Australian Longitudinal Study of Autism in Adulthood (ALSAA)

FINAL REPORT

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Australian Study of Autism in Adulthood (ALSAA)

A Longitudinal Study of Australian Autistic Adults aged 25+ years old, 2015 – 2021

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Autism CRC is the world's first national, cooperative research effort focused on autism. Taking a whole-of-life approach to autism focusing on diagnosis, education and adult life, Autism CRC researchers are working with end-users to provide evidence-based outcomes which can be translated into practical solutions for governments, service providers, education and health professionals, families and people on the autism spectrum.

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A note on terminology

We recognise that when referring to individuals on the autism spectrum, there is no one term that suits all people. In our published material and other work, when speaking of adults we use the terms 'autistic person', 'person on the autism spectrum' or 'person on the spectrum'. The term 'autistic person' uses identity first language, which reflects the belief that being autistic is a core part of a person's identity.

Autism Spectrum Disorder (ASD) is diagnostic terminology used by the healthcare sector, and is used in the context of a person being 'diagnosed with Autism Spectrum Disorder'.

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1. Executive summary

Around the time of the commencement of the Australian Longitudinal Study of Autism in Adulthood (ALSAA) in 2015, an autistic researcher commented "We know virtually nothing about what happens to us, autistic people, physically, cognitively, emotionally and socially as we pass through middle and older age" (Michael, 2016, p. 515). The ALSAA has since contributed substantially to international efforts to address knowledge about autism in adulthood. Although a stronger international and Australian research focus on this area has since emerged, significant knowledge gaps remain, with the majority of autism research continuing to focus on genetics and childhood.

The ALSAA was an online survey-based study, which followed autistic and non-autistic adults aged 25 years or older living in Australia over a 2.5-year period. It was conducted between 2015 and 2021 and data was collected at two time points, aligned to funding cycles. The ALSAA was funded by the Autism CRC and led by a project team based at the Department of Developmental Disability Neuropsychiatry (3DN) at UNSW Sydney. Close collaborations occurred with colleagues across several universities. Particularly, the ALSAA design was closely aligned with the Autism CRC's Study of Australian School Leavers with Autism (SASLA), based at the Olga Tennison Autism Research Centre (OTARC), La Trobe University and led by Professor Amanda Richdale. Common data points between ALSAA and SASLA enabled a rich collaboration to emerge with the OTARC team. The combination of the ALSAA and SASLA datasets allowed reporting of results on participants with a broad age range, from 15 to 80 years.

The ALSAA has advanced knowledge in autism in adulthood across a wide range of areas, as well as replicating emerging international knowledge in the Australian context. Particularly, it has highlighted the very high rates of anxiety and depression in Australian autistic adults, with over half of the ALSAA sample meeting clinical cut-offs for depression and for anxiety. Further, despite Australia's advanced healthcare and welfare systems, ALSAA participants experienced significant barriers accessing healthcare, underemployment and underutilisation in the workplace, loneliness, and overall reduced quality of life. The wide range of contributions arising from the ALSAA is exemplified in the numerous publications arising or in train. These include 26 peer-reviewed academic publications; another 5 manuscripts are currently undergoing peer-review, and at least 38 additional manuscripts are in various stages of development. There have been more than 25 academic conference presentations and posters relating to the ALSAA. The ALSAA has supported 6 research student completions with another 5 students underway. The ALSAA and the team's focus on autism in adulthood has also enabled several webinars, book chapters, media outputs and policy submissions.

Additional projects have also arisen from, or been supported by, the ALSAA. These include a project on the oral histories of late diagnosed autistic adults; the development of a quality of life assessment tool specifically for autistic adults; the use of big data to answer questions relating to health and well-being of autistic people; and an investigation of autistic burnout.

Importantly, throughout the ALSAA an inclusive research approach has been employed. Autistic adults have been involved and consulted, co-producing research findings. Involvement has spanned the initial stages of choosing research priorities and research questions, through to the interpretation of results and more recently the involvement of a peer researcher who has co-authored a publication on the definition of autistic burnout.

The ALSAA gathered comprehensive data and we continue to work on projects and outputs as detailed in this report. However, many areas could be examined by others. The UNSW Sydney's 3DN team is open to future collaborations with researchers interested in this area. A databank has been established by the Autism CRC with a defined approach to enable researchers to request access to the data. Unfortunately, a small number of Time 1 participants did not consent for their data to be included in the databank access process. Despite this, the ALSAA is likely to remain a valuable asset. Reflecting the emphasis on lifespan issues in community identified research priorities, the research team wishes to gather further waves of data, but available funding sources are lacking. Future efforts in this area would be further enabled by the establishment of a national registry of autistic individuals, as has occurred in other countries.

2. Background

Autism Spectrum Disorder (ASD) is the formal nomenclature for a condition with core features which include social and communication differences and restricted and repetitive patterns of behaviours or interests. Autism is associated with a wide spectrum of abilities and those on the autism spectrum experience both strengths and weaknesses as part of being autistic. Considered the most common neurodevelopmental difference, it is estimated that 1 in 50 of the US population are autistic (Dietz et al., 2020). The most recent data from the Australian Institute of Health and Welfare estimates autism prevalence at 1 in 150 Australians (Australian Institute of Health and Welfare, 2017), however this is likely a significant underestimate. Our understanding of autism has advanced rapidly in recent decades, with greater understanding of the wider range of presentations of autism than previously realised. This has contributed to a 'lost generation' of autistic adults (Lai & Baron-Cohen, 2015), who were not diagnosed in childhood; many remain undiagnosed or may not even realise that they are autistic.

Around the time of the commencement of the Australian Longitudinal Study of Autism in Adulthood (ALSAA) in 2015, an autistic researcher commented "We know virtually nothing about what happens to us, autistic people, physically, cognitively, emotionally and socially as we pass through middle and older age" (Michael, 2016, p. 515). A systematic review of the preceding 20 years of autism research identified that 94% of studies included youth and children (Jang et al., 2014). In recent years there has been an emerging literature on autism in adulthood, including the establishment of a new scientific journal *Autism in Adulthood* in 2019. However, research funding still lags behind expressed community priorities, with a focus on genetic causes and children (den Houting & Pellicano, 2019). Since the introduction of the Cooperative Research Centre for Living With Autism (Autism CRC), Australia has improved its international standing by bringing a stronger research focus to lifespan issues and research co-production.

The growing body of literature on autism in adulthood highlights the significantly higher rates of physical and mental health conditions and overall increased mortality of autistic adults compared to non-autistic adults (Howlin & Magiati, 2017). Also evident are the barriers experienced by autistic adults in accessing healthcare (Arnold et al., 2020; Nicolaidis et al., 2013). Studies report poorer outcomes in adulthood across a range of indicators, including employment (Hedley et al., 2017), community inclusion and relationships (Henninger & Taylor, 2013; Howlin & Magiati, 2017). Although awareness of these issues is growing, research in these areas remains limited by cross-sectional study designs and relatively young adult samples; the majority of participants are under 40 years of age (Levy & Perry, 2011; Seltzer et al., 2003). The ALSAA has made important

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contributions to the international literature by building understanding of autism in adulthood across a broader age range and variety of topic areas, and by bringing a focus to the experience of being an autistic adult in Australia. Importantly the ALSAA uses a longitudinal design and includes an older group of autistic adults.

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3. Introduction

3.1 What is the Australian Longitudinal Study of Autism in Adulthood (ALSAA)?

The Australian Study of Autism in Adulthood (ALSAA) was an online survey-based study, which established a cohort of autistic and non-autistic adults aged 25 years or older living in Australia. It collected data across two time points, with Time 1 commencing in 2015 and Time 2 commencing November 2017.

The ALSAA was funded by the Autism CRC and conducted by a project team based at the Department of Developmental Disability Neuropsychiatry (3DN) at UNSW Sydney. Close collaborations were established with La Trobe University, Curtin University and the University of Queensland, and these were critical to the ALSAA's success. Particularly, the ALSAA team worked closely with the project team of the Study of Australian School Leavers with Autism (SASLA) team based at LaTrobe University. The SASLA study, also funded by the Autism CRC, focused on autistic school leavers aged 15-25 years old. The two study teams worked to ensure the greatest possible harmony of data points between SASLA and ALSAA; important differences remained given the different population groups and research questions. On many occasions, these common data points enabled ALSAA and SASLA researchers to combine the datasets to report results on a broader sample aged 15 – 80 years.

3.1.1 Aims and objectives

The ALSAA aimed to identify and describe the comprehensive and unique profiles of autistic adults and compare them with adults without autism. These data were intended to support the development of approaches to improve the health and well-being of autistic adults.

Additional specific aims were identified in the development of Time 2 data gathering. These included: identifying changes and predictors of mental health and quality of life of adults on the spectrum with and without intellectual disability; an examination of the stability of autism symptomology overtime; the description of the interval changes and predictors of carer/support person coping strategies, mental health and wellbeing; and an examination of the factors associated with healthy ageing for autistic adults.

In this final report, we indicate that work across all major aims has been successfully completed. However, as is typical for research endeavours, further work is in train focused on autistic adults,

including those with intellectual disability. To ensure maximum benefit to the autistic community, this work will be completed by the 3DN team in good faith beyond the cessation of funding agreements.

3.2 Methods - How did we do it?

The methods employed in ALSAA Time 1 data collection are described in more detail in our Time 1 cohort profile publication (Arnold et al., 2019). Additional detail related to Time 2 data gathering, including the snowball sampling are included below.

3.2.1 Design

The ALSAA is a questionnaire-based, prospective, longitudinal cohort study that gathered two time points approximately 2.5 years apart. The ALSAA was designed using a collaborative process that included researchers, clinicians, autistic adults and other stakeholders. Consultation also occurred with international experts working in similar areas of longitudinal and outcomes studies of autistic adults. The ALSAA used inclusive research processes including autistic adults in the review of research questions, study materials and interpretation of findings.

3.2.2 Recruitment

Participants were recruited from around Australia, largely via promotion of the study through the Autism CRC, and its essential participants. Participants initially completed an expression of interest (EOI) form online or via telephone. We also employed snowballing to boost recruitment and retention in Time 2. Recruitment materials were provided to existing participants, and they were asked to promote the study to their networks, especially via social media.

Once confirmed as eligible (above 25 years old, living in Australia and English speaking), we emailed or posted participants the questionnaire. In the initial EOI form we were also able to collect details such as where they heard about the study, whether they had intellectual disability, where they lived, what their specific diagnosis was if autistic, and whether they would be open to receiving further information about other autism research studies.

In Time 2 data gathering, in addition to gathering follow-up data from Time 1 participants ('Time 2 Follow-up sample'), we also recruited new participants who had not previously participated in Time 1 ('Time 2 Baseline sample'). For Time 2 data gathering we were able to offer incentives to participants, in the form of a quarterly $200 gift card prize draw for those who completed their survey since the last prize draw round. In the final prize draw round we selected randomly from all

those participants who had completed the ALSAA but had not yet been included in a prize draw. Prize draw winners were announced in the quarterly participant newsletters.

3.2.3 Who participated?

Data were collected from autistic adults, carers / family members of autistic adults, and a comparison group of adult community members who were not on the autism spectrum. Data were collected via three comprehensive surveys:

1.   Self-report;

2.   Informant-report (i.e. reporting on behalf of an autistic person);

3.   and Carer / family member self-report.

As can be seen in Table 1, 251 autistic adults completed Time 1 and 157 completed Time 2 Follow-up. A total of 146 non-autistic adults participated in Time 1 of the study and 71 also completed the Time 2 Follow-up survey. Additionally, 102 Family Members and/or Carers completed Time 1, with 57 completing Time 2 Follow-up. A total of 68 Informant surveys were completed. At Time 2, an additional 247 autistic adults joined the study completing the Time 2 baseline, as well as 45 non-autistic adults, 40 carers, and 4 informant report responses. We had a total of 877 participants in the entire study, providing 1184 unique observations across the two time points of data gathering.

Table 1: Participant Completions

	Self-Report Autistic	Self-Report Controls	Carer	Informant	Total
Time 1	251	146	102	42	541
Time 2 Follow up	157	71	57	22	307
Time 2 Baseline	247	45	40	4	336
Total cross-sectional Time 1 baseline	498	191	142	46	877
Total combined Time 2 sample	404	116	97	26	643
Total data points gathered	655	262	199	68	1184

Of note is that samples can be combined across Time 1 and Time 2 Baseline to create a total cross-sectional baseline sample. Alternatively, Time 2 Follow-up and Time 2 Baseline data can be combined for cross-sectional analysis of a total Combined Time 2 sample. There are strengths and weaknesses of both these approaches.

3.2.4 Surveys

The survey instruments covered a variety of domains, including basic demographics, physical and mental health, diagnosis details, wellbeing, daily functioning, bullying and trauma experiences, and access to the National Disability Insurance Scheme (NDIS). Where possible, we employed standardised measures. Questionnaire selection and review was also completed by the ALSAA autistic and carer research advisors, as described below. Some questionnaires were rejected, whilst others required minor changes in presentation to improve the appropriateness of the overall survey tool for autistic participants. A list of measures can be found in Tables 2 and 3. The surveys were available in online or hardcopy booklet form. the latter was returned to the researchers via prepaid postage.

People with intellectual disability who could not complete the self-report survey with some support had the option of engaging a trusted person who could complete an informant version of the survey about them on their behalf. Some people without intellectual disability also opted to have an informant complete a version of the survey for them. The informant version of the survey had some differences from the self-report version. This occurred because some measures, for example the Patient Health Questionnaire-9 (PHQ-9) depression measure, did not have an informant version. However, for such domains, alternative information was usually gathered from other informant-based questionnaires. For example, information about depression and anxiety was able to be gathered in the informant report survey using the Developmental Behaviour Checklist (DBC).

The majority of measures were collected at both Time 1 and 2. However, for Time 2 data collection, some measures were dropped or added. Decisions reflected a balance of interests expressed by the Australian autism and autistic communities, study priorities, and requirements to make the survey length manageable for participants. Notably, the Repetitive Behaviours Questionairre-2 and the Glasgow Sensory Questionnaire were not repeated, given length and assuming these characteristics would be relatively stable over a 2.5-year period. The Waisman Activities of Daily Living Scale was not repeated as we observed a significant ceiling effect, that is, the majority of participants scored towards the highest score on the scale. New measures added for Time 2 including measure of social anxiety, relationships, trauma experiences, bullying and happiness. Impact of Diagnosis, Terminology and Disclosure were other important topic areas added at Time 2.

3.2.5 ALSAA Time 1 measures

Table 2: ALSAA Time 1 Measures

Measure / domain	Self-report	Informant	Carer
Demographics and personal characteristics			
Basic demographics (Age, Sex, Ethnicity, English speaking status)	✓	✓	✓
Other demographics (Education, Occupation, Family & living conditions, Income)	✓	✓	✓
Autism Characteristics			
Autism Diagnosis Details	✓	✓	
The Autism Quotient – Short[b] (AQ-Short) (Hoekstra et al., 2011)	✓	✓	✓
Repetitive Behaviours Questionnaire-2 Adult Version (RBQ-2A) (Barrett et al., 2015)	✓	✓	
The Glasgow Sensory Questionnaire (Robertson & Simmons, 2012)	✓	✓	
The Intolerance of Uncertainty Scale-12 (Carleton, Norton, & Asmundson, 2007)	✓		✓
Health & Well-Being			
Medical history	✓	✓	✓
Medication profile	✓	✓	
Smoking, alcohol and illicit drug use	✓	✓	
The Patient Health Questionnaire-15 (Spitzer et al., 1994)	✓		✓
Medical Outcomes Study Short Form Health Survey-12 (SF-12) (Ware, Kosinski, & Keller, 1996)	✓	✓	✓
The Composite Autonomic Symptom Score – 31 (COMPASS 31) (Sletten, Suarez, Low, Mandrekar, & Singer, 2012)	✓		
Pittsburgh Sleep Quality Index (Buysse, Reynolds, Monk, Berman, & Kupfer, 1989)	✓		
Flinders Fatigue Scale (Gardisar et al., 2007)	✓		
Mental & Emotional Health			
DSM-5 Dimensional Anxiety Scales: Generalized Anxiety Disorder-Adult (DSM5 GAD-A) (Craske et al., 2013)	✓		✓

Measure / domain	Self-report	Informant	Carer
The Patient Health Questionnaire-9 (PHQ-9) (Kroenke, Spitzer, & Williams, 2001)	✓		✓
The Warwick Edinburgh Mental Well-being Scale (Tennant et al., 2007)	✓		
Temperament and Emotion Regulation			
The New General Self-Efficacy Scale (Chen, Gully, & Eden, 2001)	✓		
The Emotion Regulation Questionnaire (Gross & John, 2003)	✓		✓
Developmental Behaviour Checklist-Adolescent/Adult version (DBC-A) Revised (Mohr, Tonge, Einfeld, & Taffe, 2011)		✓	
The Brief COPE (Carver, 1997)	✓		✓
Memory Complaint Questionnaire (MAC-Q) (Crook, Feher, & Larrabee, 1992)	✓		
Relationships and Social Networks			
UCLA Loneliness Scale-8 (ULS-8) (Hays & DiMatteo, 1987)	✓		
Supports and networks[a]	✓	✓	✓
Network of Relationships Inventory – Relationship Qualities Version (Furman & Buhrmester, 2009)	✓		
Social Support Questionnaire-6 (SSQ-6) (Sarason, Levine, Basham, & Sarason, 1983)[%]	✓	✓	✓
Activities, Participation and Quality of Life			
World Health Organisation Quality of Life assessment (WHOQOL) BREF (The WHOQOL Group., 1995)	✓		✓
Waisman Activities of Daily Living Scale (W-ADL) (Maenner et al., 2013)	✓	✓	
World Health Organisation Disability Assessment Schedule (WHO-DAS II) (Luciano et al., 2010)	✓	✓	✓
Vocational Index for Adults with Autism (Taylor & Seltzer, 2012)	✓	✓	
Special abilities and interests[c]	✓		
Leisure activities participation	✓		
Leisure Satisfaction Scale (LSS) (Beard & Ragheb, 1980)	✓		
Driving and transport	✓	✓	✓
Activities, Participation and Quality of Life			

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Measure / domain	Self-report	Informant	Carer
Client Service Receipt Inventory (CSRI) (Chisholm et al., 2000)	✓	✓	
Health service seeking behaviour	✓	✓	
Early intervention service history	✓	✓	
Justice system contact	✓	✓	
Preventative health screening	✓	✓	
Barriers to Health Checklist – Short Form	✓		
Caring			
Positive Affect Index (Bengston & Allen, 1993)			✓
Caregiver Activity Survey (CAS-ID) (McCarron, Gill, Lawlor, & Beagly, 2002)			✓
Zarit Burden Interview (Bedard et al., 2001)			✓

% An extract of 6 items from the SSQ was used that is different from the items typically used in the SSQ-6.

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3.2.6 ALSAA Time 2 measures

Table 3: ALSAA Time 2 Measures

Measure / domain	Self-report	Informant	Carer
Demographics and personal characteristics			
Basic demographics (Age, Sex, Ethnicity, English speaking status)	✓	✓	✓
Other demographics (Education, Occupation, Family & living conditions, Income)	✓	✓	✓
Other demographics (Household Income)[+]	✓	✓	✓
Autism Characteristics			
Autism Diagnosis Details	✓	✓	
Autism diagnostic report and clinicians	✓	✓	
The Impact of Diagnosis Scale-Revised[+]	✓		
Terminology and Disclosure of Diagnosis[+]	✓		✓
The Autism Quotient – Short[b] (AQ-Short) (Hoekstra et al., 2011)	✓	✓	✓
Repetitive Behaviours Questionnaire-2 Adult Version (RBQ-2A) (Barrett et al., 2015)*	✓	✓	
The Glasgow Sensory Questionnaire (Robertson & Simmons, 2012)*	✓	✓	
The Intolerance of Uncertainty Scale-12 (Carleton, Norton, & Asmundson, 2007)*	✓		
Terminology and Disclosure of Diagnosis[+]	✓		
Health & Well-Being			
Medical history	✓	✓	✓
Medication profile	✓	✓	
Smoking, alcohol and illicit drug use	✓	✓	
The Patient Health Questionnaire-15 (Spitzer et al., 1994)	✓		✓
Medical Outcomes Study Short Form Health Survey-12 (SF-12) (Ware, Kosinski, & Keller, 1996)	✓	✓	✓
The Composite Autonomic Symptom Score – 31 (COMPASS 31) (Sletten, Suarez, Low, Mandrekar, & Singer, 2012)*	✓		

Measure / domain	Self-report	Informant	Carer
Pittsburgh Sleep Quality Index (Buysse, Reynolds, Monk, Berman, & Kupfer, 1989)	✓		
Flinders Fatigue Scale (Gardisar et al., 2007)	✓		
Mental & Emotional Health			
DSM-5 Dimensional Anxiety Scales: Generalized Anxiety Disorder-Adult (DSM5 GAD-A) (Craske et al., 2013)	✓		✓
DSM-5 Dimensional Anxiety Scales: Social Anxiety Disorder-Adult (DSM5 SAD-A) (Craske et al., 2013) [+]	✓		✓
Mini-SPIN (social anxiety) [+]	✓		✓
Obsessive-Compulsive Inventory [+]	✓		✓
The Patient Health Questionnaire-9 (PHQ-9) (Kroenke, Spitzer, & Williams, 2001)	✓		✓
The Warwick Edinburgh Mental Well-being Scale (Tennant et al., 2007)	✓		
Temperament and Emotion Regulation			
The New General Self-Efficacy Scale (Chen, Gully, & Eden, 2001)*	✓		
The Emotion Regulation Questionnaire (Gross & John, 2003)	✓		✓
Developmental Behaviour Checklist-Adolescent/Adult version (DBC-A) Revised (Mohr, Tonge, Einfeld, & Taffe, 2011)		✓	
The Brief COPE (Carver, 1997)	✓		✓
Memory Complaint Questionnaire (MAC-Q) (Crook, Feher, & Larrabee, 1992)*	✓		
Retrospective Bullying Questionnaire [+]	✓		
Childhood Trauma (CTQ) and Recent Trauma Questionnaire (RTQ) [+]	✓		
Subjective Happiness Scale (Lyubomirksy, & Lepper, 1999) [+]	✓		✓
Satisfaction with Love Scale (Neto, 2005) [+]	✓		✓
Interoception Scale [+]	✓		
Big Five Inventory – Short (Lang et al., 2011) [+]	✓	✓	✓
Connor Davidson Resilience Scale (CD-RISC) *[+]	✓		
Relationships and Social Networks			

Measure / domain	Self-report	Informant	Carer
UCLA Loneliness Scale-8 (ULS-8) (Hays & DiMatteo, 1987)	✓		
UCLA Loneliness Scale - Revised (ULS-20) (Russell, Peplau & Cutrona, 1980). [+]	✓		
Supports and networks	✓	✓	
Network of Relationships Inventory – Relationship Qualities Version (Furman & Buhrmester, 2009)	✓		
Social Support Questionnaire-6 (SSQ-6) (Sarason, Levine, Basham, & Sarason, 1983)[%]	✓	✓	✓
Activities, Participation and Quality of Life			
World Health Organisation Quality of Life assessment (WHOQOL) BREF (The WHOQOL Group., 1995)	✓		
Waisman Activities of Daily Living Scale (W-ADL) (Maenner et al., 2013)*	✓	✓	
World Health Organisation Disability Assessment Schedule (WHO-DAS II) (Luciano et al., 2010)	✓	✓	
Vocational Index for Adults with Autism (Taylor & Seltzer, 2012)		✓	
Special abilities and interests	✓		
International Physical Activity Scale (IPAQ-S) [+]	✓	✓	
Activities, Participation and Quality of Life			
Client Service Receipt Inventory (CSRI) (Chisholm et al., 2000)	✓	✓	
Preventative health screening	✓	✓	
Barriers to Health Checklist – Short Form	✓		
Caring			
Positive Affect Index (Bengston & Allen, 1993)			✓
Caregiver Activity Survey (CAS-ID) (McCarron, Gill, Lawlor, & Beagly, 2002)			✓
Zarit Burden Interview (Bedard et al., 2001)			✓
Future planning			✓

* Indicates that the scale is in the Time 2 Baseline questionnaire only

\+ Indicates that the scale is a new addition from Time Point 1

% An extract of 6 items from the SSQ was used that is different from the items typically used in the SSQ-6.

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3.2.7 Inclusive research

By inclusive research, we mean research that involves autistic adults or other stakeholders within the research production, through consultation and working together to co-produce outputs. The ALSAA used inclusive research processes that evolved through the life of study, culminating in the employment of an autistic peer researcher.

The ALSAA Inclusive Research Protocol was established in Time 1 and was followed for most outputs using ALSAA data. This approach was expanded at times to include consultation with research advisors on specific study questions and iterative brainstorming of questionnaire items. Research advisors helped to set research priorities; assisted with measure selection; survey design and testing; reviewed specific research questions; and assisted with interpretation of findings. Typically, in preparing a research output, research advisors would be emailed a plain English summary about the study, outlining background literature, the research question, findings and potential implications of the findings. They were asked to provide feedback and suggestions on interpretations. Feedback was received via email, video call or via a pre-recorded video.

The ALSAA Research Advisory Network included a group of volunteer autistic adults and carers of autistic adults. For Time 1 the group comprised 6 autistic adults and 2 family members / carers of autistic adults. For Time 2 the ALSAA Research Advisory Network comprised, on average, 7 autistic adults and 1 carer of an autistic adult. Many of the group members were alumni of the Autism CRC Research Academy. In Time 2 we were also able to offer some reimbursement to research advisors in the form of $35 gift cards per hours of consultation; some research advisors chose to volunteer their time.

3.2.8 Ethical considerations

All participants provided informed consent. The study was approved by the Human Research Ethics Committee at UNSW Sydney, Australia (No. HC15001). An additional ethics application and consent process was required for data banking of participant responses. This is discussed further in Section 6: Ongoing data access and collaboration.

3.2.9 Data storage

Data was gathered using Qualtrics, and hardcopy responses were entered into Qualtrics by research staff or students. Data was then downloaded and cleaned for analysis. A separate participant database with identification numbers and personal details was kept at UNSW.

3.2.10 Analyses

Data cleaning and majority of preliminary data analysis was complete using the STATA statistical software package. Basic descriptive analyses in this report were completed using STATA and MS Excel. Data for individual outputs was analysed with a variety of tools including Nvivo for qualitative data, and R, STATA, MPlus or SPSS for quantitative data.

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4. Findings

The ALSAA has advanced knowledge in autism in adulthood across a wide range of areas. This is exemplified in the numerous publications described in Section 4.3 below, including 26 peer-reviewed academic publications. Another 5 manuscripts are currently undergoing peer-review, and at least 38 additional manuscripts are still in development. There have been more than 25 academic conference presentation and posters relating to the ALSAA. ALSAA has enabled us to support 6 student completions with another 5 students underway. The ALSAA and the teams focus on autism in adulthood has also enabled several webinars, book chapters, media outputs and policy submissions.

4.1 Basic demographics

The ALSAA gathered a large, nationwide sample. Below, for illustrative purposes, we present the demographics of the combined Time 1 and Time 2 Baseline sample. Despite the sample size of the ALSAA, findings from the ALSAA are not necessarily representative of the adult autism population in Australia. Particularly, the ALSAA has a female gender bias, which is common in online research and has been noted in several other online autism studies. Also, we know there is a "lost generation" (Lai & Baron-Cohen, 2015) of autistic adults in the community who are undiagnosed. We allowed autistic adults without a formal diagnosis to participate in ALSAA particularly to gather more information on this group. Ideally future efforts would establish a national registry of autistic individuals as has occurred in other countries.

4.1.1 Gender

The ALSAA autistic sample contained a larger percentage of female participants, as well as a significant proportion of participants grouping into an 'other' gender category. We included more detailed gender groupings in the Time 2 survey, to reflect emerging awareness of gender identity. Evidence suggests that the male to female ratio in autism spectrum disorder is about 3 or 4 to 1. Although a potential limitation of the ALSAA study, the female predominance presents an opportunity to explore the under-researched gender differences for autistic adults. The female predominance in our sample is likely due to the largely online nature of the study, as more females tend to participate in online autism research (e.g., Gilmour et al., 2012; Kapp et al., 2013; Kenny et al., 2015). This greater female participation is also evident in the non-autistic sample.

Figure 1: Gender of ALSAA Self-Report Participants Combined Baseline Sample

Autistic — Non-Autistic

■ Male ■ Female ■ Other   ■ Male ■ Female
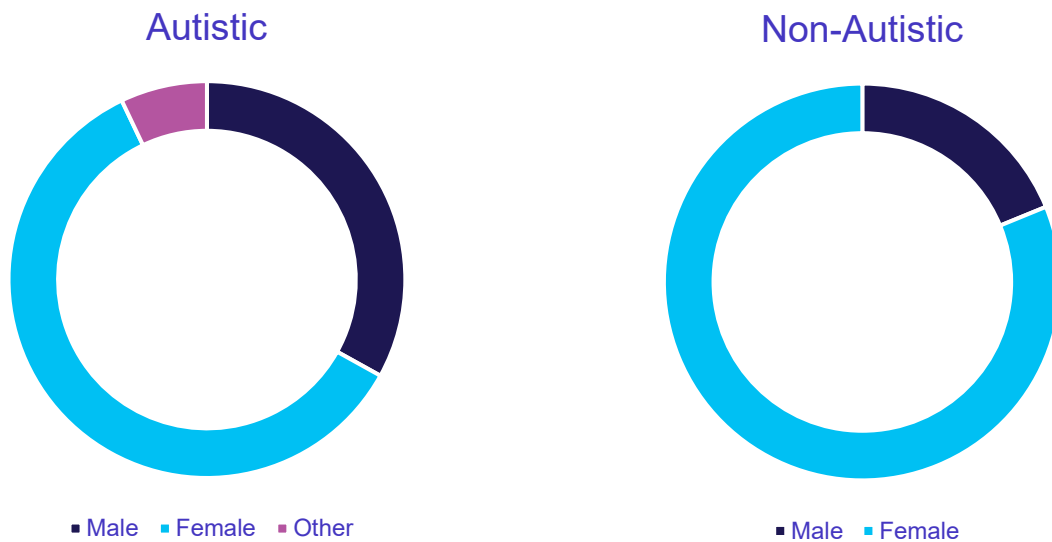
4.1.2 Location

The ALSAA included respondents from each state and territory; the largest group of autistic participants were living in New South Wales, followed by Queensland and Victoria.

Figure 2: State Distribution of ALSAA Self-Report Participants Combined Baseline Sample

State Location

■ ACT   ■ NSW   ■ NT   ■ QLD   ■ SA   ■ TAS   ■ VIC   ■ WA

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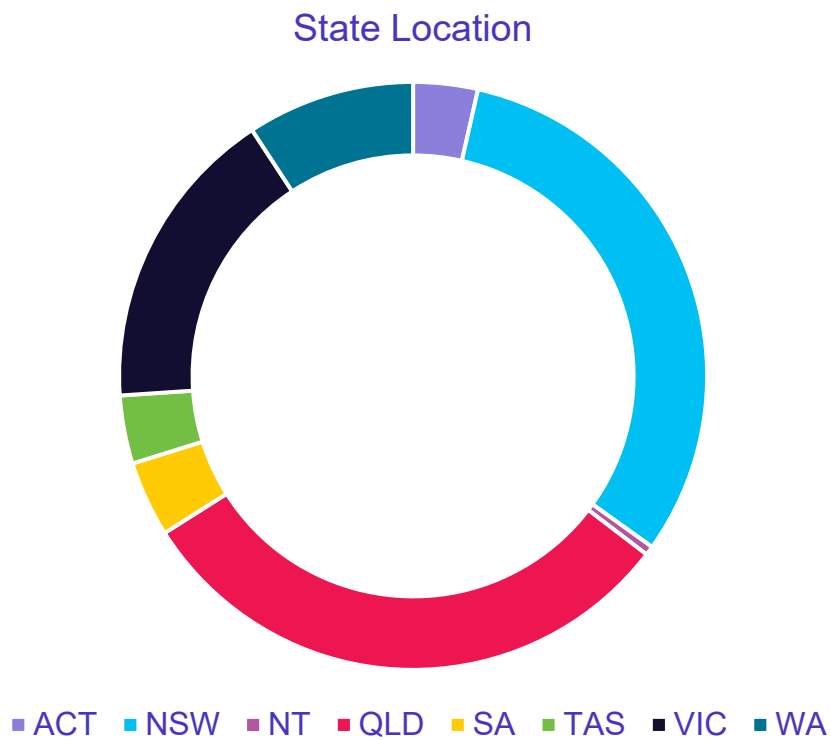
4.1.3 Remoteness

The majority of autistic participants lived in the major cities (71%), followed by inner regional areas (21%). There were no significant statistical differences between autistic and non-autistic participants based on remoteness. Eight autistic participants lived in remote Australia and 1 in very remote Australia, whereas no non-autistic participants lived in remote regions.

Figure 3: Remoteness of ALSAA Self-Report Participants Combined Baseline Sample

Autistic

- Inner Regional Australia
- Major Cities of Australia
- Outer regional Australia
- Remote Australia
- Very remote Australia

Non-Autistic

- Inner Regional Australia
- Major Cities of Australia
- Outer regional Australia
- Remote Australia
- Very remote Australia

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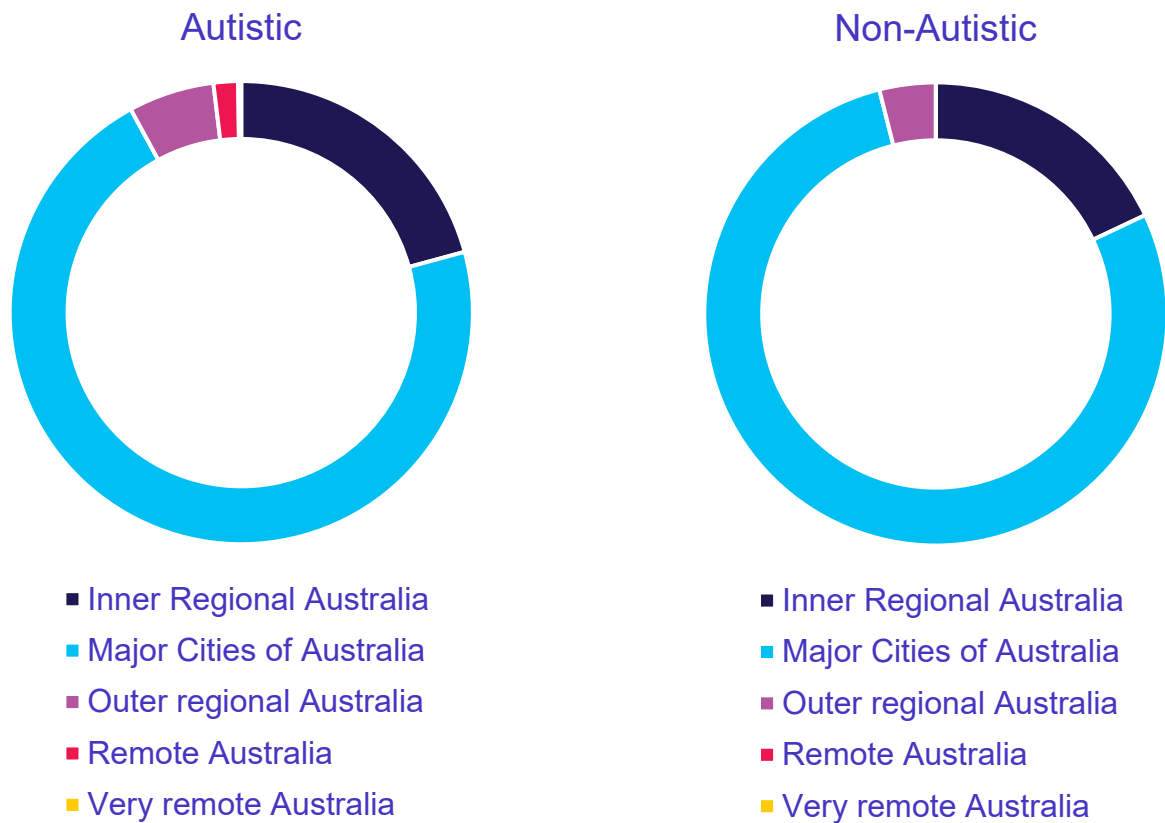
4.1.4 Living situation

Most autistic adults lived as a couple. There were differences between the living situation of autistic and non-autistic participants. A higher percentage of non-autistic people were married and lived as a couple (70% and 58% respectively).

Figure 4: Living Situation ALSAA Self-Report Participants Combined Baseline Sample

Autistic

- Living Alone
- Living as couple
- Living with parents
- Living with other relatives
- Living with others
- Other

Non-Autistic

- Living Alone
- Living as couple
- Living with parents
- Living with other relatives
- Living with others
- Other

AutismCRC
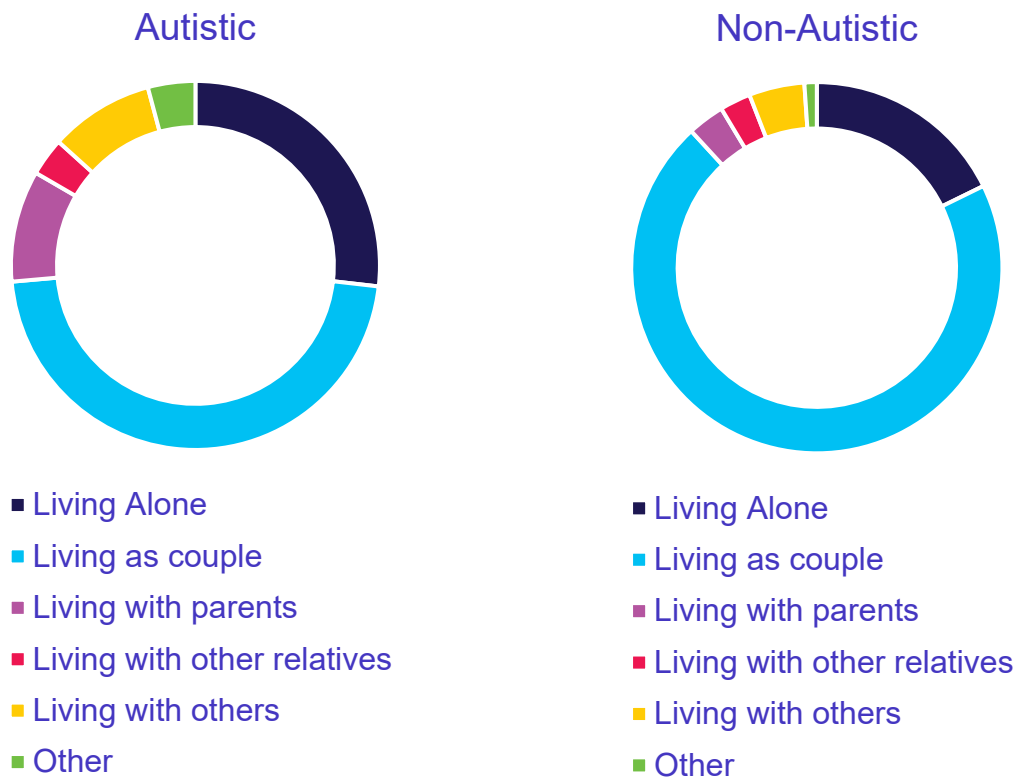
4.1.5 Marital status

Overall autistic participants were approximately evenly split between those who were either single, divorced or separated versus those who were married or in a de facto relationship. This differed from non-autistic participants, the majority of whom were married or in a de facto relationship.

Figure 5: Marital Status ALSAA Self-Report Participants Combined Baseline Sample

Autistic

- Single
- Married
- Defacto
- Never married
- Widowed
- Divorced and now single
- Separated
- Other
- Divorced and now remarried

Non-Autistic

- Single
- Married
- Defacto
- Never married
- Widowed
- Divorced and now single
- Separated
- Other
- Divorced and now remarried with de facto
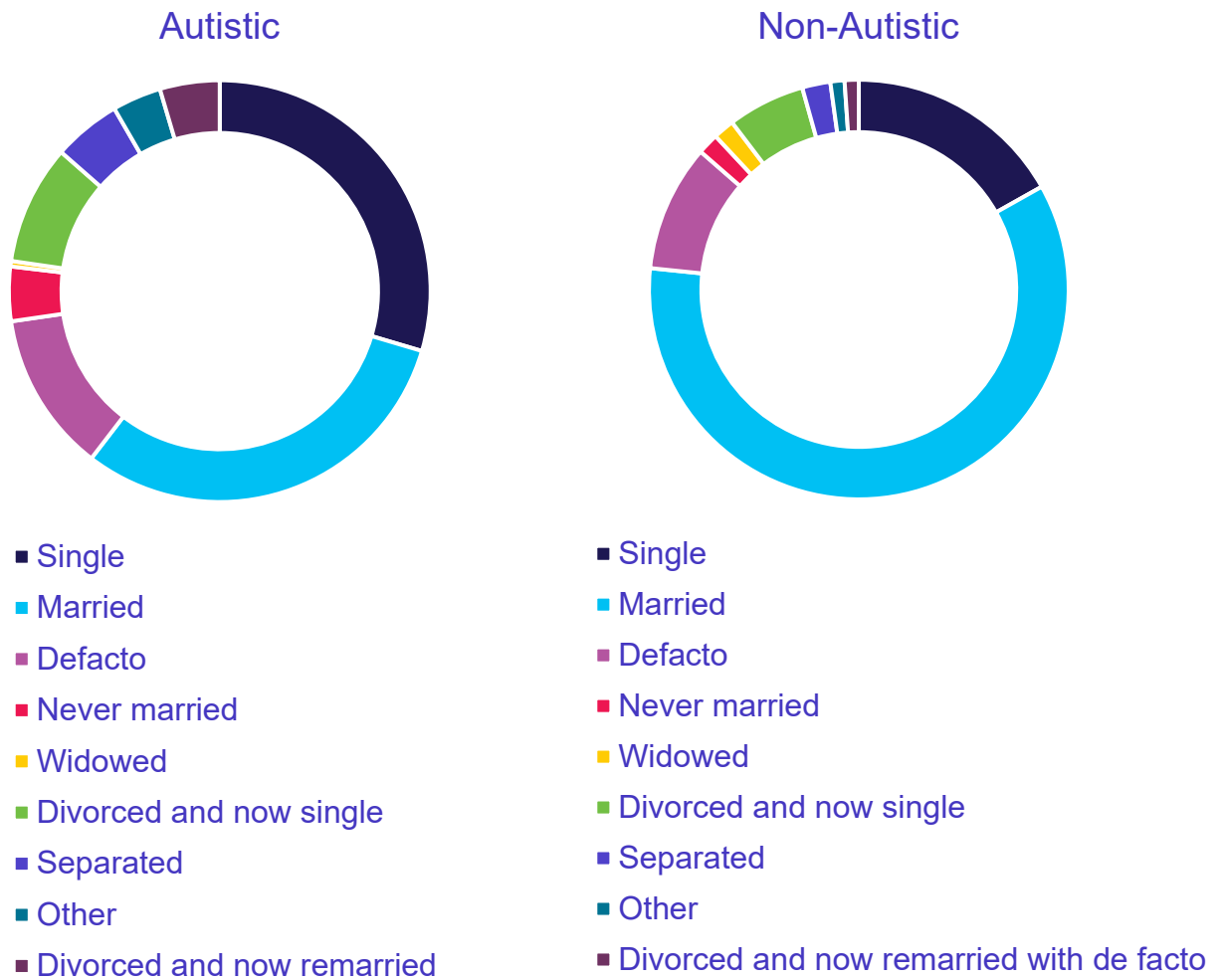
4.1.6 Employment status

Although a substantial majority of autistic participants were employed, a large percentage were not. Our forthcoming publication highlights the underemployment and underutilisation of the skills and qualifications of Australian autistic adults. Given the important benefits that employment brings, and the average age of our participants, more needs to be done to increase rates of employment for autistic adults. A larger proportion of non-autistic participants were employed than autistic (75% and 59% respectively).

Figure 6: Employment Status of ALSAA Self-Report Participants Combined Baseline Sample

Autistic

Non-Autistic

■ Employed   ■ Unemployed   ■ Employed   ■ Unemployed
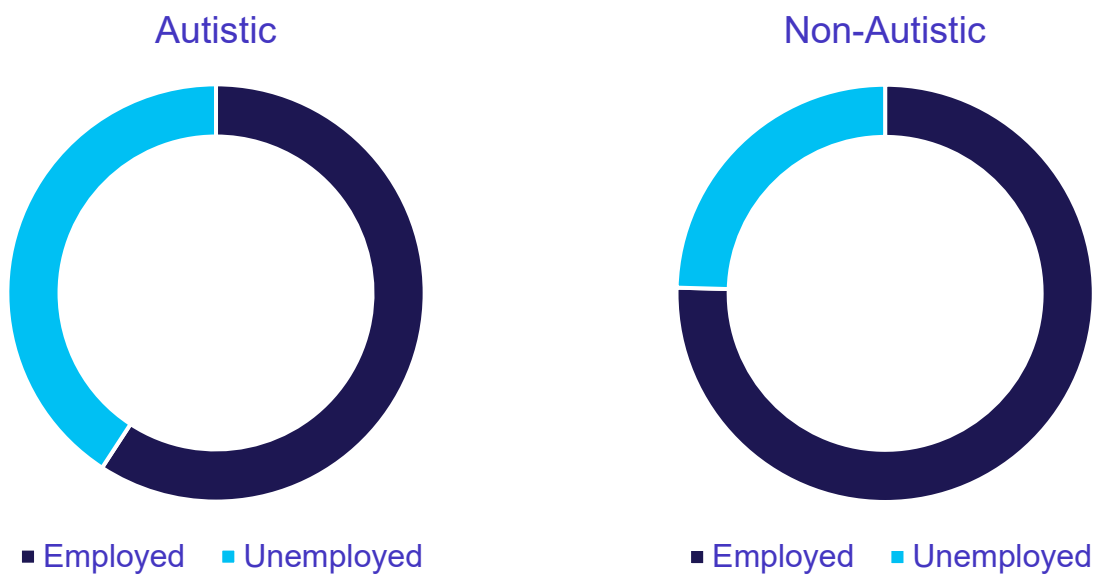
4.1.7 Autism traits

Autism traits were assessed using the Autism Quotient Short Form - 28 (AQ-28; Hoekstra et al., 2011). Over 96% of autistic participants reached cut-off on the AQ (a total score above 65), meaning that they exhibit a high number of autistic traits.

4.1.8 Mental health

Most autistic adults in our sample reported experiencing challenges with their mental health, which is consistent with other studies. Respondents completed a standard depression scale (PHQ-9), which our team has validated in a sample of autistic people. They also completed a standard anxiety measure (DSM-5 DAS GAD).

Compared with non-autistic participants, both carers and autistic participants had substantially higher rates of depression and anxiety. Looking at cut-off scores consistent with at least mild depression, 78% of autistic participants were depressed. Similarly, 60% of carers of autistic adults had at least mild depression, compared to 35% of non-autistic participants. Using a clinical cut-off for depression, 54% of autistic adults and 51% of carers were above this cut-off, compared with 13% of non-autistic participants.

Figure 7: Depression Above Cut-Off in ALSAA Self-Report Participants Combined Baseline Sample
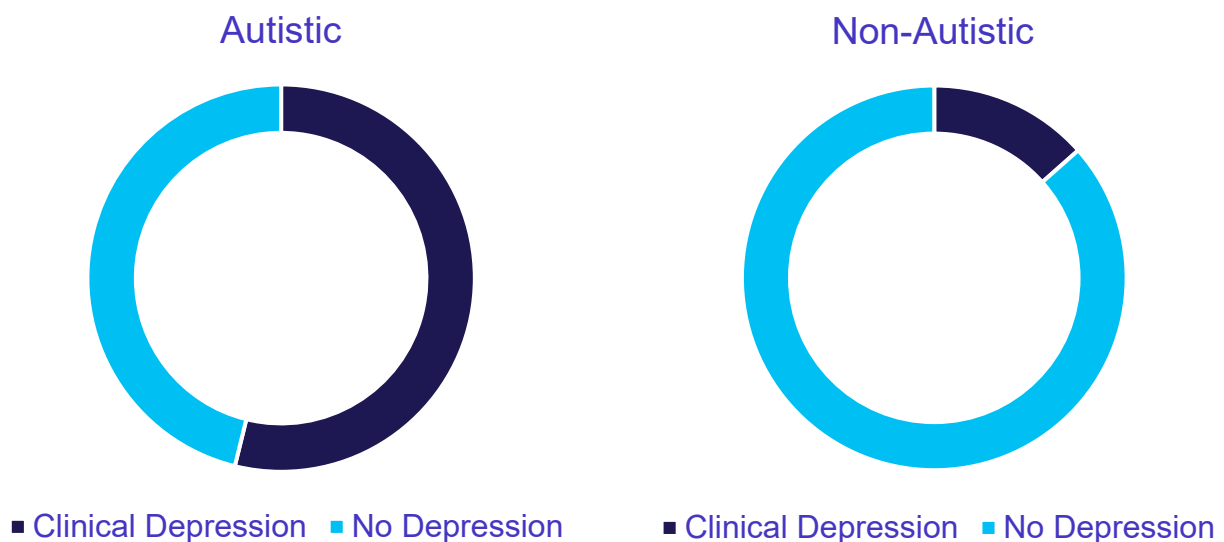
4.2 Additional Time 2 datapoints of interest

In Time 2 we added several new data points in response to priorities identified by participants, research advisors and expressed community priorities. A small selection of Time 2 specific findings are reported below; more detail will become available in our forthcoming outputs.

4.2.1 Terminology

We asked about preferences around terminology relating to autism. Most autistic respondents preferred both being referred to as "is autistic" or "on the spectrum", and also referred to themselves in this way. The majority of non-autistic respondents believed that Autism Spectrum Disorder (ASD) was the most acceptable term. Such differences in preference could relate to differences between how autistic adults perceive themselves and their autism versus how they are perceived by others. Carers also seemed to believe that one of the most acceptable terms was ASD, as well as "Has Autism" and "On the Spectrum."

4.2.2 Barriers to healthcare

Many barriers to healthcare were identified for autistic adults. We are currently in the processing of publishing a manuscript on this topic. Participants told us that: "fear, anxiety, embarrassment, or frustration keeps me from getting primary care," "I have trouble following up on care (e.g. going to pharmacy, taking prescribed drugs at the right time, mor making a follow-up appointment)," and "concerns about costs keep me from getting primary care."

4.2.3 Impact of diagnosis

We developed an Impact of Diagnosis Scale – Revised, which we were able to include in Time 2. This scale assesses the psychological and services received impact that having a diagnosis of autism in adulthood has from the perspective of the autistic adult. It assesses various domains including *Service Access, Being Understood, Self-Acceptance*, and *Understanding*. We also gathered in depth responses regarding receiving a diagnosis in adulthood.

"It was a relief to finally have an explanation to my lifelong troubles."

"I spent my entire life thinking I was dumb and there was something wrong with me. Now I know that I'm just different and quite gifted."

Impact of Diagnosis

"It changed the narrative of my entire life story."

"Getting my diagnosis was by far, without a doubt, the single most important thing that has happened to me in my life. It was so beneficial in helping me to understand myself. […] It has increased my self-confidence and allowed me to start on a journey towards discovering my true self and building a sense of identity, which I have never previously had due to constantly "pretending to be normal". Maybe most importantly, getting my diagnosis prompted me to seek out the Autistic community, and to start building connections and friendships within my Autistic tribe. Knowing that there are other people out there who accept me as I am and truly understand me is absolutely invaluable."

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4.2.4 Strengths and special interests

Despite a focus of ALSAA being the health and well-being of autistic adults and having identified concerning high rates of poorer health and mental illness, the ALSAA did also identify key strengths and special interests of autistic adults.

In all special interest categories, there were autistic respondents who showed interests comparable to non-autistics respondents. Sport was the only interest where a substantially higher proportion of non-autistic participants had an interest. Generally, it appears autistic and non-autistic adults both have a wide variety of special interests, though autistic participants reported a higher proportion of 'other' interests that could not be grouped. 190 participants noted that their special interest affects their job and 76% of these were autistic. An overwhelming 97% of autistic respondents said that their special interest distracts them in general.

Honesty, the ability to focus, memory, ability to focus on small details, and creativity were the main strengths noted amongst the autistic community. Creativity, honesty, and imagination were noted as the self-perceived strengths of the non-autistic respondents.

Figure 8: Percentage of Sample indicating Special Interests, ALSAA Self-Report Participants Combined Baseline Sample
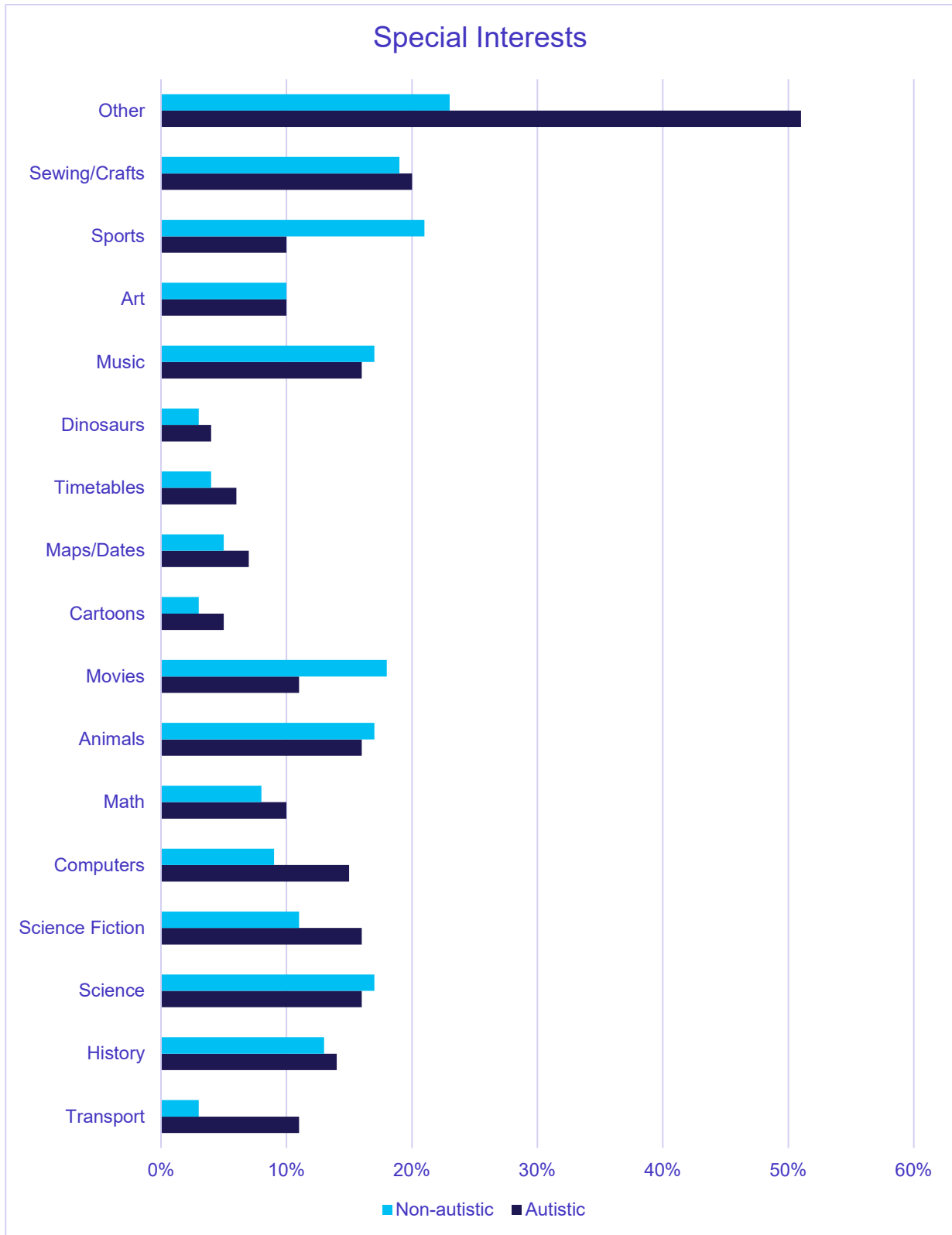
4.3 Publications

4.3.1 Choose your own adventure: Pathways to adulthood autism diagnosis in Australia

Published 9 July 2021

This study examined experiences of first-time autism diagnosis in adulthood. Quantitative findings showed the diagnostic process to be highly varied. Qualitative analysis found that adults mainly sought a diagnosis for self-understanding and support. Cost and fear of not being taken seriously were major barriers to diagnosis. While most participants were satisfied with the diagnosis, their emotional reactions were complex. Findings support the need for thoroughly implementing national guidelines, and for improved knowledge and communication in mainstream health professionals encountering clients with autistic traits.

Citation: Huang, Y., Arnold, S.R.C., Foley, K.-R., & Trollor, J.N. (2022) Choose your own adventure: Pathways to adulthood autism diagnosis in Australia. *Journal of Autism and Developmental Disorders, 52,* 2984–2996. https://doi.org/10.1007/s10803-021-05169-4

4.3.2 Factors associated with age at autism diagnosis in a community sample of Australian adults

Published 16 September 2021

This paper examined the relationship between age at autism diagnosis and other characteristics in adults. Findings showed that older current age, higher self-reported autistic traits, female gender, language other than English, family history of autism, and history of depression were related to older age at diagnosis, while intellectual disability and history of obsessive–compulsive disorder were related to younger age at diagnosis. Findings suggest more work is needed to help recognize autism in women and people from non-English-speaking backgrounds. Future studies could extend these findings by studying the effects of childhood and adulthood socioeconomic status on autism diagnosis age in adults.

Citation: Huang, Y., Arnold, S.R.C., Foley, K.-R., Lawson, L.P., Richdale, A.L., & Trollor, J.N. (2021). Factors associated with age at autism diagnosis in a community sample of Australian adults. *Autism Research*, *14*(12), 2677– 2687. https://doi.org/10.1002/aur.2610

4.3.3 Autistic adults' experiences of diagnosis disclosure

Published 3 January 2022

This study examined autistic adults' experiences of disclosing their autism diagnosis in different contexts. Almost all participants disclosed their diagnosis to someone, most commonly to friends. Over a third of participants studying and/or working at the time of survey had not disclosed to their school, university, or employer. Content analysis of open-ended responses showed participants wanted to gain understanding and support from disclosure but feared prejudice. While some reported receiving support after disclosing their diagnosis, others were faced with dismissiveness and misunderstanding. Findings highlight the need to improve autism understanding and reduce stigma in schools/universities, workplaces, and the wider community.

Citation: Huang, Y., Hwang, Y.I., Arnold, S.R.C., Lawson, L.P., Richdale, A.L., & Trollor, J.N. (2022). Autistic adults' experiences of diagnosis disclosure. *Journal of Autism and Developmental Disorders*, https://doi.org/10.1007/s10803-021-05384-z

4.3.4 Employment profiles of autistic adults in Australia

Published August 2021

The paper identified the underemployment and underutilisation of Australian autistic adults. Using Time 1 data from ALSAA, comparisons were made between autistic participants and data from the Australian workforce obtained from the Australian Bureau of Statistics (ABS). Regressions model identified that autistic traits, increased social supports and having workplace adjustments were associated with higher odds of appropriate employment. Interventions that foster inclusion workplace environments could benefit all employees.

Citation: Harvery, M., Froude, E. H., Foley, K.-R., Trollor, J. N., & Arnold, S. R. C. (2021). Employment profiles of autistic adults in Australia. *Autism Research*, *14*(10), 2061–2077. https://doi.org/10.1002/aur.2588

4.3.5 Exploring the relationship between community mobility and quality of life, employment and completing further education

Published Jun 2021

The paper identified the relationships between barriers autistic adults experience using cars and / or public transport to access the community, and overall quality of life. Using Time 1 data from

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ALSAA, comparisons were made between autistic and non-autistic participants on both their access and use of cars and / or public transport. Autistic participants had less access to both cars and public transport to access the community. Regression models showed relationships between car access, public transport, and quality of life for autistic adults. Car access and public transport were not predictors of education or employment status, though public transport use was associated with better educational outcomes, and car access was associated with both better education and employment outcomes. More work is needed to understand autistic people's perspectives and why access does not equal usage of cars and public transport. Needs of autistic people should be considered in policies relating to community environments, transport design, training of police, transit authorities and emergency responses.

Citation: In press with the Journal of Transport and Health

4.3.6 Inter-relationships between trait resilience, coping strategies and mental health outcomes in autistic adults

Published Jun 2021

In the non-autistic population resilience has been described as a key factor in protecting mental health when under stress. Autistic adults can experience high levels of stress in their everyday lives, though resilience has largely not been studied in this population. Using Time 2 data from ALSAA, this study investigated relationships between resilience, coping and mental health in autistic adults, including how effects on mental health could be mediated by a combination of variables. Results showed that resilient autistic adults used more engagement focused coping strategies and less disengagement focused strategies. Disengagement coping mediated the positive relationship between resilience and positive mental health. Overall, resilient autistic adults reported better mental health. Results suggest that both resilience and coping need to be considered when addressing mental health support for autistic adults.

Citation: In press with Autism Research

4.3.7 Factor structure and psychometric properties of the Brief COPE in autistic adults

Published Jun 2020

This paper examined the coping strategies used by autistic adults in responding to stress. Previous literature has explored how stress can negatively affect the mental health of autistic adults,

however we have yet to understand how they cope with stress. The authors used factor analysis to understand whether the Brief COPE was a validated measure to use when assessing coping strategies in an autistic population. Results supported its usefulness in measuring coping strategies for stress in autistic adults. These findings have broader clinical implications as they can inform interventions that improve coping strategies and therefore reduce stress and its effects on mental health in autistic adults.

Citation: Muniandy, M., Richdale, A. L., Arnold, S. R. C., Trollor, J. N., & Lawson, L. P. (2021). Factor structure and psychometric properties of the Brief COPE in autistic older adolescents and adults. *Research in Autism Spectrum Disorders*, *84*, 101764. https://doi.org/10.1016/j.rasd.2021.101764

4.3.8 Sleep quality in autism from adolescence to old age

Published 10 Jun 2020

Sleep issues are a common experience for autistic people. Limited research has investigated poor sleep quality beyond childhood. This study examined sleep quality in 530 autistic and non-autistic people, ranging from 15-80 years. Sleep quality, sleep onset latency (SoL), total night sleep, and sleep efficiency were measured using the Pittsburgh Sleep Quality Index. The study found that problematic sleep was higher in the autistic group (63.7%) than the control (46.4%). Poorer sleep quality and longer SoL were also experienced at a higher rate in the autistic group than the comparison group (all $p < 0.001$). Interestingly, this statistic difference did not exist in adolescence or old age, however, did exist in early adulthood and middle age. Poorer sleep quality was also more prevalent in females than males. There is a critical need for future research to focus on understanding the cause of poor sleep quality in autism and developing sleep interventions for autistic adults.

Citation: Jovevska, S., Richdale, A. L., Lawson, L. P., Uljarević, M., Arnold, S. R. C., & Trollor, J. N. (2020). Sleep Quality in Autism from Adolescence to Old Age. *Autism in Adulthood*, *2*(2), 152–162. https://doi.org/10.1089/aut.2019.0034

4.3.9 Factor structure and psychometric properties of the brief Connor-Davidson Resilience Scale for autistic adults

Published 13 Mar 2020

Identifying the appropriateness of scales to measure autistic adults is pivotal in improving understanding of their abilities and needs. Resilience is a potential protective factor against poor mental health for autistic adults. The brief Connor-Davidson Resilience Scale (CD-RISC-10) has primarily been used for assessing resilience in non-autistic people. Participants were 95 autistic adults (63% female). The CD-RISC-10 was found to be a valid measure (unidimensional structure and robust psychometric properties) for measuring trait resilience in an autistic population. Future studies may use the CD-RISC-10 to investigate resilience as a protective factor from traumatic and adverse emotional events for which autistic individuals may be particularly susceptible.

Citation: Hwang, Y. I. (Jane), Arnold, S., Trollor, J., & Uljarević, M. (2020). Factor structure and psychometric properties of the brief Connor–Davidson Resilience Scale for adults on the autism spectrum. *Autism*, *24*(6), 1572–1577. https://doi.org/10.1177/1362361320908095

4.3.10 Anxiety and depression from adolescence to old age in autism

Published Jun 2020

This study explored relationships with age for anxiety and depression in autistic adults and adolescents. It used data from the ALSAA, SASLA and the Dandelion program. More than a third of participants reported anxiety or depression to a clinically significant level. There was a slight increase in severity of anxiety and depression from adolescence to middle-adulthood, and a slight decline in older adulthood. Being female and having higher autistic traits was also associated with higher depression and anxiety. Results highlighted the importance of assessment and treatment of anxiety and depression in autism.

Citation: Uljarević, M., Hedley, D., Rose-Foley, K., Magiati, I., Cai, R. Y., Dissanayake, C., Richdale, A., & Trollor, J. (2020). Anxiety and Depression from Adolescence to Old Age in Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, *50*(9), 3155–3165. https://doi.org/10.1007/s10803-019-04084-z

4.3.11 Diagnosis of autism in adulthood: A scoping review

Published 28 Feb 2020

Frequency of autistic diagnosis in adulthood has been increasing. Despite this increase, accessibility and diagnostic processes are inconsistent and there is a lack of formal support services for autistic adults. This scoping review concluded that receiving an autism diagnosis in adulthood has an emotional impact and thus it is crucial for more adequate support services, such as counselling, to be available for autistic adults post diagnostic assessment. Furthermore, consistent and rigorous diagnostic practices are necessary when diagnosing autism in adulthood and new national guidelines need widespread implementation.

Citation: Huang, Y., Arnold, S. R., Foley, K.-R., & Trollor, J. N. (2020). Diagnosis of autism in adulthood: A scoping review. *Autism*, *24*(6), 1311–1327. https://doi.org/10.1177/1362361320903128

4.3.12 Brief report: Psychometric properties of the Patient Health Questionnaire-9 (PHQ-9) in autistic adults

Published Jun 2020

This brief report analyses whether the Patient Health Questionnaire (PHQ-9) is a valid depression screening measure for autistic individuals. To test this, data collected from autistic individuals aged 15–80 years was used. The study found that PHQ-9 is a useful tool in autism research, allowing for comparison across autistic and non-autistic participants.

Citation: Arnold, S. R. C., Uljarević, M., Hwang, Y. I., Richdale, A. L., Trollor, J. N., & Lawson, L. P. (2019). Brief Report: Psychometric properties of the Patient Health Questionaire-9 (PHQ-9) in autistic adults. *Journal of Autism and Developmental Disorders*. https://doi.org/10.1007/s10803-019-03947-9

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4.3.13 Health services for Australian autistic adults: Commentary on "The experiences, views and needs of health professionals who provide care to adults on the autism spectrum"

Published 6 May 2020

This commentary highlighted the need for further research and advocacy into Australian health services for autistic adults. At present Australia is not meeting its obligations to provide appropriate care for people with disabilities and healthcare professionals do not feel adequately competent in delivering care that is tailored to this population. Furthermore, autistic adults experience communication difficulties and anxiety that make it challenging for them to seek support and communicate their health needs. The major limitation identified in the Urbanowicz et al. (2020) study was the limited sample size and a potential social desirability bias, which could underrepresent the substantial difficulties and poor services received by autistic adults. Finally, it was commented that relying on the opinions and experiential accounts of autistic adults, rather than healthcare professionals, may be a more valid way of assessing health services.

Citation: Arnold, S. R. C., Uljarević, M., Hwang, Y. I., Richdale, A. L., Trollor, J. N., & Lawson, L. P. (2019). Brief Report: Psychometric properties of the Patient Health Questionaire-9 (PHQ-9) in autistic adults. *Journal of Autism and Developmental Disorders*. https://doi.org/10.1007/s10803-019-03947-9

4.3.14 Autism and quality of life

Published 13 Mar 2020

This study used both cross-sectional and longitudinal data to assess Quality of Life (QoL) in autistic people across the lifespan, with a focus on mental health and sleep quality as predictors of QoL. Significant predictors of QoL in both groups were: depression symptoms, psychological well-being, sleep quality and autonomic symptoms (e.g. sweating). Given known relationships between sleep and mental health, an accessible intervention addressing these may have greatest clinical impact on quality of life among autistic individuals.

Citation: Lawson, L. P., Richdale, A. L., Haschek, A., Flower, R. L., Vartuli, J., Arnold, S. R., & Trollor, J. N. (2020). Cross-sectional and longitudinal predictors of quality of life in autistic individuals from adolescence to adulthood: The role of mental health and sleep quality. *Autism*, *24*(4), 954–967. https://doi.org/10.1177/1362361320908107

4.3.15 "The single most important thing that has happened to me in my life": Development of the Impact of Diagnosis Scale – Revised (IODS-R)

Published 11 Mar 2020

This paper describes the revision of an assessment tool that measures the impact of receiving an autism diagnosis in adulthood. Working with a group of autistic research advisors, a new tool was developed, covering domains of Service Access, Being Understood and Self-Acceptance and Understanding. Scores suggested that although impact of autism diagnosis was generally perceived as positive for Self-Acceptance and Understanding, scores were neutral in other domains.

Citation: Arnold, S. R. C., Huang, Y., Hwang, Y. I. (Jane), Richdale, A. L., Trollor, J. N., & Lawson, L. P. (2020). "The Single Most Important Thing That Has Happened to Me in My Life": Development of the Impact of Diagnosis Scale—Preliminary Revision. *Autism in Adulthood*, *2*(1), 34–41. https://doi.org/10.1089/aut.2019.0059

4.3.16 Cohort profile: the Australian Longitudinal Study of Adults with Autism (ALSAA)

Published 4 Dec 2019

There is a lack of comprehensive longitudinal studies of autism in adulthood. ALSAA gathers data on autistic and non-autistic adults aged 25+. Baseline data showed high rates of depression and anxiety in autistic adults. A protocol for inclusive research was developed.

Citation: Arnold, S. R. C., Foley, K.-R., Hwang, Y. I. (Jane), Richdale, A. L., Uljarevic, M., Lawson, L. P., Cai, R. Y., Falkmer, T., Falkmer, M., Lennox, N. G., Urbanowicz, A., & Trollor, J. (2019). Cohort profile: The Australian Longitudinal Study of Adults with Autism (ALSAA). *BMJ Open*, *9*(12), e030798. https://doi.org/10.1136/bmjopen-2019-030798

4.3.17 Loneliness in adults on the autism spectrum

Published 11 Nov 2019

Loneliness is commonly experienced by autistic adults, however little research has examined the factors that contribute to this. Researchers at UNSW conducted both quantitative and qualitative analysis of data from a sample of 220 autistic and 146 non-autistic adults to identify predictors of

loneliness. Results showed that scores on the University of California, Los Angeles (UCLA) loneliness scale (ULS-8) were higher for autistic participants, with the Autism Quotient subdomains of social skills and dissatisfaction with social support being the biggest associated factors of loneliness. Thematic analysis of qualitative responses on how participants socialize helped the researchers to interpret the quantitative data more effectively.

Citation: Ee, D., Hwang, Y. I., Reppermund, S., Srasuebkul, P., Trollor, J. N., Foley, K.-R., & Arnold, S. R. C. (2019). Loneliness in adults on the autism spectrum. *Autism in Adulthood*, *1*(3), 182–193. https://doi.org/10.1089/aut.2018.0038

4.3.18 Understanding anxiety in adults on the autism spectrum: An investigation of its relationship with intolerance of uncertainty, sensory sensitivities, and repetitive behaviours

Published 14 Aug 2019

Anxiety is understood to be highly comorbid with autism. Intolerance of uncertainty is becoming readily understood as a contributing factor to this anxiety, as well as sensory sensitivities and repetitive behaviours. Self-report surveys were completed by 176 autistic (mean age = 42) and 116 non-autistic adults with findings revealing significant and positive correlations between intolerance of uncertainty, anxiety, repetitive behaviours, and sensory sensitivities in autistic sample. Intolerance of uncertainty had the strongest correlation with anxiety (r = 0.55). Managing intolerance of uncertainty at an individual level may be a sustainable method of alleviating anxiety, above and beyond attempting to minimize as much uncertainty as possible in their lives.

Citation: Hwang, Y. I. (Jane), Arnold, S., Srasuebkul, P., & Trollor, J. (2020). Understanding anxiety in adults on the autism spectrum: An investigation of its relationship with intolerance of uncertainty, sensory sensitivities and repetitive behaviours. *Autism*, *24*(2), 411–422. https://doi.org/10.1177/1362361319868907

4.3.19 The mental well-being of informal carers of autistic adults: A systematic review

Published 31 May 2019

Twenty-three studies were included in this systematic review that aimed to understand what constitutes the mental wellbeing of carers of people with developmental disabilities. The factors most consistently associated with higher wellbeing were adaptive skills and quality for the caring

relationships, whereas factors such as carer age and formal services received had weaker associations. The authors mapped these results to an existing model of carer psychological wellbeing developed by King et al (1999).

Citation: Sonido, M. T., Hwang, Y. I. (Jane), Trollor, J. N., & Arnold, S. R. C. (2020). The Mental Well-Being of Informal Carers of Adults on the Autism Spectrum: A Systematic Review. *Review Journal of Autism and Developmental Disorders*, *7*(1), 63–77. https://doi.org/10.1007/s40489-019-00177-8

4.3.20 Neuropsychiatric profile and psychotropic medication use in adults with autism spectrum disorder: Results from the Australian Longitudinal Study of Autism in Adulthood

Published 13 Nov 2018

This study examined the neuropsychiatric profile and use of psychotropic medication use in autistic adults compared to non-autistic controls. Autism was associated with increased use of psychotropic medication even when controlling for the presence of any neurological or psychiatric disorder. There were no corresponding indications for 14.4% of psychotropic medications prescribed to autistic adults. These patterns of psychotropic medication use may reflect prescribing for behavioural indications despite limited evidence to support this practice.

Citation: Cvejic, R. C., Arnold, S. R. C., Foley, K.-R., & Trollor, J. N. (2018). Neuropsychiatric profile and psychotropic medication use in adults with autism spectrum disorder: Results from the Australian Longitudinal Study of Adults with Autism. *BJPsych Open*, *4*(6), 461–466. https://doi.org/10.1192/bjo.2018.64

4.3.21 Autism in later life

Published Oct 2018

This co-produced narrative review explored the emerging evidence regarding autism and later life, focusing on literature arising from 2010 to 2019 and autistic adults over age 50. More evidence is suggested that older autistic adults experience significant physical and mental health comorbidities. Research in this area is limited, and most studies that are available have samples skewed towards middle or younger adults, and few separate results out for the older autistic age group. There is a significant gap in research knowledge for older autistic adults, and future research is needed co-produced with autistic adults.

Citation: Sonido, M., Arnold, S., Higgins, J., & Hwang, Y. I. J. (2020). Autism in Later Life: What Is Known and What Is Needed? *Current Developmental Disorders Reports*, *7*(2), 69–77. https://doi.org/10.1007/s40474-020-00192-z

4.3.22 Leisure participation and satisfaction in autistic adults and neurotypical adults

Published 22 Aug 2018

This paper explores the leisure activities in which autistic adults participate and compares this with those of non-autistic adults. It was found taking part in solitary leisure activities was comparable between both groups, but non-autistic adults were more likely to socialise in person for leisure. Overall, autistic adults were less satisfied with their leisure compared to non-autistic adults.

Citation: Stacey, T.-L., Froude, E. H., Trollor, J., & Foley, K.-R. (2019). Leisure participation and satisfaction in autistic adults and neurotypical adults. *Autism*, *23*(4), 993–1004. https://doi.org/10.1177/1362361318791275

4.3.23 Aging well on the autism spectrum: An examination of the dominant model of successful aging

Published 2 May 2018

There is a gap in our knowledge of aging with autism. The present study examined the applicability of the popular gerontology concept of "aging well" to autistic adults. Using survey data, a model of "aging well" was operationalised and applied to 92 autistic adults and 60 controls. A very small proportion (3.3%) of autistic adults were found to be aging well. Significantly less autistic adults were "maintaining physical and cognitive functioning" and "actively engaging with life" in comparison to controls. Whilst important differences in health and functioning status were found, the current dominant model of "aging well" is limited for examining autistic individuals. Suggested adjustments include development of a broader, more flexible and strengths-based model.

Citation: Hwang, Y. I., Foley, K.-R., & Trollor, J. N. (2020). Aging Well on the Autism Spectrum: An Examination of the Dominant Model of Successful Aging. *Journal of Autism and Developmental Disorders*, *50*(7), 2326–2335. https://doi.org/10.1007/s10803-018-3596-8

4.3.24 Risk and protective factors underlying depression and suicidal ideation in autism

Published 17 Mar 2018

This study examined loneliness and social support as potential risk and protective factors associated with depression and suicidal ideation in autistic adults. 49% of participants returned scores in the clinical range for depression and 36% reported recent suicidal ideation. Loneliness, satisfaction with social support, and autism traits predicted depression scores. Autism trait severity was independently related to depression, and the effects of loneliness and social support on suicidal ideation were mediated by depression. This study supports a model whereby loneliness and social support operate respectively as protective and risk factors for depression and suicidal ideation in autism.

Citation: Hedley, D., Uljarević, M., Foley, K.-R., Richdale, A., & Trollor, J. (2018). Risk and protective factors underlying depression and suicidal ideation in Autism Spectrum Disorder. *Depression and Anxiety*, *35*(7), 648–657. https://doi.org/10.1002/da.22759

4.3.25 Cross-sectional interactions between expressive suppression and cognitive reappraisal and its relationship with depressive symptoms

Published 18 Jan 2018

This study explored the relationship between emotion regulation strategies known as cognitive reappraisal and expressive suppression, and symptoms of depression in autistic adults. Those with more depressive symptoms tended to score lower on reappraisal, and higher on suppression. Both strategies were bigger predictors of depression symptoms than autism traits. Individuals who reported high suppression and low reappraisal use experienced more depressive symptoms than those who reported high use of both suppression and reappraisal.

Citation: Cai, R. Y., Richdale, A. L., Foley, K.-R., Trollor, J., & Uljarević, M. (2018). Brief report: Cross-sectional interactions between expressive suppression and cognitive reappraisal and its relationship with depressive symptoms in autism spectrum disorder. *Research in Autism Spectrum Disorders*, *45*, 1–8. https://doi.org/10.1016/j.rasd.2017.10.002

4.3.26 Problems managed and medications prescribed during encounters with people with autism spectrum disorder in Australian general practice

Published 15 Sep 2017

This paper explores the experience of autistic individuals (under 25 years of age) in general practice, by looking at the types of problems managed and medications they are prescribed. For those on the autism spectrum, management of psychological problems was significantly more common than those not on the spectrum. Moreover, rates of psychological medication prescription, especially antipsychotics and antidepressants were higher during these encounters for autistic individuals.

Citation: Birch, R. C., Foley, K.-R., Pollack, A., Britt, H., Lennox, N., & Trollor, J. N. (2017). Problems managed and medications prescribed during encounters with people with autism spectrum disorder in Australian general practice. *Autism*, 1362361317714588. https://doi.org/10.1177/1362361317714588

4.3.27 Aging well on the autism spectrum: The perspectives of autistic adults and carers

Published 11 Aug 2017

This paper involves interviews with autistic adults and carers regarding what it means to "age well" on the autism spectrum. Eight key factors were found to be important as autistic adults age: "myself" as an individual, "being autistic" specifically, "lifestyle and living well", "being supported" both formally and informally, the "life environment" such as security and culture, the role of "others", "relating to others", and finally "societal attitudes and acceptance" of autism and autistic people.

Citation: Hwang, Y. I. J., Foley, K.-R., & Trollor, J. N. (2017). Aging well on the autism spectrum: The perspectives of autistic adults and carers. *International Psychogeriatrics*, 1–14. https://doi.org/10.1017/S1041610217001521

4.3.28 Autism encyclopedia entry

Published 31 Jan 2017

Autism spectrum disorder is a neurodevelopmental disorder that is both high in prevalence and most commonly lifelong in nature. Despite this, there is a dearth of available information regarding the disorder in later life. Existing evidence indicates poor outcomes in adult life in a range of areas of health and wellbeing, though more information is needed to create a more comprehensive understanding of the circumstances and needs of autistic adults as they age.

Citation: Hwang, Y. I. (Jane), Foley, K.-R., & Trollor, J. (2016). Autism Spectrum Disorder. In N. A. Pachana (Ed.), *Encyclopedia of Geropsychology* (pp. 1–11). Springer Singapore. https://doi.org/10.1007/978-981-287-080-3_305-1

4.3.29 Management of mental ill health in autistic adults

Published 1 Nov 2015

This paper describes mental ill health in autistic adults and importantly identifies specific considerations for General Practitioners during assessment and management. Its suggestions include the incorporation of autism-specific knowledge and adaptation for:

1. Communication
2. Awareness of physical health comorbidities
3. Management of challenging behaviour
4. The environment
5. The role of carers
6. Valuing neurodiversity

Citation: Foley, K.-R., & Trollor, J. (2015). Management of mental ill health in people with autism spectrum disorder. *Australian Family Physician*, *44*(11), 784–790.

4.4 Ongoing work and outputs

Full details of the ongoing work of the team on important outputs has been provided to the Autism CRC. A summary is provided below to ensure that duplication of work in these topic areas is avoided.

The ALSAA team is currently working on publications in the following broad areas:

1. Performance in activities of daily living
2. Autism diagnosis in adulthood
3. Well-being of carers of autistic adults

Across a variety of research teams numerous projects and manuscripts are currently underway exploring additional topic areas including:

1. Coping and resilience in autistic adults
   a. Conceptual and predictive distinctiveness of coping and emotion regulation in an autistic sample
2. Investigating the predictors of employment outcomes amongst autistic adults
3. Sleep and its correlates, cross-sectional and longitudinal associations
4. Employment experiences on the autism spectrum
   a. Investigating the predictors of employment outcomes amongst autistic adults
   b. Predictors of optimal employment outcomes amongst Australian autistic adults
5. Health service barriers and usage for Australian autistic individuals"
   a. Barriers to healthcare for Australian autistic adults
   b. Preventative health check uptake in Australia autistic adults
   c. Understanding the health needs and health service use of Australian autistic adults
6. Loneliness in Australian autistic individuals
   a. Loneliness over time in Australian autistic adults
7. Pathways, predictors and impact of receiving an autism spectrum diagnosis for adults in Australia
8. Experiences of bullying and trauma in autistic individuals
   a. Violent victimisation experiences of autistic adults
   b. ASD and workplace bullying
   c. Physical and sexual violence reported by autistic adults: Risk factors and impact
   d. Traumatic experiences in autistic adults
9. Exploring the experiences of parents and carers of transition aged autistic youth

10. Does insomnia impact quality of life in autistic adults?

    a. Examining depression, sleep quality and fatigue in autistic adults and their relationship with social wellbeing

    b. Are traits associated with autism longitudinal predictors of insomnia, anxiety and depression in autistic older adolescents and adults?

    c. Network analysis: Relationships between depression and sleep difficulties in autistic adolescents and adults

    d. Exploring relationships between anxiety, wellbeing, sleep and fatigue.

    e. Exploring insomnia symptoms in autistic and non-autistic adults cross-sectionally and 2-years later

11. Autism across the lifespan: Exploring the experiences of autistic individuals with a co-occurring intellectual disability

    a. Investigating of the added impact of intellectual disability in autism

12. Quantifying gender differences among adults on the autism spectrum

    a. Changes across the lifespan by gender in RRBs and sensory features

13. Multiplex vs. simplex profiles of adults on the spectrum

14. Scale validations in autism DSM5

    a. SAD-D factor structure and convergent validity in autistic adults

    b. Trauma scale validity in autism

    c. Factor analysis of the Glasgow Sensory Questionnaire in different samples

    d. Developing a revised Impact of Diagnosis Scale

15. Understanding and preventing suicidal behaviour in individuals with autism spectrum disorder

    a. Identifying predictors of suicidality in autistic people with co-morbid Intellectual Developmental Disorder / Intellectual Disability (IDDID)

    b. A longitudinal study among autistic adults examining the effects of wellbeing and depression on suicidal ideation

16. What's in a name? Autism language preferences in the Australian autism community

17. Characterizing the emotion-related characteristics of autistic adults, and outcomes thereof

18. The cardiometabolic risk profile of people with autism

19. Coping strategies of carers of autistic adolescents and adults and their impact on carer well-being are associated with increased mental well-being.

20. Special abilities and interests of autistic adults

21. Influence of autism symptoms and transdiagnostic factors on anxiety, depression and insomnia in adolescents and adults with autism spectrum disorder

22. Health-related physical activity in autistic adults: Results from the Australian Longitudinal Study of Autism in Adulthood.

23. What's in a name? Autism language preferences in the Australian autism community

24. Roles of emotion regulation and intolerance of uncertainty in predicting mental health of autistic youth and adults using a longitudinal study

25. Understanding the impact of relationships upon Quality of Life: A comparison of autistic and neurotypical adults' self-reports.

26. Atypical interoceptive awareness in autistic adults

27. Exploring access to intervention and support services in Australian autistic adolescents and adults

28. Understanding the supports networks of carers of autistic adults

29. Exploring the rates and predictors of substance use in Australian autistic adults

4.5 Limitations

As noted, the ALSAA gathered a large and nationwide sample. However, the female bias in the gender distribution of the ALSAA sample means that some caution is needed when considering the implications for all Australian autistic adults. Higher female participation rates have been noted in other online autism research (Gilmour et al., 2012; Kapp et al., 2013; Nicolaidis et al., 2013).

Given the geographic spread of Australia and resourcing requirements, it was impossible to individually reconfirm diagnosis of autism. We did ask participants in Time 2 to send a copy of their diagnostic report, though only a smaller percentage of participants did this. In Time 1 and 2 we asked participants to provide details on their diagnosing clinician(s). Researchers have the option to use the Autism Quotient – 28 (Hoekstra et al., 2011) data gathered to restrict participants in their data analysis to those who score above the cut-off on this screen measure. Conversely, given the known "lost generation" of autistic adults (Lai & Baron-Cohen, 2015) who remain undiagnosed, we allowed the small number of self-diagnosed autistic adults who approaches us for participation to be included in the ALSAA. These participants have been included in the majority of publications arising from ALSAA data to date. We feel that this flexible approach is a strength of the ALSAA, allowing findings to be more representative of those autistic adults who for various reasons have not sought a formal diagnosis. Future users of the data will need to determine whether to limit participants to those who report a formal diagnosis.

The ALSAA is primarily a standardised questionnaire-based study, which seeks to maximise sample size and researchers' ability to make quantitative comparisons. However, in many sections of the ALSAA, open-ended survey items were added which allow potentially deeper understanding

in mixed methods analysis of ALSAA data. Furthermore, some sub studies we conducted have gathered interview or other qualitative data.

A final key limitation of ALSAA is the average 2.5-year time period between Time 1 and Time 2 data. Change in circumstance in adulthood can often take longer than two and a half years. Ideally a third and subsequent datapoint would be gathered, which would require longer-term research funding.

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5. Capacity building

5.1 Student thesis completions

Several students completed their thesis using ALSAA data.

5.1.1 Completed students

Dr Jane Hwang: Ageing Well

    University: UNSW

    Degree: Doctor of Philosophy

Taylor Stacey: Leisure Satisfaction

    University: Australian Catholic University

    Degree: Occupation Therapy (Honours)

Dr Dawn Ee: Loneliness

    University: UNSW

    Degree: Bachelor of Medical Studies / Doctor of Medicine

Dr Marisse Sonido: Carers of autistic adults

    University: UNSW

    Degree: Bachelor of Medical Studies / Doctor of Medicine

Madeleine Harsanyi: Employment of autistic adults

    University: Australian Catholic University

    Degree: Occupation Therapy (Honours)

Nicola Coleman: Activities of Daily Living

    University: Australian Catholic University

    Degree: Occupation Therapy (Honours)

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5.1.2 Continuing students

Yunhe Huang: Diagnosis in Adulthood

    University: UNSW

    Degree: Doctor of Philosophy

Georgia Bruce: Barries to Healthcare

    University: Western Sydney University

    Degree: Occupation Therapy (Honours)

Azeem Travedi: Healthcare utilisation

    University: UNSW

    Degree: Bachelor of Medical Studies (Honours) / Doctor of Medicine

Melanie Muniandy: Coping and resilience

    University: LaTrobe University

    Degree: Doctor of Philosophy

Christina Matthews: Impact of intellectual disability

    University: UNSW

    Degree: Master of Public Health

5.2 Research staff development

Numerous staff have benefitted from rich research engagement on the ALSAA over its six-year funding window. These staff include:

1) Professor Julian Trollor
2) Dr Kitty Rose-Foley, Postdoctoral Research Fellow
3) Dr Jane Hwang, Research Assistant
4) Dr Samuel Arnold, Postdoctoral Research Fellow
5) Ashley Stevens, Research Assistant

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6) Dr Marisse Sonido, Casual Research Assistant

7) Dr Natalie Roberts, Research Assistant

8) Sara Walker, Research Assistant

9) Aishani Desai, Research Assistant

5.3 Related sub projects and grants

Several subprojects have been completed or are on-going related to the ALSAA project and completed by members of the ALSAA team. Further information on these projects and related publications are available on the Autism CRC website.

1) Using Big Data to Answer Important Questions on Health and Wellbeing for People with Autism Spectrum Disorders (Autism CRC Number 3.038RI)

2) Uncovering the Hidden Histories of Late-Diagnosed Autistic Adults (Autism CRC Number 0.013RI)

3) Development of an Autism-Specific Quality of Life Assessment for use with Autistic Adults (Autism CRC Number 3.068RI)

4) Investigating Autistic Burnout (Autism CRC Number 3.076RI)

5.4 Inclusive research

ALSAA's work on the Inclusive Research Protocol, as well as engaging with autistic peer researcher Julianne Higgins on the Autistic Burnout project, led to the successful application to the Autism CRC to become a licensed Research Co-Production Partner. Information on 3DN's status as a Research Co-Production Partner can be accessed here:
https://www.autismcrc.com.au/coproduction/unsw

5.5 Community engagement and policy submissions

In addition to publication and presentation in academic and professional forums, the ALSAA team participated in numerous community engagement activities through the life of the project.

1) Written submission and invited witness to the Senate Special Enquiry into Autism, 2021.

2) Written submission and invited witness to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, 2021.

3) Invited speakers webinar for Autism Month, Autism CRC 2019

4) Radio Interview – "What is Autism?" –Eastside FM 89.7 Arts Wednesday 13 March 2019.

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5) ABC Ballarat News, "Mortality among adults on autism spectrum almost double the rate of general population", 2 Apr 2019

6) SBS TV News, "People with autism die prematurely at twice the rate of the general population, an Australian-first study has found", 26 Feb 2019

7) Sydney Morning Herald news article, "People with autism dying at twice rate of general population: new study", 26 Feb 2019

6. Ongoing data access and collaboration

There are numerous ongoing projects that utilise ALSAA data. The ALSAA gathered a comprehensive range of measurements with many areas remaining for further analysis and outputs. The UNSW 3DN team is open to future collaborations with researchers interested in this area. As described below, intensive effort was put towards ensuring on-going access to data through a databank process with the Autism CRC. At the present time, not all data from Time 1 is able to be transferred to the Autism CRC databank.

6.1 Databanking

We endeavoured to build a databank of ALSAA data which could be accessed by autism researchers into the future. Ethically, specific consent or waiver is required to store and use data in a databank. Table 4 below indicates participant completion and databank consent status for participants at each wave/timepoint.

We had not established this consent and ethical approval when we began Time 1 data gathering, because the process and arrangements for data banking had not been fully established. Ethics approval for data banking was in place prior to Time 2 data gathering (UNSW HREC, number HC17982), including the establishment of a process for retrospective consent for Time 1 participants. Time 1 participants were contacted a total of three times (twice by email and then by text message). Many Time 1 consented for Time 1 data banking. Five Time 1 participants actively refused to give databank consent and others were lost to follow-up. Overall, 321 of 541 (59%) of Time 1 participants gave their consent for their Time 1 data to be added to a databank (see Table 4).

We analysed the self-report, carer and informant data for differences in socio-demographic statistics for those who did and did not give consent for databanking. We found the only significant result to be age at completion of survey for the autistic sample in the self-report survey. The relationship is significant, however it likely to have little or no clinical significance (39.4 years for those who did not consent versus 43.2 for those who did consent). We analysed country of birth, age at completion of survey, gender, remoteness and Autism Quotient total scores.

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Table 4: Participant Completion and Databank Consent

	Self-Report Autistic	Self-Report Controls	Carer	Informant	Total
Completed Time 1	251	146	102	42	541
Gave Time 1 Databank Consent (%)	157 (63)	80 (55)	62 (61)	22 (52)	321 (59)
Completed Time 2	157	71	57	22	307
Gave Time 2 Databank Consent (%)	157 (100)	70 (99)	57 (100)	22 (100)	306 (100)
Completed Time 2 Baseline	247	45	40	4	336
Gave Time 2 Baseline Databank Consent (%)	247 (100)	45 (100)	40 (100)	4 (100)	336 (100)
Total cross-sectional baseline	498	191	142	46	877
Total cross-sectional baseline available for databanking	404 (81)	125 (65)	102 (72)	26 (57)	657 (75)
Total data points gathered	655	262	199	68	1184
Total data points available for databanking	561 (86)	195 (74)	159 (80)	48 (71)	963 (81)

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7. Implications for future research and practise

The ALSAA succeeded in gathering a large, nationwide sample of autistic and non-autistic adults and carers who completed a comprehensive battery of self-report measures. Numerous publications have arisen from this dataset, with more upcoming. Data on additional topic areas has yet to be explored and is available to interested researchers. The ALSAA succeeded in meeting all its stated aims, though work focused on intellectual disability is ongoing.

A particular future focus is required in the area of mental health for autistic adults. More than half of the autistic sample reported anxiety symptoms and more than three-quarters reported depression symptoms. These concerning statistics are compounded by barriers to accessing healthcare and education of healthcare practitioners, as stated by one participant "Most clinicians know little to nothing about autism". Another emerging area is health promotion and preventative healthcare, which should be addressed by future studies.

7.1 Key recommendations

Although we outline a list of key recommendations below, we encourage the reader to engage with publications on specific topic areas for a more comprehensive understanding of recommendations arising from our work.

1. Longer-term follow-up studies of autistic adults are required

Although there is a growing body of literature on autism in adulthood, to our knowledge there is little data available that has tracked autistic adults over longer time periods, with nothing in Australia. Change can take more than two and half years in adulthood, and to effectively identify predictors and contexts that lead to successful aging for autistic adults requires longer term studies.

2. A national autism register with a focus on adults will achieve representative results

Similar to some international efforts, and the work of the Western Australian autism register, a voluntary opt-in national register could greatly propel scientific knowledge on autism in the Australian context, and position Australia strongly in internal efforts in autism research.

3. Identification of autism in administrative datasets will assist in understanding outcomes

Research using linked administrative datasets enables large samples and important findings which influence policy decisions. Currently using administrative data to research autism in Australia is

hampered by lack of identifiers of the presence of autism spectrum disorder. Advocacy is needed for Australian, state and territory government services to include identifiers of autism and other developmental disabilities in its administrative data collections. Furthermore, the Autism CRC and community should consider support for the newly proposed National Disability Data Asset which would enable use of pre-linked multiagency data for the purposes of understanding a range of experiences and outcomes for those with autism spectrum disorder.

4. Further research is required on access to healthcare for autistic adults

Our manuscript in development regarding barriers to healthcare highlights the inequitable access to healthcare experienced by autistic adults, and the relationship of these barriers to anxiety and overall disability. More research is needed to fully understand these barriers, and to trial interventions and policy initiatives that reduce these barriers. A specific focus on access to preventative healthcare would be of benefit.

5. Upskilling of health practitioners is required to improve healthcare

Our work on psychotropic prescribing highlights substantial inappropriate use of medications for behavioural management purposes in Australia. Participants have also commented that "Most clinicians know little to nothing about autism" and "it would be nice to have a list of 'autism friendly' practices", with more work analysing this data forthcoming. We recommend work is undertaken to audit existing education provided to undergraduate healthcare practitioners particularly to identify and address deficit focused depictions of autism. We recommend the development of educational resources and capacity building across university and professional development settings.

6. Efforts to enhance community awareness of autism will assist inclusion for autistic adults

Our work on loneliness and impact of diagnosis among other areas highlights the need for an expanded understanding of autism within our broader community beyond that of stereotypical media portrayals. Frequently difficulties are encountered that relate to the double empathy problem (Milton, 2012) and the misunderstandings that occur between autistic and non-autistic adults, limiting the likelihoods of mutually beneficial relationships.

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Our values

Inclusion
Working together with those with the lived experience of autism in all we do

Innovation
New solutions for long term challenges

Evidence
Guided by evidence-based research and peer review

Independence
Maintaining autonomy and integrity

Cooperation
Bringing benefits to our partners; capturing opportunities they cannot capture alone

Australian Government
Department of Industry, Science, Energy and Resources

AusIndustry
Cooperative Research Centres Program