

# Autism CRC Research Update

Summer 2015/16



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

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## New Partners for Autism CRC

Autism CRC has welcomed Amaze, The Autistic Self Advocacy Network of Australia and New Zealand and Dr Wenn Lawson as new partners, joining 50 Participants across Australia, and internationally, working together to transform the lives of people living with autism.

As the first national collaboration between industry and research organisations in autism, Autism CRC continues to engage with partners across Australia and internationally to ensure its unique network has the necessary range of expertise and experience to develop and translate research into strategies, interventions and products that make a real difference in the lives of those on the spectrum.

“Our new partners strengthen our national program and ensure the voices of the lived experience are at the centre of all we do - informing research need, conduct, evaluation and translation,” said Autism CRC CEO, Mr Andrew Davis.

### About our new Participants:

**Amaze** is the peak body for people on the autism spectrum and their families in Victoria. Since 1967, Amaze has given information and support to people on the autism spectrum, their families, professionals, government and the community. Today it continues to provide information and also raises awareness and builds understanding of autism to bring about positive change to improve the lives of all people on the autism spectrum and their families.

[www.amaze.org.au](http://www.amaze.org.au)



**The Autistic Self Advocacy Network of Australia and New Zealand (ASAN AUNZ)** is run by Australian and New Zealander Autistic people, for Autistic people. It is part of the international autism advocacy network. ASAN AUNZ understands that Autistic citizens are capable of contributing to society and enriching the lives of their families and communities. ASAN is committed to enable Autistic citizens to achieve their full potential in society.

[www.asan-au.org](http://www.asan-au.org)



**Dr Wenn Lawson** is a psychologist specialising in training for autism spectrum conditions for over 20 years. As a researcher, an author (of more than 12 books), conference speaker, seminar presenter and university lecturer, Dr Lawson is passionate about his work. All of Dr Lawson's work is research based, practical and accessible and all of Dr Lawson's work is presented from the insight of living and working with autism.





## From the CEO

Welcome to the Summer 2015 edition of the Autism CRC Research Update Mr Andrew Davis, Autism CRC CEO

It has been another very busy time at Autism CRC as we come to the end of the 2014-15 reporting period. In this quarter, our Scholar and Participant Days were held, key initiatives such as the Research Academy have come to fruition and we welcomed new partners into the CRC.

In October, we held the first Researching Autism Together workshop, admitting 14 inaugural members into the Autism CRC Research Academy. My sincere thanks to the workshop attendees, the first members of the Academy, and the Autism CRC researchers for everyone's tremendous contributions to the week. I'd also like to thank the Project Team for their innovative work and dedication to making this week-long workshop such a great success.

We welcomed three new Participants into Autism CRC, those being Amaze, the Autistic Self Advocacy Network of Australia and New Zealand (ASAN) and Dr Wenn Lawson. These new participants will bring new perspectives and a wealth of knowledge and expertise to the CRC's work in autism research and its translation to practice.

Autism CRC is also pleased to announce the appointment of Mr Malcolm Mayfield to its Board of Directors. Mr Mayfield brings valuable skills and experience in research and contract administration to the Board. As an individual on the autism spectrum, he will also bring the perspective of the lived experience of autism to our Board.

By the end of 2015, nine of our projects will be completed and the results of these studies will be released shortly thereafter.

It is exciting to see the first project outcomes. The completion of the research phase is an important first step in delivering on our commitment to disseminate evidence-based outcomes and translating these into improved products and programs.

Consistent with this, our next investment round will have a keen focus on translation and utilisation. We will call for proposals for that round in December.

The information gained through our Australian-first longitudinal studies and other projects, along with the input from our partners, will ensure our research is translated to make a practical difference in the lives of people on the autism spectrum and fill gaps in service, policy and practice.

Brisbane chef, Dominique Rizzo, is working with researchers from Autism CRC to evaluate classes designed specifically for adults on the spectrum to learn vital cooking and nutritional skills. These aim to enhance their independence and health. Autism CRC thanks Dominique Rizzo and the volunteer participants and staff from Autism Queensland's Studio G Program.



# Australia's first autism Biobank

Dr Gail Alvares is part of a team of researchers working to establish the Autism CRC Biobank. The first of its kind in Australia, the Biobank will be an asset supporting autism research within both Autism CRC and the broader research community.

Dr Gail Alvares is a Postdoctoral Fellow based in Perth at the Telethon Kids Institute managing projects investigating early diagnosis of autism, as well as the Autism CRC Biobank.

The Biobank will be Australia's largest repository of biological material and donor information about individuals on the spectrum and their families.

"Biobank data will inform one of Autism CRC's core programs aiming to develop a national, standardised, accurate diagnostic protocol that enables the right support to be provided at the earliest possible stage," said Gail.

Completing a Bachelor of Psychology with First Class Honours, Gail received the University Medal at the University of Sydney before continuing her studies with a PhD in Medicine.

"While my PhD did not directly focus on individuals with autism, I'd been working on projects in or related to autism for about five years prior to coming to work in the Biobank," said Gail.

"The position within the CRC, working with Professor Andrew Whitehouse and other leading researchers, was an exciting opportunity to use my skills to be part of such an important research project."

Gail recently represented Autism CRC at a week-long workshop hosted by EU-AIMS in Italy.

"A scholarship was offered by Hoffman-La Roche for an Autism CRC researcher to attend the workshop and it was definitely a highlight of my time with the CRC," said Gail.

*“ It was an intensive week of learning and sharing, and a privileged opportunity to be able to exchange ideas with some of the most prominent people in the field of autism research. ”*

Families who have a child diagnosed with autism between the ages of 2 to 17 years may take part in the Biobank at any of the four sites across Australia.

Stored at the ABB Wesley Medical Research Tissue Bank, the Autism CRC Biobank will be an asset highly sought after by researchers from Australia and around the world.

Visit [autismcrc.com.au/biobank](https://autismcrc.com.au/biobank) to find out more about the Autism CRC Biobank.







# Early literacy skills

A one year innovation project has examined the emergent literacy skills of preschool children on the autism spectrum to determine whether specific early intervention strategies are required.

The Language and Literacy Project Team, led by Dr Marleen Westerveld from Griffith University, is in the final stages of analysing the data collected from 60 four- and five-year-old children on the autism spectrum.

“We know from previous research that about 50% of children with autism struggle to read and the majority of primary school children with autism show difficulties in reading comprehension,” said Dr Westerveld. “It is therefore surprising that very little research has focused on the emergent literacy skills of children with autism.”

Emergent literacy skills serve as the foundation for accurate and fluent reading with comprehension and are typically learned prior to school-entry. They include print related skills such as letter knowledge and phonological awareness that are predictive of later word recognition, as well as meaning

related skills such as vocabulary and story retelling and comprehension ability that are needed for reading comprehension.

“ *In this research project we wanted to gain an improved knowledge of the development of emergent literacy skills in children with autism, prior to school entry.* ”

Preliminary findings show that 50 – 75% of the children do well on print-related tasks of phonological awareness and letter knowledge. In contrast, only 20% of the children performed within the expected range on story comprehension and most children had difficulty retelling a story.

When asked about their home book reading practices, most families reported reading to their child from a very young age and 74% of the families said they read to their child often or very often.

“Taken together these findings indicate that children on the spectrum may show specific difficulties understanding what stories are about,” said Dr Westerveld.

These early results have led to the CRC investing in two further projects. The first will follow the same cohort of children as they finish their first year of formal schooling allowing researchers to measure and identify which emergent literacy skills may serve as predictors of literacy outcomes.

The second project will develop an individualised autism-specific shared book reading intervention for parents and their young autistic children. This strengths-based intervention will aim to foster emergent literacy skills in a context that is part of most family routines.

“Learning to read is just one of many challenges faced by these children. Yet, given that learning to read commences in the early developmental period and is inextricably linked to educational outcomes, there is a strong case for it being given greater priority in early intervention programs for children with autism. Research into emergent literacy is therefore vital to provide an empirical basis to formulate early detection and intervention strategies to improve children’s literacy to support their participation in education, and ultimately facilitate improved long-term outcomes.”\*

The Autism CRC Education Research Program aims to provide the evidence-based, autism-specific strategies to enable children to access the curriculum and school environments and succeed both socially and academically.



\*Westerveld, M. F., Trembath, D., Shellshear, L., & Paynter, J. (2015). A Systematic Review of the Literature on Emergent Literacy Skills of Preschool Children With Autism Spectrum Disorder. *The Journal of Special Education*, early online. doi: 10.1177/0022466915613593

# Building research capacity

Autism CRC held the Australian-first Researching Autism Together Workshop this quarter, graduating the first cohort of peer research ready adults on the spectrum into our Research Academy.

Autism CRC aims to include those with the lived experience of autism in all aspects of the research process. The Researching Autism Together Workshop provided participants with experiential learning in research skills, practice, management and culture to enable their participation as peers in research.

It also provided opportunities for experienced researchers to gain a better understanding about how they

might work together in partnership with people on the spectrum.

Autism CRC Director of Research and Education, Professor Sylvia Rodger said that the workshop was highly successful.

“Our 14 participants came together from all across Australia and we have been overwhelmed by the positive response,” said Professor Rodger.

“Both the participants and researchers left with a renewed respect for each other’s skills and expertise. It was truly one of the most rewarding weeks of my professional life.”

Developed by a range of leading scholars, authors and adults on the spectrum, the Research Academy is a significant step towards meaningful co-production of research within the CRC and beyond. This will lead to higher quality research practices and outcomes.

One participant, Richard Johnson said he was very thankful to be able to be a part of the Autism CRC Research Academy.

“A week of talking research facts, information, methods, design etc. but most of all discovering that in reality there are researchers that want to see us actually autistic people as more than just subjects or participants. More than just something interesting to study,” said Richard.

“It was an opportunity in fact to move to research that asks how we can ensure the best outcomes for quality of life for autistic people. What interventions actually make a difference for their life, rather than the lives of those around them and what are the things we do to support autistics to have the same options and possible outcomes that neurotypicals expect for themselves?”





# APAC15 a great success

The Asia Pacific Autism Conference (APAC) was held in Brisbane in September with almost 1,500 delegates from across Australia and the Asia Pacific.

Jointly hosted by Autism Queensland and the Australian Advisory Board on Autism Spectrum Disorders, APAC15 brought together individuals on the spectrum, their families and carers along with researchers, professionals, policy makers and educators for three days of learning.

Autism CRC was well represented with three dedicated panels focusing on the progress of our research programs in diagnosis, education and adulthood. With a further



14 Autism CRC presentations throughout the conference, the event showcased many of the CRC's research activities.

It was a very successful event and a rare opportunity to share insights and experiences with a range of organisations and individuals.

The next Asia Pacific Autism Conference will be held in Sydney in 2017 with the theme Growing With Autism. While evidence-based support and intervention remains crucial in the early years, APAC17 will have a particular focus on post-school outcomes including employment and health and wellbeing in the adult years.

You can register your interest or nominate a speaker at [apac17.org.au](http://apac17.org.au).



## 2014/15 Annual Report released

Our Annual Report outlines the progress across our three research programs in diagnosis, education and adulthood, including an overview of our activities engaging with individuals on the spectrum, policy makers and other end-users of our research. It also provides information about Autism CRC governance, management and our team of researchers. Download a copy today at [autismcrc.com.au/annual-report](http://autismcrc.com.au/annual-report)



## SAS Training Dates 2016 released soon

### Secret Agent Society Social Skills Program.

Espionage, Technology & Fun! Multiple research evaluations have demonstrated the effectiveness of Secret Agent Society in improving children's emotion regulation and social skills in clinic and school settings.

Training dates for Semester 1, 2016 will be released soon. Visit [sst-institute.net](http://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.

[autismcrc.com.au](http://autismcrc.com.au)

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