

2021-22

Annual Report







Contents

Abou	it Aut	ISM CRC	1
Our	values	S	1
Estal	blishe	d assets and a strong framework for impactful delivery	2
Our	work ı	under the CRC Program	2
Than	ık you	to our CRC Program Essential Participants (2013-2022)	3
Our	CRC F	Program	5
Our j	journe	ey	7
Repo	ort fro	m the Chair and CEO	9
Majo	r new	and ongoing projects	11
1.0	Key a	achievements	13
1.1	Asses	sment and diagnosis	14
1.2	Educa	ition, transitions and employment	19
1.3	Health	n and wellbeing	24
1.4	Autist	ic and autism communities	27
1.5	Resea	rch assets	31
2.0	Our	end-users	33
3.0	Our people and structure		
3.1	Structure		
3.2		n CRC Board	
3.3	Mana	gement Team under Autism CRC Program	38
4.0	Report on activities		
4.1	Research and development		
4.2	Research collaboration5		
4.3	Education and training		
4.4	Engagement		
4.5	Awards and honours 2021-22		
4.6			
4.7	F -F - 3		
4.8		tion and commercialisation	
4.9	Social	Science Translated Pty Ltd	77
5.0	Gove	ernance	79
5.1	Autisn	n CRC Board	79
5.2	Autisn	n CRC Committees	82
6.0	Appe	endices	
Appendix 1:		List of Autism CRC Participants	
	ndix 2:	Annual Financial Report	
	ndix 3:	Publications 2021-22	
	ndix 4:	Resources developed 2021-22	
Appendix 5:		Conference presentations 2021-22	
	ndix 6:	Intellectual property	
Apper	ndix 7:	Glossary	99

Statement of purpose: Together, discover and achieve more



Vision

Autistic people with quality of life and opportunity



Mission

Initiate, co-produce and translate collaborative research and best practice guidance that delivers positive change for all autistic people



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, across the lifespan and the spectrum

Autism CRC Ltd (Autism CRC) was established in 2013 under the Commonwealth Government's Cooperative Research Centre (CRC) Program, as the world's first national, cooperative research effort focused on autism across the lifespan. Autism CRC is no longer receiving Commonwealth funding as part of the CRC Program, but the company and collaborating partners continue to pursue our vision through legacy operations from 1 July 2022.

We are now the independent national source of evidence for best practice in relation to autism across the lifespan and the spectrum.

We provide the national capacity to develop and deliver evidence-based outcomes through our unique collaboration with autistic people, families, professionals, service providers, researchers and government. Together, we are addressing agreed needs and co-producing outputs with these stakeholders for the benefit of the community.

Our values

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



Inclusion

Valuing lived experience



Innovation

Solutions for long-term challenges



Evidence

Truth in practice



Independence

Integrity through autonomy



Cooperation

Capturing opportunities together

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. We have developed a range of practice platforms and resources, as well as valuable research assets. 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 of autistic individuals and their challenges. 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. This is reflected in the broad impact of the outputs from our work.

Our work under the CRC Program

Delivering positive change for all autistic people.

We have now successfully completed our major CRC-funded program of work. As the world's first national, cooperative research effort focused on autism across the lifespan, together, we have worked to address agreed community needs to provide autistic people with greater quality of life and opportunity. Through our post-CRC legacy operations, we will continue to address needs defined by and in co-production with the stakeholder community.

Thank you to our CRC Program Essential Participants (2013-2022)





























A full list of Participants in the Autism CRC is given in Appendix 1.

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

Participant Day

More than 100 people attended Participant Day events in April 2022; 75 face-to-face and a further 30 people via live stream.

It was a wonderful way to celebrate our many achievements as a collaboration under the CRC Program. The opening address was provided by Professor Deborah Terry AO, Vice-Chancellor and President of the University of Queensland. Professor Terry has held substantial roles at UQ and Curtin University during the time of our CRC Program. Attendees included Autism CRC Participant representatives, Member-elect and Affiliate-elect Representatives, Project Leaders and team members, Sylvia Rodger Academy alumni, PhD scholars, current and former Board members, staff members and other key stakeholders.















Our CRC Program

Together, our world-first collaboration has addressed agreed needs across the lifespan



Research projects

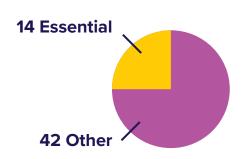
addressing needs across the lifespan



Investment

in research and its translation







CRC Participants are end-users



CRC Participants from industry and /or private sector







focused on the early years of childhood



focused on the school years



focused on areas of need in adulthood



Early years

Our work in the early years has focused on improving the validity, precision, timeliness and reliability associated with the diagnosis of autism. We've developed an evidence-based understanding of targeted pathways to early supports, and delivered national practice standards and guidance, supports and capacity-building resources for individuals, professionals and communities — all informed by evidence.



School years

Our work in the school years has focused on developing evidence-based teaching strategies, techniques, tools and programs to enable educators, therapists, carers, families and the general community to effectively respond to the diverse learning needs of students on the autism spectrum. This has included the development of inclusionED, which translates the outputs of over 25 projects focused on the school years into practices and resources for teachers around Australia.



Adulthood

Our work in adulthood 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. Where previously few Australian studies on autism adolescent and adult life existed, Autism CRC has built a comprehensive understanding of the transition to adulthood and developed a range of health, employment and wellbeing practices and resources to meet these needs.





Our journey

2013

Funding announced for world's first cooperative research centre for autism

2015

- ▶ Begin collecting data for 3 longitudinal studies across the lifespan
- Graduate Certificate in Autism Diagnosis first delivered
- Inaugural Autism CRC Research Awards
- ► First Research Program delivered to upskill autistic adults and researchers to work together as research co-producers

2017

- ▶ \$1.1m co-investment by Positive Partnerships to expand school projects to rural & remote communities
- ▶ 1,200 people & organisations provide input into the National Guideline consultation
- ► Establishment of University Peer Mentoring Program
- Inaugural Autism@Work Summit, Svdnev

2019

- ▶ Co-production Partner Initiative established
- ▶ Mortality report released, using big data
- ▶ Begin review of early surveillance in
- ▶ AARC community consultation to define 10 autism research priorities
- ► Autism@Work Summit, Melbourne
- Autism HealthPathways launched
- Adolescent/Adult Goal Setting Tool launched

2021

- Autism HealthPathways available for adoption & adaption across Australia, UK and N7
- ▶ Integrated Employment Success Tool (IEST) released
- ▶ ILC grant for National Best Practice Assessment and Diagnosis implementation
- ▶ ILC grant for inclusionED expansion & implementation
- StepWrite iPad app released
- Whole genome sequencing generated for 1,500+ Biobank participants
- Work begins on National Guideline for supporting autistic children and families
- ▶ Launch of Routledge books on inclusive education in Australian schools
- Autism@Work Virtual Summit
- Pre-emptive parent-led therapy shows significant improvement in children's social communication development
- ▶ Gut microbiome study finds no causal link between autism and the gut microbiome

2023

National Guideline for supporting children due for release

2014

- Review of diagnostic practices in Australia commissioned
- Autism CRC offically launched
- Participant recruitment for the Austrailan Autism Biobank begins

2016

- Ministerial launch of the Australian Autism Biobank
- National Guideline for Assessment and Diagnosis of Autism in Australia (National Guideline) development
- Autism in Agriculture project begins

2018

- Autism in Agriculture project receives Aspect Advancement Award
- Knowledge Centre launched, an online gateway to Autism CRC resources
- Australian Autism Research Council (AARC) established to define national priorities
- Secret Agent Society wins CRC Association Research Award
- Telstra Tech4Good grant for initial co-design & development of myWAY Employability
- Biobank data collection complete. almost 3,000 participants
- Education Needs Analysis released with insights from 1,500 participants
- Autism@Work Summit, Melbourne
- NHMRC endorsement & Ministerial launch of National Guideline
- Sylvia Rodger Academy launched to provide programs and pathways for autistic adults

2020

- Autism Teen Wellbeing website released
- Ministerial launch of inclusionED
- myWAY Employability launched
- ▶ Interventions Evidence Report released
- National Guideline Implementation Toolkit released
- Sylvia Rodger Academy Governance Program upskills 14 autistic adults in corporate governance
- Secret Agent Society digital version released enabling the program to be delivered via telehealth and remote education

2022

- ▶ Australasian Autism Research Council expands to include NZ membership
- ► Review of SACS-R autism screening tool highlights accuracy in early identification
- ▶ Launch of Participatory and Inclusive Autism Research Practice Guides
- ► Funding commitment from Commonwealth to support development of National Autism Strategy (NAS)
- ▶ IEST NZ released

CRC Program funding expires and Autism CRC welcomes in a new era

- ► First project callout under legacy operations
- National Guideline for supporting children draft to be released for community consultation
- ▶ Launch of online course for key health professionals implementing National Guideline
- inclusionED website revelopment to be released in October
- Microcredentialling courses for implementation of National Guideline to be released
- Applications open for Autistic Identity and Connection workshops - DSS Strong and Resilient Communities grant

Report from the Chair and CEO

This Annual Report marks a major milestone for Autism CRC, our Members, and other partners.

This was the final year of our foundation Cooperative Research Centre Program, with our Commonwealth CRC Funding Agreement and our Participant Agreements coming to an end on 30 June 2022. The year also saw arrangements formalised for our legacy operations, commencing on 1 July 2022, and continuing our work with, and for, the autism community utilising the same collaborative stakeholder model nationally and internationally.

Of course, we have not simply shifted from CRC Program activities one day to legacy operations the next. Autism CRC's Board and management have long had an eye to building a sustainable national reference and research-coordination organisation as a key pillar of our strategic objectives. Several initiatives have been delivered with that objective in mind over recent years. Autism CRC and its collaboration partners have together extended our research, knowledge translation and capacity-building activities beyond the CRC Program, with the financial support of Government, Members and other partners who over time have contributed almost \$20 million in addition to our original CRC Program and Participant funding.

As you read through this Annual Report, you will learn of our work with, and for, autistic people, their families and those who work to support them, enabled by a range of programs and partner contributions. The report rightly recognises and celebrates our activities, outputs and unique collaboration over the CRC Program from 2013 to 2022. It also highlights how we continue to build on those foundations to advance autism-related practice and policy beyond the CRC Program, again underpinned by the principles of co-design and co-production with stakeholders.

The last year also saw the Commonwealth Government commit to developing a National Autism Strategy, in line with the primary recommendation of the Senate Select Committee for Autism, which tabled its report in March 2022. The Strategy is to provide a coordinated framework of initiatives to improve services and supports, and life outcomes, for autistic Australians and their families.

Now established as the independent national source of evidence for best practice related to autism, Autism CRC is ideally placed to assist the Government and the autism stakeholder community to develop and implement a National Autism Strategy. To that end, we welcomed the Commonwealth's funding commitment for Autism CRC to assist the government in the development of the Strategy. That funding also supports our continuing provision of national evidence-based best practice platforms and capacity-building resources that you will read about in this Annual Report. These assets, along with our stakeholder collaboration model, provide a foundation for national actions consistent with many of the recommendations of the Senate Select Committee and a coordinated National Autism Strategy.

In marking the end of our CRC Program, we express our deep appreciation and thanks to all those who have contributed to that program over the past nine years. It has been a challenging journey, together building and then operating a collaboration – in a sector that was traditionally divided along geographic and service sector lines – to address community-agreed priorities for research and its translation to practice. Through the first such national collaboration in the world, we have more than met those challenges.

We would like to thank all who have contributed to our CRC program.

- Our Participants and partner organisations. Without their contributions, we simply could not have realised the achievements highlighted in this report. We thank our Essential Participations AEIOU Foundation, Aspect, Autism New Zealand, Autism Queensland, Curtin University, Griffith University, La Trobe University, Mater Research, Queensland Department of Education, Queensland University of Technology, F. Hoffmann-La-Roche, The University of Queensland, University of New South Wales and University of Western Australia who played a leading role in steering and delivering our CRC Program activities.
- The members of the Autism CRC Board over the past nine years for their leadership and counsel; and our founding Chair, Judy Brewer AO, who set us on a course of true collaboration and impact with and for the community.
- Our program leaders, Professors Andrew Whitehouse, Suzanne Carrington, Torbjorn Falkmer, Valsamma Eapen and Sonya Girdler, who met the challenge of establishing and driving our collaborative CRC activities; and, of course, the late Emeritus Professor Sylvia Rodger AM, whose vision and determination continue to inspire us.
- The many Project Leaders, project team members and scholars who contributed to the more than 90 projects undertaken over the course of the CRC Program; and the staff of Autism CRC who, with great dedication, have co-ordinated that work and its translation to practice, utilisation and dissemination for the benefit of our user community.

Finally, we wish to thank the autistic individuals, family members and people working with them – numbering in the hundreds of thousands – who have given generously of their wisdom, time and trust to our CRC program activities and outputs. The central involvement of these true endusers in our work has been critical, ensuring its grounding in need and translation for impact.

As you will find in reading this report, our CRC program has resulted in the development and effective implementation of national practice platforms, capacity-building resources and programs. In addition to these platforms and resources, the CRC Program also saw the development of major research assets. These are the foundations that will underpin our work post the CRC Program and assist us in supporting the development and implementation of a National Autism Strategy.

As highlighted in the Senate Select Committee report, despite gains over the last decade, there remains much to do. Life outcomes in education, vocation, physical and mental health and social connection continue to be far from optimal for the growing number of people on the autism spectrum and their families. Throughout our work, we have identified many areas of need yet to be addressed with evidence-based understanding and practice – consistently across all levels of government and service systems – including for the most marginalised, such as those in regional and remote communities and those with multiple and complex support needs.

As we now move to our legacy operations, Autism CRC has updated its Vision and Mission, both remaining consistent with the goals and operating model that have delivered the successes to date. Our Vision is to see *autistic people with quality of life and opportunity* and we will continue strive for this through our Mission to *initiate*, co-produce and translate collaborative research and best practice guidance that delivers positive change for all autistic people.

We are very pleased to welcome those organisations joining us in that Mission and our continued collaboration, with nine company Members and fifteen Affiliates having done so to date. We also welcome the continued support of the Queensland Department of Education as a project partner.

A number of major non-CRC program projects were progressed during 2021-22. These include the development of the National Guideline for supporting autistic children and their families; and mainstream capacity-building projects in the health services, education and employment sectors, funded under the Commonwealth ILC Program and building on our existing national platforms. These projects are described further in the following two pages.

Several new projects have also been commissioned, commencing in early 2022-23, with the new Member and Affiliate network. These will further our evidence-base,

guidance and capacity-building resources across existing platforms relating to assessment and diagnosis; early childhood supports; inclusive education and employment, as well as update our understanding of user-defined needs in both education and for those with multiple and complex support and/or communication needs.

We look forward to progressing these and other projects with the stakeholder community over the coming year.

The coming year is one of major opportunity for many, with the development of a National Autism Strategy. There is much ground to cover if a coordinated national approach to better services, supports and life outcomes is to be delivered. Autism CRC commits to working with government and all stakeholders in the co-design of the Strategy, founded in evidence and practice wisdom, and in supporting its timely delivery for the benefit of autistic Australians and their families.

On behalf of the Autism CRC board and team, we again express our sincere gratitude to all for their efforts and dedication over the past year and more. We look forward to continuing our collaborative work and seeing autistic people with quality of life and opportunity.





Robert van Barneveld Chair

Andrew Davis
Chief Executive Officer

We welcome our Members from 1 July 2022





















Major new and ongoing projects

After nine successful years of activities, our Cooperative Research Centre funding agreement expired on 30 June 2022. While Autism CRC will no longer be part of the CRC Program, the company and its partners will continue to pursue our vision through the same stakeholder collaborative model.

We remain committed to a national collaborative model, working with all stakeholders – individuals on the spectrum, families, professionals, service providers, researchers, and government – addressing agreed needs and co-producing outcomes with those stakeholders. Four major projects are in development or underway.



Commonwealth commitment: National Autism Strategy development facilitation and support

An election commitment by the Australian Labor Party will enable Autism CRC to support the development of a National Autism Strategy, underpinned by a national research agenda and evidence-based practice. We look forward to working with government and all stakeholders in the Strategy's development and implementation with work due to begin in late 2022.



Commissioned project: National Guideline for supporting the learning, participation, and wellbeing of autistic children and their families in Australia

......

The Guideline will support families to make informed choices when accessing services and provide professionals with a set of Good Practice Points and Recommendations to guide ethical and effective service delivery. This work builds on our comprehensive review of the international high-quality evidence-base presented in our 2020 report on the evidence for interventions.

A draft of the Guideline has been developed over a period of nine months by the 15-member Guideline Development Group with the final Guideline due for release in early 2023, following National Health and Medical Research Council (NHMRC) review. The Guideline is being developed according to the NHMRC's recommended process. Recommendations will be based on the best available research and a comprehensive consultation process with professionals and the broader community. This project is being undertaken using Autism CRC funding and in-kind contributions.

Autism CRC acknowledges the generous bequest of Basil Waugh in memory of his mother, Jean Estelle Waugh, which contributed in part to the development of the Guideline.

Having been successfully awarded a Department of Social Services Information (DSS), Linkages and Capacity Building (ILC) program grant in 2020, work is well underway on two major projects to improve mainstream services in health, education, and employment for autistic Australians.



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 in 2020 by the then Federal Minister for Families and Social Services, along with government representatives, formed to drive consistent national implementation of Guideline recommendations.

The project outputs 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, as well as undergraduate and graduate training programs. The project also aims to develop 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

This project aims to build the inclusive educational capacity of Australian schools, school leaders and educators, and increase the number of inclusive Australian workplaces. Working with key stakeholders to deepen effective, inclusive practice within and across the education and employment sectors, this project has five interrelated work streams and will expand the content, reach and uptake of two major Autism CRC platforms; inclusionED professional learning platform for teachers (inclusioned.edu.au) and myWAY Employability career planner for young people and their supporters (mywayemployabilty.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. Resources will also equip employers and service providers to better support neurodiverse job seekers and employees.

About Autism CRC Annual Report 2021-22 12

1.0 Key achievements

While our CRC Program projects have wrapped up, project work continued to build upon some of the major assets successfully delivered to date, allowing us to further the impact of key CRC Program outputs through community and mainstream services capacity-building.



121,000+

Professionals

involved in research programs or using our outputs



161,000⁻¹

Downloads

of publications, reports and resources



38,100+

Followers/subscribers

across our online community including 23,370+ eNews subscribers



390+

Resources, publications and reports

in Knowledge Centre



1.1 Assessment and diagnosis



Developed practice and protocols for consistent national outcomes

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

27,400+

Individuals registered to access the National Guideline

18,700⁺

Downloads of Interventions Evidence Report to assist families and clinicians to make informed

to assist families and clinicians to make informed decisions when choosing interventions



Delivered and developing National Guideline Implementation Tools and Training

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

640 8

Participants in New Zealand Autism Guideline
awareness and uptake evaluation

150

Autism diagnosticians
Completed or enrolled in Graduate Certificate in
Autism Diagnosis and/or ADOS-2 training

Autism CRC's work has had a significant impact on policy and practice of autism assessment and diagnosis in Australia. Since developing Australia's first National Guideline for the Assessment and Diagnosis of Autism, launched in 2018, we have focused on a range of research, translation and implementation projects in this area. These have contributed to providing best practice, evidence-based outputs to clinicians, the community, service providers, researchers, 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.

We continue to focus 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 27,400+ registered users, including 18,000 professionals.

14

Section 1 **Key achievements**Autism CRC Annual Report 2021-22





Implementation of the National Guideline

Autism CRC continues to provide specialist advice to the Expert Reference Group appointed in 2020 by the then 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 National Disability Insurance Agency (NDIA), also attend meetings of the Expert Reference Group.

While there has been widespread adoption of the National Guideline at the grassroots level by many providers across Australia, substantial benefits will only be realised through consistent, national implementation in practice, across the health, disability, and education sectors.

In December 2020 we launched a 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 along with community resources that 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.

Further Guideline implementation and capacity-building activities for mainstream services are being supported under a Commonwealth Information Linkages and Capacity Building (ILC) grant.

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. Enrolments come from all states and territories. They 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.

Supporting autistic children and their families

In November 2020, we published a landmark report for families, clinicians, researchers and policy makers, which synthesises the best available high-quality evidence about supports 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, includes a broad overview of therapies and supports for children on the autism spectrum. It also summarises 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 NDIA, shows there is still much research to do to develop high-quality evidence across all 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. Together, this highlighted the imperative to develop 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. This has led to the work now, in progress, to develop guidelines for supporting autistic children and their families.

Therapy for infants showing early signs of autism

This parent-led therapy significantly reduced children's social and communication difficulties. The study was published in *JAMA Pediatrics* and presented the first evidence worldwide that pre-emptive therapy during infancy could lead to such a significant improvement in children's social communication development that they then fell below the threshold for a 'deficit-focused' DSM-5 diagnosis of autism.

While many therapies for autism tried to replace developmental differences with more 'typical' behaviours, the pre-emptive therapy (iBASIS-VIPP) sought to work with each child's unique differences and create a social environment around the child that would help them learn in a way that was best for them.

The therapy uses video-feedback to help parents understand and appreciate the unique abilities and interests of their baby, and to use these strengths as a foundation for future development.

This world-first research was led by CliniKids at the Telethon Kids Institute and funded by the WA Children's Research Fund, Autism CRC, La Trobe University, and the Angela Wright Bennett Foundation.

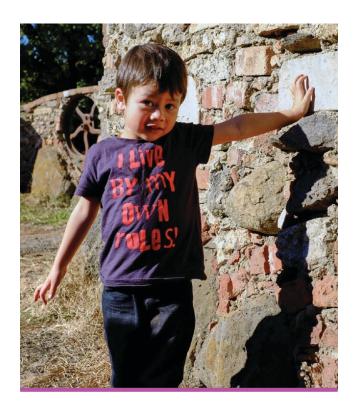
SACS-R early childhood surveillance

Developed by La Trobe University researchers – and trialled as part of an Autism CRC project – the Social Attention and Communication Surveillance-Revised (SACS-R) and SACS-Preschool (SACS-PR) are tools used to identify a set of behaviours that are characteristic of children on the spectrum from as young as 11 months old.

Findings from the Victorian trial cohort were published in JAMA Open. SACS-R was found to be extremely accurate in identifying very young children on the autism spectrum. Of the infants and toddlers aged 12-24 months identified at 'high likelihood' for an autism diagnosis by the tool, 83% later received an autism diagnosis. When used alongside a SACS-Preschool check, 96% of children on the autism spectrum were identified by their 3.5 year health check.

SACS-R is now used state-wide in Victoria and Tasmania, and training has been completed in New South Wales, Queensland, and South Australia. Health professionals in ten other countries around the world – including China, Singapore, Poland, Japan, New Zealand, Nepal and Bangladesh – have also been trained in using the tool.

When combined with effective very early childhood or preemptive therapy and supports, the surveillance tool is an excellent example of high-impact research that can make a tangible difference to people's lives.



Strengths-based approach to functioning

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.

The project co-produced user-friendly descriptions for each item of the ICF Core Sets for autism and 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 an 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.



eLearning resources for professionals

Under the ILC Program grant, Autism CRC is working with members of the Expert Reference Group to create professional resources for key clinical professions involved in the assessment and diagnosis process.

The development of an online short course, undergraduate resources and an event library, will support clinicians wanting to implement the National Guideline's recommendations into practice. Collaboration with clinical colleges and peak bodies means resources will meet the needs of professionals supporting families through an assessment and diagnostic process. The short course will be offered through Speech Pathology Australia from July 2022, with other professional societies and colleges expected to follow.

Microcredentialled courses

Recognising that professionals need flexible learning options, we also began work on the development of a suite of credit-bearing microcredentials in autism assessment and diagnosis as part of our commitment to widespread implementation of the National Guideline. Microcredentials are short study programs focusing on targeted skills in a chosen area.

The first of these courses are due to come online in late 2022. Seven microcredentials are in development and cover:

- Autism: Contemporary diagnostic frameworks
- Principles of Best Practice in Autism Assessment and Diagnosis
- Autism: diagnostic features and assessment approaches in early childhood (0-5 years)
- Autism: diagnostic features and assessment approaches in children (6-16 years)
- Autism: diagnostic features and assessment approaches in older adolescents and adults (17+ years)
- Initiating a Referral for autism diagnostic assessment
- ▶ Differential diagnosis: distinguishing autism from other neurodevelopmental and mental health conditions.

National Guideline for supporting the learning, participation, and wellbeing of autistic children and their families in Australia

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.

The initial round of community consultation was completed in April 2022 and involved more than 800 people. This included parents and caregivers, service providers, the broader autism community, and autistic people of all ages including people who communicate primarily in ways other than speech. A systematic review of the research evidence and the community consultation process have helped to form a set of draft Recommendations and Good Practice Points (draft to be released for public feedback in July 2022). Following consideration of the feedback and revision, the final Guideline is due for release in early 2023, after content and methodological review by the NMHRC and final approval by the Council.





1.2 Education, transitions and employment

40,600



Unique visitors to inclusionED online learning community for educators

4,840+ 6



Educators joined the inclusionED Community of Practice

20,900+



Unique visitors myWAY Employability career planning platform for young autistic people

350+



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

650⁺



Downloads of Integrated Employment Success Toolpractical workplace manual for employers to improve
workplace success of autistic people

1,000+🗪

Attendees at Autism@Work Summits

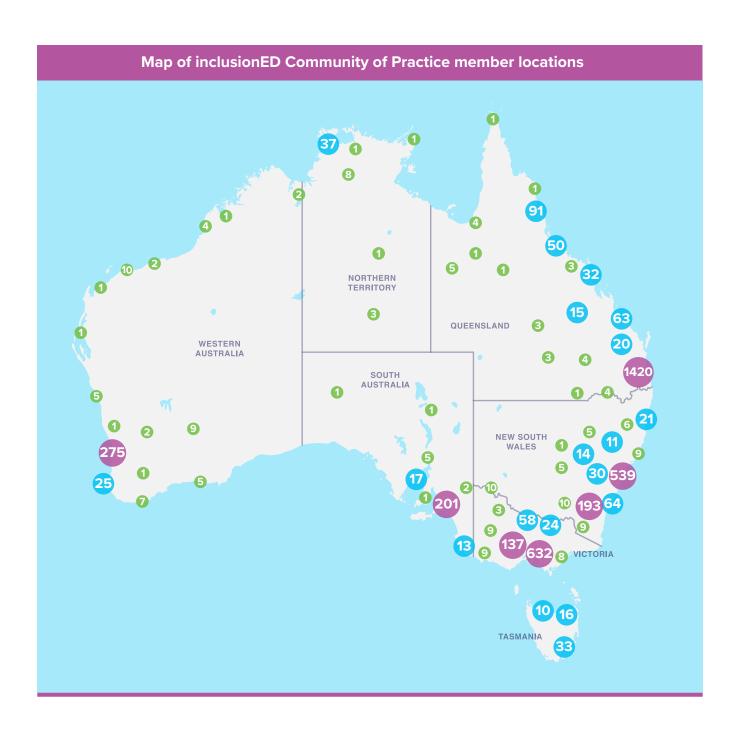
In the average Australian classroom, at least three children have a learning difficulty or neurodevelopmental condition. The support and scaffolding these children receive during school can set the trajectory for the rest of their lives, but many teachers don't feel equipped to effectively support the learning of all students in their classrooms. Beyond school, 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. It now plays an important role in the national approach to support inclusive education.

Co-designed with educators, for educators, inclusionED provides evidence-based and research-informed teaching practices, videos, printable templates and other resources, designed to support diverse learners in inclusive classrooms. The platform now includes more than 50 teaching practices across a range of topics. The team has also delivered professional development, training workshops and webinars to educators, education services and school outreach professionals.





Autism in Education Showcase

In August 2021, we highlighted a range of Autism CRC education resources and officially launched two sister books on inclusive education at the Autism in Education Showcase. In a panel discussion, autistic adults shared their lived experiences and discussed how autistic students can be better supported. Education researchers shared their research into supporting autistic students in inclusive school settings. The event attracted 380 education, allied health and research professionals. Despite rapidly changing COVID-19 conditions, 219 people attended the live event at the Queensland University of Technology (QUT), and a further 161 watched the live cast or recording.



Making the transition – myWAY Employability

Autism CRC's smart web platform – myWAY Employability – supports 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 for, and with, autistic young people. Launched in 2020, uptake has exceeded initial targets with the platform now supporting 1,880+ registered users.

The platform guides young people though 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, including sensory, communication and environmental preferences matched to relevant career information and pathways.

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.

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

Manual helps employers create inclusive workplaces

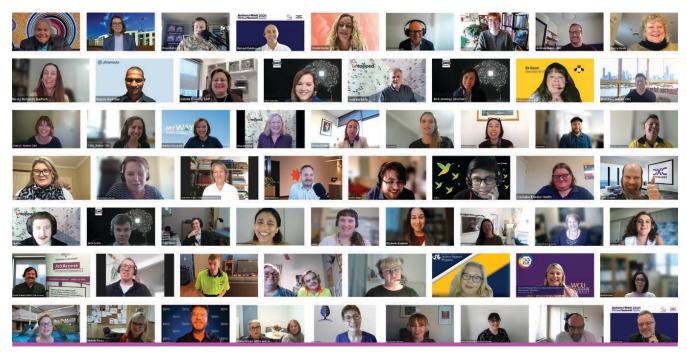
The Integrated Employment Success Tool: An evidencebased guide for autistic adults (IEST), aims to improve employer confidence, employee productivity, job retention and the overall workplace success of autistic people.

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. Through a collaboration with service provider Autism New Zealand, in May 2022 we released an alternate version. Content has been adapted to include information and weblinks about supports, services and resources available to workplaces in Aotearoa New Zealand. Autism NZ is using the IEST as an evidence-based framework in its 'Neurodivergent Employment Programmes' to support organisations to be more inclusive.

The IEST empowers employers with the skills and confidence to make changes that create more inclusive workplaces, bringing benefits to all employees and companies as a whole. It 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.





2021 Autism@Work Virtual Summit presenters and panellists.

In December 2021, Autism CRC worked with NSW Services to develop and deliver a 2-hour keynote and panel presentation to over 200 NSW public service staff. The co-produced and co-delivered presentation was part of a neurodiversity special interest group meeting and addressed topics of neurodiversity and the social model of disability, autism and being autistic in the workplace and strategies for inclusive employment based on the IEST. The panel featured four neurodivergent panellists, including three neurodivergent staff from NSW Government.

2021 Autism@Work Virtual Event

More than 500 delegates attended Australia's first Autism @Work Virtual Summit in August, hearing about the benefits of a neurodiverse workplace and exploring how to achieve Sustainable Programs, Sustainable Employment for employers and employees.

Hosted by Autism CRC and DXC Technology, the twoday event included keynote addresses from three autistic speakers:

- Clem Bastow: Screenwriter, university tutor, awardwinning cultural critic, author and autistic speaker
- Charlotte Valeur: Experienced corporate governance advisor, Board member, and neurodiversity advocate
- Lee Corless: Head of the Autism at Work Programme for EMEA and APAC Regions at JPMorgan Chase

Approximately half of the 50 event speakers were neurodivergent and included neurodivergent employers, executives and business owners. One survey respondent said, "I am in tears watching and listening to this as it represents me."

The Summit was attended by employers, autistic adults, family members and carers, educators, service providers, researchers and students from across Australia and around the world. Event attendees included 100 employers, 66 Human Resource professionals, 204 professionals (general), 123 family members/carers, 91 autistic adults, 93 service provider representatives, 38 researchers and 28 allied health care professionals (categories are not mutually exclusive). More than 90% of event survey respondents rated the event as good or excellent.

This was the first year that the event took an online format. This allowed us to reach a new and more geographically diverse audience. More than 85% of event attendees had not previously attended an Autism@Work Summit in Australia.

One survey respondent said, "What a great initiative. I wish more people could know about this, especially parents of autistic children. It has given me lots to think about and valuable insights."

A majority of survey respondents indicated their knowledge, skills, confidence and motivation improved as a result of the Summit.

We thank our co-host, DXC Technology, and event sponsors – SAP, AISA, GHD, Untapped, SunPork Group, Curtin University, ANZ, La Trobe University and BHP – for helping to make the first Autism@Work Virtual Summit such a success.



Building inclusive education capacity through inclusionED

Further co-design and development of inclusionED is progressing under the ILC 'Success in Learning; Transition to Earning' project. The aim is to build the inclusive educational capacity of Australian schools, school leaders and educators, and increase the number of inclusive Australian workplaces.

Building on the existing web platform, we have worked with teachers and stakeholders to codesign new features and content. An in-depth review of the user behaviour of 45,000 unique visitors and an online survey are providing information about the learning needs of educators and guiding further refinement of the platform.

Collaboration with the education sector, including the Australian Institute of Teaching and School Leadership (AITSL), State and Territory Departments of Education, Catholic and independent schools has been crucial to this work.

inclusionED has been updated to align with the Australian Curriculum and Australian Professional Teaching Standard. It also supports quality differentiated teaching practice under the Nationally Consistent Collection of Data, which reports on the number of students with disability and the adjustments they receive.

Passport for successful transition

Further development of myWAY Employability is underway as part of the ILC 'Success in Learning; Transition to Earning' project.

Current development is focused on collaborative career planning, enabling users to share their profile with professionals and employers supporting their career development, and linking their environmental and sensory preferences to evidence-based recommendations of workplace adjustments for inclusive employment. Originally co-designed for, and with, autistic young people aged 14-30 years old, myWAY Employability will be trialled with adults of all ages in a neurodiversity employment program in Perth and Brisbane later in 2022.



1.3 Health and wellbeing



Established pathways to improve health service delivery and wellbeing across the lifespan 3,200+



Number of times GPs have accessed Autism HealthPathways

11,600+



Unique visitors to 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

14

Primary Health Network regions adopted and/or localised Autism HealthPathways



Secret Agent Society preparing

27,000

children for life's social-emotional challenges

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

HealthPathways is a web-based information site that assists health practitioners, particularly General Practitioners (GPs), to guide patients through the health system. The autism-related content in nine Autism HealthPathways equip GPs with the tools to help personalise treatment and management to improve the healthcare journey of autistic people across the lifespan.

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.

Under a licence agreement signed in early 2021 between Autism CRC and Streamliners NZ, the 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.

To date, 14 health regions within Australia and NZ, including state and territory-wide in Tasmania, Northern Territory and Western Australia have adopted and/or localised pathways.



Dr Jake Gratten shows autistic advocate and SRA graduate, Trudy Bartlett, around the Mater Research lab where much of the gut microbiome work was carried out.

An impressive study showing that the correlation between microbiome and autism does not imply causation. Well done @doyouseewhy, Jake and team!

A/Prof, Beben Benyamin, Australian Centre for Precision Health, University of South Australia

"...important study refuting naïve idea that gut microbiome somehow causes autism - arrow of causation goes the other way.

Kevin Mitchell, Associate Professor of Genetics and

Gut microbiome as a cause for autism too hard to swallow

In November, findings from our collaborative study on stool metagenomics challenged the growing popular belief that the gut microbiome drives autism. The study results were published in the journal *Cell* and received international attention.

The findings flip causality on its head and challenge the need for experimental use of microbiome-based interventions, such as faecal microbiota transplants, that some believe may treat or minimise autistic behaviours.

Researchers found changes in the gut microbiome of people on the autism spectrum appear to be due to 'fussy eating', which is more common among autistic children due to sensory sensitivities or restricted and repetitive interests.

The study is one of the largest to date to examine what organisms are in the stool microbiome and what those organisms have the potential to do. The stool samples and dietary information of the 247 children were sourced from the Australian Autism Biobank and the Queensland Twin Adolescent Brain Project.

The findings of this study provide clear evidence that we need to help support families at mealtimes, rather than trying fad diets.

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.

New digital health software the secret of success for child mental health

While many crucial support services were forced to shut down or restrict accessibility during the COVID-19 pandemic,

the small team at Social Science Translated, a subsidiary of Autism CRC and the headquarters of the Secret Agent Society (SAS), managed a rapid transformation of their small group program into a sophisticated digital health system. This ensured the ongoing support for families and child mental health at a time of great uncertainty, and into the future.

The SAS resilience-building programs empower children with identified social and emotional needs, such as children diagnosed with autism, ADHD and anxiety disorders. The evidence-based approach is supported by 17 publications to date and is delivered by more than 2,500 allied health and education professionals trained across Australia and internationally.

The collaborative project used an advisory group of global SAS Providers to co-design this novel approach to group services. By uniquely applying technology together with clinical practice, the digital edition opens up opportunities for services to innovate in a way that makes it easier for children and families to access. The key program is the SAS Small Group Program. This is delivered by trained SAS Providers, either clinicians or educators, to small groups of children usually aged between 8-12 years to diversify and strengthen social, emotional and problem-solving skills.

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 engaging children in a fun espionage-themed process. The digital version has expanded the opportunities for children in rural and other challenging locations to benefit from the program.





1.4 Autistic and autism communities

310⁺ 🗔

Participatory and Inclusive Autism
Research Practice Guides downloaded

100+ 🖉

Sylvia Rodger Academy graduates across 3 programs



Australasian Autism Research Council (AARC)

Defining national research priorities

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





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 Australasian Autism Research Council and the Sylvia Rodger Academy, both of which continue to operate under the auspices of Autism CRC.

Participatory and Inclusive Autism Research Practice Guides

In April we were proud to announce the release of Participatory and Inclusive Autism Research Practice Guides, which provide researchers with:

- background information on participatory research
- guides for producing research with autistic people and other community members
- guides for producing research for autistic people and other community members.

Autism CRC first released inclusive research practice guides and checklists for autism research in late 2014. Previous guides were very focused on the practicalities of research. This version retains that practicality but gives guidance on 'how' to conduct participatory or inclusive research. While earlier guides have already provided a practical resource for researchers throughout our networks, the aim now is to further enhance the uptake and quality of participatory and inclusive research practices nationally and internationally.

Sylvia Rodger Academy

Sylvia Rodger Academy ran two of its established programs in 2021-22 – Future Leaders and the Research Program – and 10 alumni from previous programs were also actively involved in the newly established Self-Advocacy@Work co-design project. 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 121 graduates from across Australia and overseas through these programs. A further 13 are currently participating in the 2022 Future Leaders Program and are due to graduate later in 2022.

After so many COVID-19 interruptions, it was exciting for staff and participants to successfully deliver two face-to-face residential workshops, with a third planned for July. In April, the Sylvia Rodger Academy held a Self-Advocacy@Work three-day workshop involving 10 alumni. Working with the Autistic Self-Advocacy Network of Australia and



2020 Research Program graduates and project team

New Zealand (ASAN AUNZ), Autism CRC has developed an inclusive co-design process to ensure effective and appropriate engagement for autistic individuals, many of whom are multiply neurodivergent, have multiple disabilities and represent intersectional communities such as the LGBTQIA+ community.

The Self-Advocacy@Work project aims to co-design, develop and disseminate employment self-advocacy resources by, and for, the autistic community. Self-Advocacy@Work upskills members of the autistic community in co-design, product development and inclusive practices.

This project will see a series of accessible multi-media tools and resources to equip and empower autistic individuals to advocate for themselves in the workplace. The group are now moving to content development and user testing ahead of release in 2023.

In June, our very patient 2020 Research Program cohort finally met in-person at a three-day workshop in Brisbane. Twelve autistic participants and six autism researchers have now completed the program which upskills autistic adults and autism researchers to work together as research coproducers. This ensures that what is being researched, and

the way it is being researched is relevant to, and appropriate for, the autistic community.

Feedback from the course was very positive. One participant said, "I just want to thank you all, and say how much I loved this experience. I really enjoyed getting to meet and know you all, and... share our experiences together."

The Future Leaders Program is Australia's first holistic leadership capacity building program for autistic adults. It empowers autistic adults to explore and develop their leadership skills and networks to positively impact their communities. The 2022 Future Leaders: Community Projects Program is for those who have an idea that will make a positive impact in their community. The Program offers knowledge, skills and access to support and expertise to help participants turn ideas into an achievable project.

The 13 current Future Leaders are now working on developing and delivering their community projects, while undertaking masterclasses in chosen areas of skill development. The Future Leaders Program is delivered in partnership with Autism Spectrum Australia (Aspect).

42 Future Leaders

graduates

13 88 Future Leaders participants

Research Program graduates

Governance Program graduates

Australasian Autism Research Council

The Australasian Autism Research Council (AARC), under the auspices of the Autism CRC, provides a regular and organised mechanism to:

- consult on the state of autism research in Australasia.
- identify priorities for autism research in an Australasian context
- report on priorities for autism research in Australasia
- inform funding strategies for autism research in Australasia.

In 2022, the AARC changed its name from the Australian Autism Research Council to the Australasian Autism Research Council in line with Terms of Reference changes, which have paved the way for the AARC to welcome its first New Zealand (NZ) members from January 2022.

Its overarching goal is to ensure that the delivery of these objectives is community-led – that is, by autistic people, their families, and allies who provide services and support – for the benefit of those communities and for the broader community.

Previously, the AARC consulted with more than 1,100 members of the Australian autism community through surveys to develop community-informed priority areas. This was followed in 2020 by a series of focus groups for five Research Priority Areas (Communication; Education; Employment; Health and Wellbeing; and, Justice). The output of this process is a series of fifty research topics, ten for each of the five areas explored. The AARC is now intending to undertake a comparable process for the remaining five priorities (Built Environment; Choice in Living and Housing; Family and Carer Support; Gender, Diversity and Inclusion; and, Health and Disability Service Delivery).

Another key milestone was the publication of the first academic article arising from the AARC's work, authored by four AARC members. The editorial on the importance of including autistic perspectives in determining what research should focus on and how it should be conducted was published in Autism: The International Journal of Research and Practice. See Appendix 3 for more information.

Awards celebrate outstanding inclusive research practices and translation

Three projects received recognition for their outstanding commitment to inclusive research practices and translation of autism research as part of the 2021 Autism CRC Awards for Achievement in Autism Spectrum Research. They were:

- Raising Awareness of the Needs of Autistic Australians
- Priorities of Autistic people in Australia and their families for autism services and supports
- Investigating Autistic Burnout (#AutBurnout).

The awards acknowledge initiatives that exemplify the Autism CRC's vision, mission, and values. They recognise achievements in inclusive research practice and the

translation of autism research into practice, products, policy, and programs that benefit the autistic and broader autism communities.

This year saw a record number of applications. The awardees demonstrated high levels of engagement with autistic individuals and the autism community across three very diverse projects that have the capacity to realise long-term benefits.

Translation of autism research into practice

In Raising Awareness of the Needs of Autistic Australians, the Australian Autism Alliance (AAA) engaged Professor Sandra Jones, an autistic autism researcher from Australian Catholic University, to refine, conduct and analyse a survey of autistic adults and their family members. The outcomes informed AAA's submission to the Federal Senate Select Committee on Autism. The project received the Award in the Research Translation category.

Inclusive Research category jointly awarded

Priorities of Autistic people in Australia and their families for autism services and supports was led by Dr Trevor Clark from Aspect Research Centre for Autism Practice (ARCAP) with research funded by Autism Spectrum Australia (Aspect). The research sought to ensure that the organisational plan and the research agenda of ARCAP are directly related to the needs of autistic and autism communities in Australia. This participatory research is important to the provision of services, programs, and resources to support autistic people and their families.



Investigating Autistic Burnout co-lead Julianne Higgins



Dr Sam Arnold (centre) with Professor Julian Trollor and Research Assistant Aishani Desai

The Autism CRC project *Investigating Autistic Burnout* (#AutBurnout) – co-led and co-produced by Dr Samuel Arnold and autistic advocate and peer researcher Julianne Higgins from its inception – conducted two studies to define autistic burnout and explore its risk factors. The co-leads worked closely together throughout the entire process; from conceptualising the research, to developing the study materials and drafting the grant application, to analysing the data and interpreting and disseminating the findings.

Thanks to all our reviewers and entrants across the categories. We especially congratulate the teams of Professor Sandra Jones, Dr Trevor Clark, Dr Sam Arnold and Julianne Higgins for their outstanding work to enhance the lives of people on the spectrum.

Co-Production Partner Initiative

Evidence demonstrates that engaging autistic individuals and their families and carers as co-producers of 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 coproduction across a range of projects encompassing research areas.



1.5 Research assets



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 investment and collaboration has facilitated an increase in autism research capacity in Australia. We have overseen the creation of a portfolio of research assets that aid the acceleration of research. 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

It was an important year for the Australian Autism Biobank with several projects disseminating findings with implications for real-world impact.

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.

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, non-autistic siblings, mothers and fathers) who participated in the Australian Autism Biobank between 2014 and 2018.

The project used the expertise and innovation of Australianbased 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.

Utilisation of the Biobank

Datasets and results generated from projects are returned to the Australian Autism Biobank for further research purposes. Nine 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.

Access approvals to date cover a broad range of autism research lines of enquiry. Project outcomes published in this last year include:

- Autism CRC collaborative study on the gutmicrobiome of autistic children – Involved more than 40 researchers from Mater Research, The University of Queensland, Telethon Kids Institute, University of New South Wales, Children's Health Queensland, La Trobe University, Queensland University of Technology and Microba Life Sciences.
- Parental reporting of child development in the first year of life – The study found that parent reports of developmental differences should be taken seriously as their autism-specific concerns were predictive of an earlier autism diagnosis, and that clinicians may benefit from greater education regarding the breadth of developmental areas related to autism.

- ▶ Dental care experiences and clinical phenotypes in children on the autism spectrum Created a greater understanding of the oral health status of children on the autism spectrum, including specific challenges and needs, and will help to inform tailored and effective oral health interventions and supports.
- Autism CRC study of sleep difficulties in children on the autism spectrum – Provided insights into the biological and behavioural attributes leading to sleep difficulties in children on the autism spectrum.
- ▶ Characterising the early presentation of motor difficulties in autistic children Explored the rates of motor difficulties in children and how early motor concerns impacted on function. Found that early motor delays or concerns may assist in identifying individuals who will likely benefit from early ongoing developmental monitoring and early support.

Utilisation of the Australian Autism Biobank Applications Requests for received genomic data Approved Request for projects biological samples Peer-reviewed publications Requests to recontact from research participants Requests for Applicant phenotypic data countries

Having evidence-based research like this study will help members of the autism community to navigate this space and not spend copious amounts of money and time on fads that claim to improve the quality of life for an autistic person.

Autistic advocate Trudy Bartlett, on findings from gut microbiome study



Longitudinal studies across the lifespan

The Longitudinal Study of Australian Students with Autism (LASA) 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 explored academic achievement and participation, having collected data from home and school as well as from some of the children and teenagers themselves.

A key area of study has been anxiety in autism, with this research having helped to inform new thinking around anxiety in children on the spectrum.

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 15-80 years to gain a broader, lifelong understanding in key areas.

These longitudinal studies yielded many important insights into the experiences of Australia's autistic community and contributed to the critical evaluation and refinement of a range of established measures for use with autistic people. More than 120 peer-reviewed publications have been published using data from these three projects. The data will be made available for future approved research purposes through the Autism CRC Access Committee using similar processes to those applying for access to the Australian Autism Biobank.

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, findings and their application are grounded in user needs.

Our end-user environment is comprised of five 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 support 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, private and not-for-profit 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 and non-government organisations focused, for example, on education, health and disability; children's hospitals; and health service districts and practices.



Organisations providing employment and associated education and training.



Government policy-makers and program managers.

Autism CRC has successfully 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.

Through our engagement with these organisations, other partners and our own targeted communications, our research and outputs have engaged more than 121,000 professionals along with family members and autistic individuals.

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. Autism CRC is committed to the adoption and promotion of participatory and inclusive research practices as these:

- promote partnerships between researchers and community members, ensuring end-users have a say in the research that may impact on their lives
- produce research that is more relevant and beneficial to the community
- improve participant recruitment

 build community capacity and skills by meaningfully engaging end-users in the processes and practices of research.

In 2022, we released updated Participatory and Inclusive Autism Research Practice Guides, which provide researchers within and beyond our network with:

- background information on participatory research
- guides for producing research with autistic people and other community members
- guides for producing research for autistic people and other community members.

In addition to this, Autism CRC facilitates capacity-building research practices through the Sylvia Rodger Academy (Research Program) which upskills 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.

Regular communication with our end-users is maintained through eNews (23,400+ subscribers), targeted emails, Knowledge Centre, social media channels, webinars, events, regular face-to-face or virtual meetings. This maximises opportunities to enhance the impact, utility and translation of our outputs into policy, programs and practice resources.

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. Examples include:

- 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.
- ▶ 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. The school years program has 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 of inclusionED. A further 66 teachers have been involved in co-design workshops for resource development in 2021-22.
- Working with the Autistic Self-Advocacy Network of Australia and New Zealand (ASAN AUNZ), Autism CRC has developed an inclusive co-design process to ensure effective and appropriate engagement for autistic individuals, many of whom are multiply neurodivergent, have multiple disabilities and represent

- intersectional communities such as the LGBTQIA+ community. The Self-Advocacy@Work project aims to co-design, develop and disseminate employment self-advocacy resources by, and for, the autistic community. Self-Advocacy@Work upskills members of the autistic community in co-design, product development and inclusive practices.
- Autism@Work Events More than 1,000 people have attended our Autism@Work events since 2017. The 2021 virtual event attendees included 100 employers, 66 human resources professionals, 204 professionals (general), 123 family members/carers, 91 autistic adults, 93 service provider representatives, 38 researchers and 28 allied health care professionals (categories are not mutually exclusive).

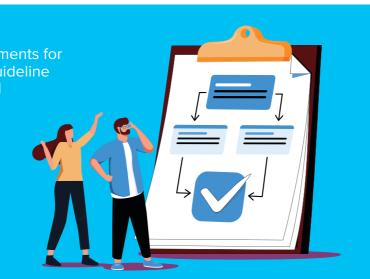
By engaging autistic individuals, parents, allied health professionals, psychologists, doctors, specialists, government, support people and service providers in development, design and testing, we have successfully produced a number of outputs that have the potential to improve the health and wellbeing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

- National Guideline for supporting the learning, participation, and wellbeing of autistic children and their families in Australia 15-member development group representing key stakeholder communities, including autistic individuals, parents/siblings/ caregivers, practitioners, and peak bodies. Community consultation to date has included 700+ community members and 100+ clinicians, allied health professionals and service providers.
- National Guideline for Assessment and Diagnosis, Implementation Toolkit, and eLearning short course – between them these resources have involved Australia-wide consultation with clinicians, allied health professionals, professional societies and colleges, service providers, the members of the autistic community. Resources from this package have been downloaded 64,200 times.
- Autism HealthPathways informed by extensive consultation with more than 50 GPs and the autistic community. 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.
- Adolescent/Adult Goal Setting Tool development included consultation with ASAN AUNZ, along with surveys and interviews with autistic people and their family members, with the final cards' images being created by a skilled autistic illustrator.

What our end-users say

Our organisation had been running autism assessments for a number of years, since about 2010. When the Guideline came out in 2019, our team sat down together and reviewed the Guideline and used it as an opportunity to reflect on our practices, reflect where we were able to meet the Guideline and where we weren't meeting the Guideline or the recommendations and what were the barriers or the challenges for us. And we really used it as a way to improve our practice.

Claire, Senior Occupational Therapist on National Guideline for Assessment and Diagnosis of Autism in Australia



As a speech pathologist working in mental health this webinar gave me information on resources for both the young people I work with and their families. The presenters were all great.

Attendee, 2021 Health, assessment and diagnosis Autism Month Webinar

This has been a wonderful session. Thank you. I'll be sharing far and wide.

Melissa, Teacher (feedback from inclusionED webinar for early career teachers)





Resources for work readiness or work experience will be excellent for our careers and pathways teams! Yes!! *high five*

Christopher, Educator (myWAY Employer resources on inclusionED)

Important new study contradicts the theory, popular among "cure autism" quacks, that changes in the gut microbiome cause #autism.

Steve, Autistic advocate (replying to release of gut microbiome findings)



Listening to the voices of autistic adults, different points of view, people in different locations, thoughtfulness of the questions and topics discussed.

Attendee, commenting of the highlights of 2021 Autistic voices Autism Month Webinar



This would have to be one of those rare times that I have attended a conference and have been able to say that it exceeded my expectations! Thankyou so very much, I look forward to the next one. I've learnt so very much both personally and from a work place perspective.

Attendee, 2021 Autism@Work Virtual Summit





You can hear more end-user perspectives in videos from our website: autismcrc.com.au/end-users-2022

35 Section 2 Our end users Autism CRC Annual Report 2021-22 3

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 partners, ensuring translation-focused research and development.

Autism CRC has ensured 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
- involving end-users directly in Autism CRC activities, enhancing project design and the applicability and uptake of outcomes.

The same model of collaboration and governance will be employed in our legacy operations from 1 July 2022. The member-based company, Autism CRC Ltd, will continue this 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 enduser community.

Those interested in being a member of Autism CRC Ltd or an affiliate in its collaboration network should contact Autism CRC at info@autismcrc.com.au.



3.2 Autism CRC Board

The Autism CRC Board is accountable to the Members of Autism CRC Ltd (the Company), including in its role in the management of the Cooperative Research Centre for Living with Autism (2013-2022), and for the ongoing 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, seven Independent Directors and one Nominee Director. Two of the Directors have an autism diagnosis, and a number of Board members are parents of children on the autism spectrum.

The Board met seven 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.





- 1 Independent Chairperson
- 7 Independent Directors
- Nominee Director

3.3 Management Team under Autism CRC Program*

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	
Sally Vidler	Marketing and Communication Manager (Acting)**	Autism CRC	
Cheryl Mangan	Manager, Research Translation	Autism CRC	
Therese Conway	Research Program Manager	Autism CRC	
Wojciech Nadachowski	Chief Operating Officer	Autism CRC	

^{*} to 30 June 2022

^{**} from April 2022

4.0 Report on activities

4.1 Research and development

With support of the Commonwealth, we concluded our protracted wind-up period to June 2022, providing the opportunity to continue work advancing the program objectives. This period allowed activities to progress to completion for those projects with mild impact from continued interruptions of the COVID-19 pandemic. The Board monitored impacted projects and resultant variations to ensure that Commonwealth milestones were delivered within existing resources over the protracted term.

Our 2021-22 work program focused largely on finalising projects, utilisation project activities and knowledge translation.

Our project work has been undertaken within the framework of Strategic, Innovation and Utilisation research projects (described over page), 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.

Project progress, including assessment of project milestone performance, schedule, expenditure and risks, was 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, Knowledge Translation; Marketing and Communication Manager; and Program Directors.

We are grateful for the efforts of all participants and partners

Autism CRC has invested in four types of research projects to deliver its CRC Program:



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.



Section 4 Report on activities Autism CRC Annual Report 2021-22



Early Years – A better start through better diagnosis

Focusing on improving the validity, precision, timeliness and reliability associated with the diagnosis of autism and evidence-based understanding of targeted pathways to early supports.

Program goals

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

facilitate the accurate diagnosis of 50% of children on the autism spectrum prior to their second birthday, and more than 70% 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 CRC-funded Early Years Program has invested in 19 CRC projects, all of which are now complete.

2021-22 snapshot

- ▶ **Genomics** A number of potentially important clinical implications emerged from our analysis of gut microbiome data in the Australian Autism Biobank. Our research supports a 'topdown' model of causality, whereby restricted diet in autism influences the gut microbiome and stool consistency, contrary to evidence from animal models suggesting a causal effect (i.e. 'bottom-up') of the microbiome on autism-related behaviours. Findings published in *Cell*.
- ▶ Sleep difficulties in children Used data from the Australian Autism Biobank to show that children and adolescents with a diagnosis of autism were more likely to have greater severity of sleep difficulties compared to both siblings and unrelated children without an autism diagnosis. Specifically, children on the autism spectrum had more bedtime resistance, greater sleep onset delay, reduced sleep duration, increased levels of sleep anxiety, more night awakenings and parasomnias and greater levels of daytime sleepiness than both siblings and unrelated children without an autism diagnosis.
- ▶ Early surveillance program for autism within General Practices in Australia Involved 122 children aged 18-24 months and their families from 60 GP clinics in NSW and Victoria. The Autism Surveillance Pathway (ASP) improved the accuracy in identifying children at 'high likelihood' of an autism diagnosis and related conditions.

- ▶ SACS-R screening tool Found to be extremely accurate in identifying very young children on the autism spectrum. Of the infants and toddlers aged 12-24 months identified at 'high likelihood' for an autism diagnosis by the tool, 83% were later diagnosed with autism. Data from trial published in JAMA Open.
- ▶ Infants displaying early signs of autism The parent-led therapy led to such a significant improvement in young children's social communication development that a major proportion of the children in the study then fell below the threshold for a 'deficit-focused' DSM-5 diagnosis of autism at three years of age. Findings published in JAMA Pediatrics.

The Early Years Program has supported five Postdoctoral Fellows and eight PhD students.

In addition to CRC-funded projects, Autism CRC has also undertaken several projects in assessment, diagnosis, and early supports.

Highlights from this reporting period include:

- ▶ National Guideline for supporting autistic children and their families Builds on Autism CRC's landmark report Interventions for children on the autism spectrum: A synthesis of research evidence. Guideline development has included a systematic review of the research evidence, a range of community consultation activities, and a structured and transparent process to draft a set of Recommendations and Good Practice Points (draft due for release in July 2022).
- ▶ National Best Practice Assessment and Diagnosis

 This year saw the development of an online
 eLearning short course to support clinicians
 wanting to implement the National Guideline for the
 Assessment and Diagnosis of Autism with clinical
 practice. Course due for release in July 2022
 through Speech Pathology Australia, with more
 professional bodies to come onboard over time.
 This work is funded by a DSS ILC Grant.



Professor Valsamma EapenProgram Director
MBBS, DPM, DFT, PhD, FRCPsych, FRANZCP

A behavioural surveillance tool to enable correct diagnosis of at least 50% of children with Autism Spectrum Disorder (ASD) before two years and at least 70% 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)
- SACS-R trial of 42,000+ children confirms need for universal surveillance of children 12-24 months. Now used across two Australian states and in 10 other countries.
- Early surveillance program for autism within General Practices involved 122 children aged 18-24 months and their families from 60 GP clinics in NSW and Victoria. The Autism Surveillance Pathway (ASP) improved the accuracy in identifying children at 'high likelihood' of an autism diagnosis and related conditions and increased GP, parent/caregiver engagement, health literacy and the barriers and enablers to the implementation of the 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.

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 followup pilot cohort study
- Defining an immune-mediated subgroup

- 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.
- Combination of early childhood surveillance with effective pre-emptive intervention for infants shows very positive implications for child development pathways and support needs.
- 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. Autism NZ made recommendations to NZ Government to address identified service gaps and needs as a result of study.
- Australia's National Guideline for Assessment and Diagnosis of Autism now has 27,400+ registered users. Recorded 64,100+ unique downloads of documents and resources from the Guideline webpage. Implementation activities include Toolkit development (fact sheets, videos, audit tool, templates and training information) and eLearning short course for clinical professionals supporting individuals and families through autism assessments and diagnosis (for release July 2022).
- Australian Autism Biobank established and functioning, with 31 approved projects to date. Nine additional datasets added since research project began including whole genome sequencing (WGS) data of 1,500 participants.
- Data from 240 Australian Autism Biobank participants helped to develop an understanding of the biological and immunological mechanisms underpinning autism with a view to providing earlier and more accurate diagnosis and supports.

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 preschool children in Autism Specific Early Learning and Care Centres (ASELCCs) around Australia

- Integration of phenotypic and biological data to identify subtypes
- Sleep difficulties in children on the spectrum

- ▶ Detailed phenotypic and intervention data from 760 children across six ASELCCs showed overall improvements in receptive language, communication skills, play, and gross motor skills. 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. This project was co-funded by DSS.
- ▶ 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. The project identified homogeneous subgroups with the aim of informing early support needs to optimise life outcomes based on the sensory profile of children.
- A range of clinical and behavioural data from 969 children on the autism spectrum, 188 siblings and 111 non-related, non-autistic children (controls) from the Australian Autism Biobank showed that children and adolescents with a diagnosis of autism were more likely to have greater severity of sleep difficulties compared to both siblings and unrelated children without an autism diagnosis.

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
- Online course resource and content aiding implementation of National Guideline. Since 2015, 83 autism diagnosticians have graduated and a further 51 have completed training in ADOS-2. This takes the total number of completions to 134 exceeding the target of 120. The ongoing sustainability of the course is evidenced by the 16 clinicians enrolled in 2022 GCAD course.
- Graduate microcredentialling units, with accreditation towards GCAD, in development. Due for release in late 2022.
- ▶ 8 PhD students (1 active) have focused on the early years.
- 5 Postdoctoral Fellows.
- A further 9 journal articles were published during the reporting period.

Early Years projects

Resulting from all Investment Rounds approved by the Board. All projects have been completed.

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 Progra	m 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 Progra	m 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	UNSW	\$50,000	\$310,600	
Total Progra	m 1 Utilisation	\$202,205	\$1,089,100		
Total Progr	ram 1 projects			\$8,157,210	\$27,607,085

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



School Years – Enhancing learning and teaching

Developing evidence-based teaching strategies, techniques, tools and programs to enable 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.

The CRC-funded School Years Program has invested in 24 projects, all are now complete.

2021-22 snapshot

- inclusionED Continues to expand in content and reach. Registered users now exceed 4,840 and 727 educators have attended inclusionED professional learning webinars, workshops and presentations in the last year alone.
- Webinars for Early Career Teachers Held at the beginning of Term 1 in 2022, four tailored webinars were attended by 120 early career teachers. Explored fundamental teaching practices from inclusionED for supporting all learners in Early and Middle Years classrooms.
- Autism in Education Showcase Highlighted a range of Autism CRC education resources and featured two panels; autistic adults shared their lived experiences and discussed how autistic students can be better supported at school, and education researchers discussed their research into supporting students on the spectrum in inclusive school settings. Attracted 380 education, allied health and research professionals (219 attended event, further 161 watched live cast or recording).
- Longitudinal Study of Australian Students with Autism (LASA) Six years of data and is one of the world's largest and longest studies following children on the spectrum over time. The study explored academic achievement and participation over time, with data collected from home, school and from some of the children/teenagers themselves. Longitudinal data will be made available for approved future research purposes through the Australian Autism Biobank in late 2022.

Middle Years Behaviour Support Project – Found that to be truly inclusive and to support the more complex needs that many students on the spectrum experience, strategies need to go beyond the traditional focus on support for academic learning and assessment.

The Program has supported three Postdoctoral Fellows in addition to seven PhDs, 14 Masters and three Honours scholars.

In addition to CRC-funded projects, Autism CRC has also undertaken a project to support success in learning.

Highlights from this reporting period include:

Expansion of content, reach and uptake of inclusionED and development of myWAY Educator - Building on the existing inclusionED web platform, the team worked with teachers and stakeholders to co-design new features and content to best meet student needs. Content has now been aligned with national curriculum, professional teaching standards and the Nationally Consistent Collection of Data on differentiated teaching. We continue to work with AITSL, Federal, State and Territory Departments of Education, along with Catholic and independent schools. The project is now developing a personalised, data-informed approach to supporting autistic individuals, connecting education, vocational training and employment sectors. Funded by DSS ILC Grant.



Professor Suzanne Carrington
Program Director
DipTeach, BEd, MEd, PhD

Output and utilisation 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, structured teaching, assistive technology for writing, robotic pedagogy, classroom acoustics, and classroom models of practice

- More than 50 teaching practices in inclusionED, developed from nine core research projects. Site has reached 40,600+ people and has 4,840+ registering users. Almost one third of registered community members are from regional Australia. More than 970 professionals have attended inclusionED professional learning webinars, workshops, and presentations, with a significant increase in these activities over the past year.
- StepWrite assistive writing app has sold 337 copies and has 412 active users. 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. During trial, students reported 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.
- Launched two sister books in 2021 through Routledge. Each is designed to support the work of teachers and specialists in inclusive educational environments.

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 is being 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) socialemotional 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 attracted 11,600+ unique visitors and 42,800 page views to date.
- Tools and protocols developed for behavioural support using teleclassroom consultation approaches.
- Secret Agent Society whole-of-class evaluation completed.
- In January 2020 launched SAS Digital Headquarters, an enhanced re-built version of the previous SAS Computer Game allowing technical longevity and modernisation of the digital learning games. Allows SAS Providers to deliver via Telehealth and provides professionals and families with fast access to increased online resources. The digital edition SAS Small Group Program has already reached 3,280+ children since it launched.
- ▶ SAS Program has been delivered to 25,000+ 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

- Australia's first educational needs analysis for students on the spectrum.
- inclusionED launched (see 2.1 for more detail).
- Worked with national education providers AITSL 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 being followed up annually for six years.

Research and development

LASA involving 1,300 participants completed the following total number of surveys:

- 1,214 Parent (average 202 each year for 6 years)
- 320 Child (average 80 each year for 4 years)
- 204 Principal (average 68 each year for 3 years)
- 529 Teacher (average 88 each year for 6 years)
- 23 Early childhood (1 year)

Outputs and outcomes

- To date 40+ peer-reviewed publications have been published using LASA data.
- One of the world's largest and longest studies following children on the spectrum over time. It includes data from home and school as well as from some of the children/teenagers themselves.
- 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 characteristic and written and social communications, and early predictors of family outcomes with early intervention.
- LASA data to be made available for approved research purposes from the end of 2022 through the Australian Autism Biobank.

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

- 24 scholars have focused on the school years:
 - 7 PhDs (one active)
 - 14 Masters
 - 3 Honours.
- 3 Postdoctoral Fellows.
- Published a further 4 journal articles and delivered 8 conference presentations during the reporting period.

School Years projects

Resulting from all Investment Rounds approved by the Board. All projects have been completed.

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 Progra	m 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 Progra	m 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 myWAY Employability: Enabling support with transition-planning for students on the spectrum	QUT/Curtin	\$57,100	\$231,915	
Total Progra	m 2 Utilisation	\$345,510	\$1,544,953		
Total Progr	ram 2 projects			\$5,515,186	\$23,603,796

[#] Base resources refers to the Research Associate who is working across all Program 2 projects.



Adulthood - Finding a place in society

Focusing 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 adults on the spectrum.

The CRC-funded Adulthood Program has invested in 22 projects. All projects have now been completed.

2021-22 snapshot

- The Integrated Employment Success Tool (IEST) New Zealand – The original workplace manual (launched in 2021) aimed at improving employer confidence, employee productivity, job retention and the overall workplace success of autistic people. This year it was adapted thanks to a collaboration between Autism CRC and Autism New Zealand. The NZ IEST includes information and weblinks about supports, services and resources available to workplaces in Aotearoa New Zealand.
- Completed the Longitudinal Study of Australian School Leavers on the Autism Spectrum (SASLA) – collecting data from 477 participants. Anxiety and/ or depression and ADHD were reported as more prevalent in autistic young people which in turn predicted an increased risk for sleep conditions and lower quality of life.
- Australian Longitudinal Study of Autism in Adulthood (ALSAA) Gathered data from autistic and non-autistic adults aged 25+ years old across two time points. It also collected information from family members and carers. Study has found the autistic adults experience significant disadvantages and barriers in many areas including access to appropriate support, and more needs to be done in equipping health practitioners and improving autism friendliness in Australian society.
- Autism@Work Virtual Summit Our 2020 summit was interrupted by COVID-19 and previous events were in person, but more than 500 delegates attended Australia's first Autism@Work Virtual

- Summit. Attendees heard about the benefits of a neurodiverse workplace and explored how to achieve *Sustainable Programs*, *Sustainable Employment* for employers and employees.
- Improved understanding of the financial wellbeing
 Sustained efforts to support autistic people to
 secure and sustain meaningful and accessible
 employment, including career support planning in
 parallel with increased choice and ease of access
 to supports and services are needed for financial
 wellbeing.
- Autism-specific Quality of Life (QoL) assessment tool – Confirmed that for autistic adults QoL is unique and often impacted by factors other than those measured in traditional QoL assessments. The findings informed a pilot QoL tool drawn from an autistic perspective, enabling meaningful measurement of the construct within the autistic community.

The Adulthood Program has supported six Postdoctoral Fellows and a total of 17 PhD (seven still active), two Masters and 13 Honours scholars.

In addition to CRC-funded projects, Autism CRC has also undertaken projects to improve transition from learning to earning.

Highlights from this reporting period include:

MyWAY Employability next stage Telstra and ILC-funded – Passport profile functionality has been developed with input from 27 stakeholders including employers, employment and disability service providers, parents/carers and autistic individuals. Functionality and content will be further tested and validated in a pilot, ahead of public launch during the second half of 2022. Twenty-five stakeholders including employers, School Leaver Employment Service (SLES) and Employment service providers have been involved in the codesign, development and testing of the enhanced myWAY Employability.



Professor Sonya Girdler
Program Director
PhD, MSc (Occupational Therapy), BSc (Occupational Therapy)

Output 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 and 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

- ALSAA and SASLA studies have produced 180+ publications, conference presentations, posters and resources, all freely available via Knowledge Centre.
- ALSAA has yielded many important insights into the experiences of autism in adulthood, including health and health services, employment, diagnosis, quality of life, loneliness, leisure participation, disclosure, the wellbeing of carers, activities of daily living, intellectual disability and physical activity.
- Anxiety and or depression and ADHD were reported as more prevalent in autistic young people which in turn predicted an increased risk for sleep conditions and lower quality of life. The information provided by SASLA Participants contributed to the refinement of mental health, vocational and other measures for use with autistic people.
- Longitudinal data will be made available for approved future research purposes through the Australian Autism Biobank in late 2022.
- Co-produced study involving autistic and non-autistic researchers, aimed to understand autistic experiences of burnout, to develop a working definition and to explore risk factors.

Output and Utilisation 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

- AAGST sold 350+ copies. Licence agreement in place with Autism Queensland since 2018. Reprint planned in 2022 and exploratory work on a digital version underway.
- Peer mentoring program resources and modules accessible via Autism CRC Knowledge Centre.
- ▶ 60+ mentors and 75+ mentees, with a further 35 students on the 2022 waitlist through Curtin Specialist Mentoring Program.
- MindChip™ social-emotional skills-based program developed and trialled.
- DriverReady program and OrienTrip public transport app for research purposes (400 downloads/700 sessions).

Output and Utilisation 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)

- Autism HealthPathways for GPs and health professionals developed 9 new pathways in consultation with health professionals. Licensing agreement with Streamliners NZ means pathways are available for adoption and adaptation in 43 health regions, caring for more than 28 million people across Australia, New Zealand and the United Kingdom. To date pathways have been licenced in 14 health regions within Australia and NZ, including state and territory-wide in Tasmania, Northern Territory and Western Australia. Pathways accessed by GPs 3,200+ 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. Study involved 29 autistic adults and 15 Health clinicians. Photovoice gallery event attracted 118 registrations. Together, the event recording and gallery video have been viewed 1,000+ 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 adolescent/adult 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

- 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 and launched in Aug 2020 has logged 20,900+ unique visitors. It now has 1,880+ registered users and 1,300+ people have attended myWAY training sessions. The smart web application is based on six years of research, trials and evaluation related to transition planning for young people on the autism spectrum. 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.
- ▶ IEST trialled with 100+ employers in Australia, released in 2021. Recorded 617 downloads from 1,115 registered users. In 2022 it was adapted for the New Zealand workplace (33 downloads to date).
- Autism@Work events have attracted 1,000+ attendees from a diverse range of industries.
- 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

Outputs and outcomes

- Two separate entities have been established and are in use
- 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 390+ resources, publications and reports.

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
- > 32 scholars have focussed on adulthood:
 - 17 PhDs (7 active)
 - 2 Masters
 - 13 Honours.
- 6 Postdoctoral Fellows.
- A further 11 peer-reviewed journal publications and 9 conference presentations were delivered in this reporting period.

Adulthood projects

Resulting from all Investment Rounds approved by the Board. All projects are now complete.

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 Progra	m 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 and 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 Progra	m 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 Progra	m 3 Utilisation		\$151,500	\$617,940	
Total Progr	am 3 projects			\$6,874,746	\$24,267,377

[#] 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

As we move forward under our legacy operations we remain committed to a national collaborative model, working with all stakeholders – individuals on the spectrum, families, professionals, service providers, researchers and government – addressing agreed needs and co-producing outcomes with those stakeholders.

Collaboration between research and end-user participants has been an essential element of our work under the CRC Program. Each funded project has involved 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 Research Program.

The following table provides a breakdown of collaborations between research and end-user/industry participants on all Autism CRC projects between 2013-2022 (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

Project numbers	Project name	Research participants	End-user / Industry participants	Total
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
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

Project numbers	Project name	Research participants	End-user / Industry participants	Total
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

Our education and training activities have built capacity within both the autism research community and the services sector. Using our large collaborative network of stakeholders, we have facilitated opportunities and educational experiences for our scholars and Postdoctoral Fellows, that will enable them to contribute significantly to the autism community in Australia and internationally.

By the end of the reporting period 86% of our 64 scholars had completed their studies; 23 PhD, 16 Masters and 16 Honours students. 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. The program has supported research in a range of topics across the lifespan:

- eight focused on the early years of childhood
- 24 focused on the school years
- > 32 focused on areas of need in adulthood.

Despite another year of COVID-19-related disruptions and hybrid events, scholars were able to present their work, mostly remotely, at leading conferences and symposia such as Australasian Society for Autism Research Conference (ASfAR) in December 2021 and the International Society for Autism Research Annual Meeting (INSAR) in May 2022. PhD scholar and lead author Chloe Yap was invited to present at the Microbiome Virtual International Forum in January 2022 after the release of the *Cell* paper, *Autism-related dietary preferences mediate autism-gut microbiome associations*. See Appendices 3-5 for a full list of publications from our scholars.

Honours Masters PhD

Ten scholars have withdrawn over the lifetime of our CRC program.

What our scholars say about being part of Autism CRC

44

Autism CRC provided an incredible platform for me to understand first-hand how translational research can be achieved well. Further to this, it provided me with the opportunity to work collaboratively with autistic researchers, participate in the research academy, and be part of a network of PhD students with similar values, beliefs, and aspirations. As an Autism CRC Scholar, I am excited and proud to have been part of a world-first in autism research where industry and research institutions were brought together to achieve applied outcomes for the autistic community. Ideally, I think future research should continue to be embedded in a model that promotes translational impact and advocates for implementation science.



Dr Aspasia (Stacey) Rabba, Early Years Program (PhD)



ZZ

I believe that the CRC offered me a number of opportunities that extend far beyond academia. This includes travelling and presenting at various conferences, exploring different projects and career options and meeting some fantastic people along the way. As a result of these amazing experiences, I have the confidence and skills to successfully complete a number of projects, design and present training and education modules for large audiences and give valuable input across multiple sections of the business (as a manager, as a clinical/project lead and as a clinician).

Amanda Mazzoni, Early Years Program (PhD)

44

Working with Autism CRC has been an eye-opening and grounding experience. It is incredibly valuable to be collaborating with an organisation that is designed to amplify the voices of Australian autistic people and coordinate research in a way that is consistent with the community's needs and values. In the best possible way, I feel greater accountability to the autistic community and am now so much more aware and humbled by the broader social sphere that my research exists within. I have specifically worked on Autism CRC's Australian Autism Biobank, which is such an exciting, unique, and world-leading resource.

Chloe Yap, PhD, Early Years Program (PhD)



44

Completing my PhD with Autism CRC provided me with unique opportunities and experiences which have been invaluable in my first few years post-PhD. Autism CRC is a cooperative, innovative and inclusive research environment, providing the opportunity to work alongside not only researchers, but autistic individuals, families and the broader autism community. Autism CRC 'opened my eyes' to the importance of co-production and continues to inspire and motivate me to conduct research which meets the needs of the autistic community.

Melissa Black, Adulthood Program (PhD)



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.



Lacey Chetcuti, Early Years Program (PhD)



44

Working with the Autism CRC has been one of the most rewarding experiences of my career. My research would not have been possible without the support and opportunities provided by the Autism CRC. I am inspired by and grateful to the many accomplished and passionate people I have met and learned from at the Autism CRC.

Mortaza Rezae, Adulthood Program (PhD)



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. 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.

Rebecca Kuzminski, Adulthood Program (PhD)



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.

Yunhe Huang, Adulthood Program (PhD)



Autism CRC provided me with opportunities to broaden my research knowledge. I am grateful for the countless opportunities Autism CRC provided for me to network and learn from other researchers outside of my field of research. Most importantly, Autism CRC's vision instilled a passion within me conduct inclusive research, focusing on projects that are meaningful and can make a genuine difference to the everyday lives of the autistic community.

Julia Tang, Adulthood Program (PhD)





My involvement with the Autism CRC provided the opportunity to engage in multidisciplinary research, and I valued highly the opportunity to be part of a team comprising multiple, diverse stakeholders.

Annalise Taylor, School Years Program (PhD)

Section 4 Report on activities Autism CRC Annual Report 2021-22

Autism CRC higher degree research students

date	Name	Degree	Uni	code	Research project	Term			
Program	1: Early Years								
Complet	ted 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			
Jan-18	Chloe Yap	PhD	UQ	1.042RC	Genomics	3 years			
Active s	Active students								
Aug-18	Alicia Montgomery	PhD	UNSW	1.059RS	Australian Autism Biobank pilot project	8 years (part-time)			

Program 2: School Years

	ted 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
	tudents					
Feb-19	Kathryn Ambrose	PhD	GU	2.007RC	Longitudinal Study of Australian Students with Autism (LASA)	3 years

Program 3: Adulthood

Complet	ted 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

Start date	Name	Degree	Uni	Project code	Research project	Term
Mar-17	Premkumar Brahmbhatt	Hons	UQ	3.015RC	Health and wellbeing for adults	1 year
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
Jan-18	Alexa Chalmers	Masters	LTU	3.016RC	Longitudinal Study of Australian School Leavers with Autism (SASLA)	2 years
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
May-18	Yunhe Huang	PhD	UNSW	3.013RC	Australian Longitudinal Study of Autistic Adults (ALSAA)	3 years
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
	tudents					
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

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 sectors.

Increasingly, end-user and government submissions express 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. This was further demonstrated in the 2022 Federal Election with bipartisan support for our role as the national body to support the development of a National Autism Strategy.

Fifty-six organisations located across Australia and overseas have been engaged as participants in the Cooperative Research Centre for Living with Autism, managed by Autism CRC Ltd. 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.

There was high engagement from our network at Participant Day events in April 2022. More than 100 people attended; 75 face-to-face and a further 30 people via live stream. It was a wonderful way to celebrate our many achievements as a collaboration under the CRC Program. Attendees included CRC Participant representatives, Member-elect and Affiliate-elect representatives for legacy operations, Project Leaders and team members, Sylvia Rodger Academy alumni, PhD scholars, current and former Board members, staff members and other key stakeholders.

Small and medium-sized enterprise engagement

CRC Program projects have involved participants from 38 end-user organisations and 26 Small and Medium-sized Enterprises (SMEs) – with several organisations falling under both categories. By engaging end-users throughout the planning and conduct of our activities, 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's network 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 and Social Science Translated Pty Ltd
- 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).

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.

Large entities and enterprises such as Aspect and F.Hoffman-La Roche Ltd have been engaged as participants, supporting aspects of keystone research and projects such as the Sylvia Rodger Academy Future Leaders Program and the Australian Autism Biobank.

Health sector end-users, particularly clinicians, have been instrumental in the development and dissemination of our diagnostic and health outputs. The Autism HealthPathways are a product 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 and New Zealand are now engaged with the Autism HealthPathways suite of resources thanks to a 2020 licensing agreement with Streamliners NZ.

The original research and development of the National Guideline included extensive national and international consultation with the clinical, allied health, service provider,



and the 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 such as Speech Pathology Australia, as we work toward nationally consistent uptake and delivery of the National Guideline.

Autism CRC is a 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 27,400 people have registered to access the National Guideline from across Australia and overseas, including 18,000 professionals from both the private and public sectors.

Education sector engagement has been fundamental to the design, development and delivery and promotion of research and translation outputs around inclusive education, transition and employment. This year, Education Services Australia (ESA) published the research insights paper "Career planning for autistic students" which promoted myWAY Employability and inclusionED. The team also provided a briefing presentation to ESA's Special Reference Group, with representatives from State and Territory Departments of Education and other career specialist stakeholders. This collaboration also provided an opportunity to present myWAY Employability to a group of senior representatives from Education departments across Australia in February 2022, and webinars for teachers and parents in March-April 2022.

We also continue to have representation on advisory boards and network groups such as:

- Department of Education Queensland, Autism Hub Advisory Board
- Autism Centre for Excellence (ACE) Advisory Board
- Technology Wellbeing Roundtable
- ▶ Telstra Foundation Tech4Good community of practice.

Other CRCs are engaged through our turnKey CRC project. Capitalising on internal expertise and our own needs, Autism CRC has been successful at building a ready-to-use software solution that is now in demand by other CRCs. turnKey CRC now supports 16 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.

Industry groups, such as potential employers looking at neurodiverse workplace programs, have been attracted to events such as our Autism@Work summits. To date, these summits have attracted over 1,000 attendees from a broader range of industries and organisations, including

the Department of Defense, Australian Federal Police, small business owners, start-ups, local councils, state government departments and large corporations. The 2021 Virtual Summit attracted 500 attendees. Engagement was very high with 100th most engaged person attending eight out of 16 sessions, meaning at least 100 people watched at least half of the sessions over the two-day event (either live or on demand). The 300th most engaged person attended three out of 16 sessions, meaning at least 300 people watched a minimum of three sessions (approximately three hours' worth of content either live or on demand). These events also attract industry partners and sponsorship from companies such as – SAP, AISA, GHD, Untapped, SunPork Group, Curtin University, ANZ, La Trobe University and BHP.

Engagement with the autistic and autism communities

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. We not only encourage this in our own work, but actively promote it throughout the research community which this year included the update and relaunch of the Participatory and Inclusive Autism Research Guides. Other examples include:

- of the National Guideline for supporting the participation, learning and wellbeing of autistic children and their families in Australia, have included tailored opportunities for the involvement of autistic children, autistic adults and autistic people of all ages who communicate mainly in ways other than speech. Activities also included parents of autistic children and adults. The project's 15-member Guideline Development Group includes key stakeholder communities including representation from autistic individuals, parents/siblings/caregivers, practitioners, and peak bodies. To date, community consultation included 800+ community members, practitioners, and service providers.
- The hidden histories of late-diagnosed autistic adults: An oral history study which 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.
- Development of an autism-specific quality of life assessment for use with autistic adults which 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. They also completed a residential workshop.

The inaugural Governance Program and third Future Leaders Program were also completed during the year. All Sylvia Rodger Academy programs are co-designed and delivered with autistic adults. As with the 2019-20 program, the Future Leaders Program is again being delivered through a collaboration with CRC Essential Participant and end-user organisation, Aspect.



4.5 Awards and honours 2021-22

Date	Personnel	Award	From	For
Jun-22	Professor Cheryl Dissanayake	Member of the Order of Australia (AM)	The Governor-General of the Commonwealth of Australia	Significant service to medical research, tertiary education and professional societies
Jun-22	Dr Gail Alvares	FHRIF Translation Fellowship	Western Australian Government	In partnership with the community develop a world first digital mental health platform for autistic children
Jan-22	Dr Kathleen Davey	Inaugural Entrepreneur of the Year Award	Australian Psychological Society	Spearheading the rapid transformation of the Secret Agent Society (SAS) Small Group Program into a sophisticated digital health system
Jan-22	Dr Stacey Rabba	Psychology of Intellectual Disability and Autism Thesis Award	Australian Psychological Society	Thesis Excellence Award for PhD Research exploring family wellbeing in parents following a child's autism diagnosis
Dec-21	Dr Wenn Lawson	National Award for Disability Leadership - Lesley Hall Award for Lifetime Achievement	Disability Leadership Institute	Lifetime contribution to the autistic and autism communities as an advocate, educator and researchers
Dec-21	Ruby Mountford	National Award for Disability Leadership - Inclusion	Disability Leadership Institute	Contributions to the LGBTIQA+ disability communities and developing an Accessibility Inclusion Action Plan for Thorne Harbour Health
Dec-21	Dr Samuel Arnold and Ms Julianne Higgins	Achievement in Autism Research – Inclusive research practice	Autism CRC	Investigating Autistic Burnout (#AutBurnout)
Dec-21	Dr Sandra Jones	Achievement in Autism Research – Inclusive translation of autism research	Autism CRC	Raising Awareness of the Needs of Autistic Australians
Dec-21	Dr Trevor Clark	Achievement in Autism Research – Inclusive research practice	Autism CRC	Priorities of Autistic People in Australia and their families for autism services and supports
July-21	Chloe Yap	2021 Queensland Women in STEM Judges Award	Queensland Museum Network and Queensland Government	Research using 'big data' approaches to improve early autism diagnosis and the development of appropriate supports

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.

We continue to improve the accessibility of our communication activities, where possible creating accessibility tagging in major documents, explainer videos, low sensory versions of videos, adding closed captioning, voiceovers or transcripts, and providing copies of presentations and recordings of events from our website and YouTube channel. This helps to improve the uptake, reach, and longevity of our dissemination activities. As an example, webinar recordings from April 2021 (previous reporting period) were viewed a total of 1,129 times in the last 12 months from our YouTube channel.

Our online community now stands at:

- 23.370 eNews subscribers
- 10,800 Facebook followers
- 2,349 Twitter followers
- 1,592 LinkedIn followers.

2021-22 communication highlights

- Received international media coverage with several large research outputs, in particular the Cell publication, Autism-related dietary preferences mediate autismgut microbiome associations, which produced a substantial volume of both mainstream and social media both within Australia and internationally. This included stories on/in The Economist. The Scientist. The Conversation. The Australian. ABC News online. The Medical News, The Medical Republic, UQ News, Child Magazines, Retail Pharmacy Magazine, Health Times, Sydney Morning Herald (and syndicated though Nine's publications), Australian Community Media syndication (Jimboomba Times, Whyalla News and 101 others), and ABC Radio, syndicated nationally. The Autism CRC Marketing and Communication team leveraged the assistance of Mater Research to promote the research outcomes and their impact.
- 2021 Autism@Work Virtual Summit attracted 1,162 individuals registrations, with 44% of registrants attending. Anecdotally, we are told by event platform provider Cvent that this is above average for a free event, which generally average around 30%.
- Recruitment for the first stage of community consultation for the development of the *National Guideline for* supporting the learning, participant and wellbeing of autistic children and their families in Australia was supported by dedicated webpages, targeted emails (reach = 20,000+) and promoted Facebook posts

- (reach = 48,000+). This drove a significant amount of traffic to these activities and resulted in more than 800 members of the community participating in a range of consultation activities.
- 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 390 journal publications and other resources. Taking into account our diverse stakeholder audience, final project reports are hosted on Knowledge Centre and generally supported by executive summaries and research snapshots. Research snapshots provide a plain language summary of project outcomes and have become a valuable communication tool.
- Timely updates and continuous improvement to website content and user experience has seen sustained engagement with the corporate website (autismcrc.com.au). The website attracted 311,396 unique page views during the reporting period.
- 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 2021-22 year include Financial Review, The Australian, Channel 9, Channel 7, Link Disability Magazine, Freedom2Live, Health Times, Scimex, Disability Support Guide and Autism Awareness Australia eUpdate, Medical Forum, Lab+Life Scientist.

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.
- Project IP which is created through CRC programs (Centre IP) along with other new IP generated through non-CRC projects and activities – 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 Project IP).
- 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 Project IP 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 Science Translated Pty Ltd) can be found in Appendix 6.

4.8 Utilisation and commercialisation

To date, more than 121,000 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 30,000 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.
- ▶ 350+ copies sold to-date.
- Second reprint commissioned for 2022.
- 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.

- Thirty-one 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.
- Nine additional datasets added since research began as a result of project activities.
- Whole genome sequencing data generated for more than 1,500 participants.



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-occuring 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
AInflammation and neuromodulation in autism	Alicia Montgomery	University NSW
Co-occuring 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 of 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

Project title	Principle investigator	Lead organisation
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
*Identifying candidate genomic variations and the pathogenic genes in Autism	Hamid Rokny	University NSW
Predictor of self-injurious behaviours, anxiety, and friendship	Andrew Whitehouse	Telethon Kids Institute
Parental observation experience and impact	Andrew Whitehouse	Telethon Kids Institute
Impact of diet on sleep	Maryam Boutros	Telethon Kids Institute
Mental health challenges	Gail Alvares	Telethon Kids Institute
*Biological, behavioural and environmental interactions assessment	Alicia Montgomery	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 webbased 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 3,200+ 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, 14 health regions within Australia and NZ, including state and territory-wide in Tasmania, Northern Territory and Western Australia have adopted and/or localised the pathways.

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 2022:
 - 11,600+ unique visitors
 - 15,600 sessions (an individual period of time a user is actively engaged, navigating, clicking, etc)
 - 42,800 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 AITSL, Education Services Australia 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.
- More than 970 professionals have attended inclusionED professional learning webinars, workshops and presentations.
- Launched platform (18 May 2020) inclusioned.edu.au. Statistics to 30 June 2021:
 - 40,600 unique visitors
 - 4,840+ registered users (well above the industry benchmark of 5% conversion to registration)
 - 63,400+ sessions (an individual period of time a user is actively engaged, navigating, clicking, scrolling, etc)
 - 405,000+ page views (including repeated views of a single page).

- Developing content 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.
- Additional functionality and new look platform due for release in October 2022.



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 NZ version adapted and released in May 2022.
- Manual and supporting templates available via registration process - users to 30 June 2022:
 - 1,115 registered users
 - 650 downloads of the manual (Aust & NZ).

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 2022:
 - 20,900+ unique visitors
 - 1,880+ registered users (well above the industry benchmark of 5% conversion to registration)
 - 32,650+ sessions (an individual period of time a user is actively engaged, navigating, scrolling, etc)
 - 168,700+ page views (including repeated views of a single page).
- Stage 3 (funded by Telstra Foundation), focusing on uptake of myWAY Employability in service delivery by disability and employment services, schools and allied health professionals. A minimum viable product including passport profile functionality has been developed with input from 27 stakeholders including employers, employment and disability service providers, parents/carers and autistic individuals. Functionality and content to be further tested and validated in a pilot, ahead of public launch during the second half of 2022.
- 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. Statistic to 30 June 2022:
 - 337 purchases, resulting in \$405 in revenue
 - 412 active users
 - 19.9K impressions (number of times the app was shown in the app store) with a conversion rate of 3%.

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, 16 CRCs have chosen to use turnKey CRC.

With the maturing operations of many of these CRCs there has been significant development in functional use of progress reporting. The turnKey team has continued to evolve the product offering, streamlining project call-out and review processes, and improving progress reporting features such as 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

4.9 Social Science Translated Pty Ltd

A wholly owned subsidiary of Autism CRC Ltd

Social Science Translated Pty Ltd (SST), formerly Social Skills Training Pty Ltd, delivers evidence-based practical resources to engage professionals, children and families to diversify life skills to achieve a vision that sees us all valuing diverse life skills that make for meaningful change in people's lives.

The key program offered by SST is the Secret Agent Society Small Group Program (SAS-SG). SST has the exclusive worldwide license for distributing and developing SAS programs, espionage-themed resources provide an evidence-based, comprehensive and captivating solution to structured social and emotional learning for children aged 8-12 years old. SST makes SAS available worldwide to children, parents and professionals through training education and allied health professionals in facilitating the SAS Small Group Program, and distributing SAS resources and access to both SAS Providers and the public.

This last year has seen SST and the SAS program achieve many milestones as well as settling into the distribution of SAS-SG now through a digital health platform. The platform has seen over 550 SAS Facilitators enter the new system to schedule over 6,000 Cadet Club Meetings across the world despite heavy pandemic restrictions impacting services and families. The platform allows for in-person, telehealth or hybrid service delivery models and over the reporting period meant undisrupted service provision across fluctuating pandemic restrictions. Services are now

expanding their reach and improving their program fidelity and data monitoring as they build child mental health and diverse social skills into the future.

The award-winning and evidence-based months-long program involves educational computer games, regular Cadet Club Meetings, Parent Groups Meetings and teacher information guided by a trained SAS Facilitator. Each small group includes a maximum of 3-4 children per Facilitator. The skills and tools learnt during sessions are practiced in real-life missions paired with a Skill Tracker used to reward skill development at home and school. At the end of the program, children graduate as 'Secret Agents' having learnt and practiced codes and tools that focus on four key life skills: emotion recognition, emotion regulation, social problem solving, and a series of social skills to align with a child's goals for friendship and teamwork goals.

In December 2021 SST was delighted to learn that Chief Executive Officer and Clinical Psychologist, Kathleen Davey was awarded the Australian Psychological Society's inaugural Entrepreneur of the Year Award for spearheading the rapid transformation of SAS-SG into a sophisticated digital health system.

Research into SAS in a variety of settings and with a variety of child cohorts continues. Dr Renae Beaumont is the author of the Secret Agent Society programs and a key researcher of the program's application. This last year



saw the publication of the latest SAS focused Randomised Controlled Trial lead by Dr Beaumont out of Weill Cornell Medicine, New York Presbyterian Hospital in the United States. In addition, the teams working at York University, United States and Carleton University, Canada have completed and published multiple papers and posters on their applied research funded through Kids Brain Health Network in Canada. During 2021-2022 multiple studies have either commenced, continued or completed, and the following articles were published:

- Temkin, A. B., Beaumont, R., Wkya, K., Hariton, J. R., Flye, B. L., Sheridan, E., ... Bennett, S. M. (2022). Secret Agent Society: A Randomized Controlled Trial of a Transdiagnostic Youth Social Skills Group Treatment. Research on Child and Adolescent Psychopathology. doi.org/10.1007/s10802-022-00919-z
- Lee, V., Roudbarani, F., Tablon Modica, P., Pouyandeh, A., & Weiss, J. A. (2022). Adaptation of Cognitive Behavior Therapy for Autistic Children During the Pandemic: A Mixed-Methods Program Evaluation. Evidence-Based Practice in Child and Adolescent Mental Health, 7(1), 76–93. doi.org/10.1080/23794925.2021.1941432
- Mootz, C. A., Lemelman, A., Giordano, J., Winter, J., & Beaumont, R. (2022). Brief Report: Feasibility of Delivering the Secret Agent Society Group Social Skills Program via Telehealth During COVID-19: A Pilot Exploration. *Journal of Autism and Developmental Disorders*. doi.org/10.1007/s10803-022-05591-2

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 as restrictions ease and the need for child and families supports is realised through various new funding initiatives globally. 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.

In this small program the effective working relationship between the Board and management is a crucial element of its success. The Social Science Translated Pty Ltd Board is appointed by Autism CRC Ltd as the sole shareholder. The SST Board met on seven occasions during the reporting period. Its Board members during this period were Carole Green (Chair), Adrian Ford (Executive Director), Andrew Davis and Paul Vincent. The Board supported a process of review to the Company name and Vision and Mission and set the scene to introduce the SST's first board appointed Chief Executive Officer, Kathleen Davey, for the year ahead.

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, RAnNutr, 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 autistics. His daughter was initially diagnosed on the spectrum 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, Aguaculture and Aguafin 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 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 Science Translated 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.



Katharine Annear (Independent Director)

BAppSc(DisStud) MDisStud ACBS

Katharine is an Academic at Flinders University, a registered Developmental Educator, and has served on local and national not for profit boards for over 20 years. These include incorporated associations and companies limited by guarantee, in the Disability and Arts industries, and National Disabled People's Organisations.

Katharine is a founding member of the ASAN AUNZ and has spent over 15 years in the autism advocacy space, in both grassroots and high-level policy settings. Katharine also sits on the ministerially appointed Autism Advisory Group for the NDIA, and the Children, Young People and Families Reference Group for the NDIA's Independent Advisory Council.

Katharine brings experience as an Autistic person who also has numerous Autistic family members. This is complimented by almost 20 years as a practicing Developmental Educator working predominantly with Autistic individuals who have complex support needs and their families.

Katharine is a passionate advocate for co-design in research and public policy and the translation of research and policy into meaningful practice for disabled people; with a particular emphasis on including the most marginalised people.



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.



Adrian Ford (Independent Director)

BSocStud, FAICD

As well as being an Independent Director on the Autism CRC, Adrian is a Board Director of Social Science Translated Pty Ltd (SST), a subsidiary of the Autism CRC. He recently stepped down from being SST's Executive Director for the past three years following the appointment of SST's first CEO. Adrian is also the principal consultant of AJF Governance Advisory.

Previously, Adrian was the CEO and Company Secretary of Autism Spectrum Australia (Aspect), Australia's largest national autism-specific service provider and was more recently the Managing Partner for The Professional Partner Group. While at Aspect, Adrian was a founding member the Australian Autism Alliance, a director and former chair of the Australian Advisory Board for Autism, Chair of the inaugural Asia Pacific Autism Conference (APAC) in 2009, Chair of APAC 2017 and Advisor to the Organising Committee of APAC 2019, held in Singapore.

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.



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 Research and Development 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 an independent director of Autism CRC, Malcolm is a member of the Australasian Autism Research Council, and is a mentor and content writer for the Sylvia Rodger Academy for the Future Leaders and Governance programs.

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 hospitals, 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)

MComm, MBus, MAICD

Scott has over 30 years' experience in senior management and leadership roles in industry sectors including retail, media, direct selling and small business with both national and international companies.

As a private philanthropist Scott has donated his time and resources to numerous not-for-profit boards and has always been guided by his strong moral compass, evidence-based research, and courageous board governance. As part of Scott's philanthropic work, he was a founding Director of the AEIOU Foundation for Children with Autism and was an active board member for the past 15 years.

Over the past eight years as a Director of the Autism CRC, Scott 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.

He is the parent of a young adult on the spectrum and understands intimately the daily challenges that this condition can bring.

Scott is proud to be associated with the hard-working staff and dedicated researchers from the Autism CRC whose peer reviewed research will benefit so many for years to come.



Paul Vincent (Independent Director)

BBus (Acc), FCA, GAICD

Paul is a Fellow of Chartered Accountants Australia and New Zealand and holds specialist accreditation in Business Valuation and Forensic Accounting with that body. Paul founded Vincents in 1989 and today remains a Director of Vincents which has grown to become a National mid-tier advisory firm of over 250. Paul has extensive experience in commercial litigation, providing expert accounting and financial evidence for commercial and criminal litigation matters. Paul's principal area of practice is quantification of damages and business valuations, to provide independent expert evidence for dispute resolution. Paul also mediates and arbitrates financial disputes. His accounting experience in his early career at KPMG covered audit, insolvency and reconstruction, corporate services, taxation and a wide range of consulting engagements.

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 has been an independent director of Autism CRC since its inception in 2013.

5.2. Autism CRC Committees

Research and Development Committee

The Research and Development Committee comprise of CRC Essential Participant nominees and members appointed by the Board. The Committee has provided a forum for consultation among these 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. From 1 July 2022, this Committee will be known as the Investment Advisory Committee as part of the transition from the CRC Program, with each Member having the right to nominate one representative.

The Research and Development Committee did not meet during the reporting period. The role of this committee will be performed by the Investment Advisory Committee for the new legacy operations. The nominees to the new Committee met with the Autism CRC Board in April 2022 to discuss future research priorities post 1 July 2022.

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 Robert van Barneveld (Chair), Adrian Ford, Katharine Annear and Paul Field.

This committee will continue to operate under the legacy governance arrangements from 1 July 2022.

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 and Malcolm Mayfield, with the CEO and CFO in attendance.

This committee will continue to operate under the legacy governance arrangements from 1 July 2022.

6.0 Appendices

Appendix 1: List of Autism CRC Participants

Participant name	Туре	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 68
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 23
AssistiveWare	Other	Industry / Private Sector/ International	
Australian Advisory Board for Autism	Other	Other / End-user	53 085 018 40
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 13
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 33
Autism Specific Early Learning and Care Centre - WA (AAWA)	Other	Industry / End-user	54 354 917 843

Participant name	Туре	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 93
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
Renae Beaumont Enterprises Pty Ltd	Other	Industry	50 129 179 675
South Australian Group Enterprises (SAGE)	Other	Private Sector / End-user	40 005 498 77!
Spectrum Space	Other	Industry / End-user	38 262 080 94
The Aspergers Syndrome Clinic	Other	Industry / Private Sector / End-user	39 090 503 60
The Association of Independent Schools Queensland	Other	Industry / Private Sector/ End-user	88 662 995 57
The Royal Children's Hospital	Other	State Government / End-user	35 655 720 54
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 2022

Consolidated Entity

	30 June 2022	30 June 2021
	\$	\$
Revenue	7,876,081	19,070,821
Revenue	7,870,081	19,070,821
Expenses		
Research costs	(3,927,070)	(9,187,621)
Employee benefits expense	(2,351,586)	(2,175,311)
Board fees and related expense	(258,954)	(241,169)
Depreciation and amortisation expense	(309,522)	(262,860)
Impairment Loss	(310,305)	(1,579,918)
Other expenses	(1,540,860)	(1,028,688)
Results from operating activities	(822,216)	4,595,254
Financing income	4,397	7,828
Finance costs	(19,291)	(25,210)
Net finance (costs)/income	(14,894)	(17,382)
(Deficit) / Surplus before tax	(837,110)	4,577,872
Income tax expense	19,011	-
(Deficit) / Surplus after tax	(818,099)	4,577,872
Other comprehensive income	-	-
Total comprehensive (loss) / income for the period	(818,099)	4,577,872

The operating deficit of the Consolidated Entity for the financial period ended 30 June 2022 was \$818,099 (2021: operating surplus of \$4,577,872). 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 was recognised against this asset. A further impairment of \$310,305 was recognised in 2022.

The reduction in operating income from FY2021 to FY2022 resulted largely from the time-only extension to the CRC Program agreement due to COVID 19 impacts on activities, with no additional cash funding from the Commonwealth or Participants for the additional 12-month period, together with a significant reduction in Participant in-kind contributions to CRC Program activities for the same period. The combined revenue impact of these was approximately \$11.4m in 2022.

In March 2021 the ACRC 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. These funds were received in FY2021 (\$2,000,000) and FY2022 (\$4,000,000), of which \$3,624,627 is yet to be applied to activities scheduled for FY2023. The impact of this funding therefore contributed \$1,919,172 and \$1,705,455 to the FY2021 and FY2022 net operating positions, respectively.

Statements of Financial Position For the financial year ended 30 June 2022

Consolidated Entity

	30 June 2022	30 June 2021
	\$	\$
Current assets		
Cash and cash equivalents	7,019,679	7,526,262
Trade and other receivables	570,484	291,330
Prepayments	55,993	44,664
Current tax asset	10,084	11,363
Inventory	14,862	-
Total current assets	7,671,102	7,873,619
Non-current assets		
Property, plant and equipment	20,116	22,581
Right-of-use asset	294,195	441,293
Trade and other receivables	-	-
Investment in wholly owned subsidiary	-	-
Intangible Assets	4,408,337	4,408,337
Total non-current assets	4,722,648	5,243,033
Total assets	12,393,750	13,116,652
Current liabilities		
Trade and other payables	583,138	478,434
Provisions	236,099	151,762
Lease Liability	153,017	146,849
Current tax liability	-	4,149
Total current liabilities	972,254	781,194
Non-current liabilities		
	57,153	_
Lease Liability	159,444	312,460
Total Non-Current Liabilities	216,597	312,460
Total liabilities	1,188,851	1,093,654
Net assets	11,204,899	12,022,998
Equity		
Equity Retained earnings	11,204,899	12,022,998

 $Cash\ and\ cash\ equivalents\ includes\ \$3,624,627\ (2021:\ \$1,919,172)\ of\ ILC\ funding\ yet\ to\ be\ applied\ to\ activities\ scheduled\ for\ FY2023.$

Autism CRC prepared Special Purpose Finance Statements in FY2022 that were subject to external audit.

The Autism CRC prepared Special Purpose Finance Statements in FY2022 that were subject to external audit.

Appendix 3: Publications 2021-22

Program 1

Barbaro, J., Sadka, N., Gilbert, M., Beattie, E., Xia, Li., Ridgeway, L., Lawson, L., Dissanayake, C. (2022). Diagnostic accuracy of the Social Attention and Communication Surveillance: Revised with Preschool tool for early autism detection in very young children. Jama Network Open, 5(3), e2146415. doi. org/10.1001/jamanetworkopen.2021.46415.

Chetcuti, L., Uljarevi, M., Varcin, K., Boutrus, M., Pillar, S., Dimov, S., Barbaro, J., Dissanayake, C., Green, J., Wan, M.W., Segal, L., Slonims, V., Whitehouse, A.J.O. & Hudry, K. (2021). Caregiver psychological distress predicts temperament and social-emotional outcomes in infants with autism traits. Research on Child and Adolescent Psychopathology, early online. doi: 10.1007/s10802-021-00838-5.

Chetcuti, L., Richdale, A.L., Haschek, A., Uljarevic, M., Lawson, L.P. (2022). Brief report: Discrete effortful control skills moderate relations between childhood behavioural inhibition and mental health difficulties in autistic youth. Journal of Autism and Developmental Disorders. doi.org/10.1007/s10803-021-05360-7.

Evans, K., van der Meer, L., Eggleston, M.J.F. et al. (2021). A Survey of Autistic Adults from New Zealand on the Autism Diagnostic Process During Adolescence and Adulthood. J Autism Dev Disord 52, 771–81. doi.org/10.1007/s10803-021-04983-0.*

Lane, A.E., Simpson, K., Masi, A., Grove, R., Moni, M.A., Montgomery, A., Roberts, J., Silove, N., Whalen, O., Whitehouse, A.J.O. & Eapen, V. (2022). Patterns of sensory modulation by age and sex in young people on the autism spectrum. Autism Research, 1-15. doi: 10.1002/aur.2762.

Masi, A., Dissanyake, C., Alach, T., Cameron, K., Fordyce, K., Frost, G., Grove, R., Heussler, H., Silove, N., Sulek, R., Tucker, M., Williams, K. & Eapen, V. (2021). Clinical outcomes and associated predictors of early intervention in Autism Spectrum Disorder: A study protocol. BMJ Open, 11(8), e047290. doi: 10.1136/bmjopen-2020-047290.

Trembath, D., Waddington, H., Sulek, R., Varcin, K., Bent, C., Ashburner, J., Eapen, V., Goodall, E., Hudry, K., Silove, N & Whitehouse, A. (2021). An evidence-based framework for determining the optimal amount of intervention for autistic children, The Lancet Child & Adolescent Health. doi: 10.1016/S2352-4642(21)00285-6.

Whitehouse AJO, Varcin KJ, Pillar S, et al. (2021). Effect of Preemptive Intervention on Developmental Outcomes Among Infants Showing Early Signs of Autism: A Randomized Clinical Trial of Outcomes to Diagnosis. JAMA Pediatrics. Online. doi:10.1001/jamapediatrics.2021.3298.

Yap, C.X., Henders, A.K., Alvares, G.A, Wood, D., Krause, L., Tyson, G.W., Restaudi, R., Wallace, L., McLaren, T., Hansell, N.K., Cleary, D., Grove, R., Hafekost, C., Harun, A., Holdsworth, H., Jellett, R., Khan, F., Lawson, L.P., Leslie, J., Frenk, M.L., Masi, A., Mathew, N.E., Muniandy, M., Nothard, M., Miller, J., Nunn, L., Holtmann, G., Strike, L., de Zubricaray, G. Thompson, P.M., McMahon, K., Wright, M.J., Visscher, P.M., Dawson, P.A., Dissanayake, C., Eapen, V. & Gratten, J. (2021). Autism-related dietary preferences mediate autism-gut microbiome associations. Cell. doi.org/10.1016.

Program 2

Ambrose, K., Simpson, K. & Adams, D. (2021). The impact of anxiety on the participation of children on the autism spectrum. Journal of Autism and Developmental Disorders, early online. doi: 10.1007/s10803-021-05162-x.

Shochet, I.M., Saggers, B.R., Carrington, S.B. et al. (2022). A School-Based Approach to Building Resilience and Mental Health Among Adolescents on the Autism Spectrum: A Longitudinal Mixed Methods Study. School Mental Health 14, 753–775. doi.org/10.1007/s12310-022-09501-w

Simpson, K. & Adams D. (2022). Brief Report: COVID restrictions had positive and negative impacts on schooling for students on the autism spectrum. Journal of Autism and Developmental Disorders. Feb 3;1-7. doi: 10.1007/s10803-022-05451-z.

Wilson, W.J., Harper-Hill, K., Armstrong, R., Downing, C., Perrykkad, K., Rafter, M. & Ashburner, J. (2021). A preliminary investigation of sound-field amplification as an inclusive classroom adjustment for children with and without Autism Spectrum Disorder. Journal of Communication Disorders, 93, 106142. doi: 10.1016/j.jcomdis.2021.106142.

Program 3

D'Arcy, E., Girdler, S.J., Falkmer, M., Falkmer, T., Whitehouse, A.J.O., Wray, J., Eapen, V. & Evans, K. (2021). Get it right, make it easy, see it all: Viewpoints of autistic individuals and parents of autistic individuals about the autism diagnostic process in Australia, early online. doi.org/10.1016/j.rasd.2021.101792.

D'Arcy, E., Wallace, K., Chamberlain, A., Evans, K., Milbourn, B., Bölte, S., Whitehouse, A.J.O. & Girdler, S. (2021) Content validation of common measures of functioning for young children against the International Classification of Functioning, Disability and Health and Code and Core Sets relevant to neurodevelopmental conditions. Autism, early online. doi: 10.1177/13623613211036809.

Gibbs, V., Hudson, J., Hwang, Y. I. (Jane), Arnold, S., Trollor, J., & Pellicano, E. (2021). Experiences of physical and sexual violence as reported by autistic adults without intellectual disability: Rate, gender patterns and clinical correlates. Research in Autism Spectrum Disorders, 89, 101866. doi. org/10.1016/j.rasd.2021.101866.

Harvery, M., Froude, E., Foley, K-R., Troller, J. & Arnold, S.R.C. (2021). Employment profiles of autistic adults in Australia. Autism Research, 14:10, 2061-2077. doi.org/10.1002/aur.2588.

Lane, A.E., Simpson, K., Masi, A., Grove, R., Moni, M.A., Montgomery, A., Roberts, J., Silove, N., Whalen, O., Whitehouse, A.J.O. & Eapen, V. (2022). Patterns of sensory modulation by age and sex in young people on the autism spectrum. Autism Research, 1-15. doi: 10.1002/aur.2762.

Huang, Y., Arnold, S.R.C., Foley, K.R., Lawson, L.P., Richdale, A.L. & Trollor, J.N. (2021). Factors associated with age at diagnosis in a community sample of Australian adults. Autism Research https://doi.org/10.1002/aur.2610.

Lilley, R., Lawson, W., Hall, G., Mahony, J., Clapham, H., Heyworth, M., Arnold, S.R.C., Trollor, J. T., Yudell, M. & Pellicano, E. (2021). 'A way to be me': Autobiographical reflections of autistic adults diagnosed in mid-to-late adulthood. Autism, early online. doi: 10.1177/13623613211050694.

Muniandy, M., Richdale, A.L., Arnold, S.R.C., Trollor, J.N. & Lawson, L.P. (2022). Associations between coping strategies and mental health outcomes in autistic adults. Autism Research. doi.org/10.1002/aur.2694.

Pellicano, E., Lawson, W., Hall., Mahony, J., Lilley, R., Heyworth, M., Clapham, H. & Yudell, M. (2022). "I Knew She'd Get It, and Get Me": Participants' Perspectives of a Participatory Autism Research Project. Autism in Adulthood. pp.120-129. doi.org/10.1089/aut.2021.0039.

Sonido, M.T., Hwang, Y.I., Sraesuebkul, P., Trollor, J.N. & Arnold, S.R.C. (2021). Predictors of the mental well-being of informal carers of adults on the autism spectrum. Journal of Autism and Developmental Disorders, doi:10.1007/s10803-021-05178-3.

Wilson, N.J., Stevens, A., Srasuebkul, P., Kersten, M., Lin, Z., Trollor, J.N. & Arnold, S.R.C. (2021). Exploring the relationship between community mobility and quality of life, employment and completing further education: Results from the Australian Longitudinal Study of Autism in Adulthood. Transport and Health, 22. doi.org/10.1016/j.jth.2021.101117.

Not program specific

Alvares, G. A., Mekertichian, K., Rose, F., Vidler, S., & Whitehouse, A. (2022). Dental care experiences and clinical phenotypes in children on the autism spectrum. Special Care Dentist. 1-12. doi.org/10.1111/scd.12746.

Poulsen, R., Brownlow, C., Lawson, W. & Pellicano, E. (2022). Meaningful research for autistic people? Ask autistics! Autism. 26(1):3-5. doi:10.1177/13623613211064421.

Reports 2020-21

Program 1

Barbaro, J., Eapen, V., Gilbert, M., Nair, R., Masi, A., Winata, T. & Khan, F. (2022). A multistate trial of an early surveillance program for autism within General Practices in Australia: Final Report. Brisbane: Autism CRC.

Dissanayake, C., Barbaro, J., Sadka, N., Barnett, T. (2022). Developmental surveillance for autism: Prospective identification of autism in infants and toddlers using Social Attention and Communication Surveillance. Final Report. Brisbane. Autism CRC.

Gratten, J., Yap, C.X. Henders, A.K, Wallace, L., McLaren, T. & Wray, N.R. (2022) Development and validation of systems genomics-based predictors for autism (Stage 1): Final Report: Brisbane, Autism CRC.

Masi, A., Eapen, V., Lane, A., Simpson, K. & Roberts, J. (2021). Sensory subtypes in children on the autism spectrum: Final Report. Brisbane: Autism CRC

Masi, A., Eapen, V., Lin, P., Moni, M.A. & Heussler, H. (2022). Sleep difficulties in children on the autism spectrum: Understanding the biological and behavioural attributes leading to sleep difficulties in children on the autism spectrum. Final Report. Brisbane: Autism CRC.

Maybery, M., Taylor, L. & Miller, E. (2022). Graduate Certificate in Autism Diagnosis: Enhancing training in autism diagnosis: Final Report. Brisbane: Autism CRC.

Montgomery A, Masi A, Silove N, Karlov L, Whitehouse A, Eapen V (2021). Defining an immune-mediated subgroup of children in the Australian Autism Biobank. Final Report. Brisbane. Autism CRC.

Roberts, J., Adams D., Simpson K., Paynter J., Westerveld M., den Houting J. & Ambrose K. (2022). The longitudinal study of Australian students with autism (LASA): Final Report. Brisbane: Autism CRC.

Program 2

Chalmers, C., Mavropoulou, S., & Silvera-Tawil, D. (2021). Evaluating the effects of a humanoid robot on the story retelling skills of children on the autism spectrum: Final Report. Brisbane: Autism CRC.

Saggers, B., Odier-Guedj, D. & Whelan, M. (2022). Collaborative Partnerships in Action: Final Report. Brisbane: Autism CRC.

Saggers, B., Tones, M., Dunne, J., Willis, J., Gibson, A., English, R., Ashburner, J., Clark, T., Carrington, S., Brereton, M., Gibbs, V., Aberdein, R. & Harper-Hill, K. (2022). Middle Years Behaviour Support Project (MYBSP): A teleconsultation approach to support the learning needs of students on the autism spectrum in the middle years of schooling in rural, remote, Indigenous, and isolated education communities. Final Report. Brisbane: Autism CRC.

Program 3

Brooker, K, Bradshaw, B, Franklin, C & Urbanowicz, A. (2021). Tools, strategies, and techniques developed to improve the health and wellbeing for autistics adults: Final report. Brisbane: Autism CRC.

Evans, K., Milbourn, B., Hayden-Evans, M., D'Arcy, E., Chamberlain, A., Roberts, B., Eapen, V., Whitehouse, A., Bölte, S., & Girdler, S. (2022). Development of an Assessment of Functioning Measure based on the ICF Core Sets for Autism Spectrum Disorder: Executive Summary. Brisbane: Cooperative Research Centre for Living with Autism.

McMeekin, D.A., Tan, T., Lee, H., Vaz, S., Cordier, R., Xia, J., Wilson, N., Haas, K., & Krishna, A. (2020). Enhancing capacity of autistic individuals to use public transport. Final Report. Brisbane: Autism CRC.*

Milbourn, B., Lawson. W., Kuzminski, R., Black, M., Scott, M., Lee, E., Roberts, B., Falkmer, M., Foley, K., Arnold, S., Evans, K., Trollor, J., Bölte, S., & Girdler, S. (2022). Development of an autism-specific Quality of Life Assessment for use with Autistic Adults: Executive Summary. Brisbane: Autism CRC.

Richdale, A., Haschek. A., Chetcuti, L., Lawson, L. (2022). Longitudinal Study of Australian School Leavers with Autism (SASLA): Final Report. Brisbane: Autism CRC.

Trollor, J., Arnold, S., Walker, S. E. (2022). Australian Study of Autism in Adulthood (ALSAA). Final Report. Brisbane. Autism CRC.

Not program specific

Robinson, A., Bartz, A. & Gatfield, O. (2021). Future Leaders 2020: Evaluation report. Brisbane: Autism CRC.

Pellicano, E., Cai, R. Y., & Hall, G. (2021). Money matters - Understanding the financial wellbeing of autistic people: Final Report Brisbane: Autism CRC.

Appendix 4: Resources developed 2021-22

Program 1

Barbaro, J., Eapen, V., Gilbert, M., Nair, R., Masi, A., Winata, T. & Khan, F. (2022). A multistate trial of an early surveillance program for autism within General Practices in Australia: Research Snapshot. Brisbane: Autism CRC.

Dissanayake, C., Barbaro, J., Sadka, N., Barnett, T. (2022). Developmental surveillance for autism: Prospective identification of autism in infants and toddlers using Social Attention and Communication Surveillance. Research Snapshot. Brisbane. Autism CRC.

Gratten, J., Yap, C.X. Henders, A.K, Wallace, L., McLaren, T. & Wray, N.R. (2022). Development and validation of systems genomics-based predictors for autism (Stage 1): Research Snapshot: Brisbane, Autism CRC.

Masi, A., Eapen, V., Lane, A., Simpson, K. & Roberts, J. (2021). Sensory subtypes in children on the autism spectrum: Research Snapshot. Brisbane: Autism CRC.

Masi, A., Eapen, V., Lin, P., Moni, M.A. & Heussler, H. (2022). Sleep difficulties in children on the autism spectrum: Understanding the biological and behavioural attributes leading to sleep difficulties in children on the autism spectrum. Research Snapshot. Brisbane: Autism CRC.

Maybery, M., Taylor, L. & Miller, E. (2022). Graduate Certificate in Autism Diagnosis: Enhancing training in autism diagnosis: Research Snapshot. Brisbane: Autism CRC.

Program 2

Chalmers, C., Mavropoulou, S., & Silvera-Tawil, D. (2021). Evaluating the effects of a humanoid robot on the story retelling skills of children on the autism spectrum: Research Snapshot. Brisbane: Autism CRC.

Harper-Hill, K., Mangan, C. & Torres, N. (2022). Early Career Teacher – Early Years: Webinar. 27 January. Brisbane: Autism CRC.

Harper-Hill, K., Mangan, C. & Torres, N. (2022). Early Career Teacher – Early Years: Webinar.2 February. Brisbane: Autism CRC.

 $\label{eq:harper-Hill, K., Mangan, C. \& Torres, N. (2022). Early Career Teacher - Middle Years: Webinar. 28 January. Brisbane: Autism CRC.$

Harper-Hill, K., Mangan, C. & Torres, N. (2022). Early Career Teacher – Middle Years: Webinar.1 February. Brisbane: Autism CRC.

Saggers, B., Odier-Guedj, D., & Whelan, M. (2022). Collaborative Partnerships in Action: Research Snapshot. Brisbane: Autism CRC.

Saggers, B., Tones, M., Dunne, J., Willis, J., Gibson, A., English, R., Ashburner, J., Clark, T., Carrington, S., Brereton, M., Gibbs, V., Aberdein, R. & Harper-Hill, K. (2022). Middle Years Behaviour Support Project (MYBSP): A teleconsultation approach to support the learning needs of students on the autism spectrum in the middle years of schooling in rural, remote, Indigenous, and isolated education communities. Research Snapshot. Brisbane: Autism

Trembath, D. & Whitehouse, A. (2022). Understanding the Supporting Children National Guideline: Webinar. 12 July. Brisbane: Autism CRC.

Program 3

Brooker, K, Bradshaw, B, Franklin, C & Urbanowicz, A. (2021). Tools, strategies, and techniques developed to improve the health and wellbeing for autistics adults: Research Snapshot. Brisbane: Autism CRC.

Milbourn, B., Lawson. W., Kuzminski, R., Black, M., Scott, M., Lee, E., Roberts, B., Falkmer, M., Foley, K., Arnold, S., Evans, K., Trollor, J., Bölte, S., & Girdler, S. (2022). Development of an autism-specific Quality of Life Assessment for use with Autistic Adults: Research Snapshot. Brisbane: Autism CRC.

Richdale, A., Haschek. A., Chetcuti, L. & Lawson, L. (2022). Longitudinal Study of Australian School Leavers with Autism (SASLA): Research Snapshot. Brisbane: Autism CRC.

Scott, M., Falkmer, M., Girdler, S., Falkmer, T. & Rodger, S. (2022). The Integrated Employment Success Tool (IEST): An evidence-based guide for employers of autistic adults [New Zealand]. Brisbane. Autism CRC.

^{*}Not previously recorded

Trollor, J., Arnold, S. & Walker, S.E. (2022). Australian Study of Autism in Adulthood (ALSAA). Research Snapshot. Brisbane. Autism CRC.

Not program specific

Alvares, G. A., Mekertichian, K., Rose, F., Vidler, S., & Whitehouse, A. (2022). Dental care experiences and clinical phenotypes in children on the autism spectrum: Research Snapshot. Brisbane: Autism CRC.

den Houting, J. (2021). Participatory and Inclusive Autism Research Practice Guides. Brisbane. Autism CRC.

Pellicano, E., Cai, R.Y. & Hall, G. (2021). Money matters - Understanding the financial wellbeing of autistic people Research Snapshot. Brisbane: Autism CRC

Appendix 5: Conference presentations 2021-22

Program 1

Yap, C.X., Henders, A. K., Alvares, G.A., Wood, D.L.A., Krause, L., Tyson, G. W., Restuadi, R., Wallace, L., McLaren, T., Hansell N.K., Cleary, D., Grove, R., Hafekost, C., Harun, A., Holdsworth, H., Jellett, R., Khan, F., Lawson, L.P., Leslie, J., Frenk, M.L., Masi, A., Mathew, N. E., Mundiandy, M., Nothard, M., Miller, J.L., Nunn, L., Holtmann, G., Strike, L.T., de Zubicaray, G. I., Thompson, P.M., McMahon, K.L., Wright, M.J., Visscher, P.M., et al. (2022). Autism-related dietary preferences mediate autism-gut microbiome associations. Microbiome International Forum, 11 January (Online).

Program 2

Clark, M. & Adams, D. (2021). Child and parent reported strengths, positive attributes and interests of children on the autism spectrum: Is there alignment? Australasian Society for Autism Research Qld Conference, 13 August, Online. Australasian Society for Autism Research.

Hurley, A., Paynter, J., O'Leary, K., Simpson, K. & Westerveld, M. (2022). Autism-friendly language and literacy library program for preschoolers, Early Childhood Australia 2021 Conference, 6-9 September, online. Early Childhood Australia

Mangan, C., Harper-Hill, K. InclusionED: supporting diverse learners. EduTECH Conference- School Teaching Congress. 17-18 August, Melbourne and Online. EduTECH.

Saggers, B. (2022). Supporting the educational needs of learners on the autism spectrum: Promoting a collective voice from parents, educators, specialists and learners on the autism spectrum. Annual Congress of Applied Psychiatry.

Shochet, I. M., Orr, J.A., Wurfl, A.M., Saggers, B.R., Carrington, S.B. & Kelly, R. L. (2021). A multi-level approach to building resilience and promoting positive mental health for adolescents on the autism spectrum: From research to community outreach. Innovations in Autism Practice Conference 21-22 October, Online. Aspect Research Centre for Autism Practice.

Shochet, I.M., Orr, J.A., Wurfl, A., M Saggers, B. R., Carrington, S.B. & Kelly R. L. (2021). Preventing depression in adolescents with autism: Adapting a multilevel model to promote individual resilience and parent protective factors. IASR International Summit on Suicide Research 19-21 October, Online. International Academy of Sex Research.

Simpson, K. & Adams, D. (2022). Identifying environmental barriers to participation for children on the autism spectrum in out of school activities, OTARC February Seminar.

Simpson, K., Stainer, M. & Adams, D. (2022). Sensory profiles of children on the autism spectrum: A six-year longitudinal study. International Society for Autism Research Annual Meeting, 11-14 May, Boston, Online. International Society for Autism Research.

Program 3

Bruce, G., Coxon, K., Arnold, S.R.C. & Weise, J. (2021). Barriers to healthcare for autistic adults. Real Therapy Solutions Annual Conference, 20 December. Real Therapy Solutions.

Higgins, J., Weise, J., Trollor, J. N., Pellicano E. & Arnold, S.R.C. (2021). Confirming the Nature of Autistic Burnout. Aspect Research Centre for Autism Practice (ARCAP) Conference, 21-22 October, Online. Aspect Research Centre for Autism Research.

Huang, Y., Arnold, S. R. C., Foley, K.R. & Trollor, J. N. (2021). A survey of support experiences after adulthood autism diagnosis. Aspect Research Centre for Autism Practice Conference, (ARCAP), 21-22 October, Online. Aspect Research Centre for Autism Practice.

Mangan, C., Ciccarelli, M., & James, B. (2021). myWAY Employability: Helping autistic young people plan and prepare for their working life. Aspect Research Centre for Autism Practice conference, Sydney and online 21-23 October. Aspect Research Centre for Autism Practice.

Mangan, C., Ciccarelli, M. & James, B. (2022). Inclusive career planning using myWAY Employability, autistic young people. Career Development Association Australia conference 12-14 May, Sydney. Career Development Association Australia.

Mangan, C., Ciccarelli, M. & James, B. (2021). myWAY Employability: personalized career planning for autistic young people. Autism@Work Summit. 24-25 August. online.

Mundiandy, M., Richdale, A.L. & Lawson, L.P. (2022). Coping-resilience profiles and experiences of stress in autistic adults. International Society for Autism Research Annual Meeting 2022, 11-14 May, Boston, Online. International Society for Autism Research.

Mundiandy, M., Richdale, A.L. & Lawson, L.P. (2021). Stress and well-being in autistic adults: exploring the moderating role of coping. Australasian Society for Autism Research Conference, 9 December, 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.

Not program specific

Pellicano, E., Heyworth, Lawson, W., M. & den Houting, J. (2022). The Foundations of Autistic Flourishing. International Society for Autism Research Annual Meeting 2022, 11-14 May, Boston, Online. International Society for Autism Research.

Appendix 6: Intellectual property

Description	Project reference	Nature of IP	Background IP
National guideline for assessment and diagnosis of autism in Australia Guideline and associated supporting resources, consultation data and analysis.	0.007RS	Copyright and confidential information.	
Autism and agriculture Employment program resources. Research design, data, analysis, reports and publications.	0.008RC	Copyright and confidential information.	
Participatory autism research Research practice guide. Research design, data, analysis, reports and publications.	0.011RS	Copyright and confidential information.	
Reliability, validity and usability of assessment of functioning tools Research design, data, analysis, reports and publications.	0.012RS	Copyright and confidential information.	
Histories of late-diagnosed autistic adults Research design, data, analysis, reports and publications.	0.013RI	Copyright and confidential information.	
Achieving financial wellbeing Research design, data, analysis, reports and publications.	0.021RS	Copyright and confidential information.	
Relate-ABLE Application design, prototype, source code, content, requirements and specifications. Research design, data, analysis, report and publications.	0.022RC	Copyright and confidential information.	
National Guideline for supporting autistic children and their families in Australia Guideline and associated supporting resources, consultation design, data and analysis.	0.080RC	Copyright and confidential information.	Copyright in the report, "Intervention for children in the autism spectrum: A synthesis of evidence" (see Project 1.077RC) owned by the National Disability Insurance Agency*
Creation of the Australian Autism Biobank Database, phenotypic and biological data, data dictionary. Research design, analysis, research reports and publications.	1.002RC	Copyright and confidential information.	
AXAS (TM) autism related risk prediction software* Software code related to AXAS tool.	1.003RC	Copyright and trademark.	Copyright in AXAS software owned by University of Queensland.
Graduate certificate in autism diagnosis Course materials, units, online content, assessment videos. Research design, data, analysis, reports and publications.	1.004RC	Copyright and confidential information.	
Developmental surveillance for autism Training materials and assessment videos. Research design, data, analysis, reports and publications.	1.005RC	Copyright and confidential information.	Copyright in Social Attention and Communication Study- Revised (SACS-R) developed and owned by La Trobe University.

Description	Project reference	Nature of IP	Background IP
Transcriptome analysis of human brain tissue Research design, data, analysis, reports and publications.	1.019RI	Copyright and confidential information.	
Brainstorm Model for stem cell transduction. Research design, data, analysis, reports and publications.	1.020RS	Copyright and confidential information.	
Diagnostic practices and reliability in Australia Research design, data, analysis, reports and publications.	1.021RS	Copyright and confidential information.	
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.	1.022RS	Copyright and confidential Information.	
Autism subtyping Research design, data, analysis, reports and publications.	1.023RS	Copyright and confidential information.	
Brain network connectivity Research design, data, analysis, reports and publications.	1.033RI	Copyright and confidential information.	
Systems genomics Research design, protocols, system genomics data, analysis, reports and publications.	1.042RC	Copyright and confidential information.	
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.	1.043RS	Copyright and confidential information.	IP in iBASIS-VIPP owned by University of Manchester, IP in SACS system owned by La Trobe University.
Diagnostic inconsistencies in New Zealand Research design, data, analysis, reports and publications.	1.058RU	Copyright and confidential information.	
Australian autism biobank pilot Research design, data, analysis, reports and publications.	1.059RU	Copyright and confidential information.	
Multistate trial of an early surveillance program in general practice Research design, data, analysis, reports and publications.	1.064RS	Copyright and confidential information.	IP in SACS system owned by La Trobe University. Frances Glascoe is the owner of IP for PEDS. The Royal Children's Hospital Melbourne holds the Australian Licence for the use of PEDS. Copyright in LTSAE and Q-CHAT-10 made available by UNSW.
Detection of white matter microstructural alterations Research design, data, analysis, reports and publications.	1.065RS	Copyright and confidential information.	

Description	Project reference	Nature of IP	Background IP
Inflammation and neuromodulation in autism	1.073RU	Copyright and confidential information.	
Research design, data, analysis, reports and publications.			
Biological and behavioural attributes leading to sleep difficulties	1.074RU	Copyright and confidential Information.	
Research design, data, analysis, reports and publications.			
Sensory subtypes in children on the autism spectrum Research design, data, analysis, reports and publications.	1.075RU	Copyright and confidential information.	
Synthesis of evidence of autism early intervention approaches*	1.077RC	Copyright and confidential information.	Note - Project IP owned by the National Disability
Research design, data, analysis, reports and publications.			Insurance Agency.
School years program (Program 2)	2.006RC	Copyright.	
Conceptual model for in-kind contributions.			
Longitudinal study of Australian students on the autism spectrum	2.007RC	Copyright and confidential information.	
Research design, data derived from parent, teacher questionnaires, analysis, reports and publications.			
Secret Agent Society whole of class	2.008RC	Copyright and	SAS Program IP owned
Secret Agent Society whole of class program, training materials. Research design, data, analysis, reports and publications.	2.008RC_PP	confidential information.	by Autism CRC subsidiary, Social Science Translated Pty Ltd, and Renae Beaumont Enterprises Pty Ltd
Education needs analysis	2.009RC	Copyright and	
Research design, data derived from teacher, student and parent surveys, analysis, reports and publications. nclusionED content and multimedia resources.		confidential Information.	
Overcoming difficulties on written expression and StepWrite StepWrite iOS app game format, design, source code and content. Teacher manuals and training materials. Research design, data, analysis, reports and publications. inclusionED content and multimedia	2.010RS 2.053RU	Copyright and confidential information.	
resources. Helping students stay on task and move between	2.011RC	Copyright and	Copyright in Structured
tasks Teacher training packages and resources for structured teaching. Research design, data, analysis, reports and publications. inclusionED content, multimedia resources.	2.011RC_PP	confidential information.	Teaching Resources owned by Aspect.
Emergent Literacy suite	2.024RI	Copyright and	Copyright in Parent-child
Shared book reading intervention and multimedia resources. Research design, data, analysis, reports and publications.	2.034RI 2.035RU	confidential Information.	book reading checklist owned by Griffith University. Child assessment data owned by AEIOU.
Autism, anxiety and school functioning Research design, data, analysis, reports and publications.	2.025RI	Copyright and confidential information.	

Description	Project reference	Nature of IP	Background IP
Lego robotics club online Robotics online resource kits, manual for teachers, inclusionED content and multimedia resources. Research design, data, analysis, reports and publications.	2.026RI	Copyright and confidential information.	
Early Years behaviour support project Methods, tools and materials for teleconsultation training and intervention support. Research design, data, analysis, reports and publications. inclusionED content and multimedia resources.	2.027RS 2.027RS_PP	Copyright and confidential information.	Copyright in My Calendar App owned by Queensland University of Technology.
Classroom acoustics Research design, data, analysis, reports and publications. inclusionED content and multimedia resources.	2.028RS	Copyright and confidential information.	
School connectedness Resourceful Adolescent Program and training materials for parents, teachers, adolescents, RAP Program adaptions for Autism (RAP-A). Research design, data, analysis, reports and publications. inclusionED content and multimedia resources.	2.029RS 2.029RS_PP	Copyright and confidential information.	Copyright in RAP Program owned by Ian Shochet. RAP-A owned by Queensland University of Technology.
School connectedness online resource Website design, source code and content utilised in www.autismteenwellbeing.com.au.	2.029RS_PP 2	Copyright and confidential information.	Copyright in RAP Program owned by Ian Shochet. RAP-A owned by Queensland University of Technology.
How was your day? Research design, data derived from parent, teacher and child surveys, analysis, reports and publications.	2.036RI	Copyright and confidential information.	
Transition models of practice Models of practice resources. Website design, source code and content. Research design, evaluation data, analysis, reports and publications. inclusionED content and multimedia resources.	2.037RS 2.037RS_PP	Copyright and confidential information.	
inclusionED 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.	2.045RU 2.063RU	Copyright and confidential information.	
Aboriginal and Torres Strait Islander Community Liaison Research design, data, analysis and reports.	2.051RS_PP	Copyright and confidential information.	
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.	2.052RU	Copyright and confidential information.	
Middle Years behaviour support project Methods, tools and materials for teleconsultation training and intervention support. Teleconsultation guide, inclusionED content and multimedia resources. Research design, evaluation data, analysis, reports and publications.	2.057RS	Copyright and confidential information.	

Description	Project reference	Nature of IP	Background IP
Effects of humanoid robots on narrative role-taking abilities in children on the spectrum	2.060RI	Copyright and confidential information.	
Research design, data and analysis. inclusionED content and multimedia resources.			
Collaborative partnerships in action	2.066RU	Copyright and	
Research design and data, analysis. inclusionED content and multimedia resources.		confidential information.	
myWay Employability educator	2.067RU	Copyright and	
Research design, data, analysis and reports. inclusionED content, training and multi-media resources.		confidential information.	
Australian longitudinal study of autistic adults	3.013RC	Copyright and	
Research design, questionnaires, data, analysis, reports and publications.		confidential information.	
Integrated Employment Success Tool (IEST)	3.014RC	Copyright and	
Human resource guide design, content and multimedia resources. Research design, data, analysis, reports and publications.		confidential information.	
NZ Integrated Employment Success Tool (IEST)	3.014RC	Copyright and	
Adaption of the original IEST. Human resource guide design and content and multimedia resources. Research design, data, analysis, reports and publications.		confidential information.	
Better OutcOmes and Successful Transitions for Autism (BOOST-A)	3.014RC 3.048RU	Copyright and confidential information.	Copyright in Career Interest Test owned by James Athanasou, licensed by Education Services Australia.
BOOST-A website design, source code, career responder system, training and multi-media resources. myWAY Employability content including the Autism Career Explorer system. Research design, data, analysis, reports and publications.			
Health and wellbeing of adults on the autism spectrum	3.015RC 3.049RU	Copyright and confidential information.	Original CHAP IP owned the University of Queensland and
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.	3.043/10		licensed to UniQuest.
Australian longitudinal study of school leavers	3.016RC	Copyright and	
Research design, data dictionary, questionnaires, data, analysis, reports and publications.		confidential information.	
Optimisation of recruitment	3.017RC	Copyright and	
Research design, data, analysis, reports and publications.		confidential information.	
Studio G: Multimedia program for young adults	3.030RI	Copyright and	
Research design, data, analysis, reports and publications.		confidential information.	
Career pathway responder system	3.031RI	Copyright and	
Research design and data, analysis, reports and publications.		confidential information.	

Description	Project reference	Nature of IP	Background IP
Peer mentoring program Program modules, manuals, facilitator and mentee materials. Mind Chip program, content, resources, design, source code and content. Research design and data, analysis, reports and publications.	3.032RS	Copyright and confidential information.	
Using big data to answer important question on health and wellbeing Research design, data, analysis, reports and publications.	3.038RI	Copyright and confidential Information.	
Supporting staff and students on the spectrum in STEM programs Website design, source code, content, decision tree protocol, multimedia content. Research design, data, analysis, reports and publications.	3.039RI	Copyright and confidential information.	
Independence in driving Driver Ready learner and instructor driving manuals, website design, source code and content. Research design, data, analysis, reports and publications.	3.040RS	Copyright and confidential information.	
Enhancing capacity to use public transport iOS app design, source code, logo, content. Research design, data, analysis, reports and publications.	3.041RS	Copyright and confidential information.	
Autism HealthPathways initiative Autism-related content for HealthPathways information website for health professionals. Research design, data, analysis, reports and publications.	3.046RI	Copyright and confidential information.	IP in HealthPathways platform owned by Streamliners NZ Ltd.
Goal-Setting tool for adolescents and adults (AAGST) Research design, analysis, evaluation data, reports and publications.	3.047RI	Copyright and confidential information.	Copyright in Family Goal Setting Tool owned by Autism Queensland.
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.	

Description	Project reference	Nature of IP	Background IP
Implementation of the National Guideline – Health Sector Capacity Building Design, development and implementation of multimedia resources and protocols. Research design, data, analysis, reports and publications.	4.078RC	Copyright and confidential information.	
Micro-credentialling courses in Autism Assessment and Diagnosis; and Continuing Professional Development online course in Autism Assessment and Diagnosis Source code, course materials, modules, online content, mapped and demonstrated learning outcomes, assessment videos and multi-media resources.	4.083RC	Copyright and confidential information.	
inclusionED content and translation guide, practice development and training inclusionED content and multimedia resources. inclusionED training programs for teachers and preservice teachers, and related materials.	5.079RC	Copyright and confidential information.	
Understanding how inclusionED can support students from learning to earning Design, development and implementation of multimedia resources and protocols. Research design, data, analysis, reports and publications.	5.081RC	Copyright and confidential information.	
Whole genome sequencing Whole Genome Sequencing data for 1,500+ Australian autism biobank trios.	2019_015WGS	Copyright and confidential information.	
Australian Autism Biobank Data generated by third parties granted access to biobank, returned as a condition of access.	Australian Autism Biobank	Copyright and confidential information.	
Future leaders program Modules, e-learning resources, research design, data, analysis, reports and publications.	Sylvia Rodger Academy	Copyright.	
Research program Visual research dictionary. Course module and e-learning resources. Research design, data, analysis, reports and publications.	Sylvia Rodger Academy	Copyright.	
Governance program Course module and e-learning resources. Research design, data, analysis, reports and publications.	Sylvia Rodger Academy	Copyright.	
Self-Advocacy@Work program Course module and e-learning resources. Research design, data, analysis, reports and publications. Website design and content.	Sylvia Rodger Academy	Copyright.	
Non project intellectual property held by Autism	CRC		
Autism CRC livery and logo		Trademark and copyright.	
autismcrc.com.au Domain name, design, source code and content.		Copyright.	

Description	Project reference	Nature of IP	Background IP
Autism CRC Connect Hub Design, source code and content.		Copyright.	
sylviarodgeracademy.com.au Domain, Sylvia Rodger Academy logo and livery.		Copyright.	
apps4autism.com Domain name, design, source code, logo and content.		Copyright.	
mywayemployability.com.au Domain name, logo and livery.		Copyright.	
inclusionED.edu.au Domain name, logo and livery.		Copyright.	
stepwrite.com.au Domain name, App store content, StepWrite logo and livery.		Copyright.	
turnkey CRC SalesForce-based CRC CRM and project management system		Copyright and confidential information.	

Intellectual property (Copyright) related to the Secret Agency Society (SAS) program owned by Social Science Translated Pty Ltd (SST), a wholly-owned subsidiary of Autism CRC Ltd for the purpose of commercialising the SAS Program. All intellectual property rights noted as owned by Renae Beaumont Enterprises Pty Ltd are the subject of an exclusive, worldwide licence to Social Science Translated Pty Ltd.

Item	Ownership
Copyright in software (the computer program, including the source code and object code, and protected as a literary work) in the computer game, including all versions thereof (on storage media such as compact disc, downloadable and online, the	Social Science Translated Pty Ltd
latter accessible as software-as-a-service); and digitised program resources.	
Copyright in graphics, fonts, images of characters and concept artwork (protected as artistic works) as used in the computer game and digitised program resources.	Social Science Translated Pty Ltd and Renae Beaumont Enterprises Pty Ltd as tenants in common; and Social Science Translated Pty Ltd.
Copyright in animated visual elements seen as a moving picture (protected as a film) as used in the computer game and digitised program resources.	Social Science Translated Pty Ltd and Renae Beaumont Enterprises Pty Ltd Pty Ltd as tenants in common; and Social Science Translated Pty Ltd.
Copyright in the composition of the SAS program sound effects and audio, including those used in the computer game and the digitised program resources (protected as musical works).	Social Science Translated Pty Ltd
Copyright in the SAS program sound samples, including those used in the computer game and the digitised program resources (protected as sound recordings).	Social Science Translated Pty Ltd
Copyright in source code, data and written content of SST Learning Management & Program Delivery System.	Social Science Translated Pty Ltd
Copyright in source code, data and written content of SST Business Systems (including licence management system, website and domain names).	Social Science Translated Pty Ltd

Patent applications owned by Social Science Translated Pty Ltd

U.S. Patent Application No. 17/113,620 "Social-Emotional Skills Improvement"

Trademarks owned by Social Science Translated Pty Ltd

The following mark is registered in Australia, Canada, United Kingdom, Madrid Protocol (TM), European Community (designated on Madrid Protocol), United States of America (designated on Madrid Protocol) and New Zealand (designated on Madrid Protocol).



The following plain text mark is registered in Australia, Canada, United Kingdom, Madrid Protocol (TM), European Community (designated on Madrid Protocol), United States of America (designated on Madrid Protocol) and New Zealand (designated on Madrid Protocol), with other international registrations pending:

Secret Agent Society

The following plain text mark is registered in Australia, Canada:

Secret Agent Society: Solving the Mystery of Social Encounters

The following are unregistered marks of Social Science Translated Pty Ltd









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
DSS	Australian Government Department of Social Services
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.
ICAN	The I CAN Network
IDPA	Integrated Diagnostic Protocol for Australia

IEST	Integrated Employment Success Tool
ILC	Information Linkages and Capacity Building (ILC) Program
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, ADHD and Tourette Syndome – 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
ОТ	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 Science Translated Pty Ltd – a wholly owned subsidiary of Autism CRC (formerly Social Skills Training Pty Ltd)
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

Valuing lived experience



Innovation

Solutions for long-term challenges



Evidence

Truth in practice



Independence

Integrity through autonomy



Cooperation

Capturing opportunities together



Autism CRC

The University of Queensland Long Pocket Precinct Level 3, Foxtail Building 80 Meiers Road Indooroopilly Qld 4068

T +61 7 3377 0600

E info@autismcrc.com.au

W autismcrc.com.au







@autismcrc



