

BMJ Open

BMJ Open is committed to open peer review. As part of this commitment we make the peer review history of every article we publish publicly available.

When an article is published we post the peer reviewers' comments and the authors' responses online. We also post the versions of the paper that were used during peer review. These are the versions that the peer review comments apply to.

The versions of the paper that follow are the versions that were submitted during the peer review process. They are not the versions of record or the final published versions. They should not be cited or distributed as the published version of this manuscript.

BMJ Open is an open access journal and the full, final, typeset and author-corrected version of record of the manuscript is available on our site with no access controls, subscription charges or pay-per-view fees (<http://bmjopen.bmj.com>).

If you have any questions on BMJ Open's open peer review process please email info.bmjopen@bmj.com

BMJ Open

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

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2019-030798
Article Type:	Cohort profile
Date Submitted by the Author:	02-Apr-2019
Complete List of Authors:	<p>Arnold, Samuel; UNSW, Department of Developmental Disability Neuropsychiatry (3DN); Autism CRC</p> <p>Foley, Kitty-Rose; Southern Cross University - Gold Coast Campus, School of Health and Human Sciences; Autism CRC</p> <p>Hwang, Ye In; UNSW, Department of Developmental Disability Neuropsychiatry (3DN); Autism CRC</p> <p>Richdale, Amanda; La Trobe University, Olga Tennison Autism Research Centre, School of Psychology and Public Health; Autism CRC</p> <p>Uljarevic, Mirko ; Stanford University, Stanford Autism Center, Division of Child and Adolescent Psychiatry, Department of Psychiatry and Behavioral Sciences, School of Medicine; La Trobe University, Olga Tennison Autism Research Centre, School of Psychology and Public Health</p> <p>Lawson, Lauren; La Trobe University, Olga Tennison Autism Research Centre, School of Psychology and Public Health; Autism CRC</p> <p>Cai, Ru; La Trobe University, Olga Tennison Autism Research Centre, School of Psychology and Public Health; Autism CRC</p> <p>Falkmer, Torbjorn; Curtin University, School of Occupational Therapy, Social Work and Speech Pathology; Autism CRC</p> <p>Falkmer, Marita; Curtin University, School of Occupational Therapy, Social Work and Speech Pathology; Autism CRC</p> <p>Lennox, Nick; University of Queensland, Australia, Queensland Centre for Intellectual and Developmental Disability, Mater Research Institute - UQ; Autism CRC</p> <p>Urbanowicz, Anna; RMIT University, Health, Society & Medicine Research Program, Social and Global Studies Centre; Autism CRC</p> <p>Trollor, Julian; UNSW, Department of Developmental Disability Neuropsychiatry (3DN); Autism CRC</p>
Keywords:	Autism, Longitudinal, Adult

SCHOLARONE™
Manuscripts

Title

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

Author Names and Affiliations

Samuel R. C. Arnold^{*a,b} <samuel.arnold@unsw.edu.au>

Kitty-Rose Foley^{*b,c} <Kitty-Rose.Foley@scu.edu.au>

Ye In (Jane) Hwang^{a,b} <jane.hwang@unsw.edu.au>

Amanda L. Richdale^{b,d} <A.Richdale@latrobe.edu.au>

Mirko Uljarevic^{e,d,b} <mirkoulj@stanford.edu>

Lauren P. Lawson^{b,d} <L.Lawson@latrobe.edu.au>

Ru Ying Cai^{b,d} <R.Cai@latrobe.edu.au>

Torbjorn Falkmer^{b,f} <T.Falkmer@curtin.edu.au>

Marita Falkmer^{b,f,g} <Marita.Falkmer@curtin.edu.au>

Nick Lennox^{b,h} <n.lennox@uq.edu.au>

Anna Urbanowicz^{b,h,i} <a.urbanowicz@rmit.edu.au>

Julian N. Trollor^{+a,b} <J.Trollor@unsw.edu.au>

Affiliations

- a- Department of Developmental Disability Neuropsychiatry (3DN), UNSW Sydney, New South Wales, Australia
- b- Cooperative Research Centre for Living with Autism (Autism CRC), Brisbane, Queensland, Australia
- c- School of Health and Human Sciences, Southern Cross University, Gold Coast, Bilinga, Queensland, Australia
- d- Olga Tennison Autism Research Centre, School of Psychology and Public Health, La Trobe University, Bundoora, Victoria, Australia
- e- Stanford Autism Center, Division of Child and Adolescent Psychiatry, Department of Psychiatry and Behavioral Sciences, School of Medicine, Stanford University.

- 1
2
3 f- School of Occupational Therapy, Social Work and Speech Pathology, Curtin
4 University, Perth, Western Australia, Australia
5
6 g- School of Education and Communication, CHILD Programme, Institution of
7 Disability Research, Jonkoping University, Jonkoping, Sweden
8
9
10 h- Queensland Centre for Intellectual and Developmental Disability, Mater Research
11 Institute - UQ, The University of Queensland, South Brisbane, Queensland, Australia
12
13 i- Health, Society & Medicine Research Program, Social and Global Studies Centre,
14 RMIT University
15
16

17 *Joint first author

18
19 +Corresponding author
20
21
22
23
24
25

26 Correspondence concerning this article should be addressed to Prof. Julian Trollor,
27 Department of Developmental Disability Neuropsychiatry (3DN), 34 Botany St, UNSW
28 Sydney, 2052, New South Wales, Australia. Telephone: +61-2-9931-9160. Email:
29 j.trollor@unsw.edu.au
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

Abstract (300 Words)

Purpose

There is a significant knowledge gap regarding the lives of adults on the autism spectrum. Some literature suggests significant health and mental health inequalities for autistic adults, yet there is a lack of comprehensive longitudinal studies exploring risk factors. Further, most research does not include the perspective of autistic adults in its conduct or design. Here we describe the baseline characteristics and inclusive research approach of a nationwide longitudinal study.

Participants

The Autism CRC's ALSAA is a questionnaire-based longitudinal study of autistic adults (25+ years old) with follow-up at 2-year intervals. Autistic advisors were involved in each stage of research apart from data analysis. Three questionnaires were developed: self-report, informant report, and carers.

Findings to date

An inclusive research protocol was developed and agreed with autistic advisors. Baseline data were collected from 295 autistic adults ($M=41.8$ years, $SD=12.0$), 146 comparison participants, and 102 carers. Majority of autistic participants (90%) had been diagnosed in adulthood ($M=35.3$ years, $SD=15.1$). When compared to controls, autistic adults scored higher on self-report measures of current depression and anxiety. Participant comments informed on-going data gathering. Participants commented on questionnaire length, difficulty with literal interpretation of forced response items, and expressed gratitude for research in this area.

Future plans

1
2
3 A large comprehensive dataset relating to autistic adults and their carers has been gathered,
4
5 creating a good platform for longitudinal follow-up and collaborative research. Baseline data
6
7 confirms poorer mental health of autistic adults. The ALSAA demonstrates a working
8
9 approach to inclusive research.
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

For peer review only

Strengths and limitations of this study

- Autism related research efforts and funding has focused on the period from infancy to mid childhood, this research focuses on autistic adults and their carers.
- The ALSAA uses an inclusive research approach to gather a comprehensive range of measures addressing identified research priorities.
- A large proportion of autistic (50%, $n=295$) and non-autistic (80%, $n=146$) females have participated in Time 1 data gathering.
- Participants self-report their autism diagnosis, and a subsample ($n=32$) are not yet formally diagnosed.
- The ALSAA is a unique resource for exploring multiple research questions regarding the lives of Australian autistic adults.

Introduction

Although autism is a lifelong condition, most autism related research efforts and funding has focused on the period from infancy to mid childhood¹. The best available evidence suggests an adult population prevalence of at least 1.1%². It is likely that autism is under-recognized or under-diagnosed in adults^{3,4}, particularly in women without intellectual disability^{2,5}.

Although an emerging body of research explores outcomes and support needs of autistic individuals beyond childhood and adolescence, studies including autistic adults remain frequently focused on younger adults⁶⁻⁸. This is reflected in recent commentary from an autistic researcher; “We know virtually nothing about what happens to us, autistic people, physically, cognitively, emotionally and socially as we pass through middle and older age”⁹(p515).

The growing body of evidence suggests higher rates of physical and mental health conditions, increased mortality and higher rates of intellectual disability than in the general population¹⁰. Autistic adults have higher prevalence of chronic medical conditions, including conditions such as stroke, vision and hearing impairments, and Parkinson’s disease¹¹⁻¹⁴. These outcomes are experienced by many autistic adults regardless of intellectual functioning⁷. It has been reported that between 25%-84% of autistic adults have a diagnosed mental health condition, with depression and anxiety the most commonly reported conditions¹⁵⁻¹⁹. Autistic adults have higher rates of suicide^{16,20}, increased mortality and reduced life expectancy²¹. Despite widespread acknowledgement of the comorbidity between autism and intellectual disability, prevalence estimates of intellectual disability in autism and vice versa have been inconsistent²². Earlier studies report that between 40 to 70% of those with autism also have an intellectual disability²³⁻²⁵ though a more recent study reports fewer adults on the autism spectrum as having intellectual disability².

1
2
3 Studies investigating outcomes related to daily activities and participation are also scarce²⁶.
4
5 Available studies report low employment rates²⁷, low community inclusion and limited social
6
7 relationships for autistic adults²⁸⁻³². A few studies have suggested that factors such as low
8
9 childhood IQ, autism severity, psychopathology, social and language development, and
10
11 access to services and intervention programs may be determinates of such outcomes ^{28, 33};
12
13 however, much remains to be understood about the sources of variability in these outcomes.
14
15

16
17
18 In general, much of the research remains limited by cross-sectional designs, mixed groups
19
20 with and without intellectual disability, and a focus on adults aged under 40 ^{7, 33-35}.
21

22
23 Longitudinal studies are crucial for exploring changing requirements over time and to inform
24
25 services how best to understand the health and wellbeing of autistic adults^{9, 36}. Whilst most
26
27 studies have focused on one aspect of life or outcomes, such as physical or mental health
28
29 comorbidities^{12, 15, 37} or quality of life^{29, 38}, very few comprehensive evaluations of health,
30
31 wellbeing and participation have been conducted³³. Further, research funding does not match
32
33 priorities identified by autistic adults, which include research on public services, improving
34
35 life skills and the future for autistic adults³⁹.
36
37

38
39 The majority of existing autism research is also limited by a lack of inclusive research
40
41 practices. There is a small but growing body of research on inclusive practices and co-
42
43 production in disability research with increasing examples in the autism field⁴⁰⁻⁴². In
44
45 principle, inclusive research must “address issues that really matter” to people with disability,
46
47 “must access and represent their views and experiences” and people “need to be treated with
48
49 respect by the research community”^{43(p16)}. Inclusive research encompasses a variety of
50
51 approaches, from including the individuals with the disability as advisors or consultants, to
52
53 working alongside academic researchers, or initiating or conducting the project as researchers
54
55 themselves⁴⁴. Due to a history of mistrust between researchers and autism self-advocacy
56
57 groups, inclusive methods are especially important in research involving adults on the
58
59
60

1
2
3 spectrum⁴⁵. Inclusive approaches ensure scientific findings are meaningful to the autism
4
5 community and sensitive to the lived experiences of individuals on the spectrum^{46, 47}.
6
7

8
9 The Cooperative Research Centre for Living with Autism (Autism CRC) Australian
10
11 Longitudinal Study of Adults with Autism (ALSAA) is Australia's first national longitudinal
12
13 study involving autistic adults aged 25 years and older. The ALSAA will contribute needed
14
15 longitudinal data across a range of health, functioning and participation domains. Data
16
17 gathered aligns with the research gaps identified above, and the priorities identified by
18
19 autistic adults⁴⁸. In comparison to current international longitudinal studies of autistic
20
21 adults⁴⁹⁻⁵¹ the ALSAA gathers a wider range of data points using standardised measures,
22
23 gathers data from a community comparison group, and importantly included autistic adults in
24
25 study design from the early stages of the project. The ALSAA will contribute to the
26
27 validation of several standardised measures for this population. Importantly, the ALSAA
28
29 gathers data specific to the unique context and service systems within Australia, pertinent
30
31 given the recent introduction of the National Disability Insurance Scheme (NDIS) and the
32
33 considerable differences in approaches to healthcare and disability across countries. The
34
35 ALSAA primarily aims to identify and comprehensively describe the profiles of Australian
36
37 autistic adults and to compare them to a control group. The aims of this paper are to describe
38
39 the methodological processes and the inclusive protocol adopted in the ALSAA, as well as to
40
41 present participant characteristics and feedback from the baseline data collection.
42
43
44
45
46
47

48 **Cohort Description**

49 *Design*

50
51
52 The ALSAA is a questionnaire-based, prospective, longitudinal cohort study with a planned
53
54 2-year follow-up. Initial design and development of the ALSAA occurred in collaboration
55
56 with researchers and clinical health professionals across Australia, including close
57
58
59
60

1
2
3 collaboration with the Autism CRC longitudinal Study of Australian School Leavers with
4 Autism (SASLA)⁵². Brief consultation also occurred with international experts and
5
6 researchers conducting similar longitudinal studies. Additionally, preliminary work on factors
7
8 influencing the research participation of autistic adults⁵³ influenced the ALSAA design,
9
10 including ensuring opportunities for participants to clarify questions, receive regular study
11
12 newsletters, and space for participants to provide explanations regarding their responses.
13
14

15
16
17 The ALSAA was developed with input from a research advisory network, consisting of
18
19 autistic adults and family members/carers of autistic adults who helped develop the surveys
20
21 to ensure the questions were relevant, accessible and valid. The ALSAA Inclusive Research
22
23 Protocol was developed based on the principles of inclusive research⁵⁴, the Autism CRC
24
25 report *Inclusive Research Practice Guides and Checklists for Autism Research*⁵⁵, and
26
27 procedures similar to those employed by Nicolaidis and colleagues⁵⁶ (see Table 1). Since the
28
29 commencement of the ALSAA, this protocol has been reviewed by seven of the autistic
30
31 advisors and one carer advisor and has guided baseline outputs and the 2-year follow-up
32
33 design. Specifically, in the design stage of the ALSAA, members of the advisory network
34
35 were asked to identify ambiguous or inappropriate language, formatting issues and measures
36
37 which they thought may be interpreted inappropriately or differently due to poor clarity or
38
39 wording. Advisors have also provided feedback on ongoing research outputs.
40
41
42
43
44
45

46 **[Insert Table 1 here]**
47

48 *Participants*

49
50
51 There are three participant groups in the ALSAA: autistic adults, non-autistic general
52
53 community comparison controls, and carers of autistic adults. Inclusion criteria required the
54
55 control and autistic participants to be aged 25 years or older, live in Australia and have
56
57 sufficient English literacy skills to complete the survey, determined during a screening phone
58
59
60

1
2
3 call or online expression of interest (EOI). If an autistic individual was unable or unwilling to
4 self-report, they were given the option to ask an informant to complete an informant version
5 of the survey on their behalf. People with intellectual disability could complete the self-report
6 survey with support or participate via an informant respondent.
7
8
9
10

11
12
13 Informant respondents and carers needed to be 18 years or older, have sufficient English
14 literacy skills, live in Australia and be able to report on the life of the autistic person. The
15 content of the informant survey is slightly different to the self-report survey (see Table 2) due
16 to some measures, such as the Patient Health Questionnaire-9 (PHQ-9)⁵⁷, having no
17 informant version available. Carers, including family members and support people for the
18 ALSAA, were defined as people who provided unpaid care and support to either a family
19 member (including spouse) or friend who in on the autism spectrum. This is based on the
20 widely accepted definition proposed by Carers Australia
21 (<http://www.carersaustralia.com.au/about-carers/>).
22
23
24
25
26
27
28
29
30
31
32
33

34 *Survey*

35
36
37 Three versions of the survey were developed: 1) self-report, for autistic adults and non-
38 autistic controls, 2) informant, for carers/support people to complete about the autistic person
39 who is unable to, or does not want to self-complete, and 3) carer survey for carers/support
40 people/family members to complete about their own health and wellbeing. Surveys could be
41 completed via a paper copy or online. The paper copy was also available in large print. The
42 surveys involved a comprehensive range of measures (see Table 2). In selecting measures,
43 preference was given to measures that had established validity with people on the spectrum
44 and to those deemed suitable by the autistic advisors.
45
46
47
48
49
50
51
52
53
54
55
56

57 **[Insert Table 2 here]**
58
59
60

1
2
3 Each survey also contained closing feedback items, asking if any questions were confusing,
4 difficult, or upsetting, and any additional topics that should be included. It also asked how
5 long the survey took to complete (open-ended response), and an overall satisfaction with the
6 survey rated on a 5-point Likert scale. A final item asked for any further feedback.
7
8
9

10 11 12 13 *Procedure*

14 15 16 *Piloting*

17
18
19 Each version of the survey was piloted by a small number of people on the spectrum, autistic
20 advisors and/or carers. Volunteers received two copies, one copy to complete, with data
21 recorded where possible in the ALSAA dataset, and the other for their feedback.
22
23

24
25
26 Considerable changes to each version of the survey were undertaken in response to feedback
27 from the autistic advisors and volunteers, including removing the Communication Checklist –
28 Adult⁵⁸, formatting changes and changes to item wordings where the item did not belong to
29 an existing standardised tool.
30
31
32
33

34 35 36 *Recruitment and Follow-up*

37
38
39 A recruitment target of 160 autistic adults was set to allow for regression analyses using
40 multiple predictor variables. Participants were recruited via advertisements through autism-
41 specific organisations, disability organisations, autism self-advocacy groups, employment
42 services, universities, Technical and Further Education (TAFE) institutes, psychology and
43 allied health private practices, carer organisations, and online autism communities. In
44 attempts to gather a sample more closely matched to Australian population estimates⁵⁹,
45 additional recruitment activities targeted adults on the spectrum with intellectual disability,
46 and males without autism. General community members, autistic adults and carers of autistic
47 adults who were willing to participate in the ALSAA contacted the research team based at
48
49
50
51
52
53
54
55
56
57
58
59
60

1
2
3 The University of New South Wales (UNSW Sydney) via telephone, email or through
4 completing a short online EOI. After eligibility screening, their details were added to the
5 participant database and they were mailed a paper copy or emailed a link to their survey
6 depending on their preference.
7
8
9
10
11
12

13 Due to a high number of responses and advice from autistic advisors, participants who self-
14 identified as being autistic, but did not have a formal diagnosis, representing the hidden
15 population and ‘lost generation’³ of autistic adults, were also recruited. Formally diagnosed
16 participants were asked to provide details of their diagnosis, year of diagnosis, and the
17 discipline and name of the practitioner(s) who diagnosed them. AQ-short cut-off scores (>65,
18 sensitivity .97, specificity .82)⁶⁰ also support diagnostic status. At the planned two-year
19 average Time 2 follow-up copies of participants’ diagnostic reports will be requested. From
20 November 2017 through 2019 participants are being recontacted using contact details
21 provided and considering their communication preferences that were recorded.
22
23
24
25
26
27
28
29
30
31
32

33 34 *Ethical Considerations*

35
36
37 Participants were supplied with the appropriate Participant Information Statement and
38 Consent Form (PISCF). For the online survey, participants were asked to confirm their
39 consent at commencement. Consent was inferred from participants who completed and
40 returned paper copies of the survey, as outlined in their PISCF. In the case where the autistic
41 adult had an intellectual disability a checklist for capacity to provide consent was used. This
42 checklist was completed by the carer/next of kin; it was adapted from a checklist developed
43 for use in the Study of Ageing in Intellectual Disability (SAGE)⁶¹. The study was approved
44 by the Human Research Ethics Committee at UNSW Sydney, Australia (No. HC15001).
45
46
47
48
49
50
51
52
53
54
55

56 57 *Data storage*

1
2
3 Online questionnaire data were entered directly by participants into Qualtrics Online Survey
4
5 Software (<https://www.qualtrics.com/>), whereas returned paper copy surveys were entered
6
7 into Qualtrics by a researcher or research assistant. Data from Qualtrics were stored on
8
9 password-protected UNSW Sydney servers. Recently, ethics approval for establishment of a
10
11 databank for the ALSAA data, to allow collaboration with external researchers has been
12
13
14 obtained.

17 *Statistical analysis*

20
21 STATA Statistical Analysis Software 14⁶² and IBM SPSS Statistics 22⁶³ were used for
22
23 cleaning, coding, and statistical analyses. For the current manuscript, STATA was used to
24
25 obtain descriptive statistics regarding recruitment, participant feedback, and participant
26
27 characteristics. For describing this cohort profile, listwise deletion was used for specific
28
29 analyses when data were missing completely at random, after checking for difference in
30
31 demographics and AQ score for dropped participants where appropriate. Subsample sizes are
32
33 noted throughout.
34
35

37 *Recruitment statistics*

40
41 Recruitment commenced in July 2015. At the close of Time 1 data gathering in November
42
43 2017, 345 autistic adults, 221 non-autistic adults, 185 carers, and 78 informants had
44
45 registered their interest in the study. Of these, 237 autistic adults, 130 non-autistic adults, 100
46
47 carers, and 42 informant reporters completed the entire survey. Overall, a total of 295 autistic
48
49 adults participated including all survey formats and partial survey completions. A small
50
51 proportion of participants were deemed ineligible during screening (see Table 3), generally
52
53 due to being under 25 years, not caring for an adult aged 25+ years old, or being located
54
55 outside of Australia. Participants were recorded as partial completions if at close of Time 1
56
57 their surveys contained the initial demographic items completed and some additional useable
58
59
60

1
2
3 data. From available data there was no significant difference in gender, $X^2(4, n=337) = 1.07$,
4
5 $p=.898$, or approximate age [$F(4, 4) = 2.04, p=.09$] based on survey commencement,
6
7 eligibility or completion status for the autistic adults.
8
9

10
11 **[Insert Table 3 here]**
12

13
14 *Time taken to complete, and satisfaction with, the survey*
15

16
17 Participants reported varying times taken to complete the entire survey. Self-reporting autistic
18
19 participants reported between 20 minutes and 12 hours to complete with an average time of
20
21 156 minutes ($n=164, SD=111$), though several responses ($n=53$) were not easily convertible
22
23 to numeric values for analysis, for example “few days”, “no idea”, or no response to the item
24
25 ($n=36$). Non-autistic, self-reporting participants reported a range of 20 minutes to 5 hours
26
27 with an average time of 106 minutes ($n=98, SD=74$). This was significantly less than self-
28
29 reporting autistic adults despite their completing almost all the same measures and domains,
30
31 $t(260)=-4.94, p<.001$. Carers took 75 minutes on average ($n=81, SD=62$) and informant
32
33 responders took 103 minutes on average ($n=27, SD=54$) to complete surveys. The majority of
34
35 participants (64%, $n=482$) reported that they were satisfied or very satisfied with the survey;
36
37 few participants were dissatisfied (6%) (Figure 1). There was no association between time
38
39 taken to complete the self-report survey and level of satisfaction ($n=262, r_s = .10, p=.09$), and
40
41 no difference in satisfaction based on survey type, $X^2(9, n=482) = 11.2, p=.26$.
42
43
44
45
46
47

48 **[Insert Figure 1 here]**
49

50
51 The most common negative feedback related to the length of surveys, or to difficulty with
52
53 literal interpretations of forced response items where participants felt the options provided did
54
55 not match their circumstances. Several participants provided feedback that they were grateful
56
57 for research in this area. Additional topics of interest were suggested, as well as the potential
58
59
60

1
2
3 removal of some questionnaires (e.g., the Brief COPE). Revision of items referring to social
4 supports was suggested, as some participants found these upsetting.
5
6
7

8 *Summary of participant characteristics*

9
10
11 The age of autistic participants ranged from 25 to 80 years, with a high proportion of females
12 (50%, $n=295$) across all autistic samples. Across all autistic participants 25% were married
13 and 36% were living as a couple. Over half (57%, $n=42$) of the informant report sample lived
14 with their parents (see Table 4), in contrast to self-reporting autistic adults who most
15 frequently lived as a couple (45%, $n=295$) or alone (26%, $n=295$). Self-reporting autistic
16 adults did not differ to control participants on rural / remoteness according to Australian
17 Statistical Geography Standard-Remoteness Area (ASGS-RA) classification, $\chi^2(4, n=378) =$
18 9.36, $p=.05$ ($n=21$ missing). They were more likely to have greater socioeconomic
19 disadvantage according to the postcode-based Socioeconomic Index for Areas (SEIFA)
20 decile, $t(376)=2.96$, $p<.01$ ($n=21$ missing, NB. SEIFA / rurality not available for all
21 postcodes), though were still above average compared to the Australian population. Time 2
22 data gathering will seek to gather household income data to more accurately determine
23 socioeconomic disadvantage.
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40

41
42 As shown in Table 5, the majority (97%, $n=295$) of all autistic participants met the AQ-Short
43 cut-off for identifying autism, compared to 30% ($n=60$) of biologically related carers and
44 22% ($n=137$) of non-autistic control participants. Asperger's syndrome was the most
45 frequently reported formal diagnosis. Self-report, formally diagnosed autistic participants on
46 average were diagnosed 6.9 years prior to survey completion, and the majority (90%; $n=217$,
47 4 missing) received their diagnosis in adulthood. A preliminary analysis of gender differences
48 for self-reporting autistic adults was also conducted. In comparison to males, self-reporting
49 formally diagnosed females did not differ significantly on age of diagnosis $t(192)=.39$, $p=.70$
50
51
52
53
54
55
56
57
58
59
60

($n=4$ missing). Comparing males with females, including non-diagnosed autistic adults, there was no difference in number of individuals currently married or in a defacto relationship, $X^2(1, n=241) = .8, p=.38$, or in their educational status, $X^2(2, n=241) = 4.66, p=.10$. Females were significantly different regarding employment status $X^2(4, n=241) = 18.77, p=.001$, though only relating to the number providing homecare ($n=19$ female vs. $n=1$ male).

In the non-autistic control sample, participant ages ranged from 25 to 79 years, with a high proportion (80%, $n=146$) of females. The majority lived as a couple (72%) and were married (62%). The control sample was significantly different to the self-reporting autistic adults (with and without a formal diagnosis) on several demographics including gender, $X^2(2, n=399) = 26.5, p<.001$, living situation, $X^2(5, n=399) = 33.2, p<.001$, marital status, $X^2(8, n=398) = 47.1, p<.001$ ($n=1$ missing), employment status, $X^2(6, n=367) = 18.3, p=.005$ ($n=32$ missing), and higher education status, $X^2(2, n=399) = 22.4, p<.001$. The control sample was also significantly less likely to meet the PHQ-9 cut-off for depression, $X^2(1, n=354) = 54.9, p<.001$ ($n=45$ missing), less likely meet the DSM5 GAD-A cut-off⁶⁴ for anxiety, $X^2(1, n=366) = 67.8, p<.001$ ($n=33$ missing), and less likely to have a history of psychiatric illness, $X^2(1, n=384) = 82.1, p<.001$ ($n=15$ missing), compared to self-reporting autistic adults. There were no significant differences for self-reporting autistic adults missing data on the PHQ-9 or DSM5 GAD-A based on age, gender or AQ score.

As shown in Table 6, the majority (43%; $n=98, 4$ missing) of carers were mothers of an autistic adult, followed by partners or spouses (23%). Carers' ages ranged from 21 to 78 years. The majority were female (83%, $n=102$), married (66%), and living as a couple (75%). Carers spent an average 63.4 ($SD=57.80, n=92$) hours per week with the adult with autism, and the average age of the autistic adult cared for was 37.5 years (range 25-96 years, $SD=13.21$). The majority of carer participants (76%, $n=102$) are linked to a self-report or informant-report responses.

1
2
3 [insert Table 4 here]

4 [insert Table 5 here]

5 [insert Table 6 here]

Findings to date

15 Using an inclusive research approach, the ALSAA has collected a detailed profile of the
16 physical and mental health, productivity, wellbeing and health service use of autistic adults
17 aged 25+ years, and their carers, living in Australia. There were high numbers of recruitment
18 responses across the four Time 1 survey populations (autistic and control adult self-report,
19 informant report on autistic adults, carer self-report). The ALSAA Time 1 data has been used
20 in several studies of psychotropic medication use⁶⁵, leisure participation⁶⁶, ageing well⁶⁷,
21 loneliness⁶⁸ and employment⁶⁹. ALSAA and SASLA pooled data has been used to explore
22 cognitive reappraisal⁷⁰, suicidal ideation⁷¹, psychometric scale validation⁷², anxiety and
23 depression⁷³. Several other outputs are in development.

Participant characteristics

36 A large number of females on the spectrum ($n=150$) have participated in the ALSAA. This
37 will provide an opportunity to explore the different expression of autism characteristics in
38 females without intellectual disability^{5, 74}. Similar to findings in other studies^{10, 31}, self-
39 reporting autistic adults had high rates of depression (52%), anxiety (55%), and a frequent
40 history of psychiatric diagnosis (89%), significantly more than the control sample. They were
41 less likely to be employed and less likely to have a university education compared with the
42 control sample.

Questionnaire feedback and completion

1
2
3 The length of the surveys may have led to some participants not completing following
4 registration, or to missing data or only partial completions. Longer survey length has been
5 linked to lower participation and completion of web-based surveys^{75, 76}. Despite emphasising
6 the ability to complete over several sessions, some participants commented that the survey
7 was “too long”. In contrast, survey length was not identified as an issue during pilot testing,
8 time to complete was not related to survey satisfaction, and some participants appreciated the
9 comprehensive nature of the surveys. Suggestions made in questionnaire feedback will be
10 incorporated in the design of the 2-year follow up. Follow-up design aims to reduce
11 assessment burden by reducing overall survey length and where appropriate pre-filling
12 repeated measures such as medical history. Additional areas of interest to the community will
13 be explored including bullying, relationships and terms used to describe individuals with an
14 autism spectrum diagnosis.

31 **Strengths and limitations**

32
33 An important strength of the study was the inclusive research approach using autistic
34 advisors. Frequently missing from autism research and other longitudinal studies, an
35 inclusive research protocol was developed for the ALSAA in consultation with autistic
36 advisors (see Table 1) and applied across all stages of the research process apart from the
37 analysis. Inclusive research has been found to increase the likelihood that findings are
38 translatable to the real world and focused on areas of need from community perspectives⁴³.
39 Best-practise processes of conducting inclusive research with autistic adults are not well
40 known, though more resources are becoming available⁷⁷ The ALSAA has engaged peer
41 researchers in some future outputs. An additional strength of the ALSAA design is its
42 consideration and partial overlap with several other national and international studies, for
43 example overlap with the Autism CRC SASLA longitudinal study allows for a lifespan
44 approach to be taken including data from late adolescence⁷⁰.

1
2
3
4
5
6 The ALSAA baseline sample is reflective of the convenience sampling methodology used.
7
8 Participants would appear non-representative of the Australian autism population given
9
10 approximate postcode-based above average socioeconomic status, a large female gender bias
11
12 for both autistic adults and controls, and that the majority of the autistic sample does not have
13
14 an intellectual disability. Earlier epidemiological estimates of autism²³ would suggest a larger
15
16 proportion of people with a diagnosis of autism and intellectual disability and a much higher
17
18 male to female ratio, though recent work questions these assumptions^{2, 78}. Self-selection in
19
20 online surveys can lead to a female gender bias⁷⁶, as also has been noted in other online
21
22 autism research⁷⁹⁻⁸¹. Commonly reported as a 4 to 1 male bias⁸², there is suggestion the true
23
24 autism gender ratio may be closer to 3 to 1⁷⁸ or lower⁷⁴ as females with autism are at a higher
25
26 risk of being underdiagnosed³.
27
28
29
30
31

32 The majority of the current autistic sample does not have an intellectual disability. Significant
33
34 barriers exist for people with intellectual disability to participate in a questionnaire-based
35
36 study⁸³. An alternative to directly gathering information from adults on the spectrum with
37
38 intellectual disability is the participation via an informant respondent. Although an informant
39
40 respondent survey was made available for the ALSAA, and despite targeted recruitment
41
42 efforts, there was low participation of people with intellectual disability.
43
44
45
46

47 A final limitation is the self-report questionnaire format of the ALSAA, particularly in
48
49 relation to self-reported diagnosis of autism and comorbid conditions without clinical
50
51 reassessment. This is offset by gathering of additional questions relating to autism diagnosis,
52
53 including asking if the respondent has a diagnostic report, name and type of clinician
54
55 providing diagnosis, and AQ scores. These variables could be used to identify subsamples
56
57 with stronger evidence of definite diagnosis of autism for separate analysis where necessary.
58
59
60

1
2
3 Further, diagnostic reports from participants will be gathered at follow-up to confirm
4 diagnosis. Gathering data from adults without a formal diagnosis is potentially a strength,
5 given the 'lost generation' of autistic adults³, significant barriers to diagnosis, and accuracy
6 issues with gold standard autism assessment tools⁸⁴; these participants could be overlooked in
7 other studies though they represent an important hidden population group. The self-report
8 format also prevents the quantification of participants' cognitive ability. The use of
9 standardised mental health screening measures with clinical cut-offs gathers some
10 information on co-occurring mental health conditions, though not as reliably as would be
11 available via clinical interview. Conversely, community-based sampling and use of self-
12 report questionnaires does allow for gathering a reasonably large sample, offsetting the risk
13 of including people with incorrect diagnostic data with increased statistical power and the
14 potential severity bias of clinical samples. Limitations and strengths of the ALSAA study
15 design will largely depend on the specific research question being explored, with sufficient
16 sample size and data points to partial-out subgroups and non-matched controls or to account
17 for common method variance as needed.

37 38 *Implications*

39
40
41 There is a significant knowledge gap regarding the lives of autistic adults. The ALSAA has
42 gathered a large comprehensive dataset relating to autistic adults and their carers, creating a
43 platform for longitudinal follow-up and collaborative research. The ALSAA is an important
44 resource for exploring multiple research questions regarding the lives of autistic adults.

45
46 However, as with all longitudinal research caution is required in drawing firm conclusions
47 from the ALSAA cohort in relation to the entire Australian autism population. Nevertheless,
48 this cohort provides the first opportunity to explore longitudinal outcomes of Australian
49 autistic adults. Having offline and informant versions of questionnaires, and questionnaires
50
51
52
53
54
55
56
57
58
59
60

1
2
3 reviewed by autistic advisors, facilitates greater accessibility for participants on the spectrum
4
5 and their carers.
6
7

8 The ALSAA study demonstrates a working approach to inclusive research with autistic
9
10 advisors. The inclusive research protocol developed in this study provides a useful basis for
11
12 other research endeavours. Following this protocol, future outputs such as peer-reviewed
13
14 manuscripts, presentations and reports from the ALSAA will also be developed in
15
16 consultation with autistic advisors or autistic peer researchers. Input from autistic advisors
17
18 has already improved the quality and relevance of initial outputs⁶⁵, identifying potential
19
20 alternative interpretations of findings based on lived experiences, and modifying the
21
22 methodology in one instance⁶⁸.
23
24
25
26

27 Some measures used in the ALSAA have not yet been validated with autistic adult samples
28
29 (e.g., DSM5 GAD-A, Emotion Regulation Questionnaire, PHQ-15). The ALSAA provides
30
31 the opportunity to explore the validity of these commonly used measures”
32
33
34

35 **Collaboration**

36
37
38 International studies involving autistic adults and utilising standardised measures are
39
40 underway in the United States, Netherlands and United Kingdom (e.g., SPARK
41
42 <http://sparkforautism.org>, AASPIRE <https://aaspire.org/>, the Netherlands Autism Register
43
44 <https://www.nederlandsautismeregister.nl> and the Adult Autism Spectrum Cohort-UK
45
46 <http://research.ncl.ac.uk/adultautismspectrum/>), though with less comprehensive ranges of
47
48 measures. During development of the ALSAA, consultation with international groups
49
50 occurred to ensure there were some synergies with these studies. Future international
51
52 comparisons will be possible, including pooling of data. This will allow for the creation of
53
54 much larger datasets and more in-depth understanding of life in adulthood for autistic people.
55
56
57
58
59
60

Further details

Contributors

Manuscript drafting was jointly led by SA and KF. All the authors had a role in contributing to the manuscript text.

Data Sharing Statement

Processes to establish data banking and sharing procedures are currently being finalised.

Please email the corresponding author regarding queries.

Ethics approval

The study was approved by the Human Research Ethics Committee at UNSW Sydney, Australia (No. HC15001).

Acknowledgements

The authors also acknowledge the valuable contribution of the Research Advisory Network members Matthew Bennett, Bob Boyce, Jen Harland, Julianne Higgins, Gabriel Nakhel, Joanne Mahony, Andrea Michael, Cheryl Strangio, and Chris Tanner whose insight and recommendations shaped this work. We also gratefully acknowledge the cooperation and participation of all participants on the autism spectrum and their carers involved in this study.

Funding

1
2
3 This work was supported by the Cooperative Research Centre for Living with Autism
4
5 (Autism CRC), established and supported under the Australian Government's Cooperative
6
7
8 Research Centres Program.
9
10
11
12
13

14 **Conflict of Interest**

15
16
17 The authors have no conflict of interest to report.
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

References

1. Seltzer MM, Shattuck PT, Abbeduto L, Greenberg JS. Trajectory of development in adolescents and adults with autism. *Mental Retardation and Developmental Disabilities*. 2004;10:234-47.
2. Brugha TS, Spiers N, Bankart J, Cooper S-A, McManus S, Scott FJ, et al. Epidemiology of autism in adults across age groups and ability levels. *The British Journal of Psychiatry*. 2016 2016/12/01;209(6):498-503. en.
3. Lai M-C, Baron-Cohen S. Identifying the lost generation of adults with autism spectrum conditions. *The Lancet Psychiatry*. 2015 2015/11/01;2(11):1013-27.
4. Van Wijngaarden-Cremers PJM, van Eeten E, Groen WB, Van Deurzen PA, Oosterling IJ, Van der Gaag RJ. Gender and Age Differences in the Core Triad of Impairments in Autism Spectrum Disorders: A Systematic Review and Meta-analysis. *Journal of Autism and Developmental Disorders*. 2014 March 01;44(3):627-35.
5. Bargiela S, Steward R, Mandy W. The Experiences of Late-diagnosed Women with Autism Spectrum Conditions: An Investigation of the Female Autism Phenotype. *Journal of Autism and Developmental Disorders*. 2016 2016/10/01;46(10):3281-94. en.
6. Jang J, Matson JL, Adams HL, Konst MJ, Cervantes PE, Goldin RL. What are the ages of persons studied in autism research: A 20-year review. *Research in Autism Spectrum Disorders*. 2014;8(12):1756-60.
7. Howlin P, Moss P. Adults with autism spectrum disorders. *Canadian Journal of Psychiatry*. 2012;57(5):275-83.
8. Nicolaidis C. Autism in Adulthood: The New Home for Our Emerging Field. *Autism in Adulthood*. 2018;1(1):1-2.
9. Michael C. Why we need research about autism and ageing. *Autism*. 2016;20(5):515-6.
10. Howlin P, Magiati I. Autism spectrum disorder: outcomes in adulthood. *Current Opinion In Psychiatry*. 2017;30(2):69-76.
11. Cashin A, Buckley T, Trollor J, Lennox N. A scoping review of what is known of the physical health of adults with autism spectrum disorder. *Journal of Intellectual Disabilities*. 2016.
12. Croen LA, Zerbo O, Qian Y, Massolo M, Rich S, Sidney S, et al. The health status of adults on the autism spectrum. *Autism*. 2015;19(7):814-23.
13. Jones KB, Cottle K, Bakian A, Farley M, Bilder D, Coon H, et al. A description of medical conditions in adults with autism spectrum disorder: a follow-up of the 1980s Utah/UCLA autism epidemiologic study. *Autism*. 2016;5:551-61.
14. Weiss JA, Riosa PB. Thriving in youth with autism spectrum disorder and intellectual disability. *Journal of Autism and Developmental Disorders*. 2015;45:2474-86.
15. Buck TR, Viskochil J, Farley M, Coon H, McMahon WM, Morgan J, et al. Psychiatric comorbidity and medication use in adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders*. 2014;44:3063-71.
16. Hedley D, Uljarević M, Wilmot M, Richdale A, Dissanayake C. Understanding depression and thoughts of self-harm in autism: A potential mechanism involving loneliness. *Research in Autism Spectrum Disorders*. 2018 2018/02/01;46:1-7.
17. Lever AG, Geurts HM. Psychiatric co-occurring symptoms and disorders in young, middle-aged, and older adults with autism spectrum disorders. *Journal of Autism and Developmental Disorders*. 2016;46:1916-30.
18. Matson JL, Williams LW. Depression and mood disorders among persons with Autism spectrum disorders. *Research in Developmental Disabilities*. 2014;35:2003-7.

19. Moss P, Howlin P, Savage S, Bolton P, Rutter M. Self and informant reports of mental health difficulties among adults with autism findings from a long-term follow-up study. *Autism*. 2015.
20. Hedley D, Uljarević M, Wilmot M, Richdale A, Dissanayake C. Brief Report: Social Support, Depression and Suicidal Ideation in Adults with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*. 2017 November 01;47(11):3669-77.
21. Hirvikoski T, Mittendorfer-Rutz E, Boman M, Larsson H, Lichtenstein P, Bolte S. Premature mortality in autism spectrum disorder. *The British Journal of Psychiatry*. 2015.
22. Matson JL, Nebel-Schwalm N. Comorbid psychopathology with autism spectrum disorder in children: an overview. *Research in Developmental Disabilities*. 2007;28:341-52.
23. Fombonne E. Epidemiology surveys of autism and other pervasive developmental disorders: an update. *Journal of Autism and Developmental Disorders*. 2003;33(4):365-82.
24. LaMalfa G, Lassi G, Bertilli M, Salvani R, Placidi GF. Autism and intellectual disability: a study of prevalence on a sample of the Italian population. *Journal of Intellectual Disability Research*. 2004;48:262-7.
25. Matson JL, Shoemaker M. Intellectual disability and its relationship to autism spectrum disorders. *Research in Developmental Disabilities*. 2009;30:1107-14.
26. Howlin P, Arciuli J, Begeer S, Brock J, Clarke K, Costley D, et al. Research on adults with autism spectrum disorder: roundtable report. *Journal of Intellectual and Developmental Disability*. 2015;40(4):388-93.
27. Hedley D, Uljarevic M, Cameron L, Halder S, Richdale AL, Dissanayake C. Employment programmes and interventions targeting adults with autism spectrum disorder: a systematic review of the literature. *Autism*. 2016:1-13.
28. Gray KM, Piccin AK, C. M., Taffe J, Parmenter TR, Hofer S, Einfeld S, et al. Outcomes in young adulthood: are we achieving community participation and inclusion? *Journal of Intellectual Disability Research*. 2014;58(8):734-45.
29. Henninger NA, Taylor JL. Outcomes in adults with autism spectrum disorders: a historical perspective. *Autism*. 2013;17(1):103-16.
30. Howlin P, Moss P, Savage S, Rutter. Social outcomes in mid- to later adulthood among individuals diagnosed with autism and average nonverbal IQ as children. *Journal of American Academy of Child & Adolescent Psychiatry*. 2013;52(6):572-81.
31. Magiati I, Tay XW, Howlin P. Cognitive, language, social and behavioural outcomes in adults with autism spectrum disorders: a systematic review of longitudinal follow-up studies in adulthood. *Clinical Psychology Review*. 2014;34:73-86.
32. Marriage S, Wolverson A, Marriage K. Autism spectrum disorder grown up: A chart review of adult functioning. *Journal of the Canadian Academy of Child and Adolescent Psychiatry*. 2009;18(4):322.
33. Levy A, Perry A. Outcomes in adolescents and adults with autism: a review of the literature. *Research in Autism Spectrum Disorders*. 2011;5:1271-82.
34. Seltzer MM, Krauss MW, Shattuck PT, Orsmond GI, Swe A, Lord C. The symptoms of autism spectrum disorders in adolescence and adulthood. *Journal of Autism and Developmental Disorders*. 2003;33:565-81.
35. Shattuck PT, Selter MM, Greenberg JS, Orsmond GI, Bolt D, Kring S, et al. Change in autism symptoms and maladaptive behaviors in adolescents and adults with an autism spectrum disorder. *Journal of Autism and Developmental Disorders*. 2007;37:1735-47.
36. Happe F, Charlton RA. Aging in autism spectrum disorders: a mini-review. *Gerontology*. 2010;58:70-8.
37. Totsika V, Felce D, Kerr M, Hastings RP. Behaviour problems, psychiatric symptoms, and quality of life for older adults with intellectual disability with and without autism. *Journal of Autism and Developmental Disorders*. 2010;40:1171-8.

- 1
 - 2
 - 3
 - 4
 - 5
 - 6
 - 7
 - 8
 - 9
 - 10
 - 11
 - 12
 - 13
 - 14
 - 15
 - 16
 - 17
 - 18
 - 19
 - 20
 - 21
 - 22
 - 23
 - 24
 - 25
 - 26
 - 27
 - 28
 - 29
 - 30
 - 31
 - 32
 - 33
 - 34
 - 35
 - 36
 - 37
 - 38
 - 39
 - 40
 - 41
 - 42
 - 43
 - 44
 - 45
 - 46
 - 47
 - 48
 - 49
 - 50
 - 51
 - 52
 - 53
 - 54
 - 55
 - 56
 - 57
 - 58
 - 59
 - 60
38. Khanna R, K. J-P, West-Strum D, Mahabaleshwarkar R. Health-related quality of life and its determinants among adults with autism. *Autism*. 2014;18(2):157-167.
39. Pellicano E, Dinsmore A, Charman T. What should autism research focus upon? Community views and priorities from the United Kingdom. *Autism*. 2014;18(1):1-5.
40. Nicolaidis C. What Can Physicians Learn from the Neurodiversity Movement? *American Medical Association Journal of Ethics*. 2012;14(6):503-10.
41. Nicolaidis C, Raymaker D, Dern S, Boisclair C, Ashkenazy E, Baggs A. Comparison of healthcare experiences in autistic and non-autistic adults: a cross-sectional online survey facilitated by an academic-community partnership. *Journal of General Internal Medicine*. 2012;28(6):761-9.
42. Kapp SK, Steward R, Crane L, Elliott D, Elphick C, Pellicano E, et al. 'People should be allowed to do what they like': Autistic adults' views and experiences of stimming. *Autism*. 2019;1362361319829628.
43. Walmsley J, Johnson K. Inclusive research with people with learning disabilities: Past, present and futures. London and New York: Jessica Kingsley Publishers 2003.
44. Bigby C, Frawley P, Ramcharan P. Conceptualising inclusive research with people with intellectual disability. *Journal of Applied Research in Intellectual Disabilities*. 2014;27(1):3-12.
45. Bagatell N. From cure to community: transforming notions of autism. *Journal of the Society for Psychological Anthropology*. 2010;38(1):33-55.
46. Milton D, Bracher M. Autistics speak but are they heard? *Medical Sociology Online*. 2013;7:61-9.
47. Nind M, Vinha H. Doing research inclusively: bridges to multiple possibilities in inclusive research. *British Journal of Learning Disabilities*. 2012;42:102-9.
48. Gatfield O, Mangan C, Haar T, Kinninurgh A, Rodger S. 2016 Research Priorities Survey Report. Brisbane, Queensland, Australia: Cooperative Research Centre for Living with Autism, 2016.
49. Gotham K, Marvin AR, Talyor JL, Warren Z, Anderson CM, Law PA, et al. Characterizing the daily life, needs, and priorities of adults with autism spectrum disorder from Interactive Autism Network. *Autism*. 2015:1-11.
50. McConachie H, Mason D, Parr JR, Garland D, Wilson C, Rodgers J. Enhancing the Validity of a Quality of Life Measure for Autistic People. *J Autism Dev Disord*. 2018 May;48(5):1596-611.
51. Seltzer MM, Greenberg JS, Taylor JL, Smith LE, Orsmond GE, Esbensen A, et al. Adolescents and adults with autism spectrum disorders. In: Amaral DG, Dawson G, Geschwind D, editors. *Autism spectrum disorders* New York: Oxford University Press; 2011.
52. Lawson L, Hascheck A, Richdale AL. SASLA Snapshot: Study of Australian School-Leavers with Autism – Baseline Profile. Melbourne, Australia: Olga Tennison Autism Research Centre (OTARC), La Trobe University, 2018.
53. Haas K, Costley D, Falkmer M, Richdale A, Sofronoff K, Falkmer T. Factors Influencing the Research Participation of Adults with Autism Spectrum Disorders. *J Autism Dev Disord*. 2016 May;46(5):1793-805.
54. Walmsley J. Normalisation, emancipatory research and inclusive research in learning disability. *Disability & Society*. 2001;16(2):188-205.
55. CRC A. Inclusive research practice guide and checklists for autism research: Version 2. Brisbane, Queensland: Autism CRC Ltd., 2016.
56. Nicolaidis C, Raymaker D, Katz M, Oshwald M, Goe R, Leottie S, et al. Community-based participatory research to adapt health measures for use by people with developmental disabilities. *Progress in Community Health Partnerships: Research, Education, and Action*. 2015;9(2):141-3.

- 1
 - 2
 - 3
 - 4
 - 5
 - 6
 - 7
 - 8
 - 9
 - 10
 - 11
 - 12
 - 13
 - 14
 - 15
 - 16
 - 17
 - 18
 - 19
 - 20
 - 21
 - 22
 - 23
 - 24
 - 25
 - 26
 - 27
 - 28
 - 29
 - 30
 - 31
 - 32
 - 33
 - 34
 - 35
 - 36
 - 37
 - 38
 - 39
 - 40
 - 41
 - 42
 - 43
 - 44
 - 45
 - 46
 - 47
 - 48
 - 49
 - 50
 - 51
 - 52
 - 53
 - 54
 - 55
 - 56
 - 57
 - 58
 - 59
 - 60
57. Kroenke K, Spitzer RL, Williams JBW. The PHQ-9: validity of a brief depression severity measure. *Journal of General Internal Medicine*. 2001;16:606-13.
58. Whitehouse AJO, Bishop DVM. *Communication Checklist - Adult*: London, UK: Pearson; 2009.
59. (AIHW) AIOHaW. *Autism in Australia*. Web Report. Canberra, Australia: AIHW, 2017 5-4-17. Report No.
60. Hoekstra RA, Vinkhuyzen AAE, Wheelwright S, Bartels M, Boomsma DI, Baron-Cohen S, et al. The construction and validation of an abridged version of the Autism-Spectrum Quotient. *Journal of Autism and Developmental Disorders*. 2011;41:589-96.
61. Evans E, Trollor J, Davis A, Bhardwaj A, O'Brien E. *Mental health and carer support in elders with ID*. Report to Ageing, Disability and Home Care, Department of Family and Community Services, NSW Australia. Sydney, Australia: Department of Developmental Disability Neuropsychiatry, UNSW Sydney, 2015.
62. StataCorp. *Stata Statistical Software: Release 14*. College Station, TX: StataCorp LP; 2015.
63. IBM_Corp. *IBM SPSS Statistics for Windows, Version 22.0*. Armonk, NY: IBM Corp; 2013.
64. Beesdo-Baum K, Klotsche J, Knappe S, Craske MG, LeBeau RT, Hoyer J, et al. Psychometric properties of the dimensional anxiety scales for DSM-V in an unselected sample of German treatment seeking patients. *Depression and Anxiety*. 2012;29(12):1014-24.
65. Cvejic RC, Arnold SRC, Foley K-R, Trollor JN. Neuropsychiatric profile and psychotropic medication use in adults with autism spectrum disorder: results from the Australian Longitudinal Study of Adults with Autism. *BJPsych Open*. 2018;4(6):461-6. Epub 11/13.
66. Stacey T-L, Froude EH, Trollor J, Foley K-R. Leisure participation and satisfaction in autistic adults and neurotypical adults. *Autism*. 2018;0(0):1362361318791275. PubMed PMID: 30132680.
67. Hwang YI, Foley K-R, Trollor JN. Aging Well on the Autism Spectrum: An Examination of the Dominant Model of Successful Aging. *Journal of Autism and Developmental Disorders*. 2018 May 02.
68. Ee D, Hwang J, Reppermund S, Srasuebkul P, Trollor J, Foley K-R, et al. Loneliness in Adults on the Autism Spectrum. 2019.
69. Harsanyi M, Foley K-R, Froude E, Trollor J, Arnold SRC. *Employment Profiles of Autistic Adults in Australia*. 2019.
70. Cai RY, Richdale AL, Foley K-R, Trollor J, Uljarević M. 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*. 2018 2018/01/01;45:1-8.
71. Hedley D, Uljarević M, Foley K-R, Richdale A, Trollor J. Risk and protective factors underlying depression and suicidal ideation in Autism Spectrum Disorder. *Depression and Anxiety*. 2018;35(7):648-57.
72. Arnold SRC, Uljarevic M, Hwang J, Richdale A, Trollor J, Lawson LP. Brief Report: Psychometric Properties of the Patient Health Questionnaire-9 (PHQ-9) in Autistic Adults. *Journal of Autism and Developmental Disorders*. 2019.
73. Uljarevic M, Hedley D, Foley K-R, Magiati I, Cai RY, Dissanayake C, et al. Anxiety and depression from adolescence to old age in autism spectrum disorder. 2019.
74. Baldwin S, Costley D. The experiences and needs of female adults with high-functioning autism spectrum disorder. *Autism*. 2016;20(4):483-95.

- 1
2
3 75. Fan W, Yan Z. Factors affecting response rates of the web survey: A systematic
4 review. *Computers in Human Behavior*. 2010 2010/03/01/;26(2):132-9.
5
6 76. Guo X, Vittinghoff E, Olgin JE, Marcus GM, Pletcher MJ. Volunteer Participation in
7 the Health eHeart Study: A Comparison with the US Population. *Scientific Reports*. 2017
8 2017/05/16/;7(1):1956.
9
10 77. Fletcher-Watson S, Adams J, Brook K, Charman T, Crane L, Cusack J, et al. Making
11 the future together: Shaping autism research through meaningful participation. *Autism*.
12 2019;0(0):1362361318786721.
13
14 78. Loomes R, Hull L, Mandy WPL. What Is the Male-to-Female Ratio in Autism
15 Spectrum Disorder? A Systematic Review and Meta-Analysis. *Journal of the American
16 Academy of Child & Adolescent Psychiatry*. 2017 2017/06/01/;56(6):466-74.
17
18 79. Gilmour L, Schalomon PM, Smith V. Sexuality in a community based sample of
19 adults with autism spectrum disorder. *Research in Autism Spectrum Disorders*. 2012
20 2012/01/01/;6(1):313-8.
21
22 80. Kapp SK, Gillespie-Lynch K, Sherman LE, Hutman T. Deficit, difference, or both?
23 Autism and neurodiversity. *Developmental Psychology*. 2013 2013;49(1):59-71.
24
25 81. Nicolaidis C, Raymaker D, McDonald K, Dern S, Boisclair C, Ashkenazy E, et al.
26 Comparison of healthcare experiences in autistic and non-autistic adults: A cross-sectional
27 online survey facilitated by an academic-community partnership. *Journal of General Internal
28 Medicine*. 2013;28(6):761-9.
29
30 82. Whiteley P, Todd L, Carr K, Shattock P. Gender Ratios in Autism, Asperger
31 Syndrome and Autism Spectrum Disorder. *Autism Insights; London*. 2010 2010;2:17.
32 English.
33
34 83. Chadwick D, Wesson C, Fiullwood C. Internet Access by People with Intellectual
35 Disabilities: Inequalities and Opportunities. *Future Internet*. 2013;5(3):376-97.
36
37 84. Fusar-Poli L, Brondino N, Rocchetti M, Panisi C, Provenzani U, Damiani S, et al.
38 Diagnosing ASD in Adults Without ID: Accuracy of the ADOS-2 and the ADI-R. *Journal of
39 Autism and Developmental Disorders*. 2017 November 01;47(11):3370-9.
40
41 85. Barrett SL, Uljarević M, Baker EK, Richdale AL, Jones CRG, Leekam SR. The Adult
42 Repetitive Behaviours Questionnaire-2 (RBQ-2A): A Self-Report Measure of Restricted and
43 Repetitive Behaviours. *Journal of Autism and Developmental Disorders*. 2015
44 2015/11/01/;45(11):3680-92.
45
46 86. Robertson AE, Simmons DR. The relationship between sensory sensitivity and
47 autistic traits in the general population. *Journal of Autism and Developmental Disorders*.
48 2012;43:775-84.
49
50 87. Carleton RN, Norton PJ, Asmundson GJG. Fearing the unknown: a short version of
51 the intolerance of uncertainty scale. *Journal of Anxiety Disorders*. 2007;21:105-17.
52
53 88. Spitzer RL, Williams JBW, Kroenke K, Linzer M, deGruy FV, Hahn SR. Utility of
54 new procedure for diagnosis mental-disorders in primary-care: the PRIME-MD 1000 study.
55 *Journal of American Medical Association*. 1994;272:1749-56.
56
57 89. Ware JE, Kosinski M, Keller SD. A 12-Item Short-Form Health Survey: construction
58 of scales and preliminary tests of reliability and validity. *Medical care*. 1996;34(3):220.
59
60 90. Sletten DM, Suarez GA, Low PA, Mandrekar J, Singer W. COMPASS 31: A refined
and abbreviated composite autonomic symptom score. *Mayo Clinic Proceedings*.
2012;87(12):1196-201.
91. Buysse DJ, Reynolds CF, Monk TH, Berman SR, Kupfer DJ. The Pittsburgh Sleep
Quality Index: a new instrument for psychiatric practise and research. *Psychiatry Reserves*.
1989;28:193-213.
92. Gardisar M, Lack L, Richards H, Harris J, Gallasch J, Boundy M, et al. The Flinders
Fatigue Scale: preliminary psychometric properties and clinical sensitivity of a new scale for

- 1
2
3 measuring daytime fatigue associated with insomnia. *Journal of Clinical Sleep Medicine*.
4 2007;3(7):722-8.
- 5 93. Craske MG, Wittchen H-U, Bogels S, Stein M, Andrews G, Lebeu R. Severity
6 measure for Generalized Anxiety Disorder - adult: American Psychiatric Association; 2013.
- 7 94. Tennant R, Hiller L, Fishwick R, Platt S, Joseph S, Weich S, et al. The Warwick-
8 Edinburgh mental well-being scale (WEMWBS): development and UK validation. *Health
9 and Quality of Life Outcomes*. 2007;5(63):1-13.
- 10 95. Chen G, Gully SM, Eden D. Validation of a new general self-efficacy scale.
11 *Organizational Research Methods*. 2001;4(1):62-83.
- 12 96. Gross JJ, John OP. Individual differences in two emotion regulation processes:
13 implications for affect, relationships, and well-being. *Journal of Personality and Social
14 Psychology*. 2003;85(2):348-62.
- 15 97. Mohr C, Tonge BJ, Einfeld SL, Taffe J. The Developmental Behaviour Checklist for
16 Adults (DBC-A) Revised. Sydney, Australia: University of Sydney and Monash University,
17 2011.
- 18 98. Carver CS. You want to measure coping but your protocol's too long: consider the
19 brief COPE. *International journal of behavioral medicine*. 1997;4(1):92-100.
- 20 99. Crook TH, 3rd, Feher EP, Larrabee GJ. Assessment of memory complaint in age-
21 associated memory impairment: the MAC-Q. *International psychogeriatrics*. 1992
22 Fall;4(2):165-76.
- 23 100. Hays RD, DiMatteo MR. A short-form measure of loneliness. *Journal of Personality
24 Assessment*. 1987;51:69-81.
- 25 101. Sarason IG, Levine HM, Basham RB, Sarason BR. Assessing social support: the
26 social support questionnaire. *Journal of Personality and Social Psychology*. 1983;44(1):127-
27 39.
- 28 102. The WHOQOL Group. The World Health Organization Quality of Life assessment
29 (WHOQOL)-BREF quality of life assessment. *Psychological Medicine*. 1995;28:551-5.
- 30 103. Maenner MJ, Smith LE, Hong J, Makuch R, Greenberg JS, Mailick MR. Evaluation
31 of an activities of daily living scale for adolescents and adults with developmental
32 disabilities. *Disability and Health Journal* 2013;6(1):8-17.
- 33 104. Luciano JV, Ayuso-Mateos JL, Aguado J, Fernandez A, Serrano-Blanco A, Roca M,
34 et al. The 12-item World Health Organisation Disability Assessment Schedule (WHO-DAS
35 II): a nonparametric item response analysis *BMC Medical Research Methodology*.
36 2010;10(45):1-9.
- 37 105. Taylor JL, Seltzer MM. Developing a vocational index for adults with autism
38 spectrum disorders. *Journal of Autism and Developmental Disorders*. 2012;42(12):2669-79.
- 39 106. Beard JG, Ragheb MG. Measuring leisure satisfaction. *Journal of Leisure Research*.
40 1980;12:20-33.
- 41 107. Chisholm D, Knapp MRJ, Knudsen HC, Amaddeo F, Gaité L, van Wijngaarden B, et
42 al. Client socio-demographic and service receipt inventory - European version: development
43 of an instrument for international research. *The British Journal of Psychiatry*. 2000;177:28-
44 33.
- 45 108. Bengtson VL, Allen KR. The life course perspective applied to families overtime. In:
46 Boss P, Doherty W, LaRossa R, Schumm W, Steinmetz S, editors. *Sourcebook of family
47 theories and methods: a contextual approach*. New York: Plenum Press; 1993. p. 469-98.
- 48 109. McCarron M, Gill M, Lawlor B, Beagly C. A pilot study of the reliability and validity
49 of the Caregiver Activity Survey - Intellectual disability (CAS-ID). *Journal of Intellectual
50 Disability Research*. 2002;46(8):605-12.
- 51
52
53
54
55
56
57
58
59
60

1
2
3 110. Bedard M, Molloy DW, Squire L, Dubois BA, Lever JA, O'Donnell M. The Zarit
4 Burden Interview: a new short version and screening version. *The Gerontologist*.
5 2001;41(5):652-7.

6
7 111. Alliance NRH. *The little book of rural health numbers*: Author; 2015. Available from:
8 <https://www.ruralhealth.org.au/book/little-book-rural-health-numbers>.

9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

For peer review only

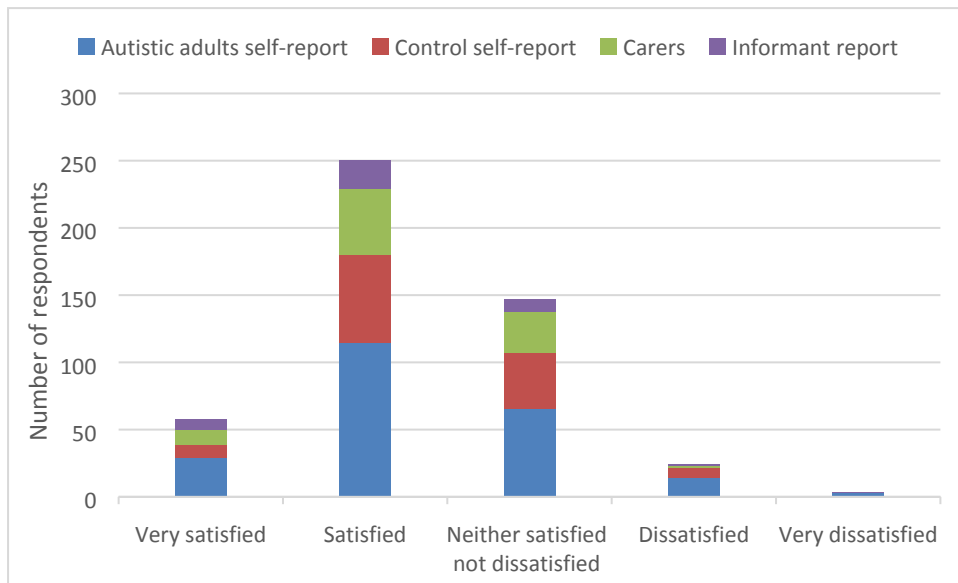
1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

Figure Caption Sheet

Figure 1. Satisfaction responses upon completion combined by survey type (n=482)

For peer review only

Figure 1 top



peer review only

Table 1

The ALSAA Inclusive Research Protocol

Step	Description of step and considerations
Step 1: Recruitment of advisors / peer- researchers	Ensure recruitment is inclusive of all potential autistic individuals including adults with intellectual disability, consider using multiple channels of recruitment (e.g., Autism associations, self-advocacy networks, carer networks, adult networks, local radio, social media and word of mouth). In Australia, seek support from the Autism CRC Research Academy*.
Step 2: Building rapport	If an established relationship does not already exist between the autistic individual and researcher, the researcher should offer to meet the individual (either face-to-face, over video conference or phone call). Be mindful that some autistic individuals may prefer to communicate via text or email and not to meet in person and should not be required to.
Step 3: Clarify what will be expected from the advisor	Outline tasks autistic advisors or peer researchers will be asked to complete. Specify the frequency and timing of when they are likely to be contacted. For specific tasks clearly provide step-by-step instructions, flexible lead-time, timeframes for feedback, area of investigation, and broad aim of the study. Make information available in Easy English or plain language as appropriate. Specify the type and nature of advice sought. Clearly describe how and where their input will be used and why their input is being sought.
Step 4: Ethics, confidentiality and acknowledgement	Describe ethics of the project and expected confidentiality. As required, specify on individual documents that the document is confidential and not to be distributed without discussion with the researcher. Can the autistic individual opt out if they would like? Outline what will happen if they choose to withdraw, e.g., this will not affect their relationship with the research team, university or any other associated organisations. It is a voluntary process. Negotiate and make explicit how the autistic advisor or peer-researcher will be acknowledged. Consider how the autistic individual may be recognised in a manuscript or research output. This may include as a co-author, in the acknowledgements section, and/or in discussing methodology and findings.
Step 5: Identify preferred communication style	Ask the autistic individual their preferred communication style for providing feedback (e.g., face-to-face, phone call, email, video, or a variety of techniques). Also, in what medium they would like to receive the results/findings e.g., academic writing style, easy English writing style, mostly graphs/pictures, mostly dot points, described in person, video, PowerPoint presentation, etc. Although not all mediums may be practical, it is important to identify the autistic advisor's preferred style and then work together to identify a medium of communication which will be understood and accessible by both the autistic advisor and the researcher.
Step 6: The sensory environment	The researcher must provide an 'autism-friendly' environment on any occasion where the autistic advisor and the researcher may be meeting in person, see p. 12-15 in the <i>Autism CRC Inclusive Research Practice Guides and Checklists for Autism Research</i> ⁵⁵ regarding creating autism-friendly environments.
Step 7: Involvement in methodological	Autistic advisors input is sought in regard to questionnaire design and interpretation of results. The researcher will need to present questionnaire design questions or quantitative or qualitative results in an understandable format, developing design issue summaries or results summaries in the

design / results / findings	medium preferred by the autistic advisor or peer-researcher. This means the researcher may need to make a number of decisions around data analysis and interpretation. Where possible, outline each of these decisions so the process is transparent and the autistic advisor can reflect on the decisions made by the researcher and whether these were appropriate in their view. Provide clear guidance on what advice is being sought, provide lead time, and the timeframe and process to follow for providing advice. How long should the advice be? In what format? Who will be reading it, who do they send the advice to? What are the researchers specifically looking for, what should the advice focus on?
Step 8: Feedback	Once the researcher receives the advice from the autistic advisor, the researcher should provide a timeframe in which the autistic advisor will receive an update on what aspects of the advice was incorporated and the effect it had/didn't have on the methodology, findings, and/or interpretation.
Step 9: Final checks	Once the manuscript or research output has been further developed, the autistic advisor should receive a copy of the manuscript prior to submission. If the autistic advisor has limited experience with academic writing, the researcher should offer to describe/provide a lay summary of the overall article for the advisor.
Step 10: Acknowledgement	Autistic advisor or peer-researcher to be acknowledged in the agreed upon manner (e.g., co-author, thanked in the acknowledgement section, acknowledged during a presentation etc.)

*The Autism CRC Research Academy (<https://www.autismcrc.com.au/research-academy>) provides training for peer researchers.

Table 2

Measurements included in the ALSAA surveys

Measure / domain	Self-report	Informant report	Carer
Demographics and personal characteristics			
Basic demographics (Age, Sex, Ethnicity, English speaking status)	✓	✓	✓
Other demographics (Education, Occupation ^a , Family & living conditions, Income)	✓	✓	✓
Autism Characteristics			
The Autism Quotient - Short ^b (AQ-Short) ⁶⁰	✓	✓	✓
Repetitive Behaviours Questionnaire-2 Adult Version (RBQ-2A) ⁸⁵	✓	✓	
The Glasgow Sensory Questionnaire ⁸⁶	✓	✓	
The Intolerance of Uncertainty Scale-12 ⁸⁷	✓		✓
Health & Well-Being			
Medical history	✓	✓	✓
Medication profile	✓	✓	
Smoking, alcohol and illicit drug use ^a	✓	✓	
The Patient Health Questionnaire-15 ⁸⁸	✓		✓
Medical Outcomes Study Short Form Health Survey-12 (SF-12) ⁸⁹	✓	✓	✓
The Composite Autonomic Symptom Score - 31 (COMPASS 31) ⁹⁰	✓		
Pittsburgh Sleep Quality Index ⁹¹	✓		
Flinders Fatigue Scale ⁹²	✓		
Mental & Emotional Health			
DSM-5 Dimensional Anxiety Scales: Generalized Anxiety Disorder-Adult (DSM5 GAD-A) ⁹³	✓		✓
The Patient Health Questionnaire-9 (PHQ-9) ⁵⁷	✓		✓
The Warwick Edinburgh Mental Well-being Scale ⁹⁴	✓		
The New General Self-Efficacy Scale ⁹⁵	✓		
The Emotion Regulation Questionnaire ⁹⁶	✓		✓
Developmental Behaviour Checklist-Adolescent/Adult version (DBC-A) Revised ⁹⁷		✓	
The Brief COPE ⁹⁸	✓		✓
Memory Complaint Questionnaire (MAC-Q) ⁹⁹	✓		
Relationships & Social Networks			
UCLA Loneliness Scale-8 (ULS-8) ¹⁰⁰	✓		
Supports and networks ^a	✓	✓	
The Social Support Questionnaire (SSQ) ¹⁰¹	✓		✓
Activities, Participation & Quality of Life			

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

WHOQOL-BREF ¹⁰²	✓		✓
Waisman Activities of Daily Living Scale (W-ADL) ¹⁰³	✓	✓	
World Health Organisation Disability Assessment Schedule (WHO-DAS II) ¹⁰⁴	✓	✓	✓
Vocational Index for Adults with Autism ¹⁰⁵	✓	✓	
Special abilities and interests ^c	✓		
Leisure activities participation	✓	✓	
Leisure Satisfaction Scale (LSS) ¹⁰⁶	✓		
Driving and transport	✓	✓	✓
Service Usage			
Client Service Receipt Inventory (CSRI) ¹⁰⁷	✓	✓	
Health service seeking behaviour	✓	✓	
Early intervention service history	✓	✓	
Justice system contact	✓	✓	
Preventative health screening	✓	✓	
Caring			
Positive Affect Index ¹⁰⁸			✓
Caregiver Activity Survey (CAS-ID) ¹⁰⁹			✓
Zarit Burden Interview ¹¹⁰			✓

^a Based on questions from the National Health Survey of Mental Health and Wellbeing (Slade, Johnston, Oakley Browne, Andrews, & Whiteford, 2009). ^bA 28-item parent-carer report adaptation using items from the AQ-Adolescent (Baron-Cohen, Hoekstra, Knickmeyer, & Wheelwright, 2006) was used for the informant-report survey ^cBased on questions from the Interactive Autism Network (<https://iancommunity.org/>)

Table 3

Recruitment statistics at close of Time 1 data gathering

Sample	Registered	Ineligible (%)	Withdrawn (%)	Partial Completion (%)	Completed (%)
Self-report autistic adults	345	6 (2)	11 (3)	16 (5)	237 (69)
Self-report non-autistic adults	221	7 (3)	20 (9)	16 (7)	130 (59)
Carer	185	22 (12)	13 (7)	2 (1)	100 (54)
Informant-report for autistic adult	78	5 (6)	9 (11)	0 (0)	42 (54)

Table 4

Participant Characteristics

Characteristic	Autistic adults self-report formally diagnosed (N=221)	Autistic adults self-report no formal diagnosis (N=32)	Autistic adults informant-report (N=42)	Carers (N=102)	Non-autistic self-report (N=146)
Age mean (SD)	41.8 (12.2)	44.2 (8.1)	32.5 (9.9)	56.3 (11.2)	43.7 (13.5)
Gender (%)					
Male	86 (39)	14 (44)	34 (81)	16 (16)	29 (20)
Female	124 (56)	17 (53)	8 (19)	85 (83)	117 (80)
Other	11 (5)	1 (3)	0	1 (1)	0
^a Ethnicity (%)					
Caucasian	194 (88)	25 (78)	38 (90)	86 (89)	122 (85)
Other	27 (12)	7 (22)	4 (9)	11 (11)	22 (15)
Multilingual (%)	26 (12)	5 (16)	0	6 (6)	18 (12)
^b SEIFA decile (SD)	6.18 (2.89)	5.74 (3.09)	6.58 (2.88)	6.60 (2.78)	7.01 (2.60)
^{bc} Rural / Remoteness					
Major City	146 (71)	17 (55)	32 (84)	72 (73)	114 (83)
Inner Regional	44 (21)	10 (32)	5 (13)	21 (21)	19 (14)
Outer Regional	12 (6)	4 (13)	1 (3)	5 (5)	5 (4)
Remote / Very Remote	4 (2)	0	0	0	0
^d Living situation (%)					
Living alone	58 (26)	9 (28)	3 (7)	14 (14)	26 (18)
Living as couple	95 (43)	18 (56)	4 (9)	74 (75)	105 (72)
Living with parents	31 (14)	0	24 (57)	0	5 (3)
Living with other relatives	3 (1)	0	1 (2)	6 (6)	3 (2)
Living with others	20 (9)	5 (16)	8 (19)	4 (4)	5 (3)
Other	14 (6)	0	2 (5)	1 (1)	2 (1)
^e Marital Status (%)					
Single	73 (33)	7 (22)	36 (86)	4 (4)	22 (15)
Married	66 (30)	12 (37)	4 (9)	65 (66)	90 (62)
De facto	17 (8)	3 (9)	0	8 (8)	14 (9)
Never married	8 (4)	3 (9)	2 (5)	2 (2)	3 (2)
Widowed	1 (0)	0	0	3 (3)	2 (1)
Divorced now single	21 (9)	3 (9)	0	8 (8)	9 (6)
Divorced now remarried / de facto	12 (5)	2 (6)	0	2 (2)	2 (1)
Separated	7 (3)	1 (3)	0	2 (2)	1 (1)
Other	16 (7)	1 (3)	0	4 (4)	3 (2)
Educational Status (%)					

Completed high school	163 (76) <i>n</i> =215	20 (64) <i>n</i> =31	21 (51) <i>n</i> =41	86 (88) <i>n</i> =98	120 (86) <i>n</i> =139
Vocational education	61 (35) <i>n</i> =174	16 (57) <i>n</i> =28	4 (11) <i>n</i> =35	17 (17) <i>n</i> =98	20 (16) <i>n</i> =127
University education	113 (65) <i>n</i> =174	12 (43) <i>n</i> =28	1 (3) <i>n</i> =35	59 (60) <i>n</i> =98	107 (84) <i>n</i> =127
^f Employment (%)					
Open employment	116 (57)	20 (69)	6 (15)	59 (60)	104 (76)
Student / other day activity	38 (19)	3 (10)	24 (60)	3 (3)	17 (12)
Retired, no volunteering	8 (4)	2 (7)	2 (5)	19 (19)	6 (4)
Homecare	17 (8)	3 (10)	0	9 (9)	9 (6)
No activity	22 (11)	1 (3)	8 (20)	9 (9)	1 (1)

^a Ethnicity: Carers, *n*=97; Non-autistic (self-report), *n*=144

^b Autistic adults (diagnosis, self-report), *n*=209; Autistic adults (no diagnosis, self-report), *n*=31; Autistic adults (informant report), *n*=38; Carers, *n*=99; Non-autistic (self-report), *n*=138

^c Australian population is 70% Major city, 18% Inner regional, 9% Outer regional, 1% Remote, 1% Very remote in the 2011 Census¹¹

^d Carers' Living situation: *n*=99

^e Carers' Marital status: *n*=98

^f Employment: Autistic adults (diagnosis, self-report), *n*=201; Autistic adults (no diagnosis, self-report), *n*=29; Autistic adults (informant report), *n*=40; Carers, *n*=99; Non-autistic (self-report), *n*=137

Table 5

Diagnostic Characteristics

Characteristic	Autistic adults self-report formally diagnosed (N=221)	Autistic adults self-report no formal diagnosis (N=32)	Autistic adults informant-report (N=42)	Carers (N=102)	Non-autistic self-report (N=146)
AQ score mean (SD)	87.6 (10.3) n=210	83.7 (8.8)	84.2 (9.5) n=36	57.3 (13.8) n=60 ^a	55.1 (11.9) n=137
Above AQ Cutoff (%)	203 (97)	31 (97)	35 (97)	18 (30)	30 (22)
^b Autism Diagnosis					
Autism spectrum disorder / condition	49 (22)	-	17 (40)	-	-
Asperger's syndrome	130 (59)	-	11 (26)	-	-
Autistic disorder	1 (0)	-	6 (14)	-	-
'High-functioning' autism	32 (14)	-	3 (7)	-	-
PDD-NOS	1 (0)	-	1 (2)	-	-
Other	6 (3)	-	2 (5)	-	-
No formal diagnosis	-	32 (100)	1 (2)	-	-
Age at Diagnosis Mean (SD)	35.3 (15.1) n=217	-	10.01 (10.8) n=38	-	-
Years since Diagnosis Mean (SD)	6.9 (8.3) n=217	-	21.9 (9.8) n=38	-	-
Intellectual Disability (%)	10 (4)	1 (3)	33 (78)	1 (1)	1 (1)
Other Developmental Disability (%)	6 (3)	2 (6)	9 (21)	0	1 (1)
^c Other Psychiatric Diagnosis(%)					
Currently	148 (69) n=213	13 (42) n=31	22 (52)	38 (39) n=100	29 (21) n=140
At any time	191 (89) n=213	28 (90) n=31	31 (74)	68 (68) n=100	67 (48) n=140
Depression (PHQ-9) above cut-off (%)	103 (52) n=199	15 (52) n=29	-	28 (29) n=97	15 (12) n=126
Anxiety (DSM5 GAD-A) above cut-off (%)	115 (56) n=206	14 (47) n=32	-	27 (27) n=99	14 (11) n=130

^a Carers were asked to complete the AQ scale only if they were a biological relative of the adult with autism

^b Autism diagnosis: Autistic adults (self-report, diagnosed), $n=220$

^c Recording of a psychiatric diagnosis apart from autism spectrum conditions or intellectual disability

For peer review only

Table 6

Carer Characteristics (N=102)

Characteristic	Frequency / Mean
Relationship to autistic person (%)	
Mother	42 (43, <i>n</i> =98)
Father	10 (10, <i>n</i> =98)
Partner/spouse	23 (23, <i>n</i> =98)
Sibling	2 (2, <i>n</i> =98)
Child	1 (1, <i>n</i> =98)
Carer – unspecified	17 (17, <i>n</i> =98)
Other	3 (3, <i>n</i> =98)
Age of autistic adult cared for mean (<i>SD</i>)	37.5 (13.2)
Hours spent per week with autistic adult mean (<i>SD</i>)	63.4 (57.8, <i>n</i> =92)

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

For peer review only

BMJ Open

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

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2019-030798.R1
Article Type:	Cohort profile
Date Submitted by the Author:	13-Jun-2019
Complete List of Authors:	<p>Arnold, Samuel; UNSW, Department of Developmental Disability Neuropsychiatry (3DN); Autism CRC</p> <p>Foley, Kitty-Rose; Southern Cross University - Gold Coast Campus, School of Health and Human Sciences; Autism CRC</p> <p>Hwang, Ye In; UNSW, Department of Developmental Disability Neuropsychiatry (3DN); Autism CRC</p> <p>Richdale, Amanda; La Trobe University, Olga Tennison Autism Research Centre, School of Psychology and Public Health; Autism CRC</p> <p>Uljarevic, Mirko ; Stanford University, Stanford Autism Center, Division of Child and Adolescent Psychiatry, Department of Psychiatry and Behavioral Sciences, School of Medicine; La Trobe University, Olga Tennison Autism Research Centre, School of Psychology and Public Health</p> <p>Lawson, Lauren; La Trobe University, Olga Tennison Autism Research Centre, School of Psychology and Public Health; Autism CRC</p> <p>Cai, Ru; La Trobe University, Olga Tennison Autism Research Centre, School of Psychology and Public Health; Autism CRC</p> <p>Falkmer, Torbjorn; Curtin University, School of Occupational Therapy, Social Work and Speech Pathology; Autism CRC</p> <p>Falkmer, Marita; Curtin University, School of Occupational Therapy, Social Work and Speech Pathology; Autism CRC</p> <p>Lennox, Nick; University of Queensland, Australia, Queensland Centre for Intellectual and Developmental Disability, Mater Research Institute - UQ; Autism CRC</p> <p>Urbanowicz, Anna; RMIT University, Health, Society & Medicine Research Program, Social and Global Studies Centre; Autism CRC</p> <p>Trollor, Julian; UNSW, Department of Developmental Disability Neuropsychiatry (3DN); Autism CRC</p>
Primary Subject Heading:	Mental health
Secondary Subject Heading:	Diagnostics
Keywords:	Autism, Longitudinal, Adult

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60



Title

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

Author Names and Affiliations

Samuel R. C. Arnold^{*a,b} <samuel.arnold@unsw.edu.au>

Kitty-Rose Foley^{*b,c} <Kitty-Rose.Foley@scu.edu.au>

Ye In (Jane) Hwang^{a,b} <jane.hwang@unsw.edu.au>

Amanda L. Richdale^{b,d} <A.Richdale@latrobe.edu.au>

Mirko Uljarevic^{e,d,b} <mirkoulj@stanford.edu>

Lauren P. Lawson^{b,d} <L.Lawson@latrobe.edu.au>

Ru Ying Cai^{b,d} <R.Cai@latrobe.edu.au>

Torbjorn Falkmer^{b,f} <T.Falkmer@curtin.edu.au>

Marita Falkmer^{b,f,g} <Marita.Falkmer@curtin.edu.au>

Nick Lennox^{b,h} <n.lennox@uq.edu.au>

Anna Urbanowicz^{b,h,i} <a.urbanowicz@rmit.edu.au>

Julian N. Trollor^{+a,b} <J.Trollor@unsw.edu.au>

Affiliations

- a- Department of Developmental Disability Neuropsychiatry (3DN), UNSW Sydney, New South Wales, Australia
- b- Cooperative Research Centre for Living with Autism (Autism CRC), Brisbane, Queensland, Australia
- c- School of Health and Human Sciences, Southern Cross University, Gold Coast, Bilinga, Queensland, Australia
- d- Olga Tennison Autism Research Centre, School of Psychology and Public Health, La Trobe University, Bundoora, Victoria, Australia
- e- Stanford Autism Center, Division of Child and Adolescent Psychiatry, Department of Psychiatry and Behavioral Sciences, School of Medicine, Stanford University.

- 1
2
3 f- School of Occupational Therapy, Social Work and Speech Pathology, Curtin
4 University, Perth, Western Australia, Australia
5
6 g- School of Education and Communication, CHILD Programme, Institution of
7 Disability Research, Jonkoping University, Jonkoping, Sweden
8
9 h- Queensland Centre for Intellectual and Developmental Disability, Mater Research
10 Institute - UQ, The University of Queensland, South Brisbane, Queensland, Australia
11
12 i- Health, Society & Medicine Research Program, Social and Global Studies Centre,
13 RMIT University
14
15
16

17 *Joint first author

18
19 +Corresponding author
20
21
22
23
24
25

26 Correspondence concerning this article should be addressed to Prof. Julian Trollor,
27 Department of Developmental Disability Neuropsychiatry (3DN), 34 Botany St, UNSW
28 Sydney, 2052, New South Wales, Australia. Telephone: +61-2-9931-9160. Email:
29 j.trollor@unsw.edu.au
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

Abstract (300 Words)

Purpose

There is a significant knowledge gap regarding the lives of adults on the autism spectrum. Some literature suggests significant health and mental health inequalities for autistic adults, yet there is a lack of comprehensive longitudinal studies exploring risk factors. Further, most research does not include the perspective of autistic adults in its conduct or design. Here we describe the baseline characteristics and inclusive research approach of a nationwide longitudinal study.

Participants

The Autism CRC's ALSAA is a questionnaire-based longitudinal study of autistic adults (25+ years old) with follow-up at 2-year intervals. Autistic advisors were involved in each stage of research apart from data analysis. Three questionnaires were developed: self-report, informant report (i.e. proxy report), and carers (i.e. carer experiences and characteristics).

Findings to date

An inclusive research protocol was developed and agreed with autistic advisors. Baseline data were collected from 295 autistic adults ($M=41.8$ years, $SD=12.0$) including 42 informant responses, 146 comparison participants, and 102 carers. The majority of autistic participants (90%) had been diagnosed in adulthood ($M=35.3$ years, $SD=15.1$). When compared to controls, autistic adults scored higher on self-report measures of current depression and anxiety. Participant comments informed on-going data gathering. Participants commented on questionnaire length, difficulty with literal interpretation of forced response items, and expressed gratitude for research in this area.

Future plans

1
2
3 A large comprehensive dataset relating to autistic adults and their carers has been gathered,
4
5 creating a good platform for longitudinal follow-up and collaborative research. Baseline data
6
7 confirms poorer mental health of autistic adults. The ALSAA demonstrates a working
8
9 approach to inclusive research.
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

For peer review only

Strengths and limitations of this study

- Autism related research efforts and funding has typically focused on the period from infancy to mid childhood, this research focuses on autistic adults and their carers.
- The ALSAA uses an inclusive research approach to gather a comprehensive range of measures addressing identified research priorities.
- A large proportion of the ALSAA sample at Time 1 were female, including 50% ($n=149$) of autistic and 80% ($n=117$) of non-autistic participants.
- Participants self-report their autism diagnosis, and a subsample ($n=32$) are not yet formally diagnosed.
- The ALSAA is a unique resource for exploring multiple research questions regarding the lives of Australian autistic adults.

Introduction

Although autism is a lifelong condition, most autism related research efforts and funding has focused on the period from infancy to mid childhood¹. The best available evidence suggests an adult population prevalence of at least 1.1%². It is likely that autism is under-recognized or under-diagnosed in adults^{3,4}, particularly in women without intellectual disability^{2,5}.

Although an emerging body of research explores outcomes and support needs of autistic individuals beyond childhood and adolescence, studies including autistic adults remain frequently focused on younger adults⁶⁻⁸. This is reflected in recent commentary from an autistic researcher; “We know virtually nothing about what happens to us, autistic people, physically, cognitively, emotionally and socially as we pass through middle and older age”⁹(p515).

The growing body of evidence suggests higher rates of physical and mental health conditions, increased mortality and higher rates of intellectual disability than in the general population¹⁰. Autistic adults have higher prevalence of chronic medical conditions, including conditions such as stroke, vision and hearing impairments, and Parkinson’s disease¹¹⁻¹⁴. These outcomes are experienced by many autistic adults regardless of intellectual functioning⁷. It has been reported that between 25%-84% of autistic adults have a diagnosed mental health condition, with depression and anxiety the most commonly reported conditions¹⁵⁻¹⁹. Autistic adults have higher rates of suicide^{16,20}, increased mortality and reduced life expectancy²¹. Despite widespread acknowledgement of the comorbidity between autism and intellectual disability, prevalence estimates of intellectual disability in autism and vice versa have been inconsistent²². Earlier studies report that between 40 to 70% of those with autism also have an intellectual disability²³⁻²⁵ though a more recent study reports fewer adults on the autism spectrum as having intellectual disability² and intelligence tests may underestimate performance of autistic individuals²⁶.

1
2
3 Studies investigating outcomes related to daily activities and participation are also scarce²⁷.
4
5 Available studies report low employment rates²⁸, low community inclusion and limited social
6
7 relationships for autistic adults²⁹⁻³³. A few studies have suggested that factors such as low
8
9 childhood IQ, autism severity, psychopathology, social and language development, and
10
11 access to services and intervention programs may be determinates of such outcomes ^{29, 34};
12
13 however, much remains to be understood about the sources of variability in these outcomes.
14
15
16
17 In general, much of the research remains limited by cross-sectional designs, mixed groups
18
19 with and without intellectual disability, and a focus on adults aged under 40 ^{7, 34-36}.
20
21
22 Longitudinal studies are crucial for exploring changing requirements over time and to inform
23
24 services how best to understand the health and wellbeing of autistic adults^{9, 37}. Whilst most
25
26 studies have focused on one aspect of life or outcomes, such as physical or mental health
27
28 comorbidities^{12, 15, 38} or quality of life^{30, 39}, very few comprehensive evaluations of health,
29
30 wellbeing and participation have been conducted³⁴. Further, research funding does not match
31
32 priorities identified by autistic adults, which include research on public services, improving
33
34 life skills and the future for autistic adults⁴⁰.
35
36
37
38
39 The majority of existing autism research is also limited by a lack of inclusive research
40
41 practices. There is a small but growing body of research on inclusive practices and co-
42
43 production in disability research with increasing examples in the autism field⁴¹⁻⁴³. In
44
45 principle, inclusive research must “address issues that really matter” to people with disability,
46
47 “must access and represent their views and experiences” and people “need to be treated with
48
49 respect by the research community”^{44(p16)}. Inclusive research encompasses a variety of
50
51 approaches, from including the individuals with the disability as advisors or consultants, to
52
53 working alongside academic researchers, or initiating or conducting the project as researchers
54
55 themselves⁴⁵. Due to a history of mistrust between researchers and autism self-advocacy
56
57 groups, inclusive methods are especially important in research involving adults on the
58
59
60

1
2
3 spectrum⁴⁶. Inclusive approaches ensure scientific findings are meaningful to the autism
4
5 community and sensitive to the lived experiences of individuals on the spectrum^{47, 48}.
6
7

8
9 The Cooperative Research Centre for Living with Autism (Autism CRC) Australian
10
11 Longitudinal Study of Adults with Autism (ALSAA) is Australia's first national longitudinal
12
13 study involving autistic adults aged 25 years and older. The ALSAA will contribute needed
14
15 longitudinal data across a range of health, functioning and participation domains. Data
16
17 gathered aligns with the research gaps identified above, and the priorities identified by
18
19 autistic adults⁴⁹. In comparison to current international longitudinal studies of autistic
20
21 adults⁵⁰⁻⁵² the ALSAA gathers a wider range of data points using standardised measures,
22
23 gathers data from a community comparison group, and importantly included autistic adults in
24
25 study design from the early stages of the project. The ALSAA will contribute to the
26
27 validation of several standardised measures for this population. Importantly, the ALSAA
28
29 gathers data specific to the unique context and service systems within Australia, pertinent
30
31 given the recent introduction of the National Disability Insurance Scheme (NDIS) and the
32
33 considerable differences in approaches to healthcare and disability across countries. The
34
35 ALSAA primarily aims to identify and comprehensively describe the profiles of Australian
36
37 autistic adults and to compare them to a control group. Longitudinal data will further allow
38
39 the determination of predictors versus correlates across a range of outcomes. The aims of this
40
41 paper are to describe the methodological processes and the inclusive protocol adopted in the
42
43 ALSAA, as well as to present participant characteristics and feedback from the baseline data
44
45 collection.
46
47
48
49
50
51
52

53 **Cohort Description**

54 *Design*

55
56
57
58
59
60

1
2
3 The ALSAA is a questionnaire-based, prospective, longitudinal cohort study with a planned
4
5 2-year follow-up and further follow-ups as resources allow. Initial design and development of
6
7 the ALSAA occurred in collaboration with researchers and clinical health professionals
8
9 across Australia, including close collaboration with the Autism CRC longitudinal Study of
10
11 Australian School Leavers with Autism (SASLA)⁵³. Brief consultation also occurred with
12
13 international experts and researchers conducting similar longitudinal studies. Additionally,
14
15 preliminary work on factors influencing the research participation of autistic adults⁵⁴
16
17 influenced the ALSAA design, including ensuring opportunities for participants to clarify
18
19 questions, receive regular study newsletters, and space for participants to provide
20
21 explanations regarding their responses.
22
23
24
25
26
27
28
29

30 *Patient and Public Involvement*

31
32
33 *How was the development of the research question and outcome measures informed by*
34
35 *patients' priorities, experience, and preferences?*
36
37

38
39 The ALSAA was developed with input from a research advisory network, initially consisting
40
41 of 6 autistic adults and 2 family members/carers of autistic adults who helped develop the
42
43 surveys to ensure the questions were relevant, accessible and valid.
44
45

46
47 *How did you involve patients in the design of this study?*
48

49
50 The ALSAA Inclusive Research Protocol was developed based on the principles of inclusive
51
52 research⁵⁵, the Autism CRC report *Inclusive Research Practice Guides and Checklists for*
53
54 *Autism Research*⁵⁶ (e.g. Checklist 3: Practices that Support Inclusion of Individuals on the
55
56 Autism Spectrum in Advisory and Reference Groups), and procedures similar to those
57
58
59
60

1
2
3 employed by Nicolaidis and colleagues⁵⁷ (e.g. choosing research questions, adapting data
4 collection instruments, interpreting results) (see Table 1).
5
6
7

8 *Were patients involved in the recruitment to and conduct of the study?*
9

10
11 Since the commencement of the ALSAA, this inclusive research protocol has been reviewed
12 by seven of the autistic advisors and one carer advisor and has guided the interactions
13 between researchers and advisors in the development of baseline outputs and the 2-year
14 follow-up design. Specifically, in the design stage of the ALSAA, members of the advisory
15 network were asked to identify ambiguous or inappropriate language, formatting issues and
16 measures which they thought may be interpreted inappropriately or differently due to poor
17 clarity or wording. An expanded group of eleven advisors had greater input in designing the
18 2-year follow-up, including the selection of focus topic areas. As per the protocol advisors are
19 given forewarning, then one month to respond to most requests from the research team, with
20 more response time as needed. Advisors have provided feedback on ongoing research outputs
21 critiquing interpretations of findings suggested by the researchers, with compensation more
22 recently available for advisors' time. Advisors to date have not been involved in data
23 analysis, though several co-produced peer-research projects are currently underway.
24
25 Advisors have also assisted in promoting recruitment materials particularly through social
26 media.
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46

47 *How will the results be disseminated to study participants?*
48

49
50 The ALSAA sends quarterly newsletters to all participants.
51
52

53 **[Insert Table 1 here]**
54
55

56 *Participants*
57
58
59
60

1
2
3 There are three participant groups in the ALSAA: autistic adults, non-autistic general
4 community comparison controls, and carers of autistic adults. Inclusion criteria required the
5 control and autistic participants to be aged 25 years or older, live in Australia and have
6 sufficient English literacy skills to complete the survey, determined during a screening phone
7 call or online expression of interest (EOI). If an autistic individual was unable or preferred
8 not to self-report, they were given the option to ask an informant to complete an informant
9 version of the survey on their behalf. People with intellectual disability could complete the
10 self-report survey with support or participate via an informant respondent.
11
12
13
14
15
16
17
18
19
20
21

22 Informant respondents and carers needed to be 18 years or older, have sufficient English
23 literacy skills, live in Australia and be able to report on the life of the autistic person. The
24 content of the informant survey is slightly different to the self-report survey (see Table 2) due
25 to some measures, such as the Patient Health Questionnaire-9 (PHQ-9)⁵⁸, having no
26 informant version available. Carers, including family members and support people for the
27 ALSAA, were defined as people who provided unpaid care and support to either a family
28 member (including spouse) or friend who in on the autism spectrum. This is based on the
29 widely accepted definition proposed by Carers Australia
30
31
32
33
34
35
36
37
38
39
40
41 (<http://www.carersaustralia.com.au/about-carers/>).
42
43

44 *Survey*

45
46
47 Three versions of the survey were developed: 1) self-report, for autistic adults and non-
48 autistic controls, 2) informant, for carers/support people to complete about the autistic person
49 who is unable to, or does not want to self-complete, and 3) carer survey for carers/support
50 people/family members to complete about their own health and wellbeing. Surveys could be
51 completed via a paper copy or online. The paper copy was also available in large print. The
52 surveys involved a comprehensive range of measures (see Table 2). In selecting measures,
53
54
55
56
57
58
59
60

1
2
3 preference was given to measures that had established validity with people on the spectrum
4
5 and to those deemed suitable by the autistic advisors.
6
7

8 **[Insert Table 2 here]**
9

10
11 Each survey also contained closing feedback items, asking if any questions were confusing,
12
13 difficult, or upsetting, and any additional topics that should be included. It also asked how
14
15 long the survey took to complete (open-ended response), and an overall satisfaction with the
16
17 survey rated on a 5-point Likert scale. A final item asked for any further feedback.
18
19

20 21 22 *Procedure*

23 24 25 *Piloting*

26
27
28 Four autistic adults piloted the self-report questionnaire and two caregivers piloted the carer
29
30 and the informant questionnaires. Volunteers received two copies, one copy to complete, with
31
32 data recorded where possible in the ALSAA dataset, and the other for their feedback.
33
34

35 Considerable changes to each version of the survey were undertaken in response to feedback
36
37 from the autistic advisors and volunteers, including removing the Communication Checklist –
38
39 Adult⁵⁹, formatting changes and changes to item wordings where the item did not belong to
40
41 an existing standardised tool.
42
43

44 45 *Recruitment and Follow-up*

46
47
48 A recruitment target of 160 autistic adults was set to allow for regression analyses using
49
50 multiple predictor variables. Power analyses, undertaken using power calculation software,
51
52 suggested this would be a sufficient sample size with power $(1 - \beta)$ set at .80 and $\alpha = .05$ to
53
54 detect a Cohen's f^2 effect size estimate of at least .1 using multiple regression models with 7
55
56 predictors. Participants were recruited via advertisements through autism-specific
57
58 organisations, disability organisations, autism self-advocacy groups, employment services,
59
60

1
2
3 universities, Technical and Further Education (TAFE) institutes, psychology and allied health
4 private practices, carer organisations, and online autism communities. In attempts to gather a
5 sample more closely matched to Australian population estimates⁶⁰, additional recruitment
6 activities targeted adults on the spectrum with intellectual disability, and males without
7 autism. General community members, autistic adults and carers of autistic adults who were
8 willing to participate in the ALSAA contacted the research team based at The University of
9 New South Wales (UNSW Sydney) via telephone, email or through completing a short online
10 EOI. After eligibility screening, their details were added to the participant database and they
11 were mailed a paper copy or emailed a link to their survey depending on their preference.
12
13
14
15
16
17
18
19
20
21
22
23

24
25 Due to a high number of responses and advice from autistic advisors, participants who self-
26 identified as being autistic, but did not have a formal diagnosis, representing the hidden
27 population and ‘lost generation’³ of autistic adults, were also recruited. Formally diagnosed
28 participants were asked to provide details of their diagnosis, year of diagnosis, and the
29 discipline and name of the practitioner(s) who diagnosed them. AQ-short cut-off scores (>65,
30 sensitivity .97, specificity .82)⁶¹ also support diagnostic status. At the planned two-year
31 average Time 2 follow-up copies of participants’ diagnostic reports will be requested, with a
32 project undertaken to review and categorise the reports. From November 2017 through 2019
33 participants are being recontacted using contact details provided and considering their
34 communication preferences that were recorded.
35
36
37
38
39
40
41
42
43
44
45
46
47

48 *Ethical Considerations*

49
50
51 Participants were supplied with the appropriate Participant Information Statement and
52 Consent Form (PISCF). For the online survey, participants were asked to confirm their
53 consent at commencement, marking checkboxes prior to proceeding. Consent was inferred
54 from participants who completed and returned paper copies of the survey, as outlined in their
55
56
57
58
59
60

1
2
3 PISCF. In the case where the autistic adult had an intellectual disability a checklist for
4 capacity to provide consent was used. This checklist was completed by the carer/next of kin;
5
6 it was adapted from a checklist developed for use in the Study of Ageing in Intellectual
7
8 Disability (SAGE)⁶². The checklist asks several question relating to the person's ability to
9
10 understand the study, benefits and risks, withdrawal and complaints, to determine if a person
11
12 responsible consent should be obtained additionally or separately. The study was approved by
13
14 the Human Research Ethics Committee at UNSW Sydney, Australia (No. HC15001).
15
16
17
18
19

20 *Data storage*

21
22
23 Online questionnaire data were entered directly by participants into Qualtrics Online Survey
24
25 Software (<https://www.qualtrics.com/>), whereas returned paper copy surveys were entered
26
27 into Qualtrics by a researcher or research assistant. Data from Qualtrics, re-identifiable by
28
29 participation code, were stored on password-protected UNSW Sydney servers. Recently,
30
31 ethics approval for establishment of a databank for the ALSAA data, to allow collaboration
32
33 with external researchers has been obtained.
34
35
36
37

38 *Statistical analysis*

39
40
41 STATA Statistical Analysis Software 14⁶³ and IBM SPSS Statistics 22⁶⁴ were used for
42
43 cleaning, coding, and statistical analyses. For the current manuscript, STATA was used to
44
45 obtain descriptive statistics regarding recruitment, participant feedback, and participant
46
47 characteristics, with the level of significance <.05. Family-wise alpha was not adjusted due to
48
49 the possibility of reducing probability of detecting true positive results⁶⁵. For describing this
50
51 cohort profile, listwise deletion was used for specific analyses when data were missing
52
53 completely at random, after checking for difference in demographics and AQ score for
54
55 dropped participants where appropriate. Subsample sizes are noted throughout.
56
57
58
59
60

Recruitment statistics

Recruitment commenced in July 2015. At the close of Time 1 data gathering in November 2017, 345 autistic adults, 221 non-autistic adults, 185 carers, and 78 informants had registered their interest in the study. Of these, 237 autistic adults, 130 non-autistic adults, 100 carers, and 42 informant reporters completed the entire survey. Overall, a total of 295 autistic adults participated including all survey formats and partial survey completions. A small proportion of participants were deemed ineligible during screening (see Table 3), generally due to being under 25 years, not caring for an adult aged 25+ years old, or being located outside of Australia. Participants were recorded as partial completions if at close of Time 1 their surveys contained the initial demographic items completed and some additional useable data. From available data there was no significant difference in gender, $\chi^2(4, n=337) = 1.07$, $p=.898$, or approximate age [$F(4, 4) = 2.04$, $p=.09$] based on survey commencement, eligibility or completion status for the autistic adults. These non-significant results were also found for the non-autistic adults across gender, $\chi^2(4, n=215) = 6.98$, $p=.137$, and age [$F(4, 4) = 0.96$, $p=.43$].

[Insert Table 3 here]

Time taken to complete, and satisfaction with, the survey

Participants reported varying times taken to complete the entire survey. Self-reporting autistic participants reported between 20 minutes and 12 hours to complete with an average time of 156 minutes ($n=164$, $SD=111$), though several responses ($n=53$) were not easily convertible to numeric values for analysis, for example “few days”, “no idea”, or no response to the item ($n=36$). Non-autistic, self-reporting participants reported a range of 20 minutes to 5 hours

1
2
3 with an average time of 106 minutes ($n=98$, $SD=74$). This was significantly less than self-
4 reporting autistic adults despite their completing almost all the same measures and domains,
5
6 $t(260)=-4.94$, $p<.001$. Carers took 75 minutes on average ($n=81$, $SD=62$) and informant
7
8 responders took 103 minutes on average ($n=27$, $SD=54$) to complete surveys. The majority of
9
10 participants (64%, $n=482$) reported that they were satisfied or very satisfied with the survey;
11
12 few participants were dissatisfied (6%) (Figure 1). There was no association between time
13
14 taken to complete the self-report survey and level of satisfaction ($n=262$, $r_s = .10$, $p=.09$), and
15
16 no difference in satisfaction based on survey type, $X^2(9, n=482) = 11.2$, $p=.26$.
17
18
19
20
21

22 **[Insert Figure 1 here]**
23

24
25 The most common negative feedback related to the length of surveys, or to difficulty with
26
27 literal interpretations of forced response items where participants felt the options provided did
28
29 not match their circumstances. Several participants provided feedback that they were grateful
30
31 for research in this area. Additional topics of interest were suggested, as well as the potential
32
33 removal of some questionnaires (e.g., the Brief COPE). Revision of items referring to social
34
35 supports was suggested, as some participants found these upsetting.
36
37
38
39

40 *Summary of participant characteristics*

41

42
43 The age of autistic participants ranged from 25 to 80 years, with a high proportion of females
44
45 (50%, $n=295$) across all autistic samples. Across all autistic participants 25% were married
46
47 and 36% were living as a couple. Over half (57%, $n=42$) of the informant report sample lived
48
49 with their parents (see Table 4), in contrast to self-reporting autistic adults who most
50
51 frequently lived as a couple (45%, $n=295$) or alone (26%, $n=295$). Self-reporting autistic
52
53 adults did not differ to control participants on rural / remoteness according to Australian
54
55 Statistical Geography Standard-Remoteness Area (ASGS-RA) classification, $X^2(4, n=378) =$
56
57 9.36, $p=.05$ ($n=21$ missing). They were more likely to have greater socioeconomic
58
59
60

1
2
3 disadvantage according to the postcode-based Socioeconomic Index for Areas (SEIFA)
4
5 decile, $t(376)=2.96, p<.01$ ($n=21$ missing, NB. SEIFA / rurality not available for all
6
7 postcodes), though were still above average compared to the Australian population. Time 2
8
9 data gathering will seek to gather household income data to more accurately determine
10
11 socioeconomic disadvantage.
12
13

14
15 Of the formally diagnosed autistic adults ($n=221$), 132 (56%) reported they have a diagnostic
16
17 report available, with 169 (76%) diagnosed by one clinician and 29 (13%) reporting diagnosis
18
19 by two or more clinician ($n=23$ missing). As shown in Table 5, the majority (97%, $n=295$) of
20
21 all autistic participants met the AQ-Short cut-off for identifying autism, compared to 30%
22
23 ($n=60$) of biologically related carers and 22% ($n=137$) of non-autistic control participants.
24
25

26
27 Asperger's syndrome was the most frequently reported formal diagnosis. Self-report,
28
29 formally diagnosed autistic participants on average were diagnosed 6.9 years prior to survey
30
31 completion, and the majority (90%; $n=217, 4$ missing) received their diagnosis in adulthood.
32
33

34
35 A preliminary analysis of gender differences for self-reporting autistic adults was also
36
37 conducted. In comparison to males, self-reporting formally diagnosed females did not differ
38
39 significantly on age of diagnosis $t(192)=.39, p=.70$ ($n=4$ missing). Comparing males with
40
41 females, including non-diagnosed autistic adults, there was no difference in number of
42
43 individuals currently married or in a defacto relationship, $X^2(1, n=241) = .8, p=.38$, or in their
44
45 educational status, $X^2(2, n=241) = 4.66, p=.10$. Females were significantly different regarding
46
47 employment status $X^2(4, n=241) = 18.77, p=.001$, though only relating to the number
48
49 providing homecare ($n=19$ female vs. $n=1$ male, see Table 4).
50
51

52
53 In the non-autistic control sample, participant ages ranged from 25 to 79 years, with a high
54
55 proportion (80%, $n=146$) of females. The majority lived as a couple (72%) and were married
56
57 (62%). The control sample was significantly different to the self-reporting autistic adults
58
59 (with and without a formal diagnosis) on several demographics including gender, $X^2(2,$
60

1
2
3 $n=399$) = 26.5, $p<.001$, living situation, $X^2(5, n=399) = 33.2, p<.001$, marital status, $X^2(8,$
4
5 $n=398) = 47.1, p<.001$ ($n=1$ missing), employment status, $X^2(6, n=367) = 18.3, p=.005$ ($n=32$
6
7 missing), and higher education status, $X^2(2, n=399) = 22.4, p<.001$. The control sample was
8
9 also significantly less likely to meet the DSM-IV-TR linked PHQ-9 cut-off for depression,
10
11 $X^2(1, n=354) = 54.9, p<.001$ ($n=45$ missing), less likely meet the DSM5 GAD-A cut-off⁶⁶ for
12
13 anxiety, $X^2(1, n=366) = 67.8, p<.001$ ($n=33$ missing), and less likely to have a history of
14
15 psychiatric illness, $X^2(1, n=384) = 82.1, p<.001$ ($n=15$ missing), compared to self-reporting
16
17 autistic adults. There were no significant differences for self-reporting autistic adults missing
18
19 data on the PHQ-9 or DSM5 GAD-A based on age, gender or AQ score.
20
21
22
23

24
25 As shown in Table 6, the majority (43%; $n=98, 4$ missing) of carers were mothers of an
26
27 autistic adult, followed by partners or spouses (23%). Carers' ages ranged from 21 to 78
28
29 years. The majority were female (83%, $n=102$), married (66%), and living as a couple (75%).
30
31 Carers spent an average 63.4 ($SD=57.80, n=92$) hours per week with the adult with autism,
32
33 and the average age of the autistic adult cared for was 37.5 years (range 25-96 years,
34
35 $SD=13.21$). The majority of carer participants (76%, $n=102$) are linked to a self-report or
36
37 informant-report responses.
38
39
40

41 [insert Table 4 here]

42 [insert Table 5 here]

43 [insert Table 6 here]

44 45 46 47 48 49 50 51 Findings to date

52
53 Using an inclusive research approach, the ALSAA has collected a detailed profile of the
54
55 physical and mental health, productivity, wellbeing and health service use of autistic adults
56
57 aged 25+ years, and their carers, living in Australia. There were high numbers of recruitment
58
59
60

1
2
3 responses across the four Time 1 survey populations (autistic and control adult self-report,
4 informant report on autistic adults, carer self-report). The ALSAA Time 1 data has been used
5 in several studies of psychotropic medication use⁶⁷, leisure participation⁶⁸, ageing well⁶⁹,
6 loneliness⁷⁰ and employment⁷¹. ALSAA and SASLA pooled data has been used to explore
7 cognitive reappraisal⁷², suicidal ideation⁷³, psychometric scale validation⁷⁴, anxiety and
8 depression⁷⁵. Several other outputs are in development, with focus on health service barriers
9 and usage, caregivers, impact of diagnosis in adulthood, further scale validations,
10 longitudinal analyses of loneliness, suicidal ideation, mental illness risk factors among others,
11 meeting the broad aim of the study to describe and compare the profiles of Australian autistic
12 adults.
13
14
15
16
17
18
19
20
21
22
23
24
25
26

27 *Participant characteristics*

28
29
30 A large number of females on the spectrum ($n=150$) have participated in the ALSAA. This
31 will provide an opportunity to explore the different expression of autism characteristics in
32 females without intellectual disability^{5, 76}. Similar to findings in other studies^{10, 32}, self-
33 reporting autistic adults had high rates of depression (52%), anxiety (55%), and a frequent
34 history of psychiatric diagnosis (89%), significantly more than the control sample. They were
35 less likely to be employed and less likely to have a university education compared with the
36 control sample.
37
38
39
40
41
42
43
44
45
46
47

48 *Questionnaire feedback and completion*

49
50 The length of the surveys may have led to some participants not completing following
51 registration, or to missing data or only partial completions. Longer survey length has been
52 linked to lower participation and completion of web-based surveys^{77, 78}. Despite emphasising
53 the ability to complete over several sessions, some participants commented that the survey
54 was “too long”. In contrast, survey length was not identified as an issue during pilot testing,
55
56
57
58
59
60

1
2
3 time to complete was not related to survey satisfaction, and some participants appreciated the
4 comprehensive nature of the surveys. Suggestions made in questionnaire feedback will be
5
6 incorporated in the design of the 2-year follow up. Follow-up design aims to reduce
7
8 assessment burden by reducing overall survey length and where appropriate pre-filling
9
10 repeated measures such as medical history. Additional areas of interest to the community will
11
12 be explored including bullying, relationships and terms used to describe individuals with an
13
14 autism spectrum diagnosis.
15
16
17
18
19

20 **Strengths and limitations**

21
22
23 An important strength of the study was the inclusive research approach using autistic
24
25 advisors. Frequently missing from autism research and other longitudinal studies, an
26
27 inclusive research protocol was developed for the ALSAA in consultation with autistic
28
29 advisors (see Table 1) and applied across all stages of the research process apart from the
30
31 analysis. Inclusive research has been found to increase the likelihood that findings are
32
33 translatable to the real world and focused on areas of need from community perspectives⁴⁴.
34
35 Best-practise processes of conducting inclusive research with autistic adults are not well
36
37 known, though more resources are becoming available⁷⁹ The ALSAA has engaged peer
38
39 researchers in some future outputs. An additional strength of the ALSAA design is its
40
41 consideration and partial overlap with several other national and international studies, for
42
43 example overlap with the Autism CRC SASLA longitudinal study allows for a lifespan
44
45 approach to be taken including data from late adolescence⁷².
46
47
48
49
50
51
52
53
54

55 The ALSAA baseline sample is reflective of the convenience sampling methodology used.
56
57 Participants would appear non-representative of the Australian autism population given
58
59 approximate postcode-based above average socioeconomic status, a large female gender bias
60

1
2
3 for both autistic adults and controls, and that the majority of the autistic sample does not have
4 an intellectual disability. Earlier epidemiological estimates of autism²³ would suggest a larger
5 proportion of people with a diagnosis of autism and intellectual disability and a much higher
6 male to female ratio, though recent work questions these assumptions^{2, 80}. Self-selection in
7 online surveys can lead to a female gender bias⁷⁸, as also has been noted in other online
8 autism research⁸¹⁻⁸³. Commonly reported as a 4 to 1 male bias⁸⁴, there is suggestion the true
9 autism gender ratio may be closer to 3 to 1⁸⁰ or lower⁷⁶ as females with autism are at a higher
10 risk of being underdiagnosed³. Limiting recruitment to participants age 25 years or older,
11 changing diagnostic practices⁸⁵, in combination with the convenience sampling, has likely led
12 to the large percentage of participants who had received their autism diagnosis in adulthood.
13
14
15
16
17
18
19
20
21
22
23
24
25
26

27 The majority of the current autistic sample does not have an intellectual disability. Significant
28 barriers exist for people with intellectual disability to participate in a questionnaire-based
29 study⁸⁶. An alternative to directly gathering information from adults on the spectrum with
30 intellectual disability is the participation via an informant respondent. Although an informant
31 respondent survey was made available for the ALSAA, and despite targeted recruitment
32 efforts, there was low participation of people with intellectual disability.
33
34
35
36
37
38
39
40

41 A final limitation is the self-report questionnaire format of the ALSAA, particularly in
42 relation to self-reported diagnosis of autism and comorbid conditions without clinical
43 reassessment. Validating autism diagnosis through clinical reassessment would be a highly
44 resource intensive exercise in a nationwide study in Australia and is beyond the resourcing
45 available to the study. This is offset by gathering of additional information relating to autism
46 diagnosis, including asking if the respondent has a diagnostic report, name and type of
47 clinician providing diagnosis, and AQ scores. These variables could be used to identify
48 subsamples with stronger evidence of definite diagnosis of autism for separate analysis where
49 necessary depending on the specific research question. Further, diagnostic reports from
50
51
52
53
54
55
56
57
58
59
60

1
2
3 participants will be requested from participants at follow-up to confirm diagnosis. Gathering
4 data from adults without a formal diagnosis is potentially a strength, given the ‘lost
5 generation’ of autistic adults³, significant barriers to diagnosis, and accuracy issues with gold
6 standard autism assessment tools⁸⁷; these participants could be overlooked in other studies
7 though they represent an important hidden population group. The self-report format also
8 prevents the quantification of participants’ cognitive ability. The use of standardised mental
9 health screening measures with clinical cut-offs gathers some information on co-occurring
10 mental health conditions, though not as reliably as would be available via clinical interview.
11 Conversely, community-based sampling and use of self-report questionnaires does allow for
12 gathering a reasonably large sample, offsetting the risk of including people with incorrect
13 diagnostic data with increased statistical power and the potential severity bias of clinical
14 samples. Limitations and strengths of the ALSAA study design will largely depend on the
15 specific research question being explored, with sufficient sample size and data points to
16 partial-out subgroups and non-matched controls or to account for common method variance
17 as needed.

38 *Implications*

39
40
41 There is a significant knowledge gap regarding the lives of autistic adults. The ALSAA has
42 gathered a large comprehensive dataset relating to autistic adults and their carers, creating a
43 platform for longitudinal follow-up and collaborative research. The ALSAA is an important
44 resource for exploring multiple research questions regarding the lives of autistic adults.

45
46 However, as with all longitudinal research caution is required in drawing firm conclusions
47 from the ALSAA cohort in relation to the entire Australian autism population. Nevertheless,
48 this cohort provides the first opportunity to explore longitudinal outcomes of Australian
49 autistic adults. Having offline and informant versions of questionnaires, and questionnaires
50
51
52
53
54
55
56
57
58
59
60

1
2
3 reviewed by autistic advisors, facilitates greater accessibility for participants on the spectrum
4
5 and their carers.
6

7
8 The ALSAA study demonstrates a working approach to inclusive research with autistic
9
10 advisors. The inclusive research protocol developed in this study provides a useful basis for
11
12 other research endeavours. Following this protocol, future outputs such as peer-reviewed
13
14 manuscripts, presentations and reports from the ALSAA will also be developed in
15
16 consultation with autistic advisors or autistic peer researchers. Input from autistic advisors
17
18 has already improved the quality and relevance of initial outputs⁶⁷, for example identifying
19
20 potential alternative interpretations of findings based on lived experiences, potential
21
22 differences in autistic interpretations of scale items, and modifying the methodology in one
23
24 instance⁷⁰ changing a purely quantitative study into a mixed methods design.
25
26
27
28
29

30 Some measures used in the ALSAA have not yet been validated with autistic adult samples
31
32 (e.g., DSM5 GAD-A, Emotion Regulation Questionnaire, PHQ-15). The ALSAA provides
33
34 the opportunity to explore the validity of these commonly used measures”
35
36
37

38 **Collaboration**

39
40 International studies involving autistic adults and utilising standardised measures are
41
42 underway in the United States, Netherlands and United Kingdom (e.g., SPARK
43
44 <http://sparkforautism.org>, AASPIRE <https://aaspire.org/>, the Netherlands Autism Register
45
46 <https://www.nederlandsautismeregister.nl> and the Adult Autism Spectrum Cohort-UK
47
48 <http://research.ncl.ac.uk/adultautismspectrum/>), though with less comprehensive ranges of
49
50 measures. During development of the ALSAA, consultation with international groups
51
52 occurred to ensure there were some synergies with these studies. Future international
53
54 comparisons will be possible, including pooling of data. This will allow for the creation of
55
56 much larger datasets and more in-depth understanding of life in adulthood for autistic people.
57
58
59
60

Further details

Contributors

Manuscript drafting was jointly led by SA & KF. All authors (YH,AR,MU,LL,RC,TF,MF,NL,AU,JT) had a role in the conduct of the research, interpretation of results, drafting of manuscript and critical review of the manuscript. SA, KF, YH, AR, MU & JT conducted data analysis and reporting. KF, YH, AR, MU, RC, TF, MF, NL, AU & JT were involved in the conceptualisation of the study.

Data Sharing Statement

Processes to establish data banking and sharing procedures are currently being finalised. Please email the corresponding author regarding queries.

Ethics approval

The study was approved by the Human Research Ethics Committee at UNSW Sydney, Australia (No. HC15001).

Acknowledgements

The authors also acknowledge the valuable contribution of the Research Advisory Network members Matthew Bennett, Bob Boyce, Jen Harland, Julianne Higgins, Gabriel Nakhel, Joanne Mahony, Andrea Michael, Cheryl Strangio, and Chris Tanner whose insight and recommendations shaped this work. We also gratefully acknowledge the cooperation and participation of all participants on the autism spectrum and their carers involved in this study.

Funding

This work was supported by the Cooperative Research Centre for Living with Autism (Autism CRC), established and supported under the Australian Government's Cooperative Research Centres Program.

Conflict of Interest

The authors have no conflict of interest to report.

References

1. Seltzer MM, Shattuck PT, Abbeduto L, Greenberg JS. Trajectory of development in adolescents and adults with autism. *Mental Retardation and Developmental Disabilities*. 2004;10:234-47.
2. Brugha TS, Spiers N, Bankart J, Cooper S-A, McManus S, Scott FJ, et al. Epidemiology of autism in adults across age groups and ability levels. *The British Journal of Psychiatry*. 2016/12/01/;209(6):498-503. en.
3. Lai M-C, Baron-Cohen S. Identifying the lost generation of adults with autism spectrum conditions. *The Lancet Psychiatry*. 2015 2015/11/01/;2(11):1013-27.
4. Van Wijngaarden-Cremers PJM, van Eeten E, Groen WB, Van Deurzen PA, Oosterling IJ, Van der Gaag RJ. Gender and Age Differences in the Core Triad of Impairments in Autism Spectrum Disorders: A Systematic Review and Meta-analysis. *Journal of Autism and Developmental Disorders*. 2014 March 01;44(3):627-35.
5. Bargiela S, Steward R, Mandy W. The Experiences of Late-diagnosed Women with Autism Spectrum Conditions: An Investigation of the Female Autism Phenotype. *Journal of Autism and Developmental Disorders*. 2016 2016/10/01/;46(10):3281-94. en.
6. Jang J, Matson JL, Adams HL, Konst MJ, Cervantes PE, Goldin RL. What are the ages of persons studied in autism research: A 20-year review. *Research in Autism Spectrum Disorders*. 2014;8(12):1756-60.
7. Howlin P, Moss P. Adults with autism spectrum disorders. *Canadian Journal of Psychiatry*. 2012;57(5):275-83.
8. Nicolaidis C. Autism in Adulthood: The New Home for Our Emerging Field. *Autism in Adulthood*. 2018;1(1):1-2.
9. Michael C. Why we need research about autism and ageing. *Autism*. 2016;20(5):515-6.
10. Howlin P, Magiati I. Autism spectrum disorder: outcomes in adulthood. *Current Opinion in Psychiatry*. 2017 2017/03//;30(2):69-76. en.
11. Cashin A, Buckley T, Trollor J, Lennox N. A scoping review of what is known of the physical health of adults with autism spectrum disorder. *Journal of Intellectual Disabilities*. 2016.
12. Croen LA, Zerbo O, Qian Y, Massolo M, Rich S, Sidney S, et al. The health status of adults on the autism spectrum. *Autism*. 2015;19(7):814-23.
13. Jones KB, Cottle K, Bakian A, Farley M, Bilder D, Coon H, et al. A description of medical conditions in adults with autism spectrum disorder: a follow-up of the 1980s Utah/UCLA autism epidemiologic study. *Autism*. 2016;5:551-61.
14. Weiss JA, Riosa PB. Thriving in youth with autism spectrum disorder and intellectual disability. *Journal of Autism and Developmental Disorders*. 2015;45:2474-86.
15. Buck TR, Viskochil J, Farley M, Coon H, McMahon WM, Morgan J, et al. Psychiatric comorbidity and medication use in adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders*. 2014;44:3063-71.
16. Hedley D, Uljarević M, Wilmot M, Richdale A, Dissanayake C. Understanding depression and thoughts of self-harm in autism: A potential mechanism involving loneliness. *Research in Autism Spectrum Disorders*. 2018 2018/02/01/;46:1-7.
17. Lever AG, Geurts HM. Psychiatric co-occurring symptoms and disorders in young, middle-aged, and older adults with autism spectrum disorders. *Journal of Autism and Developmental Disorders*. 2016;46:1916-30.
18. Matson JL, Williams LW. Depression and mood disorders among persons with Autism spectrum disorders. *Research in Developmental Disabilities*. 2014;35:2003-7.
19. Moss P, Howlin P, Savage S, Bolton P, Rutter M. Self and informant reports of mental health difficulties among adults with autism findings from a long-term follow-up study. *Autism*. 2015.
20. Hedley D, Uljarević M, Wilmot M, Richdale A, Dissanayake C. Brief Report: Social Support, Depression and Suicidal Ideation in Adults with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*. 2017 November 01;47(11):3669-77.

21. Hirvikoski T, Mittendorfer-Rutz E, Boman M, Larsson H, Lichtenstein P, Bolte S. Premature mortality in autism spectrum disorder. *The British Journal of Psychiatry*. 2015.
22. Matson JL, Nebel-Schwalm N. Comorbid psychopathology with autism spectrum disorder in children: an overview. *Research in Developmental Disabilities*. 2007;28:341-52.
23. Fombonne E. Epidemiology surveys of autism and other pervasive developmental disorders: an update. *Journal of Autism and Developmental Disorders*. 2003;33(4):365-82.
24. LaMalfa G, Lassi G, Bertilli M, Salvani R, Placidi GF. Autism and intellectual disability: a study of prevalence on a sample of the Italian population. *Journal of Intellectual Disability Research*. 2004;48:262-7.
25. Matson JL, Shoemaker M. Intellectual disability and its relationship to autism spectrum disorders. *Research in Developmental Disabilities*. 2009;30:1107-14.
26. Dawson M, Soulières I, Gernsbacher MA, Mottron L. The level and nature of autistic intelligence. *Psychol Sci*. 2007;18(8):657-62. PubMed PMID: 17680932. eng.
27. Howlin P, Arciuli J, Begeer S, Brock J, Clarke K, Costley D, et al. Research on adults with autism spectrum disorder: roundtable report. *Journal of Intellectual and Developmental Disability*. 2015;40(4):388-93.
28. Hedley D, Uljarevic M, Cameron L, Halder S, Richdale AL, Dissanayake C. Employment programmes and interventions targeting adults with autism spectrum disorder: a systematic review of the literature. *Autism*. 2016:1-13.
29. Gray KM, Piccin AK, C. M., Taffe J, Parmenter TR, Hofer S, Einfeld S, et al. Outcomes in young adulthood: are we achieving community participation and inclusion? *Journal of Intellectual Disability Research*. 2014;58(8):734-45.
30. Henninger NA, Taylor JL. Outcomes in adults with autism spectrum disorders: a historical perspective. *Autism*. 2013;17(1):103-16.
31. Howlin P, Moss P, Savage S, Rutter. Social outcomes in mid- to later adulthood among individuals diagnosed with autism and average nonverbal IQ as children. *Journal of American Academy of Child & Adolescent Psychiatry*. 2013;52(6):572-81.
32. Magiati I, Tay XW, Howlin P. Cognitive, language, social and behavioural outcomes in adults with autism spectrum disorders: a systematic review of longitudinal follow-up studies in adulthood. *Clinical Psychology Review*. 2014;34:73-86.
33. Marriage S, Wolverton A, Marriage K. Autism spectrum disorder grown up: A chart review of adult functioning. *Journal of the Canadian Academy of Child and Adolescent Psychiatry*. 2009;18(4):322.
34. Levy A, Perry A. Outcomes in adolescents and adults with autism: a review of the literature. *Research in Autism Spectrum Disorders*. 2011;5:1271-82.
35. Seltzer MM, Krauss MW, Shattuck PT, Orsmond GI, Swe A, Lord C. The symptoms of autism spectrum disorders in adolescence and adulthood. *Journal of Autism and Developmental Disorders*. 2003;33:565-81.
36. Shattuck PT, Selter MM, Greenberg JS, Orsmond GI, Bolt D, Kring S, et al. Change in autism symptoms and maladaptive behaviors in adolescents and adults with an autism spectrum disorder. *Journal of Autism and Developmental Disorders*. 2007;37:1735-47.
37. Happe F, Charlton RA. Aging in autism spectrum disorders: a mini-review. *Gerontology*. 2010;58:70-8.
38. Totsika V, Felce D, Kerr M, Hastings RP. Behaviour problems, psychiatric symptoms, and quality of life for older adults with intellectual disability with and without autism. *Journal of Autism and Developmental Disorders*. 2010;40:1171-8.
39. Khanna R, K. J-P, West-Strum D, Mahabaleshwarkar R. Health-related quality of life and its determinants among adults with autism. 8. 2014 (157-167).
40. Pellicano E, Dinsmore A, Charman T. What should autism research focus upon? Community views and priorities from the United Kingdom. *Autism*. 2014:1-5.

- 1
- 2
- 3
- 4 41. Nicolaidis C. What Can Physicians Learn from the Neurodiversity Movement? . American
- 5 Medical Association Journal of Ethics. 2012;14(6):503-10.
- 6 42. Nicolaidis C, Raymaker D, Dern S, Boisclair C, Ashkenazy E, Baggs A. Comparison of
- 7 healthcare experiences in autistic and non-autistic adults: a cross-sectional online survey facilitated
- 8 by an academic-community partnership. *Journal of General Internal Medicine*. 2012;28(6):761-9.
- 9 43. Kapp SK, Steward R, Crane L, Elliott D, Elphick C, Pellicano E, et al. 'People should be allowed
- 10 to do what they like': Autistic adults' views and experiences of stimming. *Autism*.
- 11 2019:1362361319829628.
- 12 44. Walmsley J, Johnson K. Inclusive research with people with learning disabilities: Past,
- 13 present and futures. London and New York: Jessica Kingsley Publishers 2003.
- 14 45. Bigby C, Frawley P, Ramcharan P. Conceptualising inclusive research with people with
- 15 intellectual disability. *Journal of Applied Research in Intellectual Disabilities*. 2014;27(1):3-12.
- 16 46. Bagatell N. From cure to community: transforming notions of autism. *Journal of the Society*
- 17 *for Psychological Anthropology*. 2010;38(1):33-55.
- 18 47. Milton D, Bracher M. Autistics speak but are they heard? *Medical Sociology Online*.
- 19 2013;7:61-9.
- 20 48. Nind M, Vinha H. Doing research inclusively: bridges to multiple possibilities in inclusive
- 21 research. *British Journal of Learning Disabilities*. 2012;42:102-9.
- 22 49. Gatfield O, Mangan C, Haar T, Kinninurgh A, Rodger S. 2016 Research Priorities Survey
- 23 Report. Brisbane, Queensland, Australia: Cooperative Research Centre for Living with Autism, 2016.
- 24 50. Gotham K, Marvin AR, Talyor JL, Warren Z, Anderson CM, Law PA, et al. Characterizing the
- 25 daily life, needs, and priorities of adults with autism spectrum disorder from Interactive Autism
- 26 Network. *Autism*. 2015:1-11.
- 27 51. McConachie H, Mason D, Parr JR, Garland D, Wilson C, Rodgers J. Enhancing the Validity of a
- 28 Quality of Life Measure for Autistic People. *J Autism Dev Disord*. 2018 May;48(5):1596-611. PubMed
- 29 PMID: 29188584. Pubmed Central PMCID: PMC5889785. Epub 2017/12/01. eng.
- 30 52. Seltzer MM, Greenberg JS, Taylor JL, Smith LE, Orsmond GE, Esbensen A, et al. Adolescents
- 31 and adults with autism spectrum disorders. In: Amaral DG, Dawson G, Geschwind D, editors. *Autism*
- 32 *spectrum disorders* New York: Oxford University Press; 2011.
- 33 53. Lawson L, Hascheck A, Richdale AL. SASLA Snapshot: Study of Australian School-Leavers with
- 34 Autism – Baseline Profile. Melbourne, Australia: Olga Tennison Autism Research Centre (OTARC), La
- 35 Trobe University, 2018.
- 36 54. Haas K, Costley D, Falkmer M, Richdale A, Sofronoff K, Falkmer T. Factors Influencing the
- 37 Research Participation of Adults with Autism Spectrum Disorders. *J Autism Dev Disord*. 2016
- 38 May;46(5):1793-805. PubMed PMID: 26810436. Epub 2016/01/27. eng.
- 39 55. Walmsley J. Normalisation, emancipatory research and inclusive research in learning
- 40 disability. *Disability & Society*. 2001;16(2):188-205.
- 41 56. CRC A. Inclusive research practice guide and checklists for autism research: Version 2.
- 42 Brisbane, Queensland: Autism CRC Ltd., 2016.
- 43 57. Nicolaidis C, Raymaker D, Katz M, Oshwald M, Goe R, Leottie S, et al. Community-based
- 44 participatory research to adapt health measures for use by people with developmental disabilities.
- 45 *Progress in Community Health Partnerships: Research, Education, and Action*. 2015;9(2):141-3.
- 46 58. Kroenke K, Spitzer RL, Williams JBW. The PHQ-9: validity of a brief depression severity
- 47 measure. *Journal of General Internal Medicine*. 2001;16:606-13.
- 48 59. Whitehouse AJO, Bishop DVM. Communication checklist - adult. London: The Psychological
- 49 Corporation; 2009.
- 50 60. (AIHW) ALoHaW. Autism in Australia. Web Report. Canberra, Australia: AIHW, 2017 5-4-17.
- 51 Report No.
- 52 61. Hoekstra RA, Vinkhuyzen AAE, Wheelwright S, Bartels M, Boomsma DI, Baron-Cohen S, et al.
- 53 The construction and validation of an abridged version of the Autism-Spectrum Quotient. *Journal of*
- 54 *Autism and Developmental Disorders*. 2011;41:589-96.
- 55
- 56
- 57
- 58
- 59
- 60

62. Evans E, Trollor J, Davis A, Bhardwaj A, O'Brien E. Mental health and carer support in elders with ID. Report to Ageing, Disability and Home Care, Department of Family and Community Services, NSW Australia. Sydney, Australia: Department of Developmental Disability Neuropsychiatry, UNSW Sydney, 2015.
63. StataCorp. Stata Statistical Software: Release 14. College Station, TX: StataCorp LP; 2015.
64. IBM_Corp. IBM SPSS Statistics for Windows, Version 22.0. Armonk, NY: IBM Corp; 2013.
65. Feise RJ. Do multiple outcome measures require p-value adjustment? BMC medical research methodology. 2002;2(1):8.
66. Beesdo-Baum K, Klotsche J, Knappe S, Craske MG, LeBeau RT, Hoyer J, et al. Psychometric properties of the dimensional anxiety scales for DSM-V in an unselected sample of German treatment seeking patients. *Depression and Anxiety*. 2012;29(12):1014-24.
67. Cvejic RC, Arnold SRC, Foley K-R, Trollor JN. Neuropsychiatric profile and psychotropic medication use in adults with autism spectrum disorder: results from the Australian Longitudinal Study of Adults with Autism. *BJPsych Open*. 2018;4(6):461-6. Epub 11/13.
68. Stacey T-L, Froude EH, Trollor J, Foley K-R. Leisure participation and satisfaction in autistic adults and neurotypical adults. *Autism*. 2018;0(0):1362361318791275. PubMed PMID: 30132680.
69. Hwang YI, Foley K-R, Trollor JN. Aging Well on the Autism Spectrum: An Examination of the Dominant Model of Successful Aging. *Journal of Autism and Developmental Disorders*. 2018 May 02.
70. Ee D, Hwang J, Reppermund S, Srasuebku P, Trollor J, Foley K-R, et al. Loneliness in Adults on the Autism Spectrum. 2019.
71. Harsanyi M, Foley K-R, Froude E, Trollor J, Arnold SRC. Employment Profiles of Autistic Adults in Australia. 2019.
72. Cai RY, Richdale AL, Foley K-R, Trollor J, Uljarević M. 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*. 2018 2018/01/01/;45:1-8.
73. Hedley D, Uljarević M, Foley K-R, Richdale A, Trollor J. Risk and protective factors underlying depression and suicidal ideation in Autism Spectrum Disorder. *Depression and Anxiety*. 2018;35(7):648-57.
74. Arnold SRC, Uljarevic M, Hwang J, Richdale A, Trollor J, Lawson LP. Brief Report: Psychometric Properties of the Patient Health Questionnaire-9 (PHQ-9) in Autistic Adults. *Journal of Autism and Developmental Disorders*. 2019:1-9.
75. Uljarevic M, Hedley D, Foley K-R, Magiati I, Cai RY, Dissanayake C, et al. Anxiety and depression from adolescence to old age in autism spectrum disorder. 2019.
76. Baldwin S, Costley D. The experiences and needs of female adults with high-functioning autism spectrum disorder. *Autism*. 2016;20(4):483-95. PubMed PMID: 26111537.
77. Fan W, Yan Z. Factors affecting response rates of the web survey: A systematic review. *Computers in Human Behavior*. 2010 2010/03/01/;26(2):132-9.
78. Guo X, Vittinghoff E, Olgin JE, Marcus GM, Pletcher MJ. Volunteer Participation in the Health eHeart Study: A Comparison with the US Population. *Scientific Reports*. 2017 2017/05/16/;7(1):1956. En.
79. Fletcher-Watson S, Adams J, Brook K, Charman T, Crane L, Cusack J, et al. Making the future together: Shaping autism research through meaningful participation. *Autism*. 2019;0(0):1362361318786721. PubMed PMID: 30095277.
80. Loomes R, Hull L, Mandy WPL. What Is the Male-to-Female Ratio in Autism Spectrum Disorder? A Systematic Review and Meta-Analysis. *Journal of the American Academy of Child & Adolescent Psychiatry*. 2017 2017/06/01/;56(6):466-74.
81. Gilmour L, Schalomon PM, Smith V. Sexuality in a community based sample of adults with autism spectrum disorder. *Research in Autism Spectrum Disorders*. 2012 2012/01/01/;6(1):313-8.
82. Kapp SK, Gillespie-Lynch K, Sherman LE, Hutman T. Deficit, difference, or both? Autism and neurodiversity. *Developmental Psychology*. 2013 2013/49(1):59-71. en.

- 1
2
3 83. Nicolaidis C, Raymaker D, McDonald K, Dern S, Boisclair C, Ashkenazy E, et al. Comparison of
4 healthcare experiences in autistic and non-autistic adults: A cross-sectional online survey facilitated
5 by an academic-community partnership. *Journal of General Internal Medicine*. 2013;28(6):761-9.
6
7 84. Whiteley P, Todd L, Carr K, Shattock P. *Gender Ratios in Autism, Asperger Syndrome and*
8 *Autism Spectrum Disorder*. Autism Insights; London. 2010 2010;2:17. English.
9
10 85. Whitehouse AJO, Cooper MN, Bebbington K, Alvares G, Lin A, Wray J, et al. Evidence of a
11 reduction over time in the behavioral severity of autistic disorder diagnoses. *Autism Research*.
12 2017;10(1):179-87.
13
14 86. Chadwick D, Wesson C, Fiullwood C. Internet Access by People with Intellectual Disabilities:
15 Inequalities and Opportunities. *Future Internet*. 2013;5(3):376-97.
16
17 87. Fusar-Poli L, Brondino N, Rocchetti M, Panisi C, Provenzani U, Damiani S, et al. Diagnosing
18 ASD in Adults Without ID: Accuracy of the ADOS-2 and the ADI-R. *Journal of Autism and*
19 *Developmental Disorders*. 2017 2017/11/01;47(11):3370-9.
20
21 88. Barrett SL, Uljarević M, Baker EK, Richdale AL, Jones CRG, Leekam SR. The Adult Repetitive
22 Behaviours Questionnaire-2 (RBQ-2A): A Self-Report Measure of Restricted and Repetitive
23 Behaviours. *Journal of Autism and Developmental Disorders*. 2015 2015/11/01;45(11):3680-92.
24
25 89. Robertson AE, Simmons DR. The relationship between sensory sensitivity and autistic traits
26 in the general population. *Journal of Autism and Developmental Disorders*. 2012;43:775-84.
27
28 90. Carleton RN, Norton PJ, Asmundson GJG. Fearing the unknown: a short version of the
29 intolerance of uncertainty scale. *Journal of Anxiety Disorders*. 2007;21:105-17.
30
31 91. Spitzer RL, Williams JBW, Kroenke K, Linzer M, deGruy FV, Hahn SR. Utility of new procedure
32 for diagnosis mental-disorders in primary-care: the PRIME-MD 1000 study. *Journal of American*
33 *Medical Association*. 1994;272:1749-56.
34
35 92. Ware JE, Kosinski M, Keller SD. A 12-Item Short-Form Health Survey: construction of scales
36 and preliminary tests of reliability and validity. *Medical care*. 1996;34(3):220.
37
38 93. Sletten DM, Suarez GA, Low PA, Mandrekar J, Singer W. COMPASS 31: A refined and
39 abbreviated composite autonomic symptom score. *Mayo Clinic Proceedings*. 2012;87(12):1196-201.
40
41 94. Buysse DJ, Reynolds CF, Monk TH, Berman SR, Kupfer DJ. The Pittsburgh Sleep Quality Index:
42 a new instrument for psychiatric practise and research. *Psychiatry Reserves*. 1989;28:193-213.
43
44 95. Gardisar M, Lack L, Richards H, Harris J, Gallasch J, Boundy M, et al. The Flinders Fatigue
45 Scale: preliminary psychometric properties and clinical sensitivity of a new scale for measuring
46 daytime fatigue associated with insomnia. *Journal of Clinical Sleep Medicine*. 2007;3(7):722-8.
47
48 96. Craske MG, Wittchen H-U, Bogels S, Stein M, Andrews G, Lebeu R. Severity measure for
49 Generalized Anxiety Disorder - adult: American Psychiatric Association; 2013.
50
51 97. Tennant R, Hiller L, Fishwick R, Platt S, Joseph S, Weich S, et al. The Warwick-Edinburgh
52 mental well-being scale (WEMWBS): development and UK validation. *Health and Quality of Life*
53 *Outcomes*. 2007;5(63):1-13.
54
55 98. Chen G, Gully SM, Eden D. Validation of a new general self-efficacy scale. *Organizational*
56 *Research Methods*. 2001;4(1):62-83.
57
58 99. Gross JJ, John OP. Individual differences in two emotion regulation processes: implications
59 for affect, relationships, and well-being. *Journal of Personality and Social Psychology*.
60 2003;85(2):348-62.
100. Mohr C, Tonge BJ, Einfeld SL, Taffe J. *The Developmental Behaviour Checklist for Adults (DBC-A) Revised*. Sydney, Australia: University of Sydney and Monash University, 2011.
101. Carver CS. You want to measure coping but your protocol's too long: consider the brief COPE. *International journal of behavioral medicine*. 1997;4(1):92-100. PubMed PMID: 16250744. Epub 1997/01/01. eng.
102. Crook TH, 3rd, Feher EP, Larrabee GJ. Assessment of memory complaint in age-associated memory impairment: the MAC-Q. *International psychogeriatrics*. 1992 Fall;4(2):165-76. PubMed PMID: 1477304. Epub 1992/01/01. eng.

- 1
2
3 103. Hays RD, DiMatteo MR. A short-form measure of loneliness. *Journal of Personality*
4 *Assessment*. 1987;51:69-81.
- 5 104. Sarason IG, Levine HM, Basham RB, Sarason BR. Assessing social support: the social support
6 questionnaire. *Journal of Personality and Social Psychology*. 1983;44(1):127-39.
- 7 105. The WHOQOL Group. The World Health Organization Quality of Life assessment (WHOQOL)-
8 BREF quality of life assessment. *Psychological Medicine*. 1995;28:551-5.
- 9 106. Maenner MJ, Smith LE, Hong J, Makuch R, Greenberg JS, Mailick MR. Evaluation of an
10 activities of daily living scale for adolescents and adults with developmental disabilities. *Disability*
11 *and Health Journal* 2013;6(1):8-17.
- 12 107. Luciano JV, Ayuso-Mateos JL, Aguado J, Fernandez A, Serrano-Blanco A, Roca M, et al. The
13 12-item World Health Organisation Disability Assessment Schedule (WHO-DAS II): a nonparametric
14 item response analysis *BMC Medical Research Methodology*. 2010;10(45):1-9.
- 15 108. Taylor JL, Seltzer MM. Developing a vocational index for adults with autism spectrum
16 disorders. *Journal of Autism and Developmental Disorders*. 2012;42(12):2669-79.
- 17 109. Beard JG, Ragheb MG. Measuring leisure satisfaction. *Journal of Leisure Research*.
18 1980;12:20-33.
- 19 110. Chisholm D, Knapp MRJ, Knudsen HC, Amaddeo F, Gaité L, van Wijngaarden B, et al. Client
20 socio-demographic and service receipt inventory - European version: development of an instrument
21 for international research. *The British Journal of Psychiatry*. 2000;177:28-33.
- 22 111. Bengston VL, Allen KR. The life course perspective applied to families overtime. In: Boss P,
23 Doherty W, LaRossa R, Schumm W, Steinmetz S, editors. *Sourcebook of family theories and*
24 *methods: a contextual approach*. New York: Plenum Press; 1993. p. 469-98.
- 25 112. McCarron M, Gill M, Lawlor B, Beagly C. A pilot study of the reliability and validity of the
26 Caregiver Activity Survey - Intellectual disability (CAS-ID). *Journal of Intellectual Disability Research*.
27 2002;46(8):605-12.
- 28 113. Bedard M, Molloy DW, Squire L, Dubois BA, Lever JA, O'Donnell M. The Zarit Burden
29 Interview: a new short version and screening version. *The Gerontologist*. 2001;41(5):652-7.
- 30 114. Alliance NRH. The little book of rural health numbers: Author; 2015. Available from:
31 <https://www.ruralhealth.org.au/book/little-book-rural-health-numbers>.
- 32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

Figure Caption Sheet

Figure 1. Satisfaction responses upon completion combined by survey type (n=482)

For peer review only

Table 1

The ALSAA Inclusive Research Protocol

Step	Description of step and considerations
Step 1: Recruitment of advisors / peer-researchers	Ensure recruitment is inclusive of all potential autistic individuals including adults with intellectual disability, consider using multiple channels of recruitment (e.g., Autism associations, self-advocacy networks, carer networks, adult networks, local radio, social media and word of mouth). In Australia, seek support from the Autism CRC Research Academy*.
Step 2: Building rapport	If an established relationship does not already exist between the autistic individual and researcher, the researcher should offer to meet the individual (either face-to-face, over video conference or phone call). Be mindful that some autistic individuals may prefer to communicate via text or email and not to meet in person and should not be required to.
Step 3: Clarify what will be expected from the advisor	Outline tasks autistic advisors or peer researchers will be asked to complete. Specify the frequency and timing of when they are likely to be contacted. For specific tasks clearly provide step-by-step instructions, flexible lead-time, timeframes for feedback, area of investigation, and broad aim of the study. Make information available in Easy English or plain language as appropriate. Specify the type and nature of advice sought. Clearly describe how and where their input will be used and why their input is being sought.
Step 4: Ethics, confidentiality and acknowledgement	Describe ethics of the project and expected confidentiality. As required, specify on individual documents that the document is confidential and not to be distributed without discussion with the researcher. Can the autistic individual opt out if they would like? Outline what will happen if they choose to withdraw, e.g., this will not affect their relationship with the research team, university or any other associated organisations. It is a voluntary process. Negotiate and make explicit how the autistic advisor or peer-researcher will be acknowledged. Consider how the autistic individual may be recognised in a manuscript or research output. This may include as a co-author, in the acknowledgements section, and/or in discussing methodology and findings.
Step 5: Identify preferred communication style	Ask the autistic individual their preferred communication style for providing feedback (e.g., face-to-face, phone call, email, video, or a variety of techniques). Also, in what medium they would like to receive the results/findings e.g., academic writing style, easy English writing style, mostly graphs/pictures, mostly dot points, described in person, video, PowerPoint presentation, etc. Although not all mediums may be practical, it is important to identify the autistic advisor's preferred style and then work together to identify a medium of communication which will be understood and accessible by both the autistic advisor and the researcher.
Step 6: The sensory environment	The researcher must provide an 'autism-friendly' environment on any occasion where the autistic advisor and the researcher may be meeting in person, see p. 12-15 in the <i>Autism CRC Inclusive Research Practice Guides and Checklists for Autism Research</i> ⁵⁶ regarding creating autism-friendly environments.
Step 7: Involvement in	Autistic advisors input is sought in regard to questionnaire design and interpretation of results. The researcher will need to present questionnaire

1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16	methodological design / results / findings	design questions or quantitative or qualitative results in an understandable format, developing design issue summaries or results summaries in the medium preferred by the autistic advisor or peer-researcher. This means the researcher may need to make a number of decisions around data analysis and interpretation. Where possible, outline each of these decisions so the process is transparent and the autistic advisor can reflect on the decisions made by the researcher and whether these were appropriate in their view. Provide clear guidance on what advice is being sought, provide lead time, and the timeframe and process to follow for providing advice. How long should the advice be? In what format? Who will be reading it, who do they send the advice to? What are the researchers specifically looking for, what should the advice focus on?
17 18 19 20 21	Step 8: Feedback	Once the researcher receives the advice from the autistic advisor, the researcher should provide a timeframe in which the autistic advisor will receive an update on what aspects of the advice was incorporated and the effect it had/didn't have on the methodology, findings, and/or interpretation.
22 23 24 25 26 27	Step 9: Final checks	Once the manuscript or research output has been further developed, the autistic advisor should receive a copy of the manuscript prior to submission. If the autistic advisor has limited experience with academic writing, the researcher should offer to describe/provide a lay summary of the overall article for the advisor.
28 29 30	Step 10: Acknowledgement	Autistic advisor or peer-researcher to be acknowledged in the agreed upon manner (e.g., co-author, thanked in the acknowledgement section, acknowledged during a presentation etc.)

*The Autism CRC Research Academy (<https://www.autismcrc.com.au/research-academy>) provides training for peer researchers.

Table 2

Measurements included in the ALSAA surveys

Measure / domain	Self-report	Informant report	Carer
Demographics and personal characteristics			
Basic demographics (Age, Sex, Ethnicity, English speaking status)	✓	✓	✓
Other demographics (Education, Occupation ^a , Family & living conditions, Income)	✓	✓	✓
Autism Characteristics			
The Autism Quotient - Short ^b (AQ-Short) ⁶¹	✓	✓	✓
Repetitive Behaviours Questionnaire-2 Adult Version (RBQ-2A) ⁸⁸	✓	✓	
The Glasgow Sensory Questionnaire ⁸⁹	✓	✓	
The Intolerance of Uncertainty Scale-12 ⁹⁰	✓		✓
Health & Well-Being			
Medical history	✓	✓	✓
Medication profile	✓	✓	
Smoking, alcohol and illicit drug use ^a	✓	✓	
The Patient Health Questionnaire-15 ⁹¹	✓		✓
Medical Outcomes Study Short Form Health Survey-12 (SF-12) ⁹²	✓	✓	✓
The Composite Autonomic Symptom Score - 31 (COMPASS 31) ⁹³	✓		
Pittsburgh Sleep Quality Index ⁹⁴	✓		
Flinders Fatigue Scale ⁹⁵	✓		
Mental & Emotional Health			
DSM-5 Dimensional Anxiety Scales: Generalized Anxiety Disorder-Adult (DSM5 GAD-A) ⁹⁶	✓		✓
The Patient Health Questionnaire-9 (PHQ-9) ⁵⁸	✓		✓
The Warwick Edinburgh Mental Well-being Scale ⁹⁷	✓		
The New General Self-Efficacy Scale ⁹⁸	✓		
The Emotion Regulation Questionnaire ⁹⁹	✓		✓
Developmental Behaviour Checklist-Adolescent/Adult version (DBC-A) Revised ¹⁰⁰		✓	
The Brief COPE ¹⁰¹	✓		✓
Memory Complaint Questionnaire (MAC-Q) ¹⁰²	✓		
Relationships & Social Networks			
UCLA Loneliness Scale-8 (ULS-8) ¹⁰³	✓		
Supports and networks ^a	✓	✓	
The Social Support Questionnaire (SSQ) ¹⁰⁴	✓		✓
Activities, Participation & Quality of Life			

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

WHOQOL-BREF ¹⁰⁵	✓		✓
Waisman Activities of Daily Living Scale (W-ADL) ¹⁰⁶	✓	✓	
World Health Organisation Disability Assessment Schedule (WHO-DAS II) ¹⁰⁷	✓	✓	✓
Vocational Index for Adults with Autism ¹⁰⁸	✓	✓	
Special abilities and interests ^c	✓		
Leisure activities participation	✓	✓	
Leisure Satisfaction Scale (LSS) ¹⁰⁹	✓		
Driving and transport	✓	✓	✓
Service Usage			
Client Service Receipt Inventory (CSRI) ¹¹⁰	✓	✓	
Health service seeking behaviour	✓	✓	
Early intervention service history	✓	✓	
Justice system contact	✓	✓	
Preventative health screening	✓	✓	
Caring			
Positive Affect Index ¹¹¹			✓
Caregiver Activity Survey (CAS-ID) ¹¹²			✓
Zarit Burden Interview ¹¹³			✓

^a Based on questions from the National Health Survey of Mental Health and Wellbeing (Slade, Johnston, Oakley Browne, Andrews, & Whiteford, 2009). ^b A 28-item parent-carer report adaptation using items from the AQ-Adolescent (Baron-Cohen, Hoekstra, Knickmeyer, & Wheelwright, 2006) was used for the informant-report survey ^cBased on questions from the Interactive Autism Network (<https://iancommunity.org/>)

Table 3

Recruitment statistics at close of Time 1 data gathering

Sample	Registered	Non-respondent	Ineligible (%)	Withdrawn (%)	Partial Completion (%)	Completed (%)
Self-report autistic adults	345	75 (22)	6 (2)	11 (3)	16 (5)	237 (69)
Self-report non-autistic adults	221	48 (22)	7 (3)	20 (9)	16 (7)	130 (59)
Carer	185	48 (26)	22 (12)	13 (7)	2 (1)	100 (54)
Informant-report for autistic adult	78	22 (28)	5 (6)	9 (11)	0 (0)	42 (54)

Table 4

Participant Characteristics

Characteristic	Autistic adults self-report formally diagnosed (N=221)	Autistic adults self-report no formal diagnosis (N=32)	Autistic adults informant-report (N=42)	Carers (N=102)	Non-autistic self-report (N=146)
Age mean (SD)	41.8 (12.2)	44.2 (8.1)	32.5 (9.9)	56.3 (11.2)	43.7 (13.5)
Gender (%)					
Male	86 (39)	14 (44)	34 (81)	16 (16)	29 (20)
Female	124 (56)	17 (53)	8 (19)	85 (83)	117 (80)
Other	11 (5)	1 (3)	0	1 (1)	0
^a Ethnicity (%)					
Caucasian	194 (88)	25 (78)	38 (90)	86 (89)	122 (85)
Other	27 (12)	7 (22)	4 (9)	11 (11)	22 (15)
Multilingual (%)	26 (12)	5 (16)	0	6 (6)	18 (12)
^b SEIFA decile (SD)	6.18 (2.89)	5.74 (3.09)	6.58 (2.88)	6.60 (2.78)	7.01 (2.60)
^{bc} Rural / Remoteness					
Major City	146 (71)	17 (55)	32 (84)	72 (73)	114 (83)
Inner Regional	44 (21)	10 (32)	5 (13)	21 (21)	19 (14)
Outer Regional	12 (6)	4 (13)	1 (3)	5 (5)	5 (4)
Remote / Very Remote	4 (2)	0	0	0	0
^d Living situation (%)					
Living alone	58 (26)	9 (28)	3 (7)	14 (14)	26 (18)
Living as couple	95 (43)	18 (56)	4 (9)	74 (75)	105 (72)
Living with parents	31 (14)	0	24 (57)	0	5 (3)
Living with other relatives	3 (1)	0	1 (2)	6 (6)	3 (2)
Living with others	20 (9)	5 (16)	8 (19)	4 (4)	5 (3)
Other	14 (6)	0	2 (5)	1 (1)	2 (1)
^e Marital Status (%)					
Single	73 (33)	7 (22)	36 (86)	4 (4)	22 (15)
Married	66 (30)	12 (37)	4 (9)	65 (66)	90 (62)
De facto	17 (8)	3 (9)	0	8 (8)	14 (9)
Never married	8 (4)	3 (9)	2 (5)	2 (2)	3 (2)
Widowed	1 (0)	0	0	3 (3)	2 (1)
Divorced now single	21 (9)	3 (9)	0	8 (8)	9 (6)
Divorced now remarried / de facto	12 (5)	2 (6)	0	2 (2)	2 (1)
Separated	7 (3)	1 (3)	0	2 (2)	1 (1)
Other	16 (7)	1 (3)	0	4 (4)	3 (2)
Educational Status (%)					

Completed high school	163 (76) <i>n</i> =215	20 (64) <i>n</i> =31	21 (51) <i>n</i> =41	86 (88) <i>n</i> =98	120 (86) <i>n</i> =139
Vocational education	61 (35) <i>n</i> =174	16 (57) <i>n</i> =28	4 (11) <i>n</i> =35	17 (17) <i>n</i> =98	20 (16) <i>n</i> =127
University education	113 (65) <i>n</i> =174	12 (43) <i>n</i> =28	1 (3) <i>n</i> =35	59 (60) <i>n</i> =98	107 (84) <i>n</i> =127
^f Employment (%)					
Open employment	116 (57)	20 (69)	6 (15)	59 (60)	104 (76)
Student / other day activity	38 (19)	3 (10)	24 (60)	3 (3)	17 (12)
Retired, no volunteering	8 (4)	2 (7)	2 (5)	19 (19)	6 (4)
Homecare	17 (8)	3 (10)	0	9 (9)	9 (6)
No activity	22 (11)	1 (3)	8 (20)	9 (9)	1 (1)

^a Ethnicity: Carers, *n*=97; Non-autistic (self-report), *n*=144

^b Autistic adults (diagnosis, self-report), *n*=209; Autistic adults (no diagnosis, self-report), *n*=31; Autistic adults (informant report), *n*=38; Carers, *n*=99; Non-autistic (self-report), *n*=138

^c Australian population is 70% Major city, 18% Inner regional, 9% Outer regional, 1% Remote, 1% Very remote in the 2011 Census¹¹⁴

^d Carers' Living situation: *n*=99

^e Carers' Marital status: *n*=98

^f Employment: Autistic adults (diagnosis, self-report), *n*=201; Autistic adults (no diagnosis, self-report), *n*=29; Autistic adults (informant report), *n*=40; Carers, *n*=99; Non-autistic (self-report), *n*=137

Table 5

Diagnostic Characteristics

Characteristic	Autistic adults self-report formally diagnosed (N=221)	Autistic adults self-report no formal diagnosis (N=32)	Autistic adults informant-report (N=42)	Carers (N=102)	Non-autistic self-report (N=146)
AQ score mean (SD)	87.6 (10.3) n=210	83.7 (8.8)	84.2 (9.5) n=36	57.3 (13.8) n=60 ^a	55.1 (11.9) n=137
Above AQ Cutoff (%)	203 (97)	31 (97)	35 (97)	18 (30)	30 (22)
^b Autism Diagnosis					
Autism spectrum disorder / condition	49 (22)	-	17 (40)	-	-
Asperger's syndrome	130 (59)	-	11 (26)	-	-
Autistic disorder	1 (0)	-	6 (14)	-	-
'High-functioning' autism	32 (14)	-	3 (7)	-	-
PDD-NOS	1 (0)	-	1 (2)	-	-
Other	6 (3)	-	2 (5)	-	-
No formal diagnosis	-	32 (100)	1 (2)	-	-
Age at Diagnosis Mean (SD)	35.3 (15.1) n=217	-	10.01 (10.8) n=38	-	-
Years since Diagnosis Mean (SD)	6.9 (8.3) n=217	-	21.9 (9.8) n=38	-	-
Intellectual Disability (%)	10 (4)	1 (3)	33 (78)	1 (1)	1 (1)
Other Developmental Disability (%)	6 (3)	2 (6)	9 (21)	0	1 (1)
^c Other Psychiatric Diagnosis(%)					
Currently	148 (69) n=213	13 (42) n=31	22 (52)	38 (39) n=100	29 (21) n=140
At any time	191 (89) n=213	28 (90) n=31	31 (74)	68 (68) n=100	67 (48) n=140
Depression (PHQ-9) above cut-off (%)	103 (52) n=199	15 (52) n=29	-	28 (29) n=97	15 (12) n=126
Anxiety (DSM5 GAD-A) above cut-off (%)	115 (56) n=206	14 (47) n=32	-	27 (27) n=99	14 (11) n=130

^a Carers were asked to complete the AQ scale only if they were a biological relative of the adult with autism

1
2
3 ^b Autism diagnosis: Autistic adults (self-report, diagnosed), $n=220$

4 ^c Recording of a psychiatric diagnosis apart from autism spectrum conditions or intellectual
5 disability
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

For peer review only

Table 6

Carer Characteristics (N=102)

Characteristic	Frequency / Mean
Relationship to autistic person (%)	
Mother	42 (43, <i>n</i> =98)
Father	10 (10, <i>n</i> =98)
Partner/spouse	23 (23, <i>n</i> =98)
Sibling	2 (2, <i>n</i> =98)
Child	1 (1, <i>n</i> =98)
Carer – unspecified	17 (17, <i>n</i> =98)
Other	3 (3, <i>n</i> =98)
Age of autistic adult cared for mean (<i>SD</i>)	37.5 (13.2)
Hours spent per week with autistic adult mean (<i>SD</i>)	63.4 (57.8, <i>n</i> =92)

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

For peer review only

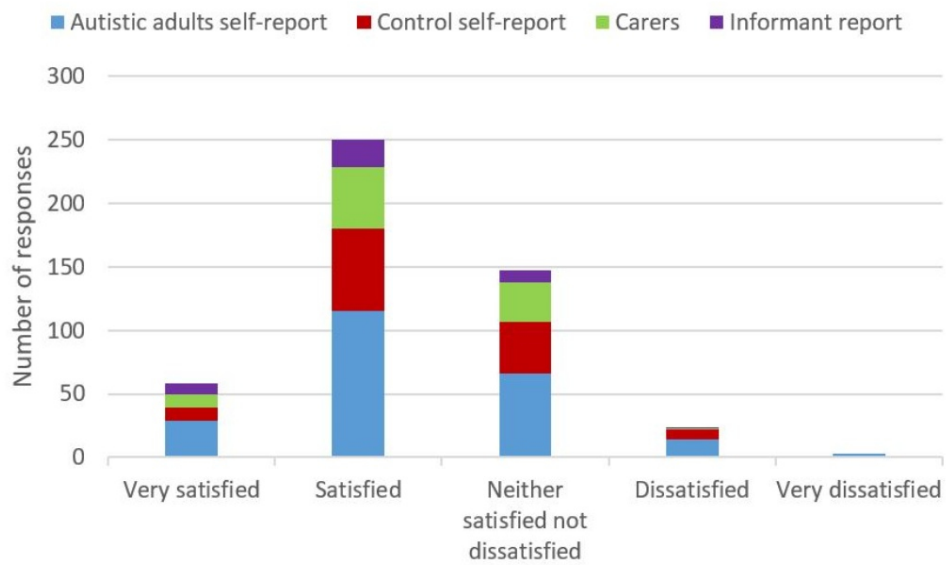


Figure 1. Satisfaction responses upon completion combined by survey type (n=482)

89x53mm (300 x 300 DPI)

BMJ Open

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

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2019-030798.R2
Article Type:	Cohort profile
Date Submitted by the Author:	15-Aug-2019
Complete List of Authors:	<p>Arnold, Samuel; UNSW, Department of Developmental Disability Neuropsychiatry (3DN); Autism CRC</p> <p>Foley, Kitty-Rose; Southern Cross University - Gold Coast Campus, School of Health and Human Sciences; Autism CRC</p> <p>Hwang, Ye In; UNSW, Department of Developmental Disability Neuropsychiatry (3DN); Autism CRC</p> <p>Richdale, Amanda; La Trobe University, Olga Tennison Autism Research Centre, School of Psychology and Public Health; Autism CRC</p> <p>Uljarevic, Mirko ; Stanford University, Stanford Autism Center, Division of Child and Adolescent Psychiatry, Department of Psychiatry and Behavioral Sciences, School of Medicine; La Trobe University, Olga Tennison Autism Research Centre, School of Psychology and Public Health</p> <p>Lawson, Lauren; La Trobe University, Olga Tennison Autism Research Centre, School of Psychology and Public Health; Autism CRC</p> <p>Cai, Ru; La Trobe University, Olga Tennison Autism Research Centre, School of Psychology and Public Health; Autism CRC</p> <p>Falkmer, Torbjorn; Curtin University, School of Occupational Therapy, Social Work and Speech Pathology; Autism CRC</p> <p>Falkmer, Marita; Curtin University, School of Occupational Therapy, Social Work and Speech Pathology; Autism CRC</p> <p>Lennox, Nick; University of Queensland, Australia, Queensland Centre for Intellectual and Developmental Disability, Mater Research Institute - UQ; Autism CRC</p> <p>Urbanowicz, Anna; RMIT University, Health, Society & Medicine Research Program, Social and Global Studies Centre; Autism CRC</p> <p>Trollor, Julian; UNSW, Department of Developmental Disability Neuropsychiatry (3DN); Autism CRC</p>
Primary Subject Heading:	Mental health
Secondary Subject Heading:	Diagnostics
Keywords:	Autism, Longitudinal, Adult

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60



Title

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

Author Names and Affiliations

Samuel R. C. Arnold^{*a,b} <samuel.arnold@unsw.edu.au>

Kitty-Rose Foley^{*b,c} <Kitty-Rose.Foley@scu.edu.au>

Ye In (Jane) Hwang^{a,b} <jane.hwang@unsw.edu.au>

Amanda L. Richdale^{b,d} <A.Richdale@latrobe.edu.au>

Mirko Uljarevic^{e,d,b} <mirkoulj@stanford.edu>

Lauren P. Lawson^{b,d} <L.Lawson@latrobe.edu.au>

Ru Ying Cai^{b,d} <R.Cai@latrobe.edu.au>

Torbjorn Falkmer^{b,f} <T.Falkmer@curtin.edu.au>

Marita Falkmer^{b,f,g} <Marita.Falkmer@curtin.edu.au>

Nick Lennox^{b,h} <n.lennox@uq.edu.au>

Anna Urbanowicz^{b,h,i} <a.urbanowicz@rmit.edu.au>

Julian N. Trollor^{+a,b} <J.Trollor@unsw.edu.au>

Affiliations

- a- Department of Developmental Disability Neuropsychiatry (3DN), UNSW Sydney, New South Wales, Australia
- b- Cooperative Research Centre for Living with Autism (Autism CRC), Brisbane, Queensland, Australia
- c- School of Health and Human Sciences, Southern Cross University, Gold Coast, Bilinga, Queensland, Australia
- d- Olga Tennison Autism Research Centre, School of Psychology and Public Health, La Trobe University, Bundoora, Victoria, Australia
- e- Stanford Autism Center, Division of Child and Adolescent Psychiatry, Department of Psychiatry and Behavioral Sciences, School of Medicine, Stanford University.

- 1
2
3 f- School of Occupational Therapy, Social Work and Speech Pathology, Curtin
4 University, Perth, Western Australia, Australia
5
6 g- School of Education and Communication, CHILD Programme, Institution of
7 Disability Research, Jonkoping University, Jonkoping, Sweden
8
9
10 h- Queensland Centre for Intellectual and Developmental Disability, Mater Research
11 Institute - UQ, The University of Queensland, South Brisbane, Queensland, Australia
12
13 i- Health, Society & Medicine Research Program, Social and Global Studies Centre,
14 RMIT University
15
16

17 *Joint first author

18
19 +Corresponding author
20
21
22
23
24
25

26 Correspondence concerning this article should be addressed to Prof. Julian Trollor,
27 Department of Developmental Disability Neuropsychiatry (3DN), 34 Botany St, UNSW
28 Sydney, 2052, New South Wales, Australia. Telephone: +61-2-9931-9160. Email:
29 j.trollor@unsw.edu.au
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

Abstract (300 Words)

Purpose

There is a significant knowledge gap regarding the lives of adults on the autism spectrum. Some literature suggests significant health and mental health inequalities for autistic adults, yet there is a lack of comprehensive longitudinal studies exploring risk factors. Further, most research does not include the perspective of autistic adults in its conduct or design. Here we describe the baseline characteristics and inclusive research approach of a nationwide longitudinal study.

Participants

The Autism CRC's ALSAA is a questionnaire-based longitudinal study of autistic adults (25+ years old) with follow-up at 2-year intervals. Autistic advisors were involved in each stage of research apart from data analysis. Three questionnaires were developed: self-report, informant report (i.e. proxy report), and carers (i.e. carer experiences and characteristics).

Findings to date

An inclusive research protocol was developed and agreed with autistic advisors. Baseline data were collected from 295 autistic adults ($M=41.8$ years, $SD=12.0$) including 42 informant responses, 146 comparison participants, and 102 carers. The majority of autistic participants (90%) had been diagnosed in adulthood ($M=35.3$ years, $SD=15.1$). When compared to controls, autistic adults scored higher on self-report measures of current depression and anxiety. Participant comments informed on-going data gathering. Participants commented on questionnaire length, difficulty with literal interpretation of forced response items, and expressed gratitude for research in this area.

Future plans

1
2
3 A large comprehensive dataset relating to autistic adults and their carers has been gathered,
4
5 creating a good platform for longitudinal follow-up repeat surveys and collaborative research.
6
7 Several outputs are in development, with focus on health service barriers and usage,
8
9 caregivers, impact of diagnosis in adulthood, further scale validations, longitudinal analyses
10
11 of loneliness, suicidal ideation, mental illness risk factors and other areas. Baseline data
12
13 confirms poorer mental health of autistic adults. The ALSAA demonstrates a working
14
15 approach to inclusive research.
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

Strengths and limitations of this study

- Autism related research efforts and funding has typically focused on the period from infancy to mid childhood, this research focuses on autistic adults and their carers.
- The ALSAA uses an inclusive research approach to gather a comprehensive range of measures addressing identified research priorities.
- A large proportion of the ALSAA sample at Time 1 were female, including 50% ($n=149$) of autistic and 80% ($n=117$) of non-autistic participants.
- Participants self-report their autism diagnosis, and a subsample ($n=32$) are not yet formally diagnosed.
- The ALSAA is a unique resource for exploring multiple research questions regarding the lives of Australian autistic adults.

Introduction

Although autism is a lifelong condition, most autism related research efforts and funding has focused on the period from infancy to mid childhood¹. The best available evidence suggests an adult population prevalence of at least 1.1%². It is likely that autism is under-recognized or under-diagnosed in adults^{3,4}, particularly in women without intellectual disability^{2,5}.

Although an emerging body of research explores outcomes and support needs of autistic individuals beyond childhood and adolescence, studies including autistic adults remain frequently focused on younger adults⁶⁻⁸. This is reflected in recent commentary from an autistic researcher; “We know virtually nothing about what happens to us, autistic people, physically, cognitively, emotionally and socially as we pass through middle and older age”⁹(p515).

The growing body of evidence suggests higher rates of physical and mental health conditions, increased mortality and higher rates of intellectual disability than in the general population¹⁰. Autistic adults have higher prevalence of chronic medical conditions, including conditions such as stroke, vision and hearing impairments, and Parkinson’s disease¹¹⁻¹⁴. These outcomes are experienced by many autistic adults regardless of intellectual functioning⁷. It has been reported that between 25%-84% of autistic adults have a diagnosed mental health condition, with depression and anxiety the most commonly reported conditions¹⁵⁻¹⁹. Autistic adults have higher rates of suicide^{16,20}, increased mortality and reduced life expectancy²¹. Despite widespread acknowledgement of the comorbidity between autism and intellectual disability, prevalence estimates of intellectual disability in autism and vice versa have been inconsistent²². Earlier studies report that between 40 to 70% of those with autism also have an intellectual disability²³⁻²⁵ though a more recent study reports fewer adults on the autism spectrum as having intellectual disability² and intelligence tests may underestimate performance of autistic individuals²⁶.

1
2
3 Studies investigating outcomes related to daily activities and participation are also scarce²⁷.
4
5 Available studies report low employment rates²⁸, low community inclusion and limited social
6
7 relationships for autistic adults²⁹⁻³³. A few studies have suggested that factors such as low
8
9 childhood IQ, autism severity, psychopathology, social and language development, and
10
11 access to services and intervention programs may be determinates of such outcomes ^{29, 34};
12
13 however, much remains to be understood about the sources of variability in these outcomes.
14
15
16
17 In general, much of the research remains limited by cross-sectional designs, mixed groups
18
19 with and without intellectual disability, and a focus on adults aged under 40 ^{7, 34-36}.
20
21
22 Longitudinal studies are crucial for exploring changing requirements over time and to inform
23
24 services how best to respond to the needs of autistic adults^{9, 37}. Whilst most studies have
25
26 focused on one aspect of life or outcomes, such as physical or mental health comorbidities^{12,}
27
28 ^{15, 38} or quality of life^{30, 39}, very few comprehensive evaluations of health, wellbeing and
29
30 participation have been conducted³⁴. Further, research funding does not match priorities
31
32 identified by autistic adults, which include research on public services, improving life skills
33
34 and the future for autistic adults⁴⁰.
35
36
37
38

39
40 The majority of existing autism research is also limited by a lack of inclusive research
41
42 practices. There is a small but growing body of research on inclusive practices and co-
43
44 production in disability research with increasing examples in the autism field⁴¹⁻⁴³. In
45
46 principle, inclusive research must “address issues that really matter” to people with disability,
47
48 “must access and represent their views and experiences” and people “need to be treated with
49
50 respect by the research community”^{44(p16)}. Inclusive research encompasses a variety of
51
52 approaches, from including the individuals with the disability as advisors or consultants, to
53
54 working alongside academic researchers, or initiating or conducting the project as researchers
55
56 themselves⁴⁵. Due to a history of mistrust between researchers and autism self-advocacy
57
58 groups, inclusive methods are especially important in research involving adults on the
59
60

1
2
3 spectrum⁴⁶. Inclusive approaches ensure scientific findings are meaningful to the autism
4
5 community and sensitive to the lived experiences of individuals on the spectrum^{47, 48}.
6
7

8
9 The Cooperative Research Centre for Living with Autism (Autism CRC) Australian
10
11 Longitudinal Study of Adults with Autism (ALSAA) is Australia's first national longitudinal
12
13 study involving autistic adults aged 25 years and older. The ALSAA will contribute needed
14
15 longitudinal data across a range of health, functioning and participation domains. Data
16
17 gathered aligns with the research gaps identified above, and the priorities identified by
18
19 autistic adults⁴⁹. In comparison to current international longitudinal studies of autistic
20
21 adults⁵⁰⁻⁵² the ALSAA gathers a wider range of data points using standardised measures and
22
23 importantly included autistic adults in study design from the early stages of the project.
24
25 Further, the ALSAA gathers data from a community comparison group which is often lacking
26
27 in prior work. The ALSAA will contribute to the validation of several standardised measures
28
29 for this population. Importantly, the ALSAA gathers data specific to the unique context and
30
31 service systems within Australia, pertinent given the recent introduction of the National
32
33 Disability Insurance Scheme (NDIS) and the considerable differences in approaches to
34
35 healthcare and disability across countries. The ALSAA primarily aims to identify and
36
37 comprehensively describe the profiles of Australian autistic adults and to compare them to a
38
39 control group. Longitudinal data will further allow the determination of predictors versus
40
41 correlates across a range of outcomes. The aims of this paper are to describe the
42
43 methodological processes and the inclusive protocol adopted in the ALSAA, as well as to
44
45 present participant characteristics and feedback from the baseline data collection.
46
47
48
49
50
51
52

53 **Cohort Description**

54 *Design*

55
56
57
58
59
60

1
2
3 The ALSAA is a questionnaire-based, prospective, longitudinal cohort study with a planned
4
5 2-year follow-up and further follow-ups as resources allow. Initial design and development of
6
7 the ALSAA occurred in collaboration with researchers and clinical health professionals
8
9 across Australia, including close collaboration with the Autism CRC longitudinal Study of
10
11 Australian School Leavers with Autism (SASLA)⁵³. Brief consultation also occurred with
12
13 international experts and researchers conducting similar longitudinal studies. Additionally,
14
15 preliminary work on factors influencing the research participation of autistic adults⁵⁴
16
17 influenced the ALSAA design, including ensuring opportunities for participants to clarify
18
19 questions, receive regular study newsletters, and space for participants to provide
20
21 explanations regarding their responses.
22
23
24
25
26
27
28
29

30 *Patient and Public Involvement*

31
32
33 *How was the development of the research question and outcome measures informed by*
34
35 *patients' priorities, experience, and preferences?*
36
37

38
39 The ALSAA was developed with input from a research advisory network, initially consisting
40
41 of 6 autistic adults and 2 family members/carers of autistic adults who helped develop the
42
43 surveys to ensure the questions were relevant, accessible and valid.
44
45

46
47 *How did you involve patients in the design of this study?*
48

49
50 The ALSAA Inclusive Research Protocol was developed based on the principles of inclusive
51
52 research⁵⁵, the Autism CRC report *Inclusive Research Practice Guides and Checklists for*
53
54 *Autism Research*⁵⁶ (e.g. Checklist 3: Practices that Support Inclusion of Individuals on the
55
56 Autism Spectrum in Advisory and Reference Groups), and procedures similar to those
57
58
59
60

1
2
3 employed by Nicolaidis and colleagues⁵⁷ (e.g. choosing research questions, adapting data
4 collection instruments, interpreting results) (see Table 1).
5
6
7

8 *Were patients involved in the recruitment to and conduct of the study?*
9

10
11 Since the commencement of the ALSAA, this inclusive research protocol has been reviewed
12 by seven of the autistic advisors and one carer advisor and has guided the interactions
13 between researchers and advisors in the development of baseline outputs and the 2-year
14 follow-up design. Specifically, in the design stage of the ALSAA, members of the advisory
15 network were asked to identify ambiguous or inappropriate language, formatting issues and
16 measures which they thought may be interpreted inappropriately or differently due to poor
17 clarity or wording. An expanded group of eleven advisors had greater input in designing the
18 2-year follow-up, including the selection of focus topic areas. As per the protocol advisors are
19 given forewarning, then one month to respond to most requests from the research team, with
20 more response time as needed. Advisors have provided feedback on ongoing research outputs
21 critiquing interpretations of findings suggested by the researchers. In Time 2 data gathering
22 and analyses, compensation has been made available for advisors' time, upon request to the
23 Autism CRC, which has become increasingly supportive of co-production approaches.
24
25 Advisors are now offered an hourly rate for each time they are consulted, with most
26 consultations limited to two hours, though several advisors still prefer to volunteer and do not
27 request compensation on most occasions. Advisors to date have not been involved in data
28 analysis, though several co-produced peer-research projects are currently underway.
29
30 Advisors have also assisted in promoting recruitment materials particularly through social
31 media.
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55

56 *How will the results be disseminated to study participants?*
57
58
59
60

1
2
3 The ALSAA sends quarterly digital newsletters to all participants. Newsletters include lay
4 summaries of any publications, conference presentations or other outputs developed using the
5 ALSAA data. They also typically contain general interest highlight(s) relating to the autism
6 or autistic community, recruitment calls for other autism research, as well as a team member
7 profile of an ALSAA researcher or autistic advisor.
8
9
10
11
12
13
14
15
16
17
18

19 **[Insert Table 1 here]**
20

21 *Participants*

22
23
24 There are three participant groups in the ALSAA: autistic adults, non-autistic general
25 community comparison controls, and carers of autistic adults. Inclusion criteria required the
26 control and autistic participants to be aged 25 years or older, live in Australia and have
27 sufficient English literacy skills to complete the survey, determined during a screening phone
28 call or online expression of interest (EOI). If an autistic individual was unable or preferred
29 not to self-report, they were given the option to ask an informant to complete an informant
30 version of the survey on their behalf. People with intellectual disability could complete the
31 self-report survey with support or participate via an informant respondent.
32
33
34
35
36
37
38
39
40
41
42
43

44 Informant respondents and carers needed to be 18 years or older, have sufficient English
45 literacy skills, live in Australia and be able to report on the life of the autistic person. The
46 content of the informant survey is slightly different to the self-report survey (see Table 2) due
47 to some measures, such as the Patient Health Questionnaire-9 (PHQ-9)⁵⁸, having no
48 informant version available. Carers, including family members and support people for the
49 ALSAA, were defined as people who provided unpaid care and support to either a family
50 member (including spouse) or friend who is on the autism spectrum. This is based on the
51
52
53
54
55
56
57
58
59
60

widely accepted definition proposed by Carers Australia

(<http://www.carersaustralia.com.au/about-carers/>).

Survey

Three versions of the survey were developed: 1) self-report, for autistic adults and non-autistic controls, 2) informant, for carers/support people to complete about the autistic person who is unable to, or does not want to self-complete, and 3) carer survey for carers/support people/family members to complete about their own health and wellbeing. Surveys could be completed via a paper copy or online. The paper copy was also available in large print. The surveys involved a comprehensive range of measures (see Table 2). In selecting measures, preference was given to measures that had been previously used or had established validity with people on the spectrum and to those deemed suitable by the autistic advisors. Most measures have not been specifically validated for autistic adults, with notable recent exceptions of the WHOQOL BREF⁵¹, SF-12⁵⁹ and the RBQ-2A⁶⁰, while the PHQ-9⁶¹ was more recently validated using a combined ALSAA and SASLA data set.

[Insert Table 2 here]

Each survey also contained closing feedback items, asking if any questions were confusing, difficult, or upsetting, and any additional topics that should be included. It also asked how long the survey took to complete (open-ended response), and an overall satisfaction with the survey rated on a 5-point Likert scale. A final item asked for any further feedback.

Procedure

Piloting

Four autistic adults piloted the self-report questionnaire and two caregivers piloted the carer and the informant questionnaires. Volunteers received two copies, one copy to complete, with

1
2
3 data recorded where possible in the ALSAA dataset, and the other for their feedback.

4
5 Considerable changes to each version of the survey were undertaken in response to feedback
6
7 from the autistic advisors and volunteers, including removing the Communication Checklist –
8
9 Adult⁶², formatting changes and changes to item wordings where the item did not belong to
10
11 an existing standardised tool.
12
13

14 15 *Recruitment and Follow-up*

16
17
18 A recruitment target of 160 autistic adults was set to allow for regression analyses using
19
20 multiple predictor variables. Power analyses, undertaken using power calculation software,
21
22 suggested this would be a sufficient sample size with power (1 - β) set at .80 and $\alpha = .05$ to
23
24 detect a Cohen's f^2 effect size estimate of at least .1 using multiple regression models with 7
25
26 predictors. Participants were recruited via advertisements through autism-specific
27
28 organisations, disability organisations, autism self-advocacy groups, employment services,
29
30 universities, Technical and Further Education (TAFE) institutes, psychology and allied health
31
32 private practices, carer organisations, and online autism communities. In attempts to gather a
33
34 sample more closely matched to Australian population estimates⁶³, additional recruitment
35
36 activities targeted adults on the spectrum with intellectual disability, and males without
37
38 autism. General community members, autistic adults and carers of autistic adults who were
39
40 willing to participate in the ALSAA contacted the research team based at The University of
41
42 New South Wales (UNSW Sydney) via telephone, email or through completing a short online
43
44 EOI. After eligibility screening, their details were added to the participant database and they
45
46 were mailed a paper copy or emailed a link to their survey depending on their preference.
47
48
49
50
51

52
53
54 Due to a high number of responses and advice from autistic advisors, participants who self-
55
56 identified as being autistic, but did not have a formal diagnosis, representing the hidden
57
58 population and 'lost generation'³ of autistic adults, were also recruited. Formally diagnosed
59
60

1
2
3 participants were asked to provide details of their diagnosis, year of diagnosis, and the
4 discipline and name of the practitioner(s) who diagnosed them. AQ-short cut-off scores (>65,
5 sensitivity .97, specificity .82)⁶⁴ also support diagnostic status. Given critiques of
6 applicability and validity of the AQ-short^{65, 66}, we plan to include the Ritvo Autism and
7 Asperger Diagnostic Scale-14 (RAADS-14)⁶⁶ in future data gathering. At the planned two-
8 year average Time 2 follow-up copies of participants' diagnostic reports will be requested,
9 with a project undertaken to review and categorise the reports. From November 2017 through
10 2019 participants are being recontacted using contact details provided and considering their
11 communication preferences that were recorded.

12 *Ethical Considerations*

13
14 Participants were supplied with the appropriate Participant Information Statement and
15 Consent Form (PISCF). For the online survey, participants were asked to confirm their
16 consent at commencement, marking checkboxes prior to proceeding. Consent was inferred
17 from participants who completed and returned paper copies of the survey, as outlined in their
18 PISCF. In the case where the autistic adult had an intellectual disability a checklist for
19 capacity to provide consent was used. This checklist was completed by the carer/next of kin;
20 it was adapted from a checklist developed for use in the Study of Ageing in Intellectual
21 Disability (SAGE)⁶⁷. The checklist asks several question relating to the person's ability to
22 understand the study, benefits and risks, withdrawal and complaints, to determine if a person
23 responsible consent should be obtained additionally or separately. The study was approved by
24 the Human Research Ethics Committee at UNSW Sydney, Australia (No. HC15001).

25 *Data storage*

26
27 Online questionnaire data were entered directly by participants into Qualtrics Online Survey
28 Software (<https://www.qualtrics.com/>), whereas returned paper copy surveys were entered
29
30

1
2
3 into Qualtrics by a researcher or research assistant. Data from Qualtrics, re-identifiable by
4 participation code, were stored on password-protected UNSW Sydney servers. Recently,
5
6 participation code, were stored on password-protected UNSW Sydney servers. Recently,
7
8 ethics approval for establishment of a databank for the ALSAA data, to allow collaboration
9
10 with external researchers, has been obtained.
11

12 13 *Statistical analysis*

14
15
16 STATA Statistical Analysis Software 14⁶⁸ and IBM SPSS Statistics 22⁶⁹ were used for
17
18 cleaning, coding, and statistical analyses. For the current manuscript, STATA was used to
19
20 obtain descriptive statistics regarding recruitment, participant feedback, and participant
21
22 characteristics, with the level of significance $<.05$. No correction was applied for multiple
23
24 statistical tests in this manuscript, as the purpose was to explore baseline differences in the
25
26 cohorts, and determine potential variables that may be useful covariates or possible
27
28 confounders in later hypothesis testing⁷⁰. For describing this cohort profile, listwise deletion
29
30 was used for specific analyses when data were missing completely at random, after checking
31
32 for difference in demographics and AQ score for dropped participants where appropriate.
33
34 Subsample sizes are noted throughout. Data were checked for kurtosis and skew. Non-
35
36 parametric Spearman rank correlation was used to determine the correlation between time
37
38 taken to complete the self-report survey and level of satisfaction.
39
40
41
42
43
44

45 *Recruitment statistics*

46
47
48 Recruitment commenced in July 2015. At the close of Time 1 data gathering in November
49
50 2017, 345 autistic adults, 221 non-autistic adults, 185 carers, and 78 informants had
51
52 registered their interest in the study. Of these, 237 autistic adults, 130 non-autistic adults, 100
53
54 carers, and 42 informant reporters completed the entire survey. Overall, a total of 295 autistic
55
56 adults participated including all survey formats and partial survey completions. A small
57
58 proportion of participants were deemed ineligible during screening (see Table 3), generally
59
60

1
2
3 due to being under 25 years, not caring for an adult aged 25+ years old, or being located
4 outside of Australia. Participants were recorded as partial completions if at close of Time 1
5 their surveys contained the initial demographic items completed and some additional useable
6 data. From available data there was no significant difference in binary gender, $\chi^2(4, n=337) =$
7 $1.07, p=.898$, or approximate age [$F(4, 4) = 2.04, p=.09$] based on survey commencement,
8 eligibility or completion status for the self-reporting autistic adults (see Table 1). These non-
9 significant results were also found for the non-autistic adults across gender, $\chi^2(4, n=215)$
10 $=6.98, p=.137$, and age [$F(4, 4) = 0.96, p=.43$].
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25

26 **[Insert Table 3 here]**

27
28
29 *Time taken to complete, and satisfaction with, the survey*

30
31
32 Participants reported varying times taken to complete the entire survey. Self-reporting autistic
33 participants reported between 20 minutes and 12 hours to complete with an average time of
34 156 minutes ($n=164, SD=111$), though several responses ($n=53$) were not easily convertible
35 to numeric values for analysis, for example “few days”, “no idea”, or no response to the item
36 ($n=36$). Non-autistic, self-reporting participants reported a range of 20 minutes to 5 hours
37 with an average time of 106 minutes ($n=98, SD=74$). This was significantly less than self-
38 reporting autistic adults despite their completing almost all the same measures and domains,
39 $t(260)=-4.94, p<.001$. Carers took 75 minutes on average ($n=81, SD=62$) and informant
40 responders took 103 minutes on average ($n=27, SD=54$) to complete surveys. Most
41 participants (64%, $n=482$) reported that they were satisfied or very satisfied with the survey;
42 few participants were dissatisfied (6%) (Figure 1). There was no association between time
43 taken to complete the self-report survey and level of satisfaction ($n=262, r_s = .10, p=.09$), and
44 no difference in satisfaction based on survey type, $\chi^2(9, n=482) = 11.2, p=.26$.
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

[Insert Figure 1 here]

Across self-reporting autistic adults, the most common negative feedback related to difficulty with literal interpretations of forced response items ($n=38$) where participants felt the options provided did not match their circumstances, or to the length of the survey ($n=17$). Several participants provided feedback that they were grateful for research in this area ($n=27$). Many additional topics of interest were suggested, with the most common being relationships, bullying, gender and sexuality, a more detailed employment section. The potential removal of some questionnaires (e.g., the Brief COPE) was also commented on. Revision of items referring to social supports was suggested, as some participants found these upsetting ($n=12$) and / or confusing ($n=7$), with comments such as “I had to really think about my social circle and realised the limited number of truly reliable and trustworthy friends I actually have, which was kind of depressing”.

Summary of participant characteristics

The age of autistic participants ranged from 25 to 80 years, with a high proportion of females (50%, $n=295$) across all autistic samples. Across all autistic participants 36% were living as a couple with 25% of the sample currently married. Over half (57%, $n=42$) of the informant report sample lived with their parents (see Table 4), in contrast to self-reporting autistic adults who most frequently lived as a couple (45%, $n=295$) or alone (26%, $n=295$). Self-reporting autistic adults did not differ from control participants on rural / remoteness according to Australian Statistical Geography Standard-Remoteness Area (ASGS-RA) classification, $X^2(4, n=378) = 9.36, p=.05$ ($n=21$ missing), with no control participants and minimal autistic participants living in remote or very remote Australia. Propensity to greater socioeconomic disadvantage according to the postcode-based Socioeconomic Index for Areas (SEIFA) decile approached significance, $t(376)=2.96, p<.01$ ($n=21$ missing, NB. SEIFA /

rurality not available for all postcodes), though they were still above average compared to the Australian population. Time 2 data gathering will seek to gather household income data to more accurately determine socioeconomic disadvantage.

Of the formally diagnosed autistic adults ($n=221$), 132 (56%) reported they have a diagnostic report available, with 169 (76%) diagnosed by one clinician and 29 (13%) reporting diagnosis by two or more clinicians ($n=23$ missing). As shown in Table 5, the majority (97%, $n=295$) of all autistic participants met the AQ-Short cut-off for identifying autism, compared to 30% ($n=60$) of biologically related carers and 22% ($n=137$) of non-autistic control participants. Asperger's syndrome was the most frequently reported formal diagnosis. Self-reporting formally diagnosed autistic participants on average were diagnosed 6.9 years prior to survey completion, and the majority (90%; $n=217$, 4 missing) received their diagnosis in adulthood. A preliminary analysis of gender differences for self-reporting autistic adults was also conducted. In comparison to males, self-reporting formally diagnosed females did not differ significantly on age of diagnosis $t(192)=.39$, $p=.70$ ($n=4$ missing). Comparing males with females, including non-diagnosed autistic adults, there was no difference in number of individuals currently married or in a defacto relationship, $X^2(1, n=241) = .8$, $p=.38$, or in their educational status, $X^2(2, n=241) = 4.66$, $p=.10$. Females were significantly different regarding employment status $X^2(4, n=241) = 18.77$, $p=.001$, though only relating to the number providing homecare ($n=19$ female vs. $n=1$ male, see Table 4).

In the non-autistic control sample, participant ages ranged from 25 to 79 years, with a high proportion (80%, $n=146$) of females. The majority lived as a couple (72%) and were married (62%). The control sample was significantly different from the self-reporting autistic adults (with and without a formal diagnosis) on several demographics including gender, $X^2(2, n=399) = 26.5$, $p<.001$, living situation, $X^2(5, n=399) = 33.2$, $p<.001$, marital status, $X^2(8, n=398) = 47.1$, $p<.001$ ($n=1$ missing), employment status, $X^2(6, n=367) = 18.3$, $p=.005$ ($n=32$

1
2
3 missing), and higher education status, $X^2(2, n=399) = 22.4, p<.001$. The control sample was
4
5 also significantly less likely to meet the DSM-IV-TR linked PHQ-9 cut-off for depression,
6
7 $X^2(1, n=354) = 54.9, p<.001$ ($n=45$ missing), less likely meet the DSM5 GAD-A cut-off⁷¹ for
8
9 anxiety, $X^2(1, n=366) = 67.8, p<.001$ ($n=33$ missing), and less likely to have a history of
10
11 psychiatric illness, $X^2(1, n=384) = 82.1, p<.001$ ($n=15$ missing), compared to self-reporting
12
13 autistic adults. There were no significant differences for self-reporting autistic adults missing
14
15 data on the PHQ-9 or DSM5 GAD-A based on age, gender or AQ score.
16
17
18
19

20
21 As shown in Table 6, the majority (43%; $n=98$, 4 missing) of carers were mothers of an
22
23 autistic adult, followed by partners or spouses (23%). Carers' ages ranged from 21 to 78
24
25 years. The majority were female (83%, $n=102$), married (66%), and living as a couple (75%).
26
27 Carers spent an average 63.4 ($SD=57.80$, $n=92$) hours per week with the adult with autism,
28
29 and the average age of the autistic adult cared for was 37.5 years (range 25-96 years,
30
31 $SD=13.21$). Most carer participants (76%, $n=102$) are linked to a self-report or informant-
32
33 report responses.
34
35
36

37 [insert Table 4 here]

38 [insert Table 5 here]

39 [insert Table 6 here]

40 41 42 43 44 45 46 Findings to date

47
48
49 Using an inclusive research approach, the ALSAA has collected a detailed profile of the
50
51 physical and mental health, productivity, wellbeing and health service use of autistic adults
52
53 aged 25+ years, and their carers, living in Australia. There were high numbers of recruitment
54
55 responses across the four Time 1 survey populations (autistic and control adult self-report,
56
57 informant report on autistic adults, carer self-report). The ALSAA Time 1 data has been used
58
59
60

1
2
3 in several studies of psychotropic medication use⁷², leisure participation⁷³, ageing well⁷⁴,
4 loneliness⁷⁵ and employment⁷⁶. ALSAA and SASLA pooled data has been used to explore
5 cognitive reappraisal⁷⁷, suicidal ideation⁷⁸, psychometric scale validation⁶¹, and anxiety and
6 depression⁷⁹. Several other outputs are in development, with focus on health service barriers
7 and usage, caregivers, impact of diagnosis in adulthood, further scale validations,
8 longitudinal analyses of loneliness, suicidal ideation, mental illness risk factors, and other
9 outputs, meeting the broad aim of the study to describe and compare the profiles of
10 Australian autistic adults.
11
12
13
14
15
16
17
18
19
20
21

22 *Participant characteristics*

23
24
25 A large number of females on the spectrum ($n=150$) have participated in the ALSAA. This
26 will provide an opportunity to explore the different expression of autism characteristics in
27 females without intellectual disability^{5, 80}. Similar to findings in other studies^{10, 32}, self-
28 reporting autistic adults had high rates of depression (52%), anxiety (55%), and a frequent
29 history of psychiatric diagnosis (89%), significantly more than the control sample. They were
30 less likely to have a university education compared with the control sample.
31
32
33
34
35
36
37
38
39

40 *Questionnaire feedback and completion*

41
42
43 The length of the surveys may have led to some participants not completing following
44 registration, or to missing data or only partial completions. Longer survey length has been
45 linked to lower participation and completion of web-based surveys^{81, 82}. Despite emphasising
46 the ability to complete over several sessions, some participants commented that the survey
47 was “too long”. In contrast, survey length was not identified as an issue during pilot testing,
48 time to complete was not related to survey satisfaction, and some participants appreciated the
49 comprehensive nature of the surveys. Suggestions made in questionnaire feedback will be
50 incorporated in the design of the 2-year follow up. Follow-up design aims to reduce
51
52
53
54
55
56
57
58
59
60

1
2
3 assessment burden by reducing overall survey length and where appropriate pre-filling
4 repeated measures such as medical history. Additional areas of interest to the community will
5 be explored including bullying, relationships and terms used to describe individuals with an
6 autism spectrum diagnosis.
7
8
9
10
11
12

13 **Strengths and limitations**

14
15
16 An important strength of the study was the inclusive research approach using autistic
17 advisors. Frequently missing from autism research and other longitudinal studies, an
18 inclusive research protocol was developed for the ALSAA in consultation with autistic
19 advisors (see Table 1) and applied across all stages of the research process apart from the
20 analysis. Inclusive research has been found to increase the likelihood that findings are
21 translatable to the real world and focused on areas of need from community perspectives⁴⁴.
22
23 Best-practise processes of conducting inclusive research with autistic adults are not well
24 known, though more resources are becoming available⁸³. Although at times advisors'
25 suggestions were in conflict with each other or beyond the scope of the study, as each advisor
26 communicated individually with the research team there was no direct conflict between
27 advisors. Feedback is given to advisors as to what advice has been used or not, and why.
28
29 Little literature was available at the time of commencing the ALSAA and processes were
30 developed iteratively based on understanding of partnering with autistic adults and guidance
31 from our advisors. Growing relationships with advisors over time, and seeking feedback as to
32 preferences for collaboration, has led to harmonious collaborative relationships between the
33 ALSAA researchers and advisors, and will continue to evolve. An important consideration
34 working with the advisors is the allowance of lead time and processing time, which has
35 created difficulty for some student projects using ALSAA data. The ALSAA has further
36 engaged peer researchers in some future outputs, including a study on autistic burnout, and
37 the co-development of research grant applications for other projects. An additional strength
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

1
2
3 of the ALSAA design is its consideration and partial overlap with several other national and
4 international studies, for example overlap with the Autism CRC SASLA longitudinal study
5
6 allows for a lifespan approach to be taken including data from late adolescence⁷⁷.
7
8
9

10
11
12
13
14 The ALSAA baseline sample is reflective of the convenience sampling methodology used.
15
16 Participants would appear non-representative of the Australian autism population given
17
18 approximate postcode-based above average socioeconomic status, a large female gender bias
19
20 for both autistic adults and controls, and that most of the autistic sample (85%) does not have
21
22 an intellectual disability. Earlier epidemiological estimates of autism²³ would suggest a larger
23
24 proportion of people with a diagnosis of autism and intellectual disability and a much higher
25
26 male to female ratio, though recent work questions these assumptions^{2, 84}. Self-selection in
27
28 online surveys can lead to a female gender bias⁸², as also has been noted in other online
29
30 autism research⁸⁵⁻⁸⁷. Commonly reported as a 4 to 1 male bias⁸⁸, there is suggestion the true
31
32 autism gender ratio may be closer to 3 to 1⁸⁴ or lower⁸⁰ as females with autism are at a higher
33
34 risk of being underdiagnosed³. Limiting recruitment to participants age 25 years or older,
35
36 changing diagnostic practices⁸⁹, in combination with the convenience sampling, has likely led
37
38 to the large percentage of participants who had received their autism diagnosis in adulthood.
39
40
41
42
43
44
45 The majority of the current autistic sample does not have an intellectual disability. Significant
46
47 barriers exist for people with intellectual disability to participate in a questionnaire-based
48
49 study⁹⁰. An alternative to directly gathering information from adults on the spectrum with
50
51 intellectual disability is the participation via an informant respondent. Although an informant
52
53 respondent survey was made available for the ALSAA, and despite targeted recruitment
54
55 efforts, there was low participation of people with intellectual disability.
56
57
58
59
60

1
2
3 A final limitation is the self-report questionnaire format of the ALSAA, particularly in
4 relation to self-reported diagnosis of autism and comorbid conditions without clinical
5 reassessment. Validating autism diagnosis through clinical reassessment would be a highly
6 resource intensive exercise in a nationwide study in Australia and is beyond the resourcing
7 available to this study. This is offset by gathering of additional information relating to autism
8 diagnosis, including asking if the respondent has a diagnostic report, name and type of
9 clinician providing diagnosis, and AQ scores. These variables could be used to identify
10 subsamples with stronger evidence of definite diagnosis of autism for separate analysis where
11 necessary depending on the specific research question. Further, diagnostic reports from
12 participants will be requested from participants at follow-up to confirm diagnosis. Gathering
13 data from adults without a formal diagnosis is potentially a strength, given the 'lost
14 generation' of autistic adults³, significant barriers to diagnosis, and accuracy issues with gold
15 standard autism assessment tools⁹¹; these participants could be overlooked in other studies
16 though they represent an important hidden population group. The self-report format also
17 prevents the quantification of participants' cognitive ability. The use of standardised mental
18 health screening measures with clinical cut-offs gathers some information on co-occurring
19 mental health conditions, though not as reliably as would be available via clinical interview.
20 Conversely, community-based sampling and use of self-report questionnaires does allow for
21 gathering a reasonably large sample, offsetting the risk of including people with incorrect
22 diagnostic data with increased statistical power and the potential severity bias of clinical
23 samples. Limitations and strengths of the ALSAA study design will largely depend on the
24 specific research question being explored, with sufficient sample size and data points to
25 partial-out subgroups and non-matched controls or to account for common method variance
26 as needed. Future researchers using the ALSAA dataset will need to consider balancing type
27 1 and type 2 errors⁷⁰. A data governance structure is being established, with requests for
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

1
2
3 ALSAA data requiring researchers to outline a statistical plan and data points they will be
4
5 using, which will assist in managing any concerns of multiple statistical testing without
6
7 correction.
8
9

10 *Implications*

11
12
13
14 There is a significant knowledge gap regarding the lives of autistic adults. The ALSAA has
15
16 gathered a large comprehensive dataset relating to autistic adults and their carers, creating a
17
18 platform for longitudinal follow-up and collaborative research. The ALSAA is an important
19
20 resource for exploring multiple research questions regarding the lives of autistic adults.
21
22

23 However, as with all longitudinal research caution is required in drawing firm conclusions
24
25 from the ALSAA cohort in relation to the entire Australian autism population. Nevertheless,
26
27 this cohort provides the first opportunity to explore longitudinal outcomes of Australian
28
29 autistic adults. Having offline and informant versions of questionnaires, and questionnaires
30
31 reviewed by autistic advisors, facilitates greater accessibility for participants on the spectrum
32
33 and their carers.
34
35
36

37
38 The ALSAA study demonstrates a working approach to inclusive research with autistic
39
40 advisors. The inclusive research protocol developed in this study provides a useful basis for
41
42 other research endeavours. Following this protocol, future outputs such as peer-reviewed
43
44 manuscripts, presentations and reports from the ALSAA will also be developed in
45
46 consultation with autistic advisors or autistic peer researchers. Input from autistic advisors
47
48 has already improved the quality and relevance of initial outputs⁷², for example identifying
49
50 potential alternative interpretations of findings based on lived experiences, potential
51
52 differences in autistic interpretations of scale items, and modifying the methodology in one
53
54 instance⁷⁵ changing a purely quantitative study into a mixed methods design.
55
56
57
58
59
60

1
2
3 Some measures used in the ALSAA have not yet been validated with autistic adult samples
4
5 (e.g., DSM5 GAD-A, Emotion Regulation Questionnaire, PHQ-15). The ALSAA provides
6
7 the opportunity to explore the validity of these commonly used measures.
8
9

10 **Collaboration**

11
12
13
14 International studies involving autistic adults and utilising standardised measures are
15
16 underway in the United States, Netherlands and United Kingdom (e.g., SPARK
17
18 <http://sparkforautism.org>, AASPIRE <https://aaspire.org/>, the Netherlands Autism Register
19
20 <https://www.nederlandsautismeregister.nl> and the Adult Autism Spectrum Cohort-UK
21
22 <http://research.ncl.ac.uk/adultautismspectrum/>), though with less comprehensive ranges of
23
24 measures. During development of the ALSAA, consultation with international groups
25
26 occurred to ensure there were some synergies with these studies. Future international
27
28 comparisons will be possible, including pooling of data. This will allow for the creation of
29
30 much larger datasets and more in-depth understanding of life in adulthood for autistic people.
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

Further details

Contributors

Manuscript drafting was jointly led by SA & KF. All authors (YH,AR,MU,LL,RC,TF,MF,NL,AU,JT) had a role in the conduct of the research, interpretation of results, drafting of manuscript and critical review of the manuscript. SA, KF, YH, AR, MU & JT conducted data analysis and reporting. KF, YH, AR, MU, RC, TF, MF, NL, AU & JT were involved in the conceptualisation of the study.

Data Sharing Statement

Processes to establish data banking and sharing procedures are currently being finalised. Please email the corresponding author regarding queries.

Ethics approval

The study was approved by the Human Research Ethics Committee at UNSW Sydney, Australia (No. HC15001).

Acknowledgements

The authors also acknowledge the valuable contribution of the Research Advisory Network members Matthew Bennett, Bob Boyce, Jen Harland, Julianne Higgins, Gabriel Nakhel, Joanne Mahony, Andrea Michael, Cheryl Strangio, and Chris Tanner whose insight and recommendations shaped this work. We also gratefully acknowledge the cooperation and participation of all participants on the autism spectrum and their carers involved in this study.

Funding

This work was supported by the Cooperative Research Centre for Living with Autism (Autism CRC), established and supported under the Australian Government's Cooperative Research Centres Program.

Conflict of Interest

The authors have no conflict of interest to report.

References

1. Seltzer MM, Shattuck PT, Abbeduto L, Greenberg JS. Trajectory of development in adolescents and adults with autism. *Mental Retardation and Developmental Disabilities*. 2004;10:234-47.
2. Brugha TS, Spiers N, Bankart J, Cooper S-A, McManus S, Scott FJ, et al. Epidemiology of autism in adults across age groups and ability levels. *The British Journal of Psychiatry*. 2016/12/01/;209(6):498-503. en.
3. Lai M-C, Baron-Cohen S. Identifying the lost generation of adults with autism spectrum conditions. *The Lancet Psychiatry*. 2015 2015/11/01/;2(11):1013-27.
4. Van Wijngaarden-Cremers PJM, van Eeten E, Groen WB, Van Deurzen PA, Oosterling IJ, Van der Gaag RJ. Gender and Age Differences in the Core Triad of Impairments in Autism Spectrum Disorders: A Systematic Review and Meta-analysis. *Journal of Autism and Developmental Disorders*. 2014 March 01;44(3):627-35.
5. Bargiela S, Steward R, Mandy W. The Experiences of Late-diagnosed Women with Autism Spectrum Conditions: An Investigation of the Female Autism Phenotype. *Journal of Autism and Developmental Disorders*. 2016 2016/10/01/;46(10):3281-94. en.
6. Jang J, Matson JL, Adams HL, Konst MJ, Cervantes PE, Goldin RL. What are the ages of persons studied in autism research: A 20-year review. *Research in Autism Spectrum Disorders*. 2014;8(12):1756-60.
7. Howlin P, Moss P. Adults with autism spectrum disorders. *Canadian Journal of Psychiatry*. 2012;57(5):275-83.
8. Nicolaidis C. Autism in Adulthood: The New Home for Our Emerging Field. *Autism in Adulthood*. 2018;1(1):1-2.
9. Michael C. Why we need research about autism and ageing. *Autism*. 2016;20(5):515-6.
10. Howlin P, Magiati I. Autism spectrum disorder: outcomes in adulthood. *Current Opinion in Psychiatry*. 2017 2017/03//;30(2):69-76. en.
11. Cashin A, Buckley T, Trollor J, Lennox N. A scoping review of what is known of the physical health of adults with autism spectrum disorder. *Journal of Intellectual Disabilities*. 2016.
12. Croen LA, Zerbo O, Qian Y, Massolo M, Rich S, Sidney S, et al. The health status of adults on the autism spectrum. *Autism*. 2015;19(7):814-23.
13. Jones KB, Cottle K, Bakian A, Farley M, Bilder D, Coon H, et al. A description of medical conditions in adults with autism spectrum disorder: a follow-up of the 1980s Utah/UCLA autism epidemiologic study. *Autism*. 2016;5:551-61.
14. Weiss JA, Riosa PB. Thriving in youth with autism spectrum disorder and intellectual disability. *Journal of Autism and Developmental Disorders*. 2015;45:2474-86.
15. Buck TR, Viskochil J, Farley M, Coon H, McMahon WM, Morgan J, et al. Psychiatric comorbidity and medication use in adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders*. 2014;44:3063-71.
16. Hedley D, Uljarević M, Wilmot M, Richdale A, Dissanayake C. Understanding depression and thoughts of self-harm in autism: A potential mechanism involving loneliness. *Research in Autism Spectrum Disorders*. 2018 2018/02/01/;46:1-7.
17. Lever AG, Geurts HM. Psychiatric co-occurring symptoms and disorders in young, middle-aged, and older adults with autism spectrum disorders. *Journal of Autism and Developmental Disorders*. 2016;46:1916-30.
18. Matson JL, Williams LW. Depression and mood disorders among persons with Autism spectrum disorders. *Research in Developmental Disabilities*. 2014;35:2003-7.
19. Moss P, Howlin P, Savage S, Bolton P, Rutter M. Self and informant reports of mental health difficulties among adults with autism findings from a long-term follow-up study. *Autism*. 2015.
20. Hedley D, Uljarević M, Wilmot M, Richdale A, Dissanayake C. Brief Report: Social Support, Depression and Suicidal Ideation in Adults with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*. 2017 November 01;47(11):3669-77.

21. Hirvikoski T, Mittendorfer-Rutz E, Boman M, Larsson H, Lichtenstein P, Bolte S. Premature mortality in autism spectrum disorder. *The British Journal of Psychiatry*. 2015.
22. Matson JL, Nebel-Schwalm N. Comorbid psychopathology with autism spectrum disorder in children: an overview. *Research in Developmental Disabilities*. 2007;28:341-52.
23. Fombonne E. Epidemiology surveys of autism and other pervasive developmental disorders: an update. *Journal of Autism and Developmental Disorders*. 2003;33(4):365-82.
24. LaMalfa G, Lassi G, Bertilli M, Salvani R, Placidi GF. Autism and intellectual disability: a study of prevalence on a sample of the Italian population. *Journal of Intellectual Disability Research*. 2004;48:262-7.
25. Matson JL, Shoemaker M. Intellectual disability and its relationship to autism spectrum disorders. *Research in Developmental Disabilities*. 2009;30:1107-14.
26. Dawson M, Soulières I, Gernsbacher MA, Mottron L. The level and nature of autistic intelligence. *Psychol Sci*. 2007;18(8):657-62. PubMed PMID: 17680932. eng.
27. Howlin P, Arciuli J, Begeer S, Brock J, Clarke K, Costley D, et al. Research on adults with autism spectrum disorder: roundtable report. *Journal of Intellectual and Developmental Disability*. 2015;40(4):388-93.
28. Hedley D, Uljarevic M, Cameron L, Halder S, Richdale AL, Dissanayake C. Employment programmes and interventions targeting adults with autism spectrum disorder: a systematic review of the literature. *Autism*. 2016:1-13.
29. Gray KM, Piccin AK, C. M., Taffe J, Parmenter TR, Hofer S, Einfeld S, et al. Outcomes in young adulthood: are we achieving community participation and inclusion? *Journal of Intellectual Disability Research*. 2014;58(8):734-45.
30. Henninger NA, Taylor JL. Outcomes in adults with autism spectrum disorders: a historical perspective. *Autism*. 2013;17(1):103-16.
31. Howlin P, Moss P, Savage S, Rutter. Social outcomes in mid- to later adulthood among individuals diagnosed with autism and average nonverbal IQ as children. *Journal of American Academy of Child & Adolescent Psychiatry*. 2013;52(6):572-81.
32. Magiati I, Tay XW, Howlin P. Cognitive, language, social and behavioural outcomes in adults with autism spectrum disorders: a systematic review of longitudinal follow-up studies in adulthood. *Clinical Psychology Review*. 2014;34:73-86.
33. Marriage S, Wolverton A, Marriage K. Autism spectrum disorder grown up: A chart review of adult functioning. *Journal of the Canadian Academy of Child and Adolescent Psychiatry*. 2009;18(4):322.
34. Levy A, Perry A. Outcomes in adolescents and adults with autism: a review of the literature. *Research in Autism Spectrum Disorders*. 2011;5:1271-82.
35. Seltzer MM, Krauss MW, Shattuck PT, Orsmond GI, Swe A, Lord C. The symptoms of autism spectrum disorders in adolescence and adulthood. *Journal of Autism and Developmental Disorders*. 2003;33:565-81.
36. Shattuck PT, Selter MM, Greenberg JS, Orsmond GI, Bolt D, Kring S, et al. Change in autism symptoms and maladaptive behaviors in adolescents and adults with an autism spectrum disorder. *Journal of Autism and Developmental Disorders*. 2007;37:1735-47.
37. Happe F, Charlton RA. Aging in autism spectrum disorders: a mini-review. *Gerontology*. 2010;58:70-8.
38. Totsika V, Felce D, Kerr M, Hastings RP. Behaviour problems, psychiatric symptoms, and quality of life for older adults with intellectual disability with and without autism. *Journal of Autism and Developmental Disorders*. 2010;40:1171-8.
39. Khanna R, K. J-P, West-Strum D, Mahabaleshwarkar R. Health-related quality of life and its determinants among adults with autism. *Research in Autism Spectrum Disorders*. 2014;8(3):157-67.
40. Pellicano E, Dinsmore A, Charman T. What should autism research focus upon? Community views and priorities from the United Kingdom. *Autism*. 2014:1-5.

- 1
- 2
- 3
- 4 41. Nicolaidis C. What Can Physicians Learn from the Neurodiversity Movement? . American
- 5 Medical Association Journal of Ethics. 2012;14(6):503-10.
- 6 42. Nicolaidis C, Raymaker D, Dern S, Boisclair C, Ashkenazy E, Baggs A. Comparison of
- 7 healthcare experiences in autistic and non-autistic adults: a cross-sectional online survey facilitated
- 8 by an academic-community partnership. *Journal of General Internal Medicine*. 2012;28(6):761-9.
- 9 43. Kapp SK, Steward R, Crane L, Elliott D, Elphick C, Pellicano E, et al. 'People should be allowed
- 10 to do what they like': Autistic adults' views and experiences of stimming. *Autism*.
- 11 2019:1362361319829628.
- 12 44. Walmsley J, Johnson K. Inclusive research with people with learning disabilities: Past,
- 13 present and futures. London and New York: Jessica Kingsley Publishers 2003.
- 14 45. Bigby C, Frawley P, Ramcharan P. Conceptualising inclusive research with people with
- 15 intellectual disability. *Journal of Applied Research in Intellectual Disabilities*. 2014;27(1):3-12.
- 16 46. Bagatell N. From cure to community: transforming notions of autism. *Journal of the Society*
- 17 *for Psychological Anthropology*. 2010;38(1):33-55.
- 18 47. Milton D, Bracher M. Autistics speak but are they heard? *Medical Sociology Online*.
- 19 2013;7:61-9.
- 20 48. Nind M, Vinha H. Doing research inclusively: bridges to multiple possibilities in inclusive
- 21 research. *British Journal of Learning Disabilities*. 2012;42:102-9.
- 22 49. Gatfield O, Mangan C, Haar T, Kinninurgh A, Rodger S. 2016 Research Priorities Survey
- 23 Report. Brisbane, Queensland, Australia: Cooperative Research Centre for Living with Autism, 2016.
- 24 50. Gotham K, Marvin AR, Talyor JL, Warren Z, Anderson CM, Law PA, et al. Characterizing the
- 25 daily life, needs, and priorities of adults with autism spectrum disorder from Interactive Autism
- 26 Network. *Autism*. 2015:1-11.
- 27 51. McConachie H, Mason D, Parr JR, Garland D, Wilson C, Rodgers J. Enhancing the Validity of a
- 28 Quality of Life Measure for Autistic People. *J Autism Dev Disord*. 2018 May;48(5):1596-611. PubMed
- 29 PMID: 29188584. Pubmed Central PMCID: PMC5889785. Epub 2017/12/01. eng.
- 30 52. Seltzer MM, Greenberg JS, Taylor JL, Smith LE, Orsmond GE, Esbensen A, et al. Adolescents
- 31 and adults with autism spectrum disorders. In: Amaral DG, Dawson G, Geschwind D, editors. *Autism*
- 32 *spectrum disorders* New York: Oxford University Press; 2011.
- 33 53. Lawson L, Hascheck A, Richdale AL. SASLA Snapshot: Study of Australian School-Leavers with
- 34 Autism – Baseline Profile. Melbourne, Australia: Olga Tennison Autism Research Centre (OTARC), La
- 35 Trobe University, 2018.
- 36 54. Haas K, Costley D, Falkmer M, Richdale A, Sofronoff K, Falkmer T. Factors Influencing the
- 37 Research Participation of Adults with Autism Spectrum Disorders. *J Autism Dev Disord*. 2016
- 38 May;46(5):1793-805. PubMed PMID: 26810436. Epub 2016/01/27. eng.
- 39 55. Walmsley J. Normalisation, emancipatory research and inclusive research in learning
- 40 disability. *Disability & Society*. 2001;16(2):188-205.
- 41 56. CRC A. Inclusive research practice guide and checklists for autism research: Version 2.
- 42 Brisbane, Queensland: Autism CRC Ltd., 2016.
- 43 57. Nicolaidis C, Raymaker D, Katz M, Oshwald M, Goe R, Leottie S, et al. Community-based
- 44 participatory research to adapt health measures for use by people with developmental disabilities.
- 45 *Progress in Community Health Partnerships: Research, Education, and Action*. 2015;9(2):141-3.
- 46 58. Kroenke K, Spitzer RL, Williams JBW. The PHQ-9: validity of a brief depression severity
- 47 measure. *Journal of General Internal Medicine*. 2001;16:606-13.
- 48 59. Khanna R, K. J-P, West-Strum D. Validity and reliability of the Medical Outcomes Study Short-
- 49 Form Health Survey version 2 (SF-12v2) among adults with autism. *Research in Developmental*
- 50 *Disabilities*. 2015;43-44:51-60.
- 51 60. Barrett SL, Uljarević M, Baker EK, Richdale AL, Jones CRG, Leekam SR. The Adult Repetitive
- 52 Behaviours Questionnaire-2 (RBQ-2A): A Self-Report Measure of Restricted and Repetitive
- 53 Behaviours. *Journal of Autism and Developmental Disorders*. 2015 2015/11/01;45(11):3680-92.
- 54
- 55
- 56
- 57
- 58
- 59
- 60

- 1
2
3 61. Arnold SRC, Uljarevic M, Hwang J, Richdale A, Trollor J, Lawson LP. Brief Report:
4 Psychometric Properties of the Patient Health Questionnaire-9 (PHQ-9) in Autistic Adults. *Journal of*
5 *Autism and Developmental Disorders*. 2019;1-9.
- 6 62. Whitehouse AJO, Bishop DVM. *Communication checklist - adult*. London: The Psychological
7 Corporation; 2009.
- 8 63. (AIHW) AloHaW. *Autism in Australia*. Web Report. Canberra, Australia: AIHW, 2017 5-4-17.
9 Report No.
- 10 64. Hoekstra RA, Vinkhuyzen AAE, Wheelwright S, Bartels M, Boomsma DI, Baron-Cohen S, et al.
11 The construction and validation of an abridged version of the Autism-Spectrum Quotient. *Journal of*
12 *Autism and Developmental Disorders*. 2011;41:589-96.
- 13 65. Lundqvist L-O, Lindner H. Is the Autism-Spectrum Quotient a Valid Measure of Traits
14 Associated with the Autism Spectrum? A Rasch Validation in Adults with and Without Autism
15 Spectrum Disorders. *Journal of Autism and Developmental Disorders*. 2017 July 01;47(7):2080-91.
- 16 66. Eriksson JM, Andersen LMJ, Bejerot S. RAADS-14 Screen: validity of a screening tool for
17 autism spectrum disorder in an adult psychiatric population. *Molecular Autism*. 2013
18 2013/12/09;4(1):49.
- 19 67. Evans E, Trollor J, Davis A, Bhardwaj A, O'Brien E. *Mental health and carer support in elders*
20 *with ID*. Report to Ageing, Disability and Home Care, Department of Family and Community Services,
21 NSW Australia. Sydney, Australia: Department of Developmental Disability Neuropsychiatry, UNSW
22 Sydney, 2015.
- 23 68. StataCorp. *Stata Statistical Software: Release 14*. College Station, TX: StataCorp LP; 2015.
- 24 69. IBM_Corp. *IBM SPSS Statistics for Windows, Version 22.0*. Armonk, NY: IBM Corp; 2013.
- 25 70. Streiner DL, Norman GR. *Correction for Multiple Testing: Is There a Resolution?* *Chest*. 2011
26 2011/07/01;140(1):16-8.
- 27 71. Beesdo-Baum K, Klotsche J, Knappe S, Craske MG, LeBeau RT, Hoyer J, et al. Psychometric
28 properites of the dimensional anxiety scales for DSM-V in an unselected sample of German
29 treatment seekeing patients. *Depression and Anxiety*. 2012;29(12):1014-24.
- 30 72. Cvejic RC, Arnold SRC, Foley K-R, Trollor JN. Neuropsychiatric profile and psychotropic
31 medication use in adults with autism spectrum disorder: results from the Australian Longitudinal
32 Study of Adults with Autism. *BJPsych Open*. 2018;4(6):461-6. Epub 11/13.
- 33 73. Stacey T-L, Froude EH, Trollor J, Foley K-R. Leisure participation and satisfaction in autistic
34 adults and neurotypical adults. *Autism*. 2018;0(0):1362361318791275. PubMed PMID: 30132680.
- 35 74. Hwang YI, Foley K-R, Trollor JN. Aging Well on the Autism Spectrum: An Examination of the
36 Dominant Model of Successful Aging. *Journal of Autism and Developmental Disorders*. 2018 May 02.
- 37 75. Ee D, Hwang J, Reppermund S, Srasuebku P, Trollor J, Foley K-R, et al. Loneliness in Adults
38 on the Autism Spectrum. *Autism in Adulthood*. 2019.
- 39 76. Harsanyi M, Foley K-R, Froude E, Trollor J, Arnold SRC. *Employment Profiles of Autistic Adults*
40 *in Australia*. 2019.
- 41 77. Cai RY, Richdale AL, Foley K-R, Trollor J, Uljarević M. Brief report: Cross-sectional interactions
42 between expressive suppression and cognitive reappraisal and its relationship with depressive
43 symptoms in autism spectrum disorder. *Research in Autism Spectrum Disorders*. 2018
44 2018/01/01;45:1-8.
- 45 78. Hedley D, Uljarević M, Foley K-R, Richdale A, Trollor J. Risk and protective factors underlying
46 depression and suicidal ideation in Autism Spectrum Disorder. *Depression and Anxiety*.
47 2018;35(7):648-57.
- 48 79. Uljarević M, Hedley D, Foley K-R, Magiati I, Cai RY, Dissanayake C, et al. Anxiety and
49 depression from adolescence to old age in autism spectrum disorder. *Journal of Autism and*
50 *Developmental Disorders*. 2019.
- 51 80. Baldwin S, Costley D. The experiences and needs of female adults with high-functioning
52 autism spectrum disorder. *Autism*. 2016;20(4):483-95. PubMed PMID: 26111537.
- 53
54
55
56
57
58
59
60

81. Fan W, Yan Z. Factors affecting response rates of the web survey: A systematic review. *Computers in Human Behavior*. 2010 2010/03/01/;26(2):132-9.
82. Guo X, Vittinghoff E, Olgin JE, Marcus GM, Pletcher MJ. Volunteer Participation in the Health eHeart Study: A Comparison with the US Population. *Scientific Reports*. 2017 2017/05/16/;7(1):1956. En.
83. Fletcher-Watson S, Adams J, Brook K, Charman T, Crane L, Cusack J, et al. Making the future together: Shaping autism research through meaningful participation. *Autism*. 2019;0(0):1362361318786721. PubMed PMID: 30095277.
84. Loomes R, Hull L, Mandy WPL. What Is the Male-to-Female Ratio in Autism Spectrum Disorder? A Systematic Review and Meta-Analysis. *Journal of the American Academy of Child & Adolescent Psychiatry*. 2017 2017/06/01/;56(6):466-74.
85. Gilmour L, Schalomon PM, Smith V. Sexuality in a community based sample of adults with autism spectrum disorder. *Research in Autism Spectrum Disorders*. 2012 2012/01/01/;6(1):313-8.
86. Kapp SK, Gillespie-Lynch K, Sherman LE, Hutman T. Deficit, difference, or both? Autism and neurodiversity. *Developmental Psychology*. 2013 2013;49(1):59-71. en.
87. Nicolaidis C, Raymaker D, McDonald K, Dern S, Boisclair C, Ashkenazy E, et al. Comparison of healthcare experiences in autistic and non-autistic adults: A cross-sectional online survey facilitated by an academic-community partnership. *Journal of General Internal Medicine*. 2013;28(6):761-9.
88. Whiteley P, Todd L, Carr K, Shattock P. Gender Ratios in Autism, Asperger Syndrome and Autism Spectrum Disorder. *Autism Insights*; London. 2010 2010;2:17. English.
89. Whitehouse AJO, Cooper MN, Bebbington K, Alvares G, Lin A, Wray J, et al. Evidence of a reduction over time in the behavioral severity of autistic disorder diagnoses. *Autism Research*. 2017;10(1):179-87.
90. Chadwick D, Wesson C, Fiullwood C. Internet Access by People with Intellectual Disabilities: Inequalities and Opportunities. *Future Internet*. 2013;5(3):376-97.
91. Fusar-Poli L, Brondino N, Rocchetti M, Panisi C, Provenzani U, Damiani S, et al. Diagnosing ASD in Adults Without ID: Accuracy of the ADOS-2 and the ADI-R. *Journal of Autism and Developmental Disorders*. 2017 2017/11/01/;47(11):3370-9.
92. Robertson AE, Simmons DR. The relationship between sensory sensitivity and autistic traits in the general population. *Journal of Autism and Developmental Disorders*. 2012;43:775-84.
93. Carleton RN, Norton PJ, Asmundson GJG. Fearing the unknown: a short version of the intolerance of uncertainty scale. *Journal of Anxiety Disorders*. 2007;21:105-17.
94. Spitzer RL, Williams JBW, Kroenke K, Linzer M, deGruy FV, Hahn SR. Utility of new procedure for diagnosis mental-disorders in primary-care: the PRIME-MD 1000 study. *Journal of American Medical Association*. 1994;272:1749-56.
95. Ware JE, Kosinski M, Keller SD. A 12-Item Short-Form Health Survey: construction of scales and preliminary tests of reliability and validity. *Medical care*. 1996;34(3):220.
96. Sletten DM, Suarez GA, Low PA, Mandrekar J, Singer W. COMPASS 31: A refined and abbreviated composite autonomic symptom score. *Mayo Clinic Proceedings*. 2012;87(12):1196-201.
97. Buysse DJ, Reynolds CF, Monk TH, Berman SR, Kupfer DJ. The Pittsburgh Sleep Quality Index: a new instrument for psychiatric practise and research. *Psychiatry Reserves*. 1989;28:193-213.
98. Gardisar M, Lack L, Richards H, Harris J, Gallasch J, Boundy M, et al. The Flinders Fatigue Scale: preliminary psychometric properties and clinical sensitivity of a new scale for measuring daytime fatigue associated with insomnia. *Journal of Clinical Sleep Medicine*. 2007;3(7):722-8.
99. Craske MG, Wittchen H-U, Bogels S, Stein M, Andrews G, Lebeu R. Severity measure for Generalized Anxiety Disorder - adult: American Psychiatric Association; 2013.
100. Tennant R, Hiller L, Fishwick R, Platt S, Joseph S, Weich S, et al. The Warwick-Edinburgh mental well-being scale (WEMWBS): development and UK validation. *Health and Quality of Life Outcomes*. 2007;5(63):1-13.
101. Chen G, Gully SM, Eden D. Validation of a new general self-efficacy scale. *Organizational Research Methods*. 2001;4(1):62-83.

- 1
2
3 102. Gross JJ, John OP. Individual differences in two emotion regulation processes: implications
4 for affect, relationships, and well-being. *Journal of Personality and Social Psychology*.
5 2003;85(2):348-62.
6
7 103. Mohr C, Tonge BJ, Einfeld SL, Taffe J. The Developmental Behaviour Checklist for Adults
8 (DBC-A) Revised. Sydney, Australia: University of Sydney and Monash University, 2011.
9 104. Carver CS. You want to measure coping but your protocol's too long: consider the brief
10 COPE. *International journal of behavioral medicine*. 1997;4(1):92-100. PubMed PMID: 16250744.
11 Epub 1997/01/01. eng.
12 105. Crook TH, 3rd, Feher EP, Larrabee GJ. Assessment of memory complaint in age-associated
13 memory impairment: the MAC-Q. *International psychogeriatrics*. 1992 Fall;4(2):165-76. PubMed
14 PMID: 1477304. Epub 1992/01/01. eng.
15 106. Hays RD, DiMatteo MR. A short-form measure of loneliness. *Journal of Personality*
16 *Assessment*. 1987;51:69-81.
17 107. Sarason IG, Levine HM, Basham RB, Sarason BR. Assessing social support: the social support
18 questionnaire. *Journal of Personality and Social Psychology*. 1983;44(1):127-39.
19 108. The WHOQOL Group. The World Health Organization Quality of Life assessment (WHOQOL)-
20 BREF quality of life assessment. *Psychological Medicine*. 1995;28:551-5.
21 109. Maenner MJ, Smith LE, Hong J, Makuch R, Greenberg JS, Mailick MR. Evaluation of an
22 activities of daily living scale for adolescents and adults with developmental disabilities. *Disability*
23 *and Health Journal* 2013;6(1):8-17.
24 110. Luciano JV, Ayuso-Mateos JL, Aguado J, Fernandez A, Serrano-Blanco A, Roca M, et al. The
25 12-item World Health Organisation Disability Assessment Schedule (WHO-DAS II): a nonparametric
26 item response analysis *BMC Medical Research Methodology*. 2010;10(45):1-9.
27 111. Taylor JL, Seltzer MM. Developing a vocational index for adults with autism spectrum
28 disorders. *Journal of Autism and Developmental Disorders*. 2012;42(12):2669-79.
29 112. Beard JG, Ragheb MG. Measuring leisure satisfaction. *Journal of Leisure Research*.
30 1980;12:20-33.
31 113. Chisholm D, Knapp MRJ, Knudsen HC, Amaddeo F, Gaité L, van Wijngaarden B, et al. Client
32 socio-demographic and service receipt inventory - European version: development of an instrument
33 for international research. *The British Journal of Psychiatry*. 2000;177:28-33.
34 114. Bengston VL, Allen KR. The life course perspective applied to families overtime. In: Boss P,
35 Doherty W, LaRossa R, Schumm W, Steinmetz S, editors. *Sourcebook of family theories and*
36 *methods: a contextual approach*. New York: Plenum Press; 1993. p. 469-98.
37 115. McCarron M, Gill M, Lawlor B, Beagly C. A pilot study of the reliability and validity of the
38 Caregiver Activity Survey - Intellectual disability (CAS-ID). *Journal of Intellectual Disability Research*.
39 2002;46(8):605-12.
40 116. Bedard M, Molloy DW, Squire L, Dubois BA, Lever JA, O'Donnell M. The Zarit Burden
41 Interview: a new short version and screening version. *The Gerontologist*. 2001;41(5):652-7.
42 117. Alliance NRH. The litte book of rural health numbers: Author; 2015. Available from:
43 <https://www.ruralhealth.org.au/book/little-book-rural-health-numbers>.
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

Figure Caption Sheet

Figure 1. Satisfaction responses upon completion combined by survey type (n=482)

For peer review only

Table 1

The ALSAA Inclusive Research Protocol

Step	Description of step and considerations
Step 1: Recruitment of advisors / peer-researchers	Ensure recruitment is inclusive of all potential autistic individuals including adults with intellectual disability, consider using multiple channels of recruitment (e.g., Autism associations, self-advocacy networks, carer networks, adult networks, local radio, social media and word of mouth). In Australia, seek support from the Autism CRC Research Academy*.
Step 2: Building rapport	If an established relationship does not already exist between the autistic individual and researcher, the researcher should offer to meet the individual (either face-to-face, over video conference or phone call). Be mindful that some autistic individuals may prefer to communicate via text or email and not to meet in person and should not be required to.
Step 3: Clarify what will be expected from the advisor	Outline tasks autistic advisors or peer researchers will be asked to complete. Specify the frequency and timing of when they are likely to be contacted. For specific tasks clearly provide step-by-step instructions, flexible lead-time, timeframes for feedback, area of investigation, and broad aim of the study. Make information available in Easy English or plain language as appropriate. Specify the type and nature of advice sought. Clearly describe how and where their input will be used and why their input is being sought.
Step 4: Ethics, confidentiality and acknowledgement	Describe ethics of the project and expected confidentiality. As required, specify on individual documents that the document is confidential and not to be distributed without discussion with the researcher. Can the autistic individual opt out if they would like? Outline what will happen if they choose to withdraw, e.g., this will not affect their relationship with the research team, university or any other associated organisations. It is a voluntary process. Negotiate and make explicit how the autistic advisor or peer-researcher will be acknowledged. Consider how the autistic individual may be recognised in a manuscript or research output. This may include as a co-author, in the acknowledgements section, and/or in discussing methodology and findings.
Step 5: Identify preferred communication style	Ask the autistic individual their preferred communication style for providing feedback (e.g., face-to-face, phone call, email, video, or a variety of techniques). Also, in what medium they would like to receive the results/findings e.g., academic writing style, easy English writing style, mostly graphs/pictures, mostly dot points, described in person, video, PowerPoint presentation, etc. Although not all mediums may be practical, it is important to identify the autistic advisor's preferred style and then work together to identify a medium of communication which will be understood and accessible by both the autistic advisor and the researcher.
Step 6: The sensory environment	The researcher must provide an 'autism-friendly' environment on any occasion where the autistic advisor and the researcher may be meeting in person, see p. 12-15 in the <i>Autism CRC Inclusive Research Practice Guides and Checklists for Autism Research</i> ⁵⁶ regarding creating autism-friendly environments.
Step 7: Involvement in	Autistic advisors input is sought in regard to questionnaire design and interpretation of results. The researcher will need to present questionnaire

1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16	methodological design / results / findings	design questions or quantitative or qualitative results in an understandable format, developing design issue summaries or results summaries in the medium preferred by the autistic advisor or peer-researcher. This means the researcher may need to make a number of decisions around data analysis and interpretation. Where possible, outline each of these decisions so the process is transparent and the autistic advisor can reflect on the decisions made by the researcher and whether these were appropriate in their view. Provide clear guidance on what advice is being sought, provide lead time, and the timeframe and process to follow for providing advice. How long should the advice be? In what format? Who will be reading it, who do they send the advice to? What are the researchers specifically looking for, what should the advice focus on?
17 18 19 20 21	Step 8: Feedback	Once the researcher receives the advice from the autistic advisor, the researcher should provide a timeframe in which the autistic advisor will receive an update on what aspects of the advice was incorporated and the effect it had/didn't have on the methodology, findings, and/or interpretation.
22 23 24 25 26 27	Step 9: Final checks	Once the manuscript or research output has been further developed, the autistic advisor should receive a copy of the manuscript prior to submission. If the autistic advisor has limited experience with academic writing, the researcher should offer to describe/provide a lay summary of the overall article for the advisor.
28 29 30	Step 10: Acknowledgement	Autistic advisor or peer-researcher to be acknowledged in the agreed upon manner (e.g., co-author, thanked in the acknowledgement section, acknowledged during a presentation etc.)

*The Autism CRC Research Academy (<https://www.autismcrc.com.au/research-academy>) provides training for peer researchers.

Table 2

Measurements included in the ALSAA surveys

Measure / domain	Self-report	Informant report	Carer
Demographics and personal characteristics			
Basic demographics (Age, Sex, Ethnicity, English speaking status)	✓	✓	✓
Other demographics (Education, Occupation ^a , Family & living conditions, Income)	✓	✓	✓
Autism Characteristics			
The Autism Quotient - Short ^b (AQ-Short) ⁶⁴	✓	✓	✓
Repetitive Behaviours Questionnaire-2 Adult Version (RBQ-2A) ⁶⁰	✓	✓	
The Glasgow Sensory Questionnaire ⁹²	✓	✓	
The Intolerance of Uncertainty Scale-12 ⁹³	✓		✓
Health & Well-Being			
Medical history	✓	✓	✓
Medication profile	✓	✓	
Smoking, alcohol and illicit drug use ^a	✓	✓	
The Patient Health Questionnaire-15 ⁹⁴	✓		✓
Medical Outcomes Study Short Form Health Survey-12 (SF-12) ⁹⁵	✓	✓	✓
The Composite Autonomic Symptom Score - 31 (COMPASS 31) ⁹⁶	✓		
Pittsburgh Sleep Quality Index ⁹⁷	✓		
Flinders Fatigue Scale ⁹⁸	✓		
Mental & Emotional Health			
DSM-5 Dimensional Anxiety Scales: Generalized Anxiety Disorder-Adult (DSM5 GAD-A) ⁹⁹	✓		✓
The Patient Health Questionnaire-9 (PHQ-9) ⁵⁸	✓		✓
The Warwick Edinburgh Mental Well-being Scale ¹⁰⁰	✓		
The New General Self-Efficacy Scale ¹⁰¹	✓		
The Emotion Regulation Questionnaire ¹⁰²	✓		✓
Developmental Behaviour Checklist-Adolescent/Adult version (DBC-A) Revised ¹⁰³		✓	
The Brief COPE ¹⁰⁴	✓		✓
Memory Complaint Questionnaire (MAC-Q) ¹⁰⁵	✓		
Relationships & Social Networks			
UCLA Loneliness Scale-8 (ULS-8) ¹⁰⁶	✓		
Supports and networks ^a	✓	✓	
The Social Support Questionnaire (SSQ) ¹⁰⁷	✓		✓
Activities, Participation & Quality of Life			

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

WHOQOL-BREF ¹⁰⁸	✓		✓
Waisman Activities of Daily Living Scale (W-ADL) ¹⁰⁹	✓	✓	
World Health Organisation Disability Assessment Schedule (WHO-DAS II) ¹¹⁰	✓	✓	✓
Vocational Index for Adults with Autism ¹¹¹	✓	✓	
Special abilities and interests ^c	✓		
Leisure activities participation	✓	✓	
Leisure Satisfaction Scale (LSS) ¹¹²	✓		
Driving and transport	✓	✓	✓
Service Usage			
Client Service Receipt Inventory (CSRI) ¹¹³	✓	✓	
Health service seeking behaviour	✓	✓	
Early intervention service history	✓	✓	
Justice system contact	✓	✓	
Preventative health screening	✓	✓	
Caring			
Positive Affect Index ¹¹⁴			✓
Caregiver Activity Survey (CAS-ID) ¹¹⁵			✓
Zarit Burden Interview ¹¹⁶			✓

^a Based on questions from the National Health Survey of Mental Health and Wellbeing (Slade, Johnston, Oakley Browne, Andrews, & Whiteford, 2009). ^b A 28-item parent-carer report adaptation using items from the AQ-Adolescent (Baron-Cohen, Hoekstra, Knickmeyer, & Wheelwright, 2006) was used for the informant-report survey ^cBased on questions from the Interactive Autism Network (<https://iancommunity.org/>)

Table 3

Recruitment statistics at close of Time 1 data gathering

Sample	Registered	Non-respondent	Ineligible (%)	Withdrawn (%)	Partial Completion (%)	Completed (%)
Self-report autistic adults	345	75 (22)	6 (2)	11 (3)	16 (5)	237 (69)
Self-report non-autistic adults	221	48 (22)	7 (3)	20 (9)	16 (7)	130 (59)
Carer	185	48 (26)	22 (12)	13 (7)	2 (1)	100 (54)
Informant-report for autistic adult	78	22 (28)	5 (6)	9 (11)	0 (0)	42 (54)

Table 4

Participant Characteristics

Characteristic	Autistic adults self-report formally diagnosed (N=221)	Autistic adults self-report no formal diagnosis (N=32)	Autistic adults informant-report (N=42)	Carers (N=102)	Non-autistic self-report (N=146)
Age mean (SD)	41.8 (12.2)	44.2 (8.1)	32.5 (9.9)	56.3 (11.2)	43.7 (13.5)
Gender (%)					
Male	86 (39)	14 (44)	34 (81)	16 (16)	29 (20)
Female	124 (56)	17 (53)	8 (19)	85 (83)	117 (80)
Other	11 (5)	1 (3)	0	1 (1)	0
^a Ethnicity (%)					
Caucasian	194 (88)	25 (78)	38 (90)	86 (89)	122 (85)
Other	27 (12)	7 (22)	4 (9)	11 (11)	22 (15)
Multilingual (%)	26 (12)	5 (16)	0	6 (6)	18 (12)
^b SEIFA decile (SD)	6.18 (2.89)	5.74 (3.09)	6.58 (2.88)	6.60 (2.78)	7.01 (2.60)
^{bc} Rural / Remoteness					
Major City	146 (71)	17 (55)	32 (84)	72 (73)	114 (83)
Inner Regional	44 (21)	10 (32)	5 (13)	21 (21)	19 (14)
Outer Regional	12 (6)	4 (13)	1 (3)	5 (5)	5 (4)
Remote / Very Remote	4 (2)	0	0	0	0
^d Living situation (%)					
Living alone	58 (26)	9 (28)	3 (7)	14 (14)	26 (18)
Living as couple	95 (43)	18 (56)	4 (9)	74 (75)	105 (72)
Living with parents	31 (14)	0	24 (57)	0	5 (3)
Living with other relatives	3 (1)	0	1 (2)	6 (6)	3 (2)
Living with others	20 (9)	5 (16)	8 (19)	4 (4)	5 (3)
Other	14 (6)	0	2 (5)	1 (1)	2 (1)
^e Marital Status (%)					
Single	73 (33)	7 (22)	36 (86)	4 (4)	22 (15)
Married	66 (30)	12 (37)	4 (9)	65 (66)	90 (62)
De facto	17 (8)	3 (9)	0	8 (8)	14 (9)
Never married	8 (4)	3 (9)	2 (5)	2 (2)	3 (2)
Widowed	1 (0)	0	0	3 (3)	2 (1)
Divorced now single	21 (9)	3 (9)	0	8 (8)	9 (6)
Divorced now remarried / de facto	12 (5)	2 (6)	0	2 (2)	2 (1)
Separated	7 (3)	1 (3)	0	2 (2)	1 (1)
Other	16 (7)	1 (3)	0	4 (4)	3 (2)
Educational Status (%)					

Completed high school	163 (76) <i>n</i> =215	20 (64) <i>n</i> =31	21 (51) <i>n</i> =41	86 (88) <i>n</i> =98	120 (86) <i>n</i> =139
Vocational education	61 (35) <i>n</i> =174	16 (57) <i>n</i> =28	4 (11) <i>n</i> =35	17 (17) <i>n</i> =98	20 (16) <i>n</i> =127
University education	113 (65) <i>n</i> =174	12 (43) <i>n</i> =28	1 (3) <i>n</i> =35	59 (60) <i>n</i> =98	107 (84) <i>n</i> =127
^f Employment (%)					
Open employment	116 (57)	20 (69)	6 (15)	59 (60)	104 (76)
Student / other day activity	38 (19)	3 (10)	24 (60)	3 (3)	17 (12)
Retired, no volunteering	8 (4)	2 (7)	2 (5)	19 (19)	6 (4)
Homecare	17 (8)	3 (10)	0	9 (9)	9 (6)
No activity	22 (11)	1 (3)	8 (20)	9 (9)	1 (1)

^a Ethnicity: Carers, *n*=97; Non-autistic (self-report), *n*=144

^b Autistic adults (diagnosis, self-report), *n*=209; Autistic adults (no diagnosis, self-report), *n*=31; Autistic adults (informant report), *n*=38; Carers, *n*=99; Non-autistic (self-report), *n*=138

^c Australian population is 70% Major city, 18% Inner regional, 9% Outer regional, 1% Remote, 1% Very remote in the 2011 Census¹¹⁷

^d Carers' Living situation: *n*=99

^e Carers' Marital status: *n*=98

^f Employment: Autistic adults (diagnosis, self-report), *n*=201; Autistic adults (no diagnosis, self-report), *n*=29; Autistic adults (informant report), *n*=40; Carers, *n*=99; Non-autistic (self-report), *n*=137

Table 5

Diagnostic Characteristics

Characteristic	Autistic adults self-report formally diagnosed (N=221)	Autistic adults self-report no formal diagnosis (N=32)	Autistic adults informant-report (N=42)	Carers (N=102)	Non-autistic self-report (N=146)
AQ score mean (SD)	87.6 (10.3) n=210	83.7 (8.8)	84.2 (9.5) n=36	57.3 (13.8) n=60 ^a	55.1 (11.9) n=137
Above AQ Cutoff (%)	203 (97)	31 (97)	35 (97)	18 (30)	30 (22)
^b Autism Diagnosis					
Autism spectrum disorder / condition	49 (22)	-	17 (40)	-	-
Asperger's syndrome	130 (59)	-	11 (26)	-	-
Autistic disorder	1 (0)	-	6 (14)	-	-
'High-functioning' autism	32 (14)	-	3 (7)	-	-
PDD-NOS	1 (0)	-	1 (2)	-	-
Other	6 (3)	-	2 (5)	-	-
No formal diagnosis	-	32 (100)	1 (2)	-	-
Age at Diagnosis Mean (SD)	35.3 (15.1) n=217	-	10.01 (10.8) n=38	-	-
Years since Diagnosis Mean (SD)	6.9 (8.3) n=217	-	21.9 (9.8) n=38	-	-
Intellectual Disability (%)	10 (4)	1 (3)	33 (78)	1 (1)	1 (1)
Other Developmental Disability (%)	6 (3)	2 (6)	9 (21)	0	1 (1)
^c Other Psychiatric Diagnosis(%)					
Currently	148 (69) n=213	13 (42) n=31	22 (52)	38 (39) n=100	29 (21) n=140
At any time	191 (89) n=213	28 (90) n=31	31 (74)	68 (68) n=100	67 (48) n=140
Depression (PHQ-9) above cut-off (%)	103 (52) n=199	15 (52) n=29	-	28 (29) n=97	15 (12) n=126
Anxiety (DSM5 GAD-A) above cut-off (%)	115 (56) n=206	14 (47) n=32	-	27 (27) n=99	14 (11) n=130

^a Carers were asked to complete the AQ scale only if they were a biological relative of the adult with autism

1
2
3 ^b Autism diagnosis: Autistic adults (self-report, diagnosed), $n=220$

4 ^c Recording of a psychiatric diagnosis apart from autism spectrum conditions or intellectual
5 disability
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

For peer review only

Table 6

Carer Characteristics (N=102)

Characteristic	Frequency / Mean
Relationship to autistic person (%)	
Mother	42 (43, <i>n</i> =98)
Father	10 (10, <i>n</i> =98)
Partner/spouse	23 (23, <i>n</i> =98)
Sibling	2 (2, <i>n</i> =98)
Child	1 (1, <i>n</i> =98)
Carer – unspecified	17 (17, <i>n</i> =98)
Other	3 (3, <i>n</i> =98)
Age of autistic adult cared for mean (<i>SD</i>)	37.5 (13.2)
Hours spent per week with autistic adult mean (<i>SD</i>)	63.4 (57.8, <i>n</i> =92)

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

For peer review only

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

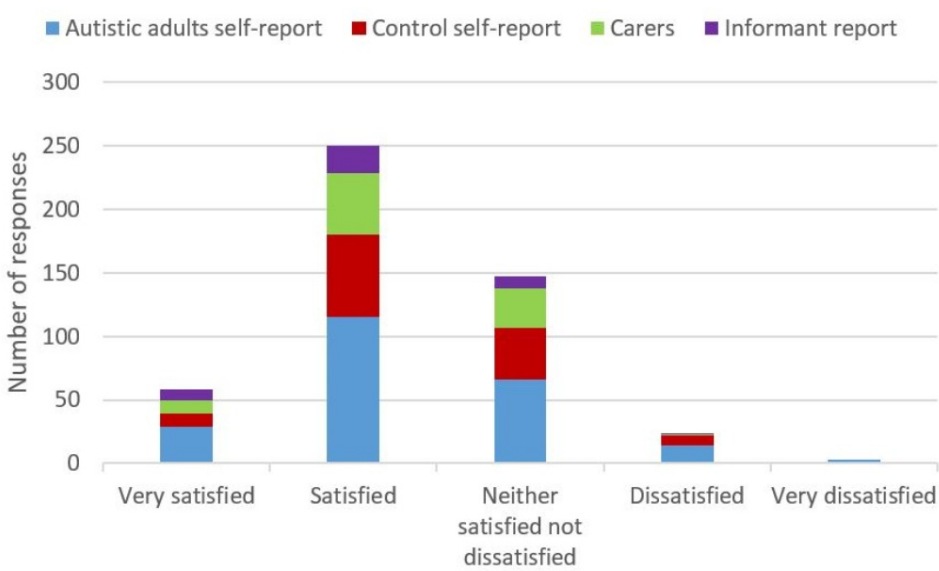


Figure 1. Satisfaction responses upon completion combined by survey type (n=482)

89x53mm (300 x 300 DPI)

BMJ Open

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

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2019-030798.R3
Article Type:	Cohort profile
Date Submitted by the Author:	30-Oct-2019
Complete List of Authors:	<p>Arnold, Samuel; UNSW, Department of Developmental Disability Neuropsychiatry (3DN); Autism CRC</p> <p>Foley, Kitty-Rose; Southern Cross University - Gold Coast Campus, School of Health and Human Sciences; Autism CRC</p> <p>Hwang, Ye In; UNSW, Department of Developmental Disability Neuropsychiatry (3DN); Autism CRC</p> <p>Richdale, Amanda; La Trobe University, Olga Tennison Autism Research Centre, School of Psychology and Public Health; Autism CRC</p> <p>Uljarevic, Mirko ; Stanford University, Stanford Autism Center, Division of Child and Adolescent Psychiatry, Department of Psychiatry and Behavioral Sciences, School of Medicine; La Trobe University, Olga Tennison Autism Research Centre, School of Psychology and Public Health</p> <p>Lawson, Lauren; La Trobe University, Olga Tennison Autism Research Centre, School of Psychology and Public Health; Autism CRC</p> <p>Cai, Ru; La Trobe University, Olga Tennison Autism Research Centre, School of Psychology and Public Health; Autism CRC</p> <p>Falkmer, Torbjorn; Curtin University, School of Occupational Therapy, Social Work and Speech Pathology; Autism CRC</p> <p>Falkmer, Marita; Curtin University, School of Occupational Therapy, Social Work and Speech Pathology; Autism CRC</p> <p>Lennox, Nick; University of Queensland, Australia, Queensland Centre for Intellectual and Developmental Disability, Mater Research Institute - UQ; Autism CRC</p> <p>Urbanowicz, Anna; RMIT University, Health, Society & Medicine Research Program, Social and Global Studies Centre; Autism CRC</p> <p>Trollor, Julian; UNSW, Department of Developmental Disability Neuropsychiatry (3DN); Autism CRC</p>
Primary Subject Heading:	Mental health
Secondary Subject Heading:	Diagnostics
Keywords:	Autism, Longitudinal, Adult

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60



Title

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

Author Names and Affiliations

Samuel R. C. Arnold^{*a,b} <samuel.arnold@unsw.edu.au>

Kitty-Rose Foley^{*b,c} <Kitty-Rose.Foley@scu.edu.au>

Ye In (Jane) Hwang^{a,b} <jane.hwang@unsw.edu.au>

Amanda L. Richdale^{b,d} <A.Richdale@latrobe.edu.au>

Mirko Uljarevic^{e,d,b} <mirkoulj@stanford.edu>

Lauren P. Lawson^{b,d} <L.Lawson@latrobe.edu.au>

Ru Ying Cai^{b,d} <R.Cai@latrobe.edu.au>

Torbjorn Falkmer^{b,f} <T.Falkmer@curtin.edu.au>

Marita Falkmer^{b,f,g} <Marita.Falkmer@curtin.edu.au>

Nick Lennox^{b,h} <n.lennox@uq.edu.au>

Anna Urbanowicz^{b,h,i} <a.urbanowicz@rmit.edu.au>

Julian N. Trollor^{+a,b} <J.Trollor@unsw.edu.au>

Affiliations

- a- Department of Developmental Disability Neuropsychiatry (3DN), UNSW Sydney, New South Wales, Australia
- b- Cooperative Research Centre for Living with Autism (Autism CRC), Brisbane, Queensland, Australia
- c- School of Health and Human Sciences, Southern Cross University, Gold Coast, Bilinga, Queensland, Australia
- d- Olga Tennison Autism Research Centre, School of Psychology and Public Health, La Trobe University, Bundoora, Victoria, Australia
- e- Stanford Autism Center, Division of Child and Adolescent Psychiatry, Department of Psychiatry and Behavioral Sciences, School of Medicine, Stanford University.

- 1
2
3 f- School of Occupational Therapy, Social Work and Speech Pathology, Curtin
4 University, Perth, Western Australia, Australia
5
6 g- School of Education and Communication, CHILD Programme, Institution of
7 Disability Research, Jonkoping University, Jonkoping, Sweden
8
9
10 h- Queensland Centre for Intellectual and Developmental Disability, Mater Research
11 Institute - UQ, The University of Queensland, South Brisbane, Queensland, Australia
12
13 i- Health, Society & Medicine Research Program, Social and Global Studies Centre,
14 RMIT University, Melbourne, Victoria, Australia
15
16

17 *Joint first author

18
19 +Corresponding author
20
21
22
23
24
25

26 Correspondence concerning this article should be addressed to Prof. Julian Trollor,
27 Department of Developmental Disability Neuropsychiatry (3DN), 34 Botany St, UNSW
28 Sydney, 2052, New South Wales, Australia. Telephone: +61-2-9931-9160. Email:
29 j.trollor@unsw.edu.au
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

Abstract (300 Words)

Purpose

There is a significant knowledge gap regarding the lives of adults on the autism spectrum. Some literature suggests significant health and mental health inequalities for autistic adults, yet there is a lack of comprehensive longitudinal studies exploring risk factors. Further, most research does not include the perspective of autistic adults in its conduct or design. Here we describe the baseline characteristics and inclusive research approach of a nationwide longitudinal study.

Participants

The Autism CRC's ALSAA is a questionnaire-based longitudinal study of autistic adults (25+ years old) with follow-up at 2-year intervals. Autistic advisors were involved in each stage of research apart from data analysis. Three questionnaires were developed: self-report, informant report (i.e. proxy report), and carers (i.e. carer experiences and characteristics).

Findings to date

An inclusive research protocol was developed and agreed with autistic advisors. Baseline data were collected from 295 autistic adults ($M=41.8$ years, $SD=12.0$) including 42 informant responses, 146 comparison participants, and 102 carers. The majority of autistic participants (90%) had been diagnosed in adulthood ($M=35.3$ years, $SD=15.1$). When compared to controls, autistic adults scored higher on self-report measures of current depression and anxiety. Participant comments informed on-going data gathering. Participants commented on questionnaire length, difficulty with literal interpretation of forced response items, and expressed gratitude for research in this area.

Future plans

1
2
3 A large comprehensive dataset relating to autistic adults and their carers has been gathered,
4
5 creating a good platform for longitudinal follow-up repeat surveys and collaborative research.
6
7 Several outputs are in development, with focus on health service barriers and usage,
8
9 caregivers, impact of diagnosis in adulthood, further scale validations, longitudinal analyses
10
11 of loneliness, suicidal ideation, mental illness risk factors and other areas. Baseline data
12
13 confirms poorer mental health of autistic adults. The ALSAA demonstrates a working
14
15 approach to inclusive research.
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

Strengths and limitations of this study

- Autism related research efforts and funding has typically focused on the period from infancy to mid childhood, this research focuses on autistic adults and their carers.
- The ALSAA uses an inclusive research approach to gather a comprehensive range of measures addressing identified research priorities.
- A large proportion of the ALSAA sample at Time 1 were female, including 50% ($n=149$) of autistic and 80% ($n=117$) of non-autistic participants.
- Participants self-report their autism diagnosis, and a subsample ($n=32$) are not yet formally diagnosed.
- The ALSAA is a unique resource for exploring multiple research questions regarding the lives of Australian autistic adults.

Introduction

Although autism is a lifelong condition, most autism related research efforts and funding has focused on the period from infancy to mid childhood¹. The best available evidence suggests an adult population prevalence of at least 1.1%². It is likely that autism is under-recognized or under-diagnosed in adults^{3,4}, particularly in women without intellectual disability^{2,5}.

Although an emerging body of research explores outcomes and support needs of autistic individuals beyond childhood and adolescence, studies including autistic adults remain frequently focused on younger adults⁶⁻⁸. This is reflected in recent commentary from an autistic researcher; “We know virtually nothing about what happens to us, autistic people, physically, cognitively, emotionally and socially as we pass through middle and older age”⁹(p515).

The growing body of evidence suggests higher rates of physical and mental health conditions, increased mortality and higher rates of intellectual disability than in the general population¹⁰. Autistic adults have higher prevalence of chronic medical conditions, including conditions such as stroke, vision and hearing impairments, and Parkinson’s disease¹¹⁻¹⁴. These outcomes are experienced by many autistic adults regardless of intellectual functioning⁷. It has been reported that between 25%-84% of autistic adults have a diagnosed mental health condition, with depression and anxiety the most commonly reported conditions¹⁵⁻¹⁹. Autistic adults have higher rates of suicide^{16,20}, increased mortality and reduced life expectancy²¹. Despite widespread acknowledgement of the comorbidity between autism and intellectual disability, prevalence estimates of intellectual disability in autism and vice versa have been inconsistent²². Earlier studies report that between 40 to 70% of those with autism also have an intellectual disability²³⁻²⁵ though a more recent study reports fewer adults on the autism spectrum as having intellectual disability² and intelligence tests may underestimate performance of autistic individuals²⁶.

1
2
3 Studies investigating outcomes related to daily activities and participation are also scarce²⁷.
4
5 Available studies report low employment rates²⁸, low community inclusion and limited social
6
7 relationships for autistic adults²⁹⁻³³. A few studies have suggested that factors such as low
8
9 childhood IQ, autism severity, psychopathology, social and language development, and
10
11 access to services and intervention programs may be determinates of such outcomes ^{29, 34};
12
13 however, much remains to be understood about the sources of variability in these outcomes.
14
15
16 In general, much of the research remains limited by cross-sectional designs, mixed groups
17
18 with and without intellectual disability, and a focus on adults aged under 40 ^{7, 34-36}.
19
20
21 Longitudinal studies are crucial for exploring changing requirements over time and to inform
22
23 services how best to respond to the needs of autistic adults^{9, 37}. Whilst most studies have
24
25 focused on one aspect of life or outcomes, such as physical or mental health comorbidities^{12,}
26
27 ^{15, 38} or quality of life^{30, 39}, very few comprehensive evaluations of health, wellbeing and
28
29 participation have been conducted³⁴. Further, research funding does not match priorities
30
31 identified by autistic adults, which include research on public services, improving life skills
32
33 and the future for autistic adults⁴⁰.
34
35
36
37
38

39 The majority of existing autism research is also limited by a lack of inclusive research
40
41 practices. There is a small but growing body of research on inclusive practices and co-
42
43 production in disability research with increasing examples in the autism field⁴¹⁻⁴³. In
44
45 principle, inclusive research must “address issues that really matter” to people with disability,
46
47 “must access and represent their views and experiences” and people “need to be treated with
48
49 respect by the research community”^{44(p16)}. Inclusive research encompasses a variety of
50
51 approaches, from including the individuals with the disability as advisors or consultants, to
52
53 working alongside academic researchers, or initiating or conducting the project as researchers
54
55 themselves⁴⁵. Due to a history of mistrust between researchers and autism self-advocacy
56
57 groups, inclusive methods are especially important in research involving adults on the
58
59
60

1
2
3 spectrum⁴⁶. Inclusive approaches ensure scientific findings are meaningful to the autism
4
5 community and sensitive to the lived experiences of individuals on the spectrum^{47, 48}.
6
7

8
9 The Cooperative Research Centre for Living with Autism (Autism CRC) Australian
10
11 Longitudinal Study of Adults with Autism (ALSAA) is Australia's first national longitudinal
12
13 study involving autistic adults aged 25 years and older. The ALSAA will contribute needed
14
15 longitudinal data across a range of health, functioning and participation domains. Data
16
17 gathered aligns with the research gaps identified above, and the priorities identified by
18
19 autistic adults⁴⁹. In comparison to current international longitudinal studies of autistic
20
21 adults⁵⁰⁻⁵² the ALSAA gathers a wider range of data points using standardised measures and
22
23 importantly included autistic adults in study design from the early stages of the project.
24
25 Further, the ALSAA gathers data from a community comparison group which is often lacking
26
27 in prior work. The ALSAA will contribute to the validation of several standardised measures
28
29 for this population. Importantly, the ALSAA gathers data specific to the unique context and
30
31 service systems within Australia, pertinent given the recent introduction of the National
32
33 Disability Insurance Scheme (NDIS) and the considerable differences in approaches to
34
35 healthcare and disability across countries. The ALSAA primarily aims to identify and
36
37 comprehensively describe the profiles of Australian autistic adults and to compare them to a
38
39 control group. Longitudinal data will further allow the determination of predictors versus
40
41 correlates across a range of outcomes. The aims of this paper are to describe the
42
43 methodological processes and the inclusive protocol adopted in the ALSAA, as well as to
44
45 present participant characteristics and feedback from the baseline data collection. Exploratory
46
47 baseline comparisons aim to identify covariates or confounders for consideration in future
48
49 studies.
50
51
52
53
54
55
56
57

58 **Cohort Description**

59
60

Design

The ALSAA is a questionnaire-based, prospective, longitudinal cohort study with a planned 2-year follow-up and further follow-ups as resources allow. Initial design and development of the ALSAA occurred in collaboration with researchers and clinical health professionals across Australia, including close collaboration with the Autism CRC longitudinal Study of Australian School Leavers with Autism (SASLA)⁵³. Brief consultation also occurred with international experts and researchers conducting similar longitudinal studies. Additionally, preliminary work on factors influencing the research participation of autistic adults⁵⁴ influenced the ALSAA design, including ensuring opportunities for participants to clarify questions, receive regular study newsletters, and space for participants to provide explanations regarding their responses.

Patient and Public Involvement

How was the development of the research question and outcome measures informed by patients' priorities, experience, and preferences?

The ALSAA was developed in conjunction with SASLA, the SASLA team conducted a stakeholders' research forum in late 2014 and obtained written feedback from participants (autistic people, families and service providers) that helped inform both studies. The SASLA team also consulted with individuals on the spectrum, parents and autism support groups. The ALSAA was developed with input from a research advisory network, initially consisting of 6 autistic adults and 2 family members/carers of autistic adults who helped determine areas of investigation, and develop the surveys to ensure the questions were relevant, accessible and valid.

1
2
3 *How did you involve patients in the design of this study?*
4
5

6 The ALSAA Inclusive Research Protocol was developed from interactions between the
7 researchers and advisors, and based on the principles of inclusive research⁵⁵, the Autism CRC
8 report *Inclusive Research Practice Guides and Checklists for Autism Research*⁵⁶ (e.g.
9 Checklist 3: Practices that Support Inclusion of Individuals on the Autism Spectrum in
10 Advisory and Reference Groups), and procedures similar to those employed by Nicolaidis
11 and colleagues⁵⁷ (e.g. choosing topic areas, adapting data collection instruments, interpreting
12 results) (see Table 1). In contrast to Nicolaidis and colleagues⁵⁷, ALSAA employs an
13 advisory approach as opposed to participatory approaches where final decision-making rests
14 with the committee, and there has not been any group or in-person consultation sessions,
15 which is a preference of some autistic advisors. Guidelines such as those developed by
16 AASPIRE⁵⁸ were not available at the time of the study design.
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31

32 *Were patients involved in the recruitment to and conduct of the study?*
33
34

35 Since the commencement of the ALSAA, this inclusive research protocol has been reviewed
36 by seven of the autistic advisors and one carer advisor and has guided the interactions
37 between researchers and advisors in the development of baseline outputs and the 2-year
38 follow-up design. Specifically, in the design stage of the ALSAA, members of the advisory
39 network were asked to identify ambiguous or inappropriate language, formatting issues and
40 measures which they thought may be interpreted inappropriately or differently due to poor
41 clarity or wording. An expanded group of eleven advisors had greater input in designing the
42 2-year follow-up, including the selection of focus topic areas. A list of topic areas was
43 suggested to the advisors based on a review of time 1 participant feedback. Advisors
44 reviewed the list and added more topics or specific research questions of interest. A few
45 advisors expressed difficulty or did not complete a task of ranking the topics, hence the
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

1
2
3 researchers were required to make the final shortlisting of new topics areas to be included in
4 data gathering. In comparison to several other studies⁵⁹ autistic adults are involved in the
5 majority of stages of the study apart from collecting data, they have been involved in review
6 of some media related lay summaries but have not typically been involved in development of
7 newsletter content. As per the protocol advisors are given forewarning, then one month to
8 respond to most requests from the research team, with more response time as needed.
9

10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

Advisors have provided feedback on ongoing research outputs critiquing interpretations of findings suggested by the researchers. In Time 2 data gathering and analyses, compensation has been made available for advisors' time, upon request to the Autism CRC, which has become increasingly supportive of co-production approaches. Advisors are now offered an hourly rate for each time they are consulted, with most consultations limited to two hours, though several advisors still prefer to volunteer and do not request compensation on most occasions. Advisors to date have not been involved in data analysis, though several co-produced peer-research projects are currently underway. Advisors have also assisted in promoting recruitment materials particularly through social media.

How will the results be disseminated to study participants?

The ALSAA sends quarterly digital newsletters to all participants. Newsletters include lay summaries of any publications, conference presentations or other outputs developed using the ALSAA data. They also typically contain general interest highlight(s) relating to the autism or autistic community, recruitment calls for other autism research, as well as a team member profile of an ALSAA researcher or autistic advisor. Advisors frequently assist in furthering the promotion of the study and outputs via social media. Our recent study on loneliness⁶⁰, included in the latest study newsletter, was a topic originally identified by advisors in time 1 data gathering, and demonstrates the inclusive approach used in the ALSAA. Advisors have

1
2
3 been approached to assist with autism related media enquiries and will continue to do so
4
5 when opportunities arise.
6
7
8
9

10
11 **[Insert Table 1 here]**
12
13

14 *Participants*

15
16
17
18 There are three participant groups in the ALSAA: autistic adults, non-autistic general
19
20 community comparison controls, and carers of autistic adults. Inclusion criteria required the
21
22 control and autistic participants to be aged 25 years or older, live in Australia and have
23
24 sufficient English literacy skills to complete the survey, determined during a screening phone
25
26 call or online expression of interest (EOI). If an autistic individual was unable or preferred
27
28 not to self-report, they were given the option to ask an informant to complete an informant
29
30 version of the survey on their behalf. People with intellectual disability could complete the
31
32 self-report survey with support or participate via an informant respondent.
33
34
35

36
37 Informant respondents and carers needed to be 18 years or older, have sufficient English
38
39 literacy skills, live in Australia and be able to report on the life of the autistic person. The
40
41 content of the informant survey is slightly different to the self-report survey (see Table 2) due
42
43 to some measures, such as the Patient Health Questionnaire-9 (PHQ-9)⁶¹, having no
44
45 informant version available. Carers, including family members and support people for the
46
47 ALSAA, were defined as people who provided unpaid care and support to either a family
48
49 member (including spouse) or friend who is on the autism spectrum. This is based on the
50
51 widely accepted definition proposed by Carers Australia
52
53 (<http://www.carersaustralia.com.au/about-carers/>).
54
55
56
57

58 *Survey*

59
60

1
2
3 Three versions of the survey were developed: 1) self-report, for autistic adults and non-
4
5 autistic controls, 2) informant, for carers/support people to complete about the autistic person
6
7 who is unable to, or does not want to self-complete, and 3) carer survey for carers/support
8
9 people/family members to complete about their own health and wellbeing. Surveys could be
10
11 completed via a paper copy or online. The paper copy was also available in large print. The
12
13 surveys involved a comprehensive range of measures (see Table 2). In selecting measures,
14
15 preference was given to measures that had been previously used or had established validity
16
17 with people on the spectrum and to those deemed suitable by the autistic advisors. Most
18
19 measures have not been specifically validated for autistic adults, with notable recent
20
21 exceptions of the WHOQOL BREF⁵¹, SF-12⁶² and the RBQ-2A⁶³, while the PHQ-9⁶⁴ was
22
23 more recently validated using a combined ALSAA and SASLA data set.
24
25
26
27
28

29 **[Insert Table 2 here]**
30

31
32 Each survey also contained closing feedback items, asking if any questions were confusing,
33
34 difficult, or upsetting, and any additional topics that should be included. It also asked how
35
36 long the survey took to complete (open-ended response), and an overall satisfaction with the
37
38 survey rated on a 5-point Likert scale. A final item asked for any further feedback.
39
40
41

42 *Procedure*

43 *Piloting*

44
45
46 Four autistic adults piloted the self-report questionnaire and two caregivers piloted the carer
47
48 and the informant questionnaires. Volunteers received two copies, one copy to complete, with
49
50 data recorded where possible in the ALSAA dataset, and the other for their feedback.
51
52
53

54
55 Considerable changes to each version of the survey were undertaken in response to feedback
56
57 from the autistic advisors and volunteers, including removing the Communication Checklist –
58
59
60

1
2
3 Adult⁶⁵, formatting changes and changes to item wordings where the item did not belong to
4
5 an existing standardised tool.
6
7

8 *Recruitment and Follow-up*

9
10
11 A recruitment target of 160 autistic adults was set to allow for regression analyses using
12
13 multiple predictor variables. Power analyses, undertaken using power calculation software,
14
15 suggested this would be a sufficient sample size with power (1 - β) set at .80 and $\alpha = .05$ to
16
17 detect a Cohen's f^2 effect size estimate of at least .1 using multiple regression models with 7
18
19 predictors. Participants were recruited via advertisements through autism-specific
20
21 organisations, disability organisations, autism self-advocacy groups, employment services,
22
23 universities, Technical and Further Education (TAFE) institutes, psychology and allied health
24
25 private practices, carer organisations, and online autism communities. In attempts to gather a
26
27 sample more closely matched to Australian population estimates⁶⁶, additional recruitment
28
29 activities targeted adults on the spectrum with intellectual disability, and males without
30
31 autism. General community members, autistic adults and carers of autistic adults who were
32
33 willing to participate in the ALSAA contacted the research team based at The University of
34
35 New South Wales (UNSW Sydney) via telephone, email or through completing a short online
36
37 EOI. After eligibility screening, their details were added to the participant database and they
38
39 were mailed a paper copy or emailed a link to their survey depending on their preference.
40
41
42
43
44
45
46

47 Due to a high number of responses and advice from autistic advisors, participants who self-
48
49 identified as being autistic, but did not have a formal diagnosis, representing the hidden
50
51 population and 'lost generation'³ of autistic adults, were also recruited. Formally diagnosed
52
53 participants were asked to provide details of their diagnosis, year of diagnosis, and the
54
55 discipline and name of the practitioner(s) who diagnosed them. AQ-short cut-off scores (>65,
56
57 sensitivity .97, specificity .82)⁶⁷ also support diagnostic status. Given critiques of
58
59
60

1
2
3 applicability and validity of the AQ-short^{68, 69}, we plan to include the Ritvo Autism and
4
5 Asperger Diagnostic Scale-14 (RAADS-14)⁶⁹ in future data gathering. At the planned two-
6
7 year average Time 2 follow-up copies of participants' diagnostic reports will be requested,
8
9
10 with a project undertaken to review and categorise the reports. From November 2017 through
11
12 2019 participants are being recontacted using contact details provided and considering their
13
14 communication preferences that were recorded.
15

16 17 18 *Ethical Considerations*

19
20
21 Participants were supplied with the appropriate Participant Information Statement and
22
23 Consent Form (PISCF). For the online survey, participants were asked to confirm their
24
25 consent at commencement, marking checkboxes prior to proceeding. Consent was inferred
26
27 from participants who completed and returned paper copies of the survey, as outlined in their
28
29 PISCF. In the case where the autistic adult had an intellectual disability a checklist for
30
31 capacity to provide consent was used. This checklist was completed by the carer/next of kin;
32
33 it was adapted from a checklist developed for use in the Study of Ageing in Intellectual
34
35 Disability (SAGE)⁷⁰. The checklist asks several question relating to the person's ability to
36
37 understand the study, benefits and risks, withdrawal and complaints, to determine if a person
38
39 responsible consent should be obtained additionally or separately. The study was approved by
40
41 the Human Research Ethics Committee at UNSW Sydney, Australia (No. HC15001).
42
43
44
45

46 47 *Data storage*

48
49
50 Online questionnaire data were entered directly by participants into Qualtrics Online Survey
51
52 Software (<https://www.qualtrics.com/>), whereas returned paper copy surveys were entered
53
54 into Qualtrics by a researcher or research assistant. Data from Qualtrics, re-identifiable by
55
56 participation code, were stored on password-protected UNSW Sydney servers. Recently,
57
58
59
60

1
2
3 ethics approval for establishment of a databank for the ALSAA data, to allow collaboration
4
5 with external researchers, has been obtained.
6
7

8 *Statistical analysis*

9
10
11 STATA Statistical Analysis Software 14⁷¹ and IBM SPSS Statistics 22⁷² were used for
12
13 cleaning, coding, and statistical analyses. For the current manuscript, STATA was used to
14
15 obtain descriptive statistics regarding recruitment, participant feedback, and participant
16
17 characteristics, with the level of significance <.05.. No correction was applied for multiple
18
19 statistical tests in this manuscript, as the purpose was to explore baseline differences in the
20
21 cohorts, and determine potential variables that may be useful covariates or possible
22
23 confounders in later hypothesis testing⁷³. For describing this cohort profile, listwise deletion
24
25 was used for specific analyses when data were missing completely at random, after checking
26
27 for difference in demographics and AQ score for dropped participants where appropriate.
28
29 Subsample sizes are noted throughout. Data were checked for kurtosis and skew. Non-
30
31 parametric Spearman rank correlation was used to determine the correlation between time
32
33 taken to complete the self-report survey and level of satisfaction.
34
35
36
37
38
39

40 *Recruitment statistics*

41
42
43 Recruitment commenced in July 2015. At the close of Time 1 data gathering in November
44
45 2017, 345 autistic adults, 221 non-autistic adults, 185 carers, and 78 informants had
46
47 registered their interest in the study. Of these, 237 autistic adults, 130 non-autistic adults, 100
48
49 carers, and 42 informant reporters completed the entire survey. Overall, a total of 295 autistic
50
51 adults participated including all survey formats and partial survey completions. A small
52
53 proportion of participants were deemed ineligible during screening (see Table 3), generally
54
55 due to being under 25 years, not caring for an adult aged 25+ years old, or being located
56
57 outside of Australia. Participants were recorded as partial completions if at close of Time 1
58
59
60

1
2
3 their surveys contained the initial demographic items completed and some additional useable
4 data. From available data there was no significant difference in binary gender, $\chi^2(4, n=337) =$
5
6 1.07, $p=.898$, or approximate age [$F(4, 4) = 2.04, p=.09$] based on survey commencement,
7
8 eligibility or completion status for the self-reporting autistic adults (see Table 1). These non-
9
10 significant results were also found for the non-autistic adults across gender, $\chi^2(4, n=215)$
11
12 =6.98, $p=.137$, and age [$F(4, 4) = 0.96, p=.43$].
13
14
15
16
17
18
19
20

21 **[Insert Table 3 here]**

22
23
24 *Time taken to complete, and satisfaction with, the survey*

25
26
27 Participants reported varying times taken to complete the entire survey. Self-reporting autistic
28 participants reported between 20 minutes and 12 hours to complete with an average time of
29
30 156 minutes ($n=164, SD=111$), though several responses ($n=53$) were not easily convertible
31
32 to numeric values for analysis, for example “few days”, “no idea”, or no response to the item
33
34 ($n=36$). Non-autistic, self-reporting participants reported a range of 20 minutes to 5 hours
35
36 with an average time of 106 minutes ($n=98, SD=74$). This was significantly less than self-
37
38 reporting autistic adults despite their completing almost all the same measures and domains,
39
40 $t(260)=-3.94, p<.001, d = -.50$. Carers took 75 minutes on average ($n=81, SD=62$) and
41
42 informant responders took 103 minutes on average ($n=27, SD=54$) to complete surveys. Most
43
44 participants (64%, $n=482$) reported that they were satisfied or very satisfied with the survey;
45
46 few participants were dissatisfied (6%) (Figure 1). There was no association between time
47
48 taken to complete the self-report survey and level of satisfaction ($n=262, r_s = .10, p=.09$), and
49
50 no difference in satisfaction based on survey type, $\chi^2(9, n=482) = 11.2, p=.26$.
51
52
53
54
55
56
57

58 **[Insert Figure 1 here]**

1
2
3 Across self-reporting autistic adults, the most common negative feedback related to difficulty
4 with literal interpretations of forced response items ($n=38$) where participants felt the options
5 provided did not match their circumstances, or to the length of the survey ($n=17$). Several
6 participants provided feedback that they were grateful for research in this area ($n=27$). Many
7 additional topics of interest were suggested, with the most common being relationships,
8 bullying, gender and sexuality, a more detailed employment section. The potential removal of
9 some questionnaires (e.g., the Brief COPE) was also commented on. Revision of items
10 referring to social supports was suggested, as some participants found these upsetting ($n=12$)
11 and / or confusing ($n=7$), with comments such as “I had to really think about my social circle
12 and realised the limited number of truly reliable and trustworthy friends I actually have,
13 which was kind of depressing”.

34 *Summary of participant characteristics*

35 The age of autistic participants ranged from 25 to 80 years, with a high proportion of females
36 (50%, $n=295$) across all autistic samples. Across all autistic participants 36% were living as a
37 couple with 25% of the sample currently married. Over half (57%, $n=42$) of the informant
38 report sample lived with their parents (see Table 4), in contrast to self-reporting autistic
39 adults who most frequently lived as a couple (45%, $n=295$) or alone (26%, $n=295$). Self-
40 reporting autistic adults did not differ from control participants on rural / remoteness
41 according to Australian Statistical Geography Standard-Remoteness Area (ASGS-RA)
42 classification, $\chi^2(4, n=378) = 9.36, p=.05, V = .16$ ($n=21$ missing), with no control
43 participants and minimal autistic participants living in remote or very remote Australia.
44 Propensity to greater socioeconomic disadvantage according to the postcode-based
45 Socioeconomic Index for Areas (SEIFA) decile was significant, $t(376)=2.96, p<.01, d = .32$
46 ($n=21$ missing, NB. SEIFA / rurality not available for all postcodes), though they were still
47
48
49
50
51
52
53
54
55
56
57
58
59
60

1
2
3 above average compared to the Australian population. Time 2 data gathering will seek to
4
5 gather household income data to more accurately determine socioeconomic disadvantage.
6
7

8
9 Of the formally diagnosed autistic adults ($n=221$), 132 (56%) reported they have a diagnostic
10
11 report available, with 169 (76%) diagnosed by one clinician and 29 (13%) reporting diagnosis
12
13 by two or more clinicians ($n=23$ missing). As shown in Table 5, the majority (97%, $n=295$)
14
15 of all autistic participants met the AQ-Short cut-off for identifying autism, compared to 30%
16
17 ($n=60$) of biologically related carers and 22% ($n=137$) of non-autistic control participants.

18
19 Asperger's syndrome was the most frequently reported formal diagnosis. Self-reporting,
20
21 formally diagnosed autistic participants on average were diagnosed 6.9 years prior to survey
22
23 completion, and the majority (90%; $n=217$, 4 missing) received their diagnosis in adulthood.
24
25 A preliminary analysis of gender differences for self-reporting autistic adults was also
26
27 conducted. In comparison to males, self-reporting formally diagnosed females did not differ
28
29 significantly on age of diagnosis $t(192)=.39$, $p=.70$, $d=.06$ ($n=4$ missing). Comparing males
30
31 with females, including non-diagnosed autistic adults, there was no difference in number of
32
33 individuals currently married or in a defacto relationship, $X^2(1, n=241) = .78$, $p=.38$, $V = -.06$,
34
35 or in their educational status, $X^2(2, n=241) = 4.66$, $p=.10$, $V = .14$. Females were significantly
36
37 different regarding employment status $X^2(4, n=219) = 18.77$, $p=.001$, $V = .29$, though only
38
39 relating to the number providing homecare ($n=19$ female vs. $n=1$ male, see Table 4).
40
41
42
43
44
45

46
47 In the non-autistic control sample, participant ages ranged from 25 to 79 years, with a high
48
49 proportion (80%, $n=146$) of females. The majority lived as a couple (72%) and were married
50
51 (62%). The control sample was significantly different from the self-reporting autistic adults
52
53 (with and without a formal diagnosis) on several demographics including gender, $X^2(2,$
54
55 $n=399) = 26.5$, $p<.001$, $V = .26$, living situation, $X^2(5, n=399) = 33.2$, $p<.001$, $V = .29$,
56
57 marital status, $X^2(8, n=398) = 47.1$, $p<.001$, $V = .34$, ($n=1$ missing), employment status, $X^2(6,$
58
59 $n=367) = 18.3$, $p=.005$, $V = .22$ ($n=32$ missing), and higher education status, $X^2(2, n=399) =$
60

1
2
3 22.4, $p < .001$, $V = .24$. Of interest, differences in education and employment were not
4
5 significant if analyses were limited to male participants. The control sample was also
6
7 significantly less likely to meet the DSM-IV-TR linked PHQ-9 cut-off for depression, $X^2(1,$
8
9 $n=354) = 54.9$, $p < .001$, $V = .39$, ($n=45$ missing), less likely meet the DSM5 GAD-A cut-off⁷⁴
10
11 for anxiety, $X^2(1, n=366) = 67.8$, $p < .001$, $V = .43$ ($n=33$ missing), and less likely to have a
12
13 history of psychiatric illness, $X^2(1, n=384) = 82.1$, $p < .001$, $V = .46$ ($n=15$ missing), compared
14
15 to self-reporting autistic adults, and remained significant if limited to female or male
16
17 participants. There were no significant differences for self-reporting autistic adults missing
18
19 data on the PHQ-9 or DSM5 GAD-A based on age, gender or AQ score.
20
21
22

23
24
25 As shown in Table 6, the majority (43%; $n=98$, 4 missing) of carers were mothers of an
26
27 autistic adult, followed by partners or spouses (23%). Carers' ages ranged from 21 to 78
28
29 years. The majority were female (83%, $n=102$), married (66%), and living as a couple (75%).
30
31 Carers spent an average 63.4 ($SD=57.80$, $n=92$) hours per week with the adult with autism,
32
33 and the average age of the autistic adult cared for was 37.5 years (range 25-96 years,
34
35 $SD=13.21$). Most carer participants (76%, $n=102$) are linked to a self-report or informant-
36
37 report responses.
38
39
40

41 [insert Table 4 here]

42 [insert Table 5 here]

43 [insert Table 6 here]

44 45 46 47 48 49 50 51 Findings to date

52
53
54 Using an inclusive research approach, the ALSAA has collected a detailed profile of the
55
56 physical and mental health, productivity, wellbeing and health service use of autistic adults
57
58 aged 25+ years, and their carers, living in Australia. There were high numbers of recruitment
59
60

1
2
3 responses across the four Time 1 survey populations (autistic and control adult self-report,
4 informant report on autistic adults, carer self-report). The ALSAA Time 1 data has been used
5 in several studies of psychotropic medication use⁷⁵, leisure participation⁷⁶, ageing well⁷⁷,
6 loneliness⁶⁰ and employment⁷⁸. ALSAA and SASLA pooled data has been used to explore
7 cognitive reappraisal⁷⁹, suicidal ideation⁸⁰, psychometric scale validation⁶⁴, and anxiety and
8 depression⁸¹. Several other outputs are in development, with focus on health service barriers
9 and usage, caregivers, impact of diagnosis in adulthood, further scale validations,
10 longitudinal analyses of loneliness, suicidal ideation, mental illness risk factors, and other
11 outputs, meeting the broad aim of the study to describe and compare the profiles of
12 Australian autistic adults. Exploratory analyses have highlighted factors such as gender,
13 education and employment that are potential confounders or covariates that need to be
14 considered in future analyses.

Participant characteristics

15
16
17 A large number of females on the spectrum ($n=150$) have participated in the ALSAA. This
18 will provide an opportunity to explore the different expression of autism characteristics in
19 females without intellectual disability^{5, 82}. Similar to findings in other studies^{10, 32}, self-
20 reporting autistic adults had high rates of depression (52%), anxiety (55%), and a frequent
21 history of psychiatric diagnosis (89%), significantly more than the control sample. They were
22 less likely to have a university education compared with the control sample.

Questionnaire feedback and completion

23
24
25 The length of the surveys may have led to some participants not completing following
26 registration, or to missing data or only partial completions. Longer survey length has been
27 linked to lower participation and completion of web-based surveys^{83, 84}. Despite emphasising
28 the ability to complete over several sessions, some participants commented that the survey
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

1
2
3 was “too long”. In contrast, survey length was not identified as an issue during pilot testing,
4
5 time to complete was not related to survey satisfaction, and some participants appreciated the
6
7 comprehensive nature of the surveys. Suggestions made in questionnaire feedback will be
8
9 incorporated in the design of the 2-year follow up. Follow-up design aims to reduce
10
11 assessment burden by reducing overall survey length and where appropriate pre-filling
12
13 repeated measures such as medical history. Additional areas of interest to the community will
14
15 be explored including bullying, relationships and terms used to describe individuals with an
16
17 autism spectrum diagnosis.
18
19
20
21

22 **Strengths and limitations**

23
24
25 An important strength of the study was the inclusive research approach using autistic
26
27 advisors. Frequently missing from autism research and other longitudinal studies, an
28
29 inclusive research protocol was developed for the ALSAA in consultation with autistic
30
31 advisors (see Table 1) and applied across all stages of the research process apart from the
32
33 analysis. Inclusive research has been found to increase the likelihood that findings are
34
35 translatable to the real world and focused on areas of need from community perspectives⁴⁴.
36
37 Best-practise processes of conducting inclusive research with autistic adults are not well
38
39 known, though more resources are becoming available⁸⁵. Although at times advisors’
40
41 suggestions were in conflict with each other or beyond the scope of the study, as each advisor
42
43 communicated individually with the research team there was no direct conflict between
44
45 advisors. Feedback is given to advisors as to what advice has been used or not, and why.
46
47 Although this potentially creates a power imbalance between the advisors and researchers,
48
49 which is also inherent in an advisory process, to date there has been little feedback from
50
51 advisors that was not able to be incorporated into the study processes or outputs. Ideally
52
53 autistic adults and researchers would reach consensus in an open forum in person. Due to
54
55 limitations with resourcing, geographical dispersion and majority of autistic advisors
56
57
58
59
60

1
2
3 preferring to provide individual feedback in writing this was difficult to achieve. Moving
4
5 forwards, we are considering implementing the “Five-Finger Decision Method”⁸⁶ to ensure
6
7 advisors input has been addressed. Little literature was available at the time of commencing
8
9 the ALSAA and processes were developed iteratively based on understanding of partnering
10
11 with autistic adults and guidance from our advisors. Our processes are largely consistent with
12
13 recent guidelines now available⁵⁸, with deviation particularly relating to recruiting a balance
14
15 of autistic community leaders and other autistic adults as advisors, a structured process for
16
17 decision making, and a lack of joint meetings / collaboration between advisors / a visioning
18
19 exercise. We may benefit from again consulting with our advisors and seeing if there is
20
21 interest in additional areas of involvement or additional peer-researched co-authored outputs.
22
23 Growing relationships with advisors over time, and seeking feedback as to preferences for
24
25 collaboration, has led to harmonious collaborative relationships between the ALSAA
26
27 researchers and advisors, and will continue to evolve. An important consideration working
28
29 with the advisors is the allowance of lead time and processing time, which has created
30
31 difficulty for some student projects using ALSAA data. The ALSAA has further engaged
32
33 peer researchers in some future outputs, including a study on autistic burnout, and the co-
34
35 development of research grant applications for other projects. An additional strength of the
36
37 ALSAA design is its consideration and partial overlap with several other national and
38
39 international studies, for example overlap with the Autism CRC SASLA longitudinal study
40
41 allows for a lifespan approach to be taken including data from late adolescence⁷⁹.
42
43
44
45
46
47
48
49
50
51

52
53 The ALSAA baseline sample is reflective of the convenience sampling methodology used.
54
55 Participants would appear non-representative of the Australian autism population given
56
57 approximate postcode-based above average socioeconomic status, a large female gender bias
58
59 for both autistic adults and controls, and that most of the autistic sample (85%) does not have
60

1
2
3 an intellectual disability. Earlier epidemiological estimates of autism²³ would suggest a larger
4 proportion of people with a diagnosis of autism and intellectual disability and a much higher
5 male to female ratio, though recent work questions these assumptions^{2, 87}. Self-selection in
6 online surveys can lead to a female gender bias⁸⁴, as also has been noted in other online
7 autism research⁸⁸⁻⁹⁰. Commonly reported as a 4 to 1 male bias⁹¹, there is suggestion the true
8 autism gender ratio may be closer to 3 to 1⁸⁷ or lower⁸² as females with autism are at a higher
9 risk of being underdiagnosed³. Limiting recruitment to participants age 25 years or older,
10 changing diagnostic practices⁹², in combination with the convenience sampling, has likely led
11 to the large percentage of participants who had received their autism diagnosis in adulthood.
12
13
14
15
16
17
18
19
20
21
22

23
24 The majority of the current autistic sample does not have an intellectual disability. Significant
25 barriers exist for people with intellectual disability to participate in a questionnaire-based
26 study⁹³. An alternative to directly gathering information from adults on the spectrum with
27 intellectual disability is the participation via an informant respondent. Although an informant
28 respondent survey was made available for the ALSAA, and despite targeted recruitment
29 efforts, there was low participation of people with intellectual disability.
30
31
32
33
34
35
36
37
38

39 A final limitation is the self-report questionnaire format of the ALSAA, particularly in
40 relation to self-reported diagnosis of autism and comorbid conditions without clinical
41 reassessment. Validating autism diagnosis through clinical reassessment would be a highly
42 resource intensive exercise in a nationwide study in Australia and is beyond the resourcing
43 available to this study. This is offset by gathering of additional information relating to autism
44 diagnosis, including asking if the respondent has a diagnostic report, name and type of
45 clinician providing diagnosis, and AQ scores. These variables could be used to identify
46 subsamples with stronger evidence of definite diagnosis of autism for separate analysis where
47 necessary depending on the specific research question. Further, diagnostic reports from
48 participants will be requested from participants at follow-up to confirm diagnosis. Gathering
49
50
51
52
53
54
55
56
57
58
59
60

1
2
3 data from adults without a formal diagnosis is potentially a strength, given the ‘lost
4
5 generation’ of autistic adults³, significant barriers to diagnosis, and accuracy issues with gold
6
7 standard autism assessment tools⁹⁴; these participants could be overlooked in other studies
8
9 though they represent an important hidden population group. The self-report format also
10
11 prevents the quantification of participants’ cognitive ability. The use of standardised mental
12
13 health screening measures with clinical cut-offs gathers some information on co-occurring
14
15 mental health conditions, though not as reliably as would be available via clinical interview.
16
17 Conversely, community-based sampling and use of self-report questionnaires does allow for
18
19 gathering a reasonably large sample, offsetting the risk of including people with incorrect
20
21 diagnostic data with increased statistical power and the potential severity bias of clinical
22
23 samples. Limitations and strengths of the ALSAA study design will largely depend on the
24
25 specific research question being explored, with sufficient sample size and data points to
26
27 partial-out subgroups and non-matched controls or to account for common method variance
28
29 as needed. Future researchers using the ALSAA dataset will need to consider balancing type
30
31 1 and type 2 errors⁷³. A data governance structure has been established, with requests for
32
33 ALSAA data requiring researchers to outline a statistical plan and data points they will be
34
35 using, which will assist in managing any concerns of multiple statistical testing without
36
37 correction. Any data requests will need to ensure that the hypotheses being tested do not
38
39 duplicate use of data points in a way that would inflate the probability of Type 1 errors.
40
41
42
43
44
45
46
47

48 *Implications*

49
50
51 There is a significant knowledge gap regarding the lives of autistic adults. The ALSAA has
52
53 gathered a large comprehensive dataset relating to autistic adults and their carers, creating a
54
55 platform for longitudinal follow-up and collaborative research. The ALSAA is an important
56
57 resource for exploring multiple research questions regarding the lives of autistic adults.
58
59 However, as with all longitudinal research caution is required in drawing firm conclusions
60

1
2
3 from the ALSAA cohort in relation to the entire Australian autism population. Nevertheless,
4 this cohort provides the first opportunity to explore longitudinal outcomes of Australian
5 autistic adults. Having offline and informant versions of questionnaires, and questionnaires
6 reviewed by autistic advisors, facilitates greater accessibility for participants on the spectrum
7 and their carers.
8
9

10
11
12
13
14
15 The ALSAA study demonstrates a working approach to inclusive research with autistic
16 advisors. The inclusive research protocol developed in this study provides a useful basis for
17 other research endeavours. Following this protocol, future outputs such as peer-reviewed
18 manuscripts, presentations and reports from the ALSAA will also be developed in
19 consultation with autistic advisors or autistic peer researchers. Input from autistic advisors
20 has already improved the quality and relevance of initial outputs⁷⁵, for example identifying
21 potential alternative interpretations of findings based on lived experiences, potential
22 differences in autistic interpretations of scale items, and modifying the methodology in one
23 instance⁶⁰ changing a purely quantitative study into a mixed methods design.
24
25
26
27
28
29
30
31
32
33
34
35
36

37 Some measures used in the ALSAA have not yet been validated with autistic adult samples
38 (e.g., DSM5 GAD-A, Emotion Regulation Questionnaire, PHQ-15). The ALSAA provides
39 the opportunity to explore the validity of these commonly used measures.
40
41
42
43
44

45 **Collaboration**

46
47 International studies involving autistic adults and utilising standardised measures are
48 underway in the United States, Netherlands and United Kingdom (e.g., SPARK
49 <http://sparkforautism.org>, AASPIRE <https://aaspire.org/>, the Netherlands Autism Register
50 <https://www.nederlandsautismeregister.nl> and the Adult Autism Spectrum Cohort-UK
51 <http://research.ncl.ac.uk/adultautismspectrum/>), though with less comprehensive ranges of
52 measures. During development of the ALSAA, consultation with international groups
53
54
55
56
57
58
59
60

1
2
3 occurred to ensure there were some synergies with these studies. Future international
4
5 comparisons will be possible, including pooling of data. This will allow for the creation of
6
7 much larger datasets and more in-depth understanding of life in adulthood for autistic people.
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

For peer review only

Further details

Contributors

Manuscript drafting was jointly led by SA & KF. All authors (YH,AR,MU,LL,RC,TF,MF,NL,AU,JT) had a role in the conduct of the research, interpretation of results, drafting of manuscript and critical review of the manuscript. SA, KF, YH, AR, MU & JT conducted data analysis and reporting. KF, YH, AR, MU, RC, TF, MF, NL, AU & JT were involved in the conceptualisation of the study.

Data Sharing Statement

Processes to establish data banking and sharing procedures are currently being finalised. Please email the corresponding author regarding queries.

Ethics approval

The study was approved by the Human Research Ethics Committee at UNSW Sydney, Australia (No. HC15001).

Acknowledgements

The authors also acknowledge the valuable contribution of the Research Advisory Network members Matthew Bennett, Bob Boyce, Jen Harland, Julianne Higgins, Gabriel Nakhel, Joanne Mahony, Andrea Michael, Cheryl Strangio, and Chris Tanner whose insight and recommendations shaped this work. We also gratefully acknowledge the cooperation and participation of all participants on the autism spectrum and their carers involved in this study.

Funding

This work was supported by the Cooperative Research Centre for Living with Autism (Autism CRC), established and supported under the Australian Government's Cooperative Research Centres Program.

Conflict of Interest

The authors have no conflict of interest to report.

References

1. Seltzer MM, Shattuck PT, Abbeduto L, Greenberg JS. Trajectory of development in adolescents and adults with autism. *Mental Retardation and Developmental Disabilities*. 2004;10:234-47.
2. Brugha TS, Spiers N, Bankart J, Cooper S-A, McManus S, Scott FJ, et al. Epidemiology of autism in adults across age groups and ability levels. *The British Journal of Psychiatry*. 2016/12/01/;209(6):498-503. en.
3. Lai M-C, Baron-Cohen S. Identifying the lost generation of adults with autism spectrum conditions. *The Lancet Psychiatry*. 2015 2015/11/01/;2(11):1013-27.
4. Van Wijngaarden-Cremers PJM, van Eeten E, Groen WB, Van Deurzen PA, Oosterling IJ, Van der Gaag RJ. Gender and Age Differences in the Core Triad of Impairments in Autism Spectrum Disorders: A Systematic Review and Meta-analysis. *Journal of Autism and Developmental Disorders*. 2014 March 01;44(3):627-35.
5. Bargiela S, Steward R, Mandy W. The Experiences of Late-diagnosed Women with Autism Spectrum Conditions: An Investigation of the Female Autism Phenotype. *Journal of Autism and Developmental Disorders*. 2016 2016/10/01/;46(10):3281-94. en.
6. Jang J, Matson JL, Adams HL, Konst MJ, Cervantes PE, Goldin RL. What are the ages of persons studied in autism research: A 20-year review. *Research in Autism Spectrum Disorders*. 2014;8(12):1756-60.
7. Howlin P, Moss P. Adults with autism spectrum disorders. *Canadian Journal of Psychiatry*. 2012;57(5):275-83.
8. Nicolaidis C. Autism in Adulthood: The New Home for Our Emerging Field. *Autism in Adulthood*. 2018;1(1):1-2.
9. Michael C. Why we need research about autism and ageing. *Autism*. 2016;20(5):515-6.
10. Howlin P, Magiati I. Autism spectrum disorder: outcomes in adulthood. *Current Opinion in Psychiatry*. 2017 2017/03//;30(2):69-76. en.
11. Cashin A, Buckley T, Trollor J, Lennox N. A scoping review of what is known of the physical health of adults with autism spectrum disorder. *Journal of Intellectual Disabilities*. 2016.
12. Croen LA, Zerbo O, Qian Y, Massolo M, Rich S, Sidney S, et al. The health status of adults on the autism spectrum. *Autism*. 2015;19(7):814-23.
13. Jones KB, Cottle K, Bakian A, Farley M, Bilder D, Coon H, et al. A description of medical conditions in adults with autism spectrum disorder: a follow-up of the 1980s Utah/UCLA autism epidemiologic study. *Autism*. 2016;5:551-61.
14. Weiss JA, Riosa PB. Thriving in youth with autism spectrum disorder and intellectual disability. *Journal of Autism and Developmental Disorders*. 2015;45:2474-86.
15. Buck TR, Viskochil J, Farley M, Coon H, McMahon WM, Morgan J, et al. Psychiatric comorbidity and medication use in adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders*. 2014;44:3063-71.
16. Hedley D, Uljarević M, Wilmot M, Richdale A, Dissanayake C. Understanding depression and thoughts of self-harm in autism: A potential mechanism involving loneliness. *Research in Autism Spectrum Disorders*. 2018 2018/02/01/;46:1-7.
17. Lever AG, Geurts HM. Psychiatric co-occurring symptoms and disorders in young, middle-aged, and older adults with autism spectrum disorders. *Journal of Autism and Developmental Disorders*. 2016;46:1916-30.
18. Matson JL, Williams LW. Depression and mood disorders among persons with Autism spectrum disorders. *Research in Developmental Disabilities*. 2014;35:2003-7.
19. Moss P, Howlin P, Savage S, Bolton P, Rutter M. Self and informant reports of mental health difficulties among adults with autism findings from a long-term follow-up study. *Autism*. 2015.
20. Hedley D, Uljarević M, Wilmot M, Richdale A, Dissanayake C. Brief Report: Social Support, Depression and Suicidal Ideation in Adults with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*. 2017 November 01;47(11):3669-77.

21. Hirvikoski T, Mittendorfer-Rutz E, Boman M, Larsson H, Lichtenstein P, Bolte S. Premature mortality in autism spectrum disorder. *The British Journal of Psychiatry*. 2015.
22. Matson JL, Nebel-Schwalm N. Comorbid psychopathology with autism spectrum disorder in children: an overview. *Research in Developmental Disabilities*. 2007;28:341-52.
23. Fombonne E. Epidemiology surveys of autism and other pervasive developmental disorders: an update. *Journal of Autism and Developmental Disorders*. 2003;33(4):365-82.
24. LaMalfa G, Lassi G, Bertilli M, Salvani R, Placidi GF. Autism and intellectual disability: a study of prevalence on a sample of the Italian population. *Journal of Intellectual Disability Research*. 2004;48:262-7.
25. Matson JL, Shoemaker M. Intellectual disability and its relationship to autism spectrum disorders. *Research in Developmental Disabilities*. 2009;30:1107-14.
26. Dawson M, Soulières I, Gernsbacher MA, Mottron L. The level and nature of autistic intelligence. *Psychol Sci*. 2007;18(8):657-62. PubMed PMID: 17680932. eng.
27. Howlin P, Arciuli J, Begeer S, Brock J, Clarke K, Costley D, et al. Research on adults with autism spectrum disorder: roundtable report. *Journal of Intellectual and Developmental Disability*. 2015;40(4):388-93.
28. Hedley D, Uljarevic M, Cameron L, Halder S, Richdale AL, Dissanayake C. Employment programmes and interventions targeting adults with autism spectrum disorder: a systematic review of the literature. *Autism*. 2016:1-13.
29. Gray KM, Piccin AK, C. M., Taffe J, Parmenter TR, Hofer S, Einfeld S, et al. Outcomes in young adulthood: are we achieving community participation and inclusion? *Journal of Intellectual Disability Research*. 2014;58(8):734-45.
30. Henninger NA, Taylor JL. Outcomes in adults with autism spectrum disorders: a historical perspective. *Autism*. 2013;17(1):103-16.
31. Howlin P, Moss P, Savage S, Rutter. Social outcomes in mid- to later adulthood among individuals diagnosed with autism and average nonverbal IQ as children. *Journal of American Academy of Child & Adolescent Psychiatry*. 2013;52(6):572-81.
32. Magiati I, Tay XW, Howlin P. Cognitive, language, social and behavioural outcomes in adults with autism spectrum disorders: a systematic review of longitudinal follow-up studies in adulthood. *Clinical Psychology Review*. 2014;34:73-86.
33. Marriage S, Wolverton A, Marriage K. Autism spectrum disorder grown up: A chart review of adult functioning. *Journal of the Canadian Academy of Child and Adolescent Psychiatry*. 2009;18(4):322.
34. Levy A, Perry A. Outcomes in adolescents and adults with autism: a review of the literature. *Research in Autism Spectrum Disorders*. 2011;5:1271-82.
35. Seltzer MM, Krauss MW, Shattuck PT, Orsmond GI, Swe A, Lord C. The symptoms of autism spectrum disorders in adolescence and adulthood. *Journal of Autism and Developmental Disorders*. 2003;33:565-81.
36. Shattuck PT, Selter MM, Greenberg JS, Orsmond GI, Bolt D, Kring S, et al. Change in autism symptoms and maladaptive behaviors in adolescents and adults with an autism spectrum disorder. *Journal of Autism and Developmental Disorders*. 2007;37:1735-47.
37. Happe F, Charlton RA. Aging in autism spectrum disorders: a mini-review. *Gerontology*. 2010;58:70-8.
38. Totsika V, Felce D, Kerr M, Hastings RP. Behaviour problems, psychiatric symptoms, and quality of life for older adults with intellectual disability with and without autism. *Journal of Autism and Developmental Disorders*. 2010;40:1171-8.
39. Khanna R, K. J-P, West-Strum D, Mahabaleshwarkar R. Health-related quality of life and its determinants among adults with autism. *Research in Autism Spectrum Disorders*. 2014;8(3):157-67.
40. Pellicano E, Dinsmore A, Charman T. What should autism research focus upon? Community views and priorities from the United Kingdom. *Autism*. 2014:1-5.

- 1
- 2
- 3
- 4 41. Nicolaidis C. What Can Physicians Learn from the Neurodiversity Movement? . American
- 5 Medical Association Journal of Ethics. 2012;14(6):503-10.
- 6 42. Nicolaidis C, Raymaker D, Dern S, Boisclair C, Ashkenazy E, Baggs A. Comparison of
- 7 healthcare experiences in autistic and non-autistic adults: a cross-sectional online survey facilitated
- 8 by an academic-community partnership. *Journal of General Internal Medicine*. 2012;28(6):761-9.
- 9 43. Kapp SK, Steward R, Crane L, Elliott D, Elphick C, Pellicano E, et al. 'People should be allowed
- 10 to do what they like': Autistic adults' views and experiences of stimming. *Autism*.
- 11 2019;1362361319829628.
- 12 44. Walmsley J, Johnson K. Inclusive research with people with learning disabilities: Past,
- 13 present and futures. London and New York: Jessica Kingsley Publishers 2003.
- 14 45. Bigby C, Frawley P, Ramcharan P. Conceptualising inclusive research with people with
- 15 intellectual disability. *Journal of Applied Research in Intellectual Disabilities*. 2014;27(1):3-12.
- 16 46. Bagatell N. From cure to community: transforming notions of autism. *Journal of the Society*
- 17 *for Psychological Anthropology*. 2010;38(1):33-55.
- 18 47. Milton D, Bracher M. Autistics speak but are they heard? *Medical Sociology Online*.
- 19 2013;7:61-9.
- 20 48. Nind M, Vinha H. Doing research inclusively: bridges to multiple possibilities in inclusive
- 21 research. *British Journal of Learning Disabilities*. 2012;42:102-9.
- 22 49. Gatfield O, Mangan C, Haar T, Kinninurgh A, Rodger S. 2016 Research Priorities Survey
- 23 Report. Brisbane, Queensland, Australia: Cooperative Research Centre for Living with Autism, 2016.
- 24 50. Gotham K, Marvin AR, Talyor JL, Warren Z, Anderson CM, Law PA, et al. Characterizing the
- 25 daily life, needs, and priorities of adults with autism spectrum disorder from Interactive Autism
- 26 Network. *Autism*. 2015:1-11.
- 27 51. McConachie H, Mason D, Parr JR, Garland D, Wilson C, Rodgers J. Enhancing the Validity of a
- 28 Quality of Life Measure for Autistic People. *J Autism Dev Disord*. 2018 May;48(5):1596-611. PubMed
- 29 PMID: 29188584. Pubmed Central PMCID: PMC5889785. Epub 2017/12/01. eng.
- 30 52. Seltzer MM, Greenberg JS, Taylor JL, Smith LE, Orsmond GE, Esbensen A, et al. Adolescents
- 31 and adults with autism spectrum disorders. In: Amaral DG, Dawson G, Geschwind D, editors. *Autism*
- 32 *spectrum disorders* New York: Oxford University Press; 2011.
- 33 53. Lawson L, Hascheck A, Richdale AL. SASLA Snapshot: Study of Australian School-Leavers with
- 34 Autism – Baseline Profile. Melbourne, Australia: Olga Tennison Autism Research Centre (OTARC), La
- 35 Trobe University, 2018.
- 36 54. Haas K, Costley D, Falkmer M, Richdale A, Sofronoff K, Falkmer T. Factors Influencing the
- 37 Research Participation of Adults with Autism Spectrum Disorders. *J Autism Dev Disord*. 2016
- 38 May;46(5):1793-805. PubMed PMID: 26810436. Epub 2016/01/27. eng.
- 39 55. Walmsley J. Normalisation, emancipatory research and inclusive research in learning
- 40 disability. *Disability & Society*. 2001;16(2):188-205.
- 41 56. CRC A. Inclusive research practice guide and checklists for autism research: Version 2.
- 42 Brisbane, Queensland: Autism CRC Ltd., 2016.
- 43 57. Nicolaidis C, Raymaker D, Katz M, Oshwald M, Goe R, Leottie S, et al. Community-based
- 44 participatory research to adapt health measures for use by people with developmental disabilities.
- 45 *Progress in Community Health Partnerships: Research, Education, and Action*. 2015;9(2):141-3.
- 46 58. Nicolaidis C, Raymaker D, Kapp SK, Baggs A, Ashkenazy E, McDonald K, et al. The AASPIRE
- 47 practice-based guidelines for the inclusion of autistic adults in research as co-researchers and study
- 48 participants. *Autism*. 2019;23(8):2007-19. PubMed PMID: 30939892.
- 49 59. Jivraj J, Sacrey L-A, Newton A, Nicholas D, Zwaigenbaum L. Assessing the influence of
- 50 researcher-partner involvement on the process and outcomes of participatory research in autism
- 51 spectrum disorder and neurodevelopmental disorders: A scoping review. *Autism*. 2014;18(7):782-93.
- 52 PubMed PMID: 24989447.
- 53 60. Ee D, Hwang J, Reppermund S, Srasuebkuul P, Trollor J, Foley K-R, et al. Loneliness in Adults
- 54 on the Autism Spectrum. *Autism in Adulthood*. 2019;3(1):11.
- 55
- 56
- 57
- 58
- 59
- 60

- 1
- 2
- 3
- 4 61. Kroenke K, Spitzer RL, Williams JBW. The PHQ-9: validity of a brief depression severity
- 5 measure. *Journal of General Internal Medicine*. 2001;16:606-13.
- 6 62. Khanna R, K. J-P, West-Strum D. Validity and reliability of the Medical Outcomes Study Short-
- 7 Form Health Survey version 2 (SF-12v2) among adults with autism. *Research in Developmental*
- 8 *Disabilities*. 2015;43-44:51-60.
- 9 63. Barrett SL, Uljarević M, Baker EK, Richdale AL, Jones CRG, Leekam SR. The Adult Repetitive
- 10 Behaviours Questionnaire-2 (RBQ-2A): A Self-Report Measure of Restricted and Repetitive
- 11 Behaviours. *Journal of Autism and Developmental Disorders*. 2015 2015/11/01/;45(11):3680-92.
- 12 64. Arnold SRC, Uljarevic M, Hwang J, Richdale A, Trollor J, Lawson LP. Brief Report:
- 13 Psychometric Properties of the Patient Health Questionnaire-9 (PHQ-9) in Autistic Adults. *Journal of*
- 14 *Autism and Developmental Disorders*. 2019:1-9.
- 15 65. Whitehouse AJO, Bishop DVM. Communication checklist - adult. London: The Psychological
- 16 Corporation; 2009.
- 17 66. (AIHW) AloHaW. Autism in Australia. Web Report. Canberra, Australia: AIHW, 2017 5-4-17.
- 18 Report No.
- 19 67. Hoekstra RA, Vinkhuyzen AAE, Wheelwright S, Bartels M, Boomsma DI, Baron-Cohen S, et al.
- 20 The construction and validation of an abridged version of the Autism-Spectrum Quotient. *Journal of*
- 21 *Autism and Developmental Disorders*. 2011;41:589-96.
- 22 68. Lundqvist L-O, Lindner H. Is the Autism-Spectrum Quotient a Valid Measure of Traits
- 23 Associated with the Autism Spectrum? A Rasch Validation in Adults with and Without Autism
- 24 Spectrum Disorders. *Journal of Autism and Developmental Disorders*. 2017 July 01;47(7):2080-91.
- 25 69. Eriksson JM, Andersen LMJ, Bejerot S. RAADS-14 Screen: validity of a screening tool for
- 26 autism spectrum disorder in an adult psychiatric population. *Molecular Autism*. 2013
- 27 2013/12/09;4(1):49.
- 28 70. Evans E, Trollor J, Davis A, Bhardwaj A, O'Brien E. Mental health and carer support in elders
- 29 with ID. Report to Ageing, Disability and Home Care, Department of Family and Community Services,
- 30 NSW Australia. Sydney, Australia: Department of Developmental Disability Neuropsychiatry, UNSW
- 31 Sydney, 2015.
- 32 71. StataCorp. Stata Statistical Software: Release 14. College Station, TX: StataCorp LP; 2015.
- 33 72. IBM_Corp. IBM SPSS Statistics for Windows, Version 22.0. Armonk, NY: IBM Corp; 2013.
- 34 73. Streiner DL, Norman GR. Correction for Multiple Testing: Is There a Resolution? *Chest*. 2011
- 35 2011/07/01/;140(1):16-8.
- 36 74. Beesdo-Baum K, Klotsche J, Knappe S, Craske MG, LeBeau RT, Hoyer J, et al. Psychometric
- 37 properites of the dimensional anxiety scales for DSM-V in an unselected sample of German
- 38 treatment seeeking patients. *Depression and Anxiety*. 2012;29(12):1014-24.
- 39 75. Cvejic RC, Arnold SRC, Foley K-R, Trollor JN. Neuropsychiatric profile and psychotropic
- 40 medication use in adults with autism spectrum disorder: results from the Australian Longitudinal
- 41 Study of Adults with Autism. *BJPsych Open*. 2018;4(6):461-6. Epub 11/13.
- 42 76. Stacey T-L, Froude EH, Trollor J, Foley K-R. Leisure participation and satisfaction in autistic
- 43 adults and neurotypical adults. *Autism*. 2018;0(0):1362361318791275. PubMed PMID: 30132680.
- 44 77. Hwang YI, Foley K-R, Trollor JN. Aging Well on the Autism Spectrum: An Examination of the
- 45 Dominant Model of Successful Aging. *Journal of Autism and Developmental Disorders*. 2018 May 02.
- 46 78. Harsanyi M, Foley K-R, Froude E, Trollor J, Arnold SRC. Employment Profiles of Autistic Adults
- 47 in Australia. 2019.
- 48 79. Cai RY, Richdale AL, Foley K-R, Trollor J, Uljarević M. Brief report: Cross-sectional interactions
- 49 between expressive suppression and cognitive reappraisal and its relationship with depressive
- 50 symptoms in autism spectrum disorder. *Research in Autism Spectrum Disorders*. 2018
- 51 2018/01/01/;45:1-8.
- 52 80. Hedley D, Uljarević M, Foley K-R, Richdale A, Trollor J. Risk and protective factors underlying
- 53 depression and suicidal ideation in Autism Spectrum Disorder. *Depression and Anxiety*.
- 54 2018;35(7):648-57.
- 55
- 56
- 57
- 58
- 59
- 60

- 1
- 2
- 3
- 4 81. Uljarević M, Hedley D, Foley K-R, Magiati I, Cai RY, Dissanayake C, et al. Anxiety and
- 5 depression from adolescence to old age in autism spectrum disorder. *Journal of Autism and*
- 6 *Developmental Disorders*. 2019.
- 7 82. Baldwin S, Costley D. The experiences and needs of female adults with high-functioning
- 8 autism spectrum disorder. *Autism*. 2016;20(4):483-95. PubMed PMID: 26111537.
- 9 83. Fan W, Yan Z. Factors affecting response rates of the web survey: A systematic review.
- 10 *Computers in Human Behavior*. 2010 2010/03/01/;26(2):132-9.
- 11 84. Guo X, Vittinghoff E, Olgin JE, Marcus GM, Pletcher MJ. Volunteer Participation in the Health
- 12 eHeart Study: A Comparison with the US Population. *Scientific Reports*. 2017 2017/05/16/;7(1):1956.
- 13 En.
- 14 85. Fletcher-Watson S, Adams J, Brook K, Charman T, Crane L, Cusack J, et al. Making the future
- 15 together: Shaping autism research through meaningful participation. *Autism*.
- 16 2019;0(0):1362361318786721. PubMed PMID: 30095277.
- 17 86. Nicolaidis C, Raymaker D, McDonald K, Dern S, Ashkenazy E, Boisclair C, et al. Collaboration
- 18 strategies in nontraditional community-based participatory research partnerships: lessons from an
- 19 academic-community partnership with autistic self-advocates. *Progress in Community Health*
- 20 *Partnerships*. 2011;5(2):143-50.
- 21 87. Loomes R, Hull L, Mandy WPL. What Is the Male-to-Female Ratio in Autism Spectrum
- 22 Disorder? A Systematic Review and Meta-Analysis. *Journal of the American Academy of Child &*
- 23 *Adolescent Psychiatry*. 2017 2017/06/01/;56(6):466-74.
- 24 88. Gilmour L, Schalomon PM, Smith V. Sexuality in a community based sample of adults with
- 25 autism spectrum disorder. *Research in Autism Spectrum Disorders*. 2012 2012/01/01/;6(1):313-8.
- 26 89. Kapp SK, Gillespie-Lynch K, Sherman LE, Hutman T. Deficit, difference, or both? Autism and
- 27 neurodiversity. *Developmental Psychology*. 2013 2013/49(1):59-71. en.
- 28 90. Nicolaidis C, Raymaker D, McDonald K, Dern S, Boisclair C, Ashkenazy E, et al. Comparison of
- 29 healthcare experiences in autistic and non-autistic adults: A cross-sectional online survey facilitated
- 30 by an academic-community partnership. *Journal of General Internal Medicine*. 2013;28(6):761-9.
- 31 91. Whiteley P, Todd L, Carr K, Shattock P. Gender Ratios in Autism, Asperger Syndrome and
- 32 Autism Spectrum Disorder. *Autism Insights*; London. 2010;2:17. English.
- 33 92. Whitehouse AJO, Cooper MN, Bebbington K, Alvares G, Lin A, Wray J, et al. Evidence of a
- 34 reduction over time in the behavioral severity of autistic disorder diagnoses. *Autism Research*.
- 35 2017;10(1):179-87.
- 36 93. Chadwick D, Wesson C, Fullwood C. Internet Access by People with Intellectual Disabilities:
- 37 Inequalities and Opportunities. *Future Internet*. 2013;5(3):376-97.
- 38 94. Fusar-Poli L, Brondino N, Rocchetti M, Panisi C, Provenzani U, Damiani S, et al. Diagnosing
- 39 ASD in Adults Without ID: Accuracy of the ADOS-2 and the ADI-R. *Journal of Autism and*
- 40 *Developmental Disorders*. 2017 2017/11/01/;47(11):3370-9.
- 41 95. Robertson AE, Simmons DR. The relationship between sensory sensitivity and autistic traits
- 42 in the general population. *Journal of Autism and Developmental Disorders*. 2012;43:775-84.
- 43 96. Carleton RN, Norton PJ, Asmundson GJG. Fearing the unknown: a short version of the
- 44 intolerance of uncertainty scale. *Journal of Anxiety Disorders*. 2007;21:105-17.
- 45 97. Spitzer RL, Williams JBW, Kroenke K, Linzer M, deGruy FV, Hahn SR. Utility of new procedure
- 46 for diagnosis mental-disorders in primary-care: the PRIME-MD 1000 study. *Journal of American*
- 47 *Medical Association*. 1994;272:1749-56.
- 48 98. Ware JE, Kosinski M, Keller SD. A 12-Item Short-Form Health Survey: construction of scales
- 49 and preliminary tests of reliability and validity. *Medical care*. 1996;34(3):220.
- 50 99. Sletten DM, Suarez GA, Low PA, Mandrekar J, Singer W. COMPASS 31: A refined and
- 51 abbreviated composite autonomic symptom score. *Mayo Clinic Proceedings*. 2012;87(12):1196-201.
- 52 100. Buysse DJ, Reynolds CF, Monk TH, Berman SR, Kupfer DJ. The Pittsburgh Sleep Quality Index:
- 53 a new instrument for psychiatric practise and research. *Psychiatry Reserves*. 1989;28:193-213.
- 54
- 55
- 56
- 57
- 58
- 59
- 60

- 1
2
3 101. Gardisar M, Lack L, Richards H, Harris J, Gallasch J, Boundy M, et al. The Flinders Fatigue
4 Scale: preliminary psychometric properties and clinical sensitivity of a new scale for measuring
5 daytime fatigue associated with insomnia. *Journal of Clinical Sleep Medicine*. 2007;3(7):722-8.
6 102. Craske MG, Wittchen H-U, Bogels S, Stein M, Andrews G, Lebeu R. Severity measure for
7 Generalized Anxiety Disorder - adult: American Psychiatric Association; 2013.
8 103. Tennant R, Hiller L, Fishwick R, Platt S, Joseph S, Weich S, et al. The Warwick-Edinburgh
9 mental well-being scale (WEMWBS): development and UK validation. *Health and Quality of Life
10 Outcomes*. 2007;5(63):1-13.
11 104. Chen G, Gully SM, Eden D. Validation of a new general self-efficacy scale. *Organizational
12 Research Methods*. 2001;4(1):62-83.
13 105. Gross JJ, John OP. Individual differences in two emotion regulation processes: implications
14 for affect, relationships, and well-being. *Journal of Personality and Social Psychology*.
15 2003;85(2):348-62.
16 106. Mohr C, Tonge BJ, Einfeld SL, Taffe J. The Developmental Behaviour Checklist for Adults
17 (DBC-A) Revised. Sydney, Australia: University of Sydney and Monash University, 2011.
18 107. Carver CS. You want to measure coping but your protocol's too long: consider the brief
19 COPE. *International journal of behavioral medicine*. 1997;4(1):92-100. PubMed PMID: 16250744.
20 Epub 1997/01/01. eng.
21 108. Crook TH, 3rd, Feher EP, Larrabee GJ. Assessment of memory complaint in age-associated
22 memory impairment: the MAC-Q. *International psychogeriatrics*. 1992 Fall;4(2):165-76. PubMed
23 PMID: 1477304. Epub 1992/01/01. eng.
24 109. Hays RD, DiMatteo MR. A short-form measure of loneliness. *Journal of Personality
25 Assessment*. 1987;51:69-81.
26 110. Sarason IG, Levine HM, Basham RB, Sarason BR. Assessing social support: the social support
27 questionnaire. *Journal of Personality and Social Psychology*. 1983;44(1):127-39.
28 111. The WHOQOL Group. The World Health Organization Quality of Life assessment (WHOQOL)-
29 BREF quality of life assessment. *Psychological Medicine*. 1995;28:551-5.
30 112. Maenner MJ, Smith LE, Hong J, Makuch R, Greenberg JS, Mailick MR. Evaluation of an
31 activities of daily living scale for adolescents and adults with developmental disabilities. *Disability
32 and Health Journal* 2013;6(1):8-17.
33 113. Luciano JV, Ayuso-Mateos JL, Aguado J, Fernandez A, Serrano-Blanco A, Roca M, et al. The
34 12-item World Health Organisation Disability Assessment Schedule (WHO-DAS II): a nonparametric
35 item response analysis *BMC Medical Research Methodology*. 2010;10(45):1-9.
36 114. Taylor JL, Seltzer MM. Developing a vocational index for adults with autism spectrum
37 disorders. *Journal of Autism and Developmental Disorders*. 2012;42(12):2669-79.
38 115. Beard JG, Ragheb MG. Measuring leisure satisfaction. *Journal of Leisure Research*.
39 1980;12:20-33.
40 116. Chisholm D, Knapp MRJ, Knudsen HC, Amaddeo F, Gaitte L, van Wijngaarden B, et al. Client
41 socio-demographic and service receipt inventory - European version: development of an instrument
42 for international research. *The British Journal of Psychiatry*. 2000;177:28-33.
43 117. Bengtson VL, Allen KR. The life course perspective applied to families overtime. In: Boss P,
44 Doherty W, LaRossa R, Schumm W, Steinmetz S, editors. *Sourcebook of family theories and
45 methods: a contextual approach*. New York: Plenum Press; 1993. p. 469-98.
46 118. McCarron M, Gill M, Lawlor B, Beagly C. A pilot study of the reliability and validity of the
47 Caregiver Activity Survey - Intellectual disability (CAS-ID). *Journal of Intellectual Disability Research*.
48 2002;46(8):605-12.
49 119. Bedard M, Molloy DW, Squire L, Dubois BA, Lever JA, O'Donnell M. The Zarit Burden
50 Interview: a new short version and screening version. *The Gerontologist*. 2001;41(5):652-7.
51 120. Alliance NRH. The litte book of rural health numbers: Author; 2015. Available from:
52 <https://www.ruralhealth.org.au/book/little-book-rural-health-numbers>.
53
54
55
56
57
58
59
60

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

For peer review only

Figure Caption Sheet

Figure 1. Satisfaction responses upon completion combined by survey type (n=482)

For peer review only

Table 1

The ALSAA Inclusive Research Protocol

Step	Description of step and considerations
Step 1: Recruitment of advisors / peer-researchers	Ensure recruitment is inclusive of all potential autistic individuals including adults with intellectual disability*, consider using multiple channels of recruitment (e.g., Autism associations, self-advocacy networks, carer networks, adult networks, local radio, social media and word of mouth). In Australia, seek support from the Autism CRC Research Academy**.
Step 2: Building rapport	If an established relationship does not already exist between the autistic individual and researcher, the researcher should offer to meet the individual (either face-to-face, over video conference or phone call). Be mindful that some autistic individuals may prefer to communicate via text or email and not to meet in person and should not be required to.
Step 3: Clarify what will be expected from the advisor	Outline tasks autistic advisors or peer researchers will be asked to complete. Specify the frequency and timing of when they are likely to be contacted. For specific tasks clearly provide step-by-step instructions, flexible lead-time, timeframes for feedback, area of investigation, and broad aim of the study. Make information available in Easy English or plain language as appropriate. Specify the type and nature of advice sought. Clearly describe how and where their input will be used and why their input is being sought.
Step 4: Ethics, confidentiality and acknowledgement	Describe ethics of the project and expected confidentiality. As required, specify on individual documents that the document is confidential and not to be distributed without discussion with the researcher. Can the autistic individual opt out if they would like? Outline what will happen if they choose to withdraw, e.g., this will not affect their relationship with the research team, university or any other associated organisations. It is a voluntary process. Negotiate and make explicit how the autistic advisor or peer-researcher will be acknowledged. Consider how the autistic individual may be recognised in a manuscript or research output. This may include as a co-author, in the acknowledgements section, and/or in discussing methodology and findings.
Step 5: Identify preferred communication style	Ask the autistic individual their preferred communication style for providing feedback (e.g., face-to-face, phone call, email, video, or a variety of techniques). Also, in what medium they would like to receive the results/findings e.g., academic writing style, easy English writing style, mostly graphs/pictures, mostly dot points, described in person, video, PowerPoint presentation, etc. Although not all mediums may be practical, it is important to identify the autistic advisor's preferred style and then work together to identify a medium of communication which will be understood and accessible by both the autistic advisor and the researcher.
Step 6: The sensory environment	The researcher must provide an 'autism-friendly' environment on any occasion where the autistic advisor and the researcher may be meeting in person, see p. 12-15 in the <i>Autism CRC Inclusive Research Practice Guides and Checklists for Autism Research</i> ⁵⁶ regarding creating autism-friendly environments.
Step 7: Involvement in	Autistic advisors input is sought in regard to areas of investigation, questionnaire design and interpretation of results. The researcher will need to

1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19	methodological design / results / findings	consider that ranking of priority areas may be a difficult task for some advisors and employ other consensus decision making strategies. The researcher will need to present questionnaire design questions or quantitative or qualitative results in an understandable format, developing design issue summaries or results summaries in the medium preferred by the autistic advisor or peer-researcher. This means the researcher may need to make a number of decisions around data analysis and interpretation. Where possible, outline each of these decisions so the process is transparent and the autistic advisor can reflect on the decisions made by the researcher and whether these were appropriate in their view. Provide clear guidance on what advice is being sought, provide lead time, and the timeframe and process to follow for providing advice. How long should the advice be? In what format? Who will be reading it, who do they send the advice to? What are the researchers specifically looking for, what should the advice focus on?
20 21 22 23	Step 8: Feedback	Once the researcher receives the advice from the autistic advisor, the researcher should provide a timeframe in which the autistic advisor will receive an update on what aspects of the advice was incorporated and the effect it had/didn't have on the methodology, findings, and/or interpretation.
24 25 26 27 28 29	Step 9: Final checks	Once the manuscript or research output has been further developed, the autistic advisor should receive a copy of the manuscript prior to submission. If the autistic advisor has limited experience with academic writing, the researcher should offer to describe/provide a lay summary of the overall article for the advisor.
30 31 32	Step 10: Acknowledgement	Autistic advisor or peer-researcher to be acknowledged in the agreed upon manner (e.g., co-author, thanked in the acknowledgement section, acknowledged during a presentation etc.)

*Although inclusive consultation occurred at time 1, the ALSAA RAN does not currently have an active member on the autism spectrum with an intellectual disability. Renewed efforts to recruit an advisor will be instigated when autism and intellectual disability focused outputs are commenced. We consult as needed with an advisor with intellectual disability not on the autism spectrum currently.

**The Autism CRC Research Academy (<https://www.autismcrc.com.au/research-academy>) provides training for peer researchers.

Table 2

Measurements included in the ALSAA surveys

Measure / domain	Self-report	Informant report	Carer
Demographics and personal characteristics			
Basic demographics (Age, Sex, Ethnicity, English speaking status)	✓	✓	✓
Other demographics (Education, Occupation ^a , Family & living conditions, Income)	✓	✓	✓
Autism Characteristics			
The Autism Quotient - Short ^b (AQ-Short) ⁶⁷	✓	✓	✓
Repetitive Behaviours Questionnaire-2 Adult Version (RBQ-2A) ⁶³	✓	✓	
The Glasgow Sensory Questionnaire ⁹⁵	✓	✓	
The Intolerance of Uncertainty Scale-12 ⁹⁶	✓		✓
Health & Well-Being			
Medical history	✓	✓	✓
Medication profile	✓	✓	
Smoking, alcohol and illicit drug use ^a	✓	✓	
The Patient Health Questionnaire-15 ⁹⁷	✓		✓
Medical Outcomes Study Short Form Health Survey-12 (SF-12) ⁹⁸	✓	✓	✓
The Composite Autonomic Symptom Score - 31 (COMPASS 31) ⁹⁹	✓		
Pittsburgh Sleep Quality Index ¹⁰⁰	✓		
Flinders Fatigue Scale ¹⁰¹	✓		
Mental & Emotional Health			
DSM-5 Dimensional Anxiety Scales: Generalized Anxiety Disorder-Adult (DSM5 GAD-A) ¹⁰²	✓		✓
The Patient Health Questionnaire-9 (PHQ-9) ⁶¹	✓		✓
The Warwick Edinburgh Mental Well-being Scale ¹⁰³	✓		
The New General Self-Efficacy Scale ¹⁰⁴	✓		
The Emotion Regulation Questionnaire ¹⁰⁵	✓		✓
Developmental Behaviour Checklist-Adolescent/Adult version (DBC-A) Revised ¹⁰⁶		✓	
The Brief COPE ¹⁰⁷	✓		✓
Memory Complaint Questionnaire (MAC-Q) ¹⁰⁸	✓		
Relationships & Social Networks			
UCLA Loneliness Scale-8 (ULS-8) ¹⁰⁹	✓		
Supports and networks ^a	✓	✓	
The Social Support Questionnaire (SSQ) ¹¹⁰	✓		✓
Activities, Participation & Quality of Life			

1				
2				
3	WHOQOL-BREF ¹¹¹	✓		✓
4	Waisman Activities of Daily Living Scale (W-ADL) ¹¹²	✓	✓	
5	World Health Organisation Disability Assessment Schedule	✓	✓	✓
6	(WHO-DAS II) ¹¹³			
7	Vocational Index for Adults with Autism ¹¹⁴	✓	✓	
8	Special abilities and interests ^c	✓		
9	Leisure activities participation	✓	✓	
10	Leisure Satisfaction Scale (LSS) ¹¹⁵	✓		
11	Driving and transport	✓	✓	✓
12	Service Usage			
13	Client Service Receipt Inventory (CSRI) ¹¹⁶	✓	✓	
14	Health service seeking behaviour	✓	✓	
15	Early intervention service history	✓	✓	
16	Justice system contact	✓	✓	
17	Preventative health screening	✓	✓	
18	Caring			
19	Positive Affect Index ¹¹⁷			✓
20	Caregiver Activity Survey (CAS-ID) ¹¹⁸			✓
21	Zarit Burden Interview ¹¹⁹			✓

^a Based on questions from the National Health Survey of Mental Health and Wellbeing (Slade, Johnston, Oakley Browne, Andrews, & Whiteford, 2009). ^bA 28-item parent-carer report adaptation using items from the AQ-Adolescent (Baron-Cohen, Hoekstra, Knickmeyer, & Wheelwright, 2006) was used for the informant-report survey ^cBased on questions from the Interactive Autism Network (<https://iancommunity.org/>)

Table 3

Recruitment statistics at close of Time 1 data gathering

Sample	Registered	Non-respondent	Ineligible (%)	Withdrawn (%)	Partial Completion (%)	Completed (%)
Self-report autistic adults	345	75 (22)	6 (2)	11 (3)	16 (5)	237 (69)
Self-report non-autistic adults	221	48 (22)	7 (3)	20 (9)	16 (7)	130 (59)
Carer	185	48 (26)	22 (12)	13 (7)	2 (1)	100 (54)
Informant-report for autistic adult	78	22 (28)	5 (6)	9 (11)	0 (0)	42 (54)

Table 4

Participant Characteristics

Characteristic	Autistic adults self-report formally diagnosed (N=221)	Autistic adults self-report no formal diagnosis (N=32)	Autistic adults informant-report (N=42)	Carers (N=102)	Non-autistic self-report (N=146)
Age mean (SD)	41.8 (12.2)	44.2 (8.1)	32.5 (9.9)	56.3 (11.2)	43.7 (13.5)
Gender (%)					
Male	86 (39)	14 (44)	34 (81)	16 (16)	29 (20)
Female	124 (56)	17 (53)	8 (19)	85 (83)	117 (80)
Other	11 (5)	1 (3)	0	1 (1)	0
^a Ethnicity (%)					
Caucasian	194 (88)	25 (78)	38 (90)	86 (89)	122 (85)
Other	27 (12)	7 (22)	4 (9)	11 (11)	22 (15)
Multilingual (%)	26 (12)	5 (16)	0	6 (6)	18 (12)
^b SEIFA decile (SD)	6.18 (2.89)	5.74 (3.09)	6.58 (2.88)	6.60 (2.78)	7.01 (2.60)
^{bc} Rural / Remoteness					
Major City	146 (71)	17 (55)	32 (84)	72 (73)	114 (83)
Inner Regional	44 (21)	10 (32)	5 (13)	21 (21)	19 (14)
Outer Regional	12 (6)	4 (13)	1 (3)	5 (5)	5 (4)
Remote / Very Remote	4 (2)	0	0	0	0
^d Living situation (%)					
Living alone	58 (26)	9 (28)	3 (7)	14 (14)	26 (18)
Living as couple	95 (43)	18 (56)	4 (9)	74 (75)	105 (72)
Living with parents	31 (14)	0	24 (57)	0	5 (3)
Living with other relatives	3 (1)	0	1 (2)	6 (6)	3 (2)
Living with others	20 (9)	5 (16)	8 (19)	4 (4)	5 (3)
Other	14 (6)	0	2 (5)	1 (1)	2 (1)
^e Marital Status (%)					
Single	73 (33)	7 (22)	36 (86)	4 (4)	22 (15)
Married	66 (30)	12 (37)	4 (9)	65 (66)	90 (62)
De facto	17 (8)	3 (9)	0	8 (8)	14 (9)
Never married	8 (4)	3 (9)	2 (5)	2 (2)	3 (2)
Widowed	1 (0)	0	0	3 (3)	2 (1)
Divorced now single	21 (9)	3 (9)	0	8 (8)	9 (6)
Divorced now remarried / de facto	12 (5)	2 (6)	0	2 (2)	2 (1)
Separated	7 (3)	1 (3)	0	2 (2)	1 (1)
Other	16 (7)	1 (3)	0	4 (4)	3 (2)
Educational Status (%)					

Completed high school	163 (76) <i>n</i> =215	20 (64) <i>n</i> =31	21 (51) <i>n</i> =41	86 (88) <i>n</i> =98	120 (86) <i>n</i> =139
Vocational education	61 (35) <i>n</i> =174	16 (57) <i>n</i> =28	4 (11) <i>n</i> =35	17 (17) <i>n</i> =98	20 (16) <i>n</i> =127
University education	113 (65) <i>n</i> =174	12 (43) <i>n</i> =28	1 (3) <i>n</i> =35	59 (60) <i>n</i> =98	107 (84) <i>n</i> =127
^f Employment (%)					
Open employment	116 (57)	20 (69)	6 (15)	59 (60)	104 (76)
Student / other day activity	38 (19)	3 (10)	24 (60)	3 (3)	17 (12)
Retired, no volunteering	8 (4)	2 (7)	2 (5)	19 (19)	6 (4)
Homecare	17 (8)	3 (10)	0	9 (9)	9 (6)
No activity	22 (11)	1 (3)	8 (20)	9 (9)	1 (1)

^a Ethnicity: Carers, *n*=97; Non-autistic (self-report), *n*=144

^b Autistic adults (diagnosis, self-report), *n*=209; Autistic adults (no diagnosis, self-report), *n*=31; Autistic adults (informant report), *n*=38; Carers, *n*=99; Non-autistic (self-report), *n*=138

^c Australian population is 70% Major city, 18% Inner regional, 9% Outer regional, 1% Remote, 1% Very remote in the 2011 Census¹²⁰

^d Carers' Living situation: *n*=99

^e Carers' Marital status: *n*=98

^f Employment: Autistic adults (diagnosis, self-report), *n*=201; Autistic adults (no diagnosis, self-report), *n*=29; Autistic adults (informant report), *n*=40; Carers, *n*=99; Non-autistic (self-report), *n*=137

Table 5

Diagnostic Characteristics

Characteristic	Autistic adults self-report formally diagnosed (N=221)	Autistic adults self-report no formal diagnosis (N=32)	Autistic adults informant-report (N=42)	Carers (N=102)	Non-autistic self-report (N=146)
AQ score mean (SD)	87.6 (10.3) n=210	83.7 (8.8)	84.2 (9.5) n=36	57.3 (13.8) n=60 ^a	55.1 (11.9) n=137
Above AQ Cutoff (%)	203 (97)	31 (97)	35 (97)	18 (30)	30 (22)
^b Autism Diagnosis					
Autism spectrum disorder / condition	49 (22)	-	17 (40)	-	-
Asperger's syndrome	130 (59)	-	11 (26)	-	-
Autistic disorder	1 (0)	-	6 (14)	-	-
'High-functioning' autism	32 (14)	-	3 (7)	-	-
PDD-NOS	1 (0)	-	1 (2)	-	-
Other	6 (3)	-	2 (5)	-	-
No formal diagnosis	-	32 (100)	1 (2)	-	-
Age at Diagnosis Mean (SD)	35.3 (15.1) n=217	-	10.01 (10.8) n=38	-	-
Years since Diagnosis Mean (SD)	6.9 (8.3) n=217	-	21.9 (9.8) n=38	-	-
Intellectual Disability (%)	10 (4)	1 (3)	33 (78)	1 (1)	1 (1)
Other Developmental Disability (%)	6 (3)	2 (6)	9 (21)	0	1 (1)
^c Other Psychiatric Diagnosis(%)					
Currently	148 (69) n=213	13 (42) n=31	22 (52)	38 (39) n=100	29 (21) n=140
At any time	191 (89) n=213	28 (90) n=31	31 (74)	68 (68) n=100	67 (48) n=140
Depression (PHQ-9) above cut-off (%)	103 (52) n=199	15 (52) n=29	-	28 (29) n=97	15 (12) n=126
Anxiety (DSM5 GAD-A) above cut-off (%)	115 (56) n=206	14 (47) n=32	-	27 (27) n=99	14 (11) n=130

^a Carers were asked to complete the AQ scale only if they were a biological relative of the adult with autism

^b Autism diagnosis: Autistic adults (self-report, diagnosed), $n=220$

^c Recording of a psychiatric diagnosis apart from autism spectrum conditions or intellectual disability

For peer review only

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

For peer review only

Table 6

Carer Characteristics (N=102)

Characteristic	Frequency / Mean
Relationship to autistic person (%)	
Mother	42 (43, <i>n</i> =98)
Father	10 (10, <i>n</i> =98)
Partner/spouse	23 (23, <i>n</i> =98)
Sibling	2 (2, <i>n</i> =98)
Child	1 (1, <i>n</i> =98)
Carer – unspecified	17 (17, <i>n</i> =98)
Other	3 (3, <i>n</i> =98)
Age of autistic adult cared for mean (<i>SD</i>)	37.5 (13.2)
Hours spent per week with autistic adult mean (<i>SD</i>)	63.4 (57.8, <i>n</i> =92)

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

For peer review only

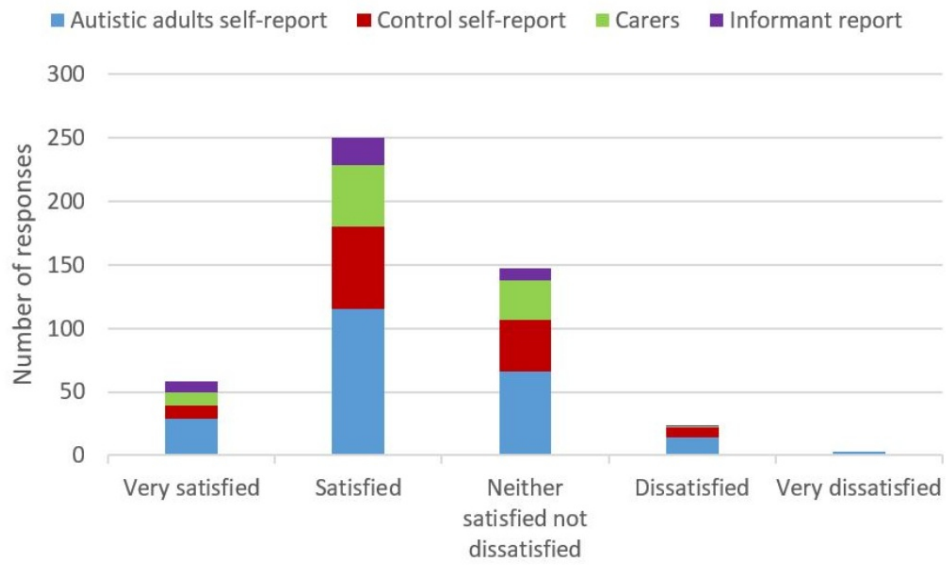


Figure 1. Satisfaction responses upon completion combined by survey type (n=482)

89x53mm (300 x 300 DPI)