

Autism CRC Research Update

Spring 2015



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

In this edition...

Results from the **Educational Needs Analysis**

Federal grant secures further research

Ru Ying's PhD research will help adults on the spectrum

Our **Research Academy** is launched

The results are in!

The Australian-first, **Autism CRC Educational Needs Analysis**, is in the final stages of data analysis.

934 PARENTS 248 EDUCATORS
179 SPECIALISTS 107 STUDENTS

The *Autism CRC Educational Needs Analysis* is a nationwide survey asking participants to identify, from their perspective, the educational needs of students on the autism spectrum within school settings.

"As we analyse the data, we are finding remarkable consistency across all groups," said Project Leader, Dr Beth Sagers.

"All participant groups were in agreement that the key factors influencing participation, engagement and learning of students with autism in educational settings are: anxiety; organising self and thoughts; rigidity to change, and; attention to tasks.

“*The Needs Analysis has helped us to further understand the challenges students face in the classroom and will help us target our interventions to support their academic and social success.*”

The educator, parent and specialist groups all identified a lack of suitable

education and training for staff as a key barrier for providing support for students on the spectrum in schools.

"The Autism CRC research projects aim to support teachers by developing evidence-based interventions that are easy to implement for the teacher, will make a huge difference to a student with autism and ultimately benefit the whole class," said Dr Sagers.

The Project Team have followed up the initial survey results with 40 qualitative interviews to provide further insights into the needs of students and those who support them in schools.





From the CEO

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

Autism CRC has brought together, for the first time, some of the best minds in autism research from across the country, working towards our vision of transforming the lives of people living with autism across the lifespan through evidence-based research.

Importantly, individuals on the spectrum are working with us to define research need and ensure we produce outcomes that will make a practical difference.

We have launched the Autism CRC Research Academy to promote and support peer research. Skilled researchers and people on the spectrum, with the expertise of their

lived experience, will be brought together for the co-production of research.

Our 48 Participants across Australia are working within Autism CRC on our three core Research Programs and we will continue to engage with stakeholders to extend our reach and remain relevant to the needs of the autism community. Our national focus, and engagement with Federal and State Governments, ensures our outcomes are delivered across Australia and beyond.

As our project teams form and perform, it is very exciting to see the progress being made. Autism CRC has now invested in 40 projects across our three Research Programs which is an investment of a nature, scale and purpose not seen before.

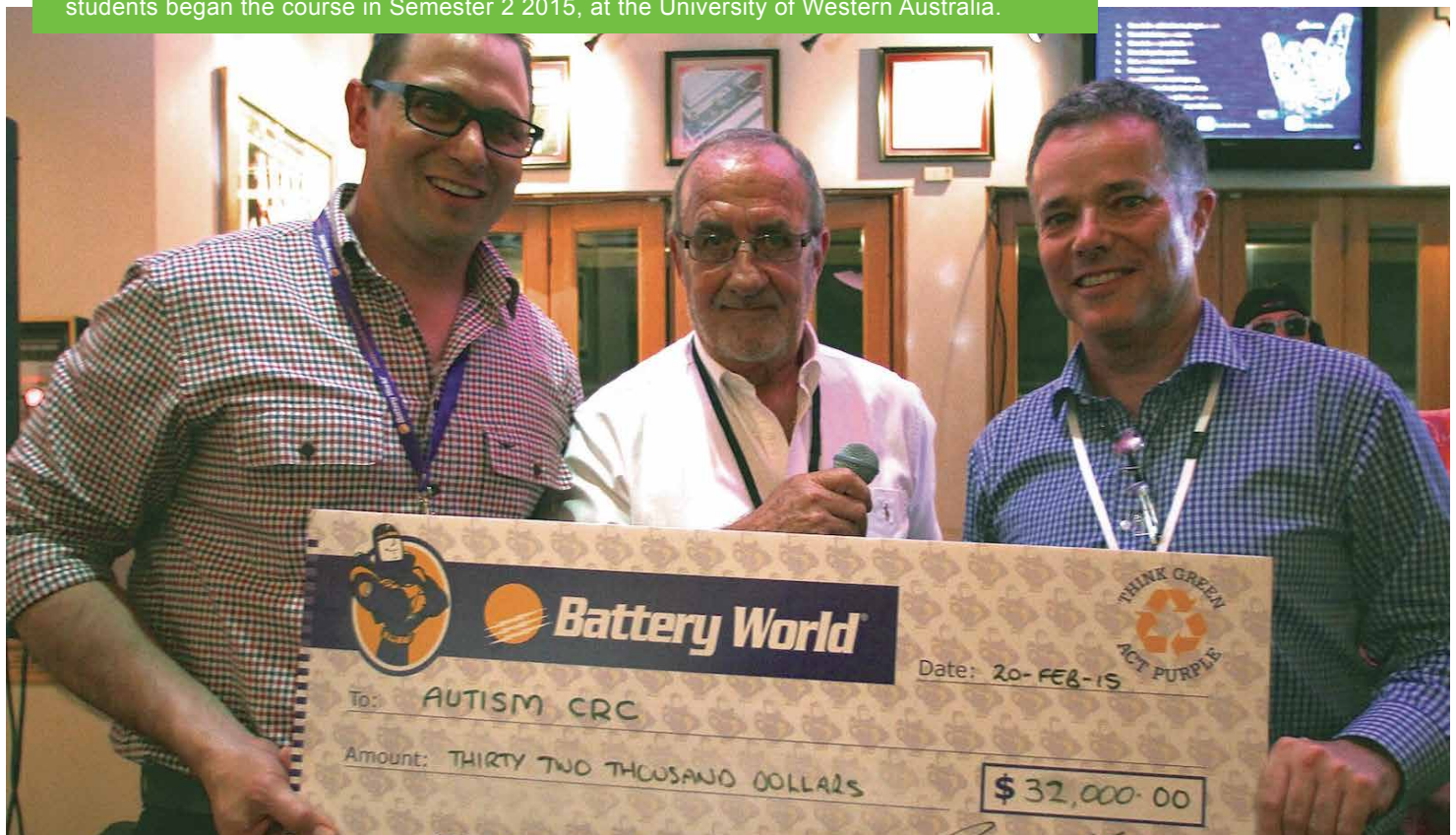
For example, more than 30% of the funds invested to date have been made in our Adult Program, representing the largest research effort focused on transforming adult lives yet seen in Australia.

We look forward to updating you on the progress, outputs and impacts of our Programs as they develop. In the meantime, please enjoy the first edition of the Autism CRC Research Update.

You can read more about **The Research Academy** and the **Researching Autism Together workshop** in this edition of the Research Update.

You can also find out ways you can get involved in Autism CRC and learn more about our research outcomes.

An extremely generous donation from Battery World has allowed us to offer a number of part scholarships for the Autism CRC Graduate Certificate in Autism Diagnosis. The first cohort of students began the course in Semester 2 2015, at the University of Western Australia.





Minister announces investment in Autism CRC

Senator the Hon Mitch Fifield, Assistant Minister for Social Services, recently announced a significant investment in a national pilot study, undertaken through Autism CRC, to assist children transitioning into mainstream primary school.

Autism CRC will undertake a new study to investigate the most effective interventions that enable children to make a positive transition from specialised early intervention settings into mainstream classrooms.

While an increasing number of children on the autism spectrum are included in mainstream school classrooms, the majority still receive their pre-schooling in special education environments or a combination of autism specific and inclusive settings.

“Children on the autism spectrum present with a unique cluster of social, communication and behavioural difficulties, including difficulty adapting to new environments,” said Autism

CRC Director of Research and Education, Professor Sylvia Rodger.

“*The transition between these educational settings represents an important challenge for the children, their families and the schools.*”

“We know that children who have a positive transition to school are likely to engage well and experience academic and social success, but in Australia there are no evidence-based guidelines in place to support children with autism through this transition.”

The research will be undertaken through the six Autism Specific Early Learning and Care Centres (ASELCCs) which are all participants in Autism CRC.

The study will follow children as they transition to school and specifically measure their social, emotional, behavioural and academic progress at school.

Minister Fifield said that Autism CRC will provide the national focus needed to ensure the best outcomes for the study. He said it was important to have a national approach to providing support and developing evidence-based interventions to help children with autism.

Autism CRC will continue to look for new avenues to invest in more research across the lifespan, including government and philanthropic grants, in order to improve the outcomes for people on the spectrum.

Ru Ying's PhD to assist young adults on the spectrum

Ru Ying Cai is currently completing her PhD through Autism CRC in Research Program 3 – Adulthood. Her research project is part of the Longitudinal Study of School Leavers which is examining the period of transition into post school outcomes.

Ru Ying Cai has just completed the first year of her PhD through Autism CRC focusing on emotion regulation in adults on the autism spectrum.

Based at the Olga Tennison Autism Research Centre (OTARC) at La Trobe University, Ru Ying initially completed a double degree in Information Systems and Science (majoring in Psychology and Computer Science) at the University of Melbourne.

After working in IT for some time after graduation, Ru Ying studied her honours year in Psychology.

"During this time, I began supporting two children on the spectrum," said Ru Ying. "I realised that autism research was a big area of need."

Working as a Research Assistant on an OTARC project led Ru Ying to undertake further research with young adults on the spectrum through her PhD.

The Autism CRC Longitudinal Study of School Leavers is measuring education and employment outcomes and factors that may impact on them such as emotion regulation, anxiety, depression, coping, quality of life, and physical health. The aim is to identify the key challenges through this important time of transition into adulthood.

"As part of this broader study, my research will explore the causal relationship between difficulty in emotion regulation, which is a common problem experienced by individuals diagnosed with autism spectrum

condition, and other issues such as depression and anxiety, which are not specific autism traits," said Ru Ying.

"There has been quite a lot of research into the role that IQ or language ability have on outcomes including further education, training and employment opportunities. However, emotion regulation in adults and the effect it has on depression, anxiety and post-school outcomes, is an area that has little research focus."

Ru Ying hopes that as a follow-up to her research, her background in IT will assist in conceptualising and developing an app to capture people's daily emotions.

“By understanding emotion triggers, and how these emotions are managed, I will gain in-depth qualitative data about emotion regulation in autism that hasn't been collected in Australia before.”

"I hope that the data will assist in further research around the variables that impact on outcomes for people on the spectrum, particularly emotion regulation, and indicate where future interventions can be developed to provide support."

"It has been great to do my PhD through the CRC. I not only have the support of my supervisors and the staff and students at OTARC, but additional support through the CRC. The CRC has provided opportunities for PhD scholars to meet and support each other and access to autism experts from right across Australia."

Visit autismcrc.com.au/school-leavers to find out more about the longitudinal study.



Our Progress

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Research Program 1 **DIAGNOSIS**

B C

Aims to develop national protocols to provide earlier and more accurate diagnosis of autism in order to get the right interventions as early as possible.

Research Progress

- The Australian-first Autism CRC Biobank has been established.
- 400+ primary healthcare professionals have been trained in a behavioural surveillance tool to enable earlier diagnosis of autism.
- A family support package is in development for families at the time of diagnosis.
- A research project aiming to identify homogeneous subgroups of children on the autism spectrum is underway to assist in more targeted and more effective early intervention.
- The Graduate Certificate in Autism Diagnosis has commenced.
- A comprehensive survey of 100 clinicians to establish a baseline of current diagnostic assessment processes for autism has been undertaken.



Research Program 2 **EDUCATION**

Aims to provide appropriate environments and programs for students with autism so that they have the best chance of social, behavioural and academic success, and equip teachers and health professionals to manage complex behaviours.

Research Progress

- A six-year study following children on the spectrum and identifying the pathways to academic and social success at school is underway.
- Projects to provide an evidence base to enhance the classroom environment, including the effect of improved acoustics and strategies for helping children transition between tasks, are underway.
- A website is being produced to assist all students in the classroom to develop better writing strategies.
- A range of social-emotional interventions are being developed to help all students recognise and regulate their emotions and deal with bullying.
- A school connectedness program has been developed and will be evaluated to support schools to develop a more inclusive culture.



Research Program 3 **ADULTHOOD**

Aims to enhance opportunities to successfully transition to post school life, participate in higher education, further training and employment, and improve the health and wellbeing of people on the autism spectrum.

Research Progress

- Two landmark four-year longitudinal studies have been launched and are actively recruiting. The first is focusing on the transition from school into post-school life and the second on adults over 25 years of age.
- One completed project identified the most effective methods of recruitment and retention of adults on the spectrum for autism research.
- Two tools have been developed and are being evaluated in clinical trials to assist in career planning and successful long term employment.
- A range of evidence-based interventions (eg. mentoring at university, exploring digital media) are being developed for young adults on the spectrum to assist them to confidently engage in social relationships, tertiary education and community activities.
- The Health Hub has been launched on the Autism CRC website providing access to tools, strategies and techniques to enhance the health and wellbeing of adults on the spectrum.

Workshop building research capacity

Autism CRC is hosting Australia's first Researching Autism Together Workshop for researchers and adults on the autism spectrum to develop the skills needed to do peer research.



AutismCRC
Research Academy

The Researching Autism Together workshop, to be held in October 2015, will train the first members of the Autism CRC Research Academy.

The workshop will enhance the ability of researchers and adults on the autism spectrum to work together as peers who contribute to what questions are asked, how research is carried out, ensuring that surveys and interview questions are "autism friendly" and, helping to interpret research findings.

Peer research, or research co-production, involves researchers and people on the autism spectrum working together as 'peers' to ensure that what is being researched and how it is being researched is relevant to and appropriate for people on the spectrum.

Peer research recognises, and equally values, the skills of researchers and the expertise that people on the spectrum have gained through their lived experience.

Evidence suggests that the benefits of peer research include: improved

research processes and better targeted measures and interventions; better community engagement and knowledge translation; improved trust of, and communication with, researchers; and better directed research funding.

The team, who are developing the curriculum for the workshop, includes adults on the spectrum along with experienced autism researchers.



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of SOCIAL ENCOUNTERS®**

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 for Semester 2 now open.

Visit sst-institute.net for more information.

Computer Game Workshop

LOCATION	DATE	CLOSE OF REGISTRATION
Sydney	14 Oct	18 Sept
Brisbane	4 Nov	21 Oct
Adelaide	18 Nov	28 Oct
Perth	3 Dec	12 Nov

Practitioner Training

LOCATION	DATE	CLOSE OF REGISTRATION
Sydney	15-16 Oct	18 Sept
Brisbane	5-6 Nov	21 Oct
Adelaide	19-20 Nov	28 Oct
Perth	1-2 Dec	12 Nov

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

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The Cooperative Research Centre for Living with Autism (Autism CRC) is the world's first national, cooperative research effort focused on autism across the lifespan.



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