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## Protocol for a prospective longitudinal study investigating the participation and educational trajectories of Australian students with autism

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## Protocol for a prospective longitudinal study investigating the participation and educational trajectories of Australian students with autism

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## Abstract

### Introduction

Autism is associated with high cost to individuals, families, communities and government. Understanding educational and participation trajectories during the school years, and factors influencing these, is fundamental to reducing financial and personal costs. The primary aim of this study is to document the trajectories of Australian students with autism during their education. The secondary aim is to examine personal (e.g. student skills) and environmental (e.g. school setting) factors associated with differing trajectories and outcomes.

### Methods and analysis

The cross-sequential longitudinal study will recruit two cohorts of 120 parents/caregivers of children with autism. Cohort 1 aged between 4-5years and Cohort 2 between 9-10 years to start the study. Information will be gathered from parents, teachers and school principals at 6 annual time points (T1 – T6). Parents will be emailed a link to an online initial questionnaire (T1) and then contacted annually and asked to complete either an extended questionnaire (T3, T5 and T6) or an abbreviated questionnaire (T2, T4). Where consent is given, the child's current school will be contacted annually (T1-T6) and teacher and school principal asked to complete questionnaires about the child and school. Parent and school questionnaires are comprised of questions about demographic and school factors that could influence trajectories and a battery of developmental and behavioural assessment tools designed to assess educational and participation trajectories and outcomes. Surveys will provide longitudinal data on educational and participation trajectories for children and adolescents with autism. In addition cross-sectional comparisons (within or between age groups) at each time point and cohort effects will be explored.

### Ethics and dissemination

Ethics approvals have been granted for this study by all recruiting sites and universities in the project. Study findings will inform policy and practice to promote successful inclusion and participation of children with autism in education. Results will be disseminated through journal publication, conference and seminar presentation.

### Strengths and Limitations

- The study will add to our understanding of the effect of characteristics of autism, family factors, school factors and interventions on educational and personal outcomes for children and young people with autism.
- Enable to development and tailoring of appropriate interventions to improve outcomes.
- Inform policy development in Health and Education in relation to service development and provision for autism communities.

- The participants may be biased towards those with sufficient time, motivation and internet access to complete extensive on-line surveys over 6 years.
- Information collected is all via parent/teacher report.

#### Key words

autism+Autism Spectrum Disorder+developmental trajectories+participation+academic outcomes+personal outcomes

## Introduction

Autism spectrum disorder, herein referred to as autism, is a lifelong neurodevelopmental condition affecting at least 1 in 100 children<sup>1</sup> characterised by impairments in social-communication and behaviour. Autism is a spectrum disorder; children, adolescents, and adults present with differing individual strengths, needs, and preferences for services and supports. Autism is associated with high cost to individuals, families, communities and government,<sup>2,3</sup> highlighting the importance of understanding the nature of autism and optimal supports.

It is important to understand the impact of difficulties or disability on function and participation. Application of the International Classification of Functioning, Disability, and Health (ICF)<sup>4</sup> framework allows us to assess the environmental impacts of characteristics of autism on daily life. Although this approach has been widely adopted in other disabilities it has only been relatively recently integrated into studies and thinking in autism.<sup>5,6</sup>

There is growing evidence that learning in conventional educational environments presents a substantial challenge for most individuals with autism. The most recent survey of educational needs in children with autism in Australia reported that 86% are “having difficulty” at school, with the majority of difficulties being in social cognitive and communication domains.<sup>7</sup> Although these difficulties are recognised both academically and clinically as potential barriers to learning, the influence of each of these factors on educational participation and achievement is yet to be explored. This is important, as almost all (95%) children with autism experience some kind of educational restriction.<sup>8</sup>

The long term impact of not affording individuals with autism appropriate educational supports at an early age is becoming increasingly apparent. Many adults with autism are unemployed, experience mental illness, have reduced independence<sup>9</sup> and are disenfranchised from mainstream society. A recent systematic review of adults with autism classed outcomes in social integration and independence as “poor” or “very poor”, with 50% or more of individuals remaining fully or largely dependent on parents or carers and requiring significant support for education, living

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2 arrangements and employment.<sup>10</sup> Unemployment is higher in those with autism than in those with  
3 speech-language impairments and intellectual disability, indicating that the combination of social,  
4 communication and behaviour challenges that are part of autism places these individuals at  
5 heightened risk for poor community participation.<sup>8</sup>  
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9 While we understand the long term outcomes for adults with autism, we know little about  
10 the experiences and trajectories of students with autism during their school years, and factors that  
11 influence these. Despite the documented difficulties that children with autism experience in school  
12 and the well-recognised need to improve educational outcomes for students with autism<sup>11</sup>, there is  
13 limited information about participation in school, the educational trajectories and the impact of  
14 educational experiences on adult outcomes. This limits the capacity of parents, teachers, allied  
15 health professionals, and others to positively influence growth in this critical developmental and  
16 educational period. It is also unknown which child, family, and environmental factors may  
17 influence these trajectories over time. Characteristics of autism potentially affecting education  
18 include communication and social characteristics in particular. Information about educational  
19 trajectories and outcomes, and the way these interact with child characteristics, including later  
20 developing characteristics, is needed to enable tailoring of interventions and educational approaches  
21 for individual children and young people with autism and their families during their schooling. Such  
22 information is also needed to understand the experience of children with autism in the educational  
23 environment and explore the impact of these experiences on their development, participation and  
24 social relating. Taken together, there is a clear need for further research into the potential  
25 relationships between characteristics of autism, the environment and outcomes, particularly  
26 educational outcomes, both academic (for example literacy) and personal (for example peer  
27 relationships).  
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31 Young people with autism have more difficulties with important transitions (e.g. between  
32 primary and secondary school), than their peers<sup>12,13</sup> which means they are likely to start school at a  
33 disadvantage compared to their typical peers. Longitudinal studies during time periods where major  
34 transitions occur have the potential to increase our understanding of interactions between key  
35 characteristics of autism, environmental factors, any interventions or supports provided during these  
36 challenging times and outcomes.  
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40 The heterogeneity of individuals with autism and their communities (e.g., caregivers,  
41 teachers, allied health clinicians, school executive) and the wide variety of interventions that  
42 individuals access (evidence based and otherwise), means it is difficult to draw conclusions from  
43 cross sectional designs, even with large participant samples. In contrast, the cross-sequential  
44 longitudinal research design we describe in this paper will reduce these limitations. This is  
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1 particularly relevant in educational settings, where factors such as school engagement and  
2 participation can be observed in a cohort over time and compared to outcomes, presently an under-  
3 documented and under-researched area.  
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### 8 **Study Aims**

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10 The primary aim of the Longitudinal study of Australian Students with Autism (LASA), is  
11 to document the educational and participation trajectories and outcomes of Australian students with  
12 autism over a six year period. The secondary aim is to examine personal (e.g., student skills,  
13 caregiver) and environmental (e.g., school setting, community supports) factors associated with  
14 varied trajectories and outcomes.  
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## 20 **Methods and Analyses**

### 21 **Study design**

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25 The LASA is a cross-sequential, prospective, longitudinal, quantitative study. Data will be  
26 collected annually over six years focussing on educational and participation outcomes from two  
27 cohorts of children with autism, Cohort 1 aged 4-5 and Cohort 2 age 9-10, at time of recruitment.  
28 The age ranges were chosen to ensure that data collection occurred over two critical transition  
29 periods; starting school and moving from primary to high school. Caregivers and education  
30 professionals will provide information annually about progress in education and participation, as  
31 well as factors hypothesised in the research literature to be associated with differing trajectories and  
32 outcomes. The project is managed by the LASA partners advisory group consisting of the primary  
33 co-applicants and is chaired by the principal investigator (name deleted).  
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### 42 **Study Funding**

43 The study is funded by the Living with Autism Cooperative Research Centre,<sup>14</sup> a federally  
44 funded program to support industry-led collaborations between industry, researchers, and the  
45 community.<sup>14</sup>  
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### 51 **Study Population**

52 Participants will be recruited across all states and territories in Australia, which has a  
53 population of approximately 23 million people, including nearly 4 million school aged children.<sup>15</sup>  
54 With a conservative estimated prevalence of 1 in 100 children, the estimated number of all school-  
55 aged children with autism at this time is over 35,000.  
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The primary participant group will be caregivers of children with autism aged 4-5 years or 9-10 years at time of recruitment. Each child must have received a clinical diagnosis of autism by health professionals in the community. Parents will be asked to provide a copy of their child's diagnostic assessment report. The Social Communication Questionnaire (SCQ)<sup>16</sup> is included in the parent questionnaire to verify the child's diagnosis. Children with additional medical diagnoses (e.g., seizure disorders, intellectual disability) will be included to ensure a study sample reflecting the population of young people with autism. Caregivers will be asked to complete questionnaires and participate in phone conversations with the research team. These tasks assume skills in spoken and written English, but no exclusion criteria will be adopted in order to recruit a sample that reflects the heterogeneity of the population. Participants self-select.

The second key participant group is educational professionals, namely principals and teachers currently working with each child with autism in formal school or distance education settings, who consent to participate in the study. No exclusionary criteria will be applied.

### **Participant selection and recruitment**

Parent/caregiver participants will be recruited nationally from organisations such as child development units and early intervention services, state autism organisations, parent support groups, autism advocacy groups and through websites, mailing lists and internet groups. Parents/caregivers will be asked to register to participate in the study through an internet link. Parents who register, will be contacted by a research team member and if their child is eligible and they agree to participate, they will be sent an online parent/caregiver questionnaire. If parent consent is given, the principal of their child's school will be contacted and asked to complete a questionnaire about the school. The principal will also be asked to consent to the research team contacting the child's teacher. If this consent is given the child's teacher will be contacted and asked to complete an online questionnaire about the child's progress and participation at school.

### **Data Collection Procedure**

Parents will be asked to complete online questionnaires annually for 6 years, comprising 6 time points (T1-T6). Following recruitment, parents will be emailed a link to an online initial questionnaire (T1). Parents will then be contacted annually and asked to complete either an extended questionnaire (at T3, T5 and T6) or an abbreviated questionnaire (at T2, T4). Parents will also be contacted annually and asked to provide educational/school or assessment reports (diagnostic reports in particular) and current school contact information. The recruitment goal for the study is 120 participants in each cohort.



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Where consent is given, the child's current school will be contacted annually and both the teacher and school principal will be asked to complete online questionnaires about the child or school respectively (T1 – T6). At each time point, parents, teachers and principals will be given one month to complete the questionnaire. During that period, they may stop and start the questionnaire as many times as they like with responses saved online. Participants who do not complete the questionnaires in that time will receive reminders via email and/or a phone call from the participant coordinator to offer assistance and confirm their willingness to continue in the study.

### Research measures

A battery of developmental and behavioural assessment tools designed to assess educational and participation trajectories and outcomes, along with theoretically driven predictors of these, was selected following a review of the literature. The length of the questionnaire was monitored so as to minimise participant burden, with the abbreviated questionnaire (at T2 and T4) taking approximately 30 minutes to complete and the extended questionnaire (at T1, T3, T5, T6) taking approximately two hours to complete.

An overview of assessments for caregivers (including detail on their reliability and validity), and the time points at which they will be collected, is provided in Table 1. An overview of assessments for schools (principals and teachers) is provided in Table 2. The parents will complete questionnaires focussing upon demographics, the primary outcome variable (child participation) and adaptive behaviour at each time point. The secondary outcomes, academic competence and family outcomes, and other explanatory factors will be measured at T1, T3, T5 and T6. These include measures of communication, sensory characteristics, behavioural and emotional difficulties, anxiety and parent stress.

The questionnaire pack for teachers will consist of a questionnaire gathering information on the available support for transition to and within their school, use of Individual Education Plans, accommodations for standardised tests, social skills support, a questionnaire on academic functioning for their student (compared to their peers) and a questionnaire designed to gather information about the student's emotional, behavioural and social profile. Finally, the principal will be asked to complete a purpose-designed questionnaire about whole-school and individualised programs or approaches for children with autism in place in their school.

Primary outcome measure

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The primary outcome is a measure of child participation, the Participation and Environment Measure – Child and Youth<sup>17</sup> (PEM-CY), completed at each data collection point. This measures a child's participation and environment across three settings: home (10 items), school (5 items) and community (10 items). For each item, parents report how often their child participates in the activity (never (0) to daily (7)), how involved the child is in the activity (minimally involved (1) to very involved (5)) and whether the parent desires change in their child's participation in the activity. If parents state that they would like a change, they are asked more about this change in terms of frequency (to do it more or less often), involvement (be more or less involved) or if they would like their child involved in a broader range of activities within this category. The PEM-CY is suitable for children aged 5 to 17 years and has been shown to be reliable, with good strong internal consistency and good inter-rater reliability (detailed in Table 1).

#### Secondary outcome measures

Secondary outcomes are a measure of academic competence<sup>18</sup> (Academic Competence Evaluation Scales; ACES) and the<sup>19</sup> Family Outcomes Survey Revised (FOS-R).

The ACES<sup>18</sup> will be administered at each data collection point. It contains 73 questions that assess the academic functioning of students, grades K-12. It measures academic skills (33 items) (reading/language arts, mathematics, critical thinking) and academic enablers (40 items) (interpersonal skills, engagement, motivation, and study skills). Teachers rate their student's academic skills relative to school expectations on a 5-point scale ranging from far below (1) to far above (5) and how important the skill is for academic success in the classroom on a 3 point scale ranging from not important (1) to critical (3). There is also a N/O option for each question if the teacher has not had the opportunity to observe the skill. For the academic enablers teachers rate how frequently their student shows the behaviours on a 5-point scale ranging from never (1) to almost always (5) and their importance in the classroom on a 3 point scale not important (1) to critical (3). There is also a N/O option for each question if the teacher has not had the opportunity to observe the skill. A raw score is obtained for each of the academic skill areas and the academic enablers areas and is interpreted in relation to the child's age and grade at school. The manual provides normative data for children with and without learning disabilities.

The FOS-R<sup>19</sup> has two sections. Section A will be administered at T1, T3, T5 and T6 and Section B at T1 only. Section A consists of 24 items and focuses on five family outcomes: (1) understanding your child's strengths, needs and abilities; (2) knowing your rights and advocating for services; (3) helping your child develop and learn; (4) having support systems and; (5) accessing the community. Section A assesses the extent to which families have achieved these outcomes on a 5-point scale

1 ranging from (1) not at all to (5) completely. Section B consists of 17 items and focuses on the three  
2 helpfulness indicators of knowing your rights; communicating your child's needs and; helping your  
3 child develop and learn. Section B assesses the helpfulness of early intervention on a 5-point scale  
4 ranging from (1) not at all helpful to (5) extremely helpful.  
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#### 8 Explanatory factors

9  
10 In order to explain the educational and participation trajectories of children with autism, factors  
11 potentially interacting with the outcomes are also examined. These factors were selected based  
12 upon a thorough literature review and are explained below, with details of each measure provided in  
13 Table 1. These factors can be categorised as child, family and educational environment factors.  
14 Child factors include behavioural and emotional difficulties as measured by the Developmental  
15 Behaviour Checklist<sup>20</sup> (DBC) completed by the parents and Strengths and Difficulties  
16 Questionnaire<sup>21</sup> (SDQ) completed by teachers, communication skills measured by the Children's  
17 Communication Checklist (CCC-2)<sup>22</sup> for verbal children or selected items from the Pragmatics  
18 Profile of Everyday Language for nonverbal children,<sup>23</sup> adaptive behaviour measured by the  
19 Vineland Adaptive Behaviour Scales<sup>24</sup> (VABS), sensory behaviours measured by the Short  
20 Sensory Profile 2<sup>25</sup> (SSP-2) and child anxiety, Anxiety Scale for Children with Autism Spectrum  
21 Disorder<sup>26</sup> (ASC-ASD-P). Parental stress measured by the Parenting Stress Index-4-Short Form<sup>27</sup>  
22 (PSI-SF-4) and family demographics will also be assessed. Educational environment will be  
23 documented through the principal, teacher and parent surveys.  
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#### 36 Data collection

37 The online questionnaires will be developed in the online survey system, Qualtrics. An internet link  
38 to the questionnaire will be sent to each participant via email which contains a personal ID that  
39 links the child participant with responses collected from their parent/caregiver, their teacher and  
40 school principal. The responses will be stored in a password protected Qualtrics database  
41 accessible by two research team members. The Project Coordinator is responsible for cleaning and  
42 removing personally identifiable information from the data. The data will only be accessible to the  
43 project team and is stored in line with National Health Medical Research Council (NHMRC)<sup>28</sup> best  
44 practice.  
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#### 52 Feedback to families and school

53 Parents will receive a written summary of their child's annual survey results. If parents wish to  
54 receive formal scored reports for the standardised child assessments included in the questionnaire,  
55 they will be required to complete a *Client Consent to Share Information Form B*. Once consent is  
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1 given the LASA research team will share the scored reports with the child's health or allied health  
2 professional nominated by the parent. This procedure is consistent with ethical mandates<sup>29</sup> designed  
3 to ensure that information is not released that is potentially distressing to parents or requires  
4 interpretation.  
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9 Caregivers, teachers and principals will receive updates about the study through an annual  
10 newsletter and access to social media pages of the Autism Centre for Excellence. Throughout the  
11 study, results will be presented in aggregate format only and presented in an accessible format for a  
12 lay audience. The Autism Centre for Excellence social media site will also keep participants  
13 informed about what is new in autism spectrum disorders and evidence based strategies.  
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### 18 19 **Data analysis**

20  
21 The data collected in the study provides longitudinal data on educational and participation  
22 trajectories for children with Autism. However, it is designed with sample sizes large enough to  
23 allow for cross-sectional comparisons (within or between age groups) at each time point. Cohort  
24 effects can also be explored by comparing data from when both groups are 9-10 years old (T1 for  
25 Cohort 2 and T6 for Cohort 1). Missing data will be examined and if appropriate, imputation  
26 implemented (the exact method contingent on the missing data). As there is likely to be less than  
27 100% retention at each follow-up, potential bias in retainment will be assessed by comparing  
28 baseline characteristics (including severity of ASD, parent self-reported stress and socio-economic  
29 status) of retained and non-retained participants using chi-squared or t-tests where appropriate.  
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36 To document the participants' educational and participation trajectories and outcomes  
37 (primary aim), descriptive statistics (frequencies, means, medians and standard deviations)  
38 pertaining to the outcome measures and putative explanatory factors will be presented for each  
39 cohort at each time point.  
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43 Group comparisons on cross-sectional data, such as comparisons between the younger and  
44 older groups or between smaller subgroups, will be performed using independent samples t-tests or  
45 equivalent non-parametric tests if the data is not normally distributed. Using independent t-tests,  
46 with  $\alpha = .05$ ,  $\beta = .80$ , and medium effect size of 0.5 a sample of 102 participants is required.<sup>30</sup> Our  
47 target sample size of 120 children in each cohort allows for an attrition rate of approximately 15%  
48 over the course of the study. Cross-sectional analysis of standardised scores will also be performed  
49 using t-test or multivariate analysis (MANOVA) and mediating or moderating factors explored  
50 using regression models.  
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56 Multiple regression will be used to examine personal and environmental factors associated  
57 with differing trajectories and outcomes (secondary aim). The interaction or influence of the  
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1 explanatory factors, such as level of adaptive behaviour (measured by the VABS), severity of  
2 Autism Symptoms (measured by the SCQ) or sensory behaviours (measured by the SSP-2) will be  
3 explored within these regression models. Should the longitudinal sample size allow, multi-level  
4 modelling will also be used.  
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8 A statistician will be engaged to work with the research team on data analysis and  
9 presentation of results.  
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### 12 **Methodological considerations**

#### 13 Questionnaire data

14 The format of this study (data collection through questionnaires) allows for recruitment of a  
15 reasonably large sample of children and families. However, it is acknowledged that all of the  
16 information for this study is collected through questionnaires and interviews, without meeting the  
17 child or family. This means that it is not possible for the data to include direct measures of ability  
18 (such as intellectual ability) or to complete formal assessments<sup>31</sup> (such as the ADOS). To address  
19 this issue, all parents will be asked to complete a validated autism screening questionnaire (Social  
20 Communication Questionnaire) and are required to send in copies of their child's diagnostic reports.  
21 Parents will also be asked to send in reports of any additional assessments, particularly cognitive  
22 assessments.  
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#### 32 Bias in recruitment

33 The nature of the present study requires a significant commitment from participants and where  
34 applicable, their teachers and principals. Parents are asked to complete six online questionnaires,  
35 four of which will take approximately two hours to complete. This may influence the recruitment  
36 procedure and may, over the duration of the study, reduce completion rates. It is therefore possible  
37 that there will be a recruitment bias (i.e., families who can afford the time to complete the  
38 questionnaire and/or who have ready access to a computer with internet access). It may also be that  
39 the research may only attract parents that have an interest in the focus of this study. To address this  
40 issue, efforts will be directed towards recruiting from a range of sources and in providing parents  
41 with the ability to log in and out of their questionnaire completion site so they can complete the  
42 questionnaire pack in small sections over one month. Demographic information alongside  
43 information about challenging behaviour (from the DBC) and parental stress (from the PSI-SF) will  
44 be compared between those who complete and those who leave the study in order to identify factors  
45 that may have contributed to non-completion.  
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#### 58 **Ethics and dissemination**

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The study has received ethical approval from all recruiting sites and universities involved in the project (see list below). All parents will provide consent for their child to join the study. Parents can also choose whether to give consent for teacher and principal questionnaires to be collected. Results from standardised questionnaires can be shared with nominated health professionals if requested by the consenting caregiver.

It is not anticipated that participants will be subject to any risks during this study. It is possible that parents may become distressed when communicating about their child's autism or associated strengths and difficulties. The survey is designed to end with questions for parents about their child's strengths and interests to end on a positive note. All parents are provided with the contact details of the project administrator (who can direct the parent to an appropriate clinically trained member of the research team) to discuss the questionnaire. The research team are willing and able to refer parents to a range of specialised support services if this is deemed necessary or helpful.

Participant information will be securely stored electronically or in the project office.

Questionnaires are completed online and personal identifiable information received (such as copies of diagnostic reports) will be stored in a locked filing cabinet. Once downloaded from the online database, all participant data will be anonymised by allocating each participant with an ID number. De-identified participant data will be saved on a password-protected secure computer drive which only members of the research team have access to. Participants' personal identifiable data will be stored in a separate location to de-identified participant data. Identifiable data will only be accessible to the project manager and the project leader.

Throughout the course of the study and once the longitudinal data collection is complete, results (de-identified and primarily aggregated) will be published in peer-reviewed mainstream and specialist journals. Presentations of study findings will be made at relevant research conferences, local research symposiums and seminars for professionals working with children with autism and those in autism research. In addition, local stakeholders (such as autism schools and NGOs) will be consulted in the development of methods for dissemination they find effective in reaching families of children with autism.

### **Significance and outlook**

This study will make an important contribution to the very limited longitudinal data on the pattern and effects of participation in children with autism. The design allows for annual cross-sectional comparisons, within subject comparisons, exploration of cohort effects (by comparing data from

1 both groups at 9-10yrs) and the six-year longitudinal analysis. Collecting data and information  
2 from a range of sources (parents, teachers and principals) allows for a holistic description of  
3 progress and change across the duration of the study.  
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8 Study results will inform clinicians, children and their families about the factors that promote or  
9 reduce participation and educational outcomes and therefore help to identify children who are most  
10 likely to benefit from specific interventions. It will also be important data for educators, who will  
11 be able to proactively monitor factors that put children with autism at risk of not achieving their full  
12 educational potential.  
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17 The study team is also focused on developing capacity of early career researchers through  
18 mentorship and supervision. It will provide data for a number of PhD, Masters and honours  
19 students who often cannot gain experience with longitudinal datasets due to time constraints and  
20 allow them to develop the methodological and statistical expertise required for such methods. This  
21 is particularly important given the identified need for longitudinal studies in a large number of  
22 health, educational and developmental areas.  
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### 29 Summary and conclusion

30 Autism is an increasingly common condition. Although profiles and presentations are highly  
31 variable, a consistent finding is poor life outcomes for adults with autism across domains such as  
32 employment and independent living. Given that the primary aim of education is the preparation of  
33 children and young people for adult life, it could be argued that the educational process is not  
34 achieving this aim for the majority of young people with autism. In this study, data will be collected  
35 at key developmental periods including times of major transition (school entry and transition from  
36 primary to high school) and factors critical to participation and educational achievement will be  
37 explored and documented. Understanding these trajectories and the factors that influence them will  
38 assist clinicians working with individual children and their families to describe expected outcome  
39 and necessary services and supports, and planning to improve educational environments.  
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49 Competing interests: None declared

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35 Authors' contributions:

36  
37 Roberts, Jacqueline; Griffith University, Autism Centre of Excellence; conceptualised and co-  
38 designed the study, developed the first draft of the manuscript, reviewed and revised the manuscript  
39 and finalised the manuscript for publication.  
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42 Adams, Dawn; Griffith University, Autism Centre of Excellence; drafted the final manuscript,  
43 reviewed and revised the manuscript.  
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46 Heussler, Helen; Mater Research Institute-University of Queensland, Children's Health  
47 Queensland; contributed to the design of the study and review of the manuscript.  
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51 with manuscript drafting, reviewed and revised the manuscript.  
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55 contributed to the design of the study, assisted with manuscript drafting and review of the  
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59 Trembath, David; Griffith University; co-designed the study, assisted with manuscript drafting,  
60 reviewed and revised the manuscript.



1 Westerveld, Marleen; Griffith University; contributed to the design of the study, assisted with  
2 manuscript drafting, read and approved the final manuscript.

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5 Williams, Katrina; University of Melbourne, Developmental Medicine; co-designed the study,  
6 assisted with manuscript drafting, reviewed and revised the manuscript.

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### 31 **References**

- 32 1. CDC. Prevalence of autism spectrum disorders among children aged 8 years: Autism and  
33 developmental disabilities monitoring network. *MMWR Surveillance Summaries*. 2014; 63: 1-  
34 22.  
35
- 36 2. Horlin C, Falkmer M, Parsons R, Albrecht MA, Falkmer T. The cost of autism spectrum  
37 disorders. 2014; *PloS one*, 9(9): e106552.  
38
- 39 3. Synergies Economic Consulting, 2011 Synergies. Economic costs of autism spectrum disorder  
40 in Australia: Updated study. Brisbane: Synergies Economic Consulting; 2011.  
41
- 42 4. World Health Organization. International Classification of Functioning, Disability and Health.  
43 Geneva:World Health Organization;2001.  
44
- 45 5. Bolte S, de Schipper E, Robison J, Wong V, Selb M, Singhal N. et al. Classification of  
46 functioning and impairment: The development of ICF core sets for autism spectrum disorder.  
47 *Autism Research*. 2014; 7: 167-172.  
48
- 49 6. de Schipper E, Lundquist A, Coghill D, de Vries P, Granlund M, Holtmann et al. Ability and  
50 disability in autism spectrum disorder: A systematic literature review employing the  
51 International Classification of Functioning, Disability and Health-Children and Youth Version.  
52 *Autism Research*. 2015; 8: 782-794. doi: 10.1002/aur.1485  
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7. ABS Survey of Disability. 2012. Available from:  
<http://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/4430.02012>
8. 4428.0 - Autism in Australia, Australian Bureau of Statistics.2012. Available  
from:[http://www.abs.gov.au/ausstats/abs@.nsf/Latestproducts/4428.0Main%20Features52012?  
opendocument&tabname=Summary&prodno=4428.0&issue=2012&num=&view=](http://www.abs.gov.au/ausstats/abs@.nsf/Latestproducts/4428.0Main%20Features52012?opendocument&tabname=Summary&prodno=4428.0&issue=2012&num=&view=)
9. Moss P, Howlin P, Savage S, Bolton P, Rutter M. Self and informant reports of mental health  
difficulties among adults with autism findings from a long-term follow-up study. *Autism*. 2015  
May 26:1362361315585916.
10. Magiati I, Tay XW, Howlin P. Cognitive, language, social and behavioural outcomes in adults  
with autism spectrum disorders: A systematic review of longitudinal follow-up studies in  
adulthood. *Clinical Psychology Review*. 2014; 34: 73-86.
11. Roberts J, Simpson K. A review of research into stakeholder perspectives on inclusion of  
students with autism in mainstream schools. *International Journal of Inclusive Education*. 2016;  
1-13.
12. Prior M, Roberts JMA, Rodger S, Williams K. Sutherland R. (2011). A review of the research  
to identify the most effective models of practice in early intervention of children with autism  
spectrum disorders. Australian Government Department of Families, Housing, Community  
Services and Indigenous Affairs, Australia. Available from  
[http://www.fahcsia.gov.au/sites/default/files/documents/09\\_2012/review\\_of\\_the\\_research\\_repor  
t\\_2011\\_0.pdf](http://www.fahcsia.gov.au/sites/default/files/documents/09_2012/review_of_the_research_report_2011_0.pdf)
13. Roberts JMA, Williams K. Autism spectrum disorder: Evidence-based/evidence-informed good  
practice for supports provided to preschool children, their families and carers. 2016. Report  
prepared for the National Disability Insurance Agency (NDIA).
14. Autism CRC.2016. Available from <http://www.autismcrc.com.au/about-crcs>
15. 4221.0 - Schools, Australia, 2015. Australian Bureau of Statistics. 2015. Available from:  
<http://www.abs.gov.au/ausstats/abs@.nsf/mf/4221.0>
16. Rutter M, Bailey MD, Lord C. *The Social Communication Questionnaire (SCQ)*. Los Angeles,  
CA: Western Psychological Services; 2003.
17. Coster W, Bedell G, Law M, et al. (2011). Psychometric evaluation of the Participation and  
Environment Measure for Children and Youth. *Developmental Medicine and Child  
Neurology*.2011; 53: 1030-1037. DOI: 10.1111/j.1469-8749.2011.04094.x
18. DiPerna JC, Elliott SN. *Academic competence evaluation scales*. San Antonio: The  
Psychological Corporation; 2000.

19. Bailey DB, Raspa M, Olmsted MG, et al. Development and psychometric validation of the family outcomes survey revised. *Journal of Early Intervention*.2011;33:6–23.
20. Einfeld S L, Tonge BJ. *Manual for the Developmental Behaviour Checklist*. Clayton, Melbourne and Sydney Monash University for Developmental Psychiatry and School of Psychiatry, University of New South Wales; 1992.
21. Goodman R. (1997). The Strengths and Difficulties Questionnaire: A Research Note. *Journal of Child Psychology and Psychiatry*. 1997; 38:581-586
22. Bishop DVM. *Children’s Communication Checklist-2 (CCC-2)*. San Antonio, TX: Pearson; 2006.
23. Dewart H, Summers S. *The Pragmatics Profile of Early Communication Skills*. London: NFER-NELSON; 1995.
24. Sparrow SS, Cicchetti DV, BallaDA. *Vineland II: Vineland Adaptive Behavior Scales*. Bloomington, MN: Pearson; 2005.
25. Dunn W. *Sensory Profile 2*. Bloomington, MN, USA: Pearson Psychcorp; 2014.
26. Rodgers J, Wigham S, McConachie H, Freeston M, HoneyE,Parr JR. Development of the anxiety scale for children with autism spectrum disorder (ASC-ASD). *Autism Research*.2016.doi:10.1002/aur.1603
27. Abidin RR.*Parenting Stress Index Professional Manual (4th ed.)*. Lutz, FL: PAR; 2012.
28. National Statement on Ethical Conduct in Human Research 2007 (Updated May 2015). The National Health and Medical Research Council, the Australian Research Council and the Australian Vice-Chancellors’ Committee. Commonwealth of Australia, Canberra
29. Australian Psychological Society. (2012). *Code of ethics*. Melbourne, Vic: Author
30. Faul F, Erdfeinder E, Lang AG,BuchnerA.G\*Power 3: A flexible statistical power analysis program for the social, behavioral, and biomedical sciences. *Behavior Research Methods*. 2007;39:175-191.
31. Lord C, Rutter M, Pamela C. Dilavore P, Risi, S. . *ADOS: Autism diagnostic observation schedule*. Hogrefe; 2008.
32. National Longitudinal Transition Study-2, US Department of Education US Department of Education. Welcome to NLTS2. Available from: <http://www.nlts2.org/index.html>.
33. Longitudinal Study of Australian Children (LSAC) Growing up in Australia: The longitudinal study of Australian children (LSAC). Available from: <http://growingupinaustralia.gov.au/>

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For peer review only

Table 1: Parent measures

Instrument	Captures	Domains	Measured at	Reliability
Family History Survey	Information on child and family demographics, child and family medical history, child's therapy and intervention	N/A	T1, T2, T3, T4, T5, T6	N/A
Participant and Environment Measures – Child and Youth <sup>17</sup>	Child's participation and environment across three settings: school and community	Level of involvement Parent satisfaction with participation at: Home, School, Community	T1, T2, T3, T4, T5, T6	Internal consistency <sup>1</sup> .59-.91 Participation frequency .59-.70 Participation involvement: .72-.83 Environmental Supportiveness: .67-.91 Test-retest reliability <sup>1</sup> Participation frequency .58-.84 Participation involvement: .69-.76 Desires change: .76-.89 Environmental Supportiveness: .85-.95
Social communication Questionnaire (SCQ) Lifetime <sup>16</sup>	Symptoms of Autism (combines with "community diagnosis" to confirm ASD)	N/A	T1	Internal Consistency <sup>2</sup> ( $\alpha$ ) = .93 Test-retest <sup>2</sup> = .81
Vineland Adaptive Behavior Scale, 2 <sup>nd</sup> Edition (VABS-II) <sup>24</sup>	Daily functional skills and adaptive behaviour.	Communication Daily Living Skills Socialisation	T1, T2, T3, T4, T5, T6	Internal Consistency <sup>3</sup> ( $\alpha$ ) Communication .84-.93 Daily Living Skills .86-.91 Socialisation .84-.93 Test-retest across domains <sup>3</sup> .76-.92

1 2 3 4 5 6 7 8 9 10 11 12 13	Children's Communication Checklist-2 (CCC-2) <sup>22</sup>	Communicative behaviours	Speech, Syntax, Semantics, Coherence, Initiation, Stereotyped language, Use of context Nonverbal communication, Social relations, Interests	T1, T3, T5, T6	Internal Consistency <sup>4</sup> ( $\alpha$ ): .73-.88 Inter-rater reliability <sup>4</sup> .61-.83
14 15 16 17 18 19 20 21 22 23	Pragmatic Profile of Everyday Communication <sup>23</sup> (selected questions)	Communicative functions and forms	Selected items on Communicative Functions, Response to Communication Interaction and Conversation Contextual Variation	T1, T3, T5, T6	
24 25 26 27 28 29 30 31	Developmental Behaviour Checklist (DBC-P) <sup>20</sup>	Behaviour and emotional problems	Disruptive/Antisocial Self-absorbed Communication Disturbance, Anxiety Social-relating	T1, T3, T5, T6	Internal Consistency <sup>5</sup> ( $\alpha$ ): .94 Inter-rater reliability <sup>6</sup> .72 <sup>5</sup>
32 33 34 35 36 37 38 39 40 41 42 43 44 45	Short Sensory Profile-2 <sub>25</sub>	Sensory behaviours	Auditory Processing Visual Processing Touch Processing Movement Processing Body Position Processing Oral Sensory Processing	T1, T3, T5, T6	Internal Consistency <sup>7</sup> .57-.92 Test re-test <sup>7</sup> .83-.92 Inter-rater <sup>7</sup> .49-.89

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Anxiety Scale for Children with Autism Spectrum Disorder (ASC-ASD-P) <sup>26</sup>	Child anxiety	Separation Anxiety Uncertainty Performance Anxiety Anxious Arousal	T2, T3, T4, T5, T6	Internal Consistency <sup>8</sup> (α): .85-.91 Separation anxiety .87 Uncertainty .88 Performance .89 Anxious arousal .88 Test re-test <sup>8</sup> (α): .84
Family Outcomes Survey Revised (FOS-R) <sup>19</sup>	Family outcomes	Understanding your child’s strengths, needs and abilities Knowing your rights and advocating for services Helping your child develop and learn Having support systems Accessing the community	T1, T3, T5, T6	Internal Consistency <sup>9</sup> (α): .73-.91
Parenting Stress Index-4-Short Form (PSI-4-SF) <sup>27</sup>	Parental stress	Parental distress Parent-child dysfunctional interaction Difficult child	T1, T3, T5, T6	Internal Consistency <sup>10</sup> (α): .98 Child: .96 Adult: .96 Test re-test <sup>10</sup> .96 Child: .63 Parent: .91

Table 2: School Measures

Instrument	Captures	Domains	Measured at	Reliability
Academic Competence Evaluation Scales (ACES) <sup>18</sup>	Academic functioning of student	Academic skills (reading/language arts, mathematics, critical thinking) Academic enablers (interpersonal skills, engagement, motivation, and study skills)	T1, T2, T3, T4, T5, T6	Internal Consistency <sup>1</sup> ( $\alpha$ ): .94-.99  Test re-test <sup>1</sup> .88-.97
Strengths and Difficulties Questionnaire - Teacher (SDQ) <sup>21</sup>	Profile of strengths and difficulties	Emotional symptoms Behavioural difficulties Hyperactivity Peer problems Prosocial behaviours	T1, T2, T3, T4, T5, T6	Internal Consistency <sup>2</sup> .73 Test re-test reliability <sup>2</sup> .62
Teacher survey (compiled from National Longitudinal Transition Study-2, <sup>31</sup> US Department of Education and other sources, including the Longitudinal Study of Australian Children (LSAC) <sup>32</sup>	Student behaviours, teaching practices and school environment		T1, T2, T3, T4, T5, T6	N/A
Principal Survey (compiled from National Longitudinal Transition Study-2, <sup>31</sup> US Department of Education and other sources, including LSAC) <sup>32</sup>	whole school context in relation to programs/approaches used to educate children with autism		T1, T2, T3, T4, T5, T6	N/A



# BMJ Open

## Protocol for a prospective longitudinal study investigating the participation and educational trajectories of Australian students with autism

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## Protocol for a prospective longitudinal study investigating the participation and educational trajectories of Australian students with autism

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## Abstract

### Introduction

Autism is associated with high cost to individuals, families, communities and government. Understanding educational and participation trajectories during the school years, and factors influencing these, is fundamental to reducing financial and personal costs. The primary aim of this study is to document the trajectories of Australian students with autism during their education. The secondary aim is to examine personal (e.g. student skills) and environmental (e.g. school setting) factors associated with differing trajectories and outcomes.

### Methods and analysis

The cross-sequential longitudinal study will recruit two cohorts of 120 parents/caregivers of children with autism. Cohort 1 aged between 4-5years and Cohort 2 between 9-10 years to start the study. Information will be gathered from parents, teachers and school principals at 6 annual time points (T1 – T6). Parents will be emailed a link to an online initial questionnaire (T1) and then contacted annually and asked to complete either an extended questionnaire (T3, T5 and T6) or an abbreviated questionnaire (T2, T4). Where consent is given, the child's current school will be contacted annually (T1-T6) and teacher and school principal asked to complete questionnaires about the child and school. Parent and school questionnaires are comprised of questions about demographic and school factors that could influence trajectories and a battery of developmental and behavioural assessment tools designed to assess educational and participation trajectories and outcomes. Surveys will provide longitudinal data on educational and participation trajectories for children and adolescents with autism. In addition cross-sectional comparisons (within or between age groups) at each time point and cohort effects will be explored.

### Ethics and dissemination

Ethics approvals have been granted for this study by all recruiting sites and universities in the project. Study findings will inform policy and practice to promote successful inclusion and participation of children with autism in education. Results will be disseminated through journal publication, conference and seminar presentation.

### Strengths and Limitations

- The study will add to our understanding of the effect of characteristics of autism, family factors, school factors and interventions on educational and personal outcomes for children and young people with autism.
- Enable the development and tailoring of appropriate interventions to improve outcomes.
- Inform policy development in Health and Education in relation to service development and provision for autism communities.

- The participants may be biased towards those with sufficient time, motivation and internet access to complete extensive on-line surveys over 6 years.
- Information collected is all via parent/teacher report.

#### Key words

autism+Autism Spectrum Disorder+developmental trajectories+participation+academic outcomes+personal outcomes

## Introduction

Autism spectrum disorder, herein referred to as autism, is a lifelong neurodevelopmental condition affecting at least 1 in 100 children<sup>1</sup> characterised by impairments in social-communication and behaviour. Autism is a spectrum disorder; children, adolescents, and adults present with differing individual strengths, needs, and preferences for services and supports. Autism is associated with high cost to individuals, families, communities and government,<sup>2,3</sup> highlighting the importance of understanding the nature of autism and optimal supports.

It is important to understand the impact of difficulties or disability on function and participation. Application of the International Classification of Functioning, Disability, and Health (ICF)<sup>4</sup> framework allows us to assess the environmental impacts of characteristics of autism on daily life. Although this approach has been widely adopted in other disabilities it has only been relatively recently integrated into studies and thinking in autism.<sup>5,6</sup>

There is growing evidence that learning in conventional educational environments presents a substantial challenge for most individuals with autism. The most recent survey of educational needs in children with autism in Australia reported that 86% are “having difficulty” at school, with the majority of difficulties being in social cognitive and communication domains.<sup>7</sup> Although these difficulties are recognised both academically and clinically as potential barriers to learning, the influence of each of these factors on educational participation and achievement is yet to be explored. This is important, as almost all (95%) children with autism experience some kind of educational restriction.<sup>8</sup>

The long term impact of not affording individuals with autism appropriate educational supports at an early age is becoming increasingly apparent. Many adults with autism are unemployed, experience mental illness, have reduced independence<sup>9</sup> and are disenfranchised from mainstream society. A recent systematic review of adults with autism classed outcomes in social integration and independence as “poor” or “very poor”, with 50% or more of individuals remaining fully or largely dependent on parents or carers and requiring significant support for education,

1 living arrangements and employment.<sup>10</sup> Unemployment is higher in those with autism than in those  
2 with speech-language impairments and intellectual disability, indicating that the combination of  
3 social, communication and behaviour challenges that are part of autism places these individuals at  
4 heightened risk for poor community participation.<sup>8</sup>  
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9 While we have some understanding of the long term outcomes for adults with autism<sup>11,12,13</sup>  
10 we know little about the experiences and trajectories of students with autism during their school  
11 years, and factors that influence these. Despite the documented difficulties that children with  
12 autism experience in school and the well-recognised need to improve educational outcomes for  
13 students with autism<sup>14</sup>, there is limited information about participation in school, the educational  
14 trajectories and the impact of educational experiences on educational outcomes. This limits the  
15 capacity of parents, teachers, allied health professionals, and others to positively influence growth  
16 in this critical developmental and educational period. It is also unknown which child, family, and  
17 environmental factors may influence these trajectories over time. Characteristics of autism  
18 potentially affecting education include both communication and social characteristics and repetitive  
19 behaviours and restricted interests. Information about educational trajectories and outcomes, and the  
20 way these interact with child characteristics, including later developing characteristics, is needed to  
21 enable tailoring of interventions and educational approaches for individual children and young  
22 people with autism and their families during their schooling. Such information is also needed to  
23 understand the experience of children with autism in the educational environment and explore the  
24 impact of these experiences on their development, participation and social relating. Taken together,  
25 there is a clear need for further research into the potential relationships between characteristics of  
26 autism, the environment and outcomes, particularly educational outcomes, both academic (for  
27 example literacy) and personal (for example peer relationships).  
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42 Young people with autism have more difficulties with important transitions (e.g. between  
43 primary and secondary school), than their peers<sup>15,16</sup> which means they are likely to start school at a  
44 disadvantage compared to their typical peers. Longitudinal studies during time periods where major  
45 transitions occur have the potential to increase our understanding of interactions between key  
46 characteristics of autism, environmental factors, any interventions or supports provided during these  
47 challenging times and outcomes.  
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51 The heterogeneity of individuals with autism and their communities (e.g. caregivers,  
52 teachers, allied health clinicians, school executive) and the wide variety of interventions that  
53 individuals access (evidence based and otherwise), means it is difficult to draw conclusions from  
54 cross sectional designs, even with large participant samples. In contrast, the cross-sequential  
55 longitudinal research design we describe in this paper will reduce these limitations. This is  
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1 particularly relevant in educational settings, where factors such as school engagement and  
2 participation can be observed in a cohort over time and compared to outcomes, presently an under-  
3 documented and under-researched area.  
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### 8 **Study Aims**

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10 The primary aim of the Longitudinal study of Australian Students with Autism (LASA), is  
11 to document the educational and participation trajectories and outcomes of Australian students with  
12 autism over a six year period. The secondary aim is to examine personal (e.g., student skills,  
13 caregiver) and environmental (e.g., school setting, community supports) factors associated with  
14 varied trajectories and outcomes.  
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## 20 **Methods and Analyses**

### 21 **Study design**

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25 The LASA is a cross-sequential, prospective, longitudinal, quantitative study. Data will be  
26 collected annually over six years focussing on educational and participation outcomes from two  
27 cohorts of children with autism, Cohort 1 age 4-5 and Cohort 2 age 9-10, at time of recruitment.  
28 The age ranges were chosen to ensure that data collection occurred over two critical transition  
29 periods; starting school and moving from primary to high school. Caregivers and education  
30 professionals will provide information annually about progress in education and participation, as  
31 well as factors hypothesised in the research literature to be associated with differing trajectories and  
32 outcomes. The project is managed by the LASA partners advisory group consisting of the primary  
33 co-applicants and is chaired by the principal investigator (name deleted).  
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### 42 **Study Funding**

43 The study is funded by the Living with Autism Cooperative Research Centre (CRC),<sup>17</sup> a  
44 federally funded program to support industry-led collaborations between industry, researchers, and  
45 the community.<sup>17</sup> The funders of this study advocate inclusive research practices process, and  
46 active inclusion of the autistic community in the research is a condition of funding. To this end,  
47 autistic people review all grant applications, shape key research questions, and review progress  
48 reports for the project. Details of the Autism CRC policies and practices relating to inclusive  
49 research are available from their website. Autistic people have also been encouraged to apply for  
50 PhD scholarships associated with the longitudinal study.  
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## Study Population

Participants will be recruited across all states and territories in Australia, which has a population of approximately 23 million people, including nearly 4 million school aged children.<sup>18</sup> With a conservative estimated prevalence of 1 in 100 children, the estimated number of all school-aged children with autism at this time is over 35,000.

The primary participant group will be caregivers of children with autism aged 4-5 years or 9-10 years at time of recruitment. Each child must have received a clinical diagnosis of autism by health professionals in the community. Parents will be asked to provide a copy of their child's diagnostic assessment report. The Social Communication Questionnaire (SCQ)<sup>19</sup> is included in the parent questionnaire to verify the child's diagnosis. Children with additional medical diagnoses (e.g., seizure disorders, intellectual disability) will be included to ensure a study sample reflecting the population of young people with autism. Caregivers will be asked to complete questionnaires and participate in phone conversations with the research team. These tasks assume skills in spoken and written English, but no exclusion criteria will be adopted in order to recruit a sample that reflects the heterogeneity of the population. Participants self-select.

The second key participant group is educational professionals, namely principals and teachers currently working with each child with autism in formal school or distance education settings, who consent to participate in the study. No exclusionary criteria will be applied.

## Participant selection and recruitment

Parent/caregiver participants will be recruited nationally from organisations such as child development units and early intervention services, state autism organisations, parent support groups, autism advocacy groups and through websites, mailing lists and internet groups. Parents/caregivers will be asked to register to participate in the study through an internet link. Parents who register, will be contacted by a research team member and if their child is eligible and they agree to participate, they will be sent an online parent/caregiver questionnaire. If parent consent is given, the principal of their child's school will be contacted and asked to complete a questionnaire about the school. The principal will also be asked to consent to the research team contacting the child's teacher. If children have several teachers, the principal will be asked to select the teacher who has the best knowledge of the child. Once this consent is given the child's teacher will be contacted and asked to complete an online questionnaire about the child's progress and participation at school.

## Data Collection Procedure

Parents will be asked to complete online questionnaires annually for 6 years, comprising 6 time points (T1-T6). Following recruitment, parents will be emailed a link to an online initial questionnaire (T1). Parents will then be contacted annually and asked to complete either an extended questionnaire (at T3, T5 and T6) or an abbreviated questionnaire (at T2, T4). Parents will also be contacted annually and asked to provide educational/school or assessment reports (diagnostic reports in particular) and current school contact information. The recruitment goal for the study is 120 participants in each cohort.

Where consent is given, the child's current school will be contacted annually and both the teacher and school principal will be asked to complete online questionnaires about the child or school respectively (T1 – T6). At each time point, parents, teachers and principals will be given one month to complete the questionnaire. During that period, they may stop and start the questionnaire as many times as they like with responses saved online. Participants who do not complete the questionnaires in that time will receive reminders via email and/or a phone call from the participant coordinator to offer assistance and confirm their willingness to continue in the study.

## Research measures

A battery of developmental and behavioural assessment tools designed to assess educational and participation trajectories and outcomes, along with theoretically driven predictors of these, was selected following a review of the literature. The length of the questionnaire was monitored so as to minimise participant burden, with the abbreviated questionnaire (at T2 and T4) taking approximately 30 minutes to complete and the extended questionnaire (at T1, T3, T5, T6) taking approximately two hours to complete.

An overview of assessments for caregivers (including detail on their reliability and validity), and the time points at which they will be collected, is provided in Table 1. An overview of assessments for schools (principals and teachers) is provided in Table 2. The parents will complete questionnaires focussing upon demographics, the primary outcome variable (child participation) and adaptive behaviour at each time point. The secondary outcomes, academic competence and family outcomes, and other explanatory factors will be measured at T1, T3, T5 and T6. These include measures of communication, sensory characteristics, behavioural and emotional difficulties, anxiety and parent stress.

The questionnaire pack for teachers will consist of a questionnaire compiled using questions from the National Longitudinal Transition Study-2<sup>20</sup>, US Department of Education and other



1 sources, including the Longitudinal Study of Australian Children (LSAC).<sup>21</sup> This focuses upon  
2 gathering information on the available support for transition to and within their school, use of  
3 Individual Education Plans, accommodations for standardised tests, social skills support, a  
4 standardised questionnaire on academic functioning for their student (compared to their peers) and a  
5 standardised questionnaire designed to gather information about the student's emotional,  
6 behavioural and social profile. Finally, the principal will be asked to complete a purpose-designed  
7 questionnaire about location, size and type of school (mainstream, specialist, special), exclusion and  
8 attendance rates and whole-school and individualised programs or approaches for children with  
9 autism in place in their school. Copies of the purpose-designed questionnaires are available via  
10 email from the corresponding author.

#### 11 Primary outcome measure

12 The primary outcome is a measure of child participation, the Participation and Environment  
13 Measure – Child and Youth<sup>22</sup> (PEM-CY), completed at each data collection point. This was  
14 selected as it measures a child's participation and environment across three settings: home (10  
15 items), school (5 items) and community (10 items). For each item, parents report how often their  
16 child participates in the activity (never (0) to daily (7)), how involved the child is in the activity  
17 (minimally involved (1) to very involved (5)) and whether the parent desires change in their child's  
18 participation in the activity. If parents state that they would like a change, they are asked more  
19 about this change in terms of frequency (to do it more or less often), involvement (be more or less  
20 involved) or if they would like their child involved in a broader range of activities within this  
21 category. The PEM-CY is suitable for children aged 5 to 17 years and has been shown to be  
22 reliable, with good strong internal consistency and good inter-rater reliability (detailed in Table 1).

#### 23 Secondary outcome measures

24 Secondary outcomes are a measure of academic competence<sup>23</sup> (Academic Competence Evaluation  
25 Scales; ACES) and the Family Outcomes Survey Revised (FOS-R)<sup>24</sup>.

26 The ACES<sup>23</sup> will be administered at each data collection point. It contains 73 questions that assess  
27 the academic functioning of students, grades K-12. It measures academic skills (33 items)  
28 (reading/language arts, mathematics, critical thinking) and academic enablers (40 items)  
29 (interpersonal skills, engagement, motivation, and study skills). Teachers rate their student's  
30 academic skills relative to school expectations on a 5-point scale ranging from far below (1) to far  
31 above (5) and how important the skill is for academic success in the classroom on a 3 point scale  
32 ranging from not important (1) to critical (3). There is also a N/O option for each question if the  
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1 teacher has not had the opportunity to observe the skill. For the academic enablers teachers rate how  
2 frequently their student shows the behaviours on a 5-point scale, ranging from never (1) to almost  
3 always (5) and their importance in the classroom on a 3 point scale, not important (1) to critical (3).  
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5 There is also a N/O option for each question if the teacher has not had the opportunity to observe  
6 the skill. A raw score is obtained for each of the academic skill areas and the academic enablers  
7 areas and is interpreted in relation to the child's age and grade at school. The manual provides  
8 normative data for children with and without learning disabilities.  
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14 The FOS-R<sup>24</sup> has two sections. Section A will be administered at T1, T5 and T6 and Section B at  
15 T1 only. Section A consists of 24 items and focuses on five family outcomes: (1) understanding  
16 your child's strengths, needs and abilities; (2) knowing your rights and advocating for services; (3)  
17 helping your child develop and learn; (4) having support systems and; (5) accessing the community.  
18 Section A assesses the extent to which families have achieved these outcomes on a 5-point scale  
19 ranging from (1) not at all to (5) completely. Section B consists of 17 items and focuses on the three  
20 helpfulness indicators of knowing your rights; communicating your child's needs and; helping your  
21 child develop and learn. Section B assesses the helpfulness of early intervention on a 5-point scale  
22 ranging from (1) not at all helpful to (5) extremely helpful.  
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### 29 Explanatory factors

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31 In order to explain the educational and participation trajectories of children with autism, factors  
32 potentially interacting with the outcomes are also examined. These factors were selected based  
33 upon a thorough literature review and are explained below, with details of each measure provided in  
34 Table 1. These factors can be categorised as child, family and educational environment factors.  
35 Child factors include behavioural and emotional difficulties, communication skills, adaptive  
36 behaviour, sensory behaviours, child anxiety, parental stress and family demographics will also be  
37 assessed. Educational environment will be documented through the principal, teacher and parent  
38 surveys.  
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### 46 Data collection

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48 The online questionnaires will be developed in the online survey system, Qualtrics. An internet link  
49 to the questionnaire will be sent to each participant via email which contains a personal ID that  
50 links the child participant with responses collected from their parent/caregiver, their teacher and  
51 school principal. The responses will be stored in a password protected Qualtrics database  
52 accessible by two research team members. The Project Coordinator is responsible for cleaning and  
53 removing personally identifiable information from the data. The data will only be accessible to the  
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1 project team and is stored in line with National Health Medical Research Council (NHMRC)<sup>25</sup> best  
2 practice.  
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#### 5 Feedback to families and school

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7 Parents will receive a written summary of their child's annual survey results. If parents wish to  
8 receive formal scored reports for the standardised child assessments included in the questionnaire,  
9 they will be required to complete a *Client Consent to Share Information Form B*. Once consent is  
10 given the LASA research team will share the scored reports with the child's health or allied health  
11 professional nominated by the parent. This procedure is consistent with ethical mandates<sup>26</sup> designed  
12 to ensure that information is not released that is potentially distressing to parents or requires  
13 interpretation.  
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17 Caregivers, teachers and principals will receive updates about the study through an annual  
18 newsletter and access to social media pages of the Autism Centre for Excellence. Throughout the  
19 study, results will be presented in aggregate format only and presented in an accessible format for a  
20 lay audience. The Autism Centre for Excellence social media site will also keep participants  
21 informed about what is new in autism spectrum disorders and evidence based strategies.  
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#### 31 **Data analysis**

32 The data collected in the study provides longitudinal data on educational and participation  
33 trajectories for children with Autism. However, it is designed with sample sizes large enough to  
34 allow for cross-sectional comparisons (within or between age groups) at each time point. Cohort  
35 effects can also be explored by comparing data from when both groups are 9-10 years old (T1 for  
36 Cohort 2 and T6 for Cohort 1). Missing data will be examined and if appropriate, imputation  
37 implemented (the exact method of which will depend upon the missing data). As there is likely to  
38 be less than 100% retention at each follow-up, potential bias in retainment will be assessed by  
39 comparing baseline characteristics (including severity of ASD, parent self-reported stress and socio-  
40 economic status) of retained and non-retained participants using model diagnostics.  
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48 To document the participants' educational and participation trajectories and outcomes  
49 (primary aim), descriptive statistics (frequencies, means, medians and standard deviations)  
50 pertaining to the outcome measures and putative explanatory factors will be presented for each  
51 cohort at each time point.  
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56 Group comparisons on cross-sectional data, such as comparisons between the younger and  
57 older groups or between smaller subgroups, will be performed using independent samples t-tests or  
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1 equivalent non-parametric tests if the data is not normally distributed. Consideration will be given  
2 to error with the use of multiple comparisons. Using independent t-tests, with  $\alpha = .05$ ,  $\beta = .80$ , and  
3 medium effect size of 0.5 a sample of 102 participants is required.<sup>27</sup> Our target sample size of 120  
4 children in each cohort allows for an attrition rate of approximately 15% over the course of the  
5 study. Cross-sectional analysis of standardised scores will also be performed using t-test or  
6 multivariate analysis (MANOVA) and mediating or moderating factors explored using regression  
7 models.  
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10 Multiple regression will be used to examine personal and environmental factors associated  
11 with differing trajectories and outcomes (secondary aim). The interaction or influence of the  
12 explanatory factors, such as level of adaptive behaviour (measured by the VABS), severity of  
13 Autism Symptoms (measured by the SCQ) or sensory behaviours (measured by the SSP-2) will be  
14 explored within these regression models.  
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16 For the longitudinal analyses, a Bayesian mixed effects model is planned. Using this approach,  
17 missing values can be treated as another variable in the modelling process. As such, there are a  
18 number of approaches available to analysing longitudinal results with missing data. Documentation  
19 of the participants' educational and participation trajectories and outcomes (primary aim) will be  
20 assessed on the PEM-CY, with through posterior predictive profile for the measure being estimated  
21 based on the significant variables. Personal and environmental factors associated with differing  
22 trajectories and outcomes (secondary aim) will also be examined in this modelling framework. The  
23 interaction or influence of the explanatory factors, such as level of adaptive behaviour (measured by  
24 the VABS), severity of Autism Symptoms (measured by the SCQ) or sensory behaviours (measured  
25 by the SSP-2) will also be considered.  
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### 43 **Methodological considerations**

#### 44 Questionnaire data

45 The format of this study (data collection through questionnaires) allows for recruitment of a  
46 reasonably large sample of children and families. However, it is acknowledged that all of the  
47 information for this study is collected through questionnaires and interviews, without meeting the  
48 child or family. This means that it is not possible for the data to include direct measures of ability  
49 (such as intellectual ability) or to complete formal assessments<sup>28</sup> (such as the ADOS). To address  
50 this issue, all parents will be asked to complete a validated autism screening questionnaire (Social  
51 Communication Questionnaire) and are required to send in copies of their child's diagnostic reports.  
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Parents will also be asked to send in reports of any additional assessments, particularly cognitive assessments.

### Bias in recruitment

The nature of the present study requires a significant commitment from participants and where applicable, their teachers and principals. Parents are asked to complete six online questionnaires, four of which will take approximately two hours to complete. This may influence the recruitment procedure and may, over the duration of the study, reduce completion rates. It is therefore possible that there will be a recruitment bias (i.e., families who can afford the time to complete the questionnaire and/or who have ready access to a computer with internet access). It may also be that the research may only attract parents that have an interest in the focus of this study. To address this issue, efforts will be directed towards recruiting from a range of sources and in providing parents with the ability to log in and out of their questionnaire completion site so they can complete the questionnaire pack in small sections over one month. Demographic information alongside information about challenging behaviour (from the DBC) and parental stress (from the PSI-SF) will be compared between those who complete and those who leave the study in order to identify factors that may have contributed to non-completion.

### Ethics and dissemination

The study has received ethical approval from all recruiting sites and universities involved in the project (see list below). All parents will provide consent for their child to join the study. Parents can also choose whether to give consent for teacher and principal questionnaires to be collected. Results from standardised questionnaires can be shared with nominated health professionals if requested by the consenting caregiver.

It is not anticipated that participants will be subject to any risks during this study. It is possible that parents may become distressed when communicating about their child's autism or associated strengths and difficulties. The survey is designed to end with questions for parents about their child's strengths and interests to end on a positive note. All parents are provided with the contact details of the project administrator (who can direct the parent to an appropriate clinically trained member of the research team) to discuss the questionnaire. The research team are willing and able to refer parents to a range of specialised support services if this is deemed necessary or helpful.

Participant information will be securely stored electronically or in the project office.

Questionnaires are completed online and personal identifiable information received (such as copies

1 of diagnostic reports) will be stored in a locked filing cabinet. Once downloaded from the online  
2 database, all participant data will be anonymised by allocating each participant with an ID number.  
3 De-identified participant data will be saved on a password-protected secure computer drive which  
4 only members of the research team have access to. Participants' personal identifiable data will be  
5 stored in a separate location to de-identified participant data. Identifiable data will only be  
6 accessible to the project manager and the project leader.  
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13 Throughout the course of the study and once the longitudinal data collection is complete, results  
14 (de-identified and primarily aggregated) will be published in peer-reviewed mainstream and  
15 specialist journals. Presentations of study findings will be made at relevant research conferences,  
16 local research symposiums and seminars for professionals working with children with autism and  
17 those in autism research. In addition, local stakeholders (such as autism schools and NGOs) will be  
18 consulted in the development of methods for dissemination they find effective in reaching families  
19 of children with autism.  
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### 25 26 27 **Significance and outlook**

28 This study will make an important contribution to the very limited longitudinal data on the pattern  
29 and effects of participation in children with autism. The design allows for annual cross-sectional  
30 comparisons, within subject comparisons, exploration of cohort effects (by comparing data from  
31 both groups at 9-10yrs) and the six-year longitudinal analysis. Collecting data and information  
32 from a range of sources (parents, teachers and principals) allows for a holistic description of  
33 progress and change across the duration of the study.  
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40 Study results will inform clinicians, children and their families about the factors that promote or  
41 reduce participation and educational outcomes and therefore help to identify children who are most  
42 likely to benefit from specific interventions. It will also be important data for educators, who will  
43 be able to proactively monitor factors that put children with autism at risk of not achieving their full  
44 educational potential.  
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50 The study team is also focused on developing capacity of early career researchers through  
51 mentorship and supervision. It will provide data for a number of PhD, Masters and honours  
52 students who often cannot gain experience with longitudinal datasets due to time constraints and  
53 allow them to develop the methodological and statistical expertise required for such methods. This  
54 is particularly important given the identified need for longitudinal studies in a large number of  
55 health, educational and developmental areas.  
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## Summary and conclusion

Autism is an increasingly common condition. Although profiles and presentations are highly variable, a consistent finding is poor life outcomes for adults with autism across domains such as employment and independent living. Given that the primary aim of education is the preparation of children and young people for adult life, it could be argued that the educational process is not achieving this aim for the majority of young people with autism. In this study, data will be collected at key developmental periods including times of major transition (school entry and transition from primary to high school) and factors critical to participation and educational achievement will be explored and documented. Understanding these trajectories and the factors that influence them will assist clinicians working with individual children and their families to describe expected outcome and necessary services and supports, and planning to improve educational environments.

Competing interests: None declared

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3 families and schools participating in this study.  
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8 Authors' contributions:

9  
10 Roberts, Jacqueline; Griffith University, Autism Centre of Excellence; conceptualised and co-  
11 designed the study, developed the first draft of the manuscript, reviewed and revised the manuscript  
12 and finalised the manuscript for publication.  
13

14 Adams, Dawn; Griffith University, Autism Centre of Excellence; drafted the final manuscript,  
15 reviewed and revised the manuscript , and approved the final manuscript.  
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17

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23 with manuscript drafting, reviewed and revised the manuscript , and approved the final manuscript.  
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31 reviewed and revised the manuscript , and approved the final manuscript.  
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35 manuscript drafting, read and approved the final manuscript , and approved the final manuscript.  
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38 Williams, Katrina; University of Melbourne, Developmental Medicine; co-designed the study,  
39 assisted with manuscript drafting, reviewed and revised the manuscript , and approved the final  
40 manuscript.  
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42 Note apart from the lead author, authors are listed alphabetically  
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## References

1. CDC. Prevalence of autism spectrum disorders among children aged 8 years: Autism and developmental disabilities monitoring network. *MMWR Surveillance Summaries*. 2014; 63: 1-22.
2. Horlin C, Falkmer M, Parsons R, Albrecht MA, Falkmer T. The cost of autism spectrum disorders. 2014; *PloS one*, 9(9): e106552.
3. Synergies Economic Consulting, 2011 Synergies. Economic costs of autism spectrum disorder in Australia: Updated study. Brisbane: Synergies Economic Consulting; 2011.
4. World Health Organization. International Classification of Functioning, Disability and Health. Geneva:World Health Organization; 2001.
5. Bolte S, de Schipper E, Robison J, Wong V, Selb M, Singhal N. et al. Classification of functioning and impairment: The development of ICF core sets for autism spectrum disorder. *Autism Research*. 2014; 7: 167-172.
6. de Schipper E, Lundequist A, Coghill D, de Vries P, Granlund M, Holtmann et al. Ability and disability in autism spectrum disorder: A systematic literature review employing the International Classification of Functioning, Disability and Health-Children and Youth Version. *Autism Research*. 2015; 8: 782-794. doi: 10.1002/aur.1485
7. ABS Survey of Disability. 2012. Available from: <http://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/4430.02012>
8. 4428.0 - Autism in Australia, Australian Bureau of Statistics.2012. Available from:<http://www.abs.gov.au/ausstats/abs@.nsf/Latestproducts/4428.0Main%20Features52012?opendocument&tabname=Summary&prodno=4428.0&issue=2012&num=&view=>
9. Moss P, Howlin P, Savage S, Bolton P, Rutter M. Self and informant reports of mental health difficulties among adults with autism findings from a long-term follow-up study. *Autism*. 2015 May 26:1362361315585916.
10. Magiati I, Tay XW, Howlin P. Cognitive, language, social and behavioural outcomes in adults with autism spectrum disorders: A systematic review of longitudinal follow-up studies in adulthood. *Clinical Psychology Review*. 2014; 34: 73-86.
11. Fein D, Barton M, Eigsti IM, Kelley E, Naigles L, Schultz RT. et al. Optimal outcome in individuals with a history of autism. *Journal of child psychology and psychiatry*. 2013; 54: 195-205.

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12. Howlin P, Savage S, Moss P, Tempier A, Rutter M. Cognitive and language skills in adults with autism: a 40-year follow-up. *Journal of Child Psychology and Psychiatry*. 2014; 55: 49-58.
  13. Magiati I, Tay XW, Howlin P. (2014). Cognitive, language, social and behavioural outcomes in adults with autism spectrum disorders: a systematic review of longitudinal follow-up studies in adulthood. *Clinical Psychology Review*. 2014; 34: 73-86.
  14. Roberts J, Simpson K. A review of research into stakeholder perspectives on inclusion of students with autism in mainstream schools. *International Journal of Inclusive Education*. 2016; 1-13.
  15. Prior M, Roberts JMA, Rodger S, Williams K, Sutherland R. (2011). A review of the research to identify the most effective models of practice in early intervention of children with autism spectrum disorders. Australian Government Department of Families, Housing, Community Services and Indigenous Affairs, Australia. Available from [http://www.fahcsia.gov.au/sites/default/files/documents/09\\_2012/review\\_of\\_the\\_research\\_report\\_2011\\_0.pdf](http://www.fahcsia.gov.au/sites/default/files/documents/09_2012/review_of_the_research_report_2011_0.pdf)
  16. Roberts JMA, Williams K. Autism spectrum disorder: Evidence-based/evidence-informed good practice for supports provided to preschool children, their families and carers. 2016. Report prepared for the National Disability Insurance Agency (NDIA).
  17. Autism CRC. 2016. Available from <http://www.autismcrc.com.au/about-crcs>
  18. 4221.0 - Schools, Australia, 2015. Australian Bureau of Statistics. 2015. Available from: <http://www.abs.gov.au/ausstats/abs@.nsf/mf/4221.0>
  19. Rutter M, Bailey MD, Lord C. The Social Communication Questionnaire (SCQ). Los Angeles, CA: Western Psychological Services; 2003.
  20. National Longitudinal Transition Study-2, US Department of Education US Department of Education. Welcome to NLTS2. Available from: <http://www.nlts2.org/index.html>.
  21. Longitudinal Study of Australian Children (LSAC) Growing up in Australia: The longitudinal study of Australian children (LSAC). Available from: <http://growingupinaustralia.gov.au/>
  22. Coster W, Bedell G, Law M, et al. (2011). Psychometric evaluation of the Participation and Environment Measure for Children and Youth. *Developmental Medicine and Child Neurology*. 2011; 53: 1030-1037. DOI: 10.1111/j.1469-8749.2011.04094.x
  23. DiPerna JC, Elliott SN. Academic competence evaluation scales. San Antonio: The Psychological Corporation; 2000.
  24. Bailey DB, Raspa M, Olmsted MG, et al. Development and psychometric validation of the family outcomes survey revised. *Journal of Early Intervention*. 2011; 33: 6-23.

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25. National Statement on Ethical Conduct in Human Research 2007 (Updated May 2015). The National Health and Medical Research Council, the Australian Research Council and the Australian Vice-Chancellors' Committee. Commonwealth of Australia, Canberra
26. Australian Psychological Society. (2012). *Code of ethics*. Melbourne, Vic: Author
27. Faul F, Erdfelder E, Lang AG, Buchner A. G\*Power 3: A flexible statistical power analysis program for the social, behavioral, and biomedical sciences. *Behavior Research Methods*. 2007;39:175-191.
28. Lord C, Rutter M, Pamela C. Dilavore P, Risi, S. ADOS: Autism diagnostic observation schedule. Hogrefe; 2008.
29. Sparrow SS, Cicchetti DV, Balla DA. Vineland II: Vineland Adaptive Behavior Scales. Bloomington, MN: Pearson; 2005.
30. Bishop DVM. Children's Communication Checklist-2 (CCC-2). San Antonio, TX: Pearson; 2006.
31. Dewart H, Summers S. The Pragmatics Profile of Early Communication Skills. London: NFER-NELSON; 1995
32. Einfeld SL, Tonge BJ. Manual for the Developmental Behaviour Checklist. Clayton, Melbourne and Sydney Monash University for Developmental Psychiatry and School of Psychiatry, University of New South Wales; 1992.
33. Dunn W. Sensory Profile 2. Bloomington, MN, USA: Pearson Psychcorp; 2014
34. Rodgers J, Wigham S, McConachie H, Freeston M, Honey E, Parr JR. Development of the anxiety scale for children with autism spectrum disorder (ASC-ASD). *Autism Research*. 2016. doi:10.1002/aur.1603
35. Abidin RR. Parenting Stress Index Professional Manual (4th ed.). Lutz, FL: PAR; 2012.
36. Goodman R. (1997). The Strengths and Difficulties Questionnaire: A Research Note. *Journal of Child Psychology and Psychiatry*. 1997; 38:581-586.

Table 1: Parent measures used within the LASA and their published reliability statistics

Instrument	Captures	Domains	Measured at	Reliability
Family History Survey	Information on child and family demographics, child and family medical history, child's therapy and intervention and the parent's perception of child social experience of school (e.g. experience of bullying)	N/A	T1, T2, T3, T4, T5, T6	N/A
Participant and Environment Measures – Child and Youth <sup>22</sup>	Child's participation and environment across three settings: school and community	Level of involvement Parent satisfaction with participation at: Home, School, Community	T1, T2, T3, T4, T5, T6	Internal consistency <sup>1</sup> .59-.91 Participation frequency .59-.70 Participation involvement: .72-.83 Environmental Supportiveness: .67-.91 Test-retest reliability <sup>1</sup> Participation frequency .58-.84 Participation involvement: .69-.76 Desires change: .76-.89 Environmental Supportiveness: .85-.95
Social communication Questionnaire (SCQ)	Symptoms of Autism (combines with "community diagnosis")	N/A	T1	Internal Consistency <sup>2</sup> ( $\alpha$ ) = .93 Test-retest <sup>2</sup> = .81

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4	Lifetime <sup>19</sup>	to confirm ASD)			
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6	Vineland Adaptive	Daily functional skills	Communication	T1, T2,	Internal Consistency <sup>3</sup> ( $\alpha$ )
7	Behavior Scale, 2 <sup>nd</sup>	and adaptive behaviour.	Daily Living Skills	T3, T4,	Communication .84-.93
8	Edition (VABS-II) <sup>29</sup>		Socialisation	T5, T6	Daily Living Skills .86-.91
9					Socialisation .84-.93
10					Test-retest across domains <sup>3</sup> .76-.92
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13					
14	Children's	Communicative	Speech, Syntax,	T1, T3,	Internal Consistency <sup>4</sup> ( $\alpha$ ): .73-.88
15	Communication	behaviours	Semantics, Coherence,	T5, T6	Inter-rater reliability <sup>4</sup> .61-.83
16	Checklist-2 (CCC-2)		Initiation, Stereotyped		
17	<sup>30</sup>		language, Use of context		
18			Nonverbal		
19			communication, Social		
20			relations, Interests		
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23					
24	Pragmatic Profile of	Communicative	Selected items on	T1, T3,	
25	Everyday	functions and forms	Communicative	T5, T6	
26	Communication <sup>31</sup>		Functions, Response to		
27	(selected questions)		Communication		
28			Interaction and		
29			Conversation		
30			Contextual Variation		
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34	Developmental	Behaviour and	Disruptive/Antisocial	T1, T3,	Internal Consistency <sup>5</sup> ( $\alpha$ ): .94
35	Behaviour Checklist	emotional problems	Self-absorbed	T5, T6	Inter-rater reliability <sup>6</sup> .72 <sup>5</sup>
36	(DBC-P) <sup>32</sup>		Communication		
37			Disturbance, Anxiety		
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Short Sensory Profile-2 <sup>33</sup>	Sensory behaviours	Auditory Processing Visual Processing Touch Processing Movement Processing Body Position Processing Oral Sensory Processing	T1, T3, T5, T6	Internal Consistency <sup>7</sup> .57-.92 Test re-test <sup>7</sup> .83-.92 Inter-rater <sup>7</sup> .49-.89
Anxiety Scale for Children with Autism Spectrum Disorder (ASC-ASD-P) <sup>34</sup>	Child anxiety	Separation Anxiety Uncertainty Performance Anxiety Anxious Arousal	T2, T3, T4, T5, T6	Internal Consistency <sup>8</sup> ( $\alpha$ ): .85-.91 Separation anxiety .87 Uncertainty .88 Performance .89 Anxious arousal .88 Test re-test <sup>8</sup> ( $\alpha$ ): .84
Family Outcomes Survey Revised (FOS-R) <sup>24</sup>	Family outcomes	Understanding your child's strengths, needs and abilities Knowing your rights and advocating for services Helping your child develop and learn Having support systems Accessing the community	T1, T5, T6	Internal Consistency <sup>9</sup> ( $\alpha$ ): .73-.91
Parenting Stress Index-4-Short Form	Parental stress	Parental distress Parent-child	T1, T3, T5, T6	Internal Consistency <sup>10</sup> ( $\alpha$ ): .98 Child: .96

(PSI-4-SF) <sup>35</sup>	dysfunctional interaction Difficult child	Adult: .96 Test re-test <sup>10</sup> .96 Child: .63 Parent: .91
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Table 2: School measures used within the LASA and their published reliability statistics

Instrument	Captures	Domains	Measured at	Reliability
Academic Competence Evaluation Scales (ACES) <sup>23</sup>	Academic functioning of student	Academic skills (reading/language arts, mathematics, critical thinking) Academic enablers (interpersonal skills, engagement, motivation, and study skills)	T1, T2, T3, T4, T5, T6	Internal Consistency <sup>1</sup> ( $\alpha$ ): .94-.99  Test re-test <sup>1</sup> .88-.97
Strengths and Difficulties Questionnaire - Teacher (SDQ) <sup>36</sup>	Profile of strengths and difficulties	Emotional symptoms Behavioural difficulties Hyperactivity Peer problems Prosocial behaviours	T1, T2, T3, T4, T5, T6	Internal Consistency <sup>2</sup> .73 Test re-test reliability <sup>2</sup> .62
Teacher survey (compiled from National Longitudinal Transition Study-2, <sup>20</sup> US Department of Education and other sources, including the Longitudinal Study of Australian Children (LSAC) <sup>21</sup>	Student behaviours, teaching practices and school environment		T1, T2, T3, T4, T5, T6	N/A

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Principal Survey (compiled from National Longitudinal Transition Study-2, <sup>20</sup> US Department of Education and other sources, including LSAC) <sup>21</sup>	whole school context in relation to programs/approaches used to educate children with autism	T1, T2, T3, T4, T5, T6	N/A
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# BMJ Open

## Protocol for a prospective longitudinal study investigating the participation and educational trajectories of Australian students with autism

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## Protocol for a prospective longitudinal study investigating the participation and educational trajectories of Australian students with autism

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## Abstract

### Introduction

Autism is associated with high cost to individuals, families, communities and government. Understanding educational and participation trajectories during the school years, and factors influencing these, is fundamental to reducing financial and personal costs. The primary aim of this study is to document the trajectories of Australian students with autism during their education. The secondary aim is to examine personal (e.g. student skills) and environmental (e.g. school setting) factors associated with differing trajectories and outcomes.

### Methods and analysis

The cross-sequential longitudinal study will recruit two cohorts of 120 parents/caregivers of children with autism. Cohort 1 aged between 4-5years and Cohort 2 between 9-10 years to start the study. Information will be gathered from parents, teachers and school principals at 6 annual time points (T1 – T6). Parents will be emailed a link to an online initial questionnaire (T1) and then contacted annually and asked to complete either an extended questionnaire (T3, T5 and T6) or an abbreviated questionnaire (T2, T4). Where consent is given, the child's current school will be contacted annually (T1-T6) and teacher and school principal asked to complete questionnaires about the child and school. Parent and school questionnaires are comprised of questions about demographic and school factors that could influence trajectories and a battery of developmental and behavioural assessment tools designed to assess educational and participation trajectories and outcomes. Surveys will provide longitudinal data on educational and participation trajectories for children and adolescents with autism. In addition cross-sectional comparisons (within or between age groups) at each time point and cohort effects will be explored.

### Ethics and dissemination

Ethics approvals have been granted for this study by all recruiting sites and universities in the project. Study findings will inform policy and practice to promote successful inclusion and participation of children with autism in education. Results will be disseminated through journal publication, conference and seminar presentation.

### Strengths and Limitations

- The study will add to our understanding of the effect of characteristics of autism, family factors, school factors and interventions on educational and personal outcomes for children and young people with autism.
- Enable the development and tailoring of appropriate interventions to improve outcomes.
- Inform policy development in Health and Education in relation to service development and provision for autism communities.

- The participants may be biased towards those with sufficient time, motivation and internet access to complete extensive on-line surveys over 6 years.
- Information collected is all via parent/teacher report.

#### Key words

autism+Autism Spectrum Disorder+developmental trajectories+participation+academic outcomes+personal outcomes

## Introduction

Autism spectrum disorder, herein referred to as autism, is a lifelong neurodevelopmental condition affecting at least 1 in 100 children<sup>1</sup> characterised by impairments in social-communication and behaviour. Autism is a spectrum disorder; children, adolescents, and adults present with differing individual strengths, needs, and preferences for services and supports. Autism is associated with high cost to individuals, families, communities and government,<sup>2,3</sup> highlighting the importance of understanding the nature of autism and optimal supports.

It is important to understand the impact of difficulties or disability on function and participation. Application of the International Classification of Functioning, Disability, and Health (ICF)<sup>4</sup> framework allows us to assess the environmental impacts of characteristics of autism on daily life. Although this approach has been widely adopted in other disabilities it has only been relatively recently integrated into studies and thinking in autism.<sup>5,6</sup>

There is growing evidence that learning in conventional educational environments presents a substantial challenge for most individuals with autism. The most recent survey of educational needs in children with autism in Australia reported that 86% are “having difficulty” at school, with the majority of difficulties being in social cognitive and communication domains.<sup>7</sup> Although these difficulties are recognised both academically and clinically as potential barriers to learning, the influence of each of these factors on educational participation and achievement is yet to be explored. This is important, as almost all (95%) children with autism experience some kind of educational restriction.<sup>8</sup>

The long term impact of not affording individuals with autism appropriate educational supports at an early age is becoming increasingly apparent. Many adults with autism are unemployed, experience mental illness, have reduced independence<sup>9</sup> and are disenfranchised from mainstream society. A recent systematic review of adults with autism classed outcomes in social integration and independence as “poor” or “very poor”, with 50% or more of individuals remaining fully or largely dependent on parents or carers and requiring significant support for education,

1 living arrangements and employment.<sup>10</sup> Unemployment is higher in those with autism than in those  
2 with speech-language impairments and intellectual disability, indicating that the combination of  
3 social, communication and behaviour challenges that are part of autism places these individuals at  
4 heightened risk for poor community participation.<sup>8</sup>  
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9 While we have some understanding of the long term outcomes for adults with autism<sup>11,12,13</sup>  
10 we know little about the experiences and trajectories of students with autism during their school  
11 years, and factors that influence these. Despite the documented difficulties that children with  
12 autism experience in school and the well-recognised need to improve educational outcomes for  
13 students with autism<sup>14</sup>, there is limited information about participation in school, the educational  
14 trajectories and the impact of educational experiences on educational outcomes. This limits the  
15 capacity of parents, teachers, allied health professionals, and others to positively influence growth  
16 in this critical developmental and educational period. It is also unknown which child, family, and  
17 environmental factors may influence these trajectories over time. Characteristics of autism  
18 potentially affecting education include both communication and social characteristics and repetitive  
19 behaviours and restricted interests. Information about educational trajectories and outcomes, and the  
20 way these interact with child characteristics, including later developing characteristics such as  
21 mental health disorders, is needed to enable tailoring of interventions and educational approaches  
22 for individual children and young people with autism and their families during their schooling. Such  
23 information is also needed to understand the experience of children with autism in the educational  
24 environment and explore the impact of these experiences on their development, participation and  
25 social relating. Taken together, there is a clear need for further research into the potential  
26 relationships between characteristics of autism, the environment and outcomes, particularly  
27 educational outcomes, both academic (for example literacy) and personal (for example peer  
28 relationships).  
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43 Young people with autism have more difficulties with important transitions (e.g. between  
44 preschool and primary school, primary to high school), than their peers<sup>15,16</sup> which means they are  
45 likely to start school at a disadvantage compared to their typical peers. Longitudinal studies during  
46 time periods where major transitions occur have the potential to increase our understanding of  
47 interactions between key characteristics of autism, environmental factors, any interventions or  
48 supports provided during these challenging times and outcomes.  
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53 The heterogeneity of individuals with autism and their communities (e.g. caregivers,  
54 teachers, allied health clinicians, school executive) and the wide variety of interventions that  
55 individuals access (evidence based and otherwise), means it is difficult to draw conclusions from  
56 cross sectional designs, even with large participant samples. In contrast, the cross-sequential  
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1 longitudinal research design we describe in this paper will reduce these limitations. This is  
2 particularly relevant in educational settings, where factors such as school engagement and  
3 participation can be observed in a cohort over time and compared to outcomes, presently an under-  
4 documented and under-researched area.  
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### 10 **Study Aims**

11 The primary aim of the Longitudinal study of Australian Students with Autism (LASA), is  
12 to document the educational and participation trajectories and outcomes of Australian students with  
13 autism over a six year period. The secondary aim is to examine personal (e.g., student skills,  
14 caregiver) and environmental (e.g., school setting, community supports) factors associated with  
15 varied trajectories and outcomes.  
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### 21 **Methods and Analyses**

#### 22 **Study design**

23 The LASA is a cross-sequential, prospective, longitudinal, quantitative study. Data will be  
24 collected annually over six years focussing on educational and participation outcomes from two  
25 cohorts of children with autism, Cohort 1 age 4-5 and Cohort 2 age 9-10, at time of recruitment.  
26 The age ranges were chosen to ensure that data collection occurred over two critical transition  
27 periods; starting school and moving from primary to high school. Caregivers and education  
28 professionals will provide information annually about progress in education and participation, as  
29 well as factors such as adaptive behaviour, hypothesised in the research literature to be associated  
30 with differing trajectories and outcomes. The project is managed by the LASA partners advisory  
31 group consisting of the primary co-applicants and is chaired by the principal investigator (name  
32 deleted).  
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#### 45 **Study Funding**

46 The study is funded by Cooperative Research Centre for the Living with Autism (Autism  
47 CRC),<sup>17</sup> a federally funded program to support industry-led collaborations between industry,  
48 researchers, and the community.<sup>17</sup> The funders of this study advocate inclusive research practices  
49 process, and active inclusion of the autistic community in the research is a condition of funding. To  
50 this end, autistic people are involved in the assessments of all grant applications, shape key research  
51 questions, review final reports for the project. Further to this, the Autism CRC has established the  
52 Autism CRC Research Academy to build the capacity for co-production/ peer research within the  
53 autistic and research communities in Australia. Details of the Autism CRC policies and practices  
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1 relating to inclusive research are available from their website  
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3 (<http://www.autismcrc.com.au/inclusive-research-practice-guides-and-checklists>). Autistic people  
4  
5 have also been encouraged to apply for higher degree research (Masters Research and PhD)  
6  
7 including 2 PhD scholarships associated with the longitudinal study.  
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9

## 10 11 **Study Population**

12 Participants will be recruited across all states and territories in Australia, which has a  
13 population of approximately 23 million people, including nearly 4 million school aged children.<sup>18</sup>  
14  
15 With a conservative estimated prevalence of 1 in 100 children, the estimated number of all school-  
16  
17 aged children with autism at this time is over 35,000.  
18

19 The primary participant group will be caregivers of children with autism aged 4-5 years or  
20  
21 9-10 years at time of recruitment. Each child must have received a clinical diagnosis of autism by  
22  
23 health professionals in the community. Parents will be asked to provide a copy of their child's  
24  
25 diagnostic assessment report. The Social Communication Questionnaire (SCQ)<sup>19</sup> is included in the  
26  
27 parent questionnaire to verify the child's diagnosis. Children with additional medical diagnoses  
28  
29 (e.g., seizure disorders, intellectual disability) will be included to ensure a study sample reflecting  
30  
31 the population of young people with autism. Caregivers will be asked to complete questionnaires  
32  
33 and participate in phone conversations with the research team. These tasks assume skills in spoken  
34  
35 and written English, but no exclusion criteria will be adopted in order to recruit a sample that  
36  
37 reflects the heterogeneity of the population. Participants self-select.

38 The second key participant group is educational professionals, namely principals and  
39  
40 teachers currently working with each child with autism in formal school or distance education  
41  
42 settings, who consent to participate in the study. No exclusionary criteria will be applied.

## 43 **Participant selection and recruitment**

44 Parent/caregiver participants will be recruited nationally from organisations such as child  
45  
46 development units and early intervention services, state autism organisations, parent support  
47  
48 groups, autism advocacy groups and through websites, mailing lists and internet groups.  
49  
50 Parents/caregivers will be asked to register to participate in the study through an internet link.  
51  
52 Parents who register, will be contacted by a research team member and if their child is eligible and  
53  
54 they agree to participate, they will be sent an online parent/caregiver questionnaire.  
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56 If parent consent is given, the principal of their child's school will be contacted and asked to  
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58 complete a questionnaire about the school. The principal will also be asked to consent to the  
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60 research team contacting the child's teacher. If children have several teachers, the principal will be

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asked to select the teacher who has the best knowledge of the child. Once this consent is given the child’s teacher will be contacted and asked to complete an online questionnaire about the child’s progress and participation at school.

For peer review only



## Data Collection Procedure

Parents will be asked to complete online questionnaires annually for 6 years, comprising 6 time points (T1-T6). Following recruitment, parents will be emailed a link to an online initial questionnaire (T1). Parents will then be contacted annually and asked to complete either an extended questionnaire (at T3, T5 and T6) or an abbreviated questionnaire (at T2, T4). Parents will also be contacted annually and asked to provide educational/school or assessment reports (diagnostic reports in particular) and current school contact information. The recruitment goal for the study is 120 participants in each cohort.

Where consent is given, the child's current school will be contacted annually and both the teacher and school principal will be asked to complete online questionnaires about the child or school respectively (T1 – T6). At each time point, parents, teachers and principals will be given one month to complete the questionnaire. During that period, they may stop and start the questionnaire as many times as they like with responses saved online. Participants who do not complete the questionnaires in that time will receive reminders via email and/or a phone call from the participant coordinator to offer assistance and confirm their willingness to continue in the study.

## Research measures

A battery of developmental and behavioural assessment tools designed to assess educational and participation trajectories and outcomes, along with theoretically driven predictors of these, was selected following a review of the literature. The length of the questionnaire was monitored so as to minimise participant burden, with the abbreviated questionnaire (at T2 and T4) taking approximately 30 minutes to complete and the extended questionnaire (at T1, T3, T5, T6) taking approximately two hours to complete.

An overview of assessments for caregivers (including detail on their reliability and validity), and the time points at which they will be collected, is provided in Table 1. An overview of assessments for schools (principals and teachers) is provided in Table 2. The parents will complete questionnaires focussing upon demographics, the primary outcome variable (child participation) and adaptive behaviour at each time point. The secondary outcomes, academic competence and family outcomes, and other explanatory factors will be measured at T1, T3, T5 and T6. These include measures of communication, sensory characteristics, behavioural and emotional difficulties, anxiety and parent stress.

The questionnaire pack for teachers will consist of a questionnaire compiled using questions from the National Longitudinal Transition Study-2<sup>20</sup>, US Department of Education and other

1 sources, including the Longitudinal Study of Australian Children (LSAC).<sup>21</sup> This focuses upon  
2 gathering information on the available support for transition to and within their school, use of  
3 Individual Education Plans, accommodations for standardised tests, social skills support, a  
4 standardised questionnaire on academic functioning for their student (compared to their peers) and a  
5 standardised questionnaire designed to gather information about the student's emotional,  
6 behavioural and social profile. Finally, the principal will be asked to complete a purpose-designed  
7 questionnaire about location, size and type of school (mainstream, specialist, special), exclusion and  
8 attendance rates and whole-school and individualised programs or approaches for children with  
9 autism in place in their school. Copies of the purpose-designed questionnaires are available via  
10 email from the corresponding author.

#### 11 Primary outcome measure

12 The primary outcome is a measure of child participation, the Participation and Environment  
13 Measure – Child and Youth<sup>22</sup> (PEM-CY), completed at each data collection point. This was  
14 selected as it measures a child's participation and environment across three settings: home (10  
15 items), school (5 items) and community (10 items). For each item, parents report how often their  
16 child participates in the activity (never (0) to daily (7)), how involved the child is in the activity  
17 (minimally involved (1) to very involved (5)) and whether the parent desires change in their child's  
18 participation in the activity. If parents state that they would like a change, they are asked more  
19 about this change in terms of frequency (to do it more or less often), involvement (be more or less  
20 involved) or if they would like their child involved in a broader range of activities within this  
21 category. The PEM-CY is suitable for children aged 5 to 17 years and has been shown to be  
22 reliable, with good strong internal consistency and good inter-rater reliability (detailed in Table 1).

#### 23 Secondary outcome measures

24 Secondary outcomes are a measure of academic competence<sup>23</sup> (Academic Competence Evaluation  
25 Scales; ACES) and the Family Outcomes Survey Revised (FOS-R)<sup>24</sup>.

26 The ACES<sup>23</sup> will be administered at each data collection point. It contains 73 questions that assess  
27 the academic functioning of students, grades K-12. It measures academic skills (33 items)  
28 (reading/language arts, mathematics, critical thinking) and academic enablers (40 items)  
29 (interpersonal skills, engagement, motivation, and study skills). Teachers rate their student's  
30 academic skills relative to school expectations on a 5-point scale ranging from far below (1) to far  
31 above (5) and how important the skill is for academic success in the classroom on a 3 point scale  
32 ranging from not important (1) to critical (3). There is also a N/O option for each question if the  
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1 teacher has not had the opportunity to observe the skill. For the academic enablers teachers rate how  
2 frequently their student shows the behaviours on a 5-point scale, ranging from never (1) to almost  
3 always (5) and their importance in the classroom on a 3 point scale, not important (1) to critical (3).  
4  
5 There is also a N/O option for each question if the teacher has not had the opportunity to observe  
6 the skill. A raw score is obtained for each of the academic skill areas and the academic enablers  
7 areas and is interpreted in relation to the child's age and grade at school. The manual provides  
8 normative data for children with and without learning disabilities.  
9

10 The FOS-R <sup>24</sup> has two sections. Section A will be administered at T1, T5 and T6 and Section B at  
11 T1 only. Section A consists of 24 items and focuses on five family outcomes: (1) understanding  
12 your child's strengths, needs and abilities; (2) knowing your rights and advocating for services; (3)  
13 helping your child develop and learn; (4) having support systems and; (5) accessing the community.  
14 Section A assesses the extent to which families have achieved these outcomes on a 5-point scale  
15 ranging from (1) not at all to (5) completely. Section B consists of 17 items and focuses on the three  
16 helpfulness indicators of knowing your rights; communicating your child's needs and; helping your  
17 child develop and learn. Section B assesses the helpfulness of early intervention on a 5-point scale  
18 ranging from (1) not at all helpful to (5) extremely helpful.  
19

### 20 Explanatory factors

21 In order to explain the educational and participation trajectories of children with autism, factors  
22 potentially interacting with the outcomes are also examined. These factors were selected based  
23 upon a thorough literature review and are explained below, with details of each measure provided in  
24 Table 1. These factors can be categorised as child, family and educational environment factors.  
25 Child factors include behavioural and emotional difficulties, communication skills, adaptive  
26 behaviour, sensory behaviours, child anxiety, parental stress and family demographics will also be  
27 assessed. Educational environment will be documented through the principal, teacher and parent  
28 surveys.  
29

### 30 Data collection

31 The online questionnaires will be developed in the online survey system, Qualtrics. An internet link  
32 to the questionnaire will be sent to each participant via email which contains a personal ID that  
33 links the child participant with responses collected from their parent/caregiver, their teacher and  
34 school principal. The responses will be stored in a password protected Qualtrics database  
35 accessible by two research team members. The Project Coordinator is responsible for cleaning and  
36 removing personally identifiable information from the data. The data will only be accessible to the  
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1 project team and is stored in line with National Health Medical Research Council (NHMRC)<sup>25</sup> best  
2 practice.  
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#### 5 Feedback to families and school

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7 Parents will receive a written summary of their child's annual survey results. If parents wish to  
8 receive formal scored reports for the standardised child assessments included in the questionnaire,  
9 they will be required to complete a *Client Consent to Share Information Form B*. Once consent is  
10 given the LASA research team will share the scored reports with the child's health or allied health  
11 professional nominated by the parent. This procedure is consistent with ethical mandates<sup>26</sup> designed  
12 to ensure that information is not released that is potentially distressing to parents or requires  
13 interpretation.  
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20 Caregivers, teachers and principals will receive updates about the study through an annual  
21 newsletter and access to social media pages of the Autism Centre for Excellence. Throughout the  
22 study, results will be presented in aggregate format only and presented in an accessible format for a  
23 lay audience. The Autism Centre for Excellence social media site will also keep participants  
24 informed about what is new in autism spectrum disorders and evidence based strategies.  
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#### 31 **Data analysis**

32 The data collected in the study provides longitudinal data on educational and participation  
33 trajectories for children with Autism. However, it is designed with sample sizes large enough to  
34 allow for cross-sectional comparisons (within or between age groups) at each time point. Cohort  
35 effects can also be explored by comparing data from when both groups are 9-10 years old (T1 for  
36 Cohort 2 and T6 for Cohort 1). Missing data will be examined and if appropriate, imputation  
37 implemented (the exact method of which will depend upon the missing data). As there is likely to  
38 be less than 100% retention at each follow-up, potential bias in retainment will be assessed by  
39 comparing baseline characteristics (including severity of ASD, parent self-reported stress and socio-  
40 economic status) of retained and non-retained participants using model diagnostics.  
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48 To document the participants' educational and participation trajectories and outcomes  
49 (primary aim), descriptive statistics (frequencies, means, medians and standard deviations)  
50 pertaining to the outcome measures and putative explanatory factors will be presented for each  
51 cohort at each time point.  
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55 Group comparisons on cross-sectional data, such as comparisons between the younger and  
56 older groups or between smaller subgroups, will be performed using independent samples t-tests or  
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equivalent non-parametric tests if the data is not normally distributed. Consideration will be given to error with the use of multiple comparisons. Using independent t-tests, with  $\alpha = .05$ ,  $\beta = .80$ , and medium effect size of 0.5 a sample of 102 participants is required.<sup>27</sup> Our target sample size of 120 children in each cohort allows for an attrition rate of approximately 15% over the course of the study. Cross-sectional analysis of standardised scores will also be performed using t-test or multivariate analysis (MANOVA) and mediating or moderating factors explored using regression models.

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Multiple regression will be used to examine personal and environmental factors associated with differing trajectories and outcomes (secondary aim). The interaction or influence of the explanatory factors, such as level of adaptive behaviour (measured by the VABS), severity of Autism Symptoms (measured by the SCQ) or sensory behaviours (measured by the SSP-2) will be explored within these regression models.

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For the longitudinal analyses, a Bayesian mixed effects model is planned. Using this approach, missing values can be treated as another variable in the modelling process. As such, there are a number of approaches available to analysing longitudinal results with missing data. Documentation of the participants' educational and participation trajectories and outcomes (primary aim) will be assessed on the PEM-CY, with through posterior predictive profile for the measure being estimated based on the significant variables. Personal and environmental factors associated with differing trajectories and outcomes (secondary aim) will also be examined in this modelling framework. The interaction or influence of the explanatory factors, such as level of adaptive behaviour (measured by the VABS), severity of Autism Symptoms (measured by the SCQ) or sensory behaviours (measured by the SSP-2) will also be considered.

### 43 44 **Methodological considerations**

#### 45 46 Questionnaire data

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The format of this study (data collection through questionnaires) allows for recruitment of a reasonably large sample of children and families. However, it is acknowledged that all of the information for this study is collected through questionnaires and interviews, without meeting the child or family. This means that it is not possible for the data to include direct measures of ability (such as intellectual ability) or to complete formal assessments<sup>28</sup> (such as the ADOS). To address this issue, all parents will be asked to complete a validated autism screening questionnaire (Social Communication Questionnaire) and are required to send in copies of their child's diagnostic reports.

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2 Parents will also be asked to send in reports of any additional assessments, particularly cognitive  
3 assessments.  
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#### 5 6 7 Bias in recruitment

8 The nature of the present study requires a significant commitment from participants and where  
9 applicable, their teachers and principals. Parents are asked to complete six online questionnaires,  
10 four of which will take approximately two hours to complete. This may influence the recruitment  
11 procedure and may, over the duration of the study, reduce completion rates. It is therefore possible  
12 that there will be a recruitment bias (i.e., families who can afford the time to complete the  
13 questionnaire and/or who have ready access to a computer with internet access). It may also be that  
14 the research may only attract parents that have an interest in the focus of this study. To address this  
15 issue, efforts will be directed towards recruiting from a range of sources and in providing parents  
16 with the ability to log in and out of their questionnaire completion site so they can complete the  
17 questionnaire pack in small sections over one month. Demographic information alongside  
18 information about challenging behaviour (from the DBC) and parental stress (from the PSI-SF) will  
19 be compared between those who complete and those who leave the study in order to identify factors  
20 that may have contributed to non-completion.  
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#### 32 **Ethics and dissemination**

33 The study has received ethical approval from all recruiting sites and universities involved in the  
34 project (see list below). All parents will provide consent for their child to join the study. Parents  
35 can also choose whether to give consent for teacher and principal questionnaires to be collected.  
36 Results from standardised questionnaires can be shared with nominated health professionals if  
37 requested by the consenting caregiver.  
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43 It is not anticipated that participants will be subject to any risks during this study. It is possible that  
44 parents may become distressed when communicating about their child's autism or associated  
45 strengths and difficulties. The survey is designed to end with questions for parents about their  
46 child's strengths and interests to end on a positive note. All parents are provided with the contact  
47 details of the project administrator (who can direct the parent to an appropriate clinically trained  
48 member of the research team) to discuss the questionnaire. The research team are willing and able  
49 to refer parents to a range of specialised support services if this is deemed necessary or helpful.  
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57 Participant information will be securely stored electronically or in the project office.

58 Questionnaires are completed online and personal identifiable information received (such as copies  
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1 of diagnostic reports) will be stored in a locked filing cabinet. Once downloaded from the online  
2 database, all participant data will be anonymised by allocating each participant with an ID number.  
3 De-identified participant data will be saved on a password-protected secure computer drive which  
4 only members of the research team have access to. Participants' personal identifiable data will be  
5 stored in a separate location to de-identified participant data. Identifiable data will only be  
6 accessible to the project manager and the project leader.  
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13 Throughout the course of the study and once the longitudinal data collection is complete, results  
14 (de-identified and primarily aggregated) will be published in peer-reviewed mainstream and  
15 specialist journals. Presentations of study findings will be made at relevant research conferences,  
16 local research symposiums and seminars for professionals working with children with autism and  
17 those in autism research. In addition, local stakeholders (such as autism schools and NGOs) will be  
18 consulted in the development of methods for dissemination they find effective in reaching families  
19 of children with autism.  
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### 25 26 27 **Significance and outlook**

28 This study will make an important contribution to the very limited longitudinal data on the pattern  
29 and effects of participation in children with autism. The design allows for annual cross-sectional  
30 comparisons, within subject comparisons, exploration of cohort effects (by comparing data from  
31 both groups at 9-10yrs) and the six-year longitudinal analysis. Collecting data and information  
32 from a range of sources (parents, teachers and principals) allows for a holistic description of  
33 progress and change across the duration of the study.  
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40 Study results will inform clinicians, children and their families about the factors that promote or  
41 reduce participation and educational outcomes and therefore help to identify children who are most  
42 likely to benefit from specific interventions. It will also be important data for educators, who will  
43 be able to proactively monitor factors that put children with autism at risk of not achieving their full  
44 educational potential.  
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50 The study team is also focused on developing capacity of early career researchers through  
51 mentorship and supervision. It will provide data for a number of PhD, Masters and honours  
52 students who often cannot gain experience with longitudinal datasets due to time constraints and  
53 allow them to develop the methodological and statistical expertise required for such methods. This  
54 is particularly important given the identified need for longitudinal studies in a large number of  
55 health, educational and developmental areas.  
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### Summary and conclusion

Autism is an increasingly common condition. Although profiles and presentations are highly variable, a consistent finding is poor life outcomes for adults with autism across domains such as employment and independent living. Given that the primary aim of education is the preparation of children and young people for adult life, it could be argued that the educational process is not achieving this aim for the majority of young people with autism. In this study, data will be collected at key developmental periods including times of major transition (school entry and transition from primary to high school) and factors critical to participation and educational achievement will be explored and documented. Understanding these trajectories and the factors that influence them will assist clinicians working with individual children and their families to describe expected outcome and necessary services and supports, and planning to improve educational environments.

Competing interests: None declared

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8 Authors' contributions:

9  
10 Roberts, Jacqueline; Griffith University, Autism Centre of Excellence; conceptualised and co-  
11 designed the study, developed the first draft of the manuscript, reviewed and revised the manuscript  
12 and finalised the manuscript for publication.  
13

14 Adams, Dawn; Griffith University, Autism Centre of Excellence; drafted the final manuscript,  
15 reviewed and revised the manuscript , and approved the final manuscript.  
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18 Heussler, Helen; Mater Research Institute-University of Queensland, Children's Health  
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20 final manuscript.  
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22 Keen, Deborah; Griffith University, Autism Centre of Excellence; co-designed the study, assisted  
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27 contributed to the design of the study, assisted with manuscript drafting and review of the  
28 manuscript, and approved the final manuscript.  
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31 reviewed and revised the manuscript , and approved the final manuscript.  
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34 Westerveld, Marleen; Griffith University; contributed to the design of the study, assisted with  
35 manuscript drafting, read and approved the final manuscript , and approved the final manuscript.  
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38 Williams, Katrina; University of Melbourne, Developmental Medicine; co-designed the study,  
39 assisted with manuscript drafting, reviewed and revised the manuscript , and approved the final  
40 manuscript.  
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42 Note apart from the lead author, authors are listed alphabetically  
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47  
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49 Ethics approval:

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56  
57

58 Sydney Children's Hospital Network HREC Clearance Number HREC/14/SCHN/253 (10.09.14)  
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## 7 **References**

- 8 1. CDC. Prevalence of autism spectrum disorders among children aged 8 years: Autism and  
9 developmental disabilities monitoring network. *MMWR Surveillance Summaries*. 2014; 63: 1-  
10 22.  
11
- 12 2. Horlin C, Falkmer M, Parsons R, Albrecht MA, Falkmer T. The cost of autism spectrum  
13 disorders. 2014; *PloS one*, 9(9): e106552.  
14
- 15 3. Synergies Economic Consulting, 2011 Synergies. Economic costs of autism spectrum disorder  
16 in Australia: Updated study. Brisbane: Synergies Economic Consulting; 2011.  
17
- 18 4. World Health Organization. International Classification of Functioning, Disability and Health.  
19 Geneva:World Health Organization; 2001.  
20
- 21 5. Bolte S, de Schipper E, Robison J, Wong V, Selb M, Singhal N. et al. Classification of  
22 functioning and impairment: The development of ICF core sets for autism spectrum disorder.  
23 *Autism Research*. 2014; 7: 167-172.  
24
- 25 6. de Schipper E, Lundequist A, Coghill D, de Vries P, Granlund M, Holtmann et al. Ability and  
26 disability in autism spectrum disorder: A systematic literature review employing the  
27 International Classification of Functioning, Disability and Health-Children and Youth Version.  
28 *Autism Research*. 2015; 8: 782-794. doi: 10.1002/aur.1485  
29
- 30 7. ABS Survey of Disability. 2012. Available from:  
31 <http://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/4430.02012>  
32
- 33 8. 4428.0 - Autism in Australia, Australian Bureau of Statistics.2012. Available  
34 from:[http://www.abs.gov.au/ausstats/abs@.nsf/Latestproducts/4428.0Main%20Features52012?](http://www.abs.gov.au/ausstats/abs@.nsf/Latestproducts/4428.0Main%20Features52012?opendocument&tabname=Summary&prodno=4428.0&issue=2012&num=&view=)  
35 [opendocument&tabname=Summary&prodno=4428.0&issue=2012&num=&view=](http://www.abs.gov.au/ausstats/abs@.nsf/Latestproducts/4428.0Main%20Features52012?opendocument&tabname=Summary&prodno=4428.0&issue=2012&num=&view=)  
36
- 37 9. Moss P, Howlin P, Savage S, Bolton P, Rutter M. Self and informant reports of mental health  
38 difficulties among adults with autism findings from a long-term follow-up study. *Autism*. 2015  
39 May 26:1362361315585916.  
40
- 41 10. Magiati I, Tay XW, Howlin P. Cognitive, language, social and behavioural outcomes in adults  
42 with autism spectrum disorders: A systematic review of longitudinal follow-up studies in  
43 adulthood. *Clinical Psychology Review*. 2014; 34: 73-86.  
44
- 45 11. Fein D, Barton M, Eigsti IM, Kelley E, Naigles L, Schultz RT. et al. Optimal outcome in  
46 individuals with a history of autism. *Journal of child psychology and psychiatry*. 2013; 54: 195-  
47 205.  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

12. Howlin P, Savage S, Moss P, Tempier A, Rutter M. Cognitive and language skills in adults with autism: a 40-year follow-up. *Journal of Child Psychology and Psychiatry*. 2014; 55: 49-58.
13. Magiati I, Tay XW, Howlin P. (2014). Cognitive, language, social and behavioural outcomes in adults with autism spectrum disorders: a systematic review of longitudinal follow-up studies in adulthood. *Clinical Psychology Review*. 2014; 34: 73-86.
14. Roberts J, Simpson K. A review of research into stakeholder perspectives on inclusion of students with autism in mainstream schools. *International Journal of Inclusive Education*. 2016; 1-13.
15. Prior M, Roberts JMA, Rodger S, Williams K. Sutherland R. (2011). A review of the research to identify the most effective models of practice in early intervention of children with autism spectrum disorders. Australian Government Department of Families, Housing, Community Services and Indigenous Affairs, Australia. Available from [http://www.fahcsia.gov.au/sites/default/files/documents/09\\_2012/review\\_of\\_the\\_research\\_report\\_2011\\_0.pdf](http://www.fahcsia.gov.au/sites/default/files/documents/09_2012/review_of_the_research_report_2011_0.pdf)
16. Roberts JMA, Williams K. Autism spectrum disorder: Evidence-based/evidence-informed good practice for supports provided to preschool children, their families and carers. 2016. Report prepared for the National Disability Insurance Agency (NDIA).
17. Autism CRC. 2016. Available from <http://www.autismcrc.com.au/about-crcs>
18. 4221.0 - Schools, Australia, 2015. Australian Bureau of Statistics. 2015. Available from: <http://www.abs.gov.au/ausstats/abs@.nsf/mf/4221.0>
19. Rutter M, Bailey MD, Lord C. The Social Communication Questionnaire (SCQ). Los Angeles, CA: Western Psychological Services; 2003.
20. National Longitudinal Transition Study-2, US Department of Education US Department of Education. Welcome to NLTS2. Available from: <http://www.nlts2.org/index.html>.
21. Longitudinal Study of Australian Children (LSAC) Growing up in Australia: The longitudinal study of Australian children (LSAC). Available from: <http://growingupinaustralia.gov.au/>
22. Coster W, Bedell G, Law M, et al. (2011). Psychometric evaluation of the Participation and Environment Measure for Children and Youth. *Developmental Medicine and Child Neurology*. 2011; 53: 1030-1037. DOI: 10.1111/j.1469-8749.2011.04094.x
23. DiPerna JC, Elliott SN. Academic competence evaluation scales. San Antonio: The Psychological Corporation; 2000.
24. Bailey DB, Raspa M, Olmsted MG, et al. Development and psychometric validation of the family outcomes survey revised. *Journal of Early Intervention*. 2011; 33: 6-23.

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25. National Statement on Ethical Conduct in Human Research 2007 (Updated May 2015). The National Health and Medical Research Council, the Australian Research Council and the Australian Vice-Chancellors' Committee. Commonwealth of Australia, Canberra
26. Australian Psychological Society. (2012). *Code of ethics*. Melbourne, Vic: Author
27. Faul F, Erdfelder E, Lang AG, Buchner A. G\*Power 3: A flexible statistical power analysis program for the social, behavioral, and biomedical sciences. *Behavior Research Methods*. 2007;39:175-191.
28. Lord C, Rutter M, Pamela C. Dilavore P, Risi, S. ADOS: Autism diagnostic observation schedule. Hogrefe; 2008.
29. Sparrow SS, Cicchetti DV, Balla DA. Vineland II: Vineland Adaptive Behavior Scales. Bloomington, MN: Pearson; 2005.
30. Bishop DVM. Children's Communication Checklist-2 (CCC-2). San Antonio, TX: Pearson; 2006.
31. Dewart H, Summers S. The Pragmatics Profile of Early Communication Skills. London: NFER-NELSON; 1995
32. Einfeld SL, Tonge BJ. Manual for the Developmental Behaviour Checklist. Clayton, Melbourne and Sydney Monash University for Developmental Psychiatry and School of Psychiatry, University of New South Wales; 1992.
33. Dunn W. Sensory Profile 2. Bloomington, MN, USA: Pearson Psychcorp; 2014
34. Rodgers J, Wigham S, McConachie H, Freeston M, Honey E, Parr JR. Development of the anxiety scale for children with autism spectrum disorder (ASC-ASD). *Autism Research*. 2016. doi:10.1002/aur.1603
35. Abidin RR. Parenting Stress Index Professional Manual (4th ed.). Lutz, FL: PAR; 2012.
36. Goodman R. (1997). The Strengths and Difficulties Questionnaire: A Research Note. *Journal of Child Psychology and Psychiatry*. 1997; 38:581-586.

Table 1: Parent measures used within the LASA and their published reliability statistics

Instrument	Captures	Domains	Measured at	Reliability
Family History Survey	Information on child and family demographics, child and family medical history, child's therapy and intervention and the parent's perception of child social experience of school (e.g. experience of bullying)	N/A	T1, T2, T3, T4, T5, T6	N/A
Participant and Environment Measures – Child and Youth <sup>22</sup>	Child's participation and environment across three settings: school and community	Level of involvement Parent satisfaction with participation at: Home, School, Community	T1, T2, T3, T4, T5, T6	Internal consistency <sup>1</sup> .59-.91 Participation frequency .59-.70 Participation involvement: .72-.83 Environmental Supportiveness: .67-.91 Test-retest reliability <sup>1</sup> Participation frequency .58-.84 Participation involvement: .69-.76 Desires change: .76-.89 Environmental Supportiveness: .85-.95
Social communication Questionnaire (SCQ)	Symptoms of Autism (combines with "community diagnosis")	N/A	T1	Internal Consistency <sup>2</sup> ( $\alpha$ ) = .93 Test-retest <sup>2</sup> = .81

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Lifetime <sup>19</sup>	to confirm ASD)				
Vineland Adaptive Behavior Scale, 2 <sup>nd</sup> Edition (VABS-II) <sup>29</sup>	Daily functional skills and adaptive behaviour.	Communication Daily Living Skills Socialisation	T1, T2, T3, T4, T5, T6	Internal Consistency <sup>3</sup> ( $\alpha$ ) Communication .84-.93 Daily Living Skills .86-.91 Socialisation .84-.93 Test-retest across domains <sup>3</sup> .76-.92	
Children's Communication Checklist-2 (CCC-2) <sup>30</sup>	Communicative behaviours	Speech, Syntax, Semantics, Coherence, Initiation, Stereotyped language, Use of context Nonverbal communication, Social relations, Interests	T1, T3, T5, T6	Internal Consistency <sup>4</sup> ( $\alpha$ ): .73-.88 Inter-rater reliability <sup>4</sup> .61-.83	
Pragmatic Profile of Everyday Communication <sup>31</sup> (selected questions)	Communicative functions and forms	Selected items on Communicative Functions, Response to Communication Interaction and Conversation Contextual Variation	T1, T3, T5, T6		
Developmental Behaviour Checklist (DBC-P) <sup>32</sup>	Behaviour and emotional problems	Disruptive/Antisocial Self-absorbed Communication Disturbance, Anxiety Social-relating	T1, T3, T5, T6	Internal Consistency <sup>5</sup> ( $\alpha$ ): .94 Inter-rater reliability <sup>6</sup> .72 <sup>5</sup>	

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5	Short Sensory	Sensory behaviours	Auditory Processing	T1, T3,	Internal Consistency <sup>7</sup> .57-.92
6	Profile-2 <sup>33</sup>		Visual Processing	T5, T6	Test re-test <sup>7</sup> .83-.92
7			Touch Processing		Inter-rater <sup>7</sup> .49-.89
8			Movement Processing		
9			Body Position		
10			Processing		
11			Oral Sensory Processing		
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15	Anxiety Scale for	Child anxiety	Separation Anxiety	T2, T3,	Internal Consistency <sup>8</sup> ( $\alpha$ ): .85-.91
16	Children with Autism		Uncertainty	T4, T5,	Separation anxiety .87
17	Spectrum Disorder		Performance Anxiety	T6	Uncertainty .88
18	(ASC-ASD-P) <sup>34</sup>		Anxious Arousal		Performance .89
19					Anxious arousal .88
20					Test re-test <sup>8</sup> ( $\alpha$ ): .84
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24	Family Outcomes	Family outcomes	Understanding your	T1, T5,	Internal Consistency <sup>9</sup> ( $\alpha$ ): .73-.91
25	Survey Revised		child's strengths, needs	T6	
26	(FOS-R) <sup>24</sup>		and abilities		
27			Knowing your rights and		
28			advocating for services		
29			Helping your child		
30			develop and learn		
31			Having support systems		
32			Accessing the		
33			community		
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38	Parenting Stress	Parental stress	Parental distress	T1, T3,	Internal Consistency <sup>10</sup> ( $\alpha$ ): .98
39	Index-4-Short Form		Parent-child	T5, T6	Child: .96
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(PSI-4-SF) <sup>35</sup>	dysfunctional interaction Difficult child	Adult: .96 Test re-test <sup>10</sup> .96 Child: .63 Parent: .91
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Table 2: School measures used within the LASA and their published reliability statistics

Instrument	Captures	Domains	Measured at	Reliability
Academic Competence Evaluation Scales (ACES) <sup>23</sup>	Academic functioning of student	Academic skills (reading/language arts, mathematics, critical thinking) Academic enablers (interpersonal skills, engagement, motivation, and study skills)	T1, T2, T3, T4, T5, T6	Internal Consistency <sup>1</sup> ( $\alpha$ ): .94-.99  Test re-test <sup>1</sup> .88-.97
Strengths and Difficulties Questionnaire - Teacher (SDQ) <sup>36</sup>	Profile of strengths and difficulties	Emotional symptoms Behavioural difficulties Hyperactivity Peer problems Prosocial behaviours	T1, T2, T3, T4, T5, T6	Internal Consistency <sup>2</sup> .73 Test re-test reliability <sup>2</sup> .62
Teacher survey (compiled from National Longitudinal Transition Study-2, <sup>20</sup> US Department of Education and other sources, including the Longitudinal Study of Australian Children (LSAC) <sup>21</sup>	Student behaviours, teaching practices and school environment		T1, T2, T3, T4, T5, T6	N/A



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Principal Survey (compiled from National Longitudinal Transition Study-2, <sup>20</sup> US Department of Education and other sources, including LSAC) <sup>21</sup>	whole school context in relation to programs/approaches used to educate children with autism	T1, T2, T3, T4, T5, T6	N/A
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