

PEER REVIEW HISTORY

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ARTICLE DETAILS

TITLE (PROVISIONAL)	Cohort profile: The Australian Longitudinal Study of Adults with Autism (ALSAA)
AUTHORS	Arnold, Samuel; Foley, Kitty-Rose; Hwang, Ye In; Richdale, Amanda; Uljarevic, Mirko; Lawson, Lauren; Cai, Ru; Falkmer, Torbjorn; Falkmer, Marita; Lennox, Nick; Urbanowicz, Anna; Trollor, Julian

VERSION 1 – REVIEW

REVIEWER	BAGHDADLI, AMARIA 1. Department of Psychiatry and Autism Resources Center, University Research and Hospital Center (CHU) of Montpellier, 34000, France. 2. Centre de Recherche en Épidémiologie et Santé des Populations, U1178, INSERM, Paris, France. 3. School of Medicine, Montpellier University, France.
REVIEW RETURNED	09-Apr-2019

GENERAL COMMENTS	<p>Article bmjopen-2019-030798 Reviewer: Amaria BAGHDADLI professor of child and adolescent psychiatry, University and Hospital of Montpellier, France.</p> <p>Thank you for the opportunity to review this cohort Profile of the Australian Longitudinal Study of Adults with Autism (ALSAA). This is a nationwide longitudinal study aiming to describe the following aspects: 1) the baseline (clinical, medical and psychosocial) characteristics of autistic adults followed in the ALSAA compared to controls adults; 2) the inclusive research approach used. The ALSAA is a questionnaire-based, prospective cohort with a planned 2-years follow-up including 2 collection Times. Its protocol, based on the inclusive research principles, is for the most part clearly expressed and detailed. Indeed, the design and development of the study were done in collaboration with researchers and clinicians across Australia, international experts conducting similar study including, and a research advisory network consisting of autistic adults and their carers. The sample consists of 3 groups: 295 autistic adults (at baseline) and 130 non-autistic community comparison controls and 100 carers of autistic adults (mainly their parents or spouses or husbands). Inclusion criteria for autistic participants and controls were: to be aged over 25 years, to live in Australia, and have sufficient English literacy to complete the survey. People with intellectual disabilities (ID) could complete the self-report survey with support or via an informant respondent, but finally the sample includes very few people with ID. Recruitment commenced in 2015. At the close of T1 (Nov 2017) 345 adults, 221 non-autistic adults, 185 carers and 78 informants</p>
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had registered their interest in the study. Of these 295 autistic adults (including 42 informant reporters) and 130 non-autistic adults and 100 carers completed the entire survey

The sample was recruited via advertisements through autism-specific organizations, and online communities. Participants self-identified as being autistic and who did not have a formal diagnosis were also recruited. Participants with formal diagnosis were asked to provide detail of their diagnosis. AQ-short cut-off scores (>65) also support the diagnosis status.

3 (online or paper) versions of the survey were developed: 1) self-report for autistic adults and their controls; 2) informant for carers to complete about the autistic persons unable to self-complete the survey; and 3) carer survey to complete about their own health and well-being. Consent was inferred from participants who completed and returned paper copies of the survey. Autistic Participants reported between 20 minutes and 12 hours to complete the entire survey.

Concordantly with previous studies, authors showed in the autistic group high rated of depression and anxiety and frequent history of psychiatric diagnosis and significantly more than control sample. The authors conclude to poorer mental health of Autistic adults and working inclusive research approach.

This paper is of interest for a number of reasons. First of all it starts off with a large sample size of autistic adults. Secondly, it uses a large non-autistic control groups. Thirdly this study has gathered a large comprehensive dataset (of the physical and mental health, productivity, well-being and health service use) relating to autistic adults and their carers living in Australia creating a platform for longitudinal and collaborative research. Consequently, it could constitute a relevant resource for exploring multiple research questions regarding the unexplored lives of autistic adults. Also, the authors are to be congratulated for undertaking this study and using data on adults lives through an inclusive research approach. It is an important added value of the study.

However, a major issue is that the autistic sample is significantly biased as comprising 50% of females, 90% of individuals diagnosed in adulthood and the majority without ID. This sample not only does not really resemble samples from North America or Europe, but also it is not representative of the autistic Australian population given the multiple bias. Another major limit of the study is that only self-report questionnaires were used, including for establishing the diagnosis of Autism and comorbid conditions without any direct examination or clinical assessment. The medical diagnoses are therefore only declarative and all the more uncertain as they were mainly established in adulthood and therefore imply a particular clinical subgroup for which differential diagnosis issues can not be ruled out with other neurodevelopmental or psychiatric disorders. The last limit is that some measures used in the study have not yet been validated with autistic samples (PHQ15; DSM5GAD A and emotion regulation questionnaire).

Comment 1. As the authors note, a limitation of their study is the lack of representativeness of the sample. How do the authors explain that 90% of adults with autism have been diagnosed in adulthood? And how they explain the gender bias in both the autistic and control groups.

	<p>Comment 2. It is not clear if the diagnostic status of autism and comorbid condition is according to ICD-10 criteria, or DSM-5 criteria", or the both. This should be clarified.</p> <p>Comment 3: Autistic participants were asked to provide details about their diagnosis. It would be useful to describe (if available) the diagnosis process (multidisciplinary approach?) used to establish Autistic status at baseline.</p> <p>Comment 4: What will be the exact modalities and procedure for reassessing (and maybe confirming) the autistic diagnosis status at the end of the follow-up.</p> <p>Comment 5: Is it planned to validate the clinical tools not yet validated, and if so at which stage of the study</p> <p>Comment 6: The consent of the participants was officially recorded as they responded to the survey. However, have they also signed a form to explicitly give their consent?</p> <p>Comment 7: in a table authors give the number of completed questionnaires but Detail about the "missing value" would be useful.</p> <p>Comment 8: A more detailed statistical analysis plan would be useful for understanding the future studies plan.</p> <p>Comment 9: Please provide details of the power analysis and the justification of the primary outcome measure</p>
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REVIEWER	Dr Deborah Kinnear University of Glasgow, Scotland, United Kingdom
REVIEW RETURNED	09-May-2019

GENERAL COMMENTS	<p>This is an interesting paper addressing the significant knowledge gap regarding the lives of adults on the autism spectrum, namely: a lack of comprehensive longitudinal studies exploring the risk factors for health and mental health inequalities. There is also a lack of research with inclusion of the perspectives of autistic adults in its conduct or design. The authors present the findings from Australia's first national longitudinal study (Australian Longitudinal Study of Adults with Autism (ALSAA)) involving autistic adults aged 25 years and older. The study gathers a wide range of data points using standardised measures, gathers data from a community comparison group and includes autistic adults in the study design. The paper sets out the methodological processes and inclusive protocol adopted in the ALSAA and presents participant characteristics and feedback from the baseline data collection. The paper overall is very well written, and clearly justifies the importance of the authors work.</p>
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REVIEWER	Kristen Gillespie-Lynch College of Staten Island & The Graduate Center, CUNY
REVIEW RETURNED	13-May-2019

GENERAL COMMENTS	<p>The proposed project addresses a key gap in the literature, risk factors that may lead to the inequalities in mental health outcomes that have been observed among autistic adults. It proposes a creative strategy to address the need for longitudinal data to attain a better understanding of adult outcomes in autism. The key idea of setting up an online recruitment mechanism that allows longitudinal assessments to examine change across time is creative and very promising. However, more detail about the specific research questions to be addressed and in particular, how they can be addressed with longitudinal data, is needed. I understand that the beauty of this type of recruitment mechanism</p>
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is that it allows one to address multiple research questions and to observe unexpected patterns in the data, but more of a sense of how this recruitment mechanism allows one to understand risk factors for inequalities in mental health care is needed, since this is initially set up as the primary rationale for the study.

The inclusion of autistic adults in study design, the focus of the study on research questions that have been highlighted by autistic self-advocates as important and the responsiveness of the study designers to feedback from the first wave of data collection is a major strength of this study. However, more clarity about the ways that autistic advisors are involved is needed to ensure that their involvement is not tokenistic. The scope and process of autistic advisors' involvement requires more clarification. It is unclear if autistic advisors provided substantive input on the research questions or played more of a clarification of measures role. It currently sounds more like they did the latter but the former would be more helpful. It is also unclear why autistic advisors were not involved in data analysis.

As the authors also note, the sample is unlikely to be representative of the broader population. More efforts to recruit a more representative sample (and a better matched comparison group) would increase the impact of this project.

Below are specific points to address:

Abstract: Briefly clarify what the difference between informant and carer report is and how many people filled out each type. Add "the" before majority.

Highlights: Add typically before focused in first highlight as there is increasing research focused on adults, though still not enough relative to younger people.

The percentages reported in the highlights are confusing. Do you mean 50% of 295? If so, state the n who are female out of the total.

Page 6: The point about intellectual disability comes out of the blue after the mental health conditions point. When discussing intellectual disability, it would also be helpful to highlight Dawson's and Mottron's research showing that commonly used IQ tests often underrepresent the IQ of autistic people.

Page 8: Clarify if only one 2 year follow up is planned (as seems to be the case in this portion of the text) or if frequent follow-ups every two years are planned as suggested earlier in the abstract.

Page 9: When introducing the composition of the AASLA, clarify how many autistic adults and carers are involved in the advisory network when introducing them. It says below how many have reviewed it so far, but it is not clear what the total number involved are or how it was determined who would review or when they were invited to do so. Indicate the timeframe and nature of their involvement and their compensation for being involved. When saying that this approach was developed based on the principles of inclusive research and Nicolaidis' work, introduce which principles in particular guided this work. Wording "has guided" in this section unclear, not clear what is guiding what. Indicate if and how advisors provided more substantive guidance on content and the constructs assessed rather than just on wording.

Page 10: The point about participants being unwilling to self-report requires some clarification. Why would an informant be asked to report if the participant was unwilling to report? There are many controversies about whether others can stand in for people who

	<p>are not able to report themselves that need to be addressed a bit more when introducing this idea.</p> <p>Page 11: The inclusion of multiple opportunities to provide feedback during the survey is a strength of the design. It might be good to add more open-ended questions as well.</p> <p>Piloting: When describing the piloting process, replace “a small number” with the exact number of autistic advisors who provided feedback if possible. A diagram would be helpful to clarify this process.</p> <p>Recruitment: Indicate how the number 160 was decided upon. Was a power analysis conducted?</p> <p>Page 12: There have been increasing critiques of the AQ. It might be good to consider a different autistic traits measure for the future like the RAADS-14 or SRS.</p> <p>Provide more clarity about the procedure surrounding the checklist evaluating capacity to consent.</p> <p>Page 13: Clarify how qualtrics data is linked to participant information in order to allow follow up assessments.</p> <p>Clarify what the alpha level is for the study. Given the very large number of assessments, a correction would be recommended.</p> <p>Page 14: Clarify the recruitment process for non-autistic participants and report if completion status varied as a function of participant characteristics for non-autistic participants. Also add the direction of the trend toward an effect of age in terms of completion for the autistic sample. Provide more detail about how age was quantified. It is a bit odd that age is approximate since the lack of research about older autistic adults is one of the rationales for the study.</p> <p>Page 15: It is not clear why there was no difference in rural/remoteness based on the p value provided here. Perhaps the alpha was lower than .05 as recommended above? Given that you will have many analyses due to the large number of measures, it will be important to report effect sizes in addition to p values and to use statistical corrections.</p> <p>Page 16: It is not clear why the control sample is not better matched to the autistic sample in terms of gender, particularly given that females are already overestimated in the autistic sample. I would suggest attempting to better match the samples. The high representation of autistic females in this sample may suggest that the sample is not representative of the broader population. More effort recruiting males and those with ID would be useful to improve the representativeness of the sample. In-person recruitment could likely help with this, particularly given that the option of paper based forms is available.</p> <p>More detail about the employment status analysis is needed to interpret it.</p> <p>It would be helpful to evaluate if those who were not yet formally diagnosed differed from those who reported that they did have a formal diagnosis.</p> <p>Page 19: Indicate how many people who participated reported an ID, how this was ascertained and how many of them participated via an informant. Also indicate if an informant participated for anyone without an ID, and if so how many times this happened. The informant approach seems a bit problematic to me so would benefit from further clarification. I now see this is in the table section. Please clarify how ID was assessed.</p> <p>There is a lot of missing data which may make it challenging to observe patterns over time.</p> <p>Page 20: More clarity about the specific research questions being explored would be helpful here (and throughout) particularly given</p>
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	<p>that the authors point out that the research questions will help determine the utility. Direct involvement of autistic people in research question development would also make the study more inclusive.</p> <p>Page 21: Clarify how the autistic advisors improved the methodology.</p>
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VERSION 1 – AUTHOR RESPONSE

Reviewer(s)' Comments to Author:

Reviewer: 1

Reviewer Name: Amaria BAGHDADLI

Institution and Country: 1. Department of Psychiatry and Autism Resources Center, University Research and Hospital Center (CHU) of Montpellier, 34000, France.

2. Centre de Recherche en Épidémiologie et Santé des Populations, U1178, INSERM, Paris, France.

3. School of Medicine, Montpellier University, France.

Please state any competing interests or state 'None declared': None declared

Please leave your comments for the authors below Article bmjopen-2019-030798

Reviewer: Amaria BAGHDADLI professor of child and adolescent psychiatry, University and Hospital of Montpellier, France.

Thank you for the opportunity to review this cohort Profile of the Australian Longitudinal Study of Adults with Autism (ALSAA). This is a nationwide longitudinal study aiming to describe the following aspects: 1) the baseline (clinical, medical and psychosocial) characteristics of autistic adults followed in the ALSAA compared to controls adults; 2) the inclusive research approach used.

The ALSAA is a questionnaire-based, prospective cohort with a planned 2-years follow-up including 2 collection Times. Its protocol, based on the inclusive research principles, is for the most part clearly expressed and detailed. Indeed, the design and development of the study were done in collaboration with researchers and clinicians across Australia, international experts conducting similar study including, and a research advisory network consisting of autistic adults and their carers.

The sample consists of 3 groups: 295 autistic adults (at baseline) and 130 non-autistic community comparison controls and 100 carers of autistic adults (mainly their parents or spouses or husbands). Inclusion criteria for autistic participants and controls were: to be aged over 25 years, to live in Australia, and have sufficient English literacy to complete the survey. People with intellectual disabilities (ID) could complete the self-report survey with support or via an informant respondent, but finally the sample includes very few people with ID.

Recruitment commenced in 2015. At the close of T1 (Nov 2017) 345 adults, 221 non-autistic adults, 185 carers and 78 informants had registered their interest in the study. Of these 295 autistic adults (including 42 informant reporters) and 130 non-autistic adults and 100 carers completed the entire survey The sample was recruited via advertisements through autism-specific organizations, and online communities. Participants self-identified as being autistic and who did not have a formal diagnosis were also recruited. Participants with formal diagnosis were asked to provide detail of their diagnosis. AQ-short cut-off scores (>65) also support the diagnosis status.

3 (online or paper) versions of the survey were developed: 1) self-report for autistic adults and their controls; 2) informant for carers to complete about the autistic persons unable to self-complete the survey; and 3) carer survey to complete about their own health and well-being. Consent was inferred from participants who completed and returned paper copies of the survey. Autistic Participants reported between 20 minutes and 12 hours to complete the entire survey.

Concordantly with previous studies, authors showed in the autistic group high rated of depression and anxiety and frequent history of psychiatric diagnosis and significantly more than control sample. The authors conclude to poorer mental health of Autistic adults and working inclusive research approach.

This paper is of interest for a number of reasons. First of all it starts off with a large sample size of autistic adults. Secondly, it uses a large non-autistic control groups. Thirdly this study has gathered a large comprehensive dataset (of the physical and mental health, productivity, well-being and health service use) relating to autistic adults and their carers living in Australia creating a platform for longitudinal and collaborative research. Consequently, it could constitute a relevant resource for exploring multiple research questions regarding the unexplored lives of autistic adults. Also, the authors are to be congratulated for undertaking this study and using data on adults lives through an inclusive research approach. It is an important added value of the study.

However, a major issue is that the autistic sample is significantly biased as comprising 50% of females, 90% of individuals diagnosed in adulthood and the majority without ID. This sample not only does not really resemble samples from North America or Europe, but also it is not representative of the autistic Australian population given the multiple bias. Another major limit of the study is that only self-report questionnaires were used, including for establishing the diagnosis of Autism and comorbid conditions without any direct examination or clinical assessment. The medical diagnoses are therefore only declarative and all the more uncertain as they were mainly established in adulthood and therefore imply a particular clinical subgroup for which differential diagnosis issues can not be ruled out with other neurodevelopmental or psychiatric disorders. The last limit is that some measures used in the study have not yet been validated with autistic samples (PHQ15; DSM5GAD A and emotion regulation questionnaire).

Comment 1. As the authors note, a limitation of their study is the lack of representativeness of the sample. How do the authors explain that 90% of adults with autism have been diagnosed in adulthood? And how they explain the gender bias in both the autistic and control groups.

***We suggest that the large proportion of adults who were diagnosed in adulthood in this study was a result of convenience sampling methods. Also, the age range of participants in this study being 25 years and older would have meant that when many adults were children, the autism diagnosis was not as well known and therefore they did not receive the diagnosis as children. Further, as many participants have relatively less support needs, they are more likely not to have been detected earlier in life. See below where this is addressed in the manuscript.

“The ALSAA baseline sample is reflective of the convenience sampling methodology used.” The female gender bias in online autism research is also discussed and has occurred in other studies “Self-selection in online surveys can lead to a female gender bias⁷⁶, as also has been noted in other online autism research⁷⁹⁻⁸¹”.

We added to the limitations that “Limiting recruitment to participants age 25 years or older, changing diagnostic practices⁸⁵, in combination with the convenience sampling, has likely led to the large percentage of participants who had received their autism diagnosis in adulthood.”

Comment 2. It is not clear if the diagnostic status of autism and comorbid condition is according to ICD-10 criteria, or DSM-5 criteria”, or the both. This should be clarified.

***In the first mention of the PHQ-9 cut-off for depression in results, we added mention of its relationship to the DSM, as is clear for the anxiety scale: “The control sample was also significantly less likely to meet the DSM-IV-TR linked 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”. Autism diagnosis and mental health conditions are self-reported, and hence may be linked to either classification criteria depending of the diagnosing clinicians, as noted in the limitations section: “A final limitation is the self-report questionnaire format of the ALSAA, particularly in relation to self-reported diagnosis of autism and comorbid conditions without clinical reassessment.”

Comment 3: Autistic participants were asked to provide details about their diagnosis. It would be useful to describe (if available) the diagnosis process (multidisciplinary approach?) used to establish Autistic status at baseline.

***The reviewer raises an interesting point and we agree adding this detail will be of interest to the readers. Therefore, we added the following to the summary of participant characteristics that “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 clinician (n=23 missing).”

Comment 4: What will be the exact modalities and procedure for reassessing (and maybe confirming) the autistic diagnosis status at the end of the follow-up.

***We expanded the sentence within the procedures to say that “At the planned two-year average Time 2 follow-up copies of participants’ diagnostic reports will be requested, with a project undertaken to review and categorise the reports.”

Comment 5: Is it planned to validate the clinical tools not yet validated, and if so at which stage of the study

***The tools will be validated as time and resources are available, we have recently published a validation of the PHQ-9 (see reference 72) and plan amongst other outputs to continue “further scale validations”.

Comment 6: The consent of the participants was officially recorded as they responded to the survey. However, have they also signed a form to explicitly give their consent?

***As noted under ethical considerations “For the online survey, participants were asked to confirm their consent at commencement. Consent was inferred from participants who completed and returned paper copies of the survey, as outlined in their PISCF.” As per our ethics approval.

Comment 7: in a table authors give the number of completed questionnaires but Detail about the “missing value” would be useful.

***We assume the reviewer is referring to Table 3, we have added a column ‘non-respondent’ to detail these values.

Comment 8: A more detailed statistical analysis plan would be useful for understanding the future studies plan.

***A more detailed statistical analysis plan is not provided as there are multiple and divergent research questions that are going to be explored in the future, as noted in the opening to the discussion: "Several other outputs are in development, with focus on health service barriers and usage, caregivers, impact of diagnosis in adulthood, further scale validations, longitudinal analyses of loneliness, suicidal ideation, mental illness risk factors among others, meeting the broad aim of the study to describe and compare the profiles of Australian autistic adults."

Comment 9: Please provide details of the power analysis and the justification of the primary outcome measure

***We expanded on our point that "A recruitment target of 160 autistic adults was set to allow for regression analyses using multiple predictor variables" adding a power analysis "Power analyses, undertaken using power calculation software, suggested this would be a sufficient sample size with power $(1 - \beta)$ set at .80 and $\alpha = .05$ to detect a Cohen's f^2 effect size estimate of at least .1 using multiple regression models with 7 predictors."

Given the broad aims of the study there is no primary outcome measure.

Reviewer: 2

Reviewer Name: Dr Deborah Kinnear

Institution and Country: University of Glasgow, Scotland, United Kingdom Please state any competing interests or state 'None declared': None declared

Please leave your comments for the authors below This is an interesting paper addressing the significant knowledge gap regarding the lives of adults on the autism spectrum, namely: a lack of comprehensive longitudinal studies exploring the risk factors for health and mental health inequalities. There is also a lack of research with inclusion of the perspectives of autistic adults in its conduct or design. The authors present the findings from Australia's first national longitudinal study (Australian Longitudinal Study of Adults with Autism (ALSAA)) involving autistic adults aged 25 years and older. The study gathers a wide range of data points using standardised measures, gathers data from a community comparison group and includes autistic adults in the study design. The paper sets out the methodological processes and inclusive protocol adopted in the ALSAA and presents participant characteristics and feedback from the baseline data collection. The paper overall is very well written, and clearly justifies the importance of the authors work.

***Thank you for your comments.

Reviewer: 3

Reviewer Name: Kristen Gillespie-Lynch

Institution and Country: College of Staten Island & The Graduate Center, CUNY Please state any competing interests or state 'None declared': None declared

Please leave your comments for the authors below The proposed project addresses a key gap in the literature, risk factors that may lead to the inequalities in mental health outcomes that have been observed among autistic adults. It proposes a creative strategy to address the need for longitudinal data to attain a better understanding of adult outcomes in autism. The key idea of setting up an online recruitment mechanism that allows longitudinal assessments to examine change across time is creative and very promising. However, more detail about the specific research questions to be

addressed and in particular, how they can be addressed with longitudinal data, is needed. I understand that the beauty of this type of recruitment mechanism is that it allows one to address multiple research questions and to observe unexpected patterns in the data, but more of a sense of how this recruitment mechanism allows one to understand risk factors for inequalities in mental health care is needed, since this is initially set up as the primary rationale for the study.

***The ALSAA has a broad aim to “to identify and comprehensively describe the profiles of Australian autistic adults and to compare them to a control group”. We added to the discussion of aims at the end of the introduction that “Longitudinal data will further allow the determination of predictors versus correlates across a range of outcomes .”

The inclusion of autistic adults in study design, the focus of the study on research questions that have been highlighted by autistic self-advocates as important and the responsiveness of the study designers to feedback from the first wave of data collection is a major strength of this study. However, more clarity about the ways that autistic advisors are involved is needed to ensure that their involvement is not tokenistic. The scope and process of autistic advisors' involvement requires more clarification. It is unclear if autistic advisors provided substantive input on the research questions or played more of a clarification of measures role. It currently sounds more like they did the latter but the former would be more helpful. It is also unclear why autistic advisors were not involved in data analysis.

***The reviewer raises important points regarding the input of the autistic advisors. Input in the initial stages of the project were the advisors reviewing and providing feedback on domains suggested by the research team. The advisors provided extensive and specific feedback and about domains of interest and different measures to include or exclude. As the project has progressed we have endeavoured to increase the input and improve the processes working with the advisory team. The publication of the Inclusive Research Framework from the Autism CRC assisted to guide these processes along with other inclusive research frameworks (e.g. from NHMRC). We acknowledge that we haven't achieved the highest level of inclusive research however we continue to strive to improve upon this. For example the advisors for wave 2, included a larger group with a more substantive input. While we have not had advisors as part of the data analysis process as yet, this is certainly the plan in upcoming co-produced papers.

We have added further clarity regards this in the Design section: “An expanded group of eleven advisors had greater input in designing the 2-year follow-up, including the selection of focus topic areas.... Advisors have provided feedback on ongoing research outputs critiquing interpretations of findings suggested by the researchers.... Advisors to date have not been involved in data analysis, though several co-produced peer-research projects are currently underway.”

As the authors also note, the sample is unlikely to be representative of the broader population. More efforts to recruit a more representative sample (and a better matched comparison group) would increase the impact of this project.

***Thank you for your comments, we will make these efforts in future recruitment and data gathering exercises.

Below are specific points to address:

Abstract: Briefly clarify what the difference between informant and carer report is and how many people filled out each type. Add “the” before majority.

***We have clarified that “Three questionnaires were developed: self-report, informant report (i.e. proxy report), and carers (i.e. carer experiences and characteristics).” We have added to the sentence that “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” has been added.

Highlights: Add typically before focused in first highlight as there is increasing research focused on adults, though still not enough relative to younger people.

***“typically” has been added.

The percentages reported in the highlights are confusing. Do you mean 50% of 295? If so, state the n who are female out of the total.

***The dot point has been reworded as follows: “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”

Page 6: The point about intellectual disability comes out of the blue after the mental health conditions point. When discussing intellectual disability, it would also be helpful to highlight Dawson’s and Mottron’s research showing that commonly used IQ tests often underrepresent the IQ of autistic people.

***We have added a comment and citation relating to Dawson et al 2007: “Earlier studies report that between 40 to 70% of those with autism also have an intellectual disability(23-25) though a more recent study reports fewer adults on the autism spectrum as having intellectual disability(2) and intelligence tests may underestimate performance of autistic individuals(26)”

Page 8: Clarify if only one 2 year follow up is planned (as seems to be the case in this portion of the text) or if frequent follow-ups every two years are planned as suggested earlier in the abstract.

***We have added “and further follow-ups as resources allow”

Page 9: When introducing the composition of the AASLA, clarify how many autistic adults and carers are involved in the advisory network when introducing them. It says below how many have reviewed it so far, but it is not clear what the total number involved are or how it was determined who would review or when they were invited to do so. Indicate the timeframe and nature of their involvement and their compensation for being involved. When saying that this approach was developed based on the principles of inclusive research and Nicolaidis’ work, introduce which principles in particular guided this work. Wording “has guided” in this section unclear, not clear what is guiding what. Indicate if and how advisors provided more substantive guidance on content and the constructs assessed rather than just on wording.

***As above, we have made several clarifications to this section, including the incorporation of the ‘Patient and Public Involvement’ questions.

“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 with input from a research advisory network, initially consisting of 6 autistic adults and 2 family members/carers of autistic adults who helped develop the surveys to ensure the questions were relevant, accessible and valid.

How did you involve patients in the design of this study?

The ALSAA Inclusive Research Protocol was developed based on the principles of inclusive research(54), the Autism CRC report Inclusive Research Practice Guides and Checklists for Autism Research(55) (e.g. Checklist 3: Practices that Support Inclusion of Individuals on the Autism Spectrum in Advisory and Reference Groups), and procedures similar to those employed by Nicolaidis and colleagues(56) (e.g. choosing research questions, adapting data collection instruments, interpreting results) (see Table 1).

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

Since the commencement of the ALSAA, this inclusive research protocol has been reviewed by seven of the autistic advisors and one carer advisor and has guided the interactions between researchers and advisors in the development of baseline outputs and the 2-year follow-up design. Specifically, in the design stage of the ALSAA, members of the advisory network were asked to identify ambiguous or inappropriate language, formatting issues and measures which they thought may be interpreted inappropriately or differently due to poor clarity or wording. An expanded group of eleven advisors had greater input in designing the 2-year follow-up, including the selection of focus topic areas. As per the protocol advisors are given forewarning, then one month to respond to most requests from the research team, with more response time as needed. Advisors have also provided feedback on ongoing research outputs critiquing interpretations of findings suggested by the researchers, with compensation more recently available for advisors' time. Advisors to date have not been involved in data analysis, though several co-produced peer-research projects are currently underway. Advisors have also assisting assisted in promoting recruitment materials particularly through social media.

How will the results be disseminated to study participants?

The ALSAA sends quarterly newsletters to all participants."

Page 10: The point about participants being unwilling to self-report requires some clarification. Why would an informant be asked to report if the participant was unwilling to report? There are many controversies about whether others can stand in for people who are not able to report themselves that need to be addressed a bit more when introducing this idea.

***For clarity we changed the word "unwilling" to "preferred not to". The text shortly goes on to describe that "The content of the informant survey is slightly different to the self-report survey (see Table 2) due to some measures, such as the Patient Health Questionnaire-9 (PHQ-9)(57), having no informant version available"

Page 11: The inclusion of multiple opportunities to provide feedback during the survey is a strength of the design. It might be good to add more open-ended questions as well.

***Thank you, we will look to add more open-ended questions in future data gathering activities.

Piloting: When describing the piloting process, replace "a small number" with the exact number of autistic advisors who provided feedback if possible. A diagram would be helpful to clarify this process.

***We have clarified that "Four autistic adults piloted the self-report questionnaire and two caregivers piloted the carer and the informant questionnaires". We feel a diagram is not warranted for this minor aspect of the process undertaken in the study.

Recruitment: Indicate how the number 160 was decided upon. Was a power analysis conducted?

***We have added a power analysis as follows: “A recruitment target of 160 autistic adults was set to allow for regression analyses using multiple predictor variables. Power analyses, undertaken using power calculation software, suggested this would be a sufficient sample size with power (1 - β) set at .80 and $\alpha = .05$ to detect a Cohen’s f^2 effect size estimate of at least .1 using multiple regression models with 7 predictors.”

Page 12: There have been increasing critiques of the AQ. It might be good to consider a different autistic traits measure for the future like the RAADS-14 or SRS.

***Thank you, we are aware of these critiques and will look to include other measures in future data gathering exercises.

Provide more clarity about the procedure surrounding the checklist evaluating capacity to consent.

***We added that “The checklist asks several question relating to the person’s ability to understand the study, benefits and risks, withdrawal and complaints, to determine if a person responsible consent should be obtained additionally or separately.”

Page 13: Clarify how qualtrics data is linked to participant information in order to allow follow up assessments.

***We added that “Data from Qualtrics, re-identifiable by participation code,”

Clarify what the alpha level is for the study. Given the very large number of assessments, a correction would be recommended.

***We added that “with the level of significance $<.05$. Family-wise alpha was not adjusted due to the possibility of reducing probability of detecting true positive results”. Further, the majority of comparisons used separate data points. In the future we will report affect sizes and apply statistical corrections depending on the research question.

Page 14: Clarify the recruitment process for non-autistic participants and report if completion status varied as a function of participant characteristics for non-autistic participants. Also add the direction of the trend toward an effect of age in terms of completion for the autistic sample. Provide more detail about how age was quantified. It is a bit odd that age is approximate since the lack of research about older autistic adults is one of the rationales for the study.

***The approximate age is only relating to a small group of potential participants who were non-respondents, as we recorded the week as opposed to the specific day they registered for the study if they registered over the phone. All other ages are calculated exactly based on DOB and date of survey completion. We added regarding the non-autistic participants “From available data there was no significant difference in gender, $X^2(4, n=337) = 1.07, p=.898$, 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, $X^2(4, n=215) = 6.98, p=.137$, and age [$F(4, 4) = 0.96, p=.43$].”

Page 15: It is not clear why there was no difference in rural/remoteness based on the p value provided here. Perhaps the alpha was lower than .05 as recommended above? Given that you will have many analyses due to the large number of measures, it will be important to report effect sizes in addition to p values and to use statistical corrections.

***We have not used statistical corrections for this manuscript as described above. The p value was equal to (above) .05 in this case so non-significant.

Page 16: It is not clear why the control sample is not better matched to the autistic sample in terms of gender, particularly given that females are already overestimated in the autistic sample. I would suggest attempting to better match the samples. The high representation of autistic females in this sample may suggest that the sample is not representative of the broader population. More effort recruiting males and those with ID would be useful to improve the representativeness of the sample. In-person recruitment could likely help with this, particularly given that the option of paper based forms is available.

***Other research as noted in our limitations section has also found this gender bias in online research. We did make efforts to gather more males and participants with ID as noted "additional recruitment activities targeted adults on the spectrum with intellectual disability, and males without autism." In general, these activities appeared to boost our participant numbers overall as opposed to specifically in the targeted groups.

More detail about the employment status analysis is needed to interpret it.

***We have added "see Table 4" to point readers to the data on which the chi-square analysis is based.

It would be helpful to evaluate if those who were not yet formally diagnosed differed from those who reported that they did have a formal diagnosis.

***This will be a target for a future research project, with a PhD scholar already looking at aspects relating to these groups.

Page 19: Indicate how many people who participated reported an ID, how this was ascertained and how many of them participated via an informant. Also indicate if an informant participated for anyone without an ID, and if so how many times this happened. The informant approach seems a bit problematic to me so would benefit from further clarification. I now see this is in the table section.

***Yes this information is available in the table.

Please clarify how ID was assessed.

***ID was self-reported

There is a lot of missing data which may make it challenging to observe patterns over time.

***Missing data will be managed depending on the research question being explored/investigated, measures used, and is likely related to the length of the survey participants completed

Page 20: More clarity about the specific research questions being explored would be helpful here (and throughout) particularly given that the authors point out that the research questions will help

determine the utility. Direct involvement of autistic people in research question development would also make the study more inclusive.

***A broad range of research questions are being explored as noted in the opening to the discussion. Autistic advisors are being involved in determining and prioritising research questions as has been further in the inclusive research section.

Page 21: Clarify how the autistic advisors improved the methodology.

***We have expanded on our comments that “Input from autistic advisors has already improved the quality and relevance of initial outputs(65), for example identifying potential alternative interpretations of findings based on lived experiences, potential differences in autistic interpretations of scale items, and modifying the methodology in one instance(68) changing a purely quantitative study into a mixed methods design.”

VERSION 2 – REVIEW

REVIEWER	BAGHDADLI, AMARIA University Research and Hospital Center (CHU) of Montpellier, Department of Psychiatry and Autism Resources Center, School of medicine; Centre de recherche en Epidemiologie et Sante des Populations, U1178 ,INSERM
REVIEW RETURNED	17-Jun-2019

GENERAL COMMENTS	The authors made all the corrections requested, and they provided all the necessary justifications. I thank them for it. Their article can now be accepted for publication
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REVIEWER	Kristen Gillespie-Lynch College of Staten Island & The Graduate Center, CUNY
REVIEW RETURNED	07-Jul-2019

GENERAL COMMENTS	<p>This paper addresses a number of important gaps in the research literature. The rationale for the study and the description of the study design process are now much more clearly described and compelling than previously.</p> <p>Below are remaining comments to address. The issues noted below about clarity concerning the analytic approach (including a clear strategy for balancing different types of error) and reliability of measures in the current sample, as well as a bit more clarity about how the involvement of autistic people has changed over time and what they have contributed thus far (though this has improved greatly from the earlier draft) are particularly important to address when setting up a large, longitudinal data base like this.</p> <p>Page 7 line 25: improve services how best to improve worded oddly</p> <p>Page 8 line 25: Make clearer that comparison groups have been lacking in prior work, not clear what the comparison to prior work is for this clause currently.</p> <p>Page 10 line 37: Clarify a bit more the shift from no compensation to current compensation (i.e. what prompted this shift and the nature of the compensation).</p> <p>Page 10 line 51: Provide a brief overview of what is included in the newsletters</p>
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	<p>Page 14 line 35: Comma needed after researchers</p> <p>Page 15 line 29: DF error seems to be incorrect as it is 4 for both treatment and error here and below. Please explain what the 4 in the chi squared for gender refers to and where the number 337 in that analysis comes from.</p> <p>Page 16 line 30: Provide the number of participants who were pleased with the focus of the research as well as the number of participants who were concerned about study length and forced choice responses. Provide examples of a few additional topics of interest that were requested and an example or two to clarify why people found the social support questions upsetting. More detail about the feedback will be useful for other researchers conducting research in this area.</p> <p>Page 16 line 48: Clarify if living as couple and married were distinct categories- if not report couple first with married as subcategory.</p> <p>Page 16 line 55: Did not differ from rather than to. Clarify what the 4 refers to.</p> <p>Page 17 line 20: Clinician needs an s.</p> <p>Page 17 line 27: Self report- wording here odd maybe needs self-reported and another word.</p> <p>Page 17 line 58: Different from</p> <p>Page 19 line 19: Among others wording odd. Need some comparison group in second part of sentence to ground the compare part of the aim.</p> <p>Page 20 line 3: Clarify if you used non-parametric analyses for things like time to complete above as it is likely that they were skewed. At beginning of results section, it would be helpful to include in the analytic approach section an overview of the grouping and analysis approach, how you checked for kurtosis and skew, and strategies to address when issues with normal distributions were observed.</p> <p>Page 20 line 32: While involvement of autistic adults is a strength, it would be good to interrogate a bit more some limitations with this involvement thus far and the process of improving involvement over time i.e. only involving them in analyses in later stages of the project, the degree to which recommendations were utilized, etc. Most of us who are doing participatory work are struggling with being truly participatory and self-reflection on the process is useful for moving the field forward. It would also be helpful to clarify what future outputs autistic people are involved in and how their involvement increased over time.</p> <p>Page 21 line 38: Clarify here what percentage of the sample was people with an ID. i know this is in the table but it would be helpful to highlight in text..</p> <p>Page 22: Clarify what proportion of the measures have been shown to be valid and/or reliable for autistic adults in past samples. Actually it would be very helpful to report alphas for all scales in the current methods section to see what the reliability is in this sample.</p> <p>The lack of correction for multiple tests should be listed as a major limitation. While you provided justification for not missing positive results, the citation used provides an overview of the controversy about corrections rather than providing a recommendation not to use corrections. They suggest highlighting the risk of type 1 versus 2 errors in the manuscript, using a global outcome measure, and providing effect sizes as a way to address issues with multiple comparisons. So it is not clear why it is not equally important in the current manuscript to avoid viewing null results as significant i.e. balancing the two types of error. Particularly given the large</p>
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	<p>number of studies derived from this data set, lack of any correction for type 2 error in each individual study seems quite problematic. You indicate in your response letter that you plan to use corrections in the future. It would be good to provide more clarity about the process of deciding when corrections are needed in an overall analytic approach section in this paper which aims to set up the value of the database so should include an overview of the approach to statistical corrections that will be used in this and future studies from this data set.</p> <p>Re the prior feedback, it would be helpful to briefly cite why there have been some critiques of the AQ, since you are currently relying upon it and what your plans are for including other autistic trait measures when moving forward as noted in your response letter but not in the paper itself.</p>
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VERSION 2 – AUTHOR RESPONSE

Reviewers' Comments to Author:

Reviewer: 1

Reviewer Name: Baghdadli

Institution and Country: University Research and Hospital Center (CHU) of Montpellier, Department of Psychiatry and Autism Resources Center, School of medicine; Centre de recherche en Epidemiologie et Sante des Populations, U1178, INSERM, France Please state any competing interests or state 'None declared': None declared

The authors made all the corrections requested, and they provided all the necessary justifications. I thank them for it. Their article can now be accepted for publication

*** Thank you for your review

Reviewer: 3

Reviewer Name: Kristen Gillespie-Lynch

Institution and Country: College of Staten Island & The Graduate Center, CUNY, USA Please state any competing interests or state 'None declared': None declared

This paper addresses a number of important gaps in the research literature. The rationale for the study and the description of the study design process are now much more clearly described and compelling than previously.

Below are remaining comments to address. The issues noted below about clarity concerning the analytic approach (including a clear strategy for balancing different types of error) and reliability of measures in the current sample, as well as a bit more clarity about how the involvement of autistic people has changed over time and what they have contributed thus far (though this has improved greatly from the earlier draft) are particularly important to address when setting up a large, longitudinal data base like this.

*** We have addressed these issues as noted specifically below.

Page 7 line 25: improve services how best to improve worded oddly

*** Thank you, we have reworded this sentence “Longitudinal studies are crucial for exploring changing requirements over time and to inform services how best to respond to the needs of autistic adults”

Page 8 line 25: Make clearer that comparison groups have been lacking in prior work, not clear what the comparison to prior work is for this clause currently.

***we have reworded the sentence and added “which is often lacking in prior work”.

Page 10 line 37: Clarify a bit more the shift from no compensation to current compensation (i.e. what prompted this shift and the nature of the compensation).

*** We have added “In Time 2 data gathering and analyses, recently 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.”

Page 10 line 51: Provide a brief overview of what is included in the newsletters

*** We have added “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.”

Page 14 line 35: Comma needed after researchers

***Comma has been added

Page 15 line 29: DF error seems to be incorrect as it is 4 for both treatment and error here and below. Please explain what the 4 in the chi squared for gender refers to and where the number 337 in that analysis comes from.

***we have clarified “there was no significant difference in binary gender” ... “for the self-reporting autistic adults (see Table 1).” This chi squared analysis is based on the first row of Table 1, some potential participants did not report gender upon registration, and given small numbers binary gender only was included in this analysis.

Page 16 line 30: Provide the number of participants who were pleased with the focus of the research as well as the number of participants who were concerned about study length and forced choice responses. Provide examples of a few additional topics of interest that were requested and an example or two to clarify why people found the social support questions upsetting. More detail about the feedback will be useful for other researchers conducting research in this area.

***This paragraph has been revised as follows: 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”.

Page 16 line 48: Clarify if living as couple and married were distinct categories- if not report couple first with married as subcategory.

***We have clarified this sentence as “Across all autistic participants 36% were living as a couple with 25% of the sample currently married”

Page 16 line 55: Did not differ from rather than to. Clarify what the 4 refers to.

***We have corrected the sentence and added the following detail to help understand the degrees of freedom “Self-reporting autistic adults did not differ from control participants on rural / remoteness according to Australian Statistical Geography Standard-Remoteness Area (ASGS-RA) classification, $\chi^2(4, n=378) = 9.36, p=.05$ (n=21 missing), with no control participants and minimal autistic participants living in remote or very remote Australia”

Page 17 line 20: Clinician needs an s.

***Corrected

Page 17 line 27: Self report- wording here odd maybe needs self-reported and another word.

***Changed to “self-reporting”

Page 17 line 58: Different from

***Changed

Page 19 line 19: Among others wording odd. Need some comparison group in second part of sentence to ground the compare part of the aim.

***Changed to “and other outputs”

Page 20 line 3: Clarify if you used non-parametric analyses for things like time to complete above as it is likely that they were skewed. At beginning of results section, it would be helpful to include in the analytic approach section an overview of the grouping and analysis approach, how you checked for kurtosis and skew, and strategies to address when issues with normal distributions were observed.

***We have added the comment to the end of the Statistical Analysis section “Data were checked for kurtosis and skew. Non-parametric Spearman rank correlation was used to determine the correlation between time taken to complete the self-report survey and level of satisfaction.”

Page 20 line 32: While involvement of autistic adults is a strength, it would be good to interrogate a bit more some limitations with this involvement thus far and the process of improving involvement over time i.e. only involving them in analyses in later stages of the project, the degree to which recommendations were utilized, etc. Most of us who are doing participatory work are struggling with

being truly participatory and self-reflection on the process is useful for moving the field forward. It would also be helpful to clarify what future outputs autistic people are involved in and how their involvement increased over time.

***We have added: "Although at times advisors suggestions were in conflict with each other or beyond the scope of the study, as each advisor communicated individually with the research team there was no direct conflict between advisors. Feedback is given to advisors as to what advice has been used or not, and why. Little literature was available at the time of commencing the ALSAA and processes were developed iteratively based on understanding of partnering with autistic adults and guidance from our advisors. Growing relationships with advisors over time and seeking feedback as to preferences for collaboration, the approach developed has led to harmonious collaborative relationships between the researchers and advisors, and will continue to evolve. An important consideration working with the advisors is the allowance of lead time and processing time, which has created difficulty for some student projects".

Page 21 line 38: Clarify here what percentage of the sample was people with an ID. i know this is in the table but it would be helpful to highlight in text..

*** A percentage has been added

Page 22: Clarify what proportion of the measures have been shown to be valid and/or reliable for autistic adults in past samples.

***We have added "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-2A59, while the PHQ-9 60 was more recently validated using a combined ALSAA and SASLA data set."

Actually it would be very helpful to report alphas for all scales in the current methods section to see what the reliability is in this sample.

***We feel this is beyond that scope of the paper that is at describing the cohort and processes used. We are working on a series of scale validations as noted, and would be reporting in more detail on the measures used in subsequent papers, such as our validation of the PHQ-9.

The lack of correction for multiple tests should be listed as a major limitation. While you provided justification for not missing positive results, the citation used provides an overview of the controversy about corrections rather than providing a recommendation not to use corrections. They suggest

highlighting the risk of type 1 versus 2 errors in the manuscript, using a global outcome measure, and providing effect sizes as a way to address issues with multiple comparisons. So it is not clear why it is not equally important in the current manuscript to avoid viewing null results as significant i.e. balancing the two types of error. Particularly given the large number of studies derived from this data set, lack of any correction for type 2 error in each individual study seems quite problematic. You indicate in your response letter that you plan to use corrections in the future. It would be good to provide more clarity about the process of deciding when corrections are needed in an overall analytic approach section in this paper which aims to set up the value of the database so should include an overview of the approach to statistical corrections that will be used in this and future studies from this data set.

***We have removed the citation referred to, and in its place added “No correction was applied for multiple statistical tests in this manuscript, as the purpose was to explore baseline differences in the cohorts, and determine potential variables that may be useful covariates or possible confounders in later hypothesis testing⁶⁵” referencing this paper
<https://www.sciencedirect.com/science/article/pii/S0012369211603401?via%3Dihub>

***We have also added to the limitations section “Future researchers using the ALSAA dataset will need to consider balancing type 1 and type 2 errors⁶⁵. A data governance structure is being established, with requests for ALSAA data requiring researchers to outline a statistical plan and data points they will be using, which will assist in managing any concerns of multiple statistical testing without correction.”

Re the prior feedback, it would be helpful to briefly cite why there have been some critiques of the AQ, since you are currently relying upon it and what your plans are for including other autistic trait measures when moving forward as noted in your response letter but not in the paper itself.

***We have added “Given critiques of applicability and validity of the AQ-short^{63, 64}, we plan to include the Ritvo Autism and Asperger Diagnostic Scale-14 (RAADS-14)⁶⁴ in future data gathering.”

VERSION 3 – REVIEW

REVIEWER	Kristen Gillespie-Lynch College of Staten Island & The Graduate Center; CUNY
REVIEW RETURNED	01-Oct-2019

GENERAL COMMENTS	The rationale for this study and associated literature review are compelling. Although transparency about the degree to which the process is inclusive and the statistics are sufficiently rigorous has definitely improved, revisions remain needed to ensure that this longitudinal study has a sufficiently strong foundation to refer back to this paper in future work. The inclusive nature of the dataset in particular needs further interrogation as lack of specificity about
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inclusive practices can lead to tokenism and pronounced power imbalances, so we can end up working against the project of making autism work more truly inclusive by watering down the meaning of inclusive through insufficient clarity and self-reflection about processes.

This is something we are all struggling with as we aim to make our work more participatory, but since your aim in this paper is to set up an inclusive database, it is particularly important to really engage with these tensions more fully.

The statistical approach also remains poorly specified. It is not yet exactly clear from the aims of the paper (where you say you describe participant characteristics) why it is important to compare the autistic and non-autistic samples and what you plan to do with these comparisons. Being very specific about the aims of the analyses will help guide the analytic approach. Since there are more females in the control group, it would be good to explore that in particular a bit more in analyses to see if future studies from this database should match on gender. We have found that our findings change when gender imbalances are corrected, so it would be far preferable for interpreting subsequent findings to aim from here on out on recruiting a control group that is matched on gender (particularly since the control group is presumably easier to recruit than the autistic group).

Here are specific ways to improve transparency:

Page 9 & 10: It would be helpful to more critically examine the degree to which the inclusive approach is similar to the approach used by Nicolaidis et al (which is a full collaboration between autistic and non-autistic people) since it is described here as similar to their approach.

For example, developing research questions is listed here in text as something autistic advisors are involved with but then is not described in Table 1 (where it seems like their input is at the measures phase).

It sounds in text like there were different levels of involvement in phase 1 and phase 2. So it would be helpful to more clearly define how their involvement in selection of focus topics in stage 2 was carried out- were they given a list of topics or did they generate topics. What was the link between topics and research questions re the point about their being involved in generating questions? It would be helpful to perhaps provide an example or two of the co-produced research projects, with a clear description about the research steps the autistic advisors were involved in.

Overall, specify more clearly when in the project autistic advisors get involved and how much input they have over research questions.

Also since you say in the table that recruitment of advisors is inclusive of people with ID, specify how many advisors currently have ID. There have been a number of concerns in the inclusive literature about the degree to which advisorships truly are inclusive of the diversity of autism, so if inclusion of cognitive diversity within the spectrum was a clear goal, specify the degree to which it was accomplished.

Also clarify the degree to which advisors are involved in preparing materials for dissemination, as this is an important aspect of inclusive process.

See Jivraj et al for why it is important to be very specific about the ways in which a process is and is not inclusive:
 Jivraj, J., Sacrey, L. A., Newton, A., Nicholas, D., & Zwaigenbaum, L. (2014). Assessing the influence of researcher-partner

	<p>involvement on the process and outcomes of participatory research in autism spectrum disorder and neurodevelopmental disorders: A scoping review. <i>Autism</i>, 18(7), 782-793.</p> <p>Page 21: More information about how divergent opinions were decided between is needed. One of the key strengths of Nicolaidis' and colleagues approach is that they have very clear guidelines on how to reach consensus. Not describing this process clearly (and not having the autistic people engage with one another as well as researchers) sets up high possibility for power imbalances favoring researchers and minimizing the degree to which the process is really inclusive given the high power differential.</p> <p>Re your point about there not being good guidelines yet for best practices, there is a very useful paper just published by Nicolaidis' group that does describe their idea of best practices very clearly. It would be helpful to use that paper to critically interrogate the degree to which your current design is or is not inclusive: Nicolaidis, C., Raymaker, D., Kapp, S. K., Baggs, A., Ashkenazy, E., McDonald, K., ... & Joyce, A. (2019). The AASPIRE practice-based guidelines for the inclusion of autistic adults in research as co-researchers and study participants. <i>Autism</i>, 1362361319830523.</p> <p>Since you are not using any corrections and are running a large number of analyses, it would be preferable to include effect sizes for all analyses.</p> <p>Page 23: When saying you should consider balancing type 1 and type 2 error, indicate how you plan to do this. Since you have been and will be drawing a lot of different analyses from this same data set, it would be good to be very clear about an overarching plan in this regard (i.e. indicate what factors will be considered by the data governance structure and how decisions will be processed- more transparency about this would be very helpful). As described at the conclusion of the paper you cite above to support your not using corrections when examining group differences (they do state that it is best to err on the side of detecting differences to control for as you note) but also conclude: "If a small number of hypotheses have been stated a priori or if the purpose of the study is exploratory, then such corrections are probably not needed. However, in the absence of hypotheses, they are required." Their latter point indicates a need for more specificity about your approach to corrections going forward.</p>
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VERSION 3 – AUTHOR RESPONSE

Reviewers' Comments to Author:

Reviewer: 3

Reviewer Name: Kristen Gillespie-Lynch

Institution and Country: College of Staten Island & The Graduate Center; CUNY, USA Please state any competing interests or state 'None declared': None declared

The rationale for this study and associated literature review are compelling.

Although transparency about the degree to which the process is inclusive and the statistics are sufficiently rigorous has definitely improved, revisions remain needed to ensure that this longitudinal

study has a sufficiently strong foundation to refer back to this paper in future work. The inclusive nature of the dataset in particular needs further interrogation as lack of specificity about inclusive practices can lead to tokenism and pronounced power imbalances, so we can end up working against the project of making autism work more truly inclusive by watering down the meaning of inclusive through insufficient clarity and self-reflection about processes.

This is something we are all struggling with as we aim to make our work more participatory, but since your aim in this paper is to set up an inclusive database, it is particularly important to really engage with these tensions more fully.

*** We have added further specificity about inclusive practices, including comparison with the AASPIRE guidelines, and further detailing areas of engagement, detailing limitations of the approach taken and steps moving forwards. Although repeated below, content changed or added includes:

“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”

“autistic adults who helped determine areas of investigation, and develop the surveys”

“Autistic advisors input is sought in regard to areas of investigation, questionnaire design and interpretation of results. The researcher will need to consider that ranking of priority areas may be a difficult task for some advisors and employ other consensus decision making strategies.”

“In contrast to Nicolaidis and colleagues⁵⁷, ALSAA employs an advisory approach as opposed to participatory approaches where final decision-making rests with the committee, and there has not been any group or in-person consultation sessions, which is a preference of some autistic advisors. Guidelines such as those developed by AASPIRE⁵⁸ were not available at the time of the study design.”

“Moving forwards, we are considering implementing the “Five-Finger Decision Method”⁸⁶ to ensure advisors input has been addressed. Little literature was available at the time of commencing the ALSAA and processes were developed iteratively based on understanding of partnering with autistic adults and guidance from our advisors. Our processes are largely consistent with recent guidelines now available⁷⁷, with deviation particularly relating to recruiting a balance of autistic community leaders and other autistic adults as advisors, a structured process for decision making, and a lack of joint meetings / collaboration between advisors / a visioning exercise. We may benefit from again consulting with our advisors and seeing if there is interest in additional areas of involvement or additional peer-researched co-authored outputs.”

“A list of topic areas was suggested to the advisors based on a review of time 1 participant feedback. Advisors reviewed the list and added more topics or specific research questions of interest. A few advisors expressed difficulty or did not complete a task of ranking the topics, hence the researchers were required to make the final shortlisting of new topics areas to be included in data gathering.” “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.”

“In comparison to several other studies⁵⁹ autistic adults are involved in the majority of stages of the study apart from collecting data, they have been involved in review of some media related lay summaries but have not typically been involved in development of newsletter content.”

“Advisors have been approached to assist with autism related media enquiries and will continue to do so when opportunities arise.”

“Although this potentially creates a power imbalance between the advisors and researchers, which is also inherent in an advisory process, to date there has been little feedback from advisors that was not able to be incorporated into the study processes or outputs. Ideally autistic adults and researchers would reach consensus in an open forum in person. Due to limitations with resourcing, geographical dispersion and majority of autistic advisors preferring to provide individual feedback in writing this was

difficult to achieve. Moving forwards, we are considering implementing the “Five-Finger Decision Method”⁸⁶ to ensure advisors input has been addressed”

The statistical approach also remains poorly specified. It is not yet exactly clear from the aims of the paper (where you say you describe participant characteristics) why it is important to compare the autistic and non-autistic samples and what you plan to do with these comparisons. Being very specific about the aims of the analyses will help guide the analytic approach.

***We have added to the aims of the cohort profile “The aims of this paper are to describe the methodological processes and the inclusive protocol adopted in the ALSAA, as well as to present participant characteristics and feedback from the baseline data collection.” That “Exploratory baseline comparisons aim to identify covariates or confounders for consideration in future studies.” In the opening to the findings to date, we have added “Exploratory analyses have highlighted factors such as gender, education and employment that are potential confounders or covariates that need to be considered in future analyses.”

Since there are more females in the control group, it would be good to explore that in particular a bit more in analyses to see if future studies from this database should match on gender. We have found that our findings change when gender imbalances are corrected, so it would be far preferable for interpreting subsequent findings to aim from here on out on recruiting a control group that is matched on gender (particularly since the control group is presumably easier to recruit than the autistic group).

*** The reviewer identifies an important issue which we have considered extensively. During development of the study we were considering usefulness and potential benefits of including a control group. We agreed that the inclusion of a control group may be specifically useful for those measures where there are not a lot of comparative data from the typical population. An example of this was our recent publication (Taylor et al) which compared leisure profiles of Autistic and non-Autistic adults. This exploration of a poorly understood construct (leisure participation) and comparison between Autistic and non-Autistic adults allowed for specific examination of factors which may be different/similar and contribute to important outcomes such as mental health. While the gender disparity is an important consideration for future studies which utilise the control group data, we feel that the impact of gender should be specifically considered for each variable. We have added some additional preliminary analysis where we checked if the significant differences identified held when limited to one gender, and added the relevant commentary e.g. “and remained significant if limited to female or male participants.” And “Of interest, differences in education and employment were not significant if analyses were limited to male participants”

***In our experience recruiting for the non-autistic group is more difficult given the limited incentives that we are able to offer. Past attempts at targeted recruitment have resulted in greater participant numbers but in all participant groups. As noted in limitations, “Limitations and strengths of the ALSAA study design will largely depend on the specific research question being explored, with sufficient sample size and data points to partial-out subgroups and non-matched controls or to account for common method variance as needed.”

Here are specific ways to improve transparency:

Page 9 & 10: It would be helpful to more critically examine the degree to which the inclusive approach is similar to the approach used by Nicolaidis et al (which is a full collaboration between autistic and non-autistic people) since it is described here as similar to their approach.

For example, developing research questions is listed here in text as something autistic advisors are involved with but then is not described in Table 1 (where it seems like their input is at the measures phase).

***We thank the reviewer for identifying this as an area requiring further clarity. We have adjusted the description of what was undertaken to ensure that this is clear to the reader. We have added “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” also that “autistic adults who helped determine areas of investigation, and develop the surveys”

*** We have added to Table 1 “Autistic advisors input is sought in regard to areas of investigation, questionnaire design and interpretation of results. The researcher will need to consider that ranking of priority areas may be a difficult task for some advisors and employ other consensus decision making strategies.”

*** We also made several edits to the “Patient and Public Involvement” section including “In contrast to Nicolaidis and colleagues⁵⁷, ALSAA employs an advisory approach as opposed to other participatory approaches where final decision making rests with the committee), and there has not been any group or in-person consultation sessions, which is a preference of some autistic advisors. Guidelines such as those developed by AASPIRE⁵⁸ were not available at the time of the study design.”

***In limitations we added “Moving forwards, we are considering implementing the “Five-Finger Decision Method”⁸⁶ to ensure advisors input has been addressed. Little literature was available at the time of commencing the ALSAA and processes were developed iteratively based on understanding of partnering with autistic adults and guidance from our advisors. Our processes are largely consistent with recent guidelines now available⁷⁷, with deviation particularly relating to recruiting a balance of autistic community leaders and other autistic adults as advisors, a structured process for decision making, and a lack of joint meetings / collaboration between advisors / a visioning exercise. We may benefit from again consulting with our advisors and seeing if there is interest in additional areas of involvement or additional peer-researched co-authored outputs.”

It sounds in text like there were different levels of involvement in phase 1 and phase 2. So it would be helpful to more clearly define how their involvement in selection of focus topics in stage 2 was carried out- were they given a list of topics or did they generate topics. What was the link between topics and research questions re the point about their being involved in generating questions? It would be helpful to perhaps provide an example or two of the co-produced research projects, with a clear description about the research steps the autistic advisors were involved in. Overall, specify more clearly when in the project autistic advisors get involved and how much input they have over research questions.

***Although autistic advisors did suggest specific research questions, these questions were used in the selection of topic areas and questionnaires, that could be later used to address research questions raised. We will refer reader to our recently published paper on loneliness as the best applied example of the inclusive research process. We revised reference to research questions and added the following: “A list of topic areas was suggested to the advisors based on a review of time 1 participant feedback. Advisors reviewed the list and added more topics or specific research questions of interest. A few advisors expressed difficulty or did not complete a task of ranking the topics, hence the researchers were required to make the final shortlisting of new topics areas to be included in data gathering.” We have also added “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.”

Also since you say in the table that recruitment of advisors is inclusive of people with ID, specify how many advisors currently have ID. There have been a number of concerns in the inclusive literature about the degree to which advisorships truly are inclusive of the diversity of autism, so if inclusion of cognitive diversity within the spectrum was a clear goal, specify the degree to which it was accomplished.

***The reviewer identifies an important point, inclusion of autistic adults with an intellectual disability as part of the advisory network was a goal of during development of timepoint 1 questionnaires. Unfortunately, we were not successful and we were unable to find an autistic adult with intellectual disability who was willing to be a part of our advisory network. We were able to find a carer of an autistic adult with intellectual disability to review our plans for the informant version of the questionnaire. We have been able to consult with an advisor with intellectual disability without autism as needed. We are continuing to work towards finding autistic adults with intellectual disability to be a part of our advisory network.

*** We have added the following note to Table 1 “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.”

Also clarify the degree to which advisors are involved in preparing materials for dissemination, as this is an important aspect of inclusive process.

See Jivraj et al for why it is important to be very specific about the ways in which a process is and is not inclusive:

Jivraj, J., Sacrey, L. A., Newton, A., Nicholas, D., & Zwaigenbaum, L. (2014). Assessing the influence of researcher–partner involvement on the process and outcomes of participatory research in autism spectrum disorder and neurodevelopmental disorders: A scoping review. *Autism*, 18(7), 782-793.

***Thank you for identifying this interesting reference. We added citation of this in the “Participant and Patient Involvement” section that “In comparison to several other studies⁵⁹ autistic adults are involved in the majority of stages of the study apart from collecting data, they have been involved in review of some media related lay summaries but have not typically been involved in development of newsletter content.” We have added the comment that “Advisors frequently assist in furthering the promotion of the study and outputs via social media.” However, as per Table 1 in regards to the preparing materials for dissemination the advisors last input has typically been “Once the manuscript or research output has been further developed, the autistic advisor should receive a copy of the manuscript prior to submission”. We have also added that “Advisors have been approached to assist with autism related media enquiries and will continue to do so when opportunities arise.”

Page 21: More information about how divergent opinions were decided between is needed. One of the key strengths of Nicolaidis' and colleagues approach is that they have very clear guidelines on how to reach consensus. Not describing this process clearly (and not having the autistic people engage with one another as well as researchers) sets up high possibility for power imbalances favoring researchers and minimizing the degree to which the process is really inclusive given the high power differential.

***We have added the following comment “Although this potentially creates a power imbalance between the advisors and researchers, which is also inherent in an advisory process, to date there has been little feedback from advisors that was not able to be incorporated into the study processes

or outputs. Ideally autistic adults and researchers would reach consensus in an open forum in person. Due to limitations with resourcing and majority of autistic advisors preferring to provide individual feedback in writing this was difficult to achieve. Moving forwards, we are considering implementing the “Five-Finger Decision Method”⁸⁶ to ensure advisors input has been addressed”

Re your point about there not being good guidelines yet for best practices, there is a very useful paper just published by Nicolaidis' group that does describe their idea of best practices very clearly. It would be helpful to use that paper to critically interrogate the degree to which your current design is or is not inclusive: Nicolaidis, C., Raymaker, D., Kapp, S. K., Baggs, A., Ashkenazy, E., McDonald, K., ... & Joyce, A. (2019). The AASPIRE practice-based guidelines for the inclusion of autistic adults in research as co-researchers and study participants. *Autism*, 1362361319830523.

***We have added the comment to the limitations that “Our processes are largely consistent with recent guidelines now available⁷⁷ , with deviation particularly relating to recruiting a balance of autistic community leaders and other autistic adults as advisors, a structured process for decision making, and a lack of joint meetings / collaboration between advisors / a visioning exercise. We may benefit from again consulting with our advisors and seeing if there is interest in additional areas of involvement or other peer-researched co-authored outputs.”

Since you are not using any corrections and are running a large number of analyses, it would be preferable to include effect sizes for all analyses.

***We have added Cramer's V and cohen's d to the relevant analyses.

Page 23: When saying you should consider balancing type 1 and type 2 error, indicate how you plan to do this. Since you have been and will be drawing a lot of different analyses from this same data set, it would be good to be very clear about an overarching plan in this regard (i.e. indicate what factors will be considered by the data governance structure and how decisions will be processed- more transparency about this would be very helpful). As described at the conclusion of the paper you cite above to support your not using corrections when examining group differences (they do state that it is best to err on the side of detecting differences to control for as you note) but also conclude: "If a small number of hypotheses have been stated a priori or if the purpose of the study is exploratory, then such corrections are probably not needed. However, in the absence of hypotheses, they are required." Their latter point indicates a need for more specificity about your approach to corrections going forward.

***As noted above, we added that “Exploratory baseline comparisons aim to identify covariates or confounders for consideration in future studies.” And that “Exploratory analyses have highlighted factors such as gender, education and employment that are potential confounders or covariates that need to be considered in future analyses.”

***Following the previous note that “A data governance structure has been established, with requests for ALSAA data requiring researchers to outline a statistical plan and data points they will be using, which will assist in managing any concerns of multiple statistical testing without correction.” we have added that “Any data requests will need to ensure that the hypotheses being tested do not duplicate use of data points in a way that would inflate the probability of Type 1 errors.”