

2022-23

Annual Report



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About **Autism CRC**



Autism CRC

Autism CRC is 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.

Autism CRC was established in 2013 as the world's first national, cooperative research effort focused on autism under the Australian Government's Cooperative Research Centres (CRC) Program. We receive funding from a number of sources, including the Australian Government. Autism CRC is no longer part of, or associated with, the CRC Program.

Statement of purpose: together, discover and achieve more



Our vision

Autistic people with quality of life and opportunity



Our mission

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



Our 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

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

Our members

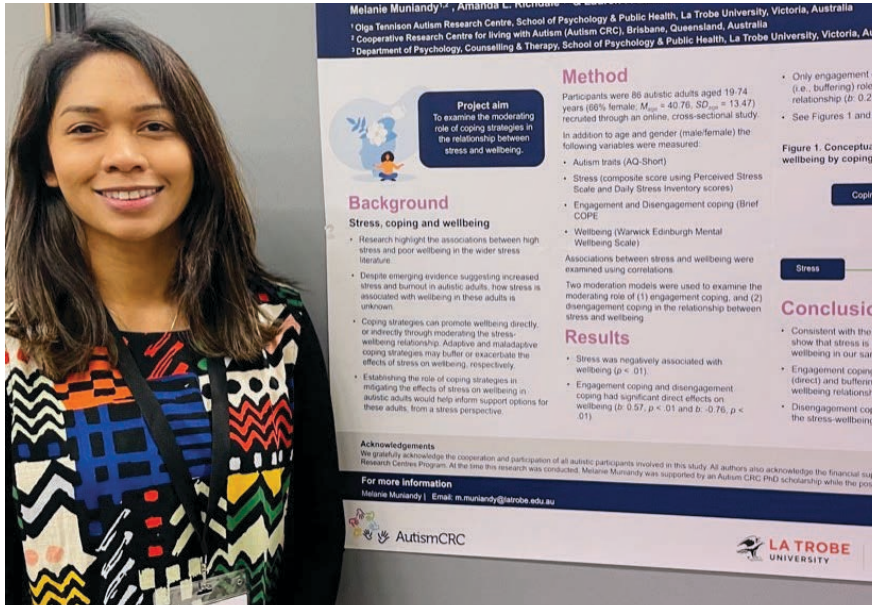
Autism CRC is committed to a national collaborative model, working with all stakeholders to address agreed needs and co-produce outcomes. Collaboration between research and end-user Members, Associates and Affiliates is an essential element of our work.



We are also grateful for the continued support of the Queensland Department of Education as project partner.

We greatly appreciate the support of our Affiliates:

- ▶ Amaze
- ▶ Autistic Self Advocacy Network of Australia New Zealand (ASAN AUNZ)
- ▶ Autism Spectrum Australia (Aspect)
- ▶ Aspergers Victoria
- ▶ Australian Psychological Society (APS)
- ▶ Autism Queensland (AQ)
- ▶ Children's Health Queensland Hospital and Health Service
- ▶ Complex Connections
- ▶ Macquarie University (MU)
- ▶ Reframing Autism
- ▶ Siblings Australia
- ▶ Spectrum Space
- ▶ Statewide Autistic Services Ltd (SASI)
- ▶ Untapped Holdings
- ▶ University of Southern Queensland (UniSQ)
- ▶ Wenn Lawson



Established assets and a strong framework for impactful delivery

Autism CRC has established an effective framework for coordinated, collaborative research and research translation with partners from 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.

We have had a significant impact on the autism landscape in Australia, prioritising research, policy and practice guidance that reflect the needs and views of end-users – including autistic individuals and families, service providers, education and health professionals, industry and government.



173,600

Professionals

involved in research programs or using our outputs



108,900

Unique visitors

to national practice and resource platforms relating to education and employment



18,000+

Followers

across our online channels including Facebook, Twitter, LinkedIn, YouTube



28,000+

Subscribers

to our eNews



\$131.5m

Investment

in research and its translation

2

National Guidelines

with all Recommendations approved by the National Health and Medical Research Council (NHMRC)



420+

Published resources

in Knowledge Centre



213,000+

Downloads

publications, reports and other resources

Report from the Chair and CEO

∴ A year of new beginnings built on solid foundations.

The past year has been one of new beginnings for Autism CRC as we moved to running in post CRC Program mode. For many, there will have been little apparent change as we continue to operate our successful collaborative model – engaging all stakeholder communities across Australia and beyond – in undertaking research on community-agreed priorities and translating the outputs to practice and policy.

In reality, much had to be done to ensure a successful transition from our CRC Program activities and arrangements to our legacy operations. Through the CRC Program, Autism CRC established itself as the national independent source of evidence for best practice, across the lifespan and the spectrum – and it was critical that we maintained the foundations of our collaboration and momentum of our activities through transition in order to provide continued support to the sector in that role. We want to thank all involved for making the transition a smooth one.

For the autistic and broader autism community, the last year has been one of great challenge, activity, promise and uncertainty.

At a national level:

- ▶ Work commenced on developing the National Autism Strategy (NAS or the Strategy), along with the National Roadmap to Improve the Health and Mental Health of Autistic People (Health Roadmap), and a National Early Years Strategy.
- ▶ The Disability Royal Commission completed its hearings ahead of its report to government.
- ▶ The National Disability Insurance Scheme (NDIS) Review and the reviews by the Joint Standing Committee on the NDIS were a major focus for the sector, both reporting before end 2023.
- ▶ Ahead of the NDIS Review, the 2023 Federal Budget included a major commitment of \$732.9M to improve the effectiveness and sustainability of the NDIS.
- ▶ Targeted action plans were operationalised under Australia's Disability Strategy 2021-31, across a range of service settings such as health and education.
- ▶ For our friends in Aotearoa New Zealand, consideration is being given to how autistic people and their families might be better supported throughout life with a more connected and coordinated approach across government, organisations, and individuals.

State and Territory governments are also taking steps towards better understanding and supports for autistic people and their families and carers, with a number developing explicit autism strategies – such as in South Australia where the government is now implementing initiatives under its State Autism Strategy.

More generally, there have been range of reviews across all levels of government on service systems delivery, particularly in education with reviews from early childhood

education and care through the school years to post-school education and training.

Whether specific to autism or more general, the broad range government reviews and initiatives are all relevant to the quality of life of autistic people and their families and carers. Autistic individuals are a part of every section of our community and engage with all service systems. Again, this multiplicity of reviews and initiatives bring much promise along with significant uncertainty for the community.

As a result, there has likely been no time where the need for an independent, trusted and national reference body has been greater – one that works in collaboration with the sector to provide accessible information and capacity-building resources, founded in quality research and evidence:

- ▶ for individuals and families and carers, so they might confidently advocate and make informed choices;
- ▶ for practitioners and service providers, so they might better provide effective supports appropriate to the strengths, needs and circumstance of individuals and their families and carers;
- ▶ for government policy-makers and program managers in developing, implementing and evaluating policy settings, services and funding arrangements;
- ▶ for the research community, informing community-defined priorities for research and participatory and inclusive research practice, as well as building on the foundation of evidence for policy and practice; and
- ▶ for the general community in raising understanding of autism and appreciation of the strengths and contributions that autistic people might bring to society, given the opportunity.

Autism CRC is very pleased to be fulfilling that national role and to contribute to the many reviews and initiatives over the past year, both directly and in support of our community partners and government.

We are working closely with the Commonwealth Government and the sector in the development of the National Autism Strategy, a strategy which should draw together the many elements of the other reviews and initiatives through the perspective of an autism lens. Our work in mapping the research evidence and policy-setting landscape across the service sectors to be addressed by the NAS is a critical foundation to Strategy considerations. Similarly important was our work on a community co-design and engagement approach for development of the Strategy, with an emphasis on how best to engage those groups in the community who are often not heard through consultation. We are pleased to be continuing our work in 2023/24 with the Commonwealth Government, the NAS Oversight Council and Working Groups (including the Health Roadmap Working Group) and the sector in the development of the Strategy and its evaluation framework.

Over the past year, Autism CRC has also been pleased to support the other major government initiatives, such as the NDIS Review and the National Disability Insurance Agency (NDIA) in its work to improve the effectiveness and sustainability of the Scheme.

We have not only supported these through the provision of evidence-based information and advice, but also with assistance with co-design approaches and understanding. Recognising that evidence-based solutions are necessary to effective practice and policy, we have continued to invest in maintaining and expanding national practice guidance and related resources. As you read through this Annual Report, you will see that we have delivered updated and new practice guidance and capacity-building resources in relation to assessment and diagnosis; the provision of supports for autistic children and their families; inclusive education; and inclusive employment. These resources are being utilised by individuals, professionals and professional associations, and education and training institutions.

We have also continued to explore community-defined priorities for research and evidence-based resources through our work associated with the Strategy and the work of the Australasian Autism Research Council. This included specific consideration of how to better understand the needs, and assess the quality of life and wellbeing, of autistic individuals with complex support and/or communication needs.

It has been another significant year for the Sylvia Rodger Academy and its growing alumni. A new individual capacity-building program on autistic identity and connection was delivered. Critically, Academy alumni have been engaged in our project activities and have played an important role in delivering autism understanding presentations for those involved in developing the Strategy and in partner organisations. Review after review and research have shown that autism awareness and understanding is an essential requirement common to all service and support systems if they are to better support autistic people and their families. The growing capacity of the Sylvia Rodger Academy is an important national asset in addressing this need.

We are very grateful to the Commonwealth Government for its funding support, both through a Strategy-related grant and the Information Linkages and Capacity-Building (ILC) Program that has allowed us to undertake this work. We thank the Commonwealth for the additional \$4M funding awarded this year (and announced in August 2023). This funding has allowed us to continue to support our existing evidence-based platforms and the development of the Strategy – during the time that the Strategy is developed, and the NDIS Review and other reviews and initiatives are completed.

These strategies and reviews will largely be completed in the first half of 2023/24. With that, a number of plans and initiatives will be defined to address the many areas

of identified need for improved services, support and understanding over the coming decade. This will require long-term investment by government and the sector in developing, implementing and sustaining evidence-based practices and policies. Our CRC Program demonstrated the benefit of such a long-term investment. The national best practice guidance and resources referred to earlier were the result of our earlier foundational investment in research and evidence. Not only will these assets need to be maintained, but investment will be required to develop the foundations and then the translated resources to address the many gaps identified by the Senate Select Committee on Autism, Strategy processes and other sector engagement.

Without such investment, both the gains made to date and the opportunity for more will be lost. We stand ready to work with government and the sector in this important work over the coming years.

Of course, all we are and have achieved as Autism CRC is due to the commitment and collaboration of our national network – our Members, Affiliates and other project partners, government, and the many autistic individuals, family members and people working with them who have engaged with us this year. On behalf of the Autism CRC Board and team, we express our sincere gratitude to all. We look forward to continuing our collaborative work and seeing autistic people with quality of life and opportunity.



A stylized, handwritten signature in black ink.

Robert van Barneveld
Chair



A stylized, handwritten signature in black ink.

Andrew Davis
Chief Executive Officer

Our work

Autism CRC commissioned several new projects in this financial year, the first with our new Member and Affiliate network. These projects sought to:

- ▶ better understand the current support needs of autistic people, their families and carers across the breadth of service systems with which they engage, including for those with multiple and complex support and/or communication needs
- ▶ analyse the current international research evidence for best-practice supports, along with the gaps both in the research evidence base and in the translation of evidence to policy and practice
- ▶ expand and maintain our range of evidence-based practice guidance and related capacity-building resources relating to assessment and diagnosis, early childhood supports, inclusive education and employment, health and wellbeing
- ▶ support the development of a National Autism Strategy and other related government initiatives by providing research evidence and capacity through our collaborative national network.

Projects



National Guideline for supporting the learning, participation, and wellbeing of autistic children (Supporting Autistic Children Guideline)

Developing guidelines for practitioners delivering supports in community and clinical settings.

Project partners: Griffith University, Telethon Kids Institute

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Implementation of the Supporting Autistic Children Guideline

This project is developing a range of implementation resources and professional learning courses for practitioners delivering supports in community and clinical settings consistent with the Guideline.

Project partners: Griffith University, Telethon Kids Institute, Autism New Zealand, The University of Queensland, Victoria University of Wellington

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Aotearoa New Zealand Autism Guideline implementation, supports and services

Findings from this project will include recommendations for implementation of the Guideline as well future approaches to autism support in Aotearoa.

Project partners: Griffith University, Telethon Kids Institute, Autism New Zealand, The University of Queensland, Victoria University of Wellington



Update to the National Guideline for the assessment and diagnosis of autism in Australia (Assessment and Diagnosis of Autism Guideline)

First published in 2018, Autism CRC is revising the Guideline to ensure it remains relevant and useful.

Project partners: Griffith University, Telethon Kids Institute, Autism New Zealand, The University of Queensland, Victoria University of Wellington



Microcredential courses in autism assessment and diagnosis

Autism CRC has developed a suite of credit-bearing microcredentials in autism assessment and diagnosis as part of our commitment to widespread implementation of the Guideline.

Project partners: The University of Western Australia, Telethon Kids Institute



Health sector capacity building – National best-practice assessment and diagnosis

This project is developing resources and protocols to build the capacity of clinicians involved in the assessment and diagnosis of autism and other neurodevelopmental conditions to ensure service delivery consistent with the Guideline.

Project partners: University of Western Australia



Quality of life and wellbeing of autistic individuals with complex support or communication needs

Autism CRC is working to identify how quality of life and wellbeing are defined by, and for, autistic individuals with complex support and communication needs. This project is also looking at what factors may enhance or reduce wellbeing.

Project partners: Griffith University, Autism New Zealand



inclusionED

This ongoing project includes an in-depth review of the existing inclusionED platform to align with national teaching standards and frameworks while enhancing and expanding the offering. The inclusionED team is also working with the education sector to build teacher capacity through school outreach and professional development to support whole-of-school communities.

Project partners: Queensland University of Technology



myWAY Employability

Ongoing development and work toward a major update to enhance the platform with features such as smart goal creation for different career stages, and a dashboard for service providers and employers to support a young person on their career journey. The project is also developing resources and training to support school-based transition planning.

Project partners: Curtin University



Removing educational barriers in Australian schools (REBAS)

Autism CRC is working to address identified gaps in educational practice and provide policy, research and practice recommendations to progress our education system by ensuring that appropriately tailored inclusive practices are applied nationally.

Project partners: Griffith University, Queensland University of Technology, Amaze, Autism Queensland, Autism Spectrum Australia (Aspect), Reframing Autism, Siblings Australia



Online training and resource package utilising the Integrated Employment Success Tool (IEST)

This project is focused on building capacity in employers to support evidence-based inclusive human resource and management practices. This will be achieved through the development and delivery of a co-produced online training and resource package utilising the IEST.

Project partners: Curtin University, Autism New Zealand, Spectrum Space, Untapped, Wenn Lawson



Mapping of current evidence, practice and policy landscape

This project has two main focuses, the first of which involves a series of research and consultation activities which will guide key issues within the National Autism Strategy (NAS or the Strategy). The second project element will advance the research priorities of the Australasian Autism Research Council (AARC).

Project partners: Griffith University, Curtin University



Strong and Resilient Communities – Autistic Identity and Connection Program

The Autistic Identity and Connection Program is empowering autistic people to develop a sense of autistic identity, connect with other autistic people and community, and upskill in self-advocacy and wellbeing. .

Project partners: Autism Spectrum Australia (Aspect)



Self-Advocacy@Work

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.

Project partners: Autistic Self Advocacy Network of Australia and New Zealand (ASAN AUNZ)



Investigating autism research priorities

This project will advance the research priorities of the AARC, which operates under the auspices of Autism CRC. The AARC was established to review and define national priorities for autism research and identify areas of research needed for the autistic and autism communities.

Project partners: Curtin University

Highlights and achievements



Highlights and achievements

National Autism Strategy

Minister's visit kicks off strategy

In late 2022, Autism CRC was commissioned by the Australian Government's Department of Social Services (DSS), to undertake foundational work to support the co-design and development of a National Autism Strategy. This included two key activities:

- ▶ comprehensive review and mapping of the research and policy landscape across key service areas
- ▶ development of a co-design process to provide a set of recommendations for inclusive community engagement and consultation in the development of the Strategy.

In February 2023, Autism CRC welcomed the Hon. Amanda Rishworth MP, Minister for Social Services, as work began on the development of the Strategy. This marks a historic step towards coordinated, evidence-based support and outcomes for autistic Australians and their families. Minister Rishworth announced \$2 million in Commonwealth funding for Autism CRC's support of the Strategy development and its research and capacity-building efforts more generally, emphasising the importance of collaboration between government and the autism community.

Autism CRC's expertise in autism research and legacy of establishing diverse, collaborative stakeholder networks will help shape best-practice in the development of the Strategy. We look forward to working with Autism CRC to develop a Strategy which engages with all levels of government and ensures that no Australian is held back or left behind.

Minister Rishworth, Minister for Social Services

The event was attended by over 50 people and families from the autistic community, service providers, research, employment, education, Autism CRC Board and staff.



Autistic teacher and advocate, Trudy Bartlett, with Minister Rishworth.



Minister Rishworth and guests at the Strategy launch.



Dr Kate Simpson, Meagan Negri and Scott Reading

NAS Oversight Council and Working Groups

In March 2023, Autism CRC supported the Australian Government's call for Expressions of Interest for the National Autism Strategy Oversight Council and Working Groups.

Minister Rishworth asked a number of organisations to manage an Expressions of Interest process to assist the appointments process for the Oversight Council and the first three Working Groups. Autism CRC and the Australasian Society for Autism Research (ASfAR) managed the call for researchers and professionals (eg health, education, social work).

A comprehensive national community engagement process and co-design of the Strategy are being guided by an Oversight Council and assisted by four Working Groups considering:

- 1 Social inclusion
- 2 Economic inclusion
- 3 Diagnosis, supports and services
- 4 National Roadmap to Improve the Health and Mental Health of Autistic People.

The call for nominations to autistic Australians and the broader autism community was managed through end-user and advocacy groups appointed by the Government.

The members of the Oversight Council and the first three Working Groups were appointed by Minister Rishworth. The fourth Working Group was established by the Commonwealth Department of Health and Aged Care.

Supporting development of the Strategy

The **mapping of current evidence, practice and policy landscape project** aimed to provide a review and synthesis of community views, research evidence, and policy relating to key service areas to be addressed in the National Autism Strategy.

Research in each service area included:

- ▶ an online survey gaining perspectives of more than 1,000 autistic people, their families/carers, and those who work to support them
- ▶ an umbrella review summarising research findings reported in systematic reviews
- ▶ a policy review summarising relevant federal, national, and state/territory level policy.

The integrated findings of each of the three forms of research highlighted gaps, and provided a strong foundation to clearly identify needs, issues and potential solutions.

The **community insights and unheard perspectives co-design project** aimed to develop a series of recommendations for inclusive community engagement in the development of the Strategy.

Through a co-design process, several population groups that may require a tailored or adapted approach to actively participate in the development of the Strategy were identified.

To support clear recommendations for inclusive community engagement, the project included:

- ▶ a literature and environmental scan on best practice community engagement and key considerations for the target population groups
- ▶ analyses of the *Community views* national survey (n=645) and co-design workshops and interviews with autistic individuals and representatives from peak bodies, autism and/or disability organisations.

The community insights and recommendations established through this body of work have potential to foster inclusive community engagement with all autistic people, including those who have not previously been involved.

The findings highlight that there is no 'one-size fits all' approach to the promotion of, and engagement in, co-design and consultation. Further, they emphasise the importance of an inclusive approach, enabling people to engage in ways that suit their individual needs and preferences – to ensure all voices and perspectives have an equitable opportunity to be heard.



A special thanks goes to the 1,000+ autistic people, their families, professionals and organisations who generously shared their experiences, ideas and perspectives through the *Community views* survey and the co-design workshops and interviews – without their significant contribution, this work would not be possible.

These reports were delivered to the Department of Social Services in early July 2023.

National Guidelines and best practice health and wellbeing

Autism CRC continues to develop practice and protocols for consistent national outcomes while establishing pathways to improve health service delivery and wellbeing across the lifespan.



32,800+

Registered users

National Guideline for Assessment and Diagnosis of Autism (ADAG)



5,700+

Registered users

Supporting Autistic Children Guideline



20,800

Downloads

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



1,000+

Respondents

Aotearoa New Zealand Autism Guideline and supports survey



6,680+

Number of times GPs

have accessed
Autism HealthPathways



14

Primary Health Network regions

adopted and/or localised
Autism HealthPathways



150+

Clinicians

completed ADAG **Short course**



7

Credit-bearing Microcredentials

upskilling clinicians in implementation of ADAG



65

Allied health students

completed ADAG
eLearning lecture and activity

Breakthrough in sleep research for autistic children

Autism CRC's study, led by Mater Research and The University of Queensland (UQ), uncovered a link between sleep disturbances in autistic children and reduced levels of specific fatty acids. This groundbreaking research, published in *Nature Medicine*, sheds light on co-occurring conditions and emphasises the importance of addressing sleep problems for improved quality of life and overall health.

Mater Research and UQ lead-author Dr Chloe Yap said this work was part of a major shift in autism research.

Guided by community priorities, we focused our work on co-occurring conditions that can create significant quality of life issues, such as sleep disturbances and feeding problems.

Dr Chloe Yap, Lead author

This study involved a unique collaboration between clinicians, the autism community and over 40 researchers. The team used blood samples from Autism CRC's Australian Autism Biobank and the Queensland Twin Adolescent Brain Project.

It investigated a panel, or lipidome, of nearly 800 different fats in the blood plasma of 765 children, including 485 diagnosed with autism. The research identified a potential causal link between reduced levels of long-chain polyunsaturated fatty acids – some of which are found in fish oil, eggs and meat – and poor sleep. However, more work is required before clinical dietary recommendations can be made.

Supporting autistic children and their families

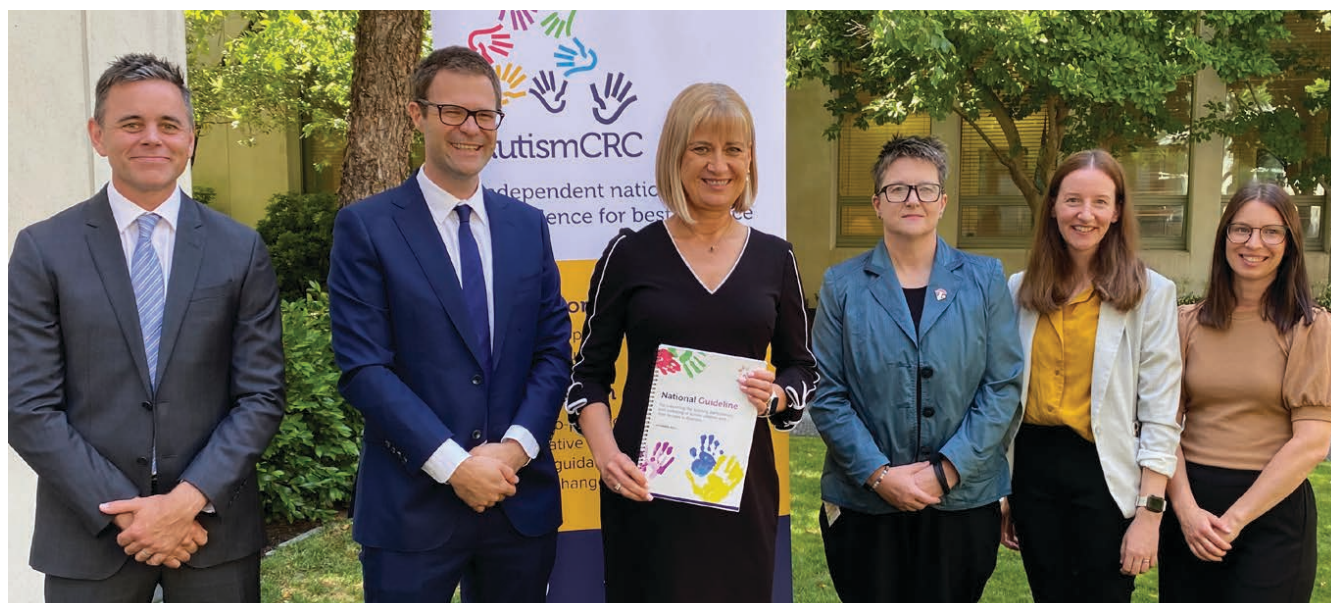
Australia's first *National Guideline for supporting the learning, participation, and wellbeing of autistic children and their families* in Australia was launched by the Hon. Justine Elliot MP, Assistant Minister for Social Services, at Australian Parliament House in February 2023.

The Guideline provides clear and consistent Recommendations and Good Practice Points for practitioners who deliver supports to autistic children and their families, to ensure they are doing so in ways that are effective, safe and desirable to children and their families. The Guideline covers:

- ▶ the guiding principles for the provision of supports for autistic children and their families
- ▶ setting appropriate goals for supports
- ▶ selecting and planning supports
- ▶ the delivery of supports
- ▶ monitoring, reviewing and safeguarding outcomes and quality.

The new Guideline focuses on the delivery of non-pharmacological supports in community and clinical settings that aim to support children aged 0-12 years. However, the Guideline has a lifespan perspective, recognising that early supports should lay the foundation for a positive future. As such, the new Guideline will assist:

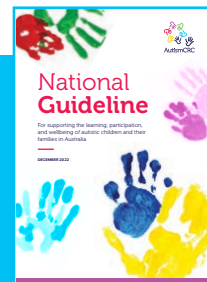
- ▶ practitioners and service providers in the development and delivery of evidence-based practices
- ▶ individuals and families in making informed choices in pursuing goals for the child and the family
- ▶ government policy-makers and funding agencies in monitoring and safeguarding quality, effective and efficient outcomes.



A/Prof. David Trembath, Prof. Andrew Whitehouse, Justine Elliot MP, Katharine Annear, Sarah Pillar & Dr Rylee Sulek at the launch of the Guideline.

Find out more

The Guideline can be accessed both as a series of interactive webpages and as a downloadable PDF document through a simple registration process from autismcrc.com.au/supporting-children



The Guideline was developed through deep consultation with more than 1,000 Australians - autistic people, family members, and practitioners.



An important element of this Guideline was the involvement of autistic people on the Guideline Development Group (GDG). This is a critical step forward and ensures that autistic voices are captured in clinical practice.

Associate Professor David Trembath, Griffith University,
Co-chair of the GDG

The National Health and Medical Research Council (NHMRC) has approved all 84 Consensus-Based Recommendations within the Guideline. This indicates that the Guideline has been developed to the highest standard.

Autism CRC funded the development of the Guideline, assisted by the generous bequest of Basil Waugh.

Implementation

With the Guideline complete, work began on developing a range of implementation resources and professional learning courses for practitioners delivering supports in community and clinical settings consistent with the Guideline. This includes a short course and eLearning lecture and activity, similar to those now available for the ADAG (see next story).

The online self-paced short course explores the Recommendations included within the Guideline. The modules and subsequent lessons within the course have been developed to allow effective implementation of the Guideline Recommendations within any setting when selecting, planning, delivering, and monitoring supports. Lessons highlight the importance of working in a partnership and coordinating supports for the learning, participation and wellbeing of autistic children and their families.

A core element of the course is the integration of three in-depth Guideline in Practice case studies which all link back to the Guideline Recommendations and important community insights. The course also includes filmed case

study conversations with parents and practitioners that explore further what the Guiding Principles really mean for a child and family, from a professional and personal perspective.

The course has been designed for practitioners, families, service providers, educators, peak bodies, and government bodies, and will be released later in 2023.

Flexible training opportunities for clinicians

Autism CRC's partnerships with universities and professional organisations continue to grow as part of our commitment to deliver accredited learning opportunities for allied health and medical professionals to improve diagnostic practices and overall care for autistic people.

Microcredentials

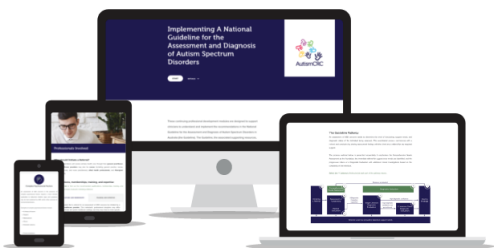
This year we completed a suite of seven credit-bearing microcredentials designed to support clinicians implementing the *National Guideline for the assessment and diagnosis of autism* in Australia. Developed with The University of Western Australia, the courses cover a range of topics including best practice assessment and diagnosis, diagnostic features and assessment approaches across the lifespan, initiating a referral, conceptual diagnostic frameworks and differential diagnosis.

Short online course

In addition to the microcredentials, we've developed a short online course, delivered through Speech Pathology Australia since July 2022, and Occupational Therapy Australia since June 2023. The self-directed course is open to all key clinical professionals and explores the Recommendations included within the Guideline. The course has attracted 150+ enrollments with 96% of surveyed clinicians reporting that they found the modules 'very useful' or 'extremely useful' to their clinical practice.

eLearning Lecture and Activity

To ensure future allied health professionals receive up-to-date training aligned with the Guideline, a tailored undergraduate eLearning lecture and activity on the assessment and diagnosis of autism was also developed



Find out more

Go to our eLearning page
autismcrc.com.au/elearning
 for the full list of professional
 learning resources.



this year. The eLearning lecture and activity are designed to be flexible and can be delivered in multiple ways, either self-paced online, lecturer-led, workshop style, or a blended delivery approach. Importantly, the lecture activity provides opportunities for engagement and collaboration across allied health courses giving students the opportunity to experience a consensus team setting.

University of South Australia (UniSA) became the first hosting partner in April 2023, with 65 Speech Pathology and Occupational Therapy students completing the activity in the first semester. Paediatric speech pathologist and lecturer, UniSA's Kady Moraby, says the teaching package will ensure UniSA graduates immediately have the skills they need when they enter the workforce. UniSA will incorporate the activity as part of the Paediatrics Physiotherapy program in semester two, 2023. University of Tasmania is also now offering the activity with several other universities expressing interest.

Update to Assessment and Diagnosis of Autism Guideline

Autism CRC first published the *National Guideline for the assessment and diagnosis of autism in Australia* in 2018. This was the first national practice guideline in Australia, and led to important changes in the way autism is understood, assessed, and diagnosed in the Australian community.

In 2022, we commissioned an update of the Guideline to ensure its continued relevance and usefulness. A 15-member Guideline Development Group, that included people with diverse perspectives, experiences, and expertise, worked to update the Guideline through a review of recent research evidence and community consultation. In May 2023, the draft was released for public feedback, reflecting our commitment to incorporating diverse perspectives, including those of autistic individuals and their families, in shaping clinical best practices. The draft was downloaded more than 3,300 times with over 300 individuals providing feedback via the online survey, along with 19 organisations.

The updated Guideline and associated documents have been finalised, and a Public Consultation Summary prepared for submission to the NHMRC in November 2023, with release soon to follow.





Quality of life for people with complex support or communication needs

The perspectives of autistic individuals with complex support or communication needs are not always shared or heard, and there is relatively little known about their perceptions of life needs and outcomes. In response, the AARC identified this as a research priority area. This project aimed to take the first step toward addressing the priorities set by the AARC.

Engaging with the autistic and autism communities, the research team developed a research protocol and conducted a systematic search of the research literature with the aim to identify:

- ▶ methods used to describe and measure the quality of life and/or wellbeing for autistic people with complex support and/or communication needs
- ▶ whose quality of life and/or wellbeing is being reported and who is reporting this.

For the purpose of this project, autistic people with complex care, support and/or communication needs were defined as autistic people with co-occurring conditions (e.g. physical, intellectual, psychiatric, sensory, neurological, language or learning disability). This definition was co-developed with the autistic and autism communities.

The study identified 236 research studies that investigated the quality of life and/or wellbeing of autistic people (aged

3–83 years). Ten per cent of the studies were conducted in Australia and only one study conducted in New Zealand. However, over 50% of the studies published were published in the last five years.

Examining who is reporting on the quality of life or wellbeing of autistic people, we found that:

- 1 Proxy informants provided information in over 30% of the studies.
- 2 Autistic individuals without any reported co-occurring conditions provided information in 31% of the studies.
- 3 Autistic individuals with a co-occurring condition provided information in 34% of the studies. However, the co-occurring conditions that the autistic participants had varied significantly and even within these studies, autistic people with specific co-occurring conditions were sometimes excluded.
- 4 Studies that did include autistic individuals with co-occurring conditions sometimes modified procedures or methods to be more accessible and inclusive.
- 5 Few studies reported using community involvement to design studies, which may then be impacting on accessibility.

This project is a foundational step that aims to inform future research in this area. By identifying those whose voices have not yet been heard, and the methods used to hear such voices, we can inform future research in a way that expands the perspectives reported, thereby ensuring the findings benefit all.

Education, transitions and employment

Autism CRC has been working to understand the barriers to employment and to improve opportunities and outcomes for autistic Australians since our first projects began. This year we've improved and expanded existing tools such as myWAY Employability, developed online training and capacity building resources using the Integrated Employment Success Tool (IEST), delivered a successful Autism@Work Summit and co-designed new resources for self-advocacy in the workplace.



6,600+

Educators
joined the inclusionED
community of practice



1,360+

Attendees
at Autism@Work Summits



4,000+

Registered users
myWAY Employability career planning
platform for young autistic people



1,300+

Downloads
Integrated Employment Success Tool (Aust & NZ)
practical workplace manual for employers to improve
workplace success of autistic people



460+

Copies sold
Adolescent/Adult Goal Setting Tool
facilitating transition planning and goal
setting (AAGST)

inclusionED evolution and growth

inclusionED just keeps growing, and now has more than 6,600 registered users.

The platform provides evidence-based and research-informed teaching practices, videos, printable templates and other resources, designed to support diverse learners in inclusive classrooms. Underpinned by the principles of Universal Design for Learning, inclusionED supports flexible approaches that can be customised for personalised student learning. inclusionED is the translation of 10 years of Autism CRC research into usable teaching practices for today's classrooms.

This past year the team brought together findings from an in-depth review of the existing platform, education priorities, professional teaching standards and consultation with the education sector to make improvements to the inclusionED platform. This included a review of identified areas of need and a gap analysis of the 46 practices published and the 17 in development.



Nicole Torres, Libby McDonald, Cheryl Mangan, Trudy Bartlett & Kelly Gorham at EduTech.

The following areas of priority were identified: anxiety, bullying, dyslexia, Attention Deficit Hyperactivity Disorder (ADHD), social stories, sensory needs, behavioural strategies, and group work. This will inform the focus of practice development into 2023-24.

An updated version of the inclusionED platform was released in October 2022. Enhancements include improved navigation and accessibility of practices, personalisation, goal setting, and a practice implementation template.

10 new practices have also been published on inclusionED in this past year, covering topics such as:

- ▶ communicating with parents
- ▶ using Universal Design for Learning in planning
- ▶ understanding and supporting comprehension
- ▶ story grammar
- ▶ supporting students to detect their own emotions from body clues.

This year almost 2,000 teachers, education professionals and parents participated in inclusionED capacity building events such as professional development training, workshops, conferences, presentations and webinars. This included the very popular 'The Inclusive Classroom' webinar series which attracted 9,000+ individual event registrations from 18 different countries. The webinars series in early 2023 featured an impressive line-up of education researchers and professionals, including those with lived experience. Topics included:

- ▶ Anxiety in the classroom
- ▶ Neurodiversity in the classroom
- ▶ Sensory needs
- ▶ Foundation practices for early career teachers
- ▶ Positively engaging families.

Each webinar featured insightful discussions and many tips on getting the most out of inclusionED's ever growing resources. Feedback was received from 584 of the 1,638 real-time attendees.

 **93%** were 'very likely' or 'likely' to recommend the webinar to a friend or colleague

 **94%** reported improvement in their knowledge or skills



Well this webinar was just truly awesome. I am an autistic student teacher and I am very passionate about how I can apply my own experience into my own developing teaching practice. I liked that there was autistic representation in the webinar and also the positive way in which the information was articulated.

inclusionED webinar attendee

Supporting engagement and removing barriers in Australian schools

To be genuinely inclusive, education systems and practices need to effectively support the strengths and meet the needs of diverse learners. Building on the success of Autism CRC's previous work, including the foundational Australian Autism Educational Needs Analysis, this project set out to:

- ▶ further our understanding of current educational strengths and needs of autistic learners, including those with high and complex needs or those who are multiply marginalised
- ▶ identify what is working and not working well in inclusive education practice for autistic learners.

It is critical to support autistic learners to flourish in education settings, promoting their growth, development, learning and holistic wellbeing.

The research highlighted that for autistic learners to thrive in their education deeper knowledge and understanding is needed regarding the great diversity, heterogeneity, attributes and experience of autistic learners and the complexity of autism. This requires ensuring appropriate



inclusive education policies are in place and are translated and actioned in practice in educational settings.

Barriers to autistic learners' education were identified as a lack of adequate understanding of autism and other kinds of neurodivergence, particularly in school settings. Concerns were also raised about the capacity of schools to include and support autistic learners, educators' lack of understanding of how to cater to individual differences, and the limited use of appropriate inclusive pedagogy.

The research found that, to enable autistic learners' educational engagement and achievement, emphasis should be placed on increasing understanding across all stakeholder groups – including policymakers, parents/carers, educators, allied health professionals, and peers. Forging stronger partnerships and fostering clear and regular communication between all stakeholders is also important. The significance of having more autistic perspectives in such collaborations and professional development programs is fundamental to their success.

myWAY Employability

The myWAY Employability web platform is designed to help autistic people shape and manage their path to participation in employment. It was first released in 2020. myWAY Employability has become a valued and successful tool for young people transitioning from school to employment and training, and for neurodivergent individuals of any age looking to better understand their strengths and challenges, set goals and achieve their dreams. The platform encourages users to break their dreams down into achievable goals and tasks, providing a roadmap to career success. Through that deep understanding, the platform also informs mentors, service providers and employers on how best to support jobseekers and employees. The platform has more than 4,000 registered users and continues to grow.

This year work began on new and more personalised functionality. This included co-design and building for a responsive goal-builder, enhanced dashboard and more templates to support different career stages, allowing users to more easily tailor goals.

Responding to user feedback, improvements include flexible invitation functionality, allowing both career explorers as well as support persons to initiate team formation. myWAY Employability supporters using the platform include mentors, employment service providers, educators and parents. A new enhanced dashboard for managing multiple career explorers also includes evidence-based recommendations to leverage strengths and accommodate workplace preferences.

A multi-state trial with an employment service provider also began this year. The trial utilises myWAY Employability to assist job-seekers plan and pursue a path to employment. An enterprise version to be developed in 2024 will allow service providers or employers to initiate use of the platform, inviting and supporting individual jobseekers or employees in use of the platform.

Online training and resource package utilising the IEST

Building on our suite of evidence-based resources, work began on developing a co-produced online training and resource package utilising Autism CRC's Integrated Employment Success Tool (IEST). The package is aimed at employers, human resources managers and trainees, and will reflect contemporary workplace practices, and considerations and strategies in the workplace environments to provide inclusive opportunities and sustainable employment for autistic workers.

These resources are due for release in 2024.

Successful Autism@Work Virtual Summit

Autism CRC hosted the 2023 Autism@Work Virtual Summit over two days in March, attracting nearly 1,000 registrations. The event featured over 40 local and international speakers across 16 sessions, including neurodivergent individuals, who shared insights and experiences related to employment and inclusion. This year's summit was focused on Building Capability for Employees and Employers.

The purpose of the event is to encourage employers to develop and embed inclusive practices in their Human Resource policies and procedures, with a focus on:

- ▶ adjusting recruitment processes to facilitate successful recruitment of more autistic people
- ▶ understanding what reasonable adjustments can be made to retain existing autistic talent.

The summit's success highlighted the importance of fostering diverse and inclusive workplaces. Event host, Orion Kelly, gave his own insightful perspective to session topics and facilitated many great discussions. A total of 94% of surveyed attendees (n=200) rated the event as excellent, very good or good.

A huge thanks to our partner in this event, DXC, and the other event sponsors: GHD Engineering, La Trobe University, Untapped, ANZ and SAP. Our thanks also to session sponsors AIG and SunPork Group.



Sector-wide initiatives and assets

Autism CRC has built a range of assets and initiatives to build capacity within the autistic and autism communities, facilitate community-driven research priorities and meet community needs.



310+

Downloads

Participatory and Inclusive
Autism Research Practice Guides



170+

Participants

Sylvia Rodger Academy
across 5 programs



**Australasian
Autism Research
Council (AARC)**

Exploring and defining
national research priorities

Sylvia Rodger Academy

Autism CRC's Sylvia Rodger Academy (SRA) 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, research and co-design. This year saw 45 autistic adults enrolled in the new SRA program – Autistic Identity and Connection.

Autistic Identity and Connection Program

This was the first SRA Program to include both a fully online version, as well as a hybrid face-to-face and online version. The Program, delivered by six established autistic leaders, aimed to give autistic participants a more complete understanding of what it means to be autistic. It also provided an opportunity to connect with other autistic people and community and develop skills in wellbeing and self-advocacy from an autistic perspective.

Participants engaged in online modules and sessions from February 2023, with those in the face-to-face and online version attending the residential workshop in May 2023. Masterclasses, for the online only version, commenced June 2023.

This program is delivered in partnership with Aspect, funded by the Australian Government Department of Social Services and was developed by and for autistic people.



It has changed my life... I no longer question my diagnosis. I am more aware of myself and my needs. I have learnt many accommodations I can make in my life to make things easier on myself. Mostly, I learnt it's OK to be autistic and I am moving into a space where I want to be autistic and proud and educate others on autism.

Autistic Identity and Connection workshop participant



2022 Future Leaders alumni and support team.

Self-Advocacy@Work

A new Self-Advocacy@Work online resources package will be available to users from November 2023. It includes a series of accessible multimedia tools and resources designed to equip and empower autistic individuals to better advocate for themselves in the workplace. This co-designed resource package was developed in collaboration with the ASAN AUNZ.

Future Leaders

The 2022 Future Leaders participated in a three-day residential workshop in Brisbane in July. 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 was for those with an idea that would make a positive impact in their community. The Program offered knowledge, skills and access to support and expertise to help participants turn ideas into an achievable project.

In the months following the workshop the 13 participants developed and delivered their community projects, while undertaking mentoring and masterclasses in chosen areas of skill development. Projects ranged from creating and delivering presentations on neuro-affirming practice to professionals, to facilitating an art therapy program for autistic people, and launching the work at an autistic-led art gallery exhibition.

The Future Leaders Program is delivered in partnership with Aspect.



Thank you so much for, I am actually lost for words. Thank you for this program, I learned loads and felt home in my first program among peers. I am excited to see how we all grow and develop as we progress. Plus supporting each other as we need it.

Future Leaders 2022 workshop participant

Australasian Autism Research Council

The AARC was established to review and define national priorities for autism research – by and for the autistic and autism communities. The AARC includes representatives from the autistic and broader autism communities, service providers, health and education professionals, government program managers and policy makers, and researchers.

We received a record-breaking 200 expressions of interest for 2023 membership of the AARC. Interest came from across Australia and New Zealand, with applicants representing a rich and diverse range of experience, perspectives and expertise. The new Council elected Professor Charlotte Brownlow and Dr Rebecca Poulsen as Co-chairs for the 2023 calendar year.

The AARC also set out to advance research priorities this year, with a project to further investigate five priority research areas. This project represents a continuation of work previously conducted by the AARC that in 2019 identified the top ten autism research priorities for Australia. In 2021, the AARC produced a report that provided additional details on the views of the autistic and autism community related to five of the ten research areas.

This work represents a process to co-create a snapshot of needs in these areas, presenting the autistic voice as central to the decision on research priorities. The report will be delivered in late 2023.

The AARC also recommended that a priority research area be addressed with a project exploring how quality of life and wellbeing are defined by, and for, autistic individuals with complex support and communication needs. A research project in this regard was consequently commissioned by Autism CRC (see page 18), with the report to be release in late 2023.

This year the AARC once again engaged the community to provide more detail and specific areas of focus related to the other five research priority areas:



Choice of living and housing



Family and carer support



Gender, diversity and inclusion



Health and disability services delivery



Built environment

Australian Autism Biobank

Autism CRC created the Australian Autism Biobank to help advance our understanding of how biological and environmental factors are linked to autistic health and wellbeing. We know these factors are important to all aspects of care, from diagnosis through to ageing.

Developing a better understanding will lead to more appropriate supports and practices for the benefit of autistic people and their families.

A biobank safely stores ethically-collected participant data and biological samples for use in approved research through one mechanism.

The Australian Autism Biobank is Australia's largest collection of data and samples from autistic children and their families. The Biobank's rich biological and phenotypic datasets provide researchers with a cross-section of:

- ▶ biological samples
- ▶ genetic data from whole genome sequencing
- ▶ participant surveys and questionnaires encompassing behavioural, socio-economic and health data.

Data access upgrade

Autism CRC is currently working to streamline arrangements for material and data access, storage and curation. This will see the integration of these processes for all Biobank and longitudinal data assets. Updated online content on these resources for the information of both researchers and the community, co-designed with the community, has also been developed. This is due for release in early 2024.

Utilisation

Three new applications for use were approved in 2022-23. To date, 34 research projects have been approved, covering a wide range of physical and mental health and wellbeing areas of need. Each time a study is completed, new data generated is added back into the Biobank, so that it continues to grow and evolve for the benefit of future generations.

Studies published in this year included:

Interactions between the lipidome and genetic and environmental factors in autism

This study (highlighted on page 15) looked at interactions between the lipidome and genetic and environmental factors in autism. It found that various plasma lipids were associated with autism diagnosis, IQ and sleep disturbances.

Dietary intake in children on the autism spectrum is altered and linked to differences in autistic traits and sensory processing styles

In this study of dietary differences linked to autism, children and teenagers on the spectrum ate fewer different foods and were less likely to eat recommended amounts of fruits and vegetables when compared to non-autistic siblings and unrelated children and teenagers. Among those on the spectrum, dietary differences were linked to age, sex, autistic traits and sensory processing styles.

turnKey CRC

Capitalising on our own internal expertise and needs, Autism CRC has successfully built turnKey CRC. The business provides a ready-to-use software solution developed especially for Cooperative Research Centres (CRCs). It allows newly funded CRCs to hit the ground running on startup, seamlessly supporting CRC program governance and management, partner engagement, contracts, cash and in-kind commitments backed by strong reporting and data visualisation capabilities.

turnKey CRC is hosted on the world's leading cloud-based relationship and business management software platform, Salesforce.

Built using a modern and intuitive user interface, turnKey CRC provides new CRCs with the power of Salesforce infrastructure to manage their work in five key ways:

- 1 CRC Program Management and Governance
- 2 Partner Engagement and Stakeholder Management
- 3 Project Lifecycle Management
- 4 Automated Contract Generation
- 5 Financial Insights

The business has grown steadily and now supports 17 CRCs.



turnKey is integral to CRCNA's operations. I don't know how we would manage the quarterly reporting of projects in our portfolio without turnKey.

CRC for Developing Northern Australia (CRCNA)

Our end-users



Our end-users

Working with, and for, our end-users is integral to all our work. This commitment is reflected in our collaborative practices and co-design efforts across research, policy and capacity-building projects.

Our end-user groups

Our end-users comprise five major groups:

- ▶ **Autistic individuals and their families and carers** – the ultimate beneficiaries of our research, policy and practice outcomes.
- ▶ **Professionals who provide advice, assessment and support** for autistic individuals. These professionals work across the public, private and not-for-profit sectors and include paediatricians, general practitioners, psychiatrists, community nurses, early childhood educators, teachers and school leaders, psychologists, occupational therapists and speech pathologists.
- ▶ **Service providers that employ professionals to provide services** to autistic individuals 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.** This includes small, medium and large enterprises.
- ▶ **Government policy-makers and program managers.** Those setting policy, providing funding and driving decisions that enact systemic change.

Research, policy and practice

Our formal collaboration of Members and Affiliates has focussed on addressing agreed needs as outlined by community research priorities, working to address the many areas of significant and unnecessary disadvantage for autistic individuals and their families with evidence-based practice and policy.

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; Commonwealth and state government departments and agencies; and critically, autistic individuals and their families.

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.

Autism CRC seeks sector input in the design and evaluation of projects, often through iterative testing and trials of project outcomes. Over the past year, we conducted a successful multi-state trial with an employment service provider utilising myWAY Employability to assist job-seekers plan and pursue a path to employment. This has allowed us to continue to enhance and expand on our suite of evidence-based resources intended to build neurodiversity-inclusive employment understanding and capacity, for the benefit of both employees and employers.

Autism CRC is represented on a number of advisory boards and network groups, such as:

- ▶ Australian Autism Alliance
- ▶ Autism Advisory Group to NDIA
- ▶ Autism Centre for Excellence (ACE) Advisory Board
- ▶ Commonwealth Department of Health and Aged Care's National Roadmap to Improve the Health and Mental Health of Autistic People Working Group
- ▶ Commonwealth Department of Social Services' ministerially-appointed Expert Reference Group of clinical and consumer representatives to help National Guideline implementation
- ▶ Department of Education Queensland, Autism Hub Advisory Board
- ▶ Technology Wellbeing Roundtable
- ▶ Telstra Foundation Tech4Good community of practice.

Capacity building

More than 52,600 professionals have been involved in our research program or have used our outputs in the last year alone. Strong partnerships with industry, government and service providers have increased reach and uptake of outputs into real-world practice. Autism CRC has worked closely with professional colleges, societies and associations, along with universities to establish hosting partnerships and to promote opportunities through our networks.

Our range of evidence-based knowledge, best practice guidance, tools, products, professional development courses and capacity building opportunities have expanded to include:

- ▶ Supporting Autistic Children Guideline – developed through deep consultation with more than 1,000 Australians including autistic people, family members, and practitioners. Over 5,700 have registered for the Guideline.
- ▶ Suite of seven credit-bearing microcredentials – developed with, and delivered through, UWA to allied health and medical professionals seeking to upskill and enhance their knowledge of best practice autism assessment, diagnosis, and referral practices aligned to the Assessment and Diagnosis of Autism Guideline. Enrolments for the reporting period totalled 71.
- ▶ Undergraduate eLearning lecture and activity on Assessment and Diagnosis of Autism Guideline practices – delivered through hosting universities and delivered to 65 Speech Pathology and Occupational Therapy students to date.
- ▶ Short online course – delivered through colleges and societies to improve best practice implementation of the Assessment and Diagnosis of Autism Guideline. More than 150 allied health and medical professionals have completed the course to date.
- ▶ inclusionED was expanded with 10 new practices added for teachers, school leaders and ancillary staff this year. More than 70,000 users have engaged with the platform and there are now over 6,600 registered members of the inclusionED community of practice.

In addition, we continue to positively influence research practices and build the capacity of researchers through the Sylvia Rodger Academy's Research Program. The Program 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.



Consultation and co-design

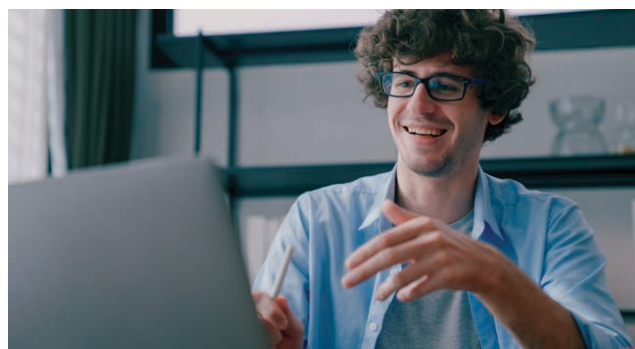
Autism CRC is committed to the adoption and promotion of participatory and inclusive research practices that:

- ▶ 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 this last year, community consultation activities for Supporting Autistic Children Guideline 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. To support its work in community consultation, the GDG formed a Reference Group, comprising representatives from organisations that play a critical role in supporting aspects of children's health, development, education, participation, and wellbeing, and/or supporting parents and families in raising autistic children. These included representatives from Aboriginal and Torres Strait Islander peoples, Culturally and Linguistically Diverse (CALD) communities and key government agencies.

Working with 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 has also built capacity by upskilling members of the autistic community in co-design, product development and inclusive practices.

This year we also sought to close the gaps in our knowledge on the quality of life and wellbeing of autistic individuals with complex support or communication needs – ensuring all voices might be heard in the work that we do.



What our end-users say

As the first hosting partner of Autism CRC's undergraduate teaching program, our graduates will have the most up-to-date, evidence-based information and knowledge of the assessment process and clinical pathway. This is a step forward to ensure our students are job-ready and able to support individuals and their families to receive the very best possible care.

Kady Moraby, Paediatric speech pathologist and lecturer, UniSA



Liked the two very different perspectives and how together it gave a holistic picture on how teachers can help understand neurodiverse kids and help them in practical ways in the classroom.

Attendee, inclusionED webinar

Our findings are a testament to what can be achieved through collaboration between researchers and community groups

Dr Chloe Yap, Researcher





It helped me to actually be around other autistic people for the first time in my life and feel far more at home and connected to other people.

Participant, Autistic Identity and Connection workshop



I thought the course was really good and made understanding the guidelines easier.

Short course user, Assessment and Diagnosis of Autism Guideline

I did learn a lot using the case studies especially given I could relate them to clinical practice. I enjoyed the history lesson too."

Microcredential user

I loved that the presenters were able to not only talk about their personal experience but were also educators AWESOME!

Attendee, inclusionED webinar



The clarity with which issues were addressed and a solid focus on understanding autistic children's experiences and listening to them. Good mix of research and personal experience to support the discussion. Appreciated the links posted in the chat thank you.

Attendee, inclusionED webinar

Our structure and governance



Our structure and governance

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.

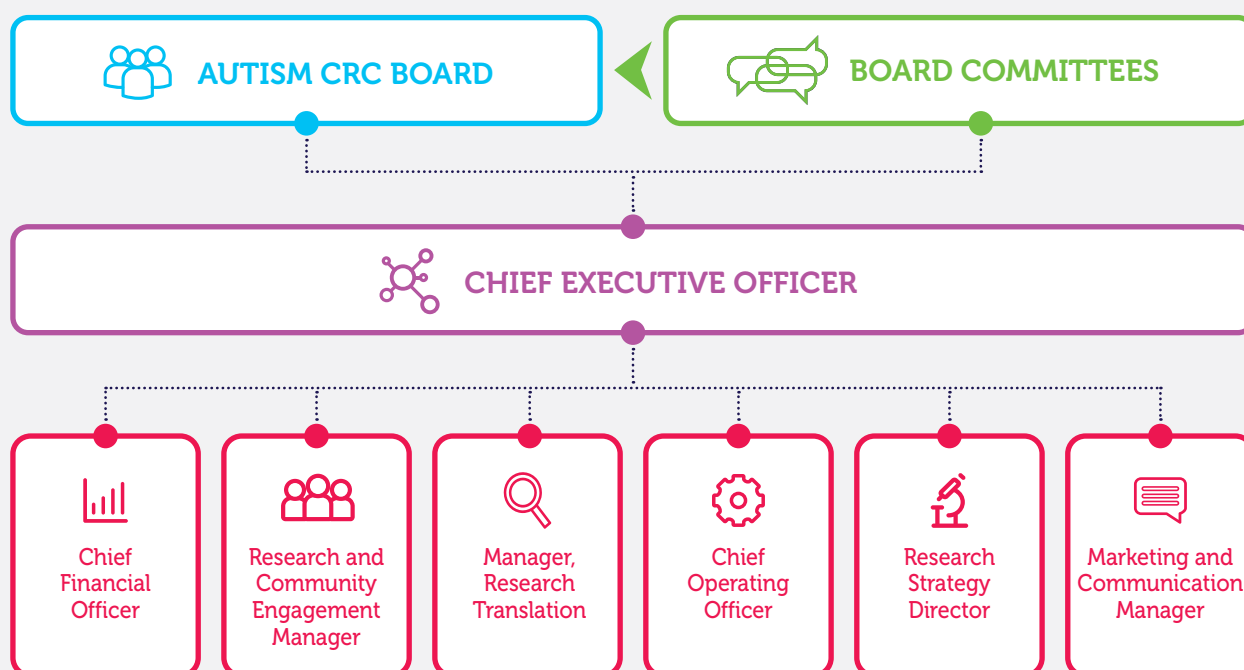
Autism CRC has ensured this by:

- ▶ 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.

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



Autism CRC Governance Structure





Autism CRC Board

The Autism CRC Board is accountable to the Members of Autism CRC Ltd (the Company) 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 and eight Independent Directors until November 2022 when two retired. Two of the Directors have an autism diagnosis, and a number of Board members are parents of autistic children.

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.

Board update

Carole Green and Paul Field retired from the Board at the Annual General Meeting (AGM) in November 2022.

Carole had been an independent director of Autism CRC since its commencement in July 2013, serving as its Deputy Chair since 2017. Carole had also served as a director of Social Science Translated since 2017 and as its Chair since 2018. She retired from all positions.

Paul was an inaugural director of Autism CRC from 2013-15, drawn to the organisation through his friendships with parents of autistic children. He was pleased to be reappointed to the Board in April 2018 until his retirement from the position in 2022.

We thank Carol and Paul for their years of valued service.

Katharine Annear was welcomed to the role of Deputy Chair of the Autism CRC Board following Carole's retirement. Katharine has been a member of the Board since July 2021.



Management Team

Name	Role	Organisation
Andrew Davis	Chief Executive Officer	Autism CRC
Andrew Borneman	Chief Financial Officer and Company Secretary	Autism CRC
Professor Andrew Whitehouse	Research Strategy Director	University of Western Australia
Cheryl Mangan	Manager, Research Translation	Autism CRC
Therese Conway (to April 2023)	Research Program Manager	Autism CRC
Dr Olivia (Liv) Gatfield	Research and Community Engagement Manager	Autism CRC
Wojciech Nadachowski	Chief Operating Officer	Autism CRC
Sally Vidler	Marketing and Communication Manager	Autism CRC

In memoriam



Emma Lovell

It is with great sadness that we marked the passing of Emma Lovell.

Emma joined Autism CRC in 2018 as our Finance Officer. A much-loved member of the Autism CRC team, Emma was committed to the realisation of our vision and doing so with her constant gifts of quiet support and a smile for her colleagues.

Emma is greatly missed by her friends and colleagues at Autism CRC.



Michael Whelan

A/Prof Michael Whelan was a significant contributor to Autism CRC, particularly the School Years Program, first during his time at Autism Queensland and then when he moved to QUT. He was involved in many of our projects. He was Project Leader for the translation project that led to the development of inclusionED and co-authored two Routledge books on inclusive education in 2021, which showcase the work of the Autism CRC's school years projects.

Michael dedicated himself to enhancing opportunity and wellbeing for autistic people and their families. He leaves a substantial legacy and is greatly missed by his friends and colleagues at Autism CRC.

Board Members



Professor Robert van Barneveld (Chair)

BAgrSc (Hon), PhD, RANutr, FAICD

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

As a past President of Autism Queensland he is familiar with the needs of families and carers of 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, Aquaculture and Aquafin CRCs.

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

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



Katharine Annear (Independent Director/Deputy Chair)

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 complemented 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 of the Autism CRC, Adrian is the Chair of the Board of Social Science Translated Pty Ltd (SST), a subsidiary of the Autism CRC.

Previous appointments have included Adrian being SST's Executive Director (2019 – 2022) and the CEO and Company Secretary of Autism Spectrum Australia (Aspect), Australia's largest national autism-specific service provider (2000 – 2019). 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 of over 40 years with not-for-profit boards and management, governance structures, strategic planning, risk management, finances, HR and policy frameworks.



Carole Green (Deputy Chair – retired 2022)

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 Pty Ltd since January 2017 and its Chair since January 2018. Since 2015, Carole has served on Autism CRC's Audit, Risk and Finance Committee, previously being a member of the Remuneration, Nomination and Selection Committee.

Having served three consecutive three-year terms as an independent director, Carole elected not to nominate for a fourth term prior to the 2022 AGM. Carole values highly her time spent with Autism CRC and wishes Autism CRC continued success for the future.



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. Shirley joined the Board of Social Science Translated Pty Ltd in 2023.

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 since 2015, 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 is 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 (Independent 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 15 years.

Over the past nine 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 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.

Autism CRC Committees

Board Committees

The Board has established a number of Committees to assist in the execution of its duties and to allow detailed consideration of various issues. Current Committees of the Board are: Audit, Risk and Finance Committee; Remuneration, Nominations and Selection Committee; and Investment Advisory Committee. Each of the Committees has its own formal charter setting out the authority delegated to it by the Board. All matters determined by these Committees are submitted to the full Board for approval.

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 consisted of Paul Vincent (Chair), Malcolm Mayfield, Carole Green (until 30 November 2022) and Scott Reading (from 30 November 2022) with the CEO and CFO in attendance.

Remuneration, Nominations and Selection Committee

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

- ▶ 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 make 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 Rob van Barneveld (Chair), Katharine Annear and Adrian Ford, with the CEO and CFO in attendance.

Investment Advisory Committee

The Investment Advisory Committee is an advisory committee of the Autism CRC Board, appointed by the Board, comprising Board representatives, Member and Associate representatives and the Co-chairs of the Australasian Autism Research Council. The Committee provides a forum for: consultation among Members and Associates and the Board; guidance on research strategy and priorities; and recommendations to the Board in relation to research and research translation project investments by Autism CRC.

The Investment Advisory Committee did not meet during the reporting period.



Subsidiary report

Social Science Translated Pty Ltd

Social Science Translated Pty Ltd (SST) provides evidence-based materials and professional training to support communities to grow a diverse set of skills. Proud to be a wholly owned subsidiary of Autism CRC Ltd, SST values the diversity amongst us all and holds a vision of a world that values diverse life skills, making meaningful change in people's lives.

Imagine a world where everyone has an equal opportunity to play to their strengths. Think about how understanding and valuing the preferences and differences in ourselves and others could make this possible.

In August 2022, the SST Board appointed Kathleen Davey as the first dedicated Chief Executive Officer for the Company. A new three-year SST strategic plan was established, and the team set out with a refreshed set of missions. As a result, SST was delighted to be one of only eight enterprises successfully chosen in the inaugural cohort of the Paul Ramsay Foundation Social Enterprise Growth Incubator delivered by Sefa Partnerships and Sefa (Social Enterprise Finance Australia). As the incubator runs across a 12-month period the SST team are being challenged, taking on new experiences, learning new skills, and meeting new networks of like-minded people striving for sustainable and growing businesses that make a real difference in people's lives.

One of the strategic objectives of the SST strategic plan is to grow the reach and impact of the award-winning and evidence-based Secret Agent Society Small Group Program. SST has the exclusive worldwide license for distributing and developing Secret Agent Society (SAS) programs, espionage-themed resources that provide an evidence-based, comprehensive and captivating solution to structured social and emotional learning for children aged 8-12 years old. At the end of the program, children graduate as 'Secret

Agents' having learnt and practised codes and tools that focus on four key life skills:

- 1 Emotion Recognition (in other people and self)
- 2 Emotion Regulation (particularly anxiety and anger)
- 3 Social Skills (for friendship, teamwork and getting along with others)
- 4 Problem Solving (as an individual and in a group).

The SST team are passionate about building a strong network of trained SAS Facilitators who are committed to preparing children for life's social and emotional challenges in a way that respects each child's diverse profile and own social-emotional goals. The process builds capacity within our clinical and educational services to deliver best practice, supporting not only the children directly, but also their parents, school staff and peers. It consists of Child Club Meetings, Parent Group Meetings, Teacher Information Sessions and Teacher Tip Sheets, paired with real-life practice Missions and a handy Skill Tracker system to monitor and reward skill development across home, school, and community activities.

The third edition of SAS Small Group, which is delivered through a digital health platform, saw a new milestone in 2023 in reaching over 5,600 children, over 1,200 SAS Facilitators and Assistants scheduling over 13,000 Cadet Club Meetings, and representing over 170 SAS Provider services across seven global regions.

The program is backed by global research. Over 20 papers and book chapters are published, including four randomised controlled trials. During 2022-2023 period a new publication joined the long list:

- Gasparro, S., Bennett, S., Wyka, K., Temkin-Yu, A., Damianides, A., Beaumont, R. (2023). The Effect of the Secret Agent Society Group Program on Parent-Teacher Agreement Regarding Children's Social Emotional Functioning. *Behavioral Sciences* 2023, 13, 322.



Adrian Ford, Paul Vincent, Kathleen Davey, Carole Green & Andrew Davis.



Global researchers came together to present on SAS at INSAR 2023 Annual Meeting in Stockholm.



Multiple other studies have either commenced, continued or completed, and are awaiting publication. The research teams from Carleton and York Universities funded through Kids Brain Health Network in Canada and the St John of God Lucena Clinic in Dublin, Ireland came together with the SST representatives at the International Society for Autism Research (INSAR) Annual Meeting in Stockholm this year. This year there were six different SAS research posters representing three global regions! Together the new research furthers evidence for SAS's role in decreased mental health challenges, attainment of social goals, improved family relationships, and improved parent and teacher alignment.

The award-winning and evidence-based SAS Small Group Program has been included on the following independently assessed lists in this last year:

- ▶ The Victorian Schools Mental Health Menu which opens up direct funding to schools in Victoria to use SAS to create positive impact within their school communities.
- ▶ The South Australian Department for Education 'Wellbeing Programs Directory'.
- ▶ The Australian Beyond Blue "Be You Programs Directory" for mental health and wellbeing programs.
- ▶ The evidence-based program profiles for Federal Department of Social Services funding through "Communities for Children Facilitating Partners" supporting community partners to reach disadvantaged families across Australia.

SST launched a new website (www.secretagentsociety.com) and updated the SST branding. Along with the new look and feel, SST also released to the SAS Network a new comprehensive SAS Implementation Guide, SAS Communications Toolkit and a Mentor Enrolment Guide to assist parents and teachers onboarding into the

program through one of the subscribed SAS Providers around the world.

Since the original version of the SAS Small Group Program was launched over a decade ago, program content and resources have been systematically updated over time to incorporate new research and best-practice evidence, as well as enhance Facilitator-led activities in response to feedback, advisory group input, and diverse learning styles. Recent activity by the SST team in collaboration with program author, Dr Renae Beaumont, saw the progressive release of updated SAS Small Group program content from July 2022. Updates focused on better conveying the flexible options for delivering the SAS Small Group Program within a neurodiversity framework, and updating some of the concepts within the core skills taught through SAS. Valuing diversity and being responsive to community needs is at the core of these most recent changes.

The Social Science Translated Pty Ltd Board is appointed by Autism CRC Ltd as the sole shareholder. The SST Board met on ten occasions during the reporting period. During this period SST saw the retirement of Carole Green, its long-standing and respected Chair of five years. Adrian Ford was appointed as Board Chair and the Board subsequently also welcomed Shirley Lanning to govern SST alongside Paul Vincent and Andrew Davis. The Board supported the transition of the new CEO and continued the effective working relationship between the Board and management, a crucial element of SST's success. Together the SST Board and CEO congratulate and respect the dedicated operations team and SAS champions around the world.

At the heart of SST are people who hold a shared passion for seeing families access best practice services, preparing as many children as possible for life's social and emotional challenges.

Getting our message out



Getting our message out

Keeping in touch

... Awareness by, and engagement with, the autistic and autism communities has grown significantly in recent years.

Autism CRC has taken full advantage of opportunities to further expand our reach and capitalise on the occasions provided by the dissemination of new research outcomes and outputs. This is reflected in the growth of participation in research surveys, community consultation and co-design. We have also increased our social media following, website traffic and event attendance.

We continue to improve the accessibility of our communication activities, creating accessibility tagging in major documents, explainer videos, developing FAQs and research snapshots, adding closed captioning, voiceovers, transcripts, creating easy-read versions of documents, and providing copies of presentations and recordings of events from our website and YouTube channel. In August we will launch a new Autism CRC podcast to expand our reach.

This year we added a targeted inclusionED Facebook page to our social media offering. Our online community has increased by 17% overall to 46,600+ followers and subscribers. This includes:

- ▶ 28,000+ eNews subscribers
- ▶ 11,950+ Facebook followers
- ▶ 2,540+ Twitter followers
- ▶ 3,130+ LinkedIn followers
- ▶ 980+ YouTube subscribers.



46,600+

Followers and subscribers

17% increase
in our online community in 2022-23

Co-design and community consultation

Autism CRC has set the standard for comprehensive community consultation and co-design processes. This year we engaged in community and cross-sector consultation for the development of the Supporting Autistic Children Guideline, and the update to the Assessment and Diagnosis of Autism Guideline.

With our established reputation as a trusted, independent, national source of evidence for best practice, the Commonwealth Department of Social Services engaged us to assist in several areas of the National Autism Strategy (NAS) development. This included developing and disseminating two streams of the Expression of Interest (EOI) process for the NAS Oversight Council and Working Groups. In addition to the call for nominations from the research and professional sector, we assisted community representative and advocacy organisations with the EOI process. This included marketing and communication support and the provision of our information system for submission and receipt of expressions of interest.



Major events and announcements

This year included the coordination and promotion of several major events and announcements, including:

- ▶ Launch of National Autism Strategy by the Commonwealth Minister for Social Services, the Hon. Amanda Rishworth MP, at an Autism CRC event in Brisbane. The event was attended by autistic individuals, family members, service providers, researchers, employment and education providers, Autism CRC Board and staff.
- ▶ Ministerial launch of the *National Guideline for supporting the learning, participation and wellbeing of autistic children and their families in Australia* (Supporting Autistic Children Guideline) at Australian Parliament House, with community members, key policy-makers and Guideline project team members in attendance.
- ▶ The Autism@Work Virtual Summit which attracted 966 registrations of which 533 were new contacts.
- ▶ The inclusionED *Inclusive Classroom* webinar series which attracted 9,700+ individual registrations from educators across 18 countries. Seventy-six per cent of registrants were new contacts to our database.
- ▶ Working with Mater Research and The University of Queensland to maximise media and industry dissemination of research outcomes and implications in relation to the study into interactions between the lipidome, genetic and environmental factors in autism published in Nature Medicine.

- ▶ The 2023 International Society for Autism Research (INSAR) Annual Meeting in Stockholm, where Autism CRC research was well represented. Researchers – many of them past Autism CRC scholars – delivered nine oral and poster presentations on a range of topics.
- ▶ The 2022 Australasian Society for Autism Research (ASfAR) held in Geelong, where Autism CRC activities were showcased in four oral presentations. The recipient of the Autism CRC Award for Achievement in Autism Spectrum Research was also announced.

Improving user experiences and uptake

With the release of the Supporting Autistic Children Guideline, accompanying webpages and an interactive online copy of the Guideline were developed. This very significant undertaking created a better user experience, allowing clinicians and other users to easily jump in and out of the Guideline, to share relevant Recommendations and Practice Points with others, and to readily view supporting evidence for each Recommendation. The new functionality has proven popular.

Announcement of the launch was our biggest direct email send to date. Three targeted emails were sent out with a combined reach of 34,500. Uptake has been strong with 5,700+ users registering to access the Guideline – 4,000 of whom were new to our database in the last year.



Awards and honours

Our network is full of talented people, dedicated to research and translation to improve the quality of life and opportunities of autistic people and their families. Here are just a few highlights from the year in review.

'Autistics in Academia' receives award

Autism CRC's 2022 Award for Achievement in Autism Spectrum Research in Inclusive Autism Research was presented to Professor Sandra Jones from Australian Catholic University at the ASfAR conference in Geelong.

Professor Jones' project, Autistics in Academia, sought to understand why the growing number of autistic academics remain largely absent from academic literature, despite the evident synergies between autistic strengths and academic careers.

The 12-month study drew upon the lived experience of researchers across all stages of the project – respectfully leveraging existing networks and relationships with the autistic community.

We congratulate Professor Sandra Jones and her team from Australian Catholic University.

Each year, Autism CRC holds Awards for Achievement in Autism Spectrum Research

The awards are open to all organisations and researchers undertaking quality research projects in the area of autism, regardless of affiliation with Autism CRC. The awards 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.

Congratulations Andrew Whitehouse

Congratulations to Autism CRC's Research Strategy Director Professor Andrew Whitehouse, on both being named a finalist for the Western Australian of the Year and receiving the Western Australian of the Year HBF Professions Award.

These are well-deserved recognition for Andrew who has worked tirelessly with Autism CRC and his team at Telethon Kids Institute and The University of Western Australia, conducting research and applying it to practice that is changing the lives of autistic Australians for the better.

"Every bit of recognition goes to the extraordinary team I'm lucky enough to work with, and the kids and families who let us into their lives and share their joys, laughs, tears, and triumphs – what a privilege that is." – Professor Whitehouse in accepting the Professions Award.



PhD Chloe Yap receives CSL Florey Next Generation Award

Congratulations to Chloe Yap, winner of the 2022 CSL Florey Next Generation Award. This is an amazing achievement for Chloe and was announced at the Australian Association of Medical Research Institutes' (AAMRI) Annual Dinner at Australian Parliament House on 29 November 2022.

Chloe's PhD explored the autism-gut microbiome link – using data from Autism CRC's Australian Autism Biobank – to debunk the myth that the gut microbiome causes autism. The work received world-wide attention in November 2022 when the results were published in the high impact journal, Cell. A great example of collaborative research with real world impacts for autistic people, and thanks to the generosity of the participants of the Australian Autism Biobank.



Appendices



Appendix 1: Annual Financial Report

Statements of Profit or Loss and Other Comprehensive Income For the financial year ended 30 June 2023

	Consolidated Entity	
	30 June 2023	30 June 2022
	\$	\$
Revenue	3,547,256	7,876,081
Expenses		
Research costs	(1,536,168)	(3,927,070)
Employee benefits expense	(2,660,377)	(2,351,586)
Board fees and related expense	(244,618)	(258,954)
Depreciation and amortisation expense	(287,452)	(309,522)
Impairment Loss	(276,700)	(310,305)
Other expenses	(1,475,344)	(1,540,860)
Results from operating activities	(2,933,403)	(822,216)
Financing income	76,638	4,397
Finance costs	(19,291)	(19,291)
Net finance (costs)/income	57,347	(14,894)
(Deficit) / Surplus before tax	(2,876,056)	(837,110)
Income tax expense	10,930	19,011
(Deficit) / Surplus after tax	(2,865,126)	(818,099)
Other comprehensive income	-	-
Total comprehensive (loss) / income for the period	(2,865,126)	(818,099)

The reduction in operating income from FY2022 to FY2023 was significantly impacted by a reduction in Commonwealth funding and deferral of Participant collaborator fees. Specifically:

- Commonwealth funding (2023: \$2,179,104; 2022: \$4,040,000); and
- Member / Participant contributions (2023: \$120,000; 2022: \$480,000).

In March 2021 Autism CRC announced \$6,000,000 funding for two major projects to help improve health services and education and employment outcomes for autistic Australians under the Information, Linkages and Capacity Building (ILC) program. These funds were received across FY2021 and FY2022, of which \$1,328,551 is yet to be applied to activities scheduled for FY2024. The impact of the timing of funding contributed \$1,705,455 and (\$2,296,096) to the FY2022 and FY2023 operating activities, respectively.

Since 2018 \$5,586,682 cash and in-kind costs associated with the Australian Autism Biobank have been recognised on the Statement of Financial Position as an intangible asset. In the financial period ending 2022 an impairment of \$310,305 was recognised against this asset and a further impairment of \$276,700 was recognised in 2023.

Statements of Financial Position For the financial year ended 30 June 2023

	Consolidated Entity	
	30 June 2023	30 June 2022
	\$	\$
Current assets		
Cash and cash equivalents	4,928,383	7,019,679
Trade and other receivables	120,605	570,484
Prepayments	56,574	55,993
Inventory	15,963	10,084
Current tax asset	7,140	14,862
Total current assets	5,128,665	7,671,102
Non-current assets		
Property, plant and equipment	14,296	20,116
Right-of-use asset	147,097	294,195
Trade and other receivables	-	-
Investment in wholly owned subsidiary	-	-
Intangible Assets	4,013,152	4,408,337
Total non-current assets	4,174,545	4,722,648
Total assets	9,303,210	12,393,750
Current liabilities		
Trade and other payables	432,349	583,138
Provisions	195,726	236,099
Deferred revenues	23,967	-
Lease Liability	166,140	153,017
Current tax liability	-	-
Total current liabilities	818,182	972,254
Non-current liabilities		
Provisions	145,255	57,153
Lease Liability	-	159,444
Total Non-Current Liabilities	145,255	216,597
Total liabilities	963,437	1,188,851
Net assets	8,339,773	11,204,899
Equity		
Retained earnings	8,339,773	11,204,899
Total equity	8,339,773	11,204,899

Cash and cash equivalents include \$1,328,551 (2022: \$3,624,627) of ILC funding yet to be applied to activities scheduled for FY2024.

Autism CRC prepared Special Purpose Finance Statements in FY2023 that were subject to external audit.

Appendix 2: Publications 2022-23

Arnold, S. R., Bruce, G., Weise, J., Mills, C. J., Trollor, J. N. & Coxon, K. (2023). Barriers to healthcare for Australian autistic adults. *Autism*. doi: [10.1177/13623613231168444](https://doi.org/10.1177/13623613231168444).

D'Arcy, E., Evans, K., Afsharnejad, B., Milbourn, B., Whitehouse, A. J. O., Bolte, S. & Girdler, S. (2022). The considerations of Australian clinicians when choosing an assessment of functioning tool for children with neurodevelopmental conditions. *Advances in Neurodevelopmental Disorders*. doi: [10.1007/s41252-022-00292-4](https://doi.org/10.1007/s41252-022-00292-4).

Eapen, V., Winata, T., Gilbert, M., et al. (2022). Parental experience of an early developmental surveillance programme for autism within Australian general practice: a qualitative study. *BMJ Open* 2022;12:e064375. doi: [10.1136/bmjopen-2022-064375](https://doi.org/10.1136/bmjopen-2022-064375).

Evans, K., Whitehouse, A. J. O., D'Arcy, E., Hayden-Evans, M., Wallace, K., Kuzminski, R., Thorpe, R., Girdler, S., Milbourn, B., Bölte, S. & Chamberlain, A. (2022). Perceived support needs of school-aged young people on the autism spectrum and their caregivers. *Int. J. Environ. Res. Public Health* 2022, 19(23), 15605. doi.org/10.3390/ijerph192315605.

Hayden-Evans, M., Milbourn, B., D'Arcy, E., Chamberlain, A., Afsharnejad, B., Evans, K., Whitehouse, A. J. O., Bölte, S. & Girdler, S. (2022). An evaluation of the overall utility of measures of functioning suitable for school-aged children on the autism spectrum: A scoping review. *Int. J. Environ. Res. Public Health*, 19(21), 14114. doi.org/10.3390/ijerph192114114.

Huang, Y., Arnold, S. R. C., Foley, K-R. & Trollor, J. N. (2022). Experiences of support following autism diagnosis in adulthood. *Journal of Autism and Developmental Disorders*. doi: [10.1007/s10803-022-05811-9](https://doi.org/10.1007/s10803-022-05811-9).

Huang, Y., Trollor, J., Foley, K-R. & Arnold, S. (2023). "I've Spent My Whole Life Striving to Be Normal": Internalized Stigma and Perceived Impact of Diagnosis in Autistic Adults. *Autism in Adulthood*. 10.1089/aut.2022.0066.

Lilley, R., Lawson, W., Hall, G., Mahony, J., Clapham, H., Heyworth, M., Arnold, A., Trollor, J., Yudell, M. & Pellicano, E. (2022). "Peas in a pod": Oral history reflections on Autistic identity in family and community by late-diagnosed adults. *Journal of Autism of Autism and Developmental Disorders*. doi: [10.1007/s10803-022-05667-z](https://doi.org/10.1007/s10803-022-05667-z).

Lin, P. I., Masi, A., Moni, M. A., Kummerfeld, S. & Eapen, V. (2022). Genetic pathways associated with sleep problems in children with Autism Spectrum Disorder. *Front Psychiatry*. Jul 8;13:904091. doi: [10.3389/fpsy.2022.904091](https://doi.org/10.3389/fpsy.2022.904091).

Mathew, N. E., Mallitt, K. A., Masi, A., Katz, T., Walker, A. K., Morris, M. J. & Ooi, C. Y. (2022). Dietary intake in children on the autism spectrum is altered and linked to differences in autistic traits and sensory processing styles. *Autism Research*. Aug 26. doi:10.1002/aur.2798.

Montgomery, A., Masi, A., Whitehouse, A., Veenstra-VanderWeele, J. & Shuffrey, L., Shen, M., Karlov, L., Uljarevic, M., Alvares, G., Woolfended, S., Silove, N., & Eapen, V. (2023). Identification of subgroups of children in the Australian Autism Biobank using latent class analysis. *Child and Adolescent Psychiatry and Mental Health*, 17(27). doi.org/10.1186/s13034-023-00565-3.

Muniandy, M., Richdale, A. L. & Lawson, L. P. (2022). Coping-resilience profiles and experiences of stress in autistic adults. *Autism Res*. 15(11), 2149-2166. doi: [10.1002/aur.2817](https://doi.org/10.1002/aur.2817).

Richdale, A. L., Chetcuti, L., Hayward, S., Abdullahi, I., Morris, E. & Lawson, L. P. (2023). The impact of sleep quality, fatigue and social wellbeing on depressive symptomatology in autistic older adolescents and young adults. *Autism Research*. doi.org/10.1002/aur.2899.

Webster, A., Bruck, S. & Saggars, B. (2022). Supporting self-determination of autistic students in transitions. *Research in Developmental Disabilities*, 128, Article 104301, doi.org/10.1016/j.ridd.2022.104301.

Yap, C. X., Henders, A. K., Alvares, G. A. et al. (2023). Interactions between the lipidome and genetic and environmental factors in autism. *Nat Med* 29, 936–949. doi.org/10.1038/s41591-023-02271-1.

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Arnold, S., Higgins, J., Weise, J., Desai, A., Pellicano, E. & Trollor, J. (2022). Investigating autistic burnout #AutBurnout: Final Report. Autism CRC. autismcrc.com.au/knowledge-centre/reports/autistic-burnout

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Appendix 3: Resources developed 2022-23

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Appendix 4: Conference presentations 2022-23

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- Chamberlain, A., D'Arcy, E., Whitehouse, A. J. O., Hayden-Evans, M., Girdler, S., Milbourn, B., Bölte, S. & Evans, K. (2023). Reliability and acceptability of the Vineland-3 for Australian children and youth with neurodevelopmental conditions [Poster]. International Society for Autism Research 2023 Annual Meeting, 3-6 May. International Society for Autism Research.
- Chamberlain, A., D'Arcy, E., Whitehouse, A. J. O., Wallace, K., Hayden-Evans, M., Girdler, S., Milbourn, B., Bölte, S. & Evans, K. (2023). Reliability, validity and acceptability of the PEDI-CAT with ASD scales for Australian children and youth on the autism spectrum [Poster]. International Society for Autism Research 2023 Annual Meeting, 3-6 May. International Society for Autism Research.
- Evans, K., Hayden-Evans, M., Vinci, B., Chamberlain, A., D'Arcy, E., Whitehouse, A. J. O., Girdler, S., Bölte, S. & Milbourn, B. (2023) Strengths, functioning and support needs from the perspective of autistic adults in Australia [Poster]. International Society for Autism Research 2023 Annual Meeting, 3-6 May. International Society for Autism Research.
- Evans, K., Whitehouse, A. J. O., D'Arcy, E., Hayden-Evans, M., Wallace, K., Kuzminski, R., Thorpe, R., Girdler, S., Milbourn, B., Bölte, S., Chamberlain, A. (2023) Perceived support needs of young people on the autism spectrum and their caregivers [Poster]. International Society for Autism Research 2023 Annual Meeting, 3-6 May. International Society for Autism Research.
- Gatfield, O., James, B., Bartz, A., Clapham, H. & Mangan, C. (2022). Respectful co-design with the autistic community: the Self-Advocacy project. Australasian Society for Autism Research Conference, 28-29 November. Australasian Society for Autism Research.
- Haar, T., Pellicano, E., Brownlow, C., Heyworth, M., Lawson, W., Poulsen, R., Hall, G. & Reinisch, T. (2023). What are the common issues and motivations discussed when autistic people, family members and professional come together to talk about priorities for autism research? It Takes All Kinds of Minds, 13-14 March, 2023 Edinburgh.
- Lawson, L. P., Richdale, A. L., Chalmers, A., Uljarevic, M., Morris, E. M. J., Arnold, S. R. C. & Trollor, J. N. (2023). Transdiagnostic pathways to understanding anxiety and depression in autistic adolescents and adults [Poster]. International Society for Autism Research 2023 Annual Meeting, 3-6 May. International Society for Autism Research.
- Montgomery, A., Masi, A., Whitehouse, A., Veenstra-VanderWeele, J., Shuffrey, L., Shen, M., Karlov, L., Uljarevic, M., Alvares, G., Woolfended, S., Silove, N. & Eapen, V. (2022). Identification of subgroups of children in the Australian Autism Biobank using latent class analysis. Australasian Society for Autism Research Conference. 28-29 November 2022. Australasian Society for Autism Research.
- Muniandy, M., Richdale, A. L. & Lawson, L. P. (2023). Stress and wellbeing in autistic adults: Exploring the moderating role of coping [Poster]. International Society for Autism Research 2023 Annual Meeting, 3-6 May. International Society for Autism Research.
- Richdale, A., Morris, E., Chetcuti, L., Hayward, S., Abdullahi, I., & Lawson L. (2022) Sleep, fatigue and depression in young autistic adults. Australasian Sleep Association.
- Rumsa, S., Girdler, S., Whitehouse, A. J. O., Chamberlain A., D'Arcy, E., Hayden-Evans, M., Milbourn, B., Afsharnejad, B., Lee, E., Tan, T., Bölte, S. & Evans, K. (2023). Developing a character strengths profile of Australian autistic adolescents [Poster]. International Society for Autism Research 2023 Annual Meeting, 3-6 May. International Society for Autism Research.
- Simpson, K. & Adams, D. (2023). Environmental factors and supports for school participation in students on the autism spectrum. Nordic Network on Disability Research Conference, 10-12 May. Nordic Network on Disability Research.
- Simpson, K., Stainer, M. & Adams, D. (2023). It's more than a score: Describing participation profiles in autistic children and adolescents [Poster]. International Society for Autism Research 2023 Annual Meeting, 3-6 May. International Society for Autism Research.
- White, J., Black, M., John Williams, P. & McGarry, S. (2023). "Let them show what they can do": Parents' perspectives on strength-based practices for autistic high school students [Poster]. International Society for Autism Research Conference, 3-6 May 2023, Sweden. International Society for Autism Research.
- White, J., McGary, S. & Black, M. (2022). The lived experience of strength-based practices in secondary school: From the voice of autistic adolescents. Australasian Society for Autism Research Conference. 28-29 November 2022. Australasian Society for Autism Research.
- Yap, C. X., Alvares, G. A., Henders, A. K., Giles, C., Huynh, K., Nguyen A., Wallace, L., McLaren, T., Yang, Y., Hernandez, L. M., Gandal, M. J., Hansell, N. K., Wright, M. J., Visscher, P., Dawson, P. A., Dissanayake, C., Eapen, V., Heussler, H. S., Whitehouse, A., J. O., Meikle, P. J., Wray, N. R. & Gratten, J. (2022). Lipidomics captures genetic and environmental complexity in neurodevelopment and autism, with convergence between sleep problems and poor diet. World Congress of Psychiatric Genetics 2022.

Appendix 5: Glossary

ADAG	Assessment and Diagnosis of Autism Guideline / National Guideline for the assessment and diagnosis of autism in Australia
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
ASfAR	Australasian Society for Autism Research Conference
Aspect	Autism Spectrum Australia
ATSI	Aboriginal and Torres Strait Islander
Autism SA	Autism South Australia
CALD	Culturally and Linguistically Diverse
CEO	Chief Executive Officer
CFO	Chief Financial Officer
CRC	Cooperative Research Centre
CRCNA	CRC for Developing Northern Australia
CRM	Customer Relationship Management
CU	Curtin University
DSS	Australian Government Department of Social Services
GCAD	Graduate Certificate in Autism Diagnosis
GP	General Practitioner
GU	Griffith University
IDPA	Integrated Diagnostic Protocol for Australia
IENT	Integrated Employment Success Tool
ILC	Information Linkages and Capacity Building Program
INSAR	International Society for Autism Research
IP	Intellectual property
LASA	Longitudinal Study of Australian Students with Autism
NAS or the Strategy	National Autism Strategy
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
NESA	New South Wales Education Standards Association
Neurodiversity	Concept that neurological differences – such as Autism, ADHD and Tourette Syndrome – are to be recognised, accepted and respected as any other human variation.
NHMRC	National Health and Medical Research Council
NSW	New South Wales
OT	Occupational Therapy
OTA	Occupational Therapy Australia
PhD	Doctor of Philosophy
QED	Queensland Department of Education
QUT	Queensland University of Technology
SACG	Supporting Autistic Children Guideline / National Guideline for supporting the learning, participation, and wellbeing of autistic children and their families in Australia
SACS-R	Social, Attention and Communication Surveillance – Revised
SAS	Secret Agent Society
SASLA	Study of Australian School Leavers with Autism
SAS-WOC	Secret Agent Society Whole-of-Class program
SME	Small and Medium-sized Enterprise
SPA	Speech Pathology Australia
SST	Social Science Translated Pty Ltd – a wholly owned subsidiary of Autism CRC (formerly Social Skills Training Pty Ltd)
UNSW	University of New South Wales
UQ	The University of Queensland
UTAS	University of Tasmania
UWA	The University of Western Australia
WHO	World Health Organisation
WMR	Wesley Medical Research



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

Our values



Inclusion

Valuing lived experience



Innovation

Solutions for long-term challenges



Evidence

Truth in practice



Independence

Integrity through autonomy



Cooperation

Capturing opportunities together