

Autism CRC Research Update

Summer 2016



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

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Australia's First National Guideline for Autism Diagnosis

A major study has been launched to develop Australia's first national diagnostic guideline for autism led by Autism CRC in collaboration with the National Disability Insurance Agency (NDIA).

There is strong evidence, most recently from studies completed by Autism CRC, of substantial variability in autism assessment processes between clinicians, between states and between rural and metropolitan areas. This is leading to delays in diagnosis, misdiagnosis, and inequity in access to services.

Commissioned under a collaboration between Autism CRC and the National Disability Insurance Agency (NDIA), a national guideline will ensure that each individual across Australia has knowledge of, and access to, best practice in autism diagnosis.

The project will be led by Professor Andrew Whitehouse (Director of the Autism CRC Diagnosis Research Program), in conjunction with Clinical Associate Professor John Wray, Professor Margot Prior, Professor Valsamma Eapen and Kiah Evans.

Professor Whitehouse from The University of Western Australia said this project will define a diagnostic process that ensures consistency and accuracy in diagnosis, is feasible to

deliver, and acceptable to those on the spectrum and their families.

"The substantial variability that exists across Australia in autism diagnostic processes causes confusion for families, clinicians and government," said Professor Whitehouse.

"Developing a national diagnostic protocol is a critical step to ensuring consistent and equitable access to autism diagnosis across Australia for both children and adults."

NDIA Deputy Chief Executive Officer, Louise Glanville, said the Agency was committed to co-design and recognised the design of the Scheme must be informed by the lived experiences of participants and people with disability.

"Working with Autism CRC provides the Agency with an opportunity to participate in an exceptional collaboration with the autism community, researchers, practitioners and service providers to improve the diagnosis and early identification and understanding of autism," Ms Glanville said.

While access to the National Disability Insurance Scheme (NDIS) is not

dependent on a diagnosis, the team will be working closely with the NDIA to ensure the guideline aligns with the processes for entry into the NDIS.

"Our aim is that all those on the autism spectrum and their families are given access to best-practice diagnostic processes. Aligning the guideline with the NDIS from the start will provide an integrated pathway to therapies and timely intervention, which will have enormous benefits for those with the lived experience of autism," said Professor Whitehouse.

Autism CRC provides the national capacity to develop and deliver evidence-based outcomes through its unique collaboration with the autism community, research organisations, service providers and government.

The study underway is part of a broader collaboration between Autism CRC and the NDIA in research across the lifespan to support the autism community to access evidence-based services.

Visit our website to find out more and to stay up to date on the progress of this project autismcrc.com.au/diagnostic-guideline



From the CEO

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

This quarter, Autism CRC celebrated three years of achievement and progress across our research programs holding our Annual General Meeting and releasing the 2015/16 Annual Report.

We have now invested in fifty projects across the lifespan with a number of resources, tools and interventions already produced.

The Autism CRC apps4autism Hackathon was also held this quarter, providing a focus for the translation of applicable CRC research outputs into prototype apps. The three-day event brought together teams of autistic adults, developers and designers, researchers and service providers who worked together to develop technology solutions that provide practical benefit to the autistic community.

We will provide further information on the outcome of the Hackathon,

and other technology-enabled solutions being developed within the CRC, in the next edition of our Research Update.

We are now almost half way through our founding eight-year research program under the Cooperative Research Centres Programme. Activities are well underway to extend the scope, reach and life of Autism CRC's work with new partnerships, such as that with the National Disability Insurance Agency, and our work with the Commonwealth Positive Partnerships Program through Aspect as manager of that Program.

Our annual Participant Day in Perth will provide an opportunity to explore areas of need that our collaboration might address, such needs to be tested, supplemented and prioritised in subsequent conversations with our key stakeholders over the next six months.

We welcomed Autism Tasmania and Autism West as the newest participants within the CRC.

We also formed a partnership with Specialisterne Centre Australia, provider of specialist employment services. Partnerships with service providers such as these help us to not only conduct research that meets the needs of the industry, but also aids the dissemination and utilisation of research outputs.

We also welcomed Ms Jacqui Molensen to the Autism CRC team as our Stakeholder Engagement Executive. Jacqui will work with the team to further develop the pathways and initiatives to ensure that our work is meaningfully informed by and benefitting our various stakeholders. Jacqui brings to us expertise in stakeholder management, government relations and philanthropy.

There is good reason to look forward with much excitement and anticipation, while mindful of the significant task yet ahead of us – one which is best addressed with a shared vision and collaboration by all of our partners.



Autism CRC celebrated the achievements of our third year of operation with an exclusive performance by Deep Blue orchestra. The performance was a collaboration between the musicians and the participants and mentors of Autism Queensland's Studio G Program for young adults on the spectrum. Autism CRC acknowledges the Queensland University of Technology (QUT) Vice-Chancellor's Office and both the Faculties of Education and Creative Industries for the generous donation that made the performance possible.

Peer mentoring resources now available for universities

An Australian-first research project to evaluate and manualise a peer mentoring program for university students is now complete. The program, developed at Curtin University, is available to all Australian universities.



Assoc Professor Sonya Girdler, from Curtin University, led the evaluation of the peer mentoring program which aims to support young adults on the spectrum at university.

Transitioning from secondary school into the university environment is a daunting time for all young people but for young adults on the spectrum, university can be a particularly challenging experience.

“A disproportionate number of students on the autism spectrum are not achieving post-secondary qualifications,” said Assoc Professor Girdler.

“Despite having the academic ability, autistic students are not reaching their potential at university.”

There is very little literature on peer mentoring and the benefits of mentoring for university students with most programs focusing solely on training in social skills.

“Secondary school provides a high level of support and guidance which no longer exists in the university environment. Students are expected to develop their own timetables and manage their workload independently.

“Without support, it is a difficult environment for people on the spectrum to navigate. The Peer Mentoring Program offers individualised support from peers to help students on the spectrum set academic and personal goals.”

The Program provides opportunities for students on the spectrum to make friends and to access the support they need as they work towards achieving these goals.

“By overcoming some of the environmental barriers, students on the spectrum can find a place where they can thrive and reach their potential, which helps to develop increased independence and self-advocacy.”

The mentors are predominately students of Occupational Therapy and Psychology who will work with people on the spectrum following graduation. These students are gaining valuable clinical skills and professional training through the Program.

In consultation with the Autism Association of Western Australia, the team at Curtin University has now developed a work experience component of the Peer Mentoring Program.

“People on the autism spectrum have difficulty gaining and maintaining appropriate employment opportunities. We have developed partnerships, both within the University and externally, to offer work experience and paid employment opportunities to the students in the Mentor Program.”

“ We hope this helps to facilitate a successful transition out of university into meaningful careers. ”

A range of resources are available on the Autism CRC website which provide the tools needed to develop a peer mentoring program in other universities including manuals for mentees and mentors. Find these on the website here:

autismcrc.com.au/mentoring

World-first program employs autistic adults in animal care



Autism CRC is collaborating with a number of partners to deliver an innovative employment scheme that will harness the diverse skills of adults on the autism spectrum to further enhance animal care. Autism CRC researchers will evaluate the program.

An initiative of SunPork Farms and Autism CRC, Autism and Agriculture aims to employ and develop career paths for adults on the spectrum in specialist animal care roles.

Individuals on the spectrum have a very high rate of unemployment or underemployment with a labour force participation rate at 34% compared with 54% participation rate for people with disabilities.

Autism CRC CEO, Mr Andrew Davis, said that autistic individuals often have the skills to do the job extremely well, but social and communication difficulties can create barriers to long term employment.

“Through this initiative, we hope autistic adults have a better chance to find a job and develop a career,” said Mr Davis.

“We know adults on the spectrum have key strengths that are of significant benefit to the workplace. SunPork Farms will harness the diverse skills

some autistic individuals have in animal care to provide sustainable employment in the agricultural industry and ultimately enhance the welfare of livestock.”

In collaboration with Specialisterne Australia, a pilot program will recruit eight autistic adults in South Australia and Queensland into paid animal care roles with a view for long term employment.

The program team will adapt and apply existing Specialisterne techniques used in the IT sector, to support candidates through the recruitment, employment and evaluation process in the agriculture sector.

“With appropriate support and training, for both the autistic candidates and SunPork Farms employees, we believe the pilot program will deliver long term benefits to our business,” said Dr Robert van Barneveld, SunPork Farms CEO and Managing Director. “Employing autistic adults will bring a range of different views and the capacity to innovate.

“ *The Autism and Agriculture pilot program has the potential to enhance the human resources capability of the agricultural industry both in Australia and internationally.* ”

Recognising this potential, the South Australian Government has generously contributed \$150,000 towards the pilot via the CRC For High Integrity Australian Pork. The long term benefits for all involved has also attracted investment from corporate partners, despite the initiative only being in its early stages of development.

“Our ultimate goal is to quantify the success of the pilot program, employ more adults on the spectrum in our business and to then offer our insights and experience to other livestock sectors who may also benefit from a more diverse workforce,” said Dr van Barneveld.

Autism CRC Annual Report 2015/16 released

The Autism CRC 2015/16 Annual Report is now available featuring highlights and achievements from our third year of operation. Thank you to everyone involved in making our unique, national collaboration a success.

Autism CRC is committed to fostering and promoting the strengths of autistic people through our research and other initiatives such as our Art Prize which was held this quarter. We received almost 100 pieces of art from across Australia each providing incredible insight into autistic strengths. The two pieces which received the most votes are featured on the cover of the Annual Report.

Download a copy of the 2015/16 Annual Report on our website at autismcrc.com.au/annualreport



School Connectedness Program trialling in schools

Autism CRC has invested in a research program aiming to develop a multi-faceted intervention, working with adolescents, parents, teachers and the school system, which focuses on promoting resilience and connectedness in schools.

Professor Ian Shochet from the Queensland University of Technology is co-leading a major research project (together with Dr Beth Saggars), trialling a school connectedness program to support adolescents on the autism spectrum.

School connectedness is “the extent to which students feel personally accepted, respected, included, and supported by others in the school and classroom”.*

Research in the past ten years has demonstrated the importance of school connectedness in the positive long-term academic and health and wellbeing outcomes of adolescents.

“Approximately 40% of differences in the level of children’s depression at school can be explained by children’s differences in their school connectedness,” said Professor Shochet.**

“While this is an alarmingly high number, it clearly demonstrates the importance of school connectedness in protecting against mental health problems and depression. Challenges in building social relationships and emotion regulation can increase the feeling of disengagement for adolescents on the spectrum.”

“If we harness this protective factor, we can make a significant impact on the development of adolescents in the long-term.”

The Autism CRC School Connectedness project team is collaborating with schools to increase the level of inclusiveness using the Resourceful Adolescent Program

(RAP) and a process known as the Index for Inclusion (provided under the leadership of Professor Suzanne Carrington and Dr Beth Saggars from QUT). RAP was originally developed in 1997 and more recently adapted for autism.

The Program works at three levels, with teachers and administrators, at the family level and at the individual level, to help adolescents on the autism spectrum regulate their emotions better and improve social relationships.

“Improved resilience and emotion regulation helps students on the spectrum to better engage with the school community and have a sense of belonging. This sense of belonging then helps to build further resilience and emotion regulation.”

A parent program, the RAP-P, supports parents to promote resilience and connectedness with their children, while a whole of school framework is implemented in collaboration with researchers and school staff.

“It is crucial to provide individualised support for adolescents on the

spectrum and their parents to enhance school connectedness.

“There is also a voluntary workshop for teachers, the RAP-T. This helps teachers to identify everyday activities and situations which can be used to promote school connectedness and inclusiveness.”

Feedback from parents and adolescents who have already taken part in the program has been very positive.

“We are very pleased with these early qualitative results. The Program will be rolled out into more schools in 2017 in order to refine its delivery and ensure its sustainability across rural, remote and urban schools,” said Professor Shochet.

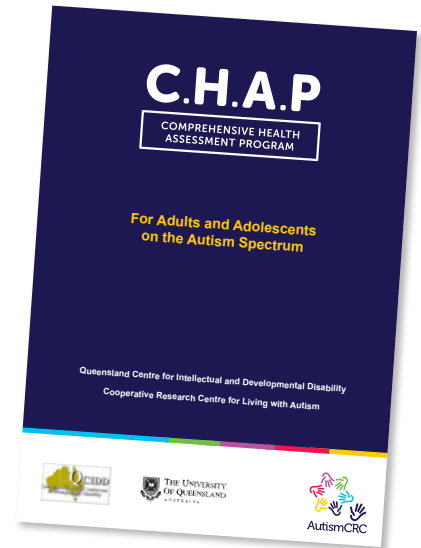
*Goodenow, Carol (1993) The psychological sense of school membership among adolescents: Scale development and educational correlates. *Psychology in the Schools*, 30(1), pp. 79–90.

**Shochet, Ian M., Dadds, Mark R., Ham, David R., & Montague, Roslyn (2006) School connectedness is an underemphasized parameter in adolescent mental health: Results of a community prediction study. *Journal of Clinical Child and Adolescent Psychology*, 35(2), pp. 170-179.



Tool to support adults to improve health and wellbeing

Autism CRC researchers at the Queensland Centre for Intellectual and Developmental Disability (QCIDD), Mater Research Institute at the University of Queensland, have developed a health assessment tool for adults and adolescents on the autism spectrum with intellectual disability.



The Comprehensive Health Assessment Program – Autism (CHAP-A) is currently undergoing trial for adults and adolescents with an intellectual disability who are on the autism spectrum.

The project is being led by Autism CRC Post-Doctoral Research Fellow, Dr Anna Urbanowicz and Professor Nick Lennox.

Originally developed to improve the interaction between GPs and patients with intellectual disability, the CHAP-A is an adapted tool to specifically support those on the spectrum.

“The aim of the tool is to give agency to individuals on the spectrum to improve their overall health and wellbeing,” said Dr Urbanowicz.

“While primarily developed for those with intellectual disability who may have more difficulty articulating their needs, the tool could also be helpful for others on the autism spectrum.”

The adaption involved consulting with adults on the spectrum and their caregivers, health professionals including general practitioners, a psychiatrist and an occupational therapist, and researchers experienced in the field of autism.

“Several randomised controlled trials and observational studies in the primary healthcare setting have demonstrated the beneficial effect for adults with an intellectual disability through improved health promotion and prevention, and the detection of new disease using the CHAP.

“We anticipate the adapted tool will provide the same benefits to those on the spectrum with an intellectual disability.”

The feedback from this trial will inform further adaptation of the CHAP-A with a final version going into a larger trial in 2017.

The CHAP-A is part of a major research program aiming to enhance the health and wellbeing of individuals on the autism spectrum throughout their lives. Resources can be found at autismcrc.com.au/health-hub.



Contact Dr Urbanowicz if you would like to know more about the study or would like to participate in the trial: autism.adulthealth@uq.edu.au

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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Australian Government
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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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