

## PEER REVIEW HISTORY

BMJ Open publishes all reviews undertaken for accepted manuscripts. Reviewers are asked to complete a checklist review form (<http://bmjopen.bmj.com/site/about/resources/checklist.pdf>) and are provided with free text boxes to elaborate on their assessment. These free text comments are reproduced below.

### ARTICLE DETAILS

<b>TITLE (PROVISIONAL)</b>	Protocol for a prospective longitudinal study investigating the participation and educational trajectories of Australian students with autism
<b>AUTHORS</b>	Roberts, Jacqueline; Adams, Dawn; Heussler, Helen; Keen, Deborah; Paynter, Jessica; Trembath, David; Westerveld, Marleen; Williams, Katrina

### VERSION 1 – REVIEW

<b>REVIEWER</b>	Kristen Gillespie-Lynch College of Staten Island/The Graduate Center of the City University of New York
<b>REVIEW RETURNED</b>	01-Jun-2017

<b>GENERAL COMMENTS</b>	<p>The proposed study aims to address an important and understudied research question (how environmental factors influence the developmental trajectories of autistic young people) by collecting longitudinal data about the educational and participation trajectories of youth on the autism spectrum. Six years of annual data collection from multiple informants is a significant strength of the study. However, given that a primary outcome of the study is participation by autistic people, the lack of their active participation in the study itself (all voices collected will be the voices of people around them) is a very significant limitation of the study as proposed. The study would benefit from at the very least collecting the students' perspectives on their educational participation each year. Even better would be active involvement of autistic people in planning the study to ensure that it is aligned with the priorities of autistic people. Please see work by Christina Nicolaidis' work for an excellent example of participatory autism research.</p> <p>The proposed study would benefit from either starting later in development or continuing for more years in order to be able to address a central question set up in the intro about how educational experiences relate to adult outcomes which the current study is not designed to address. I would recommend a third cohort to address the transition from high school to college which is the transition that is most relevant to the issues raised in the introduction. Although the writing is generally clear, some of the sentences are too long reducing clarity.</p> <p>Specific points: Page 4 line 9- Citation needed to support that we understand adult outcomes in autism. I would argue that the small number of longitudinal studies predicting outcomes in autism and the relatively small number of studies focusing on autistic adults in general do not support this statement. The next sentence poses a key gap in knowledge that the study will aim to address (relationships between experiences in school and adult outcomes).</p>
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	<p>However, the starting age of participants and the number of observations does not allow the study to address the gap in the literature it sets up as crucial because the study will end when the students are 16.</p> <p>It is also not clear why social-communication differences would be more impactful on education outcomes than RIRB, many autistic college students who I work with indicate that their focused interests make it hard for them to learn topics that are not within their focused interests.</p> <p>Page 6: It is a strength that you plan to include children with co-occurring conditions. It will be important to document those conditions carefully.</p> <p>Page 6 line 41: If the student has multiple teachers, which teacher(s) will be contacted?</p> <p>Page 7 line 26: It might be best to make all assessments the same amount of time (an hour max) to minimize attrition from jumps from small amounts of time to large amounts of time in different years.</p> <p>Page 9 explanatory factors: It would be helpful to have a measure assessing social support (e.g. friendship number and quality) and bullying as both are environmental factors that may greatly impact school engagement. It would also be helpful to assess students' interests and goals (preferably by asking them directly) as this may greatly impact engagement.</p> <p>Page 10: The updates about the study and current autism research planned to send to parents is a strength of the study.</p> <p>Page 10 line 42: More clarity about the statistical approach is needed. The analyses that are described in detail would only work for the cross-sectional research questions. More detail is needed about the longitudinal analyses as they are the part of the study that is most unique. Plans to account for multiple analyses are also needed given the relatively large number of variables (conducting a number of t-tests which can only analyze one DV at a time would lead to large risk of type 1 error).</p> <p>Page 11 line 13: The lack of behavioral measures is a significant limitation. Perhaps you could include a sub-sample that has in-depth behavioral measures to validate the survey measures.</p>
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<b>REVIEWER</b>	Professor Sarah Parsons University of Southampton, UK
<b>REVIEW RETURNED</b>	09-Jul-2017

<b>GENERAL COMMENTS</b>	<p>This is an important study which needs to be done. The authors are absolutely right that there is a substantial lack of such data available in the autism field, and that much invaluable knowledge would be gained by conducting this study.</p> <p>I have only a few minor suggestions for improving clarity in some places:</p> <p>p. 2 Strengths and limitations - should be 'Enable the development and tailoring...'</p> <p>p. 7 Research measures - given that the questionnaire pack for teachers is one of the few places in the protocol where standardised and previously tested instruments are not being used, we could do with knowing a little more about what will be asked in this survey.</p>
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	<p>For example, the type and nature of the school (mainstream, specialist, urban, rural, diversity of intake, # of children on the school roll etc) will be very important for understanding the context of the provision, and the outcome measures. I can see that some of this is indicated in Table 1 but it would be good to give a few more details here. Related to the previously untested nature of this survey, it would also be good if the team could say something about how and where they might pilot this before including it in the confirmed protocol.</p> <p>p. 8 - should be 'inter-rater reliability'. I would also suggest adding something like the following wording: (detailed in Table 1 for all measures, where available).</p> <p>p. 9 Explanatory factors - this section is rather awkwardly presented and might work better as a Table with columns to clearly show the child, family and environmental factors.</p> <p>p.11 It would be helpful to state here what size of sample would be needed in order to conduct a MLM analysis.</p>
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### VERSION 1 – AUTHOR RESPONSE

#### Reviewer comment:

The study would benefit from at the very least collecting the students' perspectives on their educational participation each year.

#### Response from authors:

The standardised measure of participation within this study (PEM-CY) does not offer a self-report version. Other participation questionnaires (e.g. CAPE/PAC) that do have self-report questions do not enquire about educational participation and only start at age 6 and above.

However, the authors have been seeking funding to add a self-report measure for child participants who are capable of responding in the remaining phases of this longitudinal study.

#### Reviewer comment

Even better would be active involvement of autistic people in planning the study to ensure that it is aligned with the priorities of autistic people.

#### Response from authors:

The funders of this study advocate inclusive research practices, and active inclusion of the autistic community in the research is a condition of funding. To this end, autistic people review all grant applications, shape key research questions, and review progress reports for the project. Autistic people have also been encouraged to apply for PhD scholarships associated with the longitudinal study. One of these scholars is currently co-authoring publications utilising data from the longitudinal study. This information has now been added to page 5 of the manuscript.

#### Reviewer comment:

Either starting later in development or continuing for more years to address a central question set up in the intro about how educational experiences relate to adult outcomes recommend a third cohort to address the transition from high school to college

Response from authors:

The LASA project is part of a large federally funded project which focuses on school age children and young people with autism, hence the focus within this age range. There is an additional longitudinal project being funded by the same funder (name deleted for review) which is recruiting 15- 25 year olds and focusing on post school transitions. The project leaders are working in collaboration to ensure research undertaken across the two projects is complementary.

Further funding will be sought at the end of this six year study to collect follow-up data with this cohort.

Reviewer comment:

Page 4 line 9- Citation needed to support that we understand adult outcomes in autism. I would argue that the small number of longitudinal studies predicting outcomes in autism and the relatively small number of studies focusing on autistic adults in general do not support this statement.

Response from authors

Citations included, wording modified (Page 4)

Reviewer comment

The next sentence poses a key gap in knowledge that the study will aim to address (relationships between experiences in school and adult outcomes). However, the starting age of participants and the number of observations does not allow the study to address the gap in the literature it sets up as crucial because the study will end when the students are 16.

Response from authors:

Wording changed from adult to educational (Page 4)

Reviewer Comment:

It is also not clear why social-communication differences would be more impactful on education outcomes than RIRB, many autistic college students who I work with indicate that their focused interests make it hard for them to learn topics that are not within their focused interests.

Response from authors:

Changed to include this as a factor (Page 4)

Reviewer comment:

Page 6 line 41: If the student has multiple teachers, which teacher(s) will be contacted?

Response from authors:

Text added to clarify this on Page 6.

Reviewer comment:

Page 7 line 26: It might be best to make all assessments the same amount of time (an hour max) to minimize attrition from jumps from small amounts of time to large amounts of time in different years.

Response from authors:

The research team discussed this issue in depth when planning the study and consulted with parents of autistic people. All agreed that it was not feasible to ask parents to complete the large assessment battery every year, and that this burden would result in large attrition. However, reducing the administration time would necessarily mean fewer measures, limiting the scope of the research. It was therefore agreed to use the alternate large/small questionnaire pack approach. Advantages include being able to examine a large number of variables both longitudinally and cross-sectionally. Cross-sectional explorations and comparisons will be essential at identifying key relationships between the variables, thereby ensuring valid or informative measures are being retained across the duration of the study.

Reviewer comment:

Page 9 explanatory factors: It would be helpful to have a measure assessing social support (e.g. friendship number and quality) and bullying as both are environmental factors that may greatly impact school engagement. It would also be helpful to assess students' interests and goals (preferably by asking them directly) as this may greatly impact engagement.

Response from authors:

Thank you for highlighting this key point. We will add a question to the parent questionnaire to ask about whether the parent feels their child has experienced bullying in school in the last 12 months. This has been noted in Table 1.

It was decided not to ask parents about friendship numbers or quality as it is difficult to standardise; some children may feel happiest with one close friend whilst others may prefer many less-close friends. This may also be a very fluid judgement, changing throughout the term and year, with many possible external factors. For this reason, this was not included as a measure in this study.

The potential introduction of a self-report as an additional opt-in study is discussed above.

A potential PhD student has been recruited who proposes to explore participant understanding of friendship and friendship quality and quantity with a subgroup of participants.

Reviewer comment:

Page 10 line 42: More clarity about the statistical approach is needed. The analyses that are described in detail would only work for the cross-sectional research questions. More detail is needed about the longitudinal analyses as they are the part of the study that is most unique. Plans to account for multiple analyses are also needed given the relatively large number of variables (conducting a number of t-tests which can only analyze one DV at a time would lead to large risk of type 1 error).

Response from authors:

Further detail has been added to the statistical analyses section, including a plan for Bayesian longitudinal analyses and a statement to highlight that consideration will be given to correct alpha levels to avoid error where appropriate.

Reviewer comment:

Page 11 line 13: The lack of behavioral measures is a significant limitation. Perhaps you could include a sub-sample that has in-depth behavioral measures to validate the survey measures.

Response from authors:

The behavioural measure we have included (referred to in Table 1), the DBC, has strong psychometric properties and describes a large range of behaviours. Whilst we agree that it would be beneficial to have observational data, this is not possible within the funding constraints of this project and the geographic spread of participants).

Reliance on parent/teacher report and the lack of direct observational measures will be noted as a limitation in any publications.

## Reviewer 2

Reviewer comment:

p. 2 Strengths and limitations - should be 'Enable the development and tailoring...'

Author response:

This has been amended in the manuscript

Reviewer comment:

p. 7 Research measures - given that the questionnaire pack for teachers is one of the few places in the protocol where standardised and previously tested instruments are not being used, we could do with knowing a little more about what will be asked in this survey. For example, the type and nature of the school (mainstream, specialist, urban, rural, diversity of intake, # of children on the school roll etc) will be very important for understanding the context of the provision, and the outcome measures. I can see that some of this is indicated in Table 1 but it would be good to give a few more details here. Related to the previously untested nature of this survey, it would also be good if the team could say something about how and where they might pilot this before including it in the confirmed protocol.

Author response:

The teacher questionnaires, which are summarised in Table 2, include two standardised measures (ACES and SDQ).

Teachers and principals are asked questions about the school set-up (for principals) and class arrangement (for teachers) which are based on the sources described in Table 2.

The paragraph describing the teacher and principal questionnaire has been amended to clarify that the questionnaire pack for teachers consisted of questionnaires compiled from National Longitudinal Transition Study-2, US Department of Education and other sources, including the Longitudinal Study of Australian Children (LSAC), and that these questionnaires have been completed by a large number of teachers internationally. We have also clarified that the principal will be asked to complete questions about location, size and type of school (mainstream, specialist, special), exclusion and attendance rates as well as questions on whole-school and individualised programs or approaches for children with autism in place in their school.

The following statement has also been added so that potentially interested parties can view a copy of the principal or teacher questionnaire: "Copies of the purpose-designed questionnaires are available via email from the corresponding author."

Reviewer comment:

p. 8 - should be 'inter-rater reliability'. I would also suggest adding something like the following wording: (detailed in Table 1 for all measures, where available).

Author response:

This amendment has been made as suggested

Reviewer comment:

p. 9 Explanatory factors - this section is rather awkwardly presented and might work better as a Table with columns to clearly show the child, family and environmental factors.

Author response:

The paragraph has been reworded to remove the measure titles (as these are all in Table 1 and 2) and just list the domains being assessed.

Reviewer comment:

p.11 It would be helpful to state here what size of sample would be needed in order to conduct a MLM analysis.

(Multi Level modelling for repeated Measures)

Author response:

After consultation with the statistician, have added additional information on the analysis plan for longitudinal data using a Bayesian Framework which removes the focus on possible MLM.

## VERSION 2 – REVIEW

<b>REVIEWER</b>	Kristen Gillespie-Lynch College of Staten Island and the Graduate Center; CUNY
<b>REVIEW RETURNED</b>	17-Aug-2017

<b>GENERAL COMMENTS</b>	<p>This revision was a pleasure to read. It was clearly and articulately written, with a logical well-thought out design, a strong rationale for the research, and careful plans for how to disseminate findings. I look forward to seeing the results of this research as they emerge. It is a major strength that autistic people provide guidance on the study and that people with comorbidities will be involved</p> <p>A few last minor points to address:</p> <p>Page 4 line 27: Provide example of “later developing characteristics”</p> <p>Line 45: explain why difficulty transitioning between types of schools will cause them to start school at disadvantage- might be better to use different example to start for flow</p> <p>Page 5 line 35: Give example of factors hypothesized in the research literature to be associated with outcomes that you will investigate</p> <p>Page line 50: The Living with Autism Cooperative Research Center sounds like a wonderful center. I am very glad that autistic people are involved in reviewing the grants and data! Please include approximately how many autistic people will be involved in this study and a bit more about their roles and incentives for being involved. It was hard to locate the relevant information on the website. Given that participatory research is very important yet very rarely done and the voices of the autistic children themselves will be missing from this study, it is important to describe clearly the ways in which the research is participatory.</p> <p>I like that you’re ending the survey on the youth's strengths and interests. It would also be helpful to provide an open ended response option of anything else participants want to add.</p>
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<b>REVIEWER</b>	Professor Sarah Parsons Southampton Education School University of Southampton U.K.
<b>REVIEW RETURNED</b>	07-Aug-2017

<b>GENERAL COMMENTS</b>	Thank you for addressing my suggestions - all the best with the study.
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## VERSION 2 – AUTHOR RESPONSE

Reviewer: 2

Reviewer Name: Professor Sarah Parsons

Institution and Country: Southampton Education School, University of Southampton, U.K.

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

Reviewer: 1

Reviewer Name: Kristen Gillespie-Lynch

Institution and Country: College of Staten Island and the Graduate Center; CUNY Please state any competing interests or state 'None declared': N/A

Please leave your comments for the authors below

This revision was a pleasure to read. It was clearly and articulately written, with a logical well-thought out design, a strong rationale for the research, and careful plans for how to disseminate findings. I look forward to seeing the results of this research as they emerge. It is a major strength that autistic people provide guidance on the study and that people with comorbidities will be involved. A few last minor points to address:

Comment:

Page 4 line 27: Provide example of "later developing characteristics"

Response:

Added

such as mental health disorders,

Comment:

Line 45: explain why difficulty transitioning between types of schools will cause them to start school at disadvantage- might be better to use different example to start for flow

Response:

Changed to

(e.g. between preschool and primary school, primary to high school)

Comment;

Page 5 line 35: Give example of factors hypothesized in the research literature to be associated with outcomes that you will investigate

Response:

Added

such as adaptive behaviour

Comment:

Page line 50: The Living with Autism Cooperative Research Center sounds like a wonderful center. I am very glad that autistic people are involved in reviewing the grants and data!

Please include approximately how many autistic people will be involved in this study and a bit more about their roles and incentives for being involved.

Paragraph revised as follows to include more information

Study Funding



Response:

The study is funded by Cooperative Research Centre for the Living with Autism (Autism CRC), 17 a federally funded program to support industry-led collaborations between industry, researchers, and the community. 17 The funders of this study advocate inclusive research practices process, and active inclusion of the autistic community in the research is a condition of funding. To this end, autistic people are involved in the assessments of all grant applications, shape key research questions, review final reports for the project. Further to this, the Autism CRC has established the Autism CRC Research Academy to build the capacity for co-production/ peer research within the autistic and research communities in Australia. Details of the Autism CRC policies and practices relating to inclusive research are available from their website (<http://www.autismcrc.com.au/inclusive-research-practice-guides-and-checklists>).

Autistic people have also been encouraged to apply for higher degree research (Masters Research and PhD) including 2 PhD scholarships associated with the longitudinal study.

It was hard to locate the relevant information on the website.

Added

<http://www.autismcrc.com.au/inclusive-research-practice-guides-and-checklists>

Comment:

Given that participatory research is very important yet very rarely done and the voices of the autistic children themselves will be missing from this study, it is important to describe clearly the ways in which the research is participatory.

I like that you're ending the survey on the youth's strengths and interests.

It would also be helpful to provide an open ended response option of anything else participants want to add.

Response:

Added to survey