

Autism CRC Research Update

Spring 2016



Transforming the lives of people living with autism across the lifespan.

In this edition...

Making **Peer Research**
Work

Behavioural surveillance
of infants

Social robotics clubs **helping**
all students

Research Priorities Survey –
results released

Research Priorities Survey: Results released

Who took part:

50 adults on the
autism spectrum

88 people living
with autism

20 professionals

Over 90% of participants
were **female** with the
most common age
group being **35-49 years**

Top three priorities:

1. therapies, management and issues related to anxiety and 'coping', and development and behaviour,
2. understanding autism, diagnostic criteria and practices, and
3. educating children on the spectrum, teachers and schools.

Autism CRC has released the results of our first Research Priorities Survey which was conducted at the end of 2015.

The study aimed to identify autism research priorities that might lead to improvements for the lives of people on the autism spectrum and the age group/s that research should focus on.

Analysed by a team which included autistic reviewers, the three top priorities broadly align to the three core CRC Research Programs: The Early Years, The School Years and Adulthood.

"Autism CRC undertook an extensive stakeholder engagement process in developing our current eight-year research plan under the Cooperative Research Centre Programme. While we continue to shape this plan to ensure quality, targeted outputs, further stakeholder engagement is necessary to ensure our resources focus on the research that will have the most impact for the autism community," said Autism CRC CEO, Mr Andrew Davis.

Planning and initiatives are underway to ensure Autism CRC builds on this eight-year plan to secure the necessary capacity and resources to sustain our unique collaborative research organisation into the future.

"While this survey involved a small sample, it is an important step in establishing Australian priority research needs, identified and agreed by our key stakeholders," said Mr Davis. "We look forward to progressing our research planning at our annual Participant Day in Perth on 7 December."

Autism CRC will continue to engage widely with stakeholders including the autism community, service providers and government to ensure our research investment is targeting the priority needs of the community.

Visit the website to find the full report providing a summary of the findings of the survey autismcrc.com.au/research-priorities





From the CEO

Welcome to the Spring 2016 edition of the Autism CRC Research Update **Mr Andrew Davis, Autism CRC CEO**

Autism CRC aims to transform the lives of the autism community through research that provides practical and tangible outputs that benefit the community.

Critical in achieving this aim is involving individuals on the autism spectrum throughout the research process – in the development of our research agenda and through all stages of planning implementation, reflection, dissemination and provision of feedback. In this issue, a range of resources are highlighted, developed to support researchers and the autism community to participate meaningfully in peer research. This is an important step in building research capacity and we will continue to work with the autistic community to provide opportunities to put these skills into action.

Equally critical in achieving our goal is to ensure research outputs are translated into resources, interventions and tools which can be used by

individuals on the spectrum, their families and the professionals who support them.

In the 2016 Investment Round, three existing projects were provided investment to translate evidence-based research outputs into products. This includes an online tool to support teenagers to successfully transition into post-school life, a dynamic eLearning web portal for educators to access the tools and resources developed through the Education Research Program, and a project to promote the dissemination and use of Health Hub resources for adults and health care professionals.

Finally, we must continue to ensure our unique collaboration has the expertise and vision to make our ambitious goal a reality. This quarter, we welcomed the I CAN Network as a participant within Autism CRC. I CAN will support the development and dissemination of CRC outputs through their work in mentoring young people on the spectrum and educating the community on autistic strengths.

Autism CRC has expanded our collaboration with Aspect, through its role in delivering the Commonwealth Positive Partnerships program. This collaboration will extend the reach of CRC projects in our Education Research Program beyond the current CRC Programme. With a focus on CALD and Indigenous communities, along with rural and remote regions, working with the Positive Partnerships program will facilitate the broader dissemination and implementation of best practice outputs in supporting students on the autism spectrum.

I look forward to catching up with many of our participants and stakeholders at our annual Scholars and Participant Days to be held in Perth on 6 and 7 December, ahead of the ASfAR Conference.

Our collaboration is a world first. By bringing together the right people, both nationally and internationally, and ensuring the voice of the lived experience is at the centre of our research, we will continue to deliver high quality research outcomes that make a difference in the lives of the autism community.

Dr Renae Beaumont, developer of the Secret Agent Society (SAS) Social Skills Program, was recently invited to speak at TEDxUQ. The event theme was Future Frontiers featuring pioneers of ground breaking research.



Developed as part of her PhD in Clinical Psychology, SAS uses fun, spy-themed games and activities to help children feel happier, calmer and braver. Multiple research evaluations have demonstrated the effectiveness of SAS in improving children's emotion regulation and social skills in clinics and school settings.

Visit sst-institute.net to learn more.

Making Peer Research Work – a range of resources launched!

Autism CRC is committed to building research capacity within the autism community and to enhance the skills of researchers to partner with people on the spectrum and their families to co-produce research.

Involving individuals on the spectrum and their families in research:

- ensures that issues important to the autistic community are identified and prioritised;
- supports the dissemination of research findings;
- helps to translate research findings into real world practice where they are utilised; and
- ensures that resources focus on research that has benefit for and impact within the autistic community.

Inclusive Research Practice Guides and Checklists Version 2

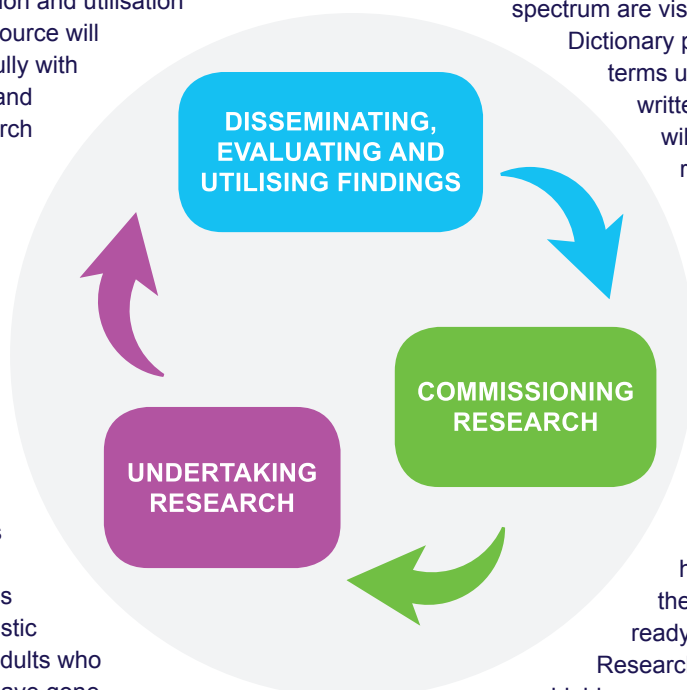
These step-by-step guides and checklists will support researchers and the autistic community to work together as peers. The second version provides further guidance for researchers in working with people on the spectrum in the dissemination, evaluation and utilisation of findings. This practical resource will assist in engaging meaningfully with individuals on the spectrum and promote higher quality research outcomes.

Future Leaders Program Evaluation

A research project is underway led by Ms Tori Haar, to quantify the impact of the Future Leaders Program held in conjunction with APAC 2013. With a focus on autistic strengths and autistic identity, many of the young adults who participated in the program have gone on to achieve great success in their chosen fields while becoming advocates for autism acceptance. The research will inform future leadership and capacity building programs that take the best features of the inaugural 2013 Future Leaders' training, and embed research and evaluation to shape their evolution.

Visual Dictionary of Research Terms

Australia's first Visual Dictionary of Research Terms, co-produced with autistic adults, has also been launched. The Visual Dictionary was one of the first projects that Research Academy members participated in alongside CRC researchers. Because some individuals on the spectrum are visual learners, The Visual Dictionary presents common research terms using illustrations as well written information. It is hoped this will enhance understanding of research terms and provide a more accessible resource to promote peer research.



Research Academy Report – second workshop announced for 2017

An evaluation of the Australian-first Researching Autism Together workshop has been released. Graduating the first cohort of peer research ready adults on the spectrum into our Research Academy, the workshop was highly successful with both the participants and researchers leaving with a renewed respect for each other's skills and expertise. Plans are now underway to run the second Research Academy workshop in 2017. The workshop is being developed based on the findings of the report to ensure the course provides the most effective foundation for co-production of research.

Visit autismcrc.com.au/peer-research to find these resources.

Social Robotics Clubs improve school engagement for all students

An evaluation of Social Robotics Clubs has demonstrated the benefits of inclusive activities in mainstream schools. A resource has been developed to provide teachers with a step-by-step guide to establish clubs in their own school.

In a collaboration between teachers at Brisbane Catholic Education and researchers at The Queensland University of Technology, a research study has revealed that inclusive activities with peers increased social connections, teamwork skills and academic engagement for students on the autism spectrum.

Part of the Education Research Program, the study evaluated how Social Robotics Clubs can support students in mainstream schools in building social networks, particularly those on the autism spectrum.

The Clubs have been running in Brisbane Catholic Education schools for 3 years. Inclusive Education Officer, Mr Nello Raciti, said that teachers had observed improved classroom engagement by the autistic students in Grade 7 and 8 who had attended the Clubs.

“It is so important for children to develop social relationships and positive school engagement in early high school.

“We knew the students were benefitting from attending the Clubs. However, this research study has allowed us to identify the specific strengths of the program and transfer these strategies into mainstream inclusive classrooms,” said Mr Raciti.

To further support teachers and the generalisation of skills learned in the Club, the researchers have developed a manual and resource kit that is accessible to teachers across Australia and helps to support their implementation of the robotics programs within their individual school context.

“Teachers working in the Social Robotics Clubs have assisted classroom teachers in capturing and generalising the learning that occurred within the Clubs and further extend them to other contexts within the school environment,” said Mr Raciti.

The students in the Clubs developed a larger potential friendship network and stronger friendships, and improved motivation and engagement in school work. The Clubs were perceived very positively by students, parents and teachers.

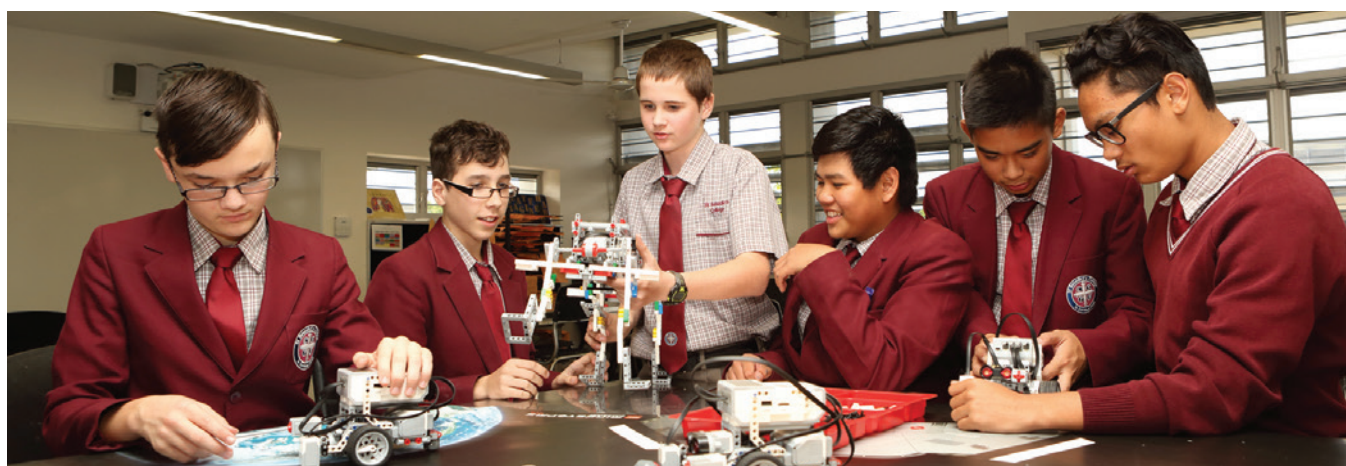
Lead researcher, Dr Beth Sagers from The Queensland University of Technology said that establishing and maintaining positive peer relationships is challenging for any student, particularly for autistic students, and can lead to poor academic engagement.

“Students on the autism spectrum have a much higher rate of exclusion than typically developing peers as their social and academic needs are often not well understood or supported,” said Dr Sagers.

“*This research has shown that socially inclusive activities that focus on the strengths and interests of those on the spectrum, such as the Social Robotics Clubs, can benefit both the students on the spectrum and their peers.*”

Autism CRC aims to provide evidence-based interventions that support students on the autism spectrum and enhance inclusive capacity and practice in classrooms and whole school communities.

Visit autismcrc.com.au/robotics-clubs to download the resource kit and read the evaluation of the program.



Earlier identification of autism

Autism CRC investment in translating the revised Social Attention and Communication Surveillance (SACS-R) program has seen over 500 primary health care professionals trained to identify early behavioural signs of autism.

Developed by Dr Josephine Barbaro from La Trobe University, SACS-R is an early detection program implemented as part of the routine assessments of infants at 12, 18 and 24 months of age.

“On average, children in Australia are currently diagnosed with autism after four years of age. Training primary health care professionals in SACS-R ensures children who are showing early signs of autism can be referred for further assessment,” said Dr Barbaro.

“SACS-R has been incredibly accurate in identifying the majority of children showing early signs of autism or other developmental delays. These children are able to access targeted intervention much earlier which is so important in order for them to reach their full potential.”

An evaluation of over 14,000 infants and toddlers who were monitored by Maternal Health Nurses in Victoria as part of the SACS-R has provided further evidence of the efficacy of the program.

“Of the 2% of children in this group referred as showing early signs of autism, 81% are meeting criteria for a diagnosis of autism. The remainder have either a language and/or developmental delay,” said Dr Barbaro.

“These results strongly replicate the evaluation of the first SACS implementation undertaken between 2006-2008*.”

The evaluation also revealed that SACS-R has been very well received by nurses with the majority reporting it has had a positive effect on their practice.

“An increase in understanding of autism in the health profession, along with a more accessible training format has enhanced the sensitivity of the program. Nurses feel confident in monitoring and referring children which has supported the application of the program.”

In a collaboration between the University of Tasmania, La Trobe University and Autism CRC, a state-wide implementation of SACS-R is now underway in Tasmania.

Every child in the state will be assessed at their 12 and 24 month routine check-ups. While the methodology will remain the same, nurses in the southern region of Tasmania will reinstate an 18 month check-up as part of the project.

“More than 6,000 children will be monitored by primary health care nurses as part of the SACS-R over a two-year period. Reinstating the 18 month check for one cohort will help us to compare the average age of children showing early indicators of autism who are referred for further assessment.”

The highly successful implementation of SACS-R is part of a range of studies which have been commissioned as part of the Autism CRC Diagnosis Research Program. Results of these studies will help to create a national, standardised, accurate diagnostic protocol that enables earlier and more accurate diagnosis of autism.

*Barbaro, J., & Dissanayake, C. (2010). Prospective identification of Autism in infancy and toddlerhood using developmental surveillance: The Social Attention and Communication Study (SACS). *Journal of Developmental and Behavioral Pediatrics*, 31, 376-385.



Partnership to support more young adults on the autism spectrum



Autism CRC is pleased to announce a formal partnership with the I CAN Network, ensuring individuals on the spectrum continue to influence and guide the Australian research agenda.

The I CAN Network is Australia's first social enterprise founded by people on the autism spectrum. The Network runs an innovative suite of programs in Australian schools, universities, TAFEs, businesses and communities based on mentoring programs run by people on the spectrum.

Chief Enabling Officer, Chris Varney said this gives the Network a unique position and perspective in the education and advocacy sector.

"Our experience allows us to promote the autistic voice in affairs or projects that impact people with autism and encourage their direct involvement in these."

I CAN's work in mentoring young people on the spectrum and educating the community on the strengths of autism aligns with Autism CRC's vision to build capacity in schools, workplaces and the greater community to provide an inclusive and empowering environment for people on the spectrum.

The collaboration with Autism CRC will help to further the autistic voice in research, education and advocacy in Australia.

"Joining the CRC and I CAN Network is another step in advancing the place of Australians on the spectrum. In this partnership, we bring together an unprecedented

research platform on autism and the first national social enterprise founded by autistics," said Chris.

"The I CAN Network is hand-in-hand with the CRC on a progressive research agenda. It's so important that this research opportunity embraces the voices and leadership of autistics. The I CAN Network is committed to helping the CRC achieve that."

Joining over 50 service providers, research organisations, industry members and autism community organisations, the I CAN Network is a valued new Participant in the world's first collaborative research effort focused on autism across the lifespan.

Secret Agent Society Training Dates for Semester 2 2016.



SOLVING the MYSTERY of SOCIAL ENCOUNTERS®

LOCATION	TRAINING EVENT	DATES	REGISTRATION CLOSES
Melbourne	SAS Two-day Facilitator Training	3-4 Nov	7 Oct
Sydney	SAS Two-day Facilitator Training	15-16 Nov	21 Oct
Brisbane	SAS Two-day Facilitator Training	29-30 Nov	4 Nov
Perth	SAS Two-day Facilitator Training	5-6 Dec	11 Nov





SAS Trainers can also come to your workplace. Contact the team to host a professional development event for your organisation, school or local network. Visit sst-institute.net for more information.

Find out more

There are many ways for you to get involved with Autism CRC.

Visit the website for news, research outcomes and ways to get involved with Autism CRC.

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