

The Australian Longitudinal Study of Adults with Autism (ALSAA)

October 2015 Newsletter

Hello and welcome to the first newsletter from the Australian Longitudinal Study of Adults with Autism (ALSAA),

This year has marked the launch of the ALSAA and we are very excited about the initial fantastic response from the autism community. See our study update on page 2 of this newsletter.

This year, we have had the pleasure to connect with many organisations and individuals on the spectrum. We have established a Research Advisory Network (read more about this network on page 3). Also, we were lucky enough to attend the Asia Pacific Autism Conference in Brisbane where we attended lots of interesting presentations, including presentations from many autistic adults.

Kitty and Jane are excited to be attending Professor Temple Grandin's presentation on 'Autism & My Sensory Based World' in Melbourne this year. Also presenting at this event are Tim Sharp and Jeannette Purkis (Autism CRC Reference Group member and excellent presenter!). If you are attending this event, please come and say hello at our Autism CRC information booth.

Finally, we are still recruiting participants for ALSAA so if you know any autistic adults, carers/family members of adults with autism or neurotypical adults who may like to help us, please pass on our contact information.

We hope you enjoy reading our first newsletter. Please contact us if you have any questions or comments.

Yours sincerely,

Professor Julian Trollor , Dr Kitty Foley and Ms Jane Hwang

**WE ARE STILL
RECRUITING !**

We need your help if you are:

- An adult on the autism spectrum 25 years or older
- Family member/carer of an adult on the spectrum
- A neurotypical adult 25 years or older to participate in our control group

Please contact us if you are interested in participating, or follow this link:

https://autismcrc.au1.qualtrics.com/SE/?SID=SV_1UoHxIKX4MOWRo1

Contact details:

ALSAA Research Team at the University of New South Wales

Phone: (02) 9385 0620

Email: autismcrc@unsw.edu.au

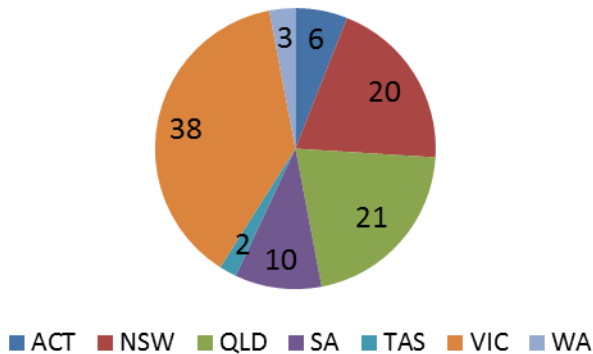


ALSAA Progress

Adults on the autism spectrum

- 99 adults have contacted us to express interest in taking part in this research
- 51 autistic adults have completed their questionnaires online and 8 completed paper questionnaires
- Another 13 carers/supporters of adults with autism and intellectual disability have agreed to complete questionnaires about the health and wellbeing of the adult with autism and intellectual disability
- Participating autistic adults to date are aged between 25 and 79 years, with average age of 41 years.
- Of the 59 people who have completed the questionnaire gender was reported as male for 23 adults (39%), female for 28 adults (47%) and other for 8 adults (14%) (including genderqueer, non-binary, transgender and gender fluid).

Percentage of participants on the spectrum by state



Neurotypical controls

- 50 neurotypical adults have expressed interest in participating in this research
- 19 controls have completed their questionnaire
- Age range of neurotypical controls is 25 to 64 years. Average age is 40 years.
- 41 (82%) females and 9 males (18%)

Carers/Supporters

- 45 carers/supporters have expressed interest in taking part in this research
- 11 carers/supporters have completed their questionnaires
- Carers/supporters are aged 26 to 77 years. Average age is 56 years
- 23 (92%) carers/supporters are female and 2 (8 %) are male

Research Advisory Network

We would like to greatly thank and acknowledge the contribution of our Research Advisory Network. Our Research Advisory Network is made up of autistic adults and carers/family members from all over Australia who are helping us with this research. Many of these adults assisted with the development of the questionnaires for ALSAA. They tirelessly reviewed and provided feedback on the questionnaires in relation to ambiguous language, formatting and overall content. Notably, we would like to acknowledge the significant contribution of Julianne Higgins, Mathew Bennett, Greg Lynn and Mandy Corkill. We are aiming to involve adults on the spectrum at every stage of this research project. If this is something that you may like to be a part of, please contact the research team. We would also like to thank the many organisations who have assisted in advertising and spreading the word about the ALSAA.

Other Research Projects Currently Recruiting

- School leavers longitudinal study – currently recruiting (a) young adults on the spectrum 15 – 24 years (b) their parents and (c) neurotypical young people age 15 – 24 years to participate in a questionnaire based study. Contact: Mirko Uljarevic M.Uljarevic@latrobe.edu.au
- Ageing well as an adult on the spectrum – currently recruiting (a) autistic adults aged 25 years and over, (b) those in care/support roles for adults on the autism spectrum, and (c) disability support workers and healthcare professionals experienced in working with adults on the autism spectrum to participate in interviews and focus groups. Contact: Jane Hwang jane.hwang@student.unsw.edu.au (02) 9385 0623
- Oral health study – currently recruiting adults on the spectrum or their substitute decision makers to participate in a survey about oral health, dental needs and barriers to services. Contact: Anna Urbanowicz a.urbanowicz@uq.edu.au
- You can help develop a tool for employers to create an autism friendly workplace – Currently recruiting a) adults on the autism spectrum 18+ years currently employed or seeking employment; b) their current employers or c) employers about to hire adults on the autism spectrum to participate. Contact Melissa Scott melissa.scott@curtin.edu.au

WHAT'S IN IT FOR YOU?

We value the time and effort that participants put into this research. We understand that is very important for you to see outcomes and actual changes because of this research. We anticipate results from ALSAA will provide invaluable information to services and autistic people about the health and wellbeing of adults on the spectrum. Also, this research will inform the development of different tools and interventions. You can keep up to date with new resources and tools as they become available at the **Autism CRC Health Hub**: www.autismcrc.com.au/healthhub

“The Heath Hub aims to provide information that supports adults to achieve their health and wellbeing goals and aspirations.”



Australian Government
Department of Industry and Science

Business
Cooperative Research
Centres Programme

Research Spotlight

'Respect the way I need to communicate with you' - Research from the United States about how autistic adults experience healthcare

Who: Christina Nicolaidis and other researchers from the United States

What: They wanted to learn about autistic adults experiences with healthcare and their ideas to improve it

What they did: The researchers interviewed 39 autistic adults and 16 people who support autistic adults

What they found: Autistic people and their supporters said that a number of factors impacted their healthcare experiences including:

- Personal/autism related factors, such as communication skills, sensory sensitivities, and slow processing speed
- Provider-related factors, such as providers knowledge about autism, incorrect assumptions about autism, use of accessible language and skill in appropriately involving supporters
- System level factors, such as complexity of the health care system, accessibility of services and stigma

They suggested that more efforts were needed to empower autistic patients, adequately train providers, increase accessibility to healthcare and decrease discrimination.

Reference: Nicolaidis, C., Raymaker, D. M., Ashkenazy, E., McDonald, K. E., Dern, S., Baggs, A., . . . Boisclair, C. (2015). "Respect the way I need to communicate with you": Healthcare experiences of adults with autism spectrum. *Autism*. doi: 10.1177/1362361315576221

Team Member Profile

Name: Jane Hwang

Role: PhD Student - UNSW

Site: NSW

What do you like most about working on the study? It is meaningful to know that I am part of a leading endeavour in a little-researched area with a greatly supportive and able team. I am also enjoying the chance to engage with participants and their families due to the emphasis on inclusive research practice, which is key to all work done by the Autism CRC.

What sort of impact do you hope this study will have in the future? I hope that this study will be able to provide a valuable contribution to our understanding of adults on the autism spectrum beyond the post-school transition years. Having this strong foundational knowledge of the health and wellbeing of adults on the autism spectrum should hopefully well-inform future policy and motivate more concentrated research efforts where needed. I am hopeful that such efforts might be adapted and applied by research teams in other (particularly non-Western) countries, too.



Australian Government
Department of Industry and Science

Business
Cooperative Research
Centres Programme