Autism CRC Research Update

Winter 2016

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

In this edition...

Diagnosis practices vary across Australia

Dr Lauren Taylor from the University of Western Australia has led a study that aims to better understand autism diagnosis standards across Australia. Phase 1 has now concluded, with the report released this quarter.

Dr Lauren Taylor has completed a major national survey of health professionals participating in diagnostic assessments as part of the Diagnosis Research Program.

Results from the study have revealed substantial variability in assessment practices between clinicians, between states and between rural and metropolitan areas.

"Anecdotally, we knew that autism diagnoses were performed differently across the country. However, in order to assess the need for changes in the system, we needed to provide an evidence base for any such discrepancy," said Dr Taylor.

"With no established biomarker for autism, currently, diagnosis is solely based on the behavioural presentation of the individual. However, the variability in early indicators of autism, and the considerable behavioural overlap with other developmental disorders, means that autism diagnosis is a complex undertaking."

A comprehensive survey was conducted nationally, gathering information from over 100 clinicians from different disciplines, states and geographical regions.

While clinicians across Australia use a common definition of autism, which is outlined in the *Diagnostic and Statistical Manual*, currently 5th edition (DSM-5), the way that an individual is assessed and diagnosed was found to be very different across the country.

> *"A 'gold standard' assessment for autism is conducted by a multi-disciplinary team and gathers information from several settings," said Dr Taylor.*

"While the report found that some clinicians have a comprehensive diagnostic method that involves an expert team using standardised diagnostic assessments, others were using less rigorous processes."

Autism CRC aims to develop a consistent, national diagnostic protocol in order to ensure children on the autism spectrum are diagnosed earlier and more accurately. This enables early access to tailored support for the children and their families.

Improving training processes is another way in which Autism CRC is promoting more consistent diagnostic standards in Australia through the development of the first Graduate Certificate in Autism Diagnosis.

"Two cohorts of clinicians from across Australia have now graduated from the course which was developed with Assoc Prof Murray Maybery from the University of Western Australia and colleagues from across Australia.

"It is hoped that the specialised knowledge and skills gained from the course will help clinicians to more accurately diagnose autism and to build capacity within their teams, whether they are in public or private practice," said Dr Taylor.

Phase 2 of this study is almost complete with results due to be released later in the year. If you would like to read the full report visit **autismcrc.com.au/diagnosisreport.**

Dr Taylor has recently taken up a postdoctoral position in autism at the University of Oxford in the United Kingdom and we wish her well.

From the CEO

Welcome to the Winter 2016 edition of the Autism CRC Research Update

Mr Andrew Davis, Autism CRC CEO

The 2016 winter season sees Autism CRC reach its third anniversary. Commencing operations in July 2013, the past three years have seen our collaboration form and grow into full operation.

For the first time, perhaps anywhere in the world, we have an effective national collaboration of service providers, researchers, government and, critically, those on the spectrum and their families, working in the field of autism to transform lives and communities for the better.

To date, Autism CRC has invested in forty-three projects across our three core Research Programs addressing needs identified across the lifespan – a breadth of investment not seen before. Ten projects have reached completion, and we are investing resources to further disseminate evidence-based outcomes and to translate outputs into products and services.

Our early work is already having impact here in Australia and internationally.

The results of two major pieces of research were released during this last quarter. Australia's first educational needs analysis surveyed almost 1,500 educators, parents and students on the spectrum. The results from this study will inform both our Education Research Program, confirming the direction and emphasis of that work, as well as policy and program development more broadly.

The second study highlighted significant discrepancies in autism diagnostic practices across Australia and confirmed the need to develop national diagnostic guidelines founded on best practice – consistent with the core objective for our Diagnosis Research Program. You can read more about the results of the study in this edition of the Research Update.

In May, we welcomed Wojciech Nadachowski to our team as Chief Operating Officer. Wojciech brings broad and highly relevant skills and experience to aid our mission to develop practical, evidence-based tools and initiatives. As a key part of his role, Wojciech will work closely with our project teams and participants to deliver the necessary translation and utilisation of CRC outputs.

The capacity of our national collaboration is increasingly being recognised, providing opportunities for additional programs of work along with the resources needed to undertake these. The work undertaken with the support of the Department of Social Services on diagnostic practices in Australia resulted from one such opportunity. Recognising that our first obligation is to continue to deliver on our current Commonwealth program and, through that, enhance our capacity, we continue to pursue such opportunities to enhance the impact of our work for our community. These provide exciting prospects for all our participants.

Thank you for your continued contributions and support for our collaboration and its vision of positively transforming the lives of individuals on the spectrum across the lifespan.

Autism CRC PhD Scholar, Amanda Mazzoni from UNSW, won the Cooperative Research Centres Association's (CRCA) Early Career Researcher Showcase in March.

Three Autism CRC Scholars submitted a video entry. Amanda, pictured with Ms Christine Emmanuel from CSIRO, was chosen as one of five finalists to present at the CRCA Conference where she was voted the overall winner by the delegates.

Technology helping all students in the classroom

Anne Ozdowska is completing her PhD through Autism CRC in the Education Research Program at the Queensland University of Technology. She has developed an app to inclusively support children on the spectrum in the classroom.

The Autism CRC Australian Educational Needs Analysis reported that students on the spectrum found writing tasks one of the most difficult classroom activities. Planning, writing neatly and writing quickly enough were the key issues highlighted by students.

Anne Ozdowska is completing her PhD through Autism CRC, developing an innovative software solution to help children on the spectrum overcome difficulties with written expression while supporting all students in the class.

With a background in IT, Anne has a unique skillset to take on such an ambitious project.

“My son Conrad is on the autism spectrum and like many children on the spectrum he struggles with writing tasks,” said Anne.

“Teachers face the daily challenge of meeting the needs of autistic children, and children with other learning differences, while maintaining an appropriate learning environment for all students.”

“Project POWTREE is designed to help all children improve their persuasive writing regardless of their learning ability.”

The use of self-regulated strategy development and assistive technology have been individually proven to improve written outcomes for students on the spectrum and for typically developing students. This app combines both strategies using the POWTREE method and Texthelp’s Read and Write for iPad writing support technology.

“I wanted to develop assistive technology that ensured children were having fun while learning in a socially inclusive way,” said Anne.

“By creating tools that incorporate evidence-based strategies with video game features, everyone in the class can benefit from the same learning strategies, but they can progress at a pace that’s appropriate for their learning ability, while having fun.”

Like all Autism CRC research projects in the Education Research Program, Project POWTREE has been developed using the Universal Design for Learning framework. This will ensure the evidence-based tools and interventions developed through the CRC can accommodate individual learning differences and styles and support the curriculum.

Project POWTREE is currently being trialled in a small number of mainstream classrooms before undertaking a major trial in Year 4-6 classrooms across Australia later this year. Contact Anne directly if you would like to take part in the trial: **a.ozdowska@hdr.qut.edu.au**

A collaboration between Autism Queensland and The Queensland University of Technology, the POWTREE app is part of a broad research program aiming to assist students on the spectrum with written expression.

If you would like to read the results of Australia’s first national Autism Educational Needs Analysis, visit the website **autismcrc.com.au/ENA-report**.

Building capacity in tertiary settings

Associate Professor Kate Sofronoff from The University of Queensland (UQ) is leading a project aiming to support tertiary students on the spectrum by enhancing the knowledge of university staff.

Assoc Prof Kate Sofronoff is developing a program designed to assist academic and professional staff to better understand and accommodate the needs of tertiary students on the autism spectrum.

There are increasingly greater numbers of students on the autism spectrum attending universities across different faculties. However in many cases, these students are not well understood by academic or professional staff.

“Academic staff generally do not have a great knowledge or understanding of autism. This can lead to staff experiencing student behaviour as challenging and difficult, particularly managing behaviours in team and group environments,” said Assoc Prof Sofronoff.

The researchers aim to develop strategies for the staff to better support students and challenge the belief that it is only the students on the spectrum who must change their behaviours.

“Our experience tells us that when we know why someone behaves in a particular way, we are more inclined to be tolerant and more inclined to try to be helpful and solution focused.

“Through a greater understanding of autism, staff are asked to think constructively about behaviours they find difficult in order to help themselves and the students,” said Assoc Prof Sofronoff.

The first workshop with staff at the Faculty of Engineering at UQ was extremely positive with over 70 participants from across the Faculty. It was led by Assoc Prof Sofronoff and Dr Tony Attwood.

> *“The workshop took instances of behaviours staff described as challenging and provided explanations and examples of why a student on the autism spectrum might think differently and have different priorities - and therefore behave in a particular way.”*

“The initial workshop was successful in helping staff recognise that, from their perspective, the student might have had a valid point, and to give the staff strategies to find a solution. We used role play to demonstrate strategies likely to be successful in the scenarios generated by staff.”

The workshop will be offered again later in the year and evaluated across different faculties at UQ. Materials are in development for an interactive website that will be available for use in any university or workplace setting.

Peer mentoring programs already exist in some universities, such as CRC partners, La Trobe and Curtin University. The research underway at UQ aims to build on this work so that there are a range of evidence-based resources available for university students and staff.

“We want to provide choice for students on the spectrum to decide for themselves what help and type of support they would like to access or participate in. We also aim to include young adults on the spectrum in this process, to help with development of resources and to build capacity for them to help others.

“Importantly, we hope to foster a greater understanding and acceptance of autism by fellow students and academic and professional staff. This is essential for a student on the spectrum to succeed in the university environment,” said Assoc Prof Sofronoff.

Ageing well on the autism spectrum

Led by researchers at the University of New South Wales, Australia's first longitudinal study of autistic adults is collecting data that will improve understanding of life in adulthood for autistic people and support the development of tools and strategies to improve health and wellbeing outcomes.

The Australian Longitudinal Study of Adults with Autism (ALSAA) is a major project in the Adulthood Research Program which aims to understand and improve the health and wellbeing of adults on the autism spectrum.

A first for Australia, there are also very few examples internationally of a study which focuses on the experiences and perspectives of adults on the spectrum.

"There is a lack of understanding of what life is like for autistic adults living in Australia," said Dr Kitty Foley, a lead researcher on the project.

"The needs and supports required for adults on the spectrum are likely to be different from the needs of children or young adults on the spectrum, but there is very little information identifying these needs."

"Data from the longitudinal study will provide an evidence base to develop an improved and clearly articulated service model for people on the spectrum as they age."

To date, 185 adults over the age of 25 and 100 carers have registered to participate in the longitudinal study. Critical to the study are participants who are not on the autism spectrum and who will act as a comparison group.

The study surveys the mental and physical health, employment, behaviour, emotions, coping, memory, friendships and the use of health services of respondents.

"This rich data source will enable us to look at the lifestyle factors which lead to good mental and physical health in the Australian context. Outcomes from the study have the potential to transform service delivery and policy for adults including older adults on the autism spectrum," said Dr Foley.

Autism CRC PhD Scholar, Jane Hwang, is interviewing a sample of participants from the longitudinal study to explore and define the concept of 'ageing well' as an autistic adult from their perspectives.

"Ageing well is an emerging concept that has had increasing scientific focus in recent years however, ageing well on the autism spectrum has not been considered within this concept," said Jane.

Jane's research aims to further explore the experiences of ageing as an autistic adult into adulthood and older adulthood.

"By understanding what ageing well means to an autistic adult, my research can build on the needs identified in the longitudinal study to assist autistic adults to live a happy and healthy life," said Jane.

This study is one of two landmark longitudinal studies being conducted in the Adulthood Research Program within the CRC. The second is following younger adults through the transition from school into higher education, further training and employment.

If you would like to take part in this important study visit **autismcrc.com.au/alsaa**. Researchers are also looking for adults without autism to take part and provide valuable input to the study.

Image caption: (Left to right) Jane Hwang, Project Leader Prof Julian Trollor, Gabriel Nakhl and Dr Kitty Foley.

Australian Biobank Launched

The Hon Sussan Ley MP, Minister for Health, Aged Care and Sport officially launched Australia's first Autism Biobank in March.

The Australian Autism Biobank will contain a detailed phenotypic and genotypic profile of each donor providing a rich and unique dataset of almost 5,000 individuals, developing a valuable asset for Australian researchers and their international collaborators.

Autism CRC Chair, Ms Judy Brewer, said that the Biobank is a highly valuable resource for Australian researchers which has the potential to put them at the forefront of biological discoveries related to autism.

"Autism CRC researchers will use Biobank data to pursue our goal of earlier and more accurate diagnosis of autism. Currently the majority of children are diagnosed after the age of four. We aim to dramatically reduce the age of diagnosis to under two years of age," said Ms Brewer.

"A standardised, national diagnostic protocol will support clinicians to accurately diagnose autism earlier to enable children on the autism spectrum to receive targeted, early intervention."

Autism CRC is a unique, world-first collaboration that has brought together key people, data and research facilities across Australia, and enabled large scale projects such as the Biobank to become a reality.

Donors are contributing data and biological samples to the Biobank through Autism CRC Partners – University of Western Australia, La Trobe University, University of New South Wales and Mater Research. The Queensland Brain Institute, University of Queensland, is processing biological samples prior to their being stored in the Biobank at the ABB Wesley Medical Research Tissue Bank.

If you would like to learn more about participating in the study, visit **autismcrc.com.au/biobank**

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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AutismCRC

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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