research programs or are using our outputs and professional development resources.

The growing number of Autism CRC outputs and products continue to have impact, attracting great interest from our wide range of end-users. The Knowledge Translation, Research, Project, and Marketing and Communication teams have worked closely to optimise utilisation of research outputs; grow our capacity to innovate, develop and promote high quality digital products; and ensure best practice digital design and delivery. Strong partnerships with industry, government and service providers have increased reach and uptake of outputs into real-world practice. More than 37,000 professionals have been involved in our research program or have used our outputs in the last year alone.

Adolescent/Adult Goal Setting Tool (AAGST)

A card-sort process to facilitate conversations about people's goals and aspirations.

- ▶ Licence agreement established with Autism Queensland.
- ▶ Launched October 2019.
- ▶ 250+ copies sold to-date.
- ▶ Second reprint planned in July 2021.
- ▶ Autism Queensland currently progressing development and trial of digitised AAGST, under existing licence agreement.

Australian Autism Biobank

Biological, behavioural and clinical information and materials available from a depository of almost 3,000 participants.

- ▶ Twenty-six separate applications for access to materials and/or data have been approved to date from researchers with disciplines ranging from systems genomics to education.
- ▶ Approved projects have requested the full range of data and samples stored by the Australian Autism Biobank.
- ▶ Five additional datasets added since research began as a result of project activities.
- ▶ Whole genome sequencing data generated for more than 1,500 participants.
- ▶ Completed feasibility study on a longitudinal follow-up of the Australian Autism Biobank participant return rates. Data useful for both the large-scale grant applications required for the continuation of the project outside Autism CRC funding and to attract industry investment.

Summary table of approved Australian Autism Biobank applications

Project title	Principle investigator	Lead organisation
Genes, brains and bodies	Liz Pellicano	Macquarie University
Biobank cohort characterisation	Gail Alvares	Telethon Kids Institute
Female autism phenotype	Rachel Grove	University of Technology Sydney
Adaptive functioning	Gail Alvares	Telethon Kids Institute
Parent concerns and co-occurring conditions	Andrew Whitehouse	Telethon Kids Institute
Parent traits and conditions	Andrew Whitehouse	Telethon Kids Institute
^A Sleep difficulties in autism	Anne Masi	University of NSW
^A Inflammation and neuromodulation in autism	Alicia Montgomery	University NSW
Co-occurring anxiety and gastrointestinal conditions	Jacob Gratten	Mater Research–University of QLD
^A Systems genomics of autism	Jacob Gratten	Institute for Molecular Biosciences- University of QLD
Behavioural and phenotypic profiles	Valsa Eapen	University of NSW
^A Sensory subtypes in children on the autism spectrum	Anne Masi	University of NSW
^A Whole genome sequencing	Andrew Whitehouse	Autism CRC
^A Systems genomics of autism-2	Jacob Gratten	Mater Research–University of QLD
Chronic stress in children on the autism spectrum	Valsa Eapen	University NSW
Maternal immune activation	Darryl Eyles	University of QLD
*Psychiatric genomic consortium	Jacob Gratten	University of QLD
Children with complex needs	Lauren Taylor	University WA
Oral health in autism	Kareen Mekertician	Australasian Association of Paediatric Dentistry
*Genetics of motor development	Jess Reynolds	Telethon Kids Institute
Precision thyroid medicine	John Walsh	University of WA
Broad autism phenotype	Valsa Eapen	University NSW
Vineland norms update	Valsa Eapen	University NSW
*Genomic analysis of pharmacotherapeutic response	Christopher Chatham	Roche
Neurodevelopmental assessment scale	Valsa Eapen	University NSW

^A Autism CRC project *Material transfer agreement (MTA) in progress



Autism HealthPathways Initiative

A platform for health professionals to inform healthcare pathways which better support autistic people.

- ▶ Launched the Autism HealthPathways Initiative, a web-based information site that assists health practitioners, particularly GPs, to guide patients through the health system.
- ▶ Developed nine new or revised pathways related to autism, disability, and developmental delays, which have been accessed by health professionals 2,600+ times.
- ▶ Licence agreement with Streamliners NZ for distribution of the Autism HealthPathways to the 43 health jurisdictions caring for more than 28 million people across New Zealand (11 sites), Australia (31 sites), and the United Kingdom (three sites).
- ▶ To date, nine Primary Health Network regions have adopted and/or localised the pathways (Mackay, Canterbury NZ, Far North Queensland, Sydney), or are in the process of (Western Australia, Darling Downs, West Moreton, Wide Bay and Western Victoria).

Autism Teen Wellbeing

A website that provides resources and strategies to help build protective factors against depression and anxiety in teenagers.

- ▶ Evaluation of the Resilient Adolescent Program for Adolescents with Autism (RAP-A-ASD) delivered and evaluated with 86 participants in six schools in Queensland and 11 Indigenous community workers in Bourke, NSW.
- ▶ Results suggest RAP-A-ASD had a significant impact in reducing anxiety and improving self-efficacy and coping.
- ▶ Established a Licence Agreement with QUT with the option to commercialise the RAP-A-ASD.
- ▶ Website launched in April 2020, **autismteenwellbeing.com.au** – users to 30 June 2021:
 - 9,200 unique visitors
 - 12,300 sessions (an individual period of time a user is actively engaged, navigating, clicking, etc)
 - 34,000 page views (including repeated views of a single page).

CHECK program

A series of training resources and e-learning modules for GPs.

- ▶ 5,020 GPs completed professional development training.

inclusionED

An online professional learning community for educators to support all learners.

- ▶ Partnered with national education providers Australian Institute of Teaching and School Leadership (AITSL), Social Ventures Australia Evidence for Learning, and Positive Partnerships to promote *inclusionED* and where appropriate create reciprocal pathways between *inclusionED* and other educator-focused online services.
- ▶ Autism CRC continues to engage with representatives from Australian Department of Education and state Departments of Education in Victoria, New South Wales, Tasmania, Queensland, and Western Australia, to promote *inclusionED* widely. Key contacts within the Australian Department of Education and state departments have been sharing promotional information and materials throughout their networks.
- ▶ *inclusionED* school-based training has been delivered to 140 teachers in Queensland and Western Australia. A proportion of these also received *myWAY Educator* training to use *myWAY Employability* in school-based transition training.
- ▶ Launched platform (18 May 2020) **inclusioned.edu.au**. Statistics to 30 June 2021:
 - 24,600 unique visitors
 - 2,760+ registered users (well above the industry benchmark of 5% conversion to registration)
 - 36,700 sessions (an individual period of time a user is actively engaged, navigating, clicking, scrolling, etc)
 - 241,300 page views (including repeated views of a single page).
- ▶ Work has commenced on a content development guide for Autism CRC and external researchers wanting to translate their research into *inclusionED* practices and multimedia content for the platform.
- ▶ Education partners engaged to support the professional development and promotion of *inclusionED* to schools and teachers include state and federal departments of education, Positive Partnerships, Speech Pathology Australia, Occupational Therapy Australia, Autism Queensland and Amaze.
- ▶ The *inclusionED* team continues working across several projects to develop *inclusionED* practices which will be released in 2021-22.



The Integrated Employment Success Tool (IEST)

A practical workplace manual to improve employer confidence, employee productivity, job retention and the overall workplace success of autistic people.

- ▶ Launched 3 June 2021, with the manual and supporting templates available via registration process – users to 30 June 2021:
 - 250+ registered users
 - 390 downloads of the manual
 - 450 downloads (combined total downloads of the supporting template resources).

myWAY Employability

A smart web platform that supports young people to plan and prepare for their working life.

- ▶ *myWAY Employability* platform launched in August 2020 (Stage 2 of this project, funded by \$450K from Telstra Foundation Tech4Good Challenge), mywayemployability.com.au. Statistics to 30 June 2021:
 - 10,060 unique visitors
 - 1,110 registered users (well above the industry benchmark of 5% conversion to registration)
 - 16,000 sessions (an individual period of time a user is actively engaged, navigating, scrolling, etc)
 - 73,800 page views (including repeated views of a single page).
- ▶ Secured further funds from Telstra Foundation for Stage 3, to focus on uptake of *myWAY Employability* in service delivery by disability and employment services, schools and allied health professionals.
- ▶ *myWAY Employability* project team continues to engage in the Telstra Foundation Tech4Good Challenge alongside youth service providers.

StepWrite

The *StepWrite* iOS iPad app helps children, including those on the autism spectrum, harness their writing potential.

- ▶ Released to the Apple App Store on 25 May 2021 for \$2.99 per download.
- ▶ In the five weeks since launch to 30 June 2021:
 - 135 purchases, resulting in \$304 in revenue
 - 117 active users.



MY WAY
EMPLOYABILITY

turnkeyCRC

A ready-to-use software application developed by Autism CRC especially for CRCs.

turnKey CRC was envisaged when developing Autism CRC's management system built on Salesforce.com. The software application allows newly funded CRCs to hit the ground running on start-up, integrating CRC program governance and management, partner engagement, contracts, cash and in-kind commitments.

Since 2017, 13 CRCs have chosen to use turnKey CRC.

With the maturing operations of many of these CRCs, especially eight from the last two rounds, there has been significant development in functional use of progress reporting.

One of the most important features we have focused on in progress reporting has been the ability for participants and partners to access key project financial and performance data once project leaders have submitted their reports. This data is made visible through an engaging dashboard of charts that show the key performance indicators for cash and in-kind budgets, milestones, publications and intellectual property. This gives each partner the ability to understand their organisation's performance within the CRC's portfolio.



"turnkey has changed the way that RMIT University manages our large portfolio of Cooperative Research Centres. This system has allowed us to monitor project development, reporting and milestones, financial commitments and many other key activities in a quick, user-friendly way that has significantly reduced the administrative overheads usually required."

Robert Ellul, SmartCrete CRC & Senior Coordinator, Major Research Initiatives, RMIT



Social Skills Training Pty Ltd

A wholly owned subsidiary of Autism CRC Ltd

Social Skills Training Pty Ltd (SST), trading as the Social Skills Training Institute, has the exclusive worldwide licence for distributing and developing the Secret Agent Society (SAS) programs, which are emotion regulation and resilience building programs for children.

SST's vision is to see children and young people empowered and resilient, pursuing their own pathway, strengths and interests. The key program offered by SST is the Secret Agent Society Small Group Program (SAS-SG). This is delivered by trained SAS Facilitators, who can be either clinicians or educators, to small groups of children usually aged between eight and 12 years to strengthen social, emotional and problem-solving skills. The program is offered over 12 to 23 modules including a six-month period of booster sessions. SAS has an outstandingly strong research base and is a world-leading clinician-led program for primary school-aged children with a range of diagnoses and undiagnosed profiles.

Dr Renae Beaumont is the founder and author of the Secret Agent Society programs and, while now based in the USA, she remains closely connected with the program. This year Dr Beaumont was recognised for her passion for improving the mental health and wellbeing of children by The Society of Clinical Child and Adolescent Psychology, Division 53 of the American Psychological Association, who awarded Dr Beaumont this year's award for Promoting Evidence-Based Mental Health.

The 2020-2021 financial year was an exceptionally challenging year for SST as the world became embroiled in the COVID-19 pandemic. As individuals and communities battled the disease, so organisations and companies were faced with difficult choices about the services and products they provided in this dramatically changed world. SST was confronted with a major challenge to its business model because SAS-SG up to then had relied on working face-to-face with children in small groups, led by trained SAS Facilitators using a range of specialist physical resources. In the new COVID world this form of support was only going to be possible if communities were largely free of COVID or had been vaccinated.

Short-term strategies were urgently implemented to assist SAS Facilitators so they could continue to offer the program using some new digital resources in a telehealth environment, but a more radical solution had to be found. The SST Board, supported by Autism CRC, took the enterprising decision to (i) transform the whole of the SAS-SG program into a digital health solution with the flexibility to use it in both face-to-face and telehealth services, and (ii) develop a self-paced online training program for SAS Facilitators so they could access training flexibly from anywhere and have ongoing access to review materials. Over nine months, in a project led by Kathleen Davey, SST's Chief Operating Officer & Clinical Psychologist, SAS-SG was fully digitised as an integrated software package and launched on time and on budget to its customer base of provider organisations along with the new training program for facilitators.

This remarkable achievement was brought to fruition under Ms Davey's leadership by Bigfish, the software developer, Thinking Cap, which provided the technical infrastructure, the SAS Facilitator Advisory Group, through a co-design process, the SST Team, along with feedback from Dr Beaumont, and the extraordinary commitment to the project by Ms Davey herself. The SAS-SG Digital Edition can now be offered face-to-face as well as online as a telehealth program to small groups of children. All the existing specialist physical resources have been fully integrated into one digital program that connects SAS Facilitators, children and the various adult mentors who support them. For the first time SAS-SG is now available worldwide as an integrated digital resource for service providers, children and families.

During a year when SST was fully absorbed with the digital transformation of SAS-SG and ensuring current providers could transition smoothly to the new edition, the program continued to be offered. Remarkably, SAS resources, whether they be physical or digital, were made available to 2,353 children through SAS-SG programs offered by providers from around the world and 191 SAS Facilitators were newly trained. This result was on par with the previous financial year which, up to then, had been SST's best year ever.



Dr Renae Beaumont with her award from the American Psychological Association for Promoting Evidence-Based Mental Health.

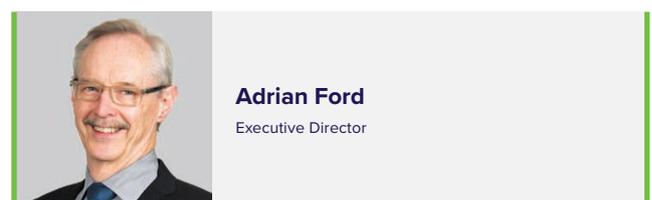
The achievement of the SAS-SG Digital Edition during the past year, has meant that SST is well placed to extend its reach overseas as well as in Australia. The Board has signed off on a global strategy of growth for the coming 18 months as SST establishes SAS-SG in markets around the world with a particular focus on the North American, British and Irish markets. SST has established footholds in all these markets, but the Digital Edition makes the program much more available and more flexible both for innovative and reactive telehealth outreach services. As part of this new positioning, SST has appointed its first overseas consultant, Melissa Legree, to support and build SAS in North America. Ms Legree is a very experienced SAS Facilitator and SAS service leader in the program and is ideally placed to help extend its reach into these markets.

Research into SAS remains a key priority for both Dr Beaumont and other research teams, particularly in Canada and Ireland. During 2020–2021 multiple studies have either commenced, continued or completed, and the following articles were published:

- ▶ Beaumont, R., Walker, H., Weiss, J., & Sofronoff, K. (2021). Randomized Controlled Trial of a Video Gaming-Based Social Skills Program for Children on the Autism Spectrum. *Journal of Autism and Developmental Disorders*, 1–14.
- ▶ MacEville, D., & Brosnan, G. (2020). Adapting an emotional regulation and social communication skills group programme to teletherapy, in response to the COVID-19 pandemic. *Irish Journal of Psychological Medicine*, 1-6.

In this small program the effective working relationship between the Board and management is a crucial element of its success. The Social Skills Training Pty Ltd Board is appointed by Autism CRC Ltd as the sole shareholder. The SST Board met on six occasions during the reporting period. Its Board members are Carole Green (Chair), Adrian Ford (Executive Director), Andrew Davis and Paul Vincent. Joe McLean resigned from the Board in December 2020 and SST thanks him for his many contributions to SST during his tenure on the Board.

SST values the generous support given by its Board to the ongoing review of its work while also thinking about its future under the dedicated leadership of its Chair, Carole Green. SST also applauds the enthusiastic and hardworking operations team who give so much to ensure this program is available to as many children and their families as possible through the network of providers who offer the program around the world.



5.0 Governance

5.1 Autism CRC Board



Professor Robert van Barneveld (Chair)

BAgrSc (Hon), PhD, RANutr, FAICD

Robert became Chair of Autism CRC in November 2017. He is an experienced Director of small and large businesses, not-for-profits, peak bodies and ASX Top 300. He has extensive experience in corporate governance, research commercialisation and management, and government liaison at state and federal levels.

As a past President of Autism Queensland he is familiar with the needs of families and carers of people on the spectrum. His daughter was initially diagnosed with autism but later re-diagnosed with Rett Syndrome.

Robert was a Director of the Pork CRC Ltd (prior to its wind-up in 2019 and remains a Director of the legacy entity, Australasian Pork Research Institute Ltd) and has led three successful CRC bids, including the Autism CRC bid. He has also been involved in the establishment and transition of CRCs and has worked as a researcher within the Pork, Aquaculture and Aquafin CRCs.

Robert is an Adjunct Professor within the School of Environmental and Rural Science at the University of New England and the School of Agriculture and Food Sciences at the University of Queensland.

Robert is also Group CEO and Managing Director of the SunPork Group of Companies, which initiated the Autism and Agriculture Program and now employs 12 autistic adults in specialist animal care roles.



Carole Green (Deputy Chair)

BAppSc (Comp), GradDipCorpGov, GradDipEd, MInfTech, MBA, CertTeach, GAICD

Carole has been an independent director of Autism CRC since its commencement in July 2013, a director of Social Skills Training Pty Ltd since January 2017 and its Chair since January 2018. Since 2015, Carole has served on Autism CRC's Audit, Risk and Finance Committee, previously being a member of the Remuneration, Nomination and Selection Committee.

Previously, Carole held positions within a number of Cooperative Research Centres (CRCs) including Strategic Manager, Wound Management Innovation CRC, as well as Chief Operating Officer, Construction Innovation CRC. She has also been Company Secretary within CRC contexts.

She has experience in establishment, strategic direction, implementation of processes and systems within CRCs, and exploitation of research outputs. Carole also has more than 20 years' experience working with tertiary education, government, and industry across science, health, education, business and IT. She has a wealth of experience in complex environments with multiple stakeholders, establishing and operating business structures, quality assurance and risk management.



Adrian Ford (Non-Executive Director)

BSocStud, FAICD

Adrian retired as CEO and Company Secretary of Autism Spectrum Australia (Aspect) in late 2019 after more than 19 years of leading Australia's largest national autism-specific service provider for autistic people, their families and their communities. At the same time he moved from being a Nominee Director to a non-Executive Director on the Autism CRC Board as well as taking on a part time role as the Executive Director of Social Skills Training Pty Ltd, a subsidiary of Autism CRC. As well, Adrian is a consultant in his own business, AJF Governance Advisory.

Adrian has extensive experience over 40 years with not-for-profit boards and management, governance structures, strategic planning, risk management, finances, HR and policy frameworks. While at Aspect Adrian was a founding member of the Australian Autism Alliance and a director and former chair of the Australian Advisory Board for Autism (AABA). Adrian also chaired the Organising Committee for the inaugural Asia Pacific Autism Conference (APAC) in 2009 and again chaired APAC in 2017. He was an advisor to the Organising Committee of APAC 2019, held in Singapore – the first held out of Australia.



Dr Shirley Lanning (Independent Director)

BSc (Hons 1), PhD, FAICD

Shirley has been an independent director of Autism CRC since its inception in 2013. During this time, she has served on the R&D Committee, the Remuneration, Nominations and Selection Committee, the Autism CRC Access Committee and the Governance Program Management Committee.

She brings extensive experience in corporate governance, marketing and communications, business development, research management and commercialization in commercial and not-for-profit organisations in the UK and Australia.

She has served as a non-executive Board Director of a number of not-for-profit organisations, including NanoVentures Australia, Nanotechnology Victoria, the Pig Research and Development Corporation and AusBiotech, and as a Member of Government Advisory Councils, including the Federal Government's Advisory Council on Intellectual Property and the Victorian Cancer Agency Consultative Council. Before moving to Australia, she was the inaugural Executive Director of the UK BioIndustry Association.

Shirley has been involved with the CRC Program for many years, serving as Federal Government Visitor to the CRC for Viticulture and the CRC for Cellular Growth Factors. She is a Fellow of the Australian Institute of Company Directors.



Malcolm Mayfield (Independent Director)

BEng (Civil), GAICD

Malcolm is the founder and Managing Director of Autism STAR Pty Ltd. As well as being on the Autism CRC Board, Malcolm is a member of the Australian Autism Research Council, on the Management Committee for the Sylvia Rodger Academy and on the project teams for Future Leaders and Governance.

Malcolm's career includes working as a researcher in the UniSA Civil Engineering Laboratories and as a contract administrator in the construction industry. In those capacities, he has worked on sports stadiums, high-rise buildings, power stations, and subdivisions, and was highly regarded in his field.

Malcolm's view of the world changed when he self-diagnosed his Asperger's Syndrome at the age of 37 and had that diagnosis confirmed a few years later. Patterns in his life that had previously been confusing began to make sense and, as part of that process of greater awareness, he realised that in order to cope and succeed as an adult and a professional, he had developed independent success strategies that could be used by others on the autism spectrum. The concept and manifestation of Autism STAR grew out of that process of self-discovery.

Malcolm's goal is to shine a light on the autism spectrum to show the world that autism is a strength to be cherished and nurtured into success for all.



Scott Reading (Nominee Director)

MCom, MBus (Logistics Management), MAICD

Scott is a Founding Director of the AEIOU Foundation for Children with Autism. AEIOU is an Essential Participant of Autism CRC and is a not-for-profit organisation which was established to deliver high-quality early intervention therapy and care. Its family centred program meets the Guidelines for Good Practice and supports children on the autism spectrum to develop essential life skills, independence, confidence and inclusion. As a parent of a child on the spectrum, Scott understands first-hand the daily challenges that this condition can bring. His son William has been diagnosed with epilepsy, intellectual impairment and low functioning autism.

Scott has over 30 years' experience in senior management and leadership roles in industry sectors including retail, media, direct selling and small business. He has extensive corporate experience with national and international companies including Coles Myer, Gordon & Gotch, Sara Lee, Tupperware

Brands and Nutrimerics. Scott's skill sets include, lobbying, sales, marketing, finance, operations, IT, events management, CRM and fundraising initiatives.

During Scott's terms as a Director of Autism CRC he has served on the Audit, Risk and Finance Committee, the Research and Development Committee, The Sylvia Roger Academy and for a short period as the Managing Director of the CRC during the company's search for a new CEO.



Paul Vincent (Independent Director)

BBus (Acc), FCA, GAICD

Paul is a Chartered Accountant and has been a Director of Vincents Chartered Accountants since 1989. He has extensive experience in commercial litigation, providing evidence for criminal matters (fraud, family law property settlements), professional negligence actions, corporate governance and directors' duty breaches. Paul also mediates and arbitrates financial disputes. His accounting experience covers audit, insolvency, management, taxation and general accounting.

Paul is a regular presenter at conferences across Australia on a range of forensic accounting topics including commercial dispute resolution, quantifying damages in commercial disputes, fraud detection and prevention and proceeds of crime related topics.



Paul Field (Independent Director)

BA (Hons), MA, FAICD

Paul has deep experience in the translation of research in the life sciences, including the development of biobanks, diagnostic tests and biomarkers. He is a strategic advisor to a number of biotechnology companies, and he has in the past worked at the government agency Austrade, facilitating foreign direct investment into Australian biotechnology.

Paul was an inaugural director of Autism CRC from 2013-15, drawn to the CRC through his friendships with parents of autistic children. He was pleased to be reappointed to the Board in April 2018.



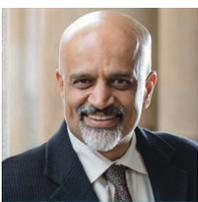
Joe McLean (Nominee Director)

B Bus (Hons), Dip Teach, GAICD

Joe McLean held the position of Director, Research Partnerships, at the University of Queensland (UQ), and joined the Autism CRC Board in April 2018. The Director, Research Partnerships supports the Pro-Vice-Chancellor (Research Partnerships) in developing strategic research partnerships with industry, government and the not-for-profit sector. The role also involves oversight of contracting research services.

Joe has more than 20 years of experience working at the interface of research and markets across a broad range of industries and disciplines. Prior to taking on the position of Director, Research Partnerships, at UQ, Joe was Head of Strategy and Growth for Triple P International Pty Ltd helping develop new markets and advising on business strategy. He spent more than 10 years at UniQuest Pty Limited becoming manager of the social sciences and humanities group as well as leading the Consulting and Research and International Development divisions.

Joe has retired from UQ and stepped down from the Autism CRC Board in December 2020. We thank him for his dedication and service to Autism CRC.



Professor Mohan Krishnamoorthy (Nominee Director)

BSc B'lore, MSc Delhi, MSc, PhD Imperial Coll.

Mohan Krishnamoorthy was Pro Vice-Chancellor (Research Partnerships) at the University of Queensland when he joined the Autism CRC Board in March 2021. The position is responsible for ensuring a strategic approach to the stewardship of the university's research partnerships with industry and institutions. Prior to joining UQ in August 2017, Mohan was at Monash University where he held the position of Pro Vice-Chancellor (Industry Partnerships) since 2015. From 2009 to 2015, Mohan was the inaugural CEO of the IITB-Monash Research Academy, a trans-national research partnership between the Indian Institute of Technology, Bombay, and Monash University, which he helped establish. Before that he was Science and Industry Manager, Program Leader and Member of the Divisional Executive of the CSIRO Mathematical and Information Sciences.

Mohan attended two Board meetings, but stepped down from the Board in April 2021 after accepting a position at RMIT University in Melbourne.

5.2 Autism CRC Committees

Research and Development Committee

The Research and Development Committee is comprised of Essential Participant nominees and members appointed by the Board. The Committee provides a forum for consultation among the Essential Participants, a point of interaction between the Essential Participants and the Board, and guidance and recommendations to the Board in relation to research and development undertaken within the Autism CRC.

There were no investment rounds during the reporting period, hence, the Research and Development Committee did not meet.

The Remuneration, Nominations and Selection Committee

The Remuneration, Nominations and Selection Committee assists the Board in fulfilling its corporate governance responsibilities including:

- ▶ providing recommendations for Director nominees to the Members
- ▶ ensuring a rotation is established whereby at least one third of Directors retire and are eligible for re-election annually
- ▶ establishing a process for the review of Board performance and the development of the Board
- ▶ undertaking succession planning for the Board
- ▶ reviewing the performance and remuneration of the CEO and making recommendations in this regard to the Chair of the Board
- ▶ reviewing the performance and remuneration framework for the Executive Team with the CEO.

During the reporting period, the Remuneration, Nominations and Selection Committee consisted of Professor Robert van Barneveld (Chair), Joe McLean (until January 2021), Paul Field and Adrian Ford.

Audit, Risk and Finance Committee

The Audit, Risk and Finance Committee assists the Board in its oversight of the integrity of financial reporting, internal control structures, audit functions and also compliance and risk management systems relating to the finance and audit functions. This Committee ensures appropriate policies and procedures are in place to underpin best practice governance and to identify and manage corporate risk for the Company.

During the reporting period, the Audit, Risk and Finance Committee met six times and consisted of Paul Vincent (Chair), Carole Green, Malcolm Mayfield, and Joe McLean (until January 2021), with the CEO and CFO also in attendance.

Transition Committee

The Transition Committee was established to provide oversight of plans and activities associated with the wind-up of the Cooperative Research Centres (CRC) Program and the transition of ACRC operations and assets to legacy arrangement post the end of the CRC Funding Agreement at 30 June 2022.

During the reporting period the Transition Committee met three times and consisted of Professor Robert van Barneveld (Chair), Carole Green, Paul Vincent, CEO Andrew Davis and CFO Andrew Borneman.

6.0 Appendices

Appendix 1: List of Autism CRC 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	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

Participant name	Type	Organisation type	ABN
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
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
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
Renaee Beaumont Enterprises Pty Ltd	Other	Industry	50 129 179 675
South Australian Group Enterprises (SAGE)	Other	Private Sector/ End-user	40 005 498 775
Spectrum Space	Other	Industry / End-user	38 262 080 944
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

Appendix 2: Annual Financial Report

Statements of Profit or Loss and Other Comprehensive Income For the financial year ended 30 June 2021

	Consolidated Entity	
	30 June 2021	30 June 2020
	\$	\$
Revenue (cash and in-kind)	19,070,821	17,792,642
Expenses		
Research costs (cash and in-kind)	(9,187,621)	(13,907,776)
Employee benefits expense	(2,175,311)	(1,994,389)
Board fees and related expense	(241,169)	(291,598)
Depreciation and amortisation expense	(262,860)	(194,282)
Impairment Loss	(1,579,918)	-
Other expenses	(1,028,688)	(1,070,576)
Results from operating activities	4,595,254	334,021
Financing income	7,828	13,570
Finance costs	(25,210)	(30,891)
Net finance (costs)/income	(17,382)	(17,321)
Surplus before tax	4,577,872	316,700
Income tax expense	-	(30,300)
Surplus after tax	4,577,872	286,400
Other comprehensive income	-	-
Total comprehensive income for the period	4,577,872	286,400

The operating surplus of the Consolidated Entity for the financial period ended 30 June 2021 was \$4,577,872 (2020: \$286,400). Since 2018 \$5,586,682 cash and in-kind costs associated with Australian Autism Biobank have been recognised on the Statement of Financial Position as an intangible asset. In the financial period ending 2021 an impairment of \$1,579,918 has been recognised against this asset.

In March 2021 the Autism CRC announced \$6,000,000 funding for two major projects to help improve health services and education and employment outcomes for autistic Australians under the Information, Linkages and Capacity Building (ILC) program. The net impact of this funding contributed close to \$2,000,000 to the FY2021 operating surplus, with most activity scheduled for FY2022 and into FY2023.

Statements of Financial Position For the financial year ended 30 June 2021

	Consolidated Entity	
	30 June 2021	30 June 2020
	\$	\$
Current assets		
Cash and cash equivalents	7,526,262	6,267,665
Trade and other receivables	291,330	282,857
Prepayments	44,664	84,087
Current tax asset	-	-
Inventory	11,363	47,807
Total current assets	7,873,619	6,682,416
Non-current assets		
Property, plant and equipment	22,581	33,451
Right-of-use asset	441,293	588,391
Trade and other receivables	-	-
Investment in wholly owned subsidiary	-	-
Formation costs	-	3
Intangible assets	4,779,159	4,387,307
Total non-current assets	5,243,033	5,009,152
Total assets	13,116,652	11,691,568
Current liabilities		
Trade and other payables	478,834	510,320
Provisions	156,762	152,787
Deferred revenues	-	2,952,795
Lease liability	146,849	140,931
Current tax liability	4,149	30,300
Total current liabilities	781,194	3,787,133
Non-current liabilities		
Lease Liability	312,460	459,309
Total Non-current liabilities	312,460	459,309
Total liabilities	1,093,654	4,246,442
Net assets	12,022,998	7,445,126
Equity		
Retained earnings	12,022,998	7,445,126
Total equity	12,022,998	7,445,126

For the purposes of the cash flows statement, cash and cash equivalents includes cash on hand and in banks and deposits at call. Cash at 30 June 2021 includes all Commonwealth funds for the delivery of the CRC Program to June 2022, along with the initial \$2,000,000 DSS ILC funds.

The Autism CRC prepared Special Purpose Finance Statements in FY2021 that were subject to external audit.

Appendix 3: Publications 2020-21

Program 1

Alvares, G.A., Australian Autism Biobank team. (2019). Demographic and Clinical Characteristics of Participants in the Australian Autism Biobank [Poster]. International Society for Autism Research 2019 Annual Meeting, 1-4 May, Canada. International Society for Autism Research.

Barbaro, J. & Freeman, N.C. (2021). Investigating gender differences in the early markers of Autism Spectrum Conditions (ASC) in infants and toddlers. *Research in Autism Spectrum Disorders*, 83, 101745. doi: 10.1016/j.rasd.2021.101745

Barbaro, J., Masi, A., Gilbert, M., Nair, R., Abdullahi, I., Descallar, J., Dissanayake, C., Eastwood, J., Hasan, I., Jalaludin, B., Karlov, L., Khan, F., Kohlhoff, J., Liaw, S.T., Lingam, R., Mendoza Diaz, A., Ong, N., Tam, C.W.M., Unwin, K., Woolfenden, S. & Eapen, V. (2021). A multistate trial of an early surveillance program for autism within General Practices in Australia. *Frontiers in Pediatrics*. doi: 10.3389/fped.2021.640359

Chetcuti, L., Ujarević, M., Varcin, K., Boutrus, M., Wan, M.W., Green, J., Iacono, T., Dissanayake, C., Whitehouse, A.J.O., Hudry, K. & the AICES team (2020). Subgroups of temperament associated with social-emotional difficulties in infants with early signs of autism. *Autism Research*, 13(12):2094-2101. doi: 10.1002/aur.2381

Chetcuti, L., Ujarević, M., Varcin, K., Boutrus, M., Wan, M.W., Slonims, V., Green, J., Segal, L., Iacono, T., Dissanayake, C., Whitehouse, A.J.O. & Hudry, K. (2020). The role of negative affectivity in concurrent relations between caregiver psychological distress and social-emotional difficulties in infants with early signs of autism. *Autism Research*, 13(8):1349-1357. doi: 10.1002/aur.2296

den Houting, J., Adams, D., Roberts, J. & Keen, D. (2020). Investigating the impact of anxious symptomatology in autistic children. *Taylor & Francis, International Journal of Disability, Development and Education*, doi: 10.1080/1034912X.2020.1727420

Hudry, K., Chetcuti, L., Boutrus, M., Pillar, S., Baker, E.K., Dimov, S., Barbaro, J., Green, J., Whitehouse, A.J.O., Varcin, K.J. & the AICES Team (2021). Performance of the Autism Observation Scale for Infants with community-ascertained infants showing early signs of autism. *Autism*, 25(2), 490-501. doi: 10.1177/1362361320965397

Kennedy, L., Smith, J., Chetcuti, L., Bent, C., Pillar, S., Varcin, K., Whitehouse, A.J.O., Hudry, K. & the AICES Team (2020). Parent and child communication predictors of language development in emergent autism [Poster]. Australasian Society for Autism Research Conference, 10-11 December 2020, Online. Australasian Society for Autism Research.

Licari, M.K., Varcin, K., Hudry, K., Leonard, H.C., Alvares, G.A., Pillar, S.V., Stevenson, P.G., Cooper, M.N., Whitehouse, A.J.O. & the AICES team (2021). The course and prognostic capability of motor difficulties in infants showing early signs of autism. *Autism Research*, 14(8), 1759-1768. doi: 10.1002/aur.2545

Luu, J., Jellet, R., Yaari, M., Gilbert, M. & Barbaro, J. (2020). A comparison of children born preterm and full-term on the autism spectrum in a prospective community sample. *Frontiers in Neurology*, 11, 597505. doi: 10.3389/fneur.2020.597505

Taylor, L.J., Eggleston, M.J.F., Thabrew, H., van der Meer, L., Waddington, H., Whitehouse, A.J.O. & Evans, K. (2021). An investigation of adherence to best practice guidelines for autism diagnosis in New Zealand. *Autism*, early online. doi: 10.1177/13623613211015757

Waddington, H., Trembath, D., Varcin, K., Sulek, R., Bent, C., Ashburner, J., Eapen, V., Goodall, E., Hudry, K., Robert, J., Silove, N. & Whitehouse, A. (2021). Interventions for children on the autism spectrum: A systematic umbrella review [Poster]. International Society for Autism Research 2021 Virtual Annual Meeting, 3 May. International Society for Autism Research.

Yap, C.X., Alvares, G.A., Henders, A.K., Lin, T., Wallace, L., Farrelly, A., McLaren, T., Berry, J., Vinkhuyzen, A.A.E., Trzaskowski, M., Zeng, J., Yang, Y., Cleary, D., Grove, R., Hafekost, C., Harun, A., Holdsworth, H., Jellet, R., Khan, F., Lawson, L.P., Leslie, J., Frenk, M.L., Masi, A., Mathew, N.E., Muniandy, M., Nothard, M., Visscher, P.M., Dawson, P.A., Dissanayake, C., Eapen, V., Heussler, H.S., Whitehouse, A.J.O., Wray, N.R. & Gratten, J. (2021). Analysis of common genetic variation and rare CNVs in the Australian Autism Biobank. *Molecular Autism*, 12(12). doi: 10.1186/s13229-020-004

Program 2

Adams, D.M., Clark, M. & Simpson, K.M. (2020). The relationship between child anxiety and the quality of life of children, and parents of children, on the autism spectrum. *Journal of Autism and Developmental Disorders*. doi: org/10.1007/s10803-019-03932-2

Beamish, W., Taylor, A.E., Macdonald, E., Hay, S., Tucker, M. & Paynter, J. (2021). Field-testing an Australian Model of Practice for teaching young school-age students on the autism spectrum. *Research in Developmental Disabilities*, early online. doi: 10.1016/j.ridd.2021.103942

Bruck, S., Robinson, A. & Gallagher, E. (2021). A Model of Practice for improving autism knowledge in teachers of mainstream students on the autism spectrum in Australia. *Australasian Journal of Special and Inclusive Education*, 1-16. doi.org/10.1017/jsi.2021.7

Bruck, S., Webster, A.A. & Clark, T. (2021). Transition support for students on the autism spectrum: a multiple stakeholder perspective. *Journal of Research in Special Education Needs*, early online. doi: 10.1111/1471-3802.12509

Carrington, S., Saggars, B., Shochet, I., Orr, J., Wurfl, A., Vanelli, J. & Nickerson, J. (2021). Researching a whole school approach to school connectedness. *International Journal of Inclusive Education*, early online. doi: 10.1080/13603116.2021.1878298

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Reports 2020-21

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Hudry, K., Varcin, K.J., Chetucti, L., Aulich, A., Bent, C.A., Smith, J., Pillar, S., Whitehouse, A.J.O. (2021). Therapy for infants showing early signs of autism: Final Report. Brisbane: Autism CRC.

van der Meer, L. & Evans, K. (2021). The autism diagnostic process in New Zealand: Final Report. Brisbane: Autism CRC.

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

Program 2

Carrington, S., Sagggers, B. & Harper-Hill, K. (2020). Aboriginal and Torres Strait Islander Community Liaison: Final Report. Brisbane: Autism CRC

Stirling, L., Dissanayake, C., Sofronoff, K., Trembath, D., Westerveld, M., Ashburner, J., Pament, L. & Pettiona, C. (2021). How was your day? Parent, teacher and child perceptions of communication about the school day with children on the autism spectrum. Final Report. Brisbane: Autism CRC.

Program 3

Krzeminska, A., Härteel, C.E.J, Carrero, J. & Samayoa Herrera, X. (2020). Autism @ Work: New insights on effective autism employment practices from a world-first global study. Final Report. Brisbane: Autism CRC.

Simmons, A., Brooker, K., Urbanowicz, A., Moohin, E.J., Kennedy, A. & Harley, D. (2021). Mackay HealthPathways Autism Initiative: Autism HealthPathways. Final Report. Brisbane: Autism CRC.

Not program specific

Bartz, A. & Gatfield, O. (2021). Governance Program 2019: Evaluation report. Brisbane: Autism CRC.

Pellicano, E., Lawson, W., Hall, G., Mahony, J., Lilley, R., Arnold, S., Trollor, J. & Yudell, M. (2020). Uncovering the hidden histories of late-diagnosed autistic adults: Final Report. Brisbane: Autism CRC.

Books and book chapters

Program 1

Rabba, A.S. (2021). Strengthening family resilience using a single-session mindset following a child's diagnosis of Autism Spectrum Disorder. In M.F.

Hoyt, J. Young & P. Rycroft (Eds), *Single session thinking and practice in global, cultural, and familial contexts: Expanding applications*. Routledge. ISBN 9780367514679.

Program 2

Aberdein, R. & Sagggers, B. (2021). Post-school transitions: Supportive strategies informed by real-life experiences. In S. Carrington, B. Sagggers, K. Harper-Hill & M. Whelan (Eds.), *Supporting Students on the Autism Spectrum in Inclusive Schools: A Practical Guide to Implementing Evidence-Based Approaches* (pp. 107-117). Routledge.

Bartlett, T. & Carrington, S. (2021). Autistic voices in autism education research. In S. Carrington, B. Sagggers, K. Harper-Hill & M. Whelan (Eds.), *Research Approaches to Supporting Students on the Autism Spectrum in Inclusive Schools: Outcomes, Challenges and Impact* (pp. 50-65). Routledge.

Beamish, W., Clark, T., Bruck, S., Taylor, A., Robinson, A., Gallagher, E., Gibbs, V. & Harper-Hill, K. (2021). Models of Practice for teachers of students on the autism spectrum. In S. Carrington, B. Sagggers, K. Harper-Hill & M. Whelan (Eds.), *Supporting Students on the Autism Spectrum in Inclusive Schools: A Practical Guide to Implementing Evidence-Based Approaches* (pp. 58-73). Routledge.

Carrington, S. & Sagggers, B. (2021). An introduction to research in inclusive education: Empirical evidence for supporting an inclusive approach for students on the autism spectrum. In S. Carrington, B. Sagggers, K. Harper-Hill & M. Whelan (Eds.), *Research Approaches to Supporting Students on the Autism Spectrum in Inclusive Schools: Outcomes, Challenges and Impact* (pp. 3-16). Routledge.

Carrington, S. & Sagggers, B., Shochet, I., Wurfl, A. & Orr, J. (2021). How to implement a whole-school approach to school connectedness. In S. Carrington, B. Sagggers, K. Harper-Hill & M. Whelan (Eds.), *Supporting Students on the Autism Spectrum in Inclusive Schools: A Practical Guide to Implementing Evidence-Based Approaches* (pp.34-44). Routledge.

Carrington, S., Sagggers, B., Harper-Hill, K. & Whelan, M. (2021). Research Approaches to Supporting Students on the Autism Spectrum in Inclusive Schools: Outcomes, Challenges and Impact. Routledge. ISBN 9780367501877.

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Edwards, C. & Sagggers, B. (2021). Developing communities of practice for educator professional learning – Developing connections in rural and remote regions. In S. Carrington, B. Sagggers, K. Harper-Hill & M. Whelan (Eds.), *Research Approaches to Supporting Students on the Autism Spectrum in Inclusive Schools: Outcomes, Challenges and Impact* (pp. 102-118). Routledge.

Harper-Hill, K., Carrington, S., Sagggers, B., & Whelan, M. (2021). Summary and propositions. In S. Carrington, B. Sagggers, K. Harper-Hill & M. Whelan (Eds.), *Research Approaches to Supporting Students on the Autism Spectrum in Inclusive Schools: Outcomes, Challenges and Impact* (pp. 121-129). Routledge.

Harper-Hill, K., Carrington, S., Sagggers, B., & Whelan, M. (2021). Summary and propositions. In S. Carrington, B. Sagggers, K. Harper-Hill & M. Whelan (Eds.), *Supporting Students on the Autism Spectrum in Inclusive Schools: A Practical Guide to Implementing Evidence-Based Approaches* (pp.151-157). Routledge.

Harper-Hill, K., Whelan, M. & Sagggers, B. (2021). Meeting the needs of all: The case to translate the evidence-base beyond autism. In S. Carrington, B. Sagggers, K. Harper-Hill & M. Whelan (Eds.), *Research Approaches to Supporting Students on the Autism Spectrum in Inclusive Schools: Outcomes, Challenges and Impact* (pp.88-101). Routledge.

Harper-Hill, K., Wilson, W., Armstrong, R., Perrykkad, K., Downing, C. & Ashburner, J. (2021). Sound amplification in school contexts: Implications for inclusive practice. In S. Carrington, B. Sagggers, K. Harper-Hill & M. Whelan (Eds.), *Supporting Students on the Autism Spectrum in Inclusive Schools: A Practical Guide to Implementing Evidence-Based Approaches* (pp.88-103). Routledge.

Hatfield, M., Ciccarelli, M., Mangan, C. & Whelan, M. (2021). Boosting post-school outcomes: Supporting adolescents on the autism spectrum to feel ready for life after school. In S. Carrington, B. Sagggers, K. Harper-Hill & M. Whelan (Eds.), *Supporting Students on the Autism Spectrum in Inclusive Schools: A Practical Guide to Implementing Evidence-Based Approaches* (pp. 118-132). Routledge.

Lawson, W. & Carrington, S. (2021). Inclusive research practice: Engaging autistic individuals and their families in research. In S. Carrington, B. Sagggers, K. Harper-Hill & M. Whelan (Eds.), *Research Approaches to Supporting Students on the Autism Spectrum in Inclusive Schools: Outcomes, Challenges and Impact* (pp. 17-31). Routledge.

Macdonald, L., Ashburner, J. & Harper-Hill, K. (2021). Using structured teaching strategies in mainstream classrooms: Research to practice. In S. Carrington, B. Saggars, K. Harper-Hill & M. Whelan (Eds.), *Supporting Students on the Autism Spectrum in Inclusive Schools: A Practical Guide to Implementing Evidence-Based Approaches* (pp. 74-87). Routledge.

Saggars, B. & Carrington, S. (2021). Moving from a special education model to an inclusive education model: Implications for supporting students on the autism spectrum in inclusive settings – An evidence-based approach. In S. Carrington, B. Saggars, K. Harper-Hill & M. Whelan (Eds.), *Supporting Students on the Autism Spectrum in Inclusive Schools: A Practical Guide to Implementing Evidence-Based Approaches* (pp. 3-13). Routledge.

Saggars, B. & Carrington, S. (2021). Supporting students on the autism spectrum in inclusive schools: Research to inform implementation of support and evidence-based practices. In S. Carrington, B. Saggars, K. Harper-Hill & M. Whelan (Eds.), *Research Approaches to Supporting Students on the Autism Spectrum in Inclusive Schools: Outcomes, Challenges and Impact* (pp.35-49). Routledge.

Shochet, I., Wurfl, A., Orr, J., Kelly, R., Saggars, B. & Carrington, S. (2021). School connectedness to support student mental health and wellbeing. In S. Carrington, B. Saggars, K. Harper-Hill & M. Whelan (Eds.), *Supporting Students on the Autism Spectrum in Inclusive Schools: A Practical Guide to Implementing Evidence-Based Approaches* (pp. 17-32). Routledge.

Webster, A., Saggars, B. & Carrington, S. (2021). Inclusive teaching for students on the autism spectrum. In S. Carrington, B. Saggars, K. Harper-Hill & M. Whelan (Eds.), *Supporting Students on the Autism Spectrum in Inclusive Schools: A Practical Guide to Implementing Evidence-Based Approaches* (pp.47-57). Routledge.

Whelan, M., Kerr, J., Harper-Hill, K. & Zelenko, O. (2021). With teachers, for teachers: Knowledge translation and professional learning. In S. Carrington, B. Saggars, K. Harper-Hill & M. Whelan (Eds.), *Research Approaches to Supporting Students on the Autism Spectrum in Inclusive Schools: Outcomes, Challenges and Impact* (pp.69-87). Routledge.

Whelan, M., Mavropoulou, S. & Browning, Y. (2021). A creative strengths-based post-school transition project for young adults on the autism spectrum: Super Conductor and the Big Game Orchestra. In S. Carrington, B. Saggars, K. Harper-Hill & M. Whelan (Eds.), *Supporting Students on the Autism Spectrum in Inclusive Schools: A Practical Guide to Implementing Evidence-Based Approaches* (pp.133-148). Routledge.

Not program specific

Ciccarelli, M. (2021) Emerging Occupational Therapy Practice Areas and the Use of Technology. In *Occupational Therapy Australia: Professional and Practice Issues – Second Edition*, Routledge. ISBN 9781000356502.

Appendix 4: Resources developed 2020-21

Program 1

Autism CRC. (2020). National Guideline Implementation Toolkit: Baseline Evaluation and Audit Tool. Brisbane: Autism CRC.

Autism CRC. (2020). National Guideline Implementation Toolkit: Comprehensive needs assessment [fact sheet, video, online content]. Brisbane: Autism CRC.

Autism CRC. (2020). National Guideline Implementation Toolkit: Diagnostic evaluation [fact sheet, video, online content]. Brisbane: Autism CRC.

Autism CRC. (2020). National Guideline Implementation Toolkit: For adults undergoing an assessment [fact sheet, video, online content]. Brisbane: Autism CRC.

Autism CRC. (2020). National Guideline Implementation Toolkit: For parents and caregivers of children undergoing an assessment [fact sheet, video, online content]. Brisbane: Autism CRC.

Autism CRC. (2020). National Guideline Implementation Toolkit: Guiding principles [fact sheet, video, online content]. Brisbane: Autism CRC.

Autism CRC. (2020). National Guideline Implementation Toolkit: Important considerations [fact sheet, video, online content]. Brisbane: Autism CRC.

Autism CRC. (2020). National Guideline Implementation Toolkit: Setting a new standard [fact sheet, video, online content]. Brisbane: Autism CRC.

Autism CRC. (2020). National Guideline Implementation Toolkit: The assessment process [fact sheet, video, online content]. Brisbane: Autism CRC.

Eapen, V., Masi, A. & Kahn, F. (2020). Australian Autism Biobank follow-up cohort pilot study: Research snapshot. Brisbane: Autism CRC.

Hudry, K., Varcin, K.J., Chetucti, L., Aulich, A., Bent, C.A., Smith, J., Pillar, S., Whitehouse, A.J.O. (2021). Therapy for infants showing early signs of autism: Research snapshot. Brisbane: Autism CRC.

Simmons, T., Kennedy, A. & Evans, K. (2021). Health, assessment and diagnosis: Autism Month Webinar. Brisbane: Autism CRC.

Trembath, D., Goodall, E. & Whitehouse, A. (2021). Interventions for children on the autism spectrum: A synthesis of evidence: Autism Month Webinar. Brisbane: Autism CRC.

van der Meer, L. & Evans, K. (2021). The autism diagnostic process in New Zealand. Research snapshot. Brisbane: Autism CRC.

Whitehouse, A., Varcin, K., Waddington, H., Sulek, R., Bent, C., Ashburner, J., Eapen, V., Goodall, E., Hudry, K., Roberts, J., Silove, N. & Trembath, D. (2020). A review of evidence for interventions for children on the autism spectrum (Summary 2 of 2: Umbrella review). Brisbane: Autism CRC.

Whitehouse, A., Varcin, K., Waddington, H., Sulek, R., Bent, C., Ashburner, J., Eapen, V., Goodall, E., Hudry, K., Roberts, J., Silove, N. & Trembath, D. (2020). Interventions for children on the autism spectrum, and their application in the Australian community (Summary 1 of 2: Narrative review). Brisbane: Autism CRC.

Whitehouse, A., Varcin, K., Waddington, H., Sulek, R., Bent, C., Ashburner, J., Eapen, V., Goodall, E., Hudry, K., Roberts, J., Silove, N. & Trembath, D. (2020). Interventions for children on the autism spectrum category overview: Animal-assisted interventions. Brisbane: Autism CRC.

Whitehouse, A., Varcin, K., Waddington, H., Sulek, R., Bent, C., Ashburner, J., Eapen, V., Goodall, E., Hudry, K., Roberts, J., Silove, N. & Trembath, D. (2020). Interventions for children on the autism spectrum category overview: Behavioural interventions. Brisbane: Autism CRC.

Whitehouse, A., Varcin, K., Waddington, H., Sulek, R., Bent, C., Ashburner, J., Eapen, V., Goodall, E., Hudry, K., Roberts, J., Silove, N. & Trembath, D. (2020). Interventions for children on the autism spectrum category overview: Cognitive behaviour therapy. Brisbane: Autism CRC.

Whitehouse, A., Varcin, K., Waddington, H., Sulek, R., Bent, C., Ashburner, J., Eapen, V., Goodall, E., Hudry, K., Roberts, J., Silove, N. & Trembath, D. (2020). Interventions for children on the autism spectrum category overview: Developmental interventions. Brisbane: Autism CRC.

Whitehouse, A., Varcin, K., Waddington, H., Sulek, R., Bent, C., Ashburner, J., Eapen, V., Goodall, E., Hudry, K., Roberts, J., Silove, N. & Trembath, D. (2020). Interventions for children on the autism spectrum category overview: Naturalistic developmental behavioural interventions. Brisbane: Autism CRC.

Whitehouse, A., Varcin, K., Waddington, H., Sulek, R., Bent, C., Ashburner, J., Eapen, V., Goodall, E., Hudry, K., Roberts, J., Silove, N. & Trembath, D. (2020). Interventions for children on the autism spectrum category overview: Sensory-based interventions. Brisbane: Autism CRC.

Whitehouse, A., Varcin, K., Waddington, H., Sulek, R., Bent, C., Ashburner, J., Eapen, V., Goodall, E., Hudry, K., Roberts, J., Silove, N. & Trembath, D. (2020). Interventions for children on the autism spectrum category overview: Technology-based interventions. Brisbane: Autism CRC.

Whitehouse, A., Varcin, K., Waddington, H., Sulek, R., Bent, C., Ashburner, J., Eapen, V., Goodall, E., Hudry, K., Roberts, J., Silove, N. & Trembath, D. (2020). Interventions for children on the autism spectrum category overview: Treatment and Education of Autistic and related Communication-handicapped Children (TEACCH) interventions. Brisbane: Autism CRC.

Program 2

Autism CRC. (2021). *StepWrite* [iPad app]. Brisbane: Autism CRC. apps.apple.com/au/app/stepwrite/id1542297076

Bradford, D., Ireland, D., McDonald, J., Tan, T., Hatfield-White, E., Regan, T., Kidd, T. & Farr-Wharton, G. (2020). 'Hear' to help chatbot: Co-development of a chatbot to facilitate participation in tertiary education for students on the autism spectrum and those with related conditions. Research snapshot. Brisbane: Autism CRC.

Carrington, S., Sagggers, B. & Harper-Hill, K. (2020). The Aboriginal and Torres Strait Islander Community Partnership. Research snapshot. Brisbane: Autism CRC.

Ciccarelli, M., Hatfield, M., Portsmouth, L., Wilmot, A., & Falkmer, M. (2020). Better Outcomes and Successful Transitions for Autism (BOOST-A): From research to practice. Research snapshot. Brisbane: Autism CRC.

Harper-Hill, K. (2020). Ask inclusionED session 1: Sensory needs [instructional video]. Brisbane: Autism CRC.

Harper-Hill, K. (2020). Ask inclusionED session 2: Use evidence to support students to independently transition between tasks [instructional video]. Brisbane: Autism CRC.

Harper-Hill, K. (2020). Ask inclusionED session 3: Use the evidence to support student's relationship with their peers [instructional video]. Brisbane: Autism CRC.

Shochet, I.M., Sagggers, B.R., Carrington, S.B., Orr, J.A, Wurfl, A.M., Mazzucchelli, T., Duncan, B.M., Kelly, R.L., Smith, C.L., Gill, C., Haas, K., & O'Hare, A. (2020). School Connectedness: Acceptance, respect and support. Research snapshot. Brisbane: Autism CRC.

Teaching practices derived from *inclusionED* core research project [Models of Practice]:

- Use visual supports to increase understanding [Teaching practice]. Autism CRC. inclusioned.edu.au/node/2292
- Providing a calm space for students [Teaching practice]. Autism CRC. inclusioned.edu.au/node/2252
- Reduce student conflict through social coaching [Teaching practice]. Autism CRC. inclusioned.edu.au/node/2290
- Strengthen school belonging and emotional trust [Teaching practice]. Autism CRC. inclusioned.edu.au/node/2289
- Reduce student anxiety with routines and visual schedules [Teaching practice]. Autism CRC. inclusioned.edu.au/node/2393

Westerveld, M., Paynter, J., Simpson, K., McCartney, D., Hurley, A., & O'Leary, K. (2020). Story Time: Providing early literacy sessions in libraries to preschoolers on the autism spectrum and their parents. Research snapshot. Brisbane: Autism CRC.

Wyeth, P. & Ciccarelli, M. (2021). Writing and transitions: Autism Month Webinar. Brisbane: Autism CRC.

Program 3

Autism CRC. (2020). myWAY Employability [web platform]. Brisbane: Autism CRC. www.mywayemployability.com.au

Kirby, A.V.; Moderator. McDonald, K.E., Cusack, J., Maddox, B., Mangan, C., Morgan, L., Roux, A., Singhal, N. & Zener, D.; Participants. (2021). An Expert Discussion on Knowledge Translation in Autism in Adulthood Research. *Autism in Adulthood*. Mar 2021:11-17. doi.org/10.1089/aut.2020.29017.avk

Krzeminska, A., Härtel, C.E.J, Carrero, J. & Samayoa Herrera, X. (2020). New insights on effective autism employment practices. Research snapshot. Brisbane: Autism CRC.

Krzeminska, A., Hartel, C., Girdler, S., Judge, D. & Slaven, D. (2021). Autism at work: Autism Month Webinar. Brisbane: Autism CRC.

Kuzminski, R., Lawson, W., Phillips, S., Purkis, Y. & Thompson, M. (2021). Quality of Life: A Photovoice Gallery & Webinar. Brisbane: Autism CRC.

Richdale, A.L., Haschek, A., Lawson, L.P., Haywards, S.M., & Abdullahi, I. (2021). Depression, Anxiety and Autistic Adults [Pamphlet]. Brisbane: Autism CRC.

Richdale, A.L., Haschek, A., Lawson, L.P., Haywards, S.M., & Abdullahi, I. (2021). Depression, Anxiety and Autistic Adults [Presentation resource]. Brisbane: Autism CRC.

Richdale, A.L., Haschek, A., Lawson, L.P., Haywards, S.M., & Abdullahi, I. (2021). Supporting mental health: What young Australian autistic adults tell us [Factsheet]. Brisbane: Autism CRC.

Richdale, A.L., Haschek, A., Lawson, L.P., Haywards, S.M., & Abdullahi, I. (2021). Supporting mental health: What young Australian autistic adults tell us [Presentation resource]. Brisbane: Autism CRC.

Simmons, A., Brooker, K., Urbanowicz, A., Moohin, E.J., Kennedy, A. & Harley, D. (2021). Autism HealthPathways. Research snapshot. Brisbane: Autism CRC.

Not program specific

Bartz, A. & Gatfield, O. (2021). Governance Program 2019: Evaluation report. Research snapshot. Brisbane: Autism CRC.

Bradshaw, P., Poulsen, R. & Bennett, M. (2021). Autistic scholars panel: Autism Month Webinar. Brisbane: Autism CRC.

Pellicano, E., Lawson, W. & Haar, V. (2021). Australian Autism Research Council 2020-21 Research Priority Update: Autism Month Webinar. Brisbane: Autism CRC.

Pellicano, E., Lawson, W., Hall, G., Mahony, J., Lilley, R., Arnold, S., Trollor, J., & Yudell, M. (2020). Uncovering the hidden histories of late-diagnosed autistic adults. Research snapshot. Brisbane: Autism CRC.

Appendix 5: Conference presentations 2020-21

Program 1

Barbaro, J. & Freeman, N. (2020). Investigating gender differences in the early markers of Autism Spectrum Conditions (ASC) in infants and toddlers. Australasian Society for Autism Research Conference, 10-11 December 2020, Online. Australasian Society for Autism Research.

Chetcuti, L., Uljarević, M., Varcin, K., Boutrus, M., Pillar, S., Dimov, S., Barbaro, J., Dissanayake, C., Wan, M.W., Whitehouse, A.J.O., Hudry, K. & the AICES Team (2020). Child temperament and caregiver psychological distress predict internalizing and externalizing symptoms in infants with early autism signs. Australasian Society for Autism Research Conference, 10-11 December 2020, Online. Australasian Society for Autism Research.

Chetcuti, L., Uljarević, M., Varcin, K., Boutrus, M., Pillar, S., Dimov, S., Barbaro, J., Dissanayake, C., Whitehouse, A.J.O., Hudry, K. & the AICES Team (2020). Subgrouping infants with early autism signs on the basis of temperament: Classification continuity and predictive utility. Australasian Society for Autism Research Conference, 10-11 December 2020, Online. Australasian Society for Autism Research.

Evans, K., Johnston, S., Boutrus, M., Eggleston, M., Taylor, L., Thabrew, H., Waddington, H., Whitehouse, A.J.O. & van der Meer, L. (2020). The autism diagnostic process in New Zealand: A call for action from parents/caregivers. Australasian Society for Autism Research Conference, 10-11 December 2020, Online. Australasian Society for Autism Research.

Evans, K., van der Meer, L., Johnston, S., Boutrus, M., Eggleston, M., Taylor, L., Thabrew, H., Waddington, H. & Whitehouse, A.J.O. (2020). Strategies for improving satisfaction with the autism diagnostic process in New Zealand: an autistic adults' perspective. Australasian Society for Autism Research Conference, 10-11 December 2020, Online. Australasian Society for Autism Research.

Hudry, K., Smith, J., Pillar, S., Varcin, K., Whitehouse, A.J.O. & the AICES Team (2020). Genuine gains from pre-emptive intervention for the language development of infants showing early signs of autism. Australasian Society for Autism Research Conference, 10-11 December 2020, Online. Australasian Society for Autism Research.

Hudry, K., Varcin, K., Chetcuti, L., Boutrus, M., Bent, C. & Whitehouse, A.J.O. (2020). Eye-tracking as an aide to the early identification of autism: Proof-of-concept for a two-minute preferential attention protocol. Australasian Society for Autism Research Conference, 10-11 December 2020, Online. Australasian Society for Autism Research.

Rabba, A.S. (2021). Strengthening family resilience following a child's diagnosis of autism: A single session model. APS College of Educational and Developmental Psychologists (CEDP) Conference 2021, 11-12 February. Online. Australian Psychological Society.

Smith, J., Chetcuti, L., Varcin, K., Bent, C., Boutrus, M., Cooper, M., Clark, A., Dimov, S., Green, J., Pillar, S., Slonims, V., Wan, M.W., Whitehouse, A.J.O., Hudry, K. & the AICES Team (2020). Are there reciprocal associations between parental sensitivity and infant language skills among dyads where infants show early signs of autism? Australasian Society for Autism Research Conference, 10-11 December 2020, Online. Australasian Society for Autism Research.

Program 2

Adams, D., Simpson, K. & Young, K. (2020). Teacher-reported signs of anxiety in students on the autism spectrum in and outside of the classroom. Australasian Society for Autism Research Conference, 10-11 December 2020, Online. Australasian Society for Autism Research.

Ambrose, K., Adams, D. & Simpson, K. (2020). The relationship between anxiety and participation in children on the autism spectrum. Australasian Society for Autism Research Conference, 10-11 December 2020, Online. Australasian Society for Autism Research.

Clark, M., Adams, D., Simpson, K. (2020). Profiles and predictors of thriving in children on the autism spectrum. Australasian Society for Autism Research Conference, 10-11 December 2020, Online. Australasian Society for Autism Research.

Simpson, K. & Adams, D. (2020). Identifying environmental barriers to participation for children on the autism spectrum in out of school activities. Australasian Society for Autism Research Conference, 10-11 December 2020, Online. Australasian Society for Autism Research.

Wicks, R., Westerveld, M., Paynter, J. & Stainer, M. (2020). Print vs. Pictures: What do children with and without autism look at during shared book reading? Australasian Society for Autism Research Conference, 10-11 December 2020, Online. Australasian Society for Autism Research.

Program 3

Arnold, S.R.C., Higgins, J., Hwang, Y.I., Richdale, A.L., Trollor, J.N. & Lawson, L.P. (2021). The Impact of Diagnosis Scale- Revised (IODS-R) [Poster]. International Society for Autism Research 2021 Virtual Annual Meeting, 3-7 May, Online. International Society for Autism Research.

Arnold, S.R.C., Lawson, L.P., Huang, Y., Hwang, Y.I., Higgins, J., Richdale, A.L., & Trollor, J.N. (2020). Development of the Impact of Diagnosis Scale-Revised (IODS-R). Australasian Society for Autism Research Conference, 10-11 December 2020, Online. Australasian Society for Autism Research.

Bradshaw, P., Urbanowicz, A., Pellicano, E., van Driel, M. & Brooker, K. (2020). Autistic adults' experiences using GP services in Australia. Australasian Society for Autism Research Conference, 10-11 December 2020, Online. Australasian Society for Autism Research.

Brooker, K., Urbanowicz, A., Mahony, J., Hall, G., Clapham, H., Isaacs, K., & Harley, D. (2020). The Autism CHAP: A Comprehensive Health Assessment Program for autistic adults with intellectual disability. Australasian Society for Autism Research Conference, 10-11 December 2020, Online. Australasian Society for Autism Research.

D'Arcy, E., Evans, K., Chamberlain, A., Hayden-Evans, M., Milbourn, B., Whitehouse, A.J.O., Eapen, V., Wray, J., Bölte, S. & Girdler, S.J. (2020). A picture of functioning, strengths, and support needs of young children diagnosed with, or suspected of, neurodevelopmental conditions: Using the international classification of functioning, disability and health as a framework [Poster]. Australasian Society for Autism Research Conference, 10-11 December 2020, Online. Australasian Society for Autism Research.

D'Arcy, E., Evans, K., Chamberlain, A., Hayden-Evans, M., Milbourn, B., Whitehouse, A.J.O., Eapen, V., Wray, J., Bölte, S. & Girdler, S.J. (2020). Capturing a holistic picture of functioning: Development and piloting of an assessment of functioning tool based on the international classification of functioning, disability and health core sets for neurodevelopmental conditions. Australasian Society for Autism Research Conference, 10-11 December 2020, Online. Australasian Society for Autism Research.

D'Arcy, E., Evans, K., Milbourn, B. & Girdler, S.J. (2020). Assessing functioning for individuals diagnosed with neurodevelopmental conditions: A snapshot of practices across Australia [Poster]. Australasian Society for Autism Research Conference, 10-11 December 2020, Online. Australasian Society for Autism Research.

D'Arcy, E., Wallace, K., Evans, K., Chamberlain, A., Milbourn, B., Bölte, S. & Girdler, S.J. (2020). Content validity of assessment of functioning and development tools for young children diagnosed with neurodevelopmental conditions: Comparison to the international classification of functioning, disability and health and core sets. Australasian Society for Autism Research Conference, 10-11 December 2020, Online. Australasian Society for Autism Research.

Higgins, J., Weise, J., Trollor, J.N., Pellicano, E., & Arnold, S.R.C. (2020). A consensus definition of autistic burnout. Australasian Society for Autism Research Conference, 10-11 December 2020, Online. Australasian Society for Autism Research.

Higgins, J., Weise, J., Trollor, J.N., Pellicano, E. & Arnold, S.R.C. (2021). Defining autistic burnout using grounded Delphi method: Autistic burnout through the eyes of experts by lived experience [Poster]. International Society for Autism Research 2021 Virtual Annual Meeting, 3-7 May, Online. International Society for Autism Research.

Huang, Y., Arnold, S.R.C., Foley, K.R. & Trollor, J.N. (2021). Predictors of autism diagnosis age in a community sample of Australian adults. International Society for Autism Research 2021 Virtual Annual Meeting, 3-7 May, Online. International Society for Autism Research.

Kuzminski, R., Falkmer, M., Philips, S., Lawson, W., Bölte, S., Girdler, S.J. & Milbourn, B. (2020). Co-production and photovoice in the digital age: Capturing quality of life. Australasian Society for Autism Research Conference, 10-11 December 2020, Online. Australasian Society for Autism Research.

Kuzminski, R.L., Falkmer, M., Phillips, S., Lawson, W., Bölte, S., Girdler, S.J. & Milbourn, B.T. (2021). Me, my environment and my quality of life: Understanding autistic quality of life using photography. International Society for Autism Research 2021 Virtual Annual Meeting, 3-7 May, Online. International Society for Autism Research.

Lawson, L.P., Wong, L., Haschek, A. & Richdale, A.L. (2020). Does mindful awareness mediate the impact of somatic arousal on anxiety or sleep quality? Australasian Society for Autism Research Conference, 10-11 December 2020, Online. Australasian Society for Autism Research.

Lilley, R., Lawson, W., Hall, G., Mahony, J., Arnold, S.R.C., Trollor, J.N., Yudell, M. & Pellicano, E. (2020). 'A way to be me': Autobiographical reflections of late-diagnosed autistic adults. Australasian Society for Autism Research Conference, 10-11 December 2020, Online. Australasian Society for Autism Research.

Mangan, C., James, B., Ciccirelli, M., Wilmott, A. & Creece, A. (2020). Human centred (digital) design and coproduction. Australasian Society for Autism Research Conference, 10-11 December 2020, Online. Australasian Society for Autism Research.

Muniandy, M., Richdale, A.L., Arnold, S.R.C., Trollor, J.N. & Lawson, L.P. (2020). Associations between coping strategies and mental health in autistic adults. Australasian Society for Autism Research Conference, 10-11 December 2020, Online. Australasian Society for Autism Research.

Muniandy, M., Richdale, A.L., Arnold, S.R.C., Trollor, J.N. & Lawson, L.P. (2020). Inter-relationship between resilience, coping strategies and mental health in autistic adults. Australasian Society for Autism Research Conference, 10-11 December 2020, Online. Australasian Society for Autism Research.

Simmons, T., Kennedy, A., Brooker, K., Harley, D. & Urbanowicz, A. (2020). Mackay HealthPathways autism initiative: Developing and evaluating clinical care pathways for autistic children, adolescents and adults. Australasian Society for Autism Research Conference, 10-11 December 2020, Online. Australasian Society for Autism Research.

Tang, J., Falkmer, M., Chen, N.T.C., Bölte, S. & Girdler, S.J. (2020). Development and feasibility of MindChipTM: A facilitator-mediated online social emotional program for autistic adults. Australasian Society for Autism Research Conference, 10-11 December 2020, Online. Australasian Society for Autism Research.

Not program specific

den Houting, J., Lawson, W. & Haar, V. (2020). Working together: The future of autism research. Australasian Society for Autism Research Conference, 10-11 December 2020, Online. Australasian Society for Autism Research.

den Houting, J. & Pellicano, E. (2020). "I think it's the way of the future?": Stakeholders' perspectives on participatory research within the Autism CRC. Australasian Society for Autism Research Conference, 10-11 December 2020, Online. Australasian Society for Autism Research.

Lawson, W., Hall, G., Mahony, J., Lilley, R., Arnold, S.R.C., Trollor, J.N., Yudell, M. & Pellicano, E. (2020). "This is a journey and I've got to keep going?": Understanding experiences of late diagnosis through an oral history approach. Australasian Society for Autism Research Conference, 10-11 December 2020, Online. Australasian Society for Autism Research.

Pellicano, E., Lawson, W., Hall, G., Mahony, J., Lilley, R., Arnold, S.R.C., Trollor, J.N. & Yudell, M. (2020). "I knew she'd get it and get me": Exploring the potential impact of a participatory approach in a study on the hidden histories of late-diagnosed autistic adults. Australasian Society for Autism Research Conference, 10-11 December 2020, Online. Australasian Society for Autism Research.

Appendix 6: Intellectual property

Description	Project reference	Nature of IP	Background IP
<p>National guideline for assessment and diagnosis of autism in Australia</p> <p>NHMRC approved guideline and associated supporting resources. Consultation data and analysis.</p>	0.007RS	Copyright and confidential information.	
<p>Autism and agriculture</p> <p>Employment program resources. Research design, data, analysis, reports and publications.</p>	0.008RC	Copyright.	
<p>Participatory autism research</p> <p>Research practice guide. Research design, data, analysis, reports and publications.</p>	0.011RS	Copyright and confidential information.	
<p>Reliability, validity and usability of assessment of functioning tools</p> <p>Research design, data, analysis, reports and publications.</p>	0.012RS	Copyright and confidential information.	
<p>Histories of late-diagnosed autistic adults</p> <p>Research design, data, analysis, reports and publications.</p>	0.013RI	Copyright and confidential information.	
<p>Achieving financial wellbeing</p> <p>Research design, data, analysis, reports and publications.</p>	0.021RS	Copyright and confidential information.	
<p>Relate-ABLE</p> <p>Application design, prototype, source code, content, requirements and specifications. Research design, data, analysis, report and publications.</p>	0.022RC	Copyright and confidential information.	
<p>Creation of the Australian Autism Biobank</p> <p>Database, phenotypic and biological data, data dictionary. Research design, analysis, research reports and publications.</p>	1.002RC	Copyright and confidential information.	
<p>AXAS (TM) autism related risk prediction software*</p> <p>Software code related to AXAS tool.</p>	1.003RC	Copyright and trademark.	AXAS software owned by University of Queensland.
<p>Graduate certificate in autism diagnosis</p> <p>Course materials, units, online content, assessment videos. Research design, data, analysis, reports and publications.</p>	1.004RC	Copyright and confidential information.	
<p>Developmental surveillance for autism</p> <p>Training materials and assessment videos. Research design, data, analysis, reports and publications.</p>	1.005RC	Copyright and confidential information.	Social Attention and Communication Study-Revised (SACS-R) developed and owned by La Trobe University.
<p>Transcriptome analysis of human brain tissue</p> <p>Research design, data, analysis, reports and publications.</p>	1.019RI	Copyright and confidential information.	
<p>Brainstorm</p> <p>Model for stem cell transduction. Research design, data, analysis, reports and publications.</p>	1.020RS	Copyright and confidential information.	
<p>Diagnostic practices and reliability in Australia</p> <p>Research design, data, analysis, reports and publications.</p>	1.021RS	Copyright and confidential information.	

Description	Project reference	Nature of IP	Background IP
<p>Pathways beyond diagnosis Family Support Program online and paper format, website source code, design and content, model of single session therapy post diagnosis and facilitator manual. Research design, data, analysis, reports and publications.</p>	1.022RS	Copyright and confidential Information.	
<p>Autism subtyping Research design, data, analysis, reports and publications.</p>	1.023RS	Copyright and confidential information.	
<p>Brain network connectivity Research design, data, analysis, reports and publications.</p>	1.033RI	Copyright and confidential information.	
<p>Systems genomics Research design, protocols, system genomics data, analysis, reports and publications.</p>	1.042RC	Copyright and confidential information.	
<p>Therapy for infants showing early signs of autism Development and/or enhancements to therapy model and associated materials. Research design, data, analysis, reports and publications.</p>	1.043RS	Copyright and confidential information.	iBASIS-VIPP owned by University of Manchester, SACS system owned by La Trobe University.
<p>Diagnostic inconsistencies in New Zealand Research design, data, analysis, reports and publications.</p>	1.058RU	Copyright and confidential information.	
<p>Australian autism biobank pilot Research design, data, analysis, reports and publications.</p>	1.059RU	Copyright and confidential information.	
<p>Multistate trial of an early surveillance program in general practice Research design, data, analysis, reports and publications.</p>	1.064RS	Copyright and confidential information.	<p>SACS system owned by La Trobe University.</p> <p>Frances Glascoe is the owner of IP for PEDS. The Royal Children's Hospital Melbourne holds the Australian Licence for the use of PEDS.</p> <p>LTSAE and Q-CHAT-10 made available by UNSW.</p>
<p>Detection of white matter microstructural alterations Research design, data, analysis, reports and publications.</p>	1.065RS	Copyright and confidential information.	
<p>Inflammation and neuromodulation in autism Research design, data, analysis, reports and publications.</p>	1.073RU	Copyright and confidential information.	
<p>Biological and behavioural attributes leading to sleep difficulties Research design, data, analysis, reports and publications.</p>	1.074RU	Copyright and confidential Information.	
<p>Sensory subtypes in children on the autism spectrum Research design, data, analysis, reports and publications.</p>	1.075RU	Copyright and confidential information.	

Description	Project reference	Nature of IP	Background IP
<p>Synthesis of evidence of autism early intervention approaches*</p> <p>Research design, data, analysis, reports and publications.</p>	1.077RC	Copyright and confidential information.	Project IP owned by the NDIA.
<p>School years program (Program 2)</p> <p>Conceptual model for in-kind contributions.</p>	2.006RC	Copyright.	
<p>Longitudinal study of Australian students on the autism spectrum</p> <p>Research design, data derived from parent, teacher questionnaires, analysis, reports and publications.</p>	2.007RC	Copyright and confidential information.	
<p>Secret Agent Society whole of class</p> <p>Secret Agent Society whole of class program, training materials. Research design, data, analysis, reports and publications.</p>	2.008RC 2.008RC_PP	Copyright and confidential information.	SAS Program IP owned by Autism CRC subsidiary, Social Skills Training Pty Ltd, and Renae Beaumont Enterprises Pty Ltd..
<p>Education needs analysis</p> <p>Research design, data derived from teacher, student and parent surveys, analysis, reports and publications. <i>inclusionED</i> content and multimedia resources.</p>	2.009RC	Copyright and confidential Information.	
<p>Overcoming difficulties on written expression and StepWrite</p> <p><i>StepWrite</i> iOS app game format, design, source code and content. Teacher manuals and training materials. Research design, data, analysis, reports and publications. <i>inclusionED</i> content and multimedia resources.</p>	2.010RS 2.053RU	Copyright and confidential information.	
<p>Helping students stay on task and move between tasks</p> <p>Teacher training packages and resources for structured teaching. Research design, data, analysis, reports and publications. <i>inclusionED</i> content, multimedia resources.</p>	2.011RC 2.011RC_PP	Copyright and confidential information.	Original Structured Teaching Resources owned by Aspect.
<p>Emergent Literacy suite</p> <p>Shared book reading intervention and multimedia resources. Research design, data, analysis, reports and publications.</p>	2.024RI 2.034RI 2.035RU	Copyright and confidential Information.	Parent-child book reading checklist owned by Griffith University. Child assessment data owned by AEIOU.
<p>Autism, anxiety and school functioning</p> <p>Research design, data, analysis, reports and publications.</p>	2.025RI	Copyright and confidential information.	
<p>Lego robotics club online</p> <p>Robotics online resource kits, manual for teachers, <i>inclusionED</i> content and multimedia resources. Research design, data, analysis, reports and publications.</p>	2.026RI	Copyright and confidential information.	
<p>Early Years behaviour support project</p> <p>Methods, tools and materials for teleconsultation training and intervention support. Research design, data, analysis, reports and publications.</p>	2.027RS 2.027RS_PP	Copyright and confidential information.	My Calendar App owned by Queensland University of Technology.
<p>Classroom acoustics</p> <p>Research design, data, analysis, reports and publications. <i>inclusionED</i> content and multimedia resources.</p>	2.028RS	Copyright and confidential information.	

Description	Project reference	Nature of IP	Background IP
<p>School connectedness Resourceful Adolescent Program and training materials for parents, teachers, adolescents, RAP Program adaptations for Autism (RAP-A). Research design, data, analysis, reports and publications. <i>inclusionED</i> content and multimedia resources.</p>	2.029RS 2.029RS_PP	Copyright and confidential information.	RAP Program owned by Ian Shochet. RAP-A owned by Queensland University of Technology.
<p>School connectedness online resource Website design, source code and content utilised in www.autismteenwellbeing.com.au.</p>	2.029RS_PP 2	Copyright and confidential information.	RAP Program owned by Ian Shochet. RAP-A owned by Queensland University of Technology.
<p>How was your day? Research design, data derived from parent, teacher and child surveys, analysis, reports and publications.</p>	2.036RI	Copyright and confidential information.	
<p>Transition models of practice Models of practice resources. Website design, source code and content. Research design, evaluation data, analysis, reports and publications. <i>inclusionED</i> content and multimedia resources.</p>	2.037RS 2.037RS_PP	Copyright and confidential information.	
<p><i>inclusionED</i> design and content development Website design, source code, content, multimedia resources, logo and livery. Community of practice and system data. Research design, evaluation data, analysis, reports and publications.</p>	2.045RU 2.063RU	Copyright and confidential information.	
<p>Aboriginal and Torres Strait Islander Community Liaison Research design, data, analysis and reports.</p>	2.051RS_PP	Copyright and confidential information.	
<p>StoryTime early literacy training program E-learning training program for librarians, multimedia resources. Research design and multimedia content and e-learning program modules. Research data, analysis, reports and publications.</p>	2.052RU	Copyright and confidential information.	
<p>Middle Years behaviour support project Methods, tools and materials for teleconsultation training and intervention support. Teleconsultation guide, <i>inclusionED</i> content and multimedia resources. Research design, evaluation data, analysis, reports and publications.</p>	2.057RS	Copyright and confidential information.	
<p>Effects of humanoid robots on narrative role-taking abilities in children on the spectrum Research design, data and analysis.</p>	2.060RI	Copyright and confidential information.	
<p>Collaborative partnerships in action Research design and data, analysis. <i>inclusionED</i> content and multimedia resources.</p>	2.066RU	Copyright and confidential information.	
<p><i>myWay</i> Employability educator Research design, data, analysis and reports. <i>inclusionED</i> content, training and multi-media resources.</p>	2.067RU	Copyright and confidential information.	
<p>Australian longitudinal study of autistic adults Research design, questionnaires, data, analysis, reports and publications.</p>	3.013RC	Copyright and confidential information.	

Description	Project reference	Nature of IP	Background IP
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<p>Better Outcomes and Successful Transitions for Autism (BOOST-A) BOOST-A website design, source code, career responder system, training and multi-media resources. <i>myWAY Employability</i> content including the Autism Career Explorer system. Research design, data, analysis, reports and publications.</p>	3.014RC 3.048RU	Copyright and confidential information.	Career Interest Test owned by James Athanasou, licensed by Education Services Australia.
<p>Health and wellbeing of adults on the autism spectrum CHECK CPD program training modules, Act on Your Life anxiety management program and Autism CHAP questionnaire and resources. Health hub website design, source code, content and materials. Research design, data, analysis, reports and publications.</p>	3.015RC 3.049RU	Copyright and confidential information.	Original CHAP IP owned the University of Queensland, and licensed to UniQuest.
<p>Australian longitudinal study of school leavers Research design, data dictionary, questionnaires, data, analysis, reports and publications.</p>	3.016RC	Copyright and confidential information.	
<p>Optimisation of recruitment Research design, data, analysis, reports and publications.</p>	3.017RC	Copyright and confidential information.	
<p>Studio G: Multimedia program for young adults Research design, data, analysis, reports and publications.</p>	3.030RI	Copyright and confidential information.	
<p>Career pathway responder system Research design and data, analysis, reports and publications.</p>	3.031RI	Copyright and confidential information.	
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Autism@Work Research design, data, analysis, reports and related publications.	3.054RI	Copyright and confidential information.	
Development of an assessment of functioning tool based on the ICF core sets Assessment tool. Research design, data, analysis, reports and publications.	3.061RI	Copyright and confidential information.	ICF Core Sets copyright owned by World Health Organisation.
'Hear' to Help chat-bot technology Chat-bot content. Research design, data, analysis, reports and publications.	3.062RI	Copyright and confidential information.	Chat-bot technology owned by CSIRO.
Autism-specific quality of life assessment tool QoL assessment tools and photovoice gallery materials. Research design, data, analysis, reports and publications.	3.068RI	Copyright and confidential information.	
myWAY Employability Tech4Good initiative (supported by Telstra Foundation) Website design, source code and content including multimedia resources. Research design, data, analysis, artefacts, reports and publications.	3.072RC	Copyright and confidential information.	
Investigating autistic burnout Research design, data, analysis, reports and publications.	3.076RI	Copyright and confidential information.	
Whole genome sequencing Whole Genome Sequencing data for 1,500+ Australian autism biobank trios.	2019_015WGS	Copyright and confidential information.	
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Appendix 7: Glossary

AASQA	Autism Academy for Software Quality Assurance
ACT on your life	Acceptance and Commitment Therapy anxiety program
ACU	Australian Catholic University
AEIOU	AEIOU Foundation
AITSL	Australian Institute of Teaching and School Leadership
ALSAA	Australian Longitudinal Study of Autistic Adults
AO	Officer of the Order of Australia Medal
ASAN AUNZ	Autistic Self Advocacy Network of Australia and New Zealand
ASD	Autism Spectrum Disorder
APAC	Asia Pacific Autism Conference
ASELCC	Autism Specific Early Learning and Care Centre
ASfAR	Australasian Society for Autism Research Conference
Aspect	Autism Spectrum Australia
ATSI	Aboriginal and Torres Strait Islander
Autism SA	Autism South Australia
BOOST-A	Better Outcomes and Successful Transitions – Autism
CALD	Culturally and Linguistically Diverse
CEO	Chief Executive Officer
CFO	Chief Financial Officer
CU	Curtin University
Autism CHAP	Comprehensive Health Assessment Program for autistic adults and adolescents
CIP	Centre Intellectual Property
CoEP	Classrooms of Excellence Program
CRC	Cooperative Research Centre
CRM	Customer Relationship Management
EVAP	Education and Vocational Assessment Protocol
EYBSP	Early Years Behaviour Support Project
GCAD	Graduate Certificate in Autism Diagnosis
GP	General Practitioner
GU	Griffith University
HFA	High Functioning Autism
Human-Centred Approach	Also referred to as Human-Centred Design Thinking – an approach to problem solving that involves human perspectives at all phases of the problem-solving process.
IASSIDD	International Association for the Scientific Study of Intellectual and Developmental Disabilities
I CAN	The I CAN Network

IDPA	Integrated Diagnostic Protocol for Australia
IEST	Integrated Employment Success Tool
INSAR	International Society for Autism Research
IP	Intellectual property
LASA	Longitudinal Study of Australian Students with Autism
LTU	La Trobe University
MoP	Models of Practice
MYBSP	Middle Years Behaviour Support Project
NBPSA	Neurodevelopmental and Behavioural Paediatric Society of Australasia
NCCD	Nationally Consistent Collection of Data on School Students with Disability
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
Neurodiversity	Concept that neurological differences – such as Autism, Attention Deficit Hyperactivity Disorder (ADHD) and Tourette Syndrome – are to be recognised, accepted and respected as any other human variation.
NESA	New South Wales Education Standards Association
NHMRC	National Health and Medical Research Council
NSW	New South Wales
OT	Occupational Therapy
PhD	Doctor of Philosophy
QED	Queensland Department of Education
QUT	Queensland University of Technology
RAP	Resourceful Adolescent Program
RAP-A	Resourceful Adolescent Program for Autism
SACS-R	Social, Attention and Communication Surveillance – Revised
SAS	Secret Agent Society
SAS-WOC	Secret Agent Society Whole-of-Class program
SASLA	Study of Australian School Leavers with Autism
SME	Small and Medium-sized Enterprise
SST	Social Skills Training Pty Ltd – a wholly owned subsidiary of Autism CRC
STEM	Science, Technology, Engineering and Maths
UNSW	University of New South Wales
UQ	University of Queensland
UTAS	University of Tasmania
UWA	University of Western Australia
WMR	Wesley Medical Research
WHO	World Health Organisation

Our values



Inclusion

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



Innovation

New solutions for long-term challenges



Evidence

Guided by evidence-based research and peer review



Independence

Maintaining autonomy and integrity



Cooperation

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



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